LIFE SATISFACTION, SELF-EFFICACY AND RELIGIOUS FAITH

IN STROKE PATIENTS LIVING IN KUWAIT

A thesis submitted for the degree of Doctor of
Philosophy

By

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Abstract

Aims:
Life satisfaction and self-efficacy are psychosocial experiences that appear to profoundly influence the rehabilitation of a stroke patient. However, relevant studies have been mostly carried out on Western stroke survivors, with limited reports on stroke experience in the Middle East. Reviewed literature suggests a positive correlation between religious faith and health outcome, however studies investigating relationships among religious faith, self-efficacy and other psychosocial variables in stroke patients are limited. The aims of this study were therefore to (1) explore stroke experience and factors associated with life satisfaction post-stroke in Kuwait, (2) to investigate the relationships between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait, and (3) to identify cultural influences on stroke survivors in Kuwait from the health professionals' point of view.

Method: The study was carried out in these four phases.
1) Phase 1:- Exploring stroke experience in patients in Kuwait with semi-structured interviews
2) Phase 2:- Client-Centred Adaptation of a Self-Efficacy measure for stroke patients living in Kuwait
3) Phase 3:- Assessing quantitative relationships between the three variables (self-efficacy, life satisfaction and religious faith) with questionnaires
4) Phase 4:- Exploring perceptions of health professionals regarding the world of the stroke patient and effects of culture on recovery and rehabilitation with semi-structured interviews

Qualitative data were analysed with thematic analysis.

Results:
Significant correlations were found between general self-efficacy, and psychosocial adaptation self-efficacy. Self-efficacy (both general and psychosocial adaptation) showed significant correlations with life satisfaction post-stroke. Religious faith was not related to either life satisfaction or self-efficacy. Health professionals' interviews identified cultural characteristics specific to stroke patients living in Kuwait. These included family involvement, prevailing attitude towards stroke, dependency and access to maids, religious beliefs, and social stigma.

Conclusion: Psychosocial self-efficacy was identified as having the strongest relationship to life satisfaction compared with the other variables tested. This study failed to show any significant relationship between religious faith and self-efficacy or life satisfaction in female stroke patients living in Kuwait. However, results from patient and health professional interviews identified religious beliefs as playing an important role in recovery, behaviour during rehabilitation and in interaction with the health professions. The qualitative aspects of this study, in particular, highlight the importance of taking into consideration religious and cultural influences during the rehabilitation of stroke patients in Kuwait.

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Chapter 1: Introduction and Overview of Study

Overview of Study

Experiences of stroke and psychosocial recovery from stroke are issues that could possibly be influenced by cultural beliefs, values and norms, although available evidence is sparse. Available research in traumatic brain injury (which will be discussed in chapter 3) suggests that culture influences how individuals report experiences post-injury, how their families react and provide support, and interactions between individuals, family members and health professions (Simpson, Mohr and Redman, 2000). Life satisfaction and locus of control during rehabilitation are two specific psychosocial variables that are influenced by cultural and religious beliefs as identified by results from other non-stroke studies (Saltapidas and Ponsford, 2007; Hampton and Marshall, 2000). Most of the available evidence about people's experience of stroke and stroke rehabilitation has been gained in Western countries, with predominantly Christian or secular belief systems. Stroke experience and attitudes to recovery in the Arab culture have not been investigated in the past. Available research studies on the influence of culture on neurological rehabilitation, in addition to being carried out on individuals affected by conditions other than stroke, have also been restricted to Japanese and Western participants, making generalisation to stroke survivors living in an Arabian culture difficult.

The Arabian culture is distinctive because the Muslim religion plays an important role in every issue of people's lives (Rashidi and Rajaran, 2001). This project specifically focuses upon the stroke experience in Kuwait. This is a unique culture, as in Kuwait an interplay between the Muslim religion, and widespread access to funds to purchase care and rehabilitation services abroad, may result in an experience of stroke and rehabilitation that is

different from those reported in other parts of the world. It is possible that stroke survivors in Kuwait have different expectations post-stroke (for example, greater fatalism). Religious coping amongst Muslims might differ from that of other cultures and religions. A few researchers have reported that Muslims use religious coping more than other cultural and religious groups of people (Loewenthal and Cinnirella, 1999; Loewenthal et al., 2001, Bhui, King, Dein et al, 2008).

Therapists involved in rehabilitation, such as physiotherapists need to be aware of cultural characteristics in order to provide culturally competent care. This invites cooperation with patients and their family members and ensures the best possible outcome is obtained. Knowledge about patients' beliefs is considered a vital part of a biopsychosocial approach (Bhui et al, 2008). The author of this project is a physical therapist with a special interest in stroke rehabilitation. Having lived and worked in the United Kingdom and Kuwait, differences in perceptions of recovery post-stroke, participation in rehabilitation, family involvement and social stigma were observed in professional practice which could be attributed to differences in culture. The issues of culture and religion are of interest to the author, and became very salient when working in Kuwait, from having a non-Muslim religion (Christian) and an African upbringing (Nigerian). The author was particularly interested in self –efficacy, and had already investigated the influence of self-efficacy on rehabilitation outcome in stroke patients in the U.K. as part of her Masters degree in Neurorehabilitation. The current project addresses the issues that arose from that initial research, and explores them in further detail. The main implication of the previous study's findings was the need to develop a self-efficacy scale specifically targeted to the needs of stroke patients. This experience led to a five-year fascinating journey firstly to explore, using a qualitative method, stroke experiences in Kuwait and then to identify issues that patients held as important in

order to adapt a self-efficacy questionnaire. Subsequent phases included preliminary validation of the adapted questionnaire, testing on stroke participants living in Kuwait, and finally interviewing health professionals living in Kuwait regarding their views about cultural influences that they experienced in the stroke rehabilitation setting and any clinical implications of the results of the previous phase of the study. The personal and professional background of the author has brought certain advantages to the data collection and analysis, being both an 'outsider' to the Kuwaiti culture in some respects, from having a different background i.e. Christian religion and African upbringing, combined with rehabilitation experience in the U.K, whilst also enjoying an 'insider' position in other respects, from having some experience as a therapist working in Kuwait.

The following sections of this chapter will introduce stroke and rehabilitation, highlighting the need to investigate self-efficacy, life satisfaction and the role of religion post-stroke, outline the aims and research questions of the current project, and describe the setting of the study (Kuwait). Final sections will provide an overview of the methods used in this study and an outline of all the other chapters of this thesis.

1.1: Stroke and Rehabilitation

Stroke according to the World Health Organisation is defined as a clinical syndrome characterised by rapidly developing clinical signs of focal (or global) disturbances of cerebral function, lasting more than 24 hours or leading to death, with no other cause than that due to vascular disruption (Truelsen, Mähönen, Tolonen et al, 2003). It is said to be the third leading cause of death in the Western world, with the first being heart disease and second being cancer (Steiner and Pierce, 2004; Dumont, Dumont, Chow et al, 2003). Two main types of stroke have been identified in the literature: ischemic and haemorrhagic strokes

(Donnan, Fisher, Macleod et al, 2008). Stroke is also a major cause of disability, and dependency in most parts of the world. Evidence suggests that rehabilitation can help reduce disability and increase functional outcome post- stroke (Rensink, Schuurmans, Lindeman et al, 2009). In addition to commonly experiencing significant physical and functional limitations as a result of a stroke, the survivor is left with a number of psychological and social issues that may require intervention. As mentioned previously, self-efficacy and life satisfaction are psychological aspects which have a significant impact on rehabilitation outcome, according to some previous studies, however these have not been investigated extensively in stroke. Other problems that may occur following on from stroke include mood disorders, anxiety, adjustment disorders, substance abuse, sexual dysfunction, sleep disturbances and behavioural problems (Bishop and Pet, 1995).

The effect of stroke on overall life satisfaction is an issue that requires more attention. Life satisfaction has been defined as: "a contentment with or acceptance of one's life circumstances or the fulfilment of one's wants and needs for one's life as a whole" (Sousa and Lyubomirsky, 2001: 667). Robinson-Smith (1993) describes life satisfaction as an evaluation of how fulfilling life is in general. It can also be known as adjustment, life quality and morale. Perceptions of life satisfaction have been reported to differ amongst people of different cultural backgrounds during neurological rehabilitation. Hampton and Marshall (2000), reported that amongst spinal cord injury patients, life satisfaction and self-efficacy differed between American and Japanese patients. Life satisfaction and self-efficacy in stroke amongst Arab Muslims such as those living in Kuwait have not been investigated in the past.

"Self-efficacy" has been defined as "people's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994: 71). This term was first used by Bandura in 1977 to describe the self – assurance in one's capability to accomplish certain tasks. Holloway and Watson (2002) describe self-efficacy as the opinion of an individual regarding their capacity to organise and execute tasks in order that selected performances are carried out successfully. There is some evidence suggesting a positive association between life satisfaction and self-efficacy. However, this relationship has not been investigated in stroke patients. Self-efficacy has become a vital element in a variety of fields such as sociology, psychology, health and education because higher self-efficacy has been shown to be related to better health, and social integration (Schwarzer and Fuchs, 1995). Researchers are curious to find out what affects self-efficacy, its influence on a variety of behaviours, and how it can be enhanced. It has been claimed to have a predictive nature, with positive self-efficacy linked with successful accomplishment of tasks (Gecas, 1989; Bandura, 1977, and 1994). In addition to this, Ewart et al (1983) reported that assessing the degree of self-efficacy regarding performance can be used to predict the possibilities of future occurrence of that behaviour. This relationship suggests that higher self-efficacy on a task will lead to a higher chance of that task /behaviour occurring more frequently in the future.

Some evidence suggests that religious faith can enhance self-efficacy beliefs (Ai, Peterson, Rodgers et al (2005). However this has not been investigated with Arab Muslim stroke survivors living in Kuwait. It is important for the rehabilitation therapist to understand more about how self-efficacy can be enhanced because according to Bandura (1994), self-efficacy beliefs affect the feelings, thoughts, motivation and behaviour of individuals. These beliefs are said to affect the choices people make in different situations, the effort and time taken to

persist with maximum effort, how obstacles are tackled and the overall feelings of the individual. Low self-efficacy in a specific setting and activity is directly related to higher levels of depression and anxiety, while high self-efficacy is related to better coping with uncertainty and illness. This enhanced coping in turn has been claimed to result in lower incidences of depression and anxiety (Schwarzer, 1992; Bandura, 1994).

There are some indications from the literature that self-efficacy has a significant effect on the outcomes of various chronic conditions, but studies investigating its role in stroke rehabilitation are very limited. A recent systematic review on self-efficacy in stroke rehabilitation indicated that self-efficacy has been shown to be associated with quality of life, depression, ADL, and physical functioning post stroke in a few studies (Jones and Riazi, 2010). Relevant evidence from this review will be discussed in more detail in chapter 2. Robinson-Smith et al (2000) investigated the relationship between self-care self-efficacy, functional independence, quality of life and depression post-stroke. They reported that higher scores on self- care self-efficacy were strongly related to positive perceptions of quality of life and less depression. They also reported a significant relationship between depression and functional independence one month post-stroke (Robinson-Smith et al, 2000). However self – efficacy was measured by a scale initially developed for cancer patients (this will be discussed in more detail in the literature review chapter). Results of this study cannot be generalised to stroke patients living in Kuwait and highlights the need for a stroke-specific scale in measuring self –efficacy.

 It is assumed that the physiological causes and sequelae of stroke are similar with patients all over the world, however the way that patients interpret their disability and appraise life post-stroke could be influenced by their individual culture. Current relocation of people across the

globe has increased the number of multi-cultural communities. This necessitates the understanding of the influences of religion and culture on the stroke experience and rehabilitation. Research specifically targeting peoples of Arabian culture and the Muslim religion is limited, and neurorehabilitation studies which include consideration of culture and religion are strikingly absent from the literature.

Spirituality and religion are significant issues that shape and reflect culture. Culture has been described as: "a tradition of knowledge and practice that is shared, albeit imperfectly, across the members of a society and across its generations" (Zou, Tam, Morris et al, 2009: 579). Spiritual and religious beliefs are also claimed to have an important influence on human health and behaviour (Miller and Thoresen, 2003). A few researchers have reported that a majority of patients have a desire to discuss issues related to spirituality with their care givers (Daaleman and Nease, 1994, King and Bushwick, 1994). Health is no longer viewed as the absence of disease but as a comprehensive "package" involving interaction between cultural, social and philosophical factors (Miller and Thoresen, 2003). With this current emphasis on a holistic approach in managing health, researching the effects of spirituality and religion has become more than ever necessary.

Evidence from health research suggests that religious beliefs and self-efficacy have a role to play in facilitating recovery and could be associated with life satisfaction as will be further discussed in the literature review chapters. This role has not been investigated before in stroke patients living in a predominantly Muslim culture like Kuwait. In order to provide patients with the best possible care, issues such as these should be investigated and recommendations implemented to assist in facilitating recovery and increased perceptions of quality of life/life satisfaction. Psychosocial issues need to be assessed specifically and

strategies put in place for both patient and significant others to help prevent deterioration of mood and functional status, isolation from their community and feelings of hopelessness. Therapists also need to be aware of the impact these issues have on physical recovery. It is hoped that an increased awareness of these psychosocial issues will lead to a more holistic management of stroke patients in Kuwait with more attention given to aiding psychosocial adaptation which might lead to higher reported quality of life and life satisfaction.

1.2: Setting

1.2.1 Kuwait- Location

Kuwait is located in the Western head of the Arabian (Persian) gulf region bordered by Iraq, Saudi Arabia and the Persian Gulf. It is 17,820 sq km (6,880 sq mi) in size, a map of Kuwait can be seen in appendix 1.

1.2.2 Population

Kuwait has a population of about 3.1 million. However less than 40% of the population are native Kuwaitis, the rest are foreign workers. In 2006, the mid-year population of Kuwait was 3,051.845. Kuwaitis made up 33% (1,008, 090) and Non Kuwaitis made up 67% (2, 043, 755) (MOH, 2006).

1.2.3 Language

The official language of Kuwait is Arabic, however English is widely understood among the younger generation who attend international schools and those who have studied abroad.

1.2.4 Religion

Islam is the official religion of Kuwait. It is estimated that 2.1 million of the population are Muslim. Conversion of Muslims to other religions is strictly forbidden. However, expatriates are allowed to freely practise other religions in their homes and authorized places of worship (US State Dept, 2005).

1.2.5 Stroke Incidence in Kuwait

Abdul- Ghaffar, El-Sonbaty and El Din Abdul- Barky et al (1997) reported an overall annual crude incidence rate of stroke of 27.6/100,000 population, and an age adjusted annual crude incidence rate of 145.6/100, 000 population. Overall case fatality was 10%. Of all the stroke cases investigated, 46.5% were carotid –artery large infarctions, 19.9% were intracerebral haemorrhage, 17% lacunar infarction, 8.3% basilar infarction, and 1.7% subarachnoid haemorrhage (Abdul-Ghaffar et al, 1997). No recent studies have been published reporting on stroke incidence or prevalence in Kuwait.

According to the Ministry of Health statistics, rate of death from cerebrovascular disease in 2005 was 16.1 /100,0000. Rate amongst Kuwaitis was 27.7/100,000 and rate amongst non-Kuwaitis was 10.3/100,000 (MOH, 2006).

In 2005, there were 1,800 individuals with stroke documented as discharged from Ministry of Health hospitals in Kuwait. Of these, 914 were Kuwaiti, and 886 non-Kuwaitis MOH, 2006). In 2005, 892 patients accompanied by attendants were taken abroad for treatment (MOH, 2006). No statistics were available regarding how many of these had stroke.

Kuwait has five general Ministry of Health hospitals in each health region, nine specialised hospitals, 78 primary health care clinics and 38 diabetic clinics. Health care is also provided by private hospitals and three hospitals belonging to oil companies (MOH, 2006). Acute stroke services are provided by all the general Ministry of Health hospitals and private hospitals. Long term rehabilitation for stroke is provided by outpatient physiotherapy departments in general hospitals and in-patients services at one specialized rehabilitation hospital. Private hospitals have outpatient physiotherapy services for long term rehabilitation.

1.3: Aims of Study:

The current study aims to explore the stroke experience in Kuwait, to use this information to tailor a self-efficacy scale suited to this patient group, to investigate factors associated with life satisfaction of stroke patients undergoing rehabilitation, and to identify associations among self-efficacy, life satisfaction and religious faith. Also the study included a final phase which aimed to explore health professionals' views of the influence of Kuwaiti culture on recovery and psychosocial issues during rehabilitation, in order to draw out further clinical implications from the qualitative and quantitative findings.

1.4: Research Questions

The overall research question of the current project is: "What influences patients' experiences of stroke and life satisfaction post-stroke in Kuwait?" More specific research questions are:

  i)   What are stroke survivors' experiences of stroke in Kuwait?

  ii) What is the relationship between self-efficacy, life satisfaction and religious faith in stroke patients living in Kuwait?

iii) What are the cultural influences on stroke experience and rehabilitation in Kuwait from the health professional's perspective?

1.5: Outline of Thesis

Chapter 1

This chapter has introduced the aims of this study and the setting (Kuwait). It has highlighted the importance of considering psychosocial issues in stroke rehabilitation and the limited research on this topic in Kuwait.

Chapter 2

This chapter discusses literature on self-efficacy and life satisfaction related to stroke and highlights gaps in existing literature. Research methods in similar studies were also investigated to develop methods for this project.

Chapter 3

This chapter explores understanding of culture, religion and spirituality as presented in the literature, and provides research findings on the association between health and religious faith. It also specifically reviews literature regarding the role of religious faith in recovery from stroke, defending the need to examine these issues in an under-researched Muslim culture.

Chapter 4

This chapter explains the methods used to investigate the stroke experience and to study the relationships between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait. Four phases of the research are described.

Chapter 5, 6, 7

These three chapters are results chapters of the various phases of the study. Phase 1 and phase 2 results will be presented in chapter 5, phase 3 results in chapter 6 and phase 4 results will be presented in chapter 7 and chapter 8.

Chapter 9

This chapter will discuss the findings of all four phases in light of current literature. Clinical applications of findings will be discussed as well as limitations of the study. Reflection on the challenges and other issues associated with conducting this project in Kuwait will also be highlighted in this chapter.

Chapter 10

This chapter will present the concluding remarks regarding the whole project, results and recommendations for future research.

Chapter 2

Chapter 2:

Self –Efficacy and Life Satisfaction in Stroke Rehabilitation

The first section of this chapter will introduce the self-efficacy concept, shed some light on possible associations between self-efficacy and patient experiences as reported in the literature. It will also discuss the gaps present in the literature and examine whether self-efficacy has an effect on stroke rehabilitation outcomes and experiences. The second section of this chapter will focus on life satisfaction and quality of life in stroke rehabilitation literature, discuss the difficulties in combining literature using both terms (i.e. life satisfaction and quality of life) and present a literature review of factors associated with life satisfaction after stroke.

2.1: Development of the Self-Efficacy Concept

Self–efficacy beliefs are the core determinants of human behaviour according to Bandura's social cognitive theory. Bandura in the 1960's challenged the prevailing thoughts of his day by explaining human behaviour as a result of interactions between the environment, biological make-up of the individual, and self-reflecting processes (Bandura, 1977, Parajas, 2002) This theory was initially known as the social learning theory however did not yet contain the term "self-efficacy". Scientific theories of human behaviour present prior to Bandura's social learning theory (Bandura,1977), were largely behaviourist theories which focused solely on the effect the environment played on human behaviour, neglecting any self-reflecting processes. Inner processes were seen only as a means to transmit behaviour caused

by external stimuli (Bandura, 1977). Bandura believed that investigating the external factors without taking into consideration internal motivational influences would not properly explain the variety of human behaviour in different settings (Bandura, 1977). Bandura (1986) explained that in order to fully understand complex human behaviour one should not deny the role that thoughts played in regulating action. Other theories present in the 1970's explained that needs, drives, impulses and other so called "motivational" forces were significant influencers of human behaviour. Proponents of this theory believed that forces within the individual explained why people behaved the way they did. Bandura's social learning theory took into consideration the role that both internal regulation and the environment played in regulating behaviour.

In 1977, Bandura added a key element to his social learning theory: "Self-efficacy". This was described as self-belief in one's capabilities to perform a specific action to achieve a specific goal. With this addition, the theory was changed from "Social learning theory" to "Social cognitive theory" to highlight the role that cognition plays in determining human behaviour and to draw attention to the difference between Bandura's theory and other learning theories present in the literature (Bandura, 1986). The social cognitive theory of Bandura thus explains behaviour as a result of self- organising, self- reflecting processes and not solely by reaction to the environmental factors or response to internal impulses.

Gecas (1989) reviewed the literature of self-efficacy and identified that the self-efficacy concept was present before Bandura's presentation of the concept, however other terms were used. He stated the following: "But self-efficacy has also been around in one form or another for a long time, embedded in such perennial philosophical concerns as the determinism and indeterminism of human action, voluntarism, intentionality, free will and causality, and other

issues of human agency" (Gecas, 1989: 291). Gecas (1989) identified two separate but at times overlapping lines of development of the self-efficacy concept: the motivational theories and the cognitive theories. Concerning motivational theories, White (1959) was the earliest found mention of a similar concept known as "Effectance motivation". Effectance motivation referred to an: "Intrinsic motivation to produce effects on the environment, that is to make things happen" (Gecas, 1989: 292). White (1959) proposed that people would move to make a desired change in their environment if they feel competent to act, and that with repetition of that action, confidence is increased. This leads to satisfaction and feelings of efficacy (White, 1959). Similar descriptions to self-efficacy can also be found in Rotter's social learning theory and the concept of locus of control. There are, however, controversies regarding the similarities of locus of control and self-efficacy (Abusabha and Achterberg, 1997), as will be explored in detail next.

2.2: Locus of Control

Locus of Control (LOC) is a construct often confused with self-efficacy (Abusabha and Achterberg, 1997). It refers to what an individual believes regarding the source of reward or reinforcement from a certain behaviour (Ai et al, 2005). Norman and Bennett (1996) described locus of control as a subjective view held regarding the relationship between one's individual behaviour and the result of that behaviour. Origins of locus of control can be found in Rotter's social learning theory in which behaviour is identified as dependent on the type, amount and value of reward or reinforcement derived from engaging in that behaviour (Rotter, 1954). Rotter's social learning theory suggested that behaviours occur based on the expected outcome of that behaviour and value of the outcome (Abusabha and Achterberg, 1997). Rotter identified two types of locus of control: internal and external locus of control. Internal locus of control refers to the belief that the individual possesses within themselves

the ability to exert influence over the situation. Ai et al (2005: 471) described internal LOC as the following: "One has an internal LOC when one believes that an internal characteristic (e.g. one's behaviour, determination or endurance) leads to one's reinforcement". External locus of control, on the other hand, is the belief of lack of personal control. However, control is placed in external forces such as another person, a superior deity or chance.

Locus of control is said to refer specifically to a certain domain e.g. health domain or social domain (Abusabha and Achterberg, 1997). Wallston et al (1987) referred to locus of control in the health domain as: "health locus of control or perceived control". This can be described as the belief that one can influence events related to one's health. Health locus of control has been shown to have a significant influence in health promotion and change in health behaviour. It has thus become one of the most widely researched areas in predicting health behaviour (Norman and Bennett, 1996). Health locus of control as a concept is made up of three domains: personal control, powerful others' control and chance or fate control (Wallston, Wallston and DeVellis, 1978).

Judge, Erez, Thoresen et al (2002) investigated whether self esteem, neuroticism, locus of control and general self-efficacy indicated the same core concept. Their first study involved locating research articles in the literature comparing these four constructs. They then conducted meta-analysis of previous research to determine relationships between all four constructs. Two hundred and fifty eight articles were located, however 49 of these were not relevant and 134 articles investigated correlation between these traits but did not identify any correlation. The remaining 75 articles identified 127 studies whereby correlations were identified between traits. Articles included had to have investigated correlations between at least two of the traits being investigated. Not all articles looked at the four traits together.

Meta- analysis was then conducted on these remaining 75 articles. Their results showed a high correlation (statistical association) between all four traits, suggesting that all four could be measuring the same construct. However, locus of control had the least correlation with the other traits. This indicated that the other traits (self esteem, neuroticism and general self-efficacy) were similar constructs with locus of control standing out as being distinct. These results highlighted the need for further in-depth investigation of these traits. Their second study (reported in same article) involved 901 participants who filled out a battery of standardized questionnaires assessing locus of control, neuroticism, self- esteem, general self-efficacy, personality traits, happiness, life satisfaction, stress, and strain. Confirmatory factor analysis was conducted to assess the commonality of the different traits being assessed. Results of study 2 showed that the four traits could not be viewed as independent separate constructs. Judge, Erez, Thoresen et al (2002) conducted two more studies to confirm their findings (all reported in same article). Both studies appeared to confirm the finding of the first two studies. All four traits appeared to measure the same underlying construct with poor discriminatory validity. The authors stated the following: "Despite these results, it is not our contention that researchers should abandon study of self-esteem, neuroticism, locus of control, or generalized self-efficacy as isolated traits. Our results suggest that there is some variance unique to each of these traits" (Judge, Ere, Thoresen et al 2002: 706). These authors emphasize that the "take-home message" of their study is not the abandonment of the use of the different terms but the awareness that there is a lot of overlap between all four traits and they should not be treated as independent constructs. They advocate the integration of literature regarding all four traits.

Results by Judge, Ere, Thoresen et al (2002), although providing one with an understanding of the similarities of these four traits, must be accepted with caution. In their first study, only

research articles showing correlations between traits were included in the meta-analysis. In other words, articles showing no relationship between traits were not included, thus providing for a skewed result from the onset. Definitions of self–efficacy and locus of control according to the literature (Abusabha and Achterberg, 1997; Ai et al, 2005) appear to be very different, so there is a good case for making a conceptual distinction. Below is a table outlining the differences between locus of control, self-efficacy and health locus of control. These results emphasize the need to integrate locus of control literature and others when investigating self –efficacy.

 Distinctions between self-efficacy and locus of control have been made by some studies. Wu, Tang and Kwok (2004) investigated the associations between self–efficacy, health locus of control and psychological distress in elderly Chinese women with chronic illnesses. The study sample consisted of 159 Chinese women aged between 60 and 89 years old. Interviews were conducted in which the following standardized measures were filled out: General Self-efficacy Scale (Schwarzer, 1993), the Multidimensional Health Locus of Control Scale (Wallston, Wallston and DeVellis, 1978), General Health questionnaire (Goldberg, 1978). Pearson's correlations were first carried out to investigate the correlations between variables. The results showed that internal and external locus of control did not correlate with each other, however internal locus of control correlated with general self-efficacy. External locus of control did not show any correlation with general self-efficacy. Psychological distress was correlated with external locus of control and inversely with general self-efficacy scores. This meant that more distressed participants report lower self-efficacy and higher reliance on external factors such as fate. Multiple regression analysis showed that high external locus of control and low self–efficacy were the best predictors of psychological distress among elderly Chinese women. However, the contribution of self-efficacy and external locus of control on

psychological distress was found to be independent of each other, somewhat challenging the findings of Judge, Ere, Thoresen et al (2002). External locus of control was identified as the most significant predictor of psychological distress after controlling for the effects of general self-efficacy.

Results of the study by Wu, Tang and Kwok (2004), support the argument that self- efficacy and locus of control measure two different dimensions of cognition. External LOC was still able to predict psychological distress even when self-efficacy was controlled for. This indicates the presence of some differences between external locus of control and self-efficacy. It seems possible to have high internal locus of control e.g. for health, believing in one's responsibility/ capacity to influence health – but low self-efficacy for managing a specific task such as giving up smoking, or managing self-care.

Shelley and Pakenham (2004) investigated the association of external health locus of control and general self-efficacy on distress in university students. They aimed to test the effects of external health locus of control and self-efficacy on distress. Two hundred and eighteen undergraduate students aged between 17 and 76 participated in this study. Measures used included the General Self-efficacy subscale of the Self-efficacy Scale by Sherer and Maddux (1982), the Powerful Others subscale from the Multidimensional Health Locus of Control Scale (Wallston, Wallston and DeVellis, 1978) and the short form Depression, Anxiety and Stress Scale (DASS) (Lovibond, 1998). Pearson correlations and regression analysis were used to investigate the associations between variables. Results of this study showed that high self-efficacy was related to reduced emotional distress, however external locus of control did not show any association with distress, in contrast to the findings of Wu et al (2004) in which external locus of control was significantly related with psychological distress. Three-way

interaction analysis showed that external locus of control when combined with self-efficacy was significantly related to psychological distress. The authors concluded that their results show that there are significant differences between self-efficacy (SE) and external health locus of control (EHLC). In other words, both SE and EHLC are independent constructs, however by acting together are significant determinants of psychological distress in university students. These latter results appear to be broadly in support of those by Wu, Tang and Kwok (2004). But results showing that EHLC did not correlate with distress are in conflict with results by Wu, Tang and Kwok (2004), who found that psychological distress correlated positively with EHLC and inversely with self-efficacy. Both studies used the multidimensional Health Locus of Control Scale in assessing locus of control. However, while the earlier study focused on elderly participants aged between 60 and 87 living with illness, Shelley and Pakenham's (2004) sample was made up of university students (presumably mostly in good health and high level of educational achievement). This could explain the differences in results related to the association of EHLC on distress.

In summary, self-efficacy and locus of control have been defined in the literature as two independent yet overlapping constructs. Table 2.1 highlights the differences between the concepts of self-efficacy, locus of control and health locus of control. Judge, Ere, Thoresen et al (2002) argued that both possibly assess the same underlying construct. However, when attempting to measure self- efficacy and locus of control, it appears that some other researchers are clear as to the differences between them. Shelley and Pakenham (2004) and Wu, Tang and Kwok (2004), have both demonstrated the independence of these two traits. Judge, Ere, Thoresen et al (2002) discuss the issue of the "Tower of Babel problem" whereby some research is ignored due to a different trait being used. They explained the possible neglect of certain parts of literature due to a supposedly different trait being measured and

thus a failure to build up the body of knowledge on a particular topic. For example, a literature review solely of studies on self-efficacy might lead to missing relevant literature on locus of control which might facilitate understanding of the effect of control and self-efficacy on human behaviour. This study will thus include some literature on locus of control with the intention that available findings on the relationships between personal control beliefs and behaviour in rehabilitation are covered.. This integration of literature was advocated by Judge, Ere, Thoresen et al (2002), to prevent what is termed the "Jangle fallacy"(Kelley, 1927 in Judge, Ere, Thoresen et al, 2002), which, according to Block (1995): "prevents the recognition of correspondences that could help build cumulative knowledge" (Block, 1995: 210).

Table 2.1: Differences in the concepts of Self-Efficacy, Locus of control and

Health locus of control (Perceived control)

	Self- Efficacy	Locus of control	Health Locus of control
Definition	"People's beliefs about their capabilities to produce designated levels of performance that exercise influence over events that affect their lives" (Bandura, 1994: 71)	"An individual's tendency to perceive events either as controlled by personal influences or by external forces" (Rotter, 1966)	"The belief that one can influence events related to one's health" (Wallston, Wallston and DeVellis, 1978)
Origins	Bandura's social learning theory (Bandura, 1977)	Rotter's social learning theory (Rotter, 1954)	Rotter's social learning theory and Bandura's social learning theory (Wallston, 1992)
Main Concept	Beliefs about task-specific self capabilities, belief in ability to successfully gain desirable outcomes on a given task (Bandura, 1977	Location of control over outcomes (Wallston, 1992)	Location of control and beliefs about behaviour and reward (Wallston, 1992)
Specificity	Task specific and specific to environment which task takes place (Abusabha and Acherberg, 1977	Domain specific i.e. health domain, social domain (Abusabha and Acherberg, 1997)	Domain specific

2.3: Literature Search

Aim of Literature Review:

To identify empirical studies of self-efficacy in stroke rehabilitation in order to identify gaps in the literature, and enhance understanding of self-efficacy in stroke rehabilitation.

Method:

The literature search involved 2 main steps. First, the following electronic databases relevant to medicine (Medline), nursing (Cumulative Index of Nursing and Allied Health Literature (CINAHL), and psychology (PsycINFO) were used to search for relevant articles. Search terms were crossed with each other and were related to self-efficacy and stroke rehabilitation such as self-efficacy, perceived control, cerebrovascular accident, physical therapy, exercise, rehabilitation. Abstracts of relevant articles were studied and relevant full articles obtained. Secondly, references of relevant articles were scrutinized to identify more relevant studies.

Limits:

The following limits were used to identify appropriate research: English only and research articles between 1996 and 2009.

Exclusion criteria

-Articles related to relatives/spouses of stroke survivor

-Articles not in English (however, note that **no Arabic literature on the topic was located**).

Results:

Figure 2.1 shows the results of the search for relevant articles. Only ten relevant studies were identified and included in the review below. The following is a narrative review of the identified literature on the topic.

Figure 2.1: Flow diagram of Literature Search (Self-efficacy in stroke Rehabilitation)

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┌─────────────────────────┐
│ 77 Citations found      │        ┌──────────────────────────────┐
│                         │───────▶│ 59 citations were excluded   │
│                         │        │ based on reading title and   │
│                         │        │ abstract – not an empirical  │
│                         │        │ study of self-efficacy       │
│                         │        └──────────────────────────────┘
│ 18 citations were       │
│ retrieved and reviewed  │
│ in more detail          │
└───────────┬─────────────┘
            │              ┌──────────────────────────────┐
            ├─────────────▶│ 1 article was in Chinese,    │
            │              │ thus excluded                │
            │              └──────────────────────────────┘
            │              ┌──────────────────────────────┐
            │              │ 3 articles were concerned    │
            ├─────────────▶│ with measures only,          │
            │              │ addressing reliability and   │
            │              │ validity of tools, thus      │
            │              │ excluded                     │
            │              └──────────────────────────────┘
            │              ┌──────────────────────────────┐
            │              │ 2 articles not relevant to   │
            ├─────────────▶│ the scope of this project    │
            │              │ i.e focused on memory,       │
            │              │ fatigue in stroke            │
            │              └──────────────────────────────┘
            │              ┌──────────────────────────────┐
            ├─────────────▶│ 2 articles were excluded     │
            │              │ because they were reviews    │
            │              │ not primary research         │
            │              │ projects                     │
            │              └──────────────────────────────┘
            ▼
┌─────────────────────────┐
│ Only 10 articles        │
│ included in final       │
│ analysis                │
└─────────────────────────┘
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2.4: Self-efficacy in Stroke Rehabilitation

At the time of this review, studies investigating self-efficacy in stroke experience and rehabilitation were very limited. The majority of the research articles located focused mainly on fall/balance self-efficacy. Below is an analysis of research regarding self-efficacy in stroke presented in two categories. Firstly, falls/balance self-efficacy research will be examined and then other self–efficacy articles not related to falls.

2.4.1 Self-efficacy and Falls

Self- efficacy and fear of falling in elderly adults and during stroke rehabilitation has been investigated by some researchers. Below is a review of literature looking at falls self-efficacy in stroke. Falls self-efficacy refers to the confidence that one can prevent one's self from falling.

Hellstrom, Lindmark, Wahlberg et al (2003) investigated the changes in fall self-efficacy over time, relationship of fall self-efficacy with functional ability and its predictive capability for activities of daily living at 10 months post-stroke. Thirty seven patients aged between 66 and 89 years participated in the study. Interviews were carried out at admission to the geriatric unit, at discharge and 10 months after the stroke. The following standardised questionnaires were administered during the interviews: Falls Efficacy Scale (Swedish version), Berg Balance Scale, Fulg-Meyer Stroke Assessment Instrument, the Functional Ambulation Classification and Functional Independence Measure. The Falls Efficacy is a 13 item questionnaire measuring an individual's perceived confidence in carrying out a variety

of tasks without falling. Items were rated on a visual analogue scale from 0 (not at all confident) to 10 (completely confident). Balance was assessed by the Berg Balance scale and the balance subscale of the Fugl-Meyer Stroke Assessment Instrument. Data were analysed with Spearmen's rho to assess correlations between falls efficacy and other measures, Mann-Whitney U test to evaluate differences between groups and Wilcoxon's signed rank test to identify significance of various changes. Linear regression analysis was also carried out to analyse predictive ability of various measures such as self-efficacy, and FIM scores on ADL disability at follow-up. Results showed a significant increase in all motor, balance and self-efficacy measures between admission and discharge. Falls self-efficacy was identified to be significantly correlated with balance and ambulation scores on admission and discharge. Patients with low fall self-efficacy scores at discharge had significantly lower scores in balance and locomotion on admission, discharge and follow up than those with high falls self-efficacy scores ($p<0.01$). Activities of daily living (ADL) 10 months post-stroke was best predicted by a model which included fall self-efficacy scores and FIM motor score at discharge. The combination accounted for 77% of variance of ADL scores, however falls self-efficacy accounted for the largest proportion of variance thus contributing the most in predicting ADL 10 months post-stroke.

Results by Hellstrom, et al (2003) provide evidence supporting the effect of rehabilitation in increasing physical function and self-efficacy post-stroke. Participants with low self-efficacy at follow-up showed poorer function and balance than those with high self-efficacy hence suggesting relationships between self-efficacy, motor function and balance. This relationship however cannot be viewed as causal. Self-efficacy cannot be concluded from the results of this study as causing or being responsible for better balance or better motor function as it may reflect awareness of these functional abilities (especially as low self-efficacy was associated

with poorer function on admission). The results, however, show falls self-efficacy to be the better predictor of ADL at 10 months than observer- based measures of balance also taken at 10 months. The authors thus advocate an incorporation of self-efficacy into assessment and treatment of the stroke survivor. This study was carried out in Sweden, thus making generalisation to Kuwait somewhat problematic due to differences in cultures and likely perception of disability. It does, however, highlight the possible role that self-efficacy could play in the rehabilitation of a stroke patient and increases awareness of the need to conduct more research on this topic specific to the rehabilitation of a stroke survivor.

Other studies also confirm results of Hellstrom, et al (2003). Salbach, Mayo, Robichaud-Ekstrand et al (2006) carried out a study assessing balance self-efficacy in persons with stroke and its predictive ability regarding physical function, health and perceived health status. Data were taken from a randomized control trial of gait- training in persons with strokes. Ninety one participants were randomly assigned into two groups: gait training group and upper limb function training group. Measures of balance, self-efficacy, cognition, depression, walking ability, activities of daily living (ADL) and perceived health status were taken. All measures were taken at three intervals: baseline, post intervention and 6-month follow-up. Measurements used included the Activities-Specific Balance Confidence Scale (ABC), Mini-mental state examination, Geriatric Depression Scale (GDS), and the Berg Balance Scale (BBS). Walking ability was measured with 5 measures: 6 minute walk test, the 5m walk, Timed Up and Go test, the Functional Ambulation Classification and dependence on walking aids. Activities of daily living (ADL) were assessed with the Barthel Index (Mahoney and Barthel, 1965). The physical function and the physical component summary of the Medical Outcomes Study 36 item short form Health Survey (SF-36) were used to assess function and physical health. Perceived health status was assessed with the visual analogue

scale (VAS) of the Euro-Qol. Data were analysed with Spearman's correlations for non parametric data, one way analysis of variance and multiple regression analysis to determine the contribution of balance self-efficacy to functional outcome. Results showed that balance self-efficacy scores were inversely related with depressive symptoms and level of support required, and positively related with independence in walking. This meant that people with higher self-efficacy were more likely to be less depressed, required less support and were walking more independently than those with lower self-efficacy. Balance self-efficacy was not shown to decrease with age. Other results reported include the following: balance self-efficacy correlated significantly with 6-month physical function, physical health and perceived health status. Multiple regression analysis revealed that balance self-efficacy was a significant predictor of physical function and health status. It accounted for 3% and 6% of variance in physical function and physical health scores respectively at the 6 month follow-up (but note the small proportion of variance accounted for even though significant). One cannot assume causal inference from the results of this study due to the correlational nature of the data.

Results of Salbach, Mayo, Robichaud-Ekstrand et al (2006), highlight the relationship between balance self-efficacy, depression, physical function and perceived health. The predictive ability of balance self-efficacy on physical function is consistent with that reported by other studies such as Hellstrom, Lindmark, Wahlberg et al (2003). However, this design still does not rule out the possibility that balance self-efficacy might reflect participants' awareness of their poor functional status rather than determining physical function.

Self-efficacy related to balance and falls has also been shown to predict history of falls. Belgen, Beninato, Sullivan et al (2006) investigated the relationship between self-efficacy

and falls history. Their sample was made up of 50 people with chronic stroke living in the community in Boston USA. Participants were aged between 35 and 87 with a mean of 59.9 years. Measures taken from participants included demographic data related to age, height, weight, alcohol use, co morbidities, date of stroke onset, and side of stroke. Falls history was assessed by self- reported number of falls within the last six months or since the onset of stroke. Self –efficacy was measured with the Falls Self-efficacy Scale which had been standardized for use with stroke survivors. Functional lower limb strength was measured by the Time Sit to Stand Test (STS). Other standardised measures used included the Berg Balance Scale, the Time Get Up and Go Test, and the Stroke Impact Scale (SIS), which measured several aspects of health. Data were analysed with the Mann-Whitney U test to compare means between groups and multiple stepwise regression to explain variance in balance and self-efficacy scores. Results showed that 40% of the sample reported falls and those with frequent falls were more afraid of falling and had lower falls-related self-efficacy scores than non-fallers. Falls-related self-efficacy was shown to be the best differentiator between those who had fallen and those who had not. Multiple regression analysis showed that "Sit to Stand (STS)" explained 52% of the variance in balance score thus implying the importance of lower limb strength to balance. Variance in fall self-efficacy was explained by knowing someone who had fallen, use of alcohol and Timed Sit to Stand Test (STS). This indicates that not only personal experience of falls might cause poor self-efficacy, but knowing of others falling, alcohol use and actual functional performance measures by Timed Sit to Stand (STS) might also lead to poor self-efficacy. Together these three explained 28% of variance in fall self-efficacy score.

Findings by Belgen et al (2006) are significant because they explain the possible influences of other issues such as knowing others who have fallen and poor functional ability on falls

self- efficacy. Fifty two percent of variance in falls self- efficacy was related to Sit to Stand function thus indicating that a significant aspect of falls self- efficacy is linked with functional ability. In other words, falls self-efficacy could simply be a reflection of participants' awareness of their physical status. The design of the study which was cross sectional and retrospective rather than longitudinal and prospective makes it somewhat difficult to assess the effect of baseline falls self-efficacy on the subsequent history of falls.

In addition to history of falls and functional outcome, life satisfaction is an important issue that could facilitate re-integration into the community. Pang, Eng and Miller (2007), investigated the contribution of balance self –efficacy on life satisfaction in community re-integration of older stroke survivors. The study sample was made up of 63 community dwelling older adults in Canada who were assessed more than one year post-stroke. Age of participants ranged between 50-87 with a mean of 65.4 years. Thirty six of the sample were male and twenty seven female. Outcome measures used included the Re-integration to Normal Life Index (RNL), the Fugl-Meyer Motor Assessment (FAM), the Six Minute Walk Test, the Berg Balance Scale, the Geriatric Depression Scale, and the Activities –Specific Balance Confidence Scale (ABC Scale). Data were analysed with Mann-Whitney U tests to determine differences between RNL index scores according to sex, type of stroke and side of weakness. Associations between variables were determined with Pearson correlation coefficients, and multiple regression analysis was carried out to investigate the contribution of balance self-efficacy to RNL index scores. Results showed that RNL scores were not significantly different according to sex, type of stroke and side of weakness. Pearson's correlation analysis revealed that ABC Scale scores showed the highest correlation with RNL index scores (r=0.527, p<.001), suggesting that balance confidence was significantly related to self-reports of re-integration to normal life. Significant correlations were also seen between

RNL index score and 6 minute walk test results, BBS scores and GDS scores. Multiple regression analysis showed that balance self-efficacy accounted for 6.5% of variance in RNL index scores, after adjusting for age, depression, gender and impairments as a result of stroke. The authors advocated the enhancement of balance self –efficacy to help stroke survivors re-integrate into the community.

Results by Pang, Eng and Miller (2007), provide some evidence of the role of balance self-efficacy in community re-integration of stroke survivors. It, however, must be noted that all participants were ambulating independently and it is unknown whether these results would apply to stroke survivors in wheel chairs or ambulating with walking aids. It does nevertheless highlight the importance of self-efficacy beliefs in moving on with life post-stroke. One cannot assume causal inference from the results of this study due to the cross sectional design. It cannot be claimed that increased self-efficacy caused a higher chance of community re-integration. However the association between self-efficacy and community re-integration is noteworthy.

Other more recent studies have investigated falls and balance related self-efficacy (Andersson et al, 2008 and Pang and Eng, 2008). Andersson et al (2008) investigated the relationship between fear of falling and functional outcome and characteristics of stroke survivors who scored high on fall-related self-efficacy. Their study involved the use of a sample of 140 stroke survivors recruited from a stroke unit who were followed up over 12 months. Participants were assessed on with the following scales: Birgitta Lindmark Motor Assessment Scale, Timed get up and go, Berg Balance Scale, Mini-Mental State examination, Geriatric Depression Scale and the Swedish version of the Falls Self-efficacy scale. Participants were asked if they had experienced a fall since discharge and to rate their vision. Results indicated

that both in participants who had fallen and those who had not had a fall, low fall-related self-efficacy was associated with poorer physical functioning. These results indicated that self-efficacy was more important than actual experience of falling amongst the stroke survivors studied, in predicting poorer functional ability.

Limitations of this study include the use of self-reported measures of falling as participants might report inaccurately both for reasons of memory and also social desirability effects. And as mentioned with other studies reviewed earlier, falls self-efficacy could simply be a reflection of participants' awareness of their physical status, hence having an expected association with poorer functioning.

Similar to results by Belgen et al (2006), Pang and Eng (2008) reported that falls-related self-efficacy was associated with falls in stroke survivors. However, their study focused solely on chronic stroke survivors with low bone mineral density (BMD), thirty-nine of such participants were included in the study. Measurements used included the Berg Balance Scale, Timed get up and go test, Stair climbing time, Six minute walk test, frequency of falls, leg muscle strength, spasticity and fall-related self-efficacy using the Activities-Specific Balance Confidence (ABC) scale. Multiple regression analysis identified that low falls-related self-efficacy was the most important independent factor associated with accidental falls. Participants in this study were all mobile hence the applicability of results to severely affected stroke survivors is questionable, and secondly, the data on falls collected was retrospective and based on self reporting which could be subject to biases, as mentioned above.

In summary, the literature reviewed above provides some evidence for the importance of falls- related and balance self-efficacy in stroke rehabilitation. Some studies have shown the ability of falls self-efficacy to predict functional outcome post-stroke (Hellstrom, Lindmark, Wahlberg et al (2003) and Andersson et al (2008). Pang, Eng and Miller (2007) provided evidence in support of balance self-efficacy being associated with their measure of re-integration into the normal lives of older stroke survivors. Belgen et al (2006) and Pang and Eng (2008) provided evidence in support of the relationship between low falls-related self-efficacy and actual falls in stroke survivors. The studies reviewed above were all carried out in the United States and in Canada, where Christian and secular ideas predominate. It is therefore unknown whether carrying out such studies in a different culture where Muslim beliefs predominate would yield different results, as fatalism and other beliefs related to religious affiliation might influence self-efficacy.

2.4.2 Other Studies Related to Self-efficacy and Stroke

Self-efficacy and locus of control during stroke rehabilitation have been investigated by other researchers (Bonetti and Johnston, 2008; LeBrasseur et al, 2006; Robinson- Smith, Johnston and Allen, 2000; Partridge and Johnson, 1989). These studies differ from those regarding falls and balance reported in the previous section in that they focus on beliefs regarding functional status in general, not specific to balance.

LeBrasseur et al (2006) investigated the contribution of behavioural factors (including self-efficacy) on disability and quality of life post stroke. They conducted a cross-sectional study in which 31 community dwelling participants who had a stroke within 6 to 24 months were involved. Self-efficacy was measured with the Ewart Self-Efficacy Scale, however this scale has not been validated for use in stroke. Other measures used included: Geriatric Depression

Scale, Sickness Impact Profile (SIP), Late Life Function and Disability Instrument, and lower limb muscle strength with the use of a computerized-interface pneumatic resistance machine. Step-wise regression analysis revealed that self-efficacy and depression were strong predictors of quality of life as measured by the SIP and Depression Scale. The authors stated the following: "These findings strongly suggest that the perception of one's ability may be as important as objective physical impairments in mediating the disablement process." (LeBrasseur et al, 2006: 1349). Caution is advised when interpreting these results for the following reasons: 1) a small sample size of 31 on which step-wise regression was conducted, 2) the Ewart Self-efficacy Scale has not been validated for use in stroke research., 3) results might not be applicable to more acute or more long-term stroke survivors as participants were limited to 6-24 months post stroke. The results, however, provide some indication that self-efficacy could be related to quality of life post stroke. These results are similar to those of an earlier study by Robinson- Smith et al (2000).

The relationship between self-care self-efficacy, functional independence, quality of life and depression post-stroke has been investigated by Robinson-Smith et al (2000). A total of 63 stroke survivors from rehabilitation institutions from the North-eastern United States participated in the study. Subjects were assessed at one and six months post-stroke and questionnaires were used to assess self-efficacy, quality of life, depression and functional independence. Self-efficacy was measured with the use of the Strategies Used by People to Promote Health Questionnaire (SUPPH). This is a 36 item questionnaire which assesses patients' confidence in their ability to carry out self care behaviours. Reliability and validity of this scale has been established (Lev and Owen, 1996). Twenty-three of the 36 items of the scale were modified by Robinson-Smith et al (2000) to be specific to their study on stroke

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survivors. Modification occurred because this scale was initially developed for patients receiving cancer treatment thus some items were inappropriate for stroke patients. However reliability and validity of the adapted scale was not established. Quality of life was measured by the Quality of Life Index –Stroke version (QLI). This is a 64 item questionnaire which measured satisfaction with and importance of the following domains: health and functioning, socioeconomic status, psychological/spiritual beliefs, and family support. Respondents rated satisfaction and importance of items pertaining to the 4 main domains on a six point scale. Reliability and validity of the QLI has been established (Ferrans and Powers, 1985). Depression was measured with the Centre for Epidemiologic Studies Depression Scale (CES-D), which is a standardised 20 item self-report of depressive symptoms in a general (community) population (Radloff and Locke, 1986). Shinar et al (1986) have demonstrated its reliability and validity for use with stroke patients. Functional independence was measured with the standardised Functional Independence measure (FIM). Data were analysed with Pearson correlations and hierarchical multiple regression.

The results showed that at one month and six months post-stroke, low ranking items on the Quality of life scale included lack of job and disturbances in sex life. Scores of self-efficacy, quality of life, depression and functional outcome all improved over time. Scores of self-care self-efficacy were strongly correlated with quality of life scores. As self-care self-efficacy increased, quality of life increased over the 6 months. Correlations between self-care self-efficacy and quality of life at 1 month and 6 months post-stroke ranged between 0.41 to 0.81 (p<.001). Self-care self-efficacy was also shown to be significantly inversely correlated with depression at 1 and 6 months post-stroke. Participants reporting higher self-care self-efficacy scored lower in depression scores. Other results showed that at 1 month post-stroke, functional independence (FIM score) was not related to quality of life, however it was related (significantly but not strongly) to depression. But at 6 month post-stroke, functional

independence showed significant relationship with quality of life but not depression. Quality of life was found to be lower in participants who were retired compared with those in professional or skilled jobs and participants living alone at six months post-stroke showed an increase in depressive symptoms compared with those living with other people (spouse, relatives, or friends). However, no explanations were given regarding the effect of relationships on depressive symptoms (although it seems possible that people's engagement with meaningful roles and occupations influences depression).

Results reported by Robinson –Smith et al (2000) provide evidence in support of a significant relationship between self care self-efficacy, quality of life and depression after stroke. Disappointingly, they failed to assess the direct correlation between self-care self-efficacy and functional independence. In addition to this, the use of the Strategies Used by People to Promote Health Questionnaire (SUPPH) to assess self-efficacy in stroke patients must be queried. The SUPPH was developed with open-ended interviews for patients receiving cancer treatment. Items related to their previous experience, expectations, stressful events and strategies used to overcome their difficulties. Adaptation of this questionnaire to make it applicable to stroke patients did not include any interviewing to ensure that the items were related to the stroke patients' experience and despite its name, it really did not specifically target self-care activities such as washing, dressing, and feeding. Interestingly, functional independence appeared to affect the stroke survivor in different ways at 1 month and 6 months post-stroke. At 1 month, functional issues contributed to depression but this was not the case at 6 months post- stroke. It is possible that with time patients accept some of their disabilities and that depression might not show a strong association with loss of function. However, quality of life at six months was related to functional independence scores.

What are the mediators responsible for the association between self-care self-efficacy and quality of life? This is a question that still needs to be answered. Although providing us with a base for understanding the effect of self-care self-efficacy on quality of life, one must apply caution in generalising these results to all stroke survivors. This study was conducted in the United States. It is possible that a similar study conducted in Kuwait might yield different results due to cultural and religious differences.

In accordance with recommendations by Judge, Ere, Thoresen et al (2002), further searches were carried out using the terms "locus of control" and "Perceived control" regarding rehabilitation of stroke patients and a study by Partridge and Johnson (1989) was located. They investigated the predictive value of perceived personal control with regards to functional recovery in 20 stroke survivors (14 women and 6 men) and 20 wrist fracture patients (2 men and 18 women). Disability was assessed in both groups of participants. Four physical measures were assessed in the stroke group: gross body movement, arm movement, leg movement and personal care activities. Three measures of disability were taken from the wrist fracture group: wrist movements, grip strength, and personal care activities. Recovery locus of control (RLOC) was assessed with the RLOC scale which was developed by the researchers. This is a 9 item scale which assessed internal and external beliefs regarding perceptions of control (external and internal locus of control). Validity and internal consistency of the scale was ascertained prior to use of the scale. The results showed that patients scoring higher on the internal beliefs part showed faster recovery than those scoring more on the external beliefs part of the RLOC scale, thus reporting the presence of a strong positive correlation between internal locus of control scores and recovery from disability. Partridge and Johnston (1989) report that these results suggest the presence of a predictive role of locus of control in stroke rehabilitation and the rehabilitation of individuals with wrist

fractures. They suggest that patients with higher internal control will recover faster than those who depend on external 'powers' (such as the therapists) to get them better. The authors stated the following regarding their results: "it might be useful to foster patients' belief in their own control, this is in contrast to most hospital care, including physiotherapy, where the emphasis is on external control…" (Partridge and Johnston, 1989: 58). This comment may have been targeted towards the more passive role patients played in their rehabilitation during the 1980's, however physiotherapists these days expect patients to be more active partners in the rehabilitation process.

Bonetti and Johnston (2008) more recently, investigated perceived control and recovery of walking behaviour in 203 stroke survivors. Assessments on participants were taken 2 weeks after discharge from hospital and 6 months later. Measures used included: Ambulation subscale of the Functional Limitation Profile, single measures of locus of control and self-efficacy, measures for perceived behaviour control (2 items) and Mental Status Questionnaire. Results showed that both self-efficacy and perceived behavioural control predicted walking limitation and recovery. However, locus of control did not predict walking behaviour. One major criticism of this study is the use of a single item to assess self efficacy, and locus of control, which may lack sensitivity. These measures were developed for the study with no reports of reliability or validity testing. This has implications for the interpretation of these results.

Conclusion

The literature reviewed above, suggests a positive association between self –efficacy and quality of life and functional outcome in stroke rehabilitation. However these studies are few in number. Findings from Robinson–Smith, et al (2000) indicate the importance of self-care

self-efficacy during rehabilitation and its association with lower levels of depression and better quality of life post-stroke. Their results also highlighted that loss of function was not necessarily associated with depression at 6 month post-stroke. These findings are significant for the current project being undertaken and it is hoped that its results will build on those of Robinson–Smith, et al (2000). LeBrasseur et al (2006) also reported similar finding regarding the association between self-efficacy and quality of life. Partridge and Johnston (1989), reported the importance of internal locus of control during rehabilitation and advocated fostering of patients internal beliefs and reducing dependence on therapists. They demonstrated the predictive role of recovery locus of control in stroke patients. Participants with higher internal locus of control showed faster recovery. One might speculate that self-efficacy might have a similar predictive role in stroke rehabilitation. Further research investigating self-efficacy specifically is required. Bonetti and Johnston (2008) did not find an association between locus of control and recovery of walking, however, self efficacy and perceived behavioural control predicted recovery. Locus of control and self-efficacy might be culturally sensitive constructs. Certain religious and cultural beliefs could foster assumptions about the desirability of external control and lower self-efficacy, potentially having implications on recovery. This necessitates carrying out research on people of different religious faiths and cultures to identify culturally sensitive measures of self-efficacy and internal control.

Although the limited research available appears to suggest that self-efficacy and perceived control may play a role in stroke rehabilitation, no study to date has investigated the effect of self-efficacy related to psychosocial adaptation during recovery. Information on self-efficacy beliefs related to psychosocial adaptation following stroke would change current management

of stroke patients if it was found to be significant. More emphasis would therefore be put on dealing with these issues during stroke rehabilitation.

2.5: Life Satisfaction and Quality of life in Stroke

This section will begin by exploring debates about the appropriate meaning and scope of the term life satisfaction, and comparing it with some of its alternatives. Life satisfaction has been defined as: "a contentment with or acceptance of one's life circumstances or the fulfilment of one's wants and needs for one's life as a whole" (Sousa and Lyubomirsky, 2001: 667). Life satisfaction has been referred to being the same as quality of life by some authors (Sousa and Lyubomirsky, 2001; King, 1995). However, the use of the term "Quality of life" was found to be more widely used than life satisfaction in health research. Some researchers view Quality of life (QOL) as a wider concept in which life satisfaction and subjective well-being are some elements, however clear distinctions between these three terms are not present in the literature reviewed. Tate and Forchheimer (2002) stated the following: "In general, subjective definitions of QOL include the following concepts: well-being, life satisfaction, morale, and happiness" (Tate and Forchheimer, 2002: 401).

2.5.1 Defining Quality of Life (QOL)

Quality of life (QOL) can be defined as contentment with areas of life that are held as important to a person (King 1995). QOL has also been defined as "an individual's perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns" (Sturm et al, 2004: 2340). In this definition, QOL is seen as a comparison between position in life and norms within a society and expectations of the individual. In King's (1995) definition, QOL

is seen in relation to issues viewed as important to the individual and not a predetermined set of issues. This definition, however, fails to take into consideration the effect that societal norms play on determining what is important to the individual. The main issue about QOL in both definitions above is the indication that it is subjective and individualistic. This provides a challenge in assessing it and may also present problems for assessing people living in less individualistic cultures. Another definition of QOL is "the impact of person's health on his or her ability to lead a fulfilling life" (Carr, Gibson and Robinson, 2001: 1240). This definition directly relates health with quality of life and appears to imply that QOL is somehow a measure of ability to live a fulfilling life, and is health-dependent. It however fails to acknowledge the subjective nature of QOL. A more appropriate term for this definition might be "Health-related quality of life (HRQOL)" (Carr et al, 2001). This term was found to be used extensively in the literature.

2.5.2 Health-related QOL

Health-related quality of life describes those specific aspects of quality of life that are affected by disease process (Sturm et al, 2004). Patients are said to assess their health-related quality of life by comparing their health expectations with their experience and clinical status (Carr, et al 2001). Regarding health- related QOL, Carr et al (2001: 1240) state that: "QOL is a broader concept and it's concerned with whether disease or impairment limits a person's ability to fulfil a normal role". This description appears to tie functional ability directly with QOL. However they fail to describe to readers what they mean by "normal role". In addition to this, describing HRQOL only in terms of normal roles and related function might limit understanding of it and provide only one side of a multifaceted construct. This will also lead to errors in assessment of severely disabled people who may have adapted to their disability

and would rate HRQOL high if other issues apart from just function were assessed such as social relationships and psychological functioning.

QOL and health-related QOL are commonly referred to as static constructs (Carr, Gibson and Robinson, 2001). However, Carr et al (2001) argue that HRQOL is a variable construct which changes depending on the point at which the assessment is done. In other words, ratings of HRQOL could change within a week or month depending on the perceptions of the person being assessed. This further adds to the difficulty in assessing HR QOL adequately. Most HRQOL measures confuse satisfaction with life and functional abilities such as walking a certain distance and performing other activities which the test-makers have assumed are psychologically important to disabled people. The QOL concept has evolved over time in ways which have lost sight of some of the subjective priorities of the people being studied.

2.5.3 Subjective Well-being

Wyller et al (1998) used the term "subjective well-being (SWB)". This term was considered a more appropriate term instead of quality of life because the authors aimed to focus more on the emotions such as satisfaction and happiness as opposed to other measures such as motor function and activities of daily living which have now been widely included in the use of the term Quality of Life. Wyller and colleagues reported that initially in the literature: "QOL was clearly related to subjective perceived emotions e.g. satisfaction and happiness" (Wyller et al, 1998: 363). Their study investigated four aspects of subjective well-being: satisfaction, strength, calmness and cheerfulness. The study will be discussed later in this chapter. Subjective well-being was described as a "more positive concept and comprises dimensions of happiness, life satisfaction, morale, self esteem and sense of coherence (Bowling, 2005: 6). Similar description is provided by Diener, Suh, Lucas, et al, (1999). They described

subjective well-being as a broad concept involving emotional response, and both global and domain-specific life satisfaction (Diener, Suh, Lucas, et al, 1999).

Summarising, the distinction in the use of the terms quality of life, life satisfaction, and subjective well-being in the literature is not clear cut. 'Quality of life' in many studies has focussed on "health-related" quality of life which differs from life satisfaction and subjective well-being. Health-related quality of life equates perceived health status with quality of life rather than the subjective assessment of one's contentment with life despite health status and disability which is the interest of the current project. Following is a literature review of factors associated with life satisfaction post-stroke.

2.6: Factors Associated with Life Satisfaction Post-stroke: a Narrative Review

As mentioned previously in this chapter, the terms quality of life, life satisfaction and subjective well-being are often used interchangeably in the literature, however close scrutiny of the assessment tools used indicate that different constructs are being measured. The majority of the articles investigating quality of life use tools measuring health-related quality of life which differs from life satisfaction, as discussed above. However, life satisfaction and subjective well-being appear to be similar constructs with differences that are difficult to establish. Subjective well-being has been described as: "an individual's global perception of life within a defined time period" (Sveen, Thommessen, Holter et al, 2004: 267). As mentioned previously, Wyller et al (1998) used the term "subjective well-being (SWB)" to place more emphasis on emotions such as satisfaction and happiness.

Choosing between a systematic review and a narrative review

No previous systematic review has been conducted on factors associated with SWB or life satisfaction in stroke. A systematic review involves "attempts to collate all empirical evidence that fits pre-specified eligibility criteria in order to answer a specific research question" (Higgins and Green, 2009: 6). It involves the application of rigorous scientific strategies, in the synthesis, assembly, and critical appraisal of all relevant studies. A systematic review is carried out in such a way as to limit bias and random errors (Higgins and Green, 2009; Egger, Smith and Altman, 2001). A systematic review may or may not involve a meta-analysis. Meta-analysis involves the use of statistical methods to combine results of two or more tests, with the aim to produce an estimate of a treatment effect (Egger et al, 2001, Cook, Mulrow and Haynes, 1997). Systematic reviews with meta-analysis are also termed quantitative systematic reviews and those that summarize studies without combining the results statistically are termed qualitative systematic reviews. Systematic reviews are critical in providing Evidence Based Practice (EBP) (Khan, Kunz, Kleijnen et al, 2003). Evidence Based Practice (EBP) can be described as: "is the judicious use of current best evidence in making decisions about health care" (Khan et al, 2003: 2).

Conducting Systematic Reviews

The aim of a systematic review is to produce a bias-free report of all relevant findings regarding a specific research question. These reports are used to investigate effectiveness of treatment methods and to improve how health care is delivered (Murphy, Robinson and Lin, 2009). This involves screening, coding, interpreting and summarising all available research which is a long process and requires appropriate resources (Turner and Nye, 2007). A systematic review is more rigorous than a traditional narrative review in that 1) it addresses a specific, clearly formulated question, 2) it uses explicit methods to identify, select and

critically appraise identified research studies, and 3) statistical methods might or might not be used to analyze, summarize and synthesise the findings of the included relevant studies. Systematic reviews are commonly used with intervention studies. They can also be used to identify frequency, rate of a particular feature or disease, diagnostic accuracy, risk factors and prognosis to a well formulated question (Egger et al, 2001). This type of review involves more than one researcher to adequately analyse and critique the literature. Higgins and Green (2009) recommend a minimum of two researchers in the evaluation of relevant databases and the relevant research studies in order to reduce biases and errors. Systematic reviews can be carried out in the following five main steps, according to Pai, McCulloch, Gorman et al (2004):-

1) Formulating the question

2) Search and inclusion of primary studies

3) Quality assessment and data extraction

4) Synthesis and summary of study results

5) Interpretation

Other researchers (Egger et al, 2001, Turner and Nye, 2007) have expanded the five steps into the following eight steps:

1) Formulate review question

2) Define inclusion and exclusion criteria

3) Locate studies

4) Select studies

5) Analyse study quality

6) Extract data

7) Analyse and present results

8) Interpret results

Challenges of systematic reviews

Turner and Nye (2007) advocate that these steps (above) be adhered to by verification through a peer review system, with two substantial experts at the second stage and a methodological expert. As this was a student project this verification process was not feasible. In addition to this, although systematic reviews provide a more thorough appraisal of the evidence, there are limitations to this type of review. Systematic reviews have been criticized to be somewhat uni-dimensional in representing the effects of complex therapeutic interventions, thus limiting application of evidence to practice (Murphy, Robinson and Lin, 2009). Unlike the medical field with available randomized controlled trials (RCT) and intervention studies to include in the systematic review, rehabilitation interventions like occupational therapy and physiotherapy involve more complex interventions in targeting function and disability with limited research evidence (Murphy, Robinson and Lin, 2009). Combining research results from different settings and study designs in a systematic review can yield misleading findings because of the use of different outcome measures and non-equivalent samples (Pai et al 2004). However, some researchers claim that combining findings from different settings/ designs increases the transferability of the results (Glasziou, Irwing, Bain et al, 2001). Results from systematic reviews do not show how effectively a strategy or treatment might be transferable to other cultures. It can thus never replace sound clinical reasoning (Cook et al, 1997). Murphy, Robinson and Lin (2009) express the view that thorough synthesis of research results in occupational therapy for a systematic review might present some difficulties due to the wide variety of interventions investigated and the use of a wide variety of outcome measures. The same might be true in other similar disciplines like physical therapy. Despite the widespread notion that systematic reviews are fully objective and balanced, a few researchers have reported significant differences in the quality of these reviews and varied answers to the same question (Shea, Grimshaw, Wells et al, 2007).

Certain biases have been identified as possibly influencing the outcome of the reports such as publication bias, language restriction, publication status and reviewers' methodological quality (Shea et al, 2007). Several tools have been developed to assess the quality of systematic reviews. These include the Critical Appraisal Skills Programme (CASP version for systematic reviews; Public Health Unit, 2006) and A Measurement Tool to Assess Reviews (AMSTAR) (Shea et al, 2007). Systematic reviews have been criticized as being too rigid in their presentation and need to be more user friendly for policy makers and managers (Lavis et al 2006). Other criticisms of systematic reviews include the following, as outlined by Dijkers (2009):

- These reviews limit themselves to randomized controlled trials (RCT) (the type of evidence traditionally regarded as having the highest quality in the 'evidence hierarchy') and in topics with no or few RCTs, these reviews only advocate the need for "more research". This was very much an issue in this project as RCTs were generally not relevant to the study of naturalistic relationships between life satisfaction and other variables.

- Studies chosen in systematic reviews into specific interventions tend to include participants with no or few comorbidities. This affects the generalisability of the results of systematic reviews to clinical populations such as older people with stroke who often have such co-morbidities .

- Outcomes provided by systematic reviews may not necessarily help in clinical decision- making because the rigid structure of these reviews make then hard to read and understand by the clinical practitioner, or to apply in the clinician's own setting.

Table 2.2: Differences between Narrative Reviews and Systematic Reviews (based on Cook, Mulrow and Haynes, 1997)

Feature	Narrative Review	Systematic Review
Question	Often broad in scope	Often a focused clinical question
Sources and search	Not always reported, potentially biased	Comprehensive sources and explicit search strategy
Selection	Not always specified, potentially biased	Criterion-based selection, uniformly applied
Appraisal	Variable	Rigorous critical appraisal following a recognised CASP tool
Synthesis	Often a qualitative summary	Both qualitative and quantitative summary (meta-analysis)
Inferences	Sometimes evidence-based	Aim to be evidence-based

Narrative Literature Reviews

Dijkers (2009) argues that narrative literature reviews have their place in synthesis of literature and in many situations might be more advantageous than systematic reviews. The aim of a narrative review is: "to lay out the most recent and best knowledge of various aspects of a problem" (Dijkers, 2009:427). A narrative review could thus be used to present information about a phenomenon, or condition, to assist the understanding of practitioners in that topic area, thus offering guidance to available research evidence. Narrative reviews allow for the investigation of broader topics than systematic reviews and allow for summarising results from different disciplines (Hammersley, 2002). They are claimed to be more

appropriate in describing the history or development of a problem and are useful in describing what we know or do not know about a phenomenon or condition (Cook et al, 1997). Table 2.2 outlines differences between systematic reviews and narrative reviews. Narrative reviews, however, have been criticized to be subjective in nature in that research articles included and critiqued are based on subjective decisions of the researcher (Bowling and Ebrahim, 2005). Dijker (2009) recommends the inclusion of a search strategy leading to narrative literature reviews, detailing how studies were chosen and judgements made, to help improve the quality of these reviews.

In the current project, a narrative review was more appropriate due to the following reasons: 1) each of the studies identified had different research questions, 2) samples e.g. age, time post- stroke and location, in the studies varied, 3) different issues were investigated as being related to life satisfaction, 4) primarily descriptive rather than intervention studies were relevant to understanding the variables associated with life satisfaction. In order to investigate a broad set of factors associated with life satisfaction, a narrative review was conducted.

Badger, Nursten, Williams et al (2000) advocate carrying out a narrative review in a methodical fashion which involves the following four key areas:

1) definition of the problem, inclusion and exclusion criteria

2) the search strategy

3) criteria for evaluation of studies

4) data extraction

Depoy and Gitlin (1998) outline a similar 5 steps in conducting a literature review

   1) Determine when to conduct a search

2) Delimit what is searched

3) Access databases, periodicals, books and documents

4) Organize the information

5) Critically evaluate the literature

6) Write the literature review

Both sets of steps were followed in this current narrative review.

2.6.1 Methods

Search Strategy

The first step of the review was to conduct a literature search using various databases (Bowling, 2002). Searches were conducted using the following electronic databases: Medline (1950-August 2009), CINAHL (1988-August 2009), PsycInfo (1980- August 2009), British Nursing Index, AMED (Allied and complementary medicine)-1985 to August 2009, Cochrane library, and Centre for Reviews and Dissemination Databases. These databases of literature contained research from a variety of disciplines such as medicine, nursing, social care, rehabilitation, psychology and sociology. The key words used were: stroke, cerebrovascular disease, life satisfaction, well-being, and psychosocial. Reference lists of all obtained articles were also scrutinized to identify additional relevant articles.

Selection criteria

Included articles in this literature review were studies following these criteria: English language articles, specific to stroke (cerebrovascular disease), studies on life satisfaction, and well-being. In the recognised scientific databases that were accessed, no Arabic literature on this topic was identified. Studies using health-related quality of life measures were eliminated from the study for reasons explained in a previous section. Other exclusion criteria included:

studies on spouses and carers, drug testing, evaluation of different measurement tools, and assessment of therapeutic programmes without the assessment of life satisfaction or well-being post- stroke. Studies using qualitative methods were also excluded, thus only quantitative studies were included. This ensured that the literature review was about factors identified statistically to be associated with life satisfaction. This was appropriate given the initial intention of this project was to develop and test a psycho-social self-efficacy scale.

Critical evaluation of each article was carried out by the researcher applying knowledge of research concepts rather than systematic application of the Critical Appraisal Skills Programme (CASP) tool (Public Health Unit, 2006). However the CASP tool served as a useful reference. Several authors have provided a series of questions that can be used as a guide during critical analysis of research articles, and these were followed to guide the evaluation. These include analysis of the purpose of the study, background information reviewed, its methods, limitations of study design, tools used, statistical tests employed and reliability and validity of results (Bowling, 2002; Depoy and Gitlin, 1998).

2.6.2 Findings

Twenty five articles were identified specifically targeting life satisfaction in stroke, however five were excluded because of the use of health-related quality of life measures despite referring to life satisfaction in the title/ abstract. Only 20 papers focused on life satisfaction and subjective well-being post-stroke and were included in the final review. Figure 2.2 shows a flow diagram of the search results. Articles will be discussed under the following headings:

a) Multiple variable research on stroke and life satisfaction

b) Research on well-being and stroke

c) Research on participation in meaningful activity and return to work

d)   Leisure activities and life satisfaction post-stroke

Articles related to these four headings will be presented in 3 separate tables: Table 2.3 (multiple variable research), Table 2.4 (Well-being), Table 2.5 (meaningful activity, return to work and leisure activities).

Figure 2.2:   Flow diagram of Literature search
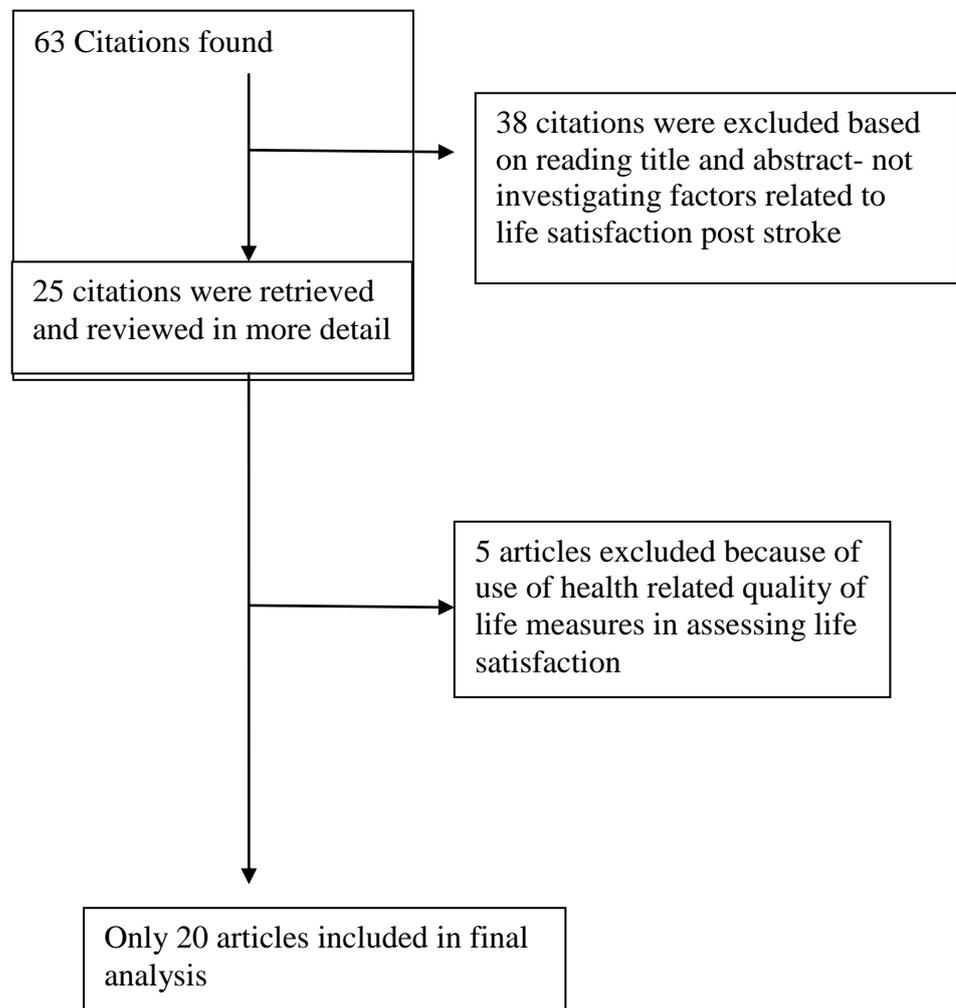
2.6.3 Discussion

i) Multiple variable Research on Stroke and Life Satisfaction

Of the 20 studies relevant to this review, 11 concerned multiple variable research on stroke and life satisfaction. Multiple variable research presented in Table 2.3, identified reduced social network and increased severity of illness/disability as significantly related to poorer life satisfaction post-stroke. Other factors identified included living conditions (living alone), aphasia, depression, reduced leisure activities post- stroke, increased hospital stay, urinary incontinence and astheno-emotional disorder. Of the eleven studies identified, only two were Non-Western (i.e one was carried out in Israel and the other in Japan). The others were carried out in Sweden, Canada and the United States.

Table 2.3:

Studies focusing on multiple variables related to life satisfaction.

Research article	Setting and Participants	Age of stroke participants/duration since stroke	Multiple variables assessed	Measurement tools used	Data Analysis	Results	Strengths of study	Weakness of the study
Astrom, Adolfsson, Asplund, Astrom, 1992	80 stroke survivors Sweden	Mean age 73years (44-100yrs) 0-12months post-stroke	Disability, social network, depression	Questionnaire of living conditions and life satisfaction, Katz Index of ADL	Chi square tests, McNemar's test, Pearson coefficients, Fisher's exact test	Major depression and ADL dependence were associated with low life satisfaction post-stroke	Standardized assessment of ADL Results compared to general elderly population Of the 98 patients considered for study 80 were included (16 died, 2 were inaccessible) Follow up carried out after 3 months	No reported reliability /validity testing of life satisfaction measure Sample not described in detail

Astrom, Asplund and Astrom, 1992	50 particip- ants	65-84yrs old. Mean age-71.4 yrs old	Functional disability, depression, mental status and social network	Living and life satisfaction questionnaire (developed for the study) Katz Index of ADL	McNemar's test and Pearson's correlations	Increased dependency, depression , reduced social network, and reduced leisure activity were related to poor life satisfaction	Longitudinal study design with data collected 4days after admission, 3 months, 1 year, 2 years, and 3 years after stroke	No reliability and validity testing of questionnaire used in study.
	Sweden	0-3 years post- stroke					Sample described in detail	Limited generalisability of results due to small sample size.
							Standardized assessment of ADL	Only 50 of the initial 98 were included in the final result by the 3rd year follow up. 37 died (no description of these), 4 had recurrent stroke and 2 had severe aphasia and mental retardation
							Pt results compared to a national sample of 294 elderly people	
Carlsson, Moller and Blomstrand, 2003	75 stroke survivors	59.6yrs (SD11.3)	Functional ability, handicap, astheno- emotional disorder (AED) perceived symptoms, depression	Barthel Index, Oxford Handicap Scale, Perceived Life Satisfaction Check list	Spearman's rank correlation and chi square test	AED symptoms correlated with life satisfaction	1 year follow up carried out	Participants younger than in other studies, so generalisability to older population questionable
	Sweden	0-1 year post- stroke					Sample described in detail	
							Standardized tools used	Stroke pts whose spouse had suffered a stroke were excluded
							Results compared with norm values from Swedish population	Only stroke patients with a spouse were included

| Edwards, Hahn, Dromerick, 2006 | 360 Stroke survivors

United States | 22-99 years Mean age 70 (SD 14)

6 months post-stroke | Stroke severity, functional status, urinary incontinence and cognitive status | National Institute of Health stroke scale (NIHSS), functional independence /assessment measure (FIM/FAM, Stroke adapted SIP, Re-Integration to Normal Living Index, Short Form 12 health survey, Activity card sort checklist. | T tests, one way ANOVA, Stepwise hierarchical logistic regression | Poor scores on FIM cognitive scale most significant predictor of life satisfaction. Urinary incontinence associated with poor satisfaction post-stroke | Standardized tools used

Large sample size compared to other studies in this review

Relevant sample details described

Retrospective analysis of data with follow up telephone calls | No reporting of ethical procedures

Use of self-report to assess urinary incontinence means a possibility of under-reporting,

No reporting regarding self-management of urinary incontinence |

Gottlieb, Golander, Bar-Tal and Gottlieb, 2001	100 stroke survivors Israel	Mean age 73+/- 8 years Mean-15 months post-stroke	Post- stroke impairment, post-stroke disability, handicap, social support, depression	Functional Independence Measure, London Handicap Scale, Life Satisfaction index, Tel Aviv Social Support Instrument	Correlation coefficients and multiple regression	Positive significant correlation between disability scores, handicap scores and life satisfaction suggesting that less disability and handicap were associated with higher life satisfaction	Random and retrospective selection from larger population study Standardized tools used to assess disability, handicap and social support Sample described in detail 21pt refused to participate but no statistical difference in stroke related characteristic Follow up carried out 1 year post discharge	Measure of life satisfaction not specific to stroke Inclusion criteria- fully independent in indoor mobility and ADL prior to stroke and living at home on follow up visit Ethical procedures not reported

Kim, Warren, Madill and Hadley, 1999	50 Stroke survivors Canada	Mean age 75yrs (SD-6) 1-3 years post-stroke	Functional status, social support, Perceived health status, depression	Ferrans and Powers Quality of life Index, FIM, Social Support Inventory, Centre for Epidemiologic Studies Depression Scale	Pearson's correlation, t tests and stepwise multiple regression analysis	Functional outcome, depression, marital status, social support, were correlated with life satisfaction. Depression was the strongest predictor	Standardized assessment tools used Life satisfaction assessment standardized for use with stroke patients Extensive literature review Sample described in detail	No reporting of ethical procedures Small sample size for the use of multiple regression Large number of participants refused to participate in study (120 approached). Limited generalizability of results due to small sample size Participants must have had their first stroke between 60 and 85yrs and been discharged from a rehab facility

Nagayoshi, Iwata and Hachisuka, 2008	Japan, 869 participants	55-91 yrs old 5.3years (plus/minus 4.8 years)	Life satisfaction, health status, functional ability, severity of aphasia , type of hemiparesis, living conditions	Satisfaction with daily life scale (SDL), Short form -36, Self rating Barthel index, self rating Frenchay Activity index	Data were analysed with the use of chi-square and ANCOVA with age as the covariate.	Living conditions, aphasia and hemiparesis were related with life satisfaction	Sample described in detail Large sample size Standardized tools used Comparison made with community dwelling elderly	No reporting of ethical procedures Assessment of life satisfaction not standardized No follow-up carried out
Osberg, DeJong, Haley et al, 1988	United States, 89 particip-ants	Not reported	Severity of illness, function at admission, wheelchair use, Social support	Horn index (severity of illness), Barthel index/Kenny scale, Single item life satisfaction score (1-5scale)	Multiple regression analysis	Social support, and severity of illness and life satisfaction 1 month post-discharge were related to life satisfaction at 1 year post discharge	Standardized tools for ADL Methodology and sample characteristics described in detail in another article	Single measure of life satisfaction 1-5 scale Exclusion criterion was a Barthel score of above 75 Limited generalisability due to strict exclusion criteria

Ostir, Berges, Ottenbacher et al, 2008	823 particip-ants, United States	>55 yrs old Mean age-72.8yrs old 3-4 Months post-stroke	Functional status, depression, and length of hospital stay	4 item positive emotion summary score from Centre for Epidemiologic Studies Depression scale (CES-D scale), Inpatient rehabilitation facilities patient assessment instrument (IRF_PAI)	Linear regression and multiple regression	Functional status at discharge was associated with positive emotion including satisfaction post-stroke.	Follow up carried out with telephone interviews 3 months post discharge Large sample size Detailed information on sample Standardised tools used From 1006 patients approach, 823 were included, 29 died and 44 refused follow up	Despite the use of a longitudinal design, positive emotion was not tested on the initial assessment and functional status was assessed only once post-discharge
Sonde and Viitanen, 2001	92 Stroke Surviv-ors Sweden	Mean age 80 (SD 7) 12 months post-stroke	Depression, functional independ-ence, and length of hospital stay	Montgomery-Asberg depression scale (MADRS), Fugl-Meyer Assessment of stroke, KATZ ADL index	T tests and chi square. Kruskal- Wallis ANOVA	Shorter hospital stay was associated with increased life satisfaction and reduced depression.	Both short stay and long stay groups had similar ADL, balance, motor and cognitive functions	Assessment of life satisfaction did not involve a standardized tool

Viitanen, Fugl-meyer, Bernspang, Fugl-meyer, 1988	60 stroke survivors 60 healthy individuals Sweden	Age-60-81 4-6 years post-stroke	Motor function, ADL ability	Self-report global and domain-specific life satisfaction scale	Chi square tests	Motor impairment and ADL disability was negatively correlated with life satisfaction	Results compared to that of 60 healthy elderly individuals Sample described in detail Standardized tool used to assess depression	Small sample size Long term stroke 4-6 years post-stroke, affects generalisability No reporting of ethical procedures Only 33% of subjects were alive at follow up 4-6 yrs post discharge Assessment of life satisfaction not standardized, assessment of motor function and ADL was not with the use of robust standardized tools

a) Social Network and Living Conditions

Nagayoshi, Iwata and Hachisuka (2008), in Japan reported that life satisfaction was associated with living conditions. Stroke survivors living with spouses and other family members reported higher satisfaction than those living alone. These results suggest that social support from family members and spouses is associated with life satisfaction post-stroke. Other earlier studies also support these findings. Astrom, Asplund and Astrom (1992) reported that amongst stroke survivors in Sweden, reduced social support was associated with reduced life satisfaction. They identified that at 3 months post-stroke social contacts with neighbours, friends and relatives other than spouses and children were reduced, and at a similar time global life satisfaction was the lowest with only 32% reporting life as being good. The authors stated the following: "failure to maintain or re-establish social ties except for those with close family members as shown by our results probably is an important determinant of poor life satisfaction late after stroke" (Astrom, Asplund and Astrom, 1992: 531). These results suggest that life satisfaction of the stroke survivor is associated with social integration not only inside but outside the immediate family. This reflects a desire of the stroke survivor to engage in other relationships outside their family circles and obtain a possible social identity from such relationships. However, they used a questionnaire developed for study, with no report of psychometric testing. This has implications for the validity and reliability of their results.

 Osberg, DeJong, Haley et al (1988) reported on the association between in- and out- of-house support and life satisfaction. In –house social support related to marital and dating status, number of persons in the household and the ratio of dependent to independent persons. Out- of- house social support related to friends, telephone contacts, participation and social activities outside the home. Stroke survivors with greater in- and out- of- house social support

reported higher life satisfaction. This emphasizes the importance of both close family and friends and social outings in enhancing life satisfaction post-stroke.

Kim, Warren, Madill and Hadley (1999), present results indicating that the perceived quality of social support was associated with life satisfaction post-stroke. Perceived social support in their study was assessed using the Social Support Inventory for Stroke Survivors. This scale has been shown to have high content validity and internal consistency. Their results showed that the most frequent source of support was from family (32% from children, 25% from spouse) and from friends (22%). The authors highlight that higher quantity of support was not related to life satisfaction, perceived quality of the support was what mattered. This study was carried out in Canada and it is unknown if similar results would be obtained in other cultures.

Social support both within family circles and outside the family were identified by the studies reviewed above as being factors associated with life satisfaction post-stroke. Different studies highlighted the importance of different aspects. While Nagayoshi, Iwata and Hachisuka (2008) in Japan reported the importance of family and spouses, Astrom, Asplund and Astrom, (1992) report that in addition to family ties, relationships outside families are also related to life satisfaction. Both results are confirmed by results of Osberg, DeJong, Haley et al (1988). These results are not contradictory but complementary, however the emphasis on family in the Japanese sample and external support in the study done in Sweden could reflect possible cultural differences.

b) Severity of Illness and Disability

Several researchers have reported on the association between severity of illness and disability, and life satisfaction. In addition to living conditions, Nagayoshi et al (2008)

reported that severity of clinical features such as hemi-paresis and aphasia were associated with poorer life satisfaction post-stroke. The association between aphasia and satisfaction was peculiar to the female stroke survivors suggesting that verbal communication was a significant factor related to life satisfaction for females. Similar reports regarding severity of disability was reported by Astrom, Asplund and Astrom (1992) and Osberg, DeJong, Haley et al (1988). Astrom, Asplund and Astrom (1992) reported that severity of functional disability was related to poorer life satisfaction. ADL functions were reported to change little after three months post-stroke. Osberg, DeJong, Haley et al (1988) highlighted the association between severity of illness, function at admission and wheelchair use on life satisfaction. Severity of illness measured by the Horn Index was directly and inversely related to life satisfaction. Patients scoring low on the Horn Index, indicating low severity, reported higher life satisfaction 12 months after discharge. Higher function at admission, indicating possible less severity, was related to life satisfaction indirectly through the influence of social support. The lack of direct statistical relationship between function and life satisfaction indicates the possible importance of social outings/ re-integation over functional ability in enhancing life satisfaction. Viitanen, Fugl-meyer, Bernspang, Fugl-meyer (1988) and Gottlieb, Golander, Bar-Tal and Gottlieb (2001) also present results showing the association between motor impairment, functional disability, handicap and life satisfaction. Viitanen et al (1988) reported that persisting motor impairment and ADL disability was related to poorer life satisfaction. Motor function and ADL disability was assessed by an occupational therapist. Motor function was classified as: Normal or slight dyscoordination, hemiparesis/hemiplegia and ADL disability was classified as: Independent, partially independent, dependent. Assessment of motor impairment and ADL disability was thus not carried out with the use of a standardized scale. Life satisfaction was also carried out by a tool designed for the study, however no testing for reliability or validity was mentioned. These issues have implications

on the acceptance of their results. Their results showed that ADL disability was related to poorer life satisfaction. Gottlieb et al (2001) reported similar findings. They carried out their study in Israel on 100 stroke survivors. Tools used were all standardized. Post-stroke disability was assessed with the Functional Independence Measure (FIM), handicap with the London Handicap Scale and Life satisfaction with the Life Satisfaction Index. Results showed significant positive correlations between scores for disability, handicap and life satisfaction. Higher scores of disability and handicap on the scales used indicated less disability/handicap. The results thus suggested that less disability and handicap were associated with better reports of life satisfaction.

More recently, Ostir, Berges, Ottenbacher et al (2008) presented results indicating the association between functional status at discharge and positive emotion which included life satisfaction. Higher total FIM scores, higher Motor and cognitive FIM scores were found to be associated with high positive emotions at discharge.

c) Depression

Depression was also identified as a factor associated with poorer life satisfaction post- stroke. Astrom, Asplund and Astrom (1992) reported that in addition to reduced social network and increased dependency, major depression after stroke reduced life satisfaction. Depressive symptoms were found in 25% of the sample at discharge. Post- stroke depression was described by the authors as affecting social functioning and at the same time can be worsened by failure to resume social activities post-stroke. They emphasized the need for early detection and treatment of depression post-stroke. Astrom, Adolfsson, Asplund, Astrom (1992), also reported the association between depression, ADL independence and life satisfaction. However, tools used to measure life satisfaction were not validated for use with stroke patients. This has implications for the validity of the results.

Edwards, Haln, Baun et al (2006), also presented results showing the association between depression and life satisfaction post-stroke. Depression was assessed with the Mental health subscale (MHS) of the Short Form 12 Health Survey. Multiple regression analysis showed that the MHS score (reflecting depression) accounted for 4% of variance in life satisfaction. Although the authors mentioned that depression was a significant predictor, the results indicated a low (4%) contribution of depression. Other more important predictors were health outcome (measured by Sickness Impact Profile) and meaningful activity. This suggests that depression in isolation might not be a strong factor related to life satisfaction, however when combined with other variables is a factor that cannot be overlooked.

These studies were carried out in Sweden and United States. There are no studies indicating any differences in the relationship between depression and life satisfaction in other cultures.

d) Other related factors

Other factors related to life satisfaction include urinary continence and hospital stay. Edwards, Hahn, Dromerick (2006) reported that urinary continence was associated with poor ratings of life satisfaction post-stroke. Incontinent stroke survivors participated less in meaningful activities, and had poorer functional independence than continent stroke survivors. Independent of stroke severity, urinary incontinence was found to be a strong predictor of reduced life satisfaction. However, Sveen, Thommessen, Holter et al (2004) present results that contradict these findings. They reported that incontinence was not associated with life satisfaction amongst their sample. Since the main emphasis of their study was to investigate leisure activities, explanation of the lack of association between urinary incontinence and satisfaction was not provided. Differences in results of both Edwards, Hahn,

Dromerick (2006) and Sveen, Thommessen, Holter et al (2004) in addition to differences in measurement of urinary incontinence could be the age of the stroke survivors. The mean age in both studies was 70 yrs old and 77yrs respectively. It is possible that the association between urinary incontinence and life satisfaction is stronger amongst younger stroke survivors. Urinary incontinence amongst young stroke survivors could affect social outings and participation in activities, however further studies are required to confirm this.

Sonde and Viitanen (2001) identified that shorter hospital stay was associated with higher reported life satisfaction post-stroke. Stroke survivors living at home at 12 months were more satisfied due to being with their family and friends than those in a rehabilitation facility despite similar levels of disability. These results highlighted the importance of home rehabilitation as opposed to extended rehabilitation in a specialised facility in enhancing life satisfaction post-stroke. The authors also emphasised that participants with shorter hospital stay did not have reduced independence at home one year post-stroke. Although it is possible that shorter hospital stay be a proxy measure for less disability/ less stroke severity, the authors mentioned that levels of disability were the same in both early and late discharge groups.

Carlsson, Moller and Blomstrand (2003) reported the association between Astheno-emotional disorder (AED) and life satisfaction in individuals with mild strokes. Astheno-emotional disorder includes symptoms such as fatigue, concentration difficulties, memory disturbances, emotional liability, stress resistance, anxiety and uneasiness. Life satisfaction was assessed with the Life satisfaction checklist (LiSat). Result showed a strong between AED, depression and life satisfaction. However it must be noted that the mean age of participants in this study was 59.6 years. Their sample appeared to be significantly younger than those in other studies.

It is possible that amongst younger stroke survivors, AED symptoms are related with life satisfaction, however it is unknown if the results will be the same in older stroke survivors.

ii) Research on Well-being and Stroke

Four studies were identified investigating the relationship between multiple variables and subjective well-being post-stroke, and these can be seen in Table 2.4. Two of the studies were carried out in Sweden, one in Canada and one in the United Kingdom. All the studies identified concerning well-being and stroke were included in the review.

Table 2.4: Studies on Well-being and Stroke

Research article	Setting and participant	Age of participants and	Independent variables	Assessment tools	Data analysis	Results	Strengths of study	Weaknesses of Study
Haslam, Holme, Haslam et al, 2008	U.K 53 participants	28-89 yrs old Mean age 66 (SD=12.8) 8.6 months post-stroke	Multiple group membership, Perceived cognitive function	Exeter Identity Transition scale (EXIT), Cognitive failures questionnaire,	Pearson's correlational analysis Path (mediation) analysis	Life satisfaction was associated with multiple group membership pre and post-stroke	Standardized tests used except EXIT Extensive literature review 53 of 66 people approaches took part	Direction of causal relationship unclear, No detail about clinical info about sample EXIT not validated for neurological patients, Small sample size for path analysis
Clarke, Marshall, Black et al, 2002	Canada 282 stroke participants	Mean age 76 (SD-5)	Health and socioeconomic info, self-reports of previous strokes, cognitive function, functional ability	Ryff measure of psychological well-being 5 questions from the Medical Outcomes Study SF36	Multiple regression	Stroke participants had lower reported well-being associated with physical and cognitive disabilities. Social resources were associated with higher well-being.	Adequate sample size for multiple regression analysis Limited literature review Detailed information on sample Comparison with community elders without stroke	Ryff measure not validated for stroke patients Only 5 questions from the SF36 were used to screen for mental health Characteristics of the sample of 75 on initial assessment was not described

Wyller, Holmen, Laake et al, 1998	Norway, 1417 stroke participants, 1439 stroke free individuals	Mean age - 71 (SD =12.6)	Perceived health, functional ability, working conditions, chronic disease	Postal questionnaire	Two sample factor analysis	Gender, age physical and mental health, and social network were associated with subjective well-being	Large sample size, Non stroke sample included for comparison Random sample from a larger health survey	No reliability and validity testing of postal questionnaire No reporting of clinical characteristics of sample No reporting of ethical procedure
Lofgren, Gustafson and Nyberg, 1999	Sweden, 47 stroke participants	Mean age 75 (SD 8) 0-3 years post-stroke	ADL, mental status, Depression	Philadelphia Geriatric Centre Morale Scale (PGCMS), Montgometry-Aberg Depression rating Scale, the Katz ADL index, mini-mental state examination, Brunnstrom-Fugl-Meyer Scale	Regression analysis, Spearman's correlations, Pearson's correlations	Depression was most closely related to wellbeing (PGCMS score)	Follow up carried out 3 years post-stroke Standardized instruments used	Small sample size for doing a regression analysis Participants had severe pareses and cognitive problems Detailed information on participants not reported Of the 100 initially participants only 57 were alive and eligible at 3 year follow up. No details of the others.

The four articles investigating factors related to subjective wellbeing post- stroke identified the following factors: group membership, physical and mental disabilities, social network and depression. Haslam, Holme, Haslam et al (2008) reported that multiple group membership pre- and post-stroke correlated significantly with subjective well-being. Belonging to social groups was described as an important source of social identity for individuals which could be disrupted post-stroke. Individuals belonging to multiple groups before the stroke were more likely to report higher well-being after the stroke. This relationship was pronounced when the pre –existing group memberships were maintained after the stroke, indicating the importance of a wide stable social network post-stroke. They also identified that perceptions of cognitive failures affected the ability to maintain group memberships. Higher incidence of perceived cognitive failures also resulted in reduced life satisfaction. Limitations of this study include the difficulty in drawing inferences about the nature of the relationship due to correlational data analysis, it is possible that stroke survivors with more positive well-being were more likely to maintain their pre-existing group memberships. It may also be the case that stroke survivors with more positive well-being were more likely to disclose, in a positive manner, the maintenance of these memberships. In addition to this, one of the scales used to measure group memberships, the Exeter Identity Transition scale (EXITS) has not been validated for use with neurological patients. This has implications for the validity of the results reported by this study.

Similar to the studies reviewed previously which focused on life satisfaction, social network and social resources were identified as associated with subjective well-being. Wyller, Holmen, Laake et al (1998) reported that social network in addition to age, gender, mental and physical health was associated with subjective well-being. SWB was found to be higher amongst women than men. Clarke, Marshall, Black et al (2002) reported results concerning

the association between social resource and subjective well-being. While physical and cognitive disabilities were found to be associated with lower reported subjective well-being, increased social resources were associated with a higher sense of well-being. Increased social resources included larger social network and increased positive relationships with others. The authors reported that social resources acted as a buffer against the negative effects of physical disability on subjective well-being post-stroke. Stroke survivors with less social support or those dissatisfied with their social support had a stronger association between functional disability and subjective wellbeing than those with adequate social support. However, the Ryff measure used in this study was not validated for stroke patients.

The study by Lofgren, Gustafson and Nyberg (1999) support findings regarding the relationship between depression and reduced subjective well-being. These results are not surprising as there is an overlap between depression and subjective well-being as variables, in other words similar constructs are being measured. The authors highlighted the importance of early detection of depression in stroke rehabilitation.

Studies investigating factors associated with subjective well-being have reported results similar to those described previously regarding life satisfaction. Social network, physical and cognitive disabilities and depression were identified to be related to subjective well-being. These studies were all carried out in Western countries it is unknown if similar results would be obtained from non Western cultures.

iii) Research on Participation in Meaningful Activity and Return to Work

Five studies were identified which focused on meaningful activity and return to work post-stroke, and life satisfaction/ SWB. These can be seen in Table 2.5 below. One of these studies

was conducted in the United States, two in Sweden, one in Norway, and one in Israel. Edwards, Haln, Baun et al (2006) reported that amongst 219 stroke survivors in the United States, decrease in participation in meaningful activity and depression were related to poorer life satisfaction post- stroke. Results concerning the importance of participation in activity are supported by Hartman-Maeir, Soroker, Ring et al (2007). Their study was carried out in Israel on 56 stroke survivors. In addition to activities of daily living, participation in activity, assessed with the Activity Sort Card (ASC), was the strongest factor related to life satisfaction post-stroke. The ACS measures participation in 55 activities (social, physical, leisure activities) and is reported to be reliable and valid in use with neurological disabilities. This highlights the need to encourage the stroke survivor to return to participating in activities they enjoy doing or new activities within their physical capabilities. However, it must be noted that participants rating high on the ACS must have had higher levels of independence and functional status. No attempts were made during data analysis to control for functional status/ability to perform instrumental ADL. It is possible that assessment of meaningful activity is a proxy for functional status and instrumental ADL.

Return to work was also reported to be a factor related to life satisfaction post-stroke. Vestling, Ramel, Iwarsson (2005) reported that stroke survivors rating higher on the importance of the intrinsic aspects of work had higher ratings of life satisfaction. This indicates the importance of work for psychosocial aspects in the younger stroke survivor's life. Returning to work was more associated with life satisfaction when participants valued aspects other than the financial benefits of returning to work such as relationships with others and intrinsic satisfaction. Participants in this study were aged around 54 years old, therefore, it is possible that an older group may not yield the same result. Return to work is 'normative' for this age group and failure to return may plunge the participants into very unfamiliar and

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stigmatised social groups. Vestling, Tufvesson, Iwarsson (2003) reported that stroke survivors retuning to work reported a higher subjective well-being and life satisfaction than those who did not return to work. The possibility of returning to work was higher with stroke survivors who could walk, had preserved cognitive ability and who were in a white collar profession. Stroke survivors with higher levels of independence were also more likely to return to work. Although those returning to work had a higher subjective well-being, other factors such as independence, mobility and preserved cognitive ability could be the reasons for such results.

**Table 2.5: Research on Participation
in meaningful activity and return to work**

Authors	Setting and Participants	Age and time since stroke	Independent variables	Assessment tools	Data analysis	Results	Strengths of study	Weaknesses of study
Edwards, Haln, Baun et al, 2006	219 Stroke participants United States	Mean age 64 yrs (SD=15.8) 0-6months post-stroke	Stroke severity, functional independence and leisure activities	NIHSS, Functional Independence Measure (FIM), Stroke adapted sickness impact profile, Reintegration to normal living scale (RNL), short form 12 health survey, Activity card sort interview	Student t tests and chi sq tests, Pearson's and spearman's correlations and multiple regression	Predictors of life satisfaction post-stroke were stroke related symptoms, decrease in participation in meaningful activity and depression	Characteristic of sample detailed Standardized scales used	Mild stroke survivors-limited generalisability of results Stroke survivors with depression were excluded. Sample <6 months post-stroke. Results may not be generalisable to chronic stroke survivors
Hartman-Maeir, Soroker, Ring et al, 2007	56 Stroke participants Israel	Mean=57.7 SD=11.6 About 1 year post-stroke	Functional Independence, participation in leisure activity, return to work, Depression	Self-report life satisfaction questionnaire, Geriatric Depression Scale, Functional Independence Measure, Instrumental Activities of Daily Living Questionnaire (IADLQ), Activity Card Sort (ACS)	Student t tests, Correlational analysis, Multiple regression	Life satisfaction was related to basic activities of daily living, Instrumental activities of daily living and participation in activity (which was the strongest related factor)	Information on study sample provided Follow up conducted 1 year post-stroke Standardized tools used	Young stroke sample thus limited generalisability to older stroke survivors Small sample size for multiple regression analysis Sample was made up of mostly male participants (n=42)

Vestling, Ramel, Iwarsson, 2005	65 Stroke Survivors Sweden	54 yrs old	Work related characteristics	Postal questionnaire Subjective well-being scale from Gothenburg QOL Instrument	Chi Square or fishers exact test Kruskal Wallis test Mann Whitney U-test	Satisfaction post-stroke was related to ratings of importance of intrinsic aspects of work.	Standardized assessment of subjective well-being 21 dropouts reported but no significance between dropouts and respondents	Small sample size Postal questionnaire not standardised Young stroke survivors. Limited generalisability to older stroke survivors
Vestling, Tufvesson, Iwarsson, 2003	120 Stroke Survivors Sweden	Younger than 60yrs old Minimum 6 months post-stroke	return to work	Subjective well-being (SWB) scale from Gothenburg QOL Instrument, Functional Independent measure, Assessment of life satisfaction	Chi Square, multiple logistic regression and Mann Whitney U test	Individuals returning to work had higher SWB and life satisfaction as a whole: financial situation, leisure and friends /acquaintances but not with satisfaction with family life. White collar worker pre stroke was the most important predictor	2 separate self administered well validated instruments were used	Level of disability not controlled for Time post-stroke varied across sample Young stroke survivors only Limited generalisability of results to older age group Results on 6 months post-stroke survivors
Sveen, Thommesse,	82 stroke survivors Norway	Mean age=77.5	Instrumental ADL, Language functioning,	Generalized health questionnaire, Nottingham	ANOVA	Satisfaction was associated with leisure	64 of 24 patients participated (6	Leisure activities might be a proxy for functional status

			Urinary continence	extended ADL scale, Ullevaal aphasia screening test		activities. Aphasia and continence were not statistically associated with satisfaction.	died by follow up and 6 refused to participate) Validated tools used Demographic and functional characteristics of sample reported	Sample 6 months post-stroke not generalisable to chronic stroke
Bautz-Holter et al, 2004		6 months post-stroke						

iv) Leisure Activities and life satisfaction post-stroke

Two studies were identified which focused on the relationship between leisure activities and satisfaction post-stroke. Sveen, Thommessen, Bautz-Holter et al (2004) reported that amongst 82 stroke survivors in Norway, life satisfaction was significantly related with leisure activities. Leisure activities were measured with the leisure subscale of the Nottingham Extended ADL Scale. Participants in this study were on average 77 years old and were assessed at 6 months post-stroke. Leisure activities showed the strongest association with satisfaction and well-being post-stroke. The authors highlighted the need to incorporate leisure activities in rehabilitation planning. In a study carried out in Sweden, Astrom, Asplund and Astrom (1992) reported that reduced leisure activities post-stroke was associated with poorer life satisfaction. Their study sample was made up of 50 stroke participants aged between 65 and 84 years old (mean of 71 yrs old), assessed 3 years post-stroke. The results of both studies indicate that at 6 months up to 3 years post-stroke, leisure activities are associated with life satisfaction. However both studies were carried out on Western samples and it is unknown if similar results would be obtained in other non-Western cultures were leisure activities might take different forms and have different meanings. In addition to this, assessment of leisure activities could be a proxy for functional ability. Functional status was not controlled for in these studies.

2.6.3 Limitations of Studies

Studies varied in sample size from 50 to 1417 participants (Astrom, Asplund and Astrom, 1992, Wyller, Holmen, Laake et al, 1998). The use of different assessment tools makes the comparison of results between studies difficult. In addition to this, a few studies (Astrom, Asplund and Astrom,1992; Wyller, Holmen, Laake et al, 1998) developed questionnaires specifically for their studies without reporting any validation and reliability studies on their

questionnaire. The majority of the studies were carried out in Western countries with two in Israel and one in Japan making generalisation to non-Western cultures difficult. Neither non-Western country mentioned above has a dominant Muslim population which makes generalisation of their results to a stroke population in Kuwait uncertain.

2.6.4 Summary of Literature Review

This review aimed to identify stroke studies investigating factors associated with life satisfaction post-stroke, and to consider the relevance of their findings in stroke rehabilitation. In order to summarize the available evidence effectively, articles were divided into 4 main categories: research on multiple variables associated with life satisfaction, research on variables related to subjective well- being, and research on the association between meaningful activity or return to work, and life satisfaction, and leisure activities.

Studies identified reported a wide range of variables to be associated with life satisfaction post-stroke. These included social support and network, mental and physical disabilities, depression, meaningful/leisure activities and return to work. With the exception of three studies, one in Japan and two in Israel, the other studies were carried out in Western countries. None were conducted with a predominantly Muslim population. It is unknown if these highlighted factors continue to be related to life satisfaction irrespective of culture. The study carried out in Japan highlighted an emphasis on family support while Western studies, in addition to family support, mentioned the importance of relationships outside the family, suggesting that culture might be an important variable. In- house support and out- of- house support were both found to be associated with life satisfaction. Stroke survivors reported that at about 3 months post-stroke, contact with friends and relatives, apart from spouse and children, decreased and at this time, life satisfaction was at its lowest. The combined effects

of reduced external social support and increased dependency were associated with poorer life satisfaction post-stroke. Research on subjective well-being identified the same influential factors: social support, depression, physical and mental difficulties.

Other factors identified to be related to poorer life satisfaction post-stroke include urinary incontinence and increased hospital stay. Reduced hospital stay by the provision of rehabilitation at home was identified to be associated with higher reports of life satisfaction because stroke survivors had their families and friends around them. No negative effects of reduced hospital stay were identified.

Younger stroke survivors returning to work rated their life satisfaction as being higher, however this could be related to other factors such as better ability to walk, less dependency and minimally affected cognitive status. These results cannot be generalized to older samples. In addition to this, these studies were carried out in Western countries which are more accepting and encouraging for stroke survivors to return to work. This may not be the case in other countries where disability associated with stroke carries a negative stigma and employers are less likely to re-employ stroke survivors. Leisure activities were identified as being associated with life satisfaction in stroke survivors aged between 65 and 84 years old, however leisure activity could simply represent better functioning in these studies. As mentioned previously, these results cannot be generalized to include a non Western population. Leisure activities may not hold the same meaning as they do in Western cultures.

These results have highlighted the need to conduct research specific to life satisfaction in other cultures. Social support, living arrangements, return to work and leisure activities identified as factors related to life satisfaction post-stroke in this review could be influenced

by the cultural background of the stroke survivors and their families. Arab Muslims in Kuwait live in extended family structures and may have different attitudes to disability hence differences in these factors could possibly influence life satisfaction, however this has not been investigated in the past. The overall aim of the current project is thus to investigate the experience of stroke in Kuwait and life satisfaction post-stroke.

Chapter 3

Chapter 3

The Role of Culture and Religion in Health Outcomes and

Rehabilitation: Literature Review

This chapter will focus on cultural differences in experience and behaviour related to illness, aims to review definitions of religion and spirituality in Western and Arabian contexts, and examines studies showing association or lack of association, between religious/ spiritual indices and health.

3.1: Introduction

The World Health Organization (WHO) in 1948 defined "health" as: "physical, mental, and social well-being and not merely the absence of disease" (WHO, 1948: 100). This definition highlighted three important aspects of health: physical, mental and social. However spiritual/ religious influences were not mentioned. Coleen (2003) stated that: "The WHO definition was a big improvement over the previous focus on physical symptoms alone as a health indicator, and this definition provided the foundation for the concept of well-being or optimal function, and subsequently, health promotion" (Coleen 2003: 261). Western concepts of health appear to have been built into the WHO definition of health in which acknowledgments of possible associations between spirituality, religion and health is lacking. This could have possibly led to a paucity of research in this area. Miller and Thoresen (2003) proposed two main reasons for the neglect of research on this area: "the assumption that

spirituality cannot be studied scientifically, and the assumption that spirituality should not be studied scientifically". (Miller and Thoresen 2003: 24).

More recently, health professionals have been advocating a "holistic care" of patients. Rashidi and Rajaran (2001) describe holistic care as addressing the physical, psychological, social, and spiritual dimensions of the patient. The word: "holistic" may at times be used in reference to complementary therapies like acupuncture, yoga, and aromatherapy (Rozzano, 2001). In contrast, Rashidi and Rajaran (2001) in discussing managing Muslim women patients in the United States, provide an Islamic view on holistic care. They describe holistic care as taking into account Islamic beliefs and practices that integrate the spiritual, emotional, and physical aspects of the self. They therefore argue that taking into consideration the culture of an individual is central to the provision of holistic care. In the management of Muslim patients, their religion affects all aspects of their life and is a key part of their culture hence cannot be separated during the provision of medical care and rehabilitation (Rashidi and Rajaran, 2001). Luna (1989) emphasizes the importance of understanding the social structure and cultural context in promoting a sense of care when working with the Arab Muslim patient in both Muslim countries and multicultural contexts (Luna, 1989). Similar views have been expressed by Rassool (2000), Miller and Petro-Nustas (2002) and Halligan, (2006).

Zou, Tam Morris et al (2009: 579) define culture as: "a tradition of knowledge and practice that is shared, albeit imperfectly, across the members of a society and across its generations". Winkelman (2009: 3) describes culture as involving: "learned patterns of shared group behaviour". Earlier definitions of culture appear to convey a similar meaning. For example, Kroeber and Klukhohn (1952) define culture as shared implicit values, beliefs and attitudes,

and behaviours within a community and between different generations. Culture can also be described as a group of shared beliefs based on ethnicity, gender, religion, social class and sexual orientation (Skaff and Gardiner, 2003). 'Culture' in this project will be used in the context of the definitions above in this chapter.

Culture influences perceptions of what it means to be healthy, attitudes towards disability, and coping strategies (Brown, Ballard and Gregg, 1994; Gallaher and Hough, 2001; Snead and Davis, 2002). Interpretations of symptoms and illness behaviours are also influenced by cultural norms (Gallaher and Hough, 2001). For example, studies have reported differences in experience of traumatic brain injury and spinal cord injury based on differences in cultural backgrounds (these studies will be reviewed later in this chapter). The extent of influence of cultural beliefs on stroke experience has not been investigated.

Studies have suggested that illness locus of control (LOC) varies according to cultural background (Saltapides and Ponsford, 2008). LOC can influence the experience of illness, coping, the strategies employed and acceptance of disability. Some evidence suggests that in Western countries, individuals have a higher internal LOC (Stanhope, 2002), thus indicating they take more personal responsibility over their symptoms. While in some non- Western cultures, LOC is more externalized, and the ill person is not viewed as responsible for managing the illness/ limiting the effects of these symptoms (Stanhope, 2002). According to Skaff and Gardiner (2003: 84): "Culture exerts a major influence on the beliefs and values that people carry around with them regarding their relationship with the environment and what is desirable and possible in terms of personal control". In chronic pain patients, Bates and Rankin (1994) reported that LOC was related to cultural identity. In this study, both factors (LOC and cultural identity) influenced adaptation to chronic pain. Their study sample

was made up of White Americans and African Americans. Results indicated that African Americans, despite reporting similar pain intensity as White patients, reported higher levels of pain unpleasantness, emotional response and pain behaviour. Control can have different cultural meanings and manifestations across various racial and ethnic groups (Stanhope, 2002). This challenges the notion that a Western model of culture is the 'gold standard' which other cultures are compared against (Skaff and Gardiner, 2003). There is therefore a need to have broader views about control and to incorporate cultural variations in the meaning and mechanism of control.

Life satisfaction has also been reported to be affected by cultural background. When investigating life satisfaction, Hampton and Marshall highlighted the importance of taking into consideration culture. An individual's subjective evaluation of their life was explained to be affected by cultural norms and values (Hampton and Marshall, 2000). This study will be discussed later in this chapter.

3.2: Culture and Neurological Rehabilitation

Simpson, Mohr and Redman (2000), investigated cultural variations in the understanding of traumatic brain injury (TBI) and brain injury rehabilitation. They interviewed 39 people with TBI and their family members from Italian, Lebanese and Vietnamese backgrounds living in Australia. Interviews were semi- structured with the use of bilingual interviewers. Two focus groups were also part of the study (one with health professionals from the rehabilitation unit and another with interpreters used in the study). The semi-structured interviews covered areas such as: background of client/family member, understanding of brain injury and symptoms, goals of individual and family, and perception of treatment goals of the rehabilitation professionals, perception of rehabilitation services, communication and language, and

cultural issues. Interviews were analysed using inductive thematic analysis. Results revealed that TBI patients from all three cultural backgrounds (Italian, Lebanese and Vietnamese) reported similar physical, cognitive and psychosocial challenges post-TBI. Physical challenges included impaired gait, reduced fine motor skills, reduced senses (hearing, taste, vision) and dizziness. Cognitive challenges included poor concentration, communication difficulties and difficulty with organizational skills. Psycho-social changes reported were mainly changes in mood and difficulty controlling temper. Culture did not appear to influence the report of these challenges. Despite these apparently similar experiences of TBI, the understandings of rehabilitation, goals and the roles of health professionals varied amongst the TBI participants and their family members. However, their views were not specific to any cultural background. Some viewed rehabilitation as training, while others saw it as a means to help get them back to 100% recovery. Regarding dissatisfaction, while Italian and Lebanese TBI participants and their family members made complaints about some areas of the health service or rehabilitation, no complaints were made by the Vietnamese. This may have indicated that Vietnamese family members did not want to challenge any of the services they were provided with, even when dissatisfied. Family support was a strong theme identified in all cultural groups. Burden of care was also reported with family members, with problems such as losing sleep, weight loss, reporting feelings of exhaustion, anxiety and depression. Stigma and social isolation was also another common theme identified. Family members reported concealing information from friends and other family members. TBI participants also mentioned withdrawing from their usual social circles due to feelings of shame and stigma associated with disability. The following statements highlight the understanding of the word "brain injury" and stigma associated with it. The authors wrote: "An Arabic bilingual interviewer observed that a respondent was not comfortable with the term 'brain injury' when used in Arabic, and hypothesized that 'anything wrong with the brain' in Arabic may be

understood as a sort of madness and that's shameful'. Similar views were expressed by Vietnamese and Italian respondents/family members…" (Simpson, Mohr and Redman, 2000: 136). Regarding cultural differences in perceived shame, the researchers pointed out that amongst the Vietnamese, TBI was associated with shame brought on the whole family and not only the individual with TBI.

Results by Simpson, Mohr and Redman (2000), suggest that there are certain cultural differences in the experience of rehabilitation and stigma associated with brain injury. On the other hand, reports of physical, cognitive and psychosocial challenges appear to be consistent across the three cultural backgrounds. Due to the small sample size of each of the cultural groups, caution is required in generalizing the results to reflect the experience of any one particular cultural group. Regardless, these results highlight a possible influence that cultural background can play in rehabilitation. Although carried out with TBI participants, similar differences might be observed in perceptions of stroke rehabilitation by people from different cultures.

Saltapidas and Ponsford (2007) investigated the influence of culture on motivation, participation and outcome of rehabilitation in people with Traumatic Brain Injuries (TBI). They aimed to compare these variables in participants with TBI from an English speaking culture in Australia versus those from minority culturally and linguistically diverse (CALD) backgrounds. Seventy participants took part in this study, 38 were from an English Speaking background (ESB) and 32 were from the minority culturally and linguistically diverse background (CALD). Participants were aged between 17 and 72 and average time since they sustained TBI was 27 months. Information collected from the participants included demographic information and English proficiency, measurements of acculturation and

motivation. Acculturation was measured with the Brief Acculturation Scale (BAS), and motivation assessed with the Motivation for Traumatic Brain Injury Rehabilitation Questionnaire (MOT-Q). Other data collected included number of out-patient rehabilitation sessions attended and employment status. The TBI rehabilitation Outcome Attitude Rating Scale and The Craig Handicap Assessment and Reporting Technique (CHART) were also used to measure changes in life role and participation limitation respectively. Data were analysed with independent sample t tests. Results showed that although there were no differences in pre-injury employment status or motivation and rehabilitation participation, individuals from a CALD background reported greater distress about the changes of their roles as parents and homemakers than those from an ESB. Participation limitation was greater in the CALD group (less mobility, fewer hours out of bed, and less use of transportation), than in the ESB group. They also needed more assistance with cognitive difficulties and showed less social interaction despite similar levels of physical disability with the ESB group.

Results by Saltapidas and Ponsford (2007) showed that individuals with TBI from minority backgrounds, despite similar socioeconomic and rehabilitation access, had significantly different outcomes than those of English language backgrounds (White Australians). Fewer of the CALD participants returned to employment and more reported greater dependence on others for ADL despite similar ratings on physical functioning. Interpretations of these results could also be affected by the culture of the researchers. While dependence on others in the ESB group might be viewed as related to poorer outcome, such dependence in the CALD group might be a positive reflection of their culture in coping with disease/ impairment. Other limitations of the study included the use of measurement tools which have not been validated for CALD participants and the possibility that the validated tools reflect issues held as

important in the English language-based culture. This study highlights the need to develop culturally relevant tools when investigating cultural differences in behaviour and experience of injury.

Other studies have reported differences in experience of TBI based on culture but raise different issues to the study by Saltapidas and Ponsford (2007). Brown, McCauley, Levin et al (2004) investigated differences in perceptions of health functioning and quality of life amongst minorities with mild to moderate traumatic brain injury (MTBI) in Texas, USA. The study sample consisted of 135 MTBI and 83 patients with general trauma (GT). Participants were recruited three months after their injuries and the following assessment tools were used: Medical Outcomes Study 36-item Short Form Health Survey (SF36) to measure health perception, Community Integration Questionnaire (to measure functional outcome), Social support Questionnaire, Structured Clinical Interview (SCID) for the diagnosis and Statistical Manual of Mental Disorders (standardized measure of depression), Center For Epidemiological Studies –Depression and the Visual Analogue Scale for Depression. Assessment was carried out at 3 months and 6 moths post injury. Results showed that minority MTBI patients reported having worse health. African American MTBI participants reported having the worst health functioning. European American and Hispanic Americans reported similar levels of health status and functioning. African Americans reported relatively higher levels of pain than patients from other cultural backgrounds. Hispanic MTBI patients reported having less social support than the other groups. African Americans reported having more social support available to them than the European American and Hispanic Americans. No significant differences in mood changes were noted between the three cultural groups.

Results by Brown et al (2004) highlight the cultural differences in reported health functioning in patients with mild to moderate traumatic brain injury. However little is mentioned about whether the racial groups were functionally equivalent. Functional ability, levels of disability and participation restrictions were not controlled for. It is possible that minority participants had worse physical functioning hence rated their health as being worse. Another possible explanation of these cultural differences could be related to differences in acceptance of symptoms of illness in different cultures, or manner of expressing symptoms and challenges.

Reported social support was also a difference identified amongst the racial groups. African Americans, despite reporting higher family support, showed worse function post TBI. It is possible that increased support led to dependency hence worse functioning. This relationship was not investigated. It is also possible that people worse affected by brain injury need more support. Social support in this study was assessed by the number of people available for support and satisfaction with this support, but the type of support, i.e. emotional or instrumental, was not reported. The researchers did not report on stigma issues, or attitudes towards dependency amongst the various cultural groups. Functional outcome was measured with the Community Integration Questionnaire, however the actual level of physical disability was not assessed. It is not known whether all racial groups were functionally equivalent. This has implications on acceptance and interpretation of these results. In addition to these limitations, these results cannot be generalized to people living in other countries.

Watanabe, Shiel, McLellan et al (2001) compared cultural differences related to problems experienced amongst families of TBI patients in the United Kingdom and Japan. The study sample was made up of 18 family carers from the U.K and 12 from Japan. Questionnaires were used to collect data included: Family's Experience and Attitudes Questionnaire, Family

Problems and Solution Questionnaire, Family Need Questionnaire. These three questionnaires were developed for this study with no previous testing of reliability or validity. Questionnaires were administered by face to face interview amongst the U.K participants, however eight of the 12 family members in Japan opted to fill in the questionnaire independently and send it via post and 4 were interviewed (i.e. there was variability in administration which could affect validity). Chi Square tests were used to analyze data. Results showed that there were differences in experience of caring for a TBI family member between the British and Japanese samples. Japanese family members were more concerned about how other relatives would view the family member with TBI because of his/her changes in behaviour. British family members were less likely to have this concern. Family members in both groups reported difficulties in caring for a TBI patient such as tiredness and frustration, and no differences were observed in their responses. However, regarding action to manage such problems, British family members listed a variety of actions while only one Japanese family member mentioned an action to solve the problems they were facing. While both groups of carers acknowledged the need for information and training about TBI, the British family members reported having access to such resources from a variety of sources while the Japanese group did not know where to access such information.

Results by Watanabe et al (2001) highlight differences in experience of caring for a TBI family member in two different cultures and parts of the world (U.K and Japan). Differences were mainly observed in concern about opinions of other family members, actions to solve problems with care giving, and access to resources on TBI. Japanese family members were more secretive about the condition of the TBI family member and also had less access to resources, suggesting greater concerns with stigma, but also perhaps less family support. Caution must be taken prior to acceptance of these results due to different methods of data

collection between the U.K and Japanese groups. Eight of the Japanese family members chose to fill out a postal questionnaire instead of the face to face interview used by all the British family members. This could have resulted in different answers than if the questionnaire was administered in an interview. It is possible that Japanese participants did not want to disclose coping strategies used in dealing with problems associated in care-giving hence no comments were made on that area. It is also possible that they feared challenging the authority or expertise of medically qualified researchers. This left the impression that they could not suggest actions to deal with their problems while the British sample listed a variety of actions. In addition, sample size of both British and Japanese family members were small (18 and 12 respectively) for the method used (questionnaires) and chi square analysis. Although back translation methods were used to ensure that the Japanese questionnaires were as similar as possible to the English ones, these questionnaires were based on expected responses from the Western literature and clinical experience. Despite these limitations, the results highlight possible cultural differences in experience of caring for a TBI family member in the U.K and in Japan. The findings also suggest differing assumptions about disability and the self-reliance of carers. Other studies have highlighted similar issues regarding social stigma related to disability in Japanese culture. Matssu , Ide , Naito et al (1999) reported that a sample of Japanese workers showed reluctance to use community dementia services for the elderly due to social embarrassment.   Prigatano et al (1997) reported that amongst brain injured Japanese individuals, reliance on others was considered a disgrace. It is however unknown whether similar views regarding disability are present in the Arabian culture.

The studies reviewed above related to TBI, but other studies have been conducted on spinal cord injury patients highlighting the possible differences in experience of disease and

rehabilitation due to cultural backgrounds. Hampton and Marshall (2000) compared culture, self-efficacy and Life satisfaction between American and Chinese patients. Two hundred and sixty three people with spinal cord injury (133 American and 130 Chinese) participated in their study. The following four questionnaires including demographic information were filled out by all participants: The Life Situation Survey (LSS), the Individualism-Collectivism Scale, the General Self-Efficacy Scale (GSES) and the Self Rated Health Status Scale (SRHS). Questionnaires were sent out by mail and all participants received $5.00 or 40 Chinese Yuan. Questionnaires were translated into Chinese by two bilingual persons (a psychology student and a psychologist) using a back translation process (English-Chinese-English). Data were analysed with multivariate analysis of variance, multiple regression analysis and stepwise regression analysis. Results indicated that significant differences in culture were present between American and Chinese people with spinal cord injuries. The American sample had significantly higher scores on 'separation from ingroup' and lower scores on family integration and self-reliance when compared to the Chinese. High separation from ingroup scores emphase the highly individualistic nature of American culture as opposed to the collectivism in the Chinese culture. Results also showed that American patients had a significantly higher life satisfaction than Chinese. However this result should be interpreted with caution because the tools used in assessment were developed in the West and so might reflect issues important to patients in the West and not in China. Self-efficacy was observed to be the strongest predictor of life satisfaction in the Chinese group. The second most important predictor was perceived health status. Among the American group, four variables were significantly related with life satisfaction: perceived health status, self-efficacy, self reliance, and marital status. This meant that people who perceived themselves as being in good health, with high self-efficacy beliefs and were married were more satisfied with their lives than those with lower self-efficacy, who were unmarried and who rated their

health as being poor. High self-reliance was reported as been associated with lower satisfaction with life. It is however possible that the scores regarding high self-reliance were a proxy for low social support. In both cultures self –efficacy had a significant association with life satisfaction.

Results of the study by Hampton and Marshall (2000), although carried out with people living with spinal cord injury, shed light on possible cultural differences amongst people with the same neurological conditions. It also highlights the possible dangers of using Western scales in non-Western populations despite cultural adaptation with the back translation method. Items assessed on a standardized Western scale could nonetheless reflect issues held as important to patients in the Western world.

Summary

There is little empirical research on culture and stroke experience, studies reported above highlight possible differences in experience and behaviour that could be attributed to cultural differences in other neurological conditions, mainly traumatic brain injury (TBI) and spinal cord injury. Simpson et al (2000) reported certain similarities and differences in the experiences of Japanese, Arabs and Vietnamese individuals affected by TBI and their family members. Similarities included their concerns with the physical, cognitive and psychological changes that occurred post injury. Differences in TBI experience amongst the three groups were mainly in how they related with the health professionals. Japanese individuals with TBI and their families were less willing to criticize and complain about the care they received. The issue of social stigma and shame was present in all three groups, however, amongst the Vietnamese, shame was perceived to be related to the whole family not just the individual. Watanabe et al (2001), presented results showing that Japanese family members of

individuals with TBI were more likely than U.K families to be concerned about what other family members thought about inappropriate behaviour of the TBI- affected individual. This probably relates to feelings of shame and social stigma within their communities. Hampton and Marshall (2000) showed that Japanese participants scored higher in family integration than American individuals with spinal cord injury however, the American participants had higher life satisfaction scores. These results suggest that family integration post neurological injury like TBI and spinal cord injury could be an important aspect of Japanese culture, more so than in Western Anglo-centric cultures. However some of these results might be due to the way that assessment was carried out and the assessment tools used. Saltapidas and Ponsford (2007) also presented results showing differences in TBI experience based on culture. Individuals with TBI of the culturally and linguistically diverse (CALD) minority in Australia reported more distress in change of family roles and less social interaction than those from English language backgrounds. In addition to this, outcome post- TBI was reported to be poorer in the CALD group. However, this group showed functionally poorer scores which confuses interpretations of outcomes. Explanations of poorer scores include less internal locus of control (LOC), however it could also be because the participants were more affected by TBI or because the assessment tools reflected issues held as important in the English language majority group. This highlights the need to developed culturally sensitive tools which reflect what is held to be important by the people in the cultures being investigated.

These studies were mostly carried out on patients with TBI and only one study was on people with spinal cord injury. Such individuals tend to be younger, and are more likely to be male, compared with stroke patients, so generalisation of findings is uncertain. It is unknown whether similar differences could occur in stroke experience and rehabilitation across cultures, or the cultural characteristics specific to stroke patients living in Kuwait. The

Muslim religion is a main part of the culture in Kuwait. This warrants a closer investigation into the association between religion and health outcomes. Hence the following sections will discuss the relationship between religion and experiences of illness.

3.3: Religious Faith, Coping with Illness and Health Outcome

Association between religious faith and health has been shown to be significant in many studies, however the psychological basis for this association remains unclear (Holt, Schulz and Wynn, 2007). This information is important in understanding the relevance of religious faith during the recovery process and rehabilitation especially in the Arabian culture where religion is a major part of everyday life (Rashidi and Rajaran, 2001). It is hoped that information from this chapter will provide a base to aid the rehabilitation therapist (physical therapist, occupational therapist, speech therapist or others involved in the rehabilitation process) understand what experiences related to religion enhance or negatively influence the goals that patients are trying the achieve, and their motivation.

This section aims to review Western and Arabian definitions of religion and spirituality, to review studies related to religious faith and coping, and in addition to identify possible factors presented in the literature as mediating this relationship.

Literature Search

The literature search involved 2 main steps. First, the following electronic databases relevant to medicine (Medline), Nursing (Cumulative Index of Nursing and Allied Health Literature (CINAHL)), psychology (PsycINFO) and Allied and complementary medicine database (AMED) were used to search for relevant articles. Search terms were crossed with each other and were related to religion and health association such as religion, religiosity, religiousness,

mental health, health outcome, coping, relationship and association. Abstracts of relevant articles were studied and relevant full articles obtained. Secondly, references of relevant articles were scrutinized to identify more relevant studies.

Limits:

The following limits were used to identify appropriate research: English only and research articles.

Exclusion criteria

-Articles related to relatives/spouses of stroke survivor

-Non English language articles

No Arabic literature was identified on this topic. The following is a narrative review on the topic area. Advantages of narrative reviews were discussed previously in chapter 2.

3.3.1 Defining Religion and Spirituality

Empirical studies on religion, spirituality and religiousness have tended to treat these three concepts as synonymous, however Miller and Thoresen (2003) argue that these are three distinct yet overlapping constructs (Miller and Thoresen, 2003). A similar view was expressed by Giaquinto et al (2007). They reported that although these concepts are similar they are not synonymous (Giaquinto et al, 2007). A lot of difficulty exists in trying to define these three terms due to the cultural diversity of the world today.

Religion can be described as the feelings, acts, and experiences of a person regarding whatever they may consider the sacred (James, 1961). Matthews et al (1998) refers to religious commitment as being associated with a community of faith and involving shared practices and beliefs. Spirituality on the other hand is described as "personal views and

behaviours that express a sense of relatedness to the transcendental dimension or to something greater than the self" (Matthews et al, 1998: 119). A similar description of these two terms is given by Williams and Sternthal (2007). They refer to religion as "aspects of belief and behaviour, including spirituality, that are related to the sacred or supernatural and are grounded in a religious community or tradition" (Williams and Sternthal, 2007: 48). Spirituality is described as "an individual's attempt to find meaning in life, which can include a sense of involvement with the transcendent outside institutional boundaries" (Williams and Sternthal, 2007: 48). Giaquinto at al (2007) described spirituality as being concerned with the transcendent, with addressing, ultimately, questions about life's meaning, assuming there is more than what can be seen or understood. Religiosity was viewed in terms of shared doctrinal beliefs and participation in certain behaviours (Giaquinto et al, 2007). Miller and Thoresen, (2003) attempted to differentiate between religion and religiousness. Religion was described more as a social phenomenon and religiousness as the extent to which an individual "may or may not be rooted in the religion" (p.28). Religion and spirituality appear to be viewed as different constructs in the Western world and in the available literature reported above. Spirituality is referred to as being broader, relating to meaning of life and purpose, and religion is thought to be related to the belief of a set doctrine and certain identifying behaviours shared with others. Spirituality is viewed as a personal experience while religion is viewed as a shared experience. However defining these two constructs still remains a challenge.

According to Rassool (2000) in the Islamic context, there is no difference documented between the term "Spirituality" and "Religion". "The concept of religion is embedded in the umbrella of spirituality. In the Islamic context, there is no spirituality without religious thoughts and practices, and the religion provides the spiritual paths of salvation and a way of

life" (Rassool, 2000: 1479). This view of spirituality and religion is guided by the Holy Qu'ran and further sayings and deeds of the Holy prophet known as the Hadith. This suggests the presence of differences between spirituality/ religion in Western and Islamic contexts, thus highlighting the need to investigate the association between religion and health in Islamic contexts also as results from previous studies in the West may not be applicable.

3.3.2 Religion and Coping with Illness and Mortality

Using the search strategy outlined in the previous section, research articles dealing with religion and health outcomes were identified. These articles concerned two main topics: coping with illness and mortality.

Fitchett, Rybarczyk, Demarco et al (1999) investigated the relationship between religious coping and health outcomes in medical rehabilitation patients using a longitudinal method. The study sample was made up of 96 participants aged between 29 and 86 years old. The majority of them were Catholic (43%), 42% identified themselves as Protestant, 5% as Jewish and 2% as having no religious affiliation. Participants were interviewed within 5 days of admissions, close to discharge and at 4-month post discharge via a telephone interview. Measures used in this study included the following validated scales: Index of Religion, Brief Religious Coping Scale (Brief RCOPE), Spiritual Injury Scale, Brief Depression Scale, Satisfaction with Life Scale and Perceived Social Support. Data were analyzed with zero-order correlations and multivariate regression equations. Results of this study showed that after controlling for baseline measures of each of the dependent variables i.e. religiosity, depression, mobility and life satisfaction, religion variables did not make a positive contribution to recovery or adjustment. However, participants with loss of mobility and those with poorer recovery appeared to have higher religious coping scores than those showing

improvements in mobility. Interestingly, their results showed that negative religious coping was significantly associated with poor adjustment. Negative religious coping was identified in cases where participants viewed their illness as a punishment from God and this was found to be associated with depression (r=0.21, p<0.05) (Fitchett et al 1999).

Participants in the study described above were mostly from a Catholic and Protestant background living in the US. These results therefore cannot be generalised to a non Christian population or an Arabian population. However the results do suggest an association between loss of mobility and religious coping scores. This could indicate that people with poorer recovery might possess higher religious coping strategies, however due to the correlational data inferences of causality cannot be made. Similar results regarding religious faith and health outcomes were reported by Franklin et al (2007) as discussed below.

Franklin, et al (2007) investigated the association between religious fatalism and health outcome amongst African Americans in the Nashville community of the United States. This was part of a larger project aimed to identify and reduce diabetes and heart disease in the African American community. A total of 1273 telephone interviews were conducted in which various questionnaires were administered. The validated Religious Health Fatalism Questionnaire (RHFQ-HI) was used to measure fatalistic beliefs, measures of health utilization, health behaviours and chronic illness were also used. Fatalism can be defined as: "the belief that an individual's health outcome is predetermined or purposed by a higher power and not within the individual's control" (Franklin, et al 2007: 564). Results showed that African Americans reported significantly higher scores on fatalism than their white counterparts. Individuals who scored higher on chronic illness were more likely to possess fatalistic beliefs. The findings that African Americans tended to endorse fatalistic beliefs

more than whites in this study highlights the importance of potential cross culturalcross-cultural differences in the religion/health association. The authors reported that their hypothesis that fatalistic beliefs were associated with unhealthy behaviours and increased frequency of chronic illnesses was partially confirmed. Despite the noted association, care must be taken as not to interpret this to mean that fatalistic beliefs are responsible for the increase in chronic illness amongst these individuals. It is possible that fatalistic beliefs might be a means of religious coping for individuals with chronic illnesses, or generated by the experience of illness and helplessness. However, it is also possible that fatalistic beliefs cause the individuals to possess a reduced self-efficacy in self management of chronic conditions. These results are noteworthy, however it is difficult to conclude a cause and effect association from correlational data. It is possible that due to the nature of their chronic illnesses, fatalistic beliefs develop to help with coping. Rather than generalising about subjective religious beliefs as a whole, it might be more useful to identify which specific aspects of the religious beliefs could possibly have a negative impact on the patient's self-efficacy, specific to different rehabilitation goals. This study highlights the importance of further research into issues surrounding religious beliefs and control/self-efficacy in recovery from illness. Ai, Peterson, Rodgers et al (2005) present results indicating that different aspects of religious faith can be related to increased or decreased sense of control during recovery.

Ai, Peterson, Rodgers et al (2005) investigated the effects of religious faith on locus of control in cardiac patients. Despite looking at locus of control, and not specifically self-efficacy, their results are relevant to this PhD study. Ai et al (2005) described internal control as a type of event-specific self-efficacy, thus making their findings relevant to the current project. Their study sample was made up of 224 middle- and older- aged patients due to

undergo cardiac surgery. Participants underwent two interviews, the first one was on the date of their pre –surgical medical interview and the second was a telephone interview one day prior to their surgery. The following validated tools were used: Multidimensional Health Locus of Control (Wallston, Wallston and Devilles, 1978), Three-Factor Religiosity scale, Center for Epidemiological Studies-Depression (CES-D) scale (Radloff and Locke, 1986) and Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, and Farley, 1988). Prayer coping was assessed with the 3-item Using Private Prayer as a Means for Coping scale (Ai et al., 2002).

Results of their study showed that subjective religiosity was positively correlated with reduced internal control and increased 'powerful others' health locus of control. This indicated that participants who rated themselves highly on subjective religiosity tended to report less personal control over their health issues. However the use of prayer as a coping strategy was positively associated with internal health locus of control. This is an indication that participants reporting higher use of prayer as a strategy reported higher personal control of their situation. It is possible that external control or powerful others locus of control in situations beyond patients' control such as cardiac surgery or stroke might help alleviate some of the stress associated with inability to change the situation. Thus care must be taken in interpretation of results by Ai et al (2005) as meaning that subjective religiosity results in less internal control and less responsibility for one's health. However, it is possible that religious surrender and misinterpretation of the patient's role in medical treatment and rehabilitation could lead to reduced self –efficacy in various aspects of recovery.

3.3.3 Religious Faith and Mortality/ Survival

There appears to be evidence suggesting the inverse association between religious faith and mortality (Powell et al, 2003; Williams and Sternthal, 2007). McCullough, Larson, Hoyt et al (2000) conducted a meta-analysis of 42 independent samples investigating the association between religious involvement and all cause mortality. They identified 41 research reports, which were relevant to their investigation. All except two were based on data from the US, two were based on data from cancer patients in Norway. Forty two independent samples were included in the meta analysis from 29 of the 41 research reports, with a total of about 126,000 people represented. Meta-analysis showed that odds for survival for people with higher religious involvement were 129% of the odds of survival for those with lower religious involvement. Religious involvement was assessed by frequency of attendance at religious activities. Religious involvement was thus reported to be related with higher chances of survival. They found that studies controlling for demographics, psychosocial or health related variables showed the least association between religion and mortality, indicating that these variables play a significant role in the association between religious involvement and survival. The inverse association between religious involvement and mortality was found to be greater in women than men. Studies in which religious involvement was assessed using public means such as attendance at religious services/ activities showed stronger associations than those using other measures of religious involvement. This indicates the positive effects from psychosocial elements of attending religious activities. The authors advocate controlling baseline health in order that the associations between religion and mortality are not exaggerated. McCullough et al also advocate the controlling of social variables as well. It might be quite difficult to control for social support or health behaviours as these are hard to quantify and may be significant aspects of religious involvement. The authors conclude that a favourable association has been demonstrated between religious involvement and survival,

and future research should focus on the mechanisms responsible for such association. Other researchers have reported similar findings. Hill et al (2005) investigated the association between religious attendance and mortality in Mexican Americans in an 8 year follow up study. They reported that participants who attended church once per week showed a 32% reduction in risk of death when compared to those who did not attend such religious activities. These authors concluded that: "weekly church attendance may reduce the risk of mortality among older Mexican Americans" (Hill et al, 2005). However it must be noted that religious attendance might be a proxy for better physical functioning thus not a valid representation of religious faith, or it could be a social interaction activity that improves feelings of belonging and wellbeing.

Similar results regarding relationships between religious attendance and mortality were reported earlier in 1999. Hummer et al reported on a longitudinal US survey of 21 000 adults investigating the association between religious attendance, health and behavioural correlates with mortality. They reported that people who did not attend religious services were 1.87 times more likely to be dead at the follow up period of 8 years than those who attended religious services more than once a week. The authors interpreted this as a "seven-year difference in life expectancy at age 20 between those who never attend and those who attend more than once a week" (Hummer at al, 1999). Oman et al (2002) presented results in support of those of Hummer et al (1999). They investigated the relationship between religious attendance and mortality in different causes of death. Data were collected between 1965 and 1996 from 6545 residents in California, US. They reported a higher rates of circulatory, cancer, digestive, and respiratory mortality ($p < 0.05$) in residents who never attended church (Oman et al, 2002).

Care must be taken when interpreting results of the studies reviewed above in which church attendance was firstly used to measure religious involvement, and secondly correlated with mortality. Although the results show an association between church attendance and mortality, as the authors themselves also mention, people who are sick are less likely to attend church. This could be due to the physical and financial demands of getting ones self to church more than once a week. It is also possible that individuals with less social support are unable to get themselves to church thus social support being a more important mediator of health and longevity, rather than religious attendance. Some non-attending individuals may nevertheless engage in religious activities in their own home. These correlational results do not imply causality. They cannot be interpreted as showing that religious attendance reduces mortality. Nonetheless, the findings are worthy of further investigation, to examine more closely the variables which mediate the relationships found in these studies.

3.3.4 Religious Faith and Coping with Stroke

Literature related to religion and coping with stroke is limited. Using a search strategy as mentioned above with the inclusion of the terms stroke and Cerebrovascular accident (CVA), a few articles were located dealing with religious faith and coping with stroke. Two research teams have suggested that spiritual practices may aid in dealing with the emotional problems post-stroke and regaining a sense of control and life purpose (Robinson-Smith et al, 2000; Ellison and Levin, 1998). Specifically, prayer seems important. Lev (1992) suggests that prayer can facilitate coping and aid in the reduction of stress (as noted in the study by Ai et al above), however this claim is not specific to stroke patients. Robinson–Smith et al (2000) studied the associations between self-efficacy, quality of life and depression in stroke patients. This article was reviewed in depth in chapter 1 on self-efficacy in stroke. Their results showed that self- care self- efficacy was positively associated with quality of life and

negatively associated with depression post-stroke. Thirty six percent of stroke participants in their study expressed that prayer was a significant part of their coping strategy and was effective in increasing their self-care self-efficacy post-stroke. The researchers also identified a statistically significant positive difference in perceived quality of life between those who expressed a higher personal faith in God when compared to those who expressed little personal faith in God (t=-2.66, p<.01) (Robinson-Smith et al, 2000). Robinson-Smith (2002) investigated the use of prayer as a coping strategy in stroke survivors. This study was part of a larger project investigating self-care self-efficacy, quality of life and depression at 1 month and 6 months post-stroke (Robinson-Smith et al 2000). The study sample was made up of 8 participants who were purposively selected because they had identified themselves as using prayer as a coping strategy post-stroke. Six of the participants were female and two were male. Participants were aged between 57 and 85 years with the following religious affiliations: Roman Catholic (n=4), Lutheran (n=1), Episcopal (n=1) and none reported (n=2). The study was carried out in Northeastern area of United States. Stroke participants were interviewed and responded to the following 3 open ended questions:

1. In what ways does prayer help you cope since the stroke?

2. What kinds of prayers have you used to cope with the stroke?

3. Are there other ways that prayer has helped you since the stroke?

All interviews were audio recorded and transcribed verbatim. Transcripts were then analysed using a five step process of content analysis developed by McCracken (1988). The researcher identified 4 major themes of praying being used as a coping strategy namely: connecting to God, ways of praying now, reaching back to early family life, and finding strength through prayer. Other themes identified included considering self, other and nature; becoming more focused on everyday; linking present and past; being unburdened and comforted. Robison-Smith (2002) argued that: "Prayer functioned as a source of God's strength and comfort. It

was also used as a way to relieve the burden and ease the crises assisted with stroke" (Robinson-Smith, 2002: 362).

An obvious criticism of the above study is the use of only 8 participants. However in a qualitative study, a sample of eight is common as the main issue is not providing information for generalization but exploring in detail the experiences of a smaller group of participants to enrich and theorize on an under-researched topic. Another point that is also unclear is the religion of the participants and the type of prayer employed and its frequency. Prayer is also a word clearly understood in a variety of cultures, however, it involves different activities. For example, prayer in the Muslim religion involves a pattern of movement without which the activity would not be described as prayer. In a Western context, prayer may simply mean "talking privately to God" however this is not termed as prayer in an Arabian context. Clarification of the word "Prayer" is required in such a study as this and more emphasis regarding frequency and content. Regardless of the above criticisms, the findings do suggest that focusing externally to one's self for comfort and strength, together with belief in a divine entity, can have positive effects on coping post-stroke. However, the relationship between this strategy and the rather problematic aspects of external locus of control need some further clarification.

Giaquinto, Spiridigliozzi and Caracciolo (2007) assessed the possibility that religious beliefs protected individuals from emotional distress post-stroke. One hundred and thirty two hospitalized individuals (in Italy, predominately Christian) with a definite diagnosis of stroke participated in this study. Each participant received a semi-structured interview in which the following scales were completed, as well as open-ended questions: Mini Mental State Examination, Cumulative Illness Rating Scale, Functional Independence Measure, spiritual

and religious belief was measured by the Royal Free Interview (RFI) and The Hospital Anxiety and Depression Scale (HADS). The results showed an inverse association between HADS scores and RFI scores. In other words, patients with lower anxiety and depression scores showed higher scores on religious beliefs, while participants with higher anxiety and depression scores identified themselves to possess fewer religious beliefs. Emotional distress scores (HADS) were also found to be significantly related to disability as measured by the functional independence measure. In other words, participants who were more disabled were more likely to have higher scores on depression and anxiety. They reported that religious beliefs do influence the ability to cope with distress post-stroke and could possibly act in a protective role against emotional distress (Giaquinto et al, 2007).

Giaquinto et al (2007), provide some evidence showing the possible influence of religious beliefs on emotional distress in stroke. Limitations of the study include: inability to clearly differentiate spirituality and religiosity and difficulty making causal inferences from correlational data. This relates to issues about the direction of influence in the measured variables and the possibility of other non-measured variables being responsible for the relationships obtained. In addition to this, results such as these cannot be generalised to other religions or cultures.

Donnellon et al (2006) reviewed the literature concerning coping strategies after stroke. One hundred and two studies dealing with this topic were identified, however only 14 studies met the criteria for inclusion. Of these 14 studies, only one study included investigation of the relationship between religion and health outcome and the findings were not specific to stroke patients. This study reported that positive religious coping strategies assisted in providing patients with a sense of meaning and helped to increase self-efficacy during stressful

situations in patients undergoing medical rehabilitation (Fitchett et al 1999). In the 14 studies reviewed by Donnellon et al (2006), 10 different coping measures were identified but the review was unable to identify clearly effective coping strategies in stroke rehabilitation. Rather disappointingly with respect to this current literature review, 13 of the 14 studies assessed a variety of constructs without giving any mention of spirituality or religion despite the growing body of evidence in other health disciplines of their possible role in coping with illness. This review by Donnellon et al points out the limited research available on the role of religion and spirituality in stroke rehabilitation.

3.3.5 Negative Effects of Religion on Health

Studies investigating the negative effects of religion on health appear to be limited in the literature (Pargament et al 2001). Williams and Sternthal (2007) reviewed a few studies discussing the negative effect of religion on health. They identified that certain aspects of religion can cause individuals to be judgmental and hostile towards others and the self. Although the social aspect of religion can provide a sense of support during illness, failure to conform to strict beliefs and practices can become an increased source of stress (Chatters, 2000, Trenholm et al, 1998). Presumably this can result in personal guilt as well as criticism from others.

Smith et al (2003) conducted a meta-analysis of 147 separate investigations related to religiousness and depressive symptoms. They identified evidence suggesting an association between negative coping such as blaming God for problems, and avoidance of difficulties by engaging in religious activities, and depressive symptoms. Pargament et al (2001) investigated the association between religious struggle and mortality. Religious struggle was identified by the following statements: "wondered whether God had abandoned me;

questioned God's love for me; decided the devil made this happen; felt punished by God for my lack of devotion" (Pargament et al, 2001: 1184) Their study involved 596 patients aged 55 and over with different medical diagnoses. They highlighted the limited number of studies focusing on the negative association of religiousness on health and theirs was the only study investigating the negative effect and its association with mortality. The results of their study showed that religious struggle was predictive of mortality. Cox regression analysis yielded the following results RR, 1.05; 95% CI, 1.00-1.10;x=4.37; P=.04, indicating religious struggle was a significant predictor of mortality. The authors suggest possible early identification of patients experiencing religious struggle during medical assessment and referral to a clergy might possibly increase/improve the outcome of at-risk patients. However, it is possible that religious struggle could be a proxy for depression or poor physical functioning, yet these factors were not taken into consideration. Caution is required in accepting these results. Individuals experiencing religious struggle may have been in a worse medical and physical condition that those not experiencing religious struggle. In addition to this, these results cannot be generalised to an Arabian population, as predominantly gained from Western/ Christian participants.

The above literature reviewed provides evidence in support of a positive association between certain aspects of religious commitment, for example, church attendance, and health. A few studies have identified possible harmful aspects of religion to health (or, at least, recovery), through viewing ill-health or disability as a punishment, for example. It must be noted that a majority of the studies reviewed above were conducted in the US on a predominantly Christian population. Reports from other religious faiths e.g. Islam, Judaism, Hinduism, are strikingly absent. Religious attendance requirements differ between males and females in other religious faiths and a religious service, as mentioned in many of the papers reviewed,

do not occur in other faiths as they do in the Christian religion. Further research is required focusing on other religious faiths and the involvement and meaning of religion in coping with stroke.

Regardless of the above criticisms, there is an indication that religiosity is associated with better health. However little qualitative work has been carried out to investigate these issues, and this is recommended in order to help in understanding what aspects of religious beliefs might be beneficial.

3.4: Factors mediating the relationship between religious faith and health

Several possible mediating factors have been proposed as being responsible for the association between religious faith and health outcomes, however research data in support of these claims is lacking. Mediating factors refer to issues that have been identified as facilitating or being responsible for the observed relationship between religious faith and health outcomes. Mediating factors identified in the literature include: social support, lifestyle/health behaviour, positive psychological states, and a sense of meaning. Ellison and Levin (1998) highlighted the following seven explanatory factors linking religion to health: " (1) regulation of individual lifestyles and health behaviours, (2) provision of social resources (e.g., social ties, formal and informal support), (3) promotion of positive self-perceptions (e.g., self-esteem, feelings of personal mastery), (4) provision of specific coping resources (e.g. particular cognitive or behavioural responses to stress), (5) generation of other positive emotions (e.g., love, forgiveness), (6) promotion of healthy beliefs, and (7) additional hypothesized mechanisms, such as the existence of a healing bioenergy" (Ellison and Levin, 1998: 703). These factors will be discussed in more detail subsequently in this chapter.

i) Regulation of Individual Lifestyle and Health Behaviours Through Religious Commitment:

Health and disease are to some extent related to behaviour and lifestyle (Moreira-Almeida et al, 2006). Religious participation may enhance physical well-being by modifying health behaviour in ways that could decrease the risk of falling ill (Ellison and Levin, 1998). Numerous studies have reported the negative relationship between certain dimensions of religion and alcohol, tobacco and substance abuse (Cochran, Beeghley and Bock, 1988; Koenig, George, Meador et al, 1994).

Wallace and Forman (1998), investigated religion's role in promoting health and reducing risk of disease and death among American youth. The study used data from a national survey: University of Michigan's Monitoring the Future Project. This included data from about 15000-19000 high school seniors from 1976-1996. Participants completed a self - administered machine-readable questionnaire in which the following 3 dimensions of religion were assessed: religious importance, attendance, and denominational affiliation. In measuring religious importance, participants were asked a single question: How important is religion to your life? Options for responses ranged from 1 (not important) to 4 (very important). Religious attendance was measured by the following single question: How often do you attend religious services? Response options ranged from 1 (never) to 4 (more than once a week). Finally, denomination affiliation was assessed by the question: What is your religious preference? In assessing risky behaviour, participants were asked to rate the frequency of their participation in the following behaviours: carrying a weapon (i.e., gun, knife, or club) to school, engaging in interpersonal violence, seat belt use, drinking while driving, and riding while drinking. Other behaviours assessed were: substance abuse and lifestyle behaviours

such as diet exercise and sleep. Multivariate analyses were used to investigate the relationship between the 3 dimensions of religion measured and reported health-compromising behaviours. Results of this study showed that religious youths were less likely than non-religious youth to participate in health-compromising behaviours and were more likely to engage in behaviours that had positive effects on health. More specifically, religious attendance and importance were found to be significantly and positively related to wearing a seatbelt and negatively to violence and driving under the influence of alcohol. Youth who attended church weekly were found to exercise more, get adequate sleep and eat in a healthier fashion than those reporting infrequent or non-church attendance. Analyses of the trend of behaviours between 1976 to 1996 showed that the relationships between religion and risky behaviour persisted over time. Researchers also found that in years with an increase in marijuana among youth, use among religious seniors appeared to remain unaffected.

Results by Wallace and Forman (1998) provide some evidence in support of a positive association between religion and healthy lifestyle behaviours, however it still remains unclear whether religion influences health through encouraging healthy behaviours and discouraging negative health-compromising behaviours (ie. the basis of the relationship remains unclear). It may also be a 'proxy' variable standing in for something else like social support, as those who report more religious commitment may have closer ties to family and other community members. In addition to this, it may not to possible to apply these results to other religions. Participants of this study were predominantly of the Christian faith and located in the US where church attendance is the norm. However, as pointed out throughout the last chapter, other religious faiths do not necessarily involve attendance at a religious service. This study also focused on healthy youth and it still remains unclear as to the application of these results to elderly individuals with conditions such as cerebrovascular incident (CVA). The study

however indicates that this might be an area for further research which might aid in an increased understanding of the role that religion plays in influencing health behaviour.

Krause (2003) studied the role of religion in abstinence from alcohol among African American elderly persons when compared to White elderly persons. The sample contained 750 white and 750 black elderly persons aged above 66 years living in America and all participants were of the Christian faith due to difficulties devising measures to assess religiousness of other faiths. Participants were interviewed with the following 5 key variables measured: abstinence from alcohol, denominational preference, church attendance, private prayer, and religious meaning. Abstinence from alcohol was assessed with a single item, participants were asked if they consumed beer, wine or liquor. Those who consumed alcohol were given a score of 0 and those who did not were given a score of 1 (a rather insensitive measure). In assessing denominational preference, participants who were affiliated with a fundamentalist congregation were given a score of 1 and all other respondents were given a score of 0. Church attendance was measured by asking: How often do you attend religious services? Participants attending more than several times a week were allocated a higher score than those who did not attend or were not frequent attendees. Scores ranged from 9 (several times a week) to 1 (never). In assessing private prayer, participants were asked how many times they prayed alone. The scores allocated ranged from 8 (several times a day) to 1 (never). In assessing religious meaning participants were asked to rate their level of agreement to the following 3 statements: (1) God put me in this life for a purpose; (2) God has a specific plan for my life; (3) God has a reason for everything that happens to me. Scores given in relation to the responses ranged from 4 (strongly agree) to 1 (strongly disagree).

Data were analysed with the use of two statistical procedures. Logistic regression analyses was used to study the association between race and denominational preference, and a series of multiple regression analyses tested the relationship between race, church attendance, private prayer and religious meaning. Results of the various analyses yielded the following results: white elderly participants were identified to be less likely than black participants to be associated with fundamentalist congregations, and attended church less frequently than did the black participants. In addition to this, white participants prayed less often and were less likely to find a sense of meaning in religion than the black participants. In assessing the relationship between race, religion and alcohol use, binary format logistic regression analyses were performed. Logistic regression was performed in a controlled hierarchical manner with three steps: firstly the relationship between race, and region of country was examined. A demographic control measure was entered into the equation at this stage to reduce previously documented demographics of correlates of alcohol use. In the next model, religious measures such a denominational preference, church attendance, private prayer and religious meaning were entered into the equation. The last model consisted of investigating the relationship between denominational preference and church attendance, private prayer, and religious meaning, Results of this 3-step analysis yielded the following results: race was found to still be related to abstinence from alcohol use, even after controlling for well known demographic influencing factors such as age, marital status, education and region of country. Elderly white participants were found to be 38% less likely to abstain from alcohol consumption than black participants. Religion was found to be associated with the decision to abstain from alcohol intake in the elderly, and participants associated with fundamentalist congregations were found to be less likely to drink alcohol than older people who did not attend fundamentalist congregations. Other results revealed that church attendance or frequency of private prayer were not associated with alcohol use.

The results described above indicated that older Blacks were less likely than older Whites to consume alcohol because older Blacks were more likely to be affiliated with fundamentalist denominations. In addition to this, older African Americans were more likely than older Whites to derive a sense of meaning from their faith (Krause, 2003). Religious meaning was found to show a stronger relationship with low alcohol intake in the participants than affiliation with a fundamentalist congregation. Krause stated the following: "People who find meaning in religion are more likely to avoid the use of alcohol regardless of whether they affiliate with a fundamentalist congregation" (Krause, 2003: 527).

Results by Krause (2003) provide some evidence suggesting that certain aspects of religion are associated with behavioural and lifestyle decisions such as abstinence from alcohol intake that can have positive long term effects on health. Results showing that church attendance and private prayer were not associated with abstinence suggests that the decision to abstain from alcohol use might be more related to societal religious norms as taught by the type of congregation with which participants were associated. However, the study failed to clearly distinguish between abnormal excessive alcohol intake and alcohol intake that might be deemed acceptable as in the case of a glass of wine with a meal.

Regardless of the above criticism, results of this study highlight significant lifestyle decisions associated with espousing religion. These lifestyle changes could in turn have positive effects on health and recovery from illness. This study was conducted in America on participants of the Christian faith thus generalization to other faiths might not be possible. However, the next article reviewed focuses on lifestyle decisions amongst Muslims living in the US.

Islam and Johnson (2003) investigated the association between religious influences and known smoking risk factors in Muslim Arab American adolescents in an Islamic school in the United States. Participants included 480 7th to 12th grades aged between 12 and 19, during the 1998 and 1999 school year. A questionnaire was administered to the students in which they had to respond to either YES/NO questions or a 4-point scale declaring level of agreement (Totally agree – totally disagree). Statements included in the questionnaire were regarding: peer smoking, perceived norms, family smoking, family advice against smoking, perceived positive beliefs about smoking, perceived negative consequences of smoking, religious influence, gender-specific norms, susceptibility to smoking, experimentation with cigarettes (ever smoking), and past 30 day smoking. Results of this study showed that religious beliefs and perceived negative consequences of smoking had significant influences on students' decisions to take up smoking. Increased risk of smoking was associated with peer smoking (beta=1.099, $p<0.0001$), peer norms (beta=0.12, $p=0.0008$), positive beliefs about smoking (beta=0.103, $p=0.02$) and being of the male gender (beta=0.564, $p=0.015$). Decreased risk of ever-smoking was significantly associated with religious advice (beta=0.323, $p=0.008$) and belief in negative consequences of smoking (beta=0.209, $p<0.0001$). Other relevant results showed that amongst female participants, religious influence was a protective factor against smoking (beta=0.59, $p=0.002$). However this was not the case for boys ($p>0.05$) (Islam and Johnson , 2003).

Results by Islam and Johnson (2003) provide some insight into religious influence on smoking behaviour in teenagers (aged 12-19). Interestingly, their results show that the protective factor of religious beliefs had a stronger influence on girls than it did on boys. Perhaps this is related to stricter community norms regarding females smoking rather than personal choices to adhere to healthy behaviours. Another explanation for this could be that

females tend to be more religious than males hence an increase in its influence to modify behaviour. Given that this study was done in the US, despite its focus on Muslim Arabs, its generalisation to Kuwait is somewhat difficult. However, it does highlight possible gender differences that could be present in an Islamic community like Kuwait. Health and lifestyle choices are significant aspects of Islam. Hence, although these findings suggest that the association between health and religion is largely mediated via lifestyle and health behaviour in participants of Islamic faith, there are limited empirical studies to support this.

ii) Social Support:

Social support derived from being part of religious communities is another potential mediating factor in the relationship between religion and health. Interpersonal relationships with others can provide support during distress and a sense of belonging (Williams and Sternthal, 2007). Strawbrige, Sherma, Colen et al (2001) reported significant positive changes in social ties and health, related to religious attendance.

Salsman, Brown, Brechting et al (2005) investigated the mediating role of optimism and social support in the relationship between religiousness and psychological adjustment. The study sample was made up of 217 students from University of Kentucky, USA. Participation involved filling out a packet of questionnaires measuring religiousness, spirituality, optimism, social support, social desirability, psychological distress and subjective well-being. Religiousness was measured by the Intrinsic/Extrinsic Religiousness Scale-Revised, which is a 14-item measure assessing internal and external motivations for religious beliefs and practices. The initial eight items were related to intrinsic motivations and the other six items related to extrinsic motivations. Participants had to rate their responses on a 5-point Likert scale that ranged from: 1 strongly disagree to 5 strongly agree. Spirituality was assessed with

the Spiritual Transcendence Scale (STS), which is a 24-item self-report tool. The STS is made up of three subscales: connectedness, prayer fulfilment and universality subscales. Optimism was measured with the Life Orientation Test- Revised (LOT-R) measure which is a self-report consisting of 6 items. Respondents had to rate their level of agreement on a 4 - point Likert scale with responses ranging from 1(I agree a lot) to 4 (I disagree a lot). Psychological distress was measured with the Brief Symptom Inventory (BSI) on which participants had to respond to 53 items related to current psychological symptoms. Responses were rated on a 5 point scale which ranged from 0 (no discomfort) to 4 (extreme discomfort). Social well-being was measured using the Satisfaction with Life Scale. This is a 5 item scale on which participants had to rate their level of agreements with statements related to personal evaluation of satisfaction with life.

Data were analysed to find out whether or not optimism and social support mediated the association between religiousness, spirituality variables and psychological variables. In order for optimism and social support to be labelled as a mediators in this study, there had to first be a relationship between the independent variables (religiousness and spirituality) and the dependent variables (psychological variables). Secondly, a significant relationship between the independent variable and the mediating variables (optimism and social support) must have been identified. Thirdly, the mediators had to also be significantly related to the dependent variables and finally there should be a significant decrease in the association of the independent and dependent variable once the mediators were controlled for. Results of this study showed that all scores of religiousness and spirituality were positively related to one another (p<0 .01) and also positively associated with social support (r=0.17 to 0.26, all p<0.05). Religiousness and spirituality scores were also positively associated with optimism scores except for the scores for extrinsic religiousness. Intrinsic religiousness scores and

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prayer fulfilment (subscale of the spirituality measure) were found to be positively associated with subjective well-being. Optimism was identified as mediating the association between intrinsic religiousness and psychological distress. The authors reported that optimism and intrinsic religiousness accounted for 36% of variance in psychological distress and once optimism was controlled for, intrinsic religiousness accounted for only 0.01% of variance. This was seen as optimism providing full mediation of the association between intrinsic religiousness and psychological distress. Optimism was also identified to partially mediate the relationship between intrinsic religiousness and satisfaction with life. Optimism and intrinsic religiousness combined accounted for 45% of the variance in satisfaction with life. However, this variance reduced to 2.3% when optimism was controlled for and only the effects of intrinsic religiousness assessed. This led to the conclusion that optimism provides partial mediation in the relationship between intrinsic religiousness and satisfaction with life. Optimism was also identified to mediate the relationship between prayer fulfilment and satisfaction with life. Optimism and prayer fulfilment combined accounted for 43% of variance in predicting life satisfaction however, this variance reduced to 1.1% once optimism was controlled for. Social support was identified to have a mediating role similar to that of optimism. The authors stated the following: "social support fully mediated the relationship between intrinsic religiousness and psychological distress, and partially mediated the relationship between intrinsic religiousness and satisfaction with life and between prayer fulfilment and satisfaction with life" (Salsman et al, 2005:527).

Salsman et al (2005) carried out a replication study (reported in the same reference as given above) to see whether their findings would indicate a consistent pattern. The results of the first study described above had shown that optimism and social support mediated the relationship between religiousness and psychological adjustment, and also spirituality and

psychological adjustment. The replication study was made up of 159 students from the same university as the first sample. 46% of participants were Protestant, 30% were Catholic, 14% reported no religious affiliation and 10% reported other religious affiliation. The same questionnaire pack measuring religiousness, spirituality, optimism, social support, social desirability, psychological distress and subjective well-being was utilized and data were analysed as described above with the initial study. Results reported were similar to those of the initial study. All scores of spirituality and religiousness were positively related with each other and positively associated to social support. With the exception of extrinsic religiousness (as with the initial study), all scores of religiousness and spirituality were positively associated with optimism. However, in evaluating associations between religiousness, spirituality and psychological adjustment, findings were very different from the initial study. None of the religiousness and spirituality variables was found to be significantly related with psychological distress, however significant associations were found with satisfaction with life. Further results of the replication study showed that optimism and social support mediated the relationship between intrinsic religiousness and satisfaction with life. This mediating role was also identified between prayer fulfilment and satisfaction with life as in the initial study. The replication study was, however, unable to identify the mediating role of optimism and social support between religiousness and psychological distress.

Results by Salsman et al (2005), demonstrated that not all dimensions of religiousness were associated with psychological adjustment/well-being. Intrinsic religiousness and finding fulfilment in prayer, were variables showing the strongest association with psychological adjustment and satisfaction with life. Another key finding of their study was the mediating role of optimism and social support. This supports the hypothesis that optimism and social support might be associated with dimensions of religiousness that could be responsible for

the positive association of religion and health as reported in the first section of this chapter. However, these results could not be replicated in the follow up study, suggesting the presence of other mediating variables in this complex relationship. Limitations of the study mentioned by the authors include the imbalanced gender distribution of the sample: 52 men and 161 women. With such a low number of men, one could argue that these results can only be applicable to women, given that research has previously shown women to be more religious than men (Brown, Parks, Zimmerman and Phillips, 2001). Although the study investigated the effect of optimism and social support on religiousness and psychological adjustment relationship, participants were typical university students not particularly experiencing any distressing life issues requiring psychological adjustment. Perhaps a sample group of participants experiencing some degrees of distress might have helped shed more light on this association. About 90% of the sample was of various denominational groups however, they were all of the Christian faith. This therefore makes the applicability of these results to other faiths difficult. However, this study has identified that issues such as optimism and social support could be significant mediators in the relationship between religiousness and health and further research in other parts of the world and with other religious faiths are required to compare findings.

The students above were not experiencing (as a group) major life stress, but this next study looks at people who have been through the crisis of cardiac surgery. Oxman, Freeman and Manheimer (1995) examined the relationship between social support and religion to mortality in elderly patients after cardiac surgery in the United States. This was a prospective study design with 232 initial participants who were scheduled for elective coronary artery bypass or aortic valve replacement, of which 21 died by 6 months post surgery. Participants were interviewed before their operation to assess functional impairments, social network, and

religious variables. They were also asked to complete a variety of self-report measures to assess perceived social support and personality traits. Participants were contacted post-surgery for another interview at 1 month and 6 months. The following measures were used at pre and post surgery assessments: Sickness Impact Profile, Hamilton Rating Scale for Depression, Neuroticism and extraversion openness five-factor inventory. Three aspects of social support were assessed: type of social support provider (spouse, confidante, relative, friend, and groups), types and amount of social support (emotional, tangible, and informational support) and perceived adequacy of support (which was measured by the Multidimensional Scale of Perceived Social Support). In assessing dimensions of religion, 5 questions were asked which related to religious denomination, attendance at religious functions, available religious social contact, strength and comfort, and sense of religiousness. Data were analysed with the use of Chi-square tests, t-tests, and multivariate analysis. Results of this study provided the following findings: participants who did not participate in organized groups were identified to be three times more at risk of death at 6 months post surgery than those who participated actively in groups. In addition to this, those who reported not having any strength and comfort from religion were also three times more at risk of death that those who reported some even a little comfort from religion. Oxman et al (1995) further reported that those who did not feel deeply religious showed an increased risk of death. Other results reported included the following: Lack of group participation was significantly correlated with neuroticism (r=0.22; p= 0.001), depression (r= 0.19; p= 0.004) and extraversion (r= 0.15; p= 0.04) (Oxman et al, 1995). An interesting finding was that lack of group participation was not significantly related to absence of strength and comfort from religion, in other words strength and comfort from religion acted independently from the social aspect of religion.

Results from Oxman et al (1995) indicate that social support and finding comfort and meaning in religion are associated with lower risk of death post-cardiac surgery. Interestingly, finding comfort and strength in religion acted independently of social support. When combined, their effects were highly significant and noteworthy. However the underpinning processes are still unclear. For example, it is unclear whether finding meaning and comfort in religion lowers a person's stress levels and levels of stress hormones such as adrenaline. One major limitation of this study, however, is the small sample size of 21 deaths. As mentioned by the researchers, this small size warrants caution in acceptance of their conclusions, together with the specific context (USA, predominately Christian sample).

iii) Religious Faith and Psychological Well-being

Improved psychological well-being derived from participation in religious activities has been suggested to be a possible mediator in the relationship between religion and health. Some studies have shown a positive correlation between religion and well-being (Fry, 2000).

Fry (2000) investigated the contribution of different dimensions of religion, spirituality and meaning of life in predicting wellbeing in elderly people living in the community and in a variety of institutions. Participants included 160 community dwelling elderly persons and 160 elderly persons living in institutions such as seniors' lodges, hospice-type quarters and semi-supervised group living accommodation facilities (the latter being referred to as the 'Institutionalized sample') in South Alberta, Canada. The mean age for participants living in the community was 71.9 and 69.2 for the institutionalized sample. 65% of participants were Christian Protestant, 10% were Anglican, 10% Methodist and the rest (15%) Catholics and Mormons. Questionnaires assessing psychological well-being, personal meaning, social support and access to social resources, physical health problems, frequency of negative

events, religious involvement, spirituality, and access of religious support services were administered to all participants. Psychological well-being was measured with a scale developed by the authors, which assessed three aspects: depression, anxiety and unhappiness. Participants had to rate these items and their opposites (i.e. cheerfulness, calmness and happiness respectively) on a 9 point scale reflecting their mood in the last 4 months. Self-esteem was also assessed in a similar way on a nine-point scale. The following subscales of the Life Attitude Profile (LAP, Reker & Peacock, 1981) measured personal meaning: Life purpose, Will to Meaning, Future meaning. Social support and access to social resources were measured by the Multidimensional Scale of Perceived Social Support (MSPSS, Zimet et al, 1988). Religious involvement was measured by five questions assessing importance of religion in their daily life, frequency of attendance to religious services, intensity of formal religious involvement, participation in informal religious activity and degree of comfort in religion during times of suffering and distress. Participants had to rate these five items on a 6-point scale with "six" denoting increased frequency or involved and "One" denoting lack of importance and participation. Spirituality was assessed with two items measuring frequency of engaging in private prayer, meditation or personal contemplation and the extent to which the participant felt inner peace and a sense of being in touch with self.

Data were analysed using a stepwise hierarchical regression analysis model. Results showed that institutionalized elderly people exhibited lower scores on measures of well-being, lower sense of personal meaning, fewer social resources, higher frequency of negative life events and more physical problems when compared with elderly participants living in the community. Despite results showing less religious and spiritual activity amongst institutionalized individuals, they reported greater importance to religion and reported gaining more from religious activity (comfort and support) than the community dwelling

elderly reported. Regression analysis of the community dwelling group showed that existential variables (personal meaning for life, participation in spiritual activity and sense of inner peace) accounted for 23% of variance in well-being scores. Beta scores reported were beta=0.52, $p<0.01$ for personal meaning for life, beta=0.46, $p<0.01$ for participation in spiritual activity and beta=0.36, $p<0.01$ for sense of inner peace. Regression analysis of the institutionalized sample identified that personal meaning and comfort from religion was identified to be a strong predictor of well-being (beta=0.36, $p<0.01$; beta=0.38, p, 0.01 respectively). Access to religious resources and support made a significant contribution to the variance of wellbeing in participants living in institutions (Beta=0.45, $p<0.001$). Regression analysis of the combined sample (community dwelling group and institutionalized sample) showed that demographic factors such as marital status and income accounted for 8% of variance in wellbeing, traditional variables such as social resources and physical health accounted for 10% of variance. The strongest predictors of wellbeing were the existential variables, which accounted for 24% of variance. Out of the seven existential variables, participation in religious activity and comfort derived from religion were found to be the most significant predictors of wellbeing for the combined sample (beta=0.34, $p<0.01$; beta=0.39, $p<0.001$, respectively).

The results of this study provide some evidence in support of the possible influence of religion and spirituality on psychological well-being in the elderly. An interesting finding was the differences seen between the community dwelling group and the institutionalized sample. Despite reporting being less religious and spiritual, the institutionalized sample showed that comfort and sense of meaning were stronger predictors of well-being while with the community dwelling sample, participation in spiritual activity, meaning for life and sense of inner peace were the strongest predictors. This indicates that factors influencing the

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association between religion and well-being might be determined by variables such as type of social support and housing arrangement. It also suggests that religion could become even more important as a source of support when other supports are reduced, as in an institutionalized setting. This could imply that elderly patients in a setting such as a stroke unit might present with different predictors of well-being than those living at home. Further investigation focusing on the differences of religious influence at different stages of rehabilitation and in different settings (stroke unit, rehabilitation centre, patient attending out patient facilities) and comfort provided by other religions would shed more light on this issue.

This study showed that different dimensions of religiosity and spirituality accounted for a 27% and 24% of variance in well-being in the community dwelling elderly persons and institutionalized elderly persons. Fry (2000) from the results of this study, advocates the inclusion of religious and spiritual activities as part of the support care of elderly persons. These activities are viewed as strategies to give them hope and aid in coping with different circumstances. The following was stated: "Assuming that future studies provide similar evidence concerning the positive influence of religion and spirituality, medical professionals and health care providers in institutions for the elderly should join hands with pastoral care professionals in providing emotional resources and support for developing a `will to live' through personal meaning" (Fry 2000, p 384).

Results by Fry (2000) reflect the influence of mostly the Christian faith on wellbeing of elderly persons living in Alberta, Canada. Although it gives one the indication of possible influences of religiosity and spirituality on psychological well-being, care must be taken in directly applying these results to other religious faiths in other parts of the world. The study

did not seem to include non-religious people, so we cannot exclude alternative supports being gained from sources other than religion. Concepts of health and rehabilitation appear to differ amongst the variety of faiths. However, advocating inclusion of religious and spiritual activity in care and rehabilitation of elderly patients might be even more necessary in an Arabian culture where religion is openly expressed and a significant part of most people's daily life. In order to adopt such inclusion, more research is required to identify which dimensions of religiosity and spirituality would facilitate greater self-efficacy and subjective well-being.

Flori, Brown, Cortina et al (2006) investigated the mediating influence of locus of control in the relationship between religiosity and life satisfaction. Data were taken from a larger study known as the Americans' Changing Lives (ACL). The study sample used was made up of 3,617 participants aged between 24 and 96 years old living within local communities of the United States of America in good health. Interviews were conducted with the participants lasting about 86 minutes in which the following variables were assessed: sociodemographics, religiosity, control beliefs, and life satisfaction. Religiosity was assessed by a self-report of religiousness, extent of deriving comfort from religion, attendance and access to religious resources. Internal and External control beliefs were assessed. Internal control was measured with two items from the Pearlin Mastery Model Scale (Pearlin, Lieberman, Menghan, & Mullan, 1981). Participants were asked to rate the following 2 statements on a scale of (1) strongly agree to (4) strongly disagree: "sometimes I feel that I am being pushed around in life" and "There is really no way I can solve the problems I have". External control was assessed by the following three statements in which the participants had to rate their level of agreement on a 4-point scale as described above: ''When bad things happen, we are not

supposed to know why. We are just supposed to accept them.'' ''People die when it is their time to die, and nothing can change that.'' 'If bad things happen, it is because they were meant to be". Life satisfaction was assessed with the following three statements: 1) Now please think about your life as a whole. How satisfied are you with it? 2) As I look back on my life I am fairly well satisfied, 3) My life could be happier than it is now. Participants had to rate the first statement on a scale of 1 (completely) to 5 (not at all) and the last two statements were rated on a scale of 1 (strongly agree) to 4 (strongly disagree).

A series of t tests were used to identify differences amongst the different sociodemographic groups. Older adults showed higher scores on religiosity and external control while younger adults reported significantly higher scores in internal control and lower religiosity scores. Life satisfaction was significantly higher in the older adults than the younger ones. Structural models were constructed to test their various hypotheses of the mediating roles of loci of control. In the overall sample, religiosity was shown have a positive association with external control ($p<0.05$) however religiosity did not have a significant relationship with internal control. Internal control showed a significant positive correlation with life satisfaction ($p<0.01$), external control also had a significant positive effect on life satisfaction ($p<0.01$). Religiosity also had a significantly positive effect on life satisfaction. Further results specific to subgroups showed that the pathway between religiosity and internal control differed according to the age and gender of the participant. This pathway was positive in older adults but negative in younger adults. Older adults were more able to use religiosity to increase life satisfaction through an increase in internal control than did the younger adults. This pathway was also found to be negative in younger males and positive in younger females. Result of Flori, Brown, Cortina et al (2006), showed that internal and external loci of control are significant mediators in the relationship between religiosity and life satisfaction however

significant differences were identified according to age and gender. The main pathway responsible for the differences seen due to age and gender was the pathway between religiosity and internal control. This pathway was not significant in younger adults. This meant that older adults were more able to use religiosity to increase life satisfaction through an increase in internal control than did the younger adults. Differences between males and females showed a similar pattern, with the pathway between religiosity and internal control significantly positive amongst females but negative for males. This suggests that women were more able to use religious faith to increase internal control while for the men, religious faith was associated with external locus of control.

A few issues must be raised before acceptance /generalisation of the results described above. Firstly, measurements of religiosity, control beliefs, and life satisfaction were done with no more than four items each. This may not be a valid measurement of these complex variables, and is likely to be relatively insensitive to individual differences. The sample was made up mostly of participants of the Christian faith, which makes generalisation to other faiths impossible. Also, this was a healthy community sample. However, the results do give us indications of gender and age differences in mediating factors of the religiosity and life satisfaction relationship. Loci of control are particularly important issues in rehabilitation of a patient of the Islamic faith. For some patients, external loci of control (such as reliance on God) and the therapist could be viewed as responsible for their progress and related life satisfaction. There is a great need to understand to what extent these beliefs exist and how they affect the rehabilitation patient.

Chapter Summary

This chapter focused mainly on cultural differences in experience and behaviour related to illness, aimed to review definitions of religion and spirituality in Western and Arabian contexts, and examined studies showing association or lack of association, between religious/ spiritual indexes and health. Factors that may mediate the relationship between religion and health outcome were also discussed.

Definitions of spirituality and religion appear to be different in Western and Arabian contexts. While in Arabian contexts they both refer to a clearly defined spiritual path to salvation and a way of life (Rassool, 2000), in Western research literature religion refers to shared doctrines, beliefs and practices and spirituality involving search for meaning and purpose (Giaquinto at al, 2007).

Research studies appeared to show a positive relationship between religious practices and coping with illness, however there is limited literature available investigating the association and effects of religious variables on the stroke experience during rehabilitation or outcome of rehabilitation. Available studies point out that religion could play a role in reducing emotional distress post-stroke, however in cases where patients believe their stroke was a punishment from God, emotional distress increased (Giaquinto et al, 2007). This highlights the need to assess what type of religious coping strategies patients are using and identify any negative coping such as denial or blaming. Other studies showed that prayer was a significant coping resource post-stroke among religious people/ believers. Prayer helped to ease the burden of sudden disability associated with stroke (Robinson-Smith, 2002). However, prayer may have different meanings in the Muslim religion, as it is a structured activity rather than an experience of private reflection.

Other studies carried out on non- stroke participants have reported a variety of results regarding the association between religion and health outcome/behaviour. Fitchett et al (1999) reported that amongst medical rehabilitation patients, religion did not facilitate adjustment or recovery, however negative religious coping (such as blaming God) was associated with depression. Similar results have not been reported specific to stroke patients. Franklin, et al (2007) reported that fatalistic beliefs were associated with unhealthy behaviours and increased frequency of chronic illnesses amongst an African American sample compared with a White American sample. However it must be noted that results showing that individuals with poorer health outcomes tended to rate highly on fatalism could indicate the use of religious coping strategies to deal with their failing health (or that failing health provokes fatalism in some people). This study highlighted the differences in fatalistic beliefs and health behaviour amongst people of different cultural backgrounds. Ai et al (2005) reported that subjective religiosity was positively correlated both with reduced internal control and increased powerful others health locus of control amongst cardiac patients. However, patients using prayer as a coping strategy reported increased internal control. These results indicated the need to identify what aspects of religious beliefs facilitate or inhibit personal control and self-efficacy. The studies described above were all carried out on Western participants and it is unknown if similar results exists amongst people of different religions and cultures.

The available literature reviewed above, regarding factors which may mediate any relationship between religion and health, appears to suggest the possible multifactorial involvement of healthy behaviours, social support and improved psychological well-being as underpinning any association between religion and health. Healthy behaviours are

encouraged by particular religions. Islam, for example, discourages alcohol drinking and smoking which could in turn affect the healing process post-stroke. However empirical studies supporting this are absent from the literature. Social support has been shown to be a significant aspect of religious participation that could affect coping post-illness but the underlying mechanisms of how social support could affect recovery remains unclear. The association between religious participation, and psychological well-being has been demonstrated by some of the studies reviewed above. However all the studies reviewed were carried out on predominantly Christian participants living in the US, it is yet unknown if similar results will be obtained from such studies done in the Middle East with Muslim participants.

Furthermore, the majority of the research done on religious faith and health outcomes, as reviewed above, has used quantitative research methods with a large variety of quantitative assessment tools. Perhaps the use the qualitative research methods would yield different results and a deeper understanding of how religious faith and practices influence adjustment and satisfaction with life after a stroke.

In the current project, a mixture of qualitative and quantitative methods was used to explore stroke experience and the relationships between the psychosocial variables: self- efficacy, life satisfaction and religious faith. The initial phases consisted of semi-structured interviews to explore patients' experience of stroke and rehabilitation. Themes from these interviews were then used to adapt and develop a tool for measuring self –efficacy (SE) for stroke survivors living in Kuwait. The adapted SE questionnaire, a standardized measure of religious faith and a single item measure of life satisfaction were used in the following phase to investigate the relationship between the three variables being investigated. Qualitative methods were also

used in the final phase of the study to explore the views of health professionals regarding their views of influences of culture on rehabilitation, and clinical application of the findings from previous phases of the project.

Chapter 4

Chapter 4: Methods

Development of Methods

4.1: Introduction

Stroke is a disabling condition that affects not only the physical capabilities of an individual but also the psychological and social areas of their lives. Self-efficacy and life satisfaction are important psychological aspects of the stroke patient's life, however research on the relationships between these aspects of experience has been limited. The literature reviewed identified a significant gap in the available knowledge on self-efficacy in stroke rehabilitation and the associations between religious faith, self-efficacy and life satisfaction. These associations are especially important for patients living in the Arabian culture as religion plays an important role in their lives.

The overall research question of the current project was: "What influences patients' experiences of stroke and life satisfaction post-stroke in Kuwait?" More specific research questions were:

1) What are stroke survivors' experiences of stroke in Kuwait?

2) What is the relationship between self-efficacy, life satisfaction and religious faith in stroke patients living in Kuwait?

3) From the health professional's perspective, what are the cultural influences on stroke experience and rehabilitation in Kuwait and the clinical implications of findings of Phase 3 of this project?

Four main phases were involved in this study:

1) Phase 1:- Exploring the stroke experience in patients living in Kuwait through qualitative interviews

2) Phase 2:- Development of a quantitative tool for use in Kuwait on the basis of Phase 1 interviews: Client-Centred Adaptation of a Self-Efficacy measure for stroke patients living in Kuwait

3) Phase 3:- assessing quantitative relationships between the three variables; self-efficacy, life satisfaction and religious faith

4) Phase 4:- Exploring health professionals' perceptions and beliefs regarding effects of culture on recovery and rehabilitation, through qualitative interviews

A mixture of qualitative and quantitative methods was used in the various phases of this study. According to Patton (2002), the use of a mixed method in research is advantageous because both types of method have different strengths and weaknesses. He stated the following: "Because qualitative and quantitative methods involve differing strengths and weakness, they constitute alternative but not mutually exclusive strategies for research. Both qualitative and quantitative data can be collected in the same study." (Patton, 2002: 14). Bryman and Teevan (2005) also advocate the use of a mixed method which they term a multi-strategy approach. In recommending the integration of the two research traditions and the different strengths and weakness of both methods, Depoy and Gitlin (2005: 28) stated: "A multi method approach enables you to generate more in-depth, nuanced or complex knowledge about phenomena". The argument for the use of a mixed method (multi-method

strategy) will be further discussed after a description of different research philosophies and broad critique of qualitative and quantitative research methods. The use of mixed methods was identified to be appropriate for answering the three research questions. Using qualitative methods allow exploration of views and opinions and was deemed appropriate for exploring stroke experience and health professionals' perceptions to address research questions 1 and 3. Quantitative methods investigate sizes and frequencies of common variables and can demonstrate if associations among variables are significant, using inferential statistics. Quantitative methods were appropriate for answering research question 2.

4.1.1 Different Philosophies in Research

Research methods are based on certain assumptions about what knowledge is and how to measure it. Depoy and Gitlin (2005: 24) described the philosophical foundations of research methods as: "Main perspectives on reality and how to obtain knowledge". Each research methodology is thus said to be based on specific epistemological and ontological perspectives. Ontological perspectives relate to defining "what is reality" while epistemological perspectives relate to how reality can be investigated (Bryman and Teevan, 2005). It has been argued that the use and appropriateness of different approaches tend to be based on opinions regarding their underlying epistemology and ontology (Sim and Wright 2000). Some researchers, however, argue against the rigid claims that specific epistemologies underpin quantitative and qualitative methods exclusively (Bryman and Teevan, 2005). The following is a description of two main philosophical perspectives underlying quantitative and qualitative research: Positivism and Phenomenology. These will be discussed briefly to provide the background for the different methods used in this study and to provide justification of the use of mixed methods in this study.

i) Positivism

This is said to be the main epistemological perspective associated with quantitative research methods (Bowling, 2002). This philosophy assumes that the world can be studied objectively through valid and reliable measurements (DePoy and Gitlin, 2005). According to Sim and Wright (2000:8): "Another central tenet of positivism is that there is a single objective reality, which is the same for all of us, irrespective of our individual values, attitudes or perspectives". Positivists thus assume that we all share a single objective reality and that this can be measured (Bowling, 2002). Research methods adopting this philosophy include standardized and structured interviews, and quantitative research methods (Bowling, 2002). This perspective leads to valuing of validity and reliability in measurement as it is assumed that there is a common objective reality for all. Standardised psychological scales can also be considered positivist in underpinning philosophy. Positivism is criticised as being somewhat deficient because it neglects the unique meaning of situations to individuals (Bowling, 2002).

ii) Phenomenology

This epistemological perspective is based on the viewpoint that the meaning of situations can only be understood from the perspective of individuals who have experienced it (Sim and Wright, 2000). In the phenomenological perspective, more than one subjective reality exists and individuals are assumed to construct their reality as they interact with the world and each other (DePoy and Gitlin, 2005). Phenomenology is thus concerned with understanding meanings to the individual and not objective behavioural responses to external stimuli. The role of the researcher in phenomenological studies is to co-construct the data and analysis, and to become aware of expectations about the phenomena in question, in order to explore the participants' lifeworld 'afresh'. Research methods adopting a phenomenological philosophy include open-ended unstructured interviews and some types of participant

observation. Phenomenology is said to be one of the   epistemological perspectives underlying qualitative research (Bowling, 2002; Sim and Wright, 2000).

The next section describes qualitative and quantitative research in broad terms, their other differences apart from the epistemological perspectives, and arguments about combining both methods despite their differences.

4.1.2 Qualitative Research Methods

According Albert Einstein- "Not everything that can be counted counts and not everything that counts can be counted" (Patton, 2002)

Qualitative methods allow for the investigation of concepts and experiences in greater subjective detail than quantitative methods (Patton, 2002). According to Denzin and Lincoln (2000:8): "The word qualitative implies an emphasis on the qualities of entities and on process and meanings that are not experimentally examined or measured (if measured at all) in terms of quantity, amount, intensity or frequency". A variety of methods are used in qualitative research to collect information. These include case study, personal experience, introspection, life story, interview, artefacts, cultural texts and production, observational, historical, interactional and visual texts. The main aim for all data collection in qualitative research is to describe and give meaning to social experience and influences on individual lives. Research methods associated with qualitative research include: ethnography/participant observation, qualitative interviewing, focus groups, conversational analysis and analysis of written texts and documents (Bryman and Teevan, 2005).

i) Critique of Qualitative Research Methodology

Users of qualitative research methods are sometimes critiqued as being journalists or 'soft' scientists and their work is seen as not being objective enough, unscientific or only exploratory (Bryman and Teevan, 2005; Denzin and Lincoln, 2000). It is argued that qualitative researchers have no way of proving that their findings are 'true' and so their outcome could be described as fiction (Denzin and Lincoln, 2000). Other criticisms of qualitative research methods include difficulty in replicating, problems of generalisation and lack of transparency in the analysis (Bryman and Teevan, 2005). Qualitative researchers, however, argue against the view that their findings cannot be acknowledged as truth. Truth in qualitative research is seen in respect to its meaning to the participant (interpretivism) and viewed as an on-going process of development that occurs as one interacts with the world and other people (constructionism). In other words, interpretivism is a view point in which human experience is explained through empathic understanding and interpretation of reasons for such experience. Constructionism is based on the notion that people are social actors and through interacting with their environments they create a reality that changes constantly (Bryman and Teevan, 2005). This argument has resulted in qualitative researchers developing alternative understandings of validity and reliability, which will be explored later in this chapter.

4.1.3 Quantitative Research Methods

Quantitative methods, on the other hand, focus on measuring relationships between variables rather than processes. They utilize reliable and valid measures to investigate experiences, usually of large numbers of cases. However, in many cases, data can only fit into the limited number of responses available in the standardized measures used (Patton, 2002). The main preoccupation of quantitative research, as described by Bryman and Teevan, (2005), include

measurement, causality, generalisation and replication. The focus is thus on frequencies and strengths of relationships among variables rather than personal meanings. Measurements are the foundations of all quantitative research. Social phenomena are viewed as responses that can be measured accurately. Hence the achievement of reliability and validity is very important in quantitative research. These terms will be defined and discussed later on in the chapter.

Quantitative research into some aspects of psychosocial phenomena is criticized due to its arguable over-emphasis on measurements and neglect of investigation into personal meanings of situations (Denzin and Lincoln, 2000). In addition, measurements of psychosocial variables (especially those using standardized scales) are said to give a false sense of precision and accuracy.

4.1.4 Differences between Quantitative and Qualitative Research

Denzin and Lincoln (2000), discuss three main ways in which qualitative research differs from quantitative research.1) Capturing the individual's point of view, 2) Examining the constraints of everyday, 3) Securing rich descriptions.

Capturing the individual's point of view relates to the ability of qualitative research to draw out how an individual understands the phenomenon or concept being investigated. These are subjective explanations of why or how the world works, based on many factors including the experiences and previous knowledge gained by the individual. Qualitative analysis is able to document rich descriptions of an individual's feelings, experiences and understanding of any phenomena. Quantitative analysis, on the other hand, deals with certain measurable

phenomena that can be investigated, with certain advantages such as being potentially replicable.

Other differences between these two research methods discussed by Bryman and Teevan (2005) include the following:

a) Qualitative research methods usually emphasise words while quantitative emphasise numbers.

b) In qualitative research the participant's view is the main focus of the study, however in quantitative research the variables a researcher is specifically studying are the main focus which provides greater control over the study protocol.

c) Qualitative researchers tend to get psychologically close to their participants to secure rich data, however in quantitative research researchers are often not as close as they value objectivity and neutrality.

4.1.5 Combining Qualitative and Quantitative Research Methodology

Depoy and Gitlin (2005) advocate integrating the two research traditions, arguing that "An integrated approach involves selecting and combining designs and methods from both traditions so that one complements the other to benefit or contribute to an understanding of the whole" (Depoy and Gitlin, 2005: 28).

Bryman and Teevan, (2005) also advocate the combining of both types of research methods: termed a multi-strategy research. They argue that epistemological and ontological commitments attached to different research methodologies are not as fixed and unchangeable as they are historically described to be. Qualitative research can facilitate quantitative research when used to provide hypotheses and can also be used in getting more in-depth

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knowledge of variables measured. On the other hand, quantitative research can facilitate qualitative research, for example, when used to identify appropriate participants for interviews (e.g. with the use of a structured questionnaire). Quantitative research methods can also be used to gain certain information more efficiently (e.g using a questionnaire to obtain information about past behaviour not obtained by other methods, or to gain information from a wider sample than would be possible using qualitative methods). Both methods can be used together to secure participants' perspectives and offer a way to investigate different aspects of a phenomenon (Bryman and Teevan, 2005).

4.1.6 Why adopt a mixed method in this study?

The nature of the concepts being investigated necessitated the use of a mixed method to obtain data rich enough to provide both an in-depth understanding and also to offer some generalisability so that findings might influence clinical practice in the Middle East. Self-efficacy, religious faith and life satisfaction are all concepts that do not yield themselves to full study with quantitative methods alone. These are personal issues that depend on many factors including culture, age, past experience and mood. Standardized scales for measuring self-efficacy, religious faith and life satisfaction have been developed in Western countries but may not be appropriate for use in other cultures. Culturally adapting such measures by translation alone, makes such scales usable in other languages and cultures, however does not necessarily target issues that are important to people's experience. Carrying out this study using standardised scales without the initial phases of qualitative inquiry, would be as though one tried to force-fit the Arabian culture into the 'standardized' model of stroke experience in the West. Thus using standardized Western scales without an understanding of issues important to the stroke experience in an Arab country might lead to results not truly reflecting the nature of these investigated variables or the particularly salient aspects of experience.

Qualitative research gathers the 'emic' or insider's perspective which is important when developing a culturally sensitive questionnaire. Thus the initial phases (phase 1 and 2) of this study were firstly to investigate stroke experience in the Kuwait and then to develop a culturally appropriate self-efficacy questionnaire for the Kuwaiti population. The subsequent quantitative aspect of the study using the structured questionnaire (together with other standardised questionnaires) allowed for the investigation of important issues with a larger number of participants and investigation of the strengths of relationships between variables. Figure 4:1 presents a flow chart of the various phases of the project. The last phase of this project involved investigating health professionals' perspectives on cultural influences on stroke experience and rehabilitation in Kuwait and clinical implications of findings of Phase 3 with the use of semi-structured interviews. No standardised questionnaire was available to assess these perceptions and moreover, a qualitative method was appropriate to explore this under-researched topic.

The rest of this methods chapter will highlight the procedures carried out in each of the four phases of this project.

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┌─────────────────────────────────────────┐
│ Phase 1: Exploring stroke experience      │
│ in Kuwait                                 │
│ *Semi-structured interviews with 15       │
│ participants in Kuwait (13 with           │
│ translator, 2 in English)                 │
│ *Thematic analysis                        │
└─────────────────────────────────────────┘
                    │
                    ▼
┌─────────────────────────────────────────┐
│ Phase 2: Adapting A Self-efficacy         │
│ Scale                                     │
│ *Literature search of existing scale      │
│ *Themes from Interviews in phase 1        │
│ *Reliability and validity testing         │
└─────────────────────────────────────────┘
                    │
                    ▼
┌─────────────────────────────────────────┐
│ Phase 3: Assessing relationships          │
│ between life satisfaction, self-efficacy  │
│ and religious faith                       │
│                                           │
│   • Interview administered                │
│     questionnaires                        │
│   • Descriptive stats, t tests, Pearson   │
│     correlation                           │
│   • Exploratory Multiple regression       │
└─────────────────────────────────────────┘
                    │
                    ▼
┌─────────────────────────────────────────┐
│ Phase 4: Health professional (HP)         │
│ perspectives on cultural influences on    │
│ stroke experience and rehabilitation in   │
│ Kuwait                                    │
│ *Semi-structured interview with 12 HPs    │
│ * Thematic analysis of transcripts        │
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Figure 4.1: Flow Chart of the Various Phases of the Project

4.2: Phase 1- Exploring the Stroke Experience in Patients in Kuwait.

A qualitative research methodology was adopted to explore the experiences of stroke \patients living in Kuwait. Four interviews were initially carried out in the United Kingdom as a pilot to ensure that the questions asked helped to explore stroke experience and rehabilitation extensively. The aims of this phase were to explore the experience of stroke and rehabilitation in stroke patients in Kuwait with the further intention of using the emergent themes to adapt a scale for the measurement of psychosocial self-efficacy that was culturally relevant to patients in Kuwait. This next step was accomplished in Phase 2.

4.2.1 Interviews

This first phase of the study used semi-structured interviews to explore the experience of life after stroke. According to Patton (2000), interviews help to understand view points of another person and using interview guides helps to make interviewing a large number of people more systematic and comprehensive (Patton, 2000). Semi-structured interviews helped provide a guide as to the issues discussed and helped to make the best use of time.

Semi-structured interviews are described as: "a context in which the interviewer has a series of questions in the general form of an interview schedule but is allowed to vary the sequence of questions" (Bryman and Teevan, 2005: 71). This method of interviewing allows for flexibility to ensure that the interviewees' explanations and understandings are taken into account. Other types in interviews used in qualitative research includes: unstructured interviews and focus group interviews.

Kvale (1996) proposed a list of ten criteria for an interviewer, these include being: knowledgeable, structuring, gentle, open, critical, and interpreting. Other criteria included were:- steering, clear, remembering and interpreting. Bryman and Teevan (2005) added two further criteria to Kvale's ten criteria, namely, that the interviewer should be balanced and ethically sensitive. By "balanced", they are referring to not talking too much nor too little to keep the flow of the discussion. These criteria were followed during interviewing participants in the current project.

4.2.2 Semi-Structured Interviews of Stroke Experience and Rehabilitation

i) Aims of the Study:

To investigate experience of stroke and rehabilitation in stroke patients in the U.K and Kuwait.

ii) Setting: The pilot study took place at a hospital in Northwest London and the main study in a rehabilitation hospital in Kuwait.

iii) Ethical committee approval: This proposal was submitted for ethical approval at Brunel University, School of Health Sciences and Social Care, Central Ethics Committee in the U.K (COREC), and departmental teams at the hospitals where the study took place prior to commencing recruitment of subjects. Informed consent was obtained from all participating subjects. No identifying information was left on transcripts and all quotations used were anonymous.

For the Kuwaiti sample, ethical permission was obtained from the physiotherapy department's head on providing documentation confirming ethical permission from Brunel

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University and COREC, as that was the accepted procedure at the start of the project. All participants were informed about the details of the requirements of the study and consent was obtained prior to conducting interviews. See appendix 2 for consent form and information sheets and appendix 3 for ethics approval letters.

iv) Participants and population: Only patients volunteering to participate were included. Four stroke survivors were recruited from a London hospital for the pilot study and 15 from a large Hospital in Kuwait. Eight of these were female and the others male. Ages ranged from 45 to 80 yrs old.

v) **Inclusion criteria**:

- Stroke patients attending outpatient physiotherapy clinic
- Patients diagnosed with a cerebrovascular accident or stroke on CT scan.
- Stroke patients (as mentioned above) with cognitive functioning and speech adequate for participation.

vi) **Exclusion criteria:**

- Patients unable to give consent due to cognitive deficits
- Patients with other neurological conditions e.g. multiple sclerosis, Parkinson disease, peripheral neuropathy
- Patients with previous documented psychiatric history.

vii) **Recruitment:**

Permission was sought from hospital managers on receipt of COREC ethical approval for UK sample and departmental head for the Kuwait sample to conduct this phase of the study in

their outpatient physiotherapy rehabilitation facilities. All procedures required to ensure safe working on the hospital site prior to commencing the project were strictly followed i.e. obtaining an honorary contract with the hospital if required. Patients were approached before or after their physiotherapy session in the waiting room by the main researcher to seek their consent to participate in this study. Information sheets about the study were provided (translated into Arabic where necessary) and individuals were allowed to take information sheets away to discuss with relatives or spouses prior to consent being given. Participants were informed about their right not to consent or to withdraw and that their rehabilitation would not be affected by their willingness to participate or withdrawal from the study. See appendix 2 for information sheet and consent form. Translation of these documents for the Kuwaiti sample were done by an official translation company experienced in translation of academic and medical documents (See appendix 5).

viii) **Procedure:**

Interviews were carried out in a quiet room or physiotherapy cubicle to allow for privacy and confidentiality in the out-patient physiotherapy facilities. Those wishing to have a relative or spouse present were allowed to do so. Each interview lasted about 45 minutes long and was audiorecorded for transcribing. In the Kuwait sample an interpreter was present to translate the questions to Arabic and their responses to English. The following questions were asked using a semi- structured format and further questions, as needed, in between to facilitate disclosure.

1) How has the stroke impacted your life?
2) How do you feel about the future?
3) How are you getting on in therapy?
4) What would you like to achieve from rehabilitation?

5) What limitations do you feel are stopping you doing more?

6) What successes have you achieved since beginning rehabilitation?

The 6 questions listed above were asked one at a time giving time for the subject to elaborate on each question, and with additional questions as needed, to gain further clarity and depth of information. The interview was organised to end with positive achievement in order to help maintain participants' mood and self-efficacy. Transcription of these tapes was done by the author.

ix) Data Analysis

The main aim of the interviews was to generate a common list of themes relevant to stroke experience and rehabilitation from patients living in Kuwait. Thematic analysis was carried out.

Thematic Analysis

Thematic Analysis can be described as a: "method for identifying, analysing and reporting patterns (themes) within data. It minimally organises and describes your data set in detail," (Braun and Clarke, 2006: 79). It has also been described as a process involving searching for themes to facilitate understanding of a phenomenon (Fereday and Muir-Cochrane, 2006). Boyatzis (1998) describes thematic analysis as a process rather than a distinct method of qualitative analysis. Rather unusually, he viewed it as a process that can be used with most qualitative methods to translate "qualitative information into quantitative data, if this is desired by the researcher" (Boyatzis, 1998: 4). Thematic analysis is thus described as a: "process for encoding qualitative information" (Boyatzis, 1998: 4).

According to Riley and Hawe (2005: 229), thematic analysis involves grouping of "like with like" codes in the building of themes, which in turn facilitate understanding of a phenomenon. Thematic analysis is said to possess the ability to be used across a variety of philosophical paradigms (Braun and Clarke: 2006). This allows for flexibility in use yet providing rich description of data (Boyatzis, 1998). However, more negatively, it is argued to have no clear guidelines, lacks transparency and can be carried out in many different ways (Buetow, 2010; Mays, Pope and Popay, 2005).

Fereday and Muir-Cochrane (2006), describe the emergence of two methods of thematic analysis: the inductive approach of Boyatzis (1998) and the deductive approach outlined by Crabtree and Miller (1999). The inductive method of Boyatzis (1998) involves recognition of codes from the data rather than from a predetermined theoretical basis or other sources external to the data. Crabtree and Miller's (1999) deductive approach involves the formation of an a priori template of codes which is applied in the analysis of the data. The template of codes could be based on theoretical assumptions, research questions, previous research findings and in some cases from an initial scan of the study data (Fereday and Muir-Cochrane, 2006). In other words, the difference between these two approaches is that the deductive approach starts with an a priori list of codes and then looks for these in the data. The current project followed guidelines outlined by Braun and Clarke (2006). This was an inductive approach in which codes were recognised from within the data. A step by step description of the procedure used has been reported later in this chapter.

Other criticisms of thematic analysis include the uncertainty as to the stage in which the themes are identified/finalised and whether the findings reflect the frequency of the theme in participants' accounts or their explanatory significance (Mays, Pope and Popay, 2005).

Buetow (2010) points out that thematic analysis is limited in that it focuses on recurrence of codes and not their subjective importance. However, Marks and Yardley (2004) describe thematic analysis as focusing on the meanings of the themes' both manifest and latent contents ('manifest' referring to the observable characteristics such as recurrence of words and 'latent' referring to meanings that are not directly observable but can be inferred). Thematic analysis as a method has not been reported as a separate strategy in a considerable number of authoritative research textbooks (e.g. Denzin and Lincoln, 2005; Seale, Gobo and Gubrium, 2004; Silverman, 2005; Patton, 2002; Gray, 2009), however it is widely used as the initial (or sole) part of other qualitative methods of analysis (Buetow, 2010; Braun and Clarke: 2006; Boyatzis: 1998), and is regularly described as the chosen analytic method in many research articles.

Boyatzis (1998) outlines three major obstacles to effective thematic analysis. These are 1) projection; 2) sampling and 3) mood and style. Projection refers to the possibility of researchers attributing their own personal values and attitudes to that of the participants or events being investigated. Boyatzis argued (1998; p13): "With ambiguous qualitative information, there is more opportunity for an invitation to projection from the researcher than in most other types of research. The stronger a researcher's ideology or theory, the more he or she will be tempted to project his or her values or conceptualisations of the events onto the people from whom the raw information has been collected." Sampling refers to issues that can contaminate the qualitative data such as the use of a convenience sample which is not indicative of the main population being investigated. Mood and style refers to the subjective factors such as fatigue, frustration and confusion which can influence data collection, processing and analysis (Boyatzis, 1998). These three barriers to thematic analysis highlighted by Boyatzis (1998) appear to also affect other approaches to qualitative research

analysis rather than being solely limitations of thematic analysis. These three issues were kept in mind during the current project and strategies suggested by Boyatzis (1998) were put in place to ensure the production of an effective thematic analysis.

Braun and Clarke (2006) outlined the following advantages of thematic analysis:

Advantages of Thematic Analysis (based on Braun and Clarke: 2006)

-Flexibility

-Accessible to researchers with little or no experience of qualitative research.

-Results are generally accessible to an educated general public.

-Can usefully summarize key features of a large body of data, and/or offer a 'thick description' of the data set.

-Can generate unanticipated insights.

-Allows for social as well as psychological interpretations of data.

-Can be useful for producing qualitative analyses suited to informing policy development

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Thematic analysis allowed for the organising and summarizing of experiences in both phase 1 and phase 4 which were appropriate for this project (Mays, Pope, Popay, 2005), as the aims were: 1) to obtain themes for the adaptation of a self-efficacy scale for the local population, 2) to explore health professionals' perception of the stroke experience in Kuwait and clinical application of results. Previous researchers have used thematic analysis of interview data to generate items for development of questionnaires (George, Mackinnon, Kong et al, 2006; Rigby et al, 2003). Rigby et al (2003) used thematic analysis in the development of the MS Self-efficacy scale. Other studies have used thematic analysis in investigating stroke experience (Tariah, Hersch and Ostward, 2006; Dowswell, Lawler, Dowswell et al, 2000). Recently Strudwick and Morris (2010) used thematic analysis of interviews to explore the

experiences of African-Caribbean informal stroke carers in the UK. Niyomathai, Tonmukayakul, Wonghongkul et al (2010) investigated strength in caring for stroke survivors at home, with thematic analysis of interview transcripts. Gilworth, Phil, Cert et al (2009) also used this type of analysis on transcripts from semi-structured interviews of stroke survivors returning to work. In the current project, thematic analysis was used on interview transcripts of stroke survivors and also used to explore perception of health professionals working with stroke patients.

Thematic analysis used in this project involved assessment of transcripts individually for main themes regarding impact of stroke on life post-stroke, thoughts about the future and experience of rehabilitation. The following 6 phases of thematic analysis as explained by Braun and Clarke (2006) were carried out:

Phase 1: Familiarization with the data:- This involved reading of the transcripts repetitively in order to immerse oneself in the data. This ensured that the depth and breadth of the content was understood. Initial ideas were jotted down on the margins of the transcript.

Phase 2: Generation of initial codes:- This phase was initiated once the whole transcript of the interview had become very familiar to the researcher. It involved identifying the interesting relevant information called codes. A code can be defined as: "the most basic segment or element of the raw data or information that can be assessed in a meaningful way regarding the phenomenon" (Boyatzis, 1998:63).

Phase 3: Searching for themes:-This phase involved collating relevant codes together to form themes. It began once all the data had been initially coded.

Phase 4: Reviewing themes: - This phase involved refinement of themes. For example two themes were put together to form one larger theme or the splitting of a general theme into two with more specificity. Two levels of reviewing were involved in this phase. The first level

involved checking that the initial codes matched with the themes they were put under. A thematic map was then drawn to show the themes and relevant codes under them. The second level involved checking that all the themes reflected the whole data set. In other words, adequacy of all the themes was assessed to evaluate that they were acceptable and gave a complete representation of the data set. Additional codes were also identified in this phase and added to the thematic map or new themes were formed.

Phase 5:- Defining and naming themes: - This was the final analysis stage of this method and it involved refining all the themes and identifying what the essence of each theme was about. It also involved naming of the theme in a way that was concise and could reveal what the theme was about.

Phase 6:- Producing the report: - This is the report of the thematic analysis and can be seen in the results chapter 5.

Thematic analysis was also chosen as the means of qualitative analysis in the study because it allowed for flexibility when dealing with transcripts of interviews in Kuwait where in some cases depth of experience and feelings could not be explored because of the language barrier. An alternative, such as interpretative phenomenological analysis, was not appropriate for these more limited data.

Since the aim of this phase was to explore issues relevant to the stroke experience in Kuwait for adaptation of a self-efficacy scale, thematic analysis was adequate to achieve this. Having no epistemological tradition, it suited the aims of this primarily quantitative stage of the research, as well as following the traditions of others who have used thematic analysis to identify items for questionnaires (as illustrated above). Thematic analysis thus provided a rich analysis and identified relevant themes that could be used in the development of the study

questionnaire. Second coding of a proportion of the transcripts to enhance trustworthiness was also carried out by the research supervisor (see appendix 6 for an example of a coded transcript).

Alternative Methods of Analysis

Two main alternative methods of analysis would have been Interpretative Phenomenological Analysis (IPA) had the data been richer, or content analysis.

Interpretative Phenomenological Analysis (IPA)

The aim of IPA is to explore participants' understandings of a particular issue, mostly experiences and meanings of their own bodies, illnesses and identity change (Smith, Osborn and Jarman, 1999). As this approach "is concerned with the detailed examination of human lived experience" (Smith, Flowers and Larkin, 2009; 32), rich interview data are a prerequisite. Barreca and Wilkins (2008) used IPA approach in investigating the perceptions, feelings and beliefs of a group of nurses in stroke rehabilitation. Their study's aim was to explore the lived experience of nurses and not their perceived view of what the stroke participants were experiencing, which was the focus of the current project.

Although IPA was planned at the start of this project, this was not chosen for use, as patients' interviews were rather thin due to translation. The later health professional interviews were considered not suited to IPA for different reasons. IPA was inappropriate as the health professionals were describing their perceptions of patient experiences and behaviour, together with their academic perspectives and perceptions of the clinical applications of the study's findings, and rarely described their own emotional experiences in any depth.

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Content Analysis

Some researchers have used various types of content analysis for similar data to that gathered in the current study (Marks and Yardley, 2004). Traditionally, content analysis involves the quantifying of recurring themes within a document or text (Marks and Yardley, 2004). Content analysis was developed in the 1950s as a method of analysing media text in a quantifiable reproducible manner (Berelson, 1952). In this method, text is broken down into units that can be counted, however, by doing so, there was the possibility of loss of meaning of the text. Content analysis is often used in media research with the emphasis being on the frequency of words/phrases (Graneheim, and Lundman, 2004). In some agreement with this view, Mays, Pope and Popay (2005) describe content analysis as a systematic technique for categorising data into themes and then counting how often each category or theme occurs in order to identify dominant findings and, thereby, make some generalisations. Somewhat differently, Content analysis can also be defined as: "a systematic, replicable technique for compressing many words of text into fewer content categories based on explicit rules of coding" (Stemier, 2001: 1). Stone (2007) described content analysis as: "a qualitative research method in which standardized measurements are applied to metrically defined units of text and these are used to characterize and compare documents" (p.291). Content analysis is more usually carried out on text documents such as media text, interview transcripts and dairies, but not on field notes from participant observation (Patton, 2002). Content analysis as a distinct method is mentioned in various key qualitative research textbooks, however details on how to carry it out are not mentioned (e.g. Denzin and Lincoln, 2000; Patton, 2002; Silverman, 2005). This relative absence of guidelines gives the impression of a possible vagueness regarding how to carry it out.

There also appear to be different methods of content analysis reported in the literature (Graneheim and Lundman, 2004). As noted above, content analysis originally focused on quantifiable aspects of text content but there are also now qualitative variants (Titscher et al, 2000). Qualitative content analysis was developed to maintain meaning and insights within text (Priest, Roberts and Woods: 2002). Thus qualitative content analysis is also known as 'thematic' content analysis (Wilkinson, 2004). It is often used in health and education research (Graneheim, and Lundman, 2004). Both qualitative and quantitative content analysis involves coding of similar segments of text and counting the frequencies of these codes (Morgan, 1993). However, they differ in how the codes are produced and what is done with the frequency of the codes. In qualitative content analysis, codes are identified from within the data and not from pre-existing categories. Codes are identified from careful reading of the text and not generally from the use of computer programmes as in quantitative content analysis (Morgan, 1993). While the frequencies of codes are used in quantitative content analysis to summarise the data, in qualitative content analysis the frequency of the codes are used in the second phase of analysis, which involves the interpretation of the meaning of the text. Graneheim, and Lundman (2004) highlight that within qualitative content analysis there are different ways in which the analysis could be performed. Some analyses focus on the 'Manifest' content while others focus on the 'Latent' content. Manifest content refers to the "visible, obvious components" of the text, while latent content refers to the: "relationship aspect and involves an interpretation of the underlying meaning of the text" (Graneheim, and Lundman, 2004: 106).

Other authors have described different methods of conducting thematic analysis. Burnard (1991) describes a 'thematic content analysis' which involves 14 stages. In his method of qualitative content analysis, open coding of the transcripts was carried out to identify

categories of themes and then each transcript was worked through with the list of categories. Similar codes were grouped together under appropriate categories according to their meaning. However, in Burnard's description there is no mention of the use of frequency of codes. This highlights the varied procedure in carrying out qualitative content analysis. Burnard (1991) stressed that there are different methods of analysing qualitative data and it is important to be aware of their limitations.

Advantages of content analysis include: transparency, in other words, according to some authors, its procedures can be replicated yet are flexible (Stemier, 2001; Bryman and Teevan, 2008). However, it is argued to place emphasis on the frequency of the themes rather than their significance to the participants (Mays, Pope and Popay, 2005). This limitation might be in reference to quantitative content analysis and perhaps not qualitative content analysis. Going further, Bryman (2008) highlights the following limitations of content analysis: 1) emphasis is placed on measurement rather than the importance of themes to participants; 2) it is difficult to ascertain the reason behind the observed phenomenon through content analysis; 3) how the themes are located/ decided upon is still uncertain and dependent on the decision of the researcher. Gray (2009) criticises content analysis as being unable to explore associations and directions of relationships between investigated variables. Silverman (1998) objects to the use of content analysis in analysing text documents such as interview transcripts. He argues that content analysis limits the meaning a person brings to certain words thus hindering the interpretative process.

Holloway and Jefferson (2000) challenge the practice of coding data into fragments in both thematic and content analysis. They argue that the fragmentation of the data results in neglect of the whole and it is possible that researchers organise the material according to their sense

of how it should connect. Insights are thus seen to be reduced to trivial levels for consistency of judgement (Marks and Yardley, 2004). Similar objections to content analysis were raised by Atkinson (1992), who viewed content analysis as forcing data into predetermined categories whilst leaving uncategorized activities uninvestigated.

There does not appear to be a consensus in the literature about what content analysis or qualitative content analysis entails. Some studies use the term content analysis, others qualitative content analysis or thematic content analysis when referring to what appear to be similar processes. Graneheim and Lundman (2004) stated the following: "Qualitative content analysis as described in published literature shows conflicting opinions and unsolved issues regarding meaning and use of concepts, procedures and interpretation" (p.105).

Content analysis has been used in studies investigating stroke experience. Stone (2007) used this method of analysis on internet narratives from patients with AVM haemorrhage, to identify common themes and to compare male narratives with female ones. The approach used involved importing units of text into the QSR NUD*IST computerized index system and then open coding (i.e coding of units of text according to analysts' subjective judgement). Coded texts were then placed into different categories. Coding was carried out by two people to ensure thoroughness. Jones, Mandy and Partridge (2008) used content analysis (developed by Burnard 1991) in the analysis of in-depth interviews with stroke survivors. This method of thematic content analysis described by Burnard (1991) was mentioned earlier in this chapter.

 Content analysis was not used in the current project being discussed because of the lack of consensus in the literature regarding how to carry it out i.e the detailed procedures involved. There are also noteworthy limitations to the widely known method of counting codes and the

emphasis on frequency rather than meaning of the text, as previously discussed. In addition to this, with a small sample, it is not appropriate to count the incidence of themes, and with translation limitations, people might have been expressing similar ideas in different words. Thematic content analysis might have been an appropriate choice, however as demonstrated in this chapter, there are also conflicting guidelines regarding how this can be carried out.

Some advocates of content analysis (and to a lesser extent thematic analysis) advocate the goal of consistency of coding, by more than one researcher, and gaining high levels of agreement (Singletary, 1993). Whereas more phenomenological researchers accept that there are inevitable subjective judgements being made in the coding or interpretative process and that the researcher is an inevitable part of the analysis process (Smith, Flowers and Larkin, 2009; Finlay and Gough, 2003).

4.3: Phase 2- Development of a Self-efficacy- scale for the Kuwaiti Population

The need to adapt health scales or develop new scales for other cultures and languages has increased because of a rise in multinational research studies. Scales developed in English speaking countries require more than translation in order to be applicable in other countries (Beaton, Bombardier, Guillemin et al, 2000). Adaptation may be needed due to different priorities amongst the different cultures. Issues perceived as important in the Western Anglo-centric culture may not be as important in the Arabian culture. Self-reflection and life satisfaction have been shown to be culturally sensitive constructs (Heine, 2003). This study adopted a culturally- sensitive approach to the development of tools for assessing self-efficacy in stroke patients living in Kuwait.

4.3.1 History of Measurement of Attitudes

Attitudes can be defined as: "the sum total of a man's inclinations and feelings, prejudice or bias, preconceived notions about any specific topic" (Thurstone, 1927: 531). Symonds (1928) describes seven meanings of the word attitudes: motives, muscular adjustment, generalised conduct, readiness to adjust, emotional responses, feelings and verbally accepting or rejecting responses. Once attitudes are verbally expressed, an opinion is voiced. An opinion is thus viewed as the verbal representation of an attitude and thus can be a means to measure attitude (Thurstone, 1927).

Measuring attitudes began in 1927 by Thurstone's publication titled: "Attitudes can be measured". Thurstone's technique of attitude measurement was based on the assumption that all attitudes fell on a continuum ranging from strongly accepting to strongly rejecting a particular value. Thus he devised a scale in which responses were divided according to equal appearing intervals. Respondents had to check statements which they agreed with and a mean score was calculated. His scale was developed by first getting a list of all possible attitudes towards the given issue by asking several groups of people to write their opinions down on a piece of paper. Then the literature was searched for brief statements that would form parts of the scale. The list of relevant statements was then sorted into eleven different piles by two or three hundred subjects according to different level of agreement with the issue being assessed (Thurstone, 1927).

Since then, different ways of measuring attitudes have been developed. Rating scales and Semantic differential are two commonly used attitudinal measurement methods currently being used (Cross, 2005). The Likert scale is a type of rating scale commonly used attitudinal measurement scale used in questionnaires. Respondents are asked to rate their level of

agreement or disagreement to certain statements posed. It was developed by Rensis Likert in 1932. Several levels of the Likert scale can be used: 5-level, 7 level and 10 level. The 5-level Likert scale contains responses as follows: 1 (Strongly disagree), 2 (Disagree), 3 (neither agree nor disagree), 4 (Agree), 5 (Strongly agree). Responses to statements can be reviewed individually or a group score obtained by adding up the various scores on the questionnaire.

Semantic Differential is a method of assessing attitudes whereby respondents rate their reaction to stimuli or words, or the meanings of concepts on a bipolar scale with contrasting adjectives to either end. It was developed by Charles Osgood in 1957. This method of assessing attitude involves respondents having to choose their stance between two bipolar words describing an issue (usually associated with describing self-image). Examples of bipolar words used in this scale include: bitter-sweet, beautiful-ugly, warm-cold.

E.g: honest 1 2 3 4 5 6 7 dishonest

A semantic differential scale has between 12 to 18 such adjectives; however in some cases more pairs of adjectives are used. This method of measuring attitudes has been critiqued as lacking reliability and validity (Lee, 1971). However these issues can be targeted by simply administering the scale a second time to test reliability and accompanying it with another standardized measure to establish its validity (Al-Hindawe, 1996).

The current study (of this project) adopted the use of a 10- point rating scale to measure self-efficacy and life satisfaction. This differed from a Likert scale in that it measured strength of confidence (not level of agreement) on a 10 point scale with 1 denoting "no confidence at all" and 10: "Totally confident". The single item measure of life satisfaction was also a 10- point rating scale. Religious faith was measured with the Santa Clara Strength of Religious Faith Questionnaire (SCSROF) which uses a Likert scale in measuring level of agreement with the

items listed. The scales used in this project will be discussed in more detail in later sections of this chapter.

4.3.2 Questionnaire Design and Development

A questionnaire is a measurement tool for collecting data regarding attitudes and other types of self-report (Oppenheim, 1992). There are different types of questionnaires: mail questionnaires, self administered questionnaires, interview administered questionnaire, group questionnaires and electronic/web-based questionnaires.

i) Mail Questionnaires have the advantage of low cost of data collection and processing. There is also the reduced risk of interviewer bias and it can be used to reach participants who are widely dispersed or abroad. However disadvantages include low return rate and unsuitability for participants with poor literacy. Using mail questionnaires does not allow for clarification of questions or checking to ensure that the full questionnaires have been completed, it also inappropriate for use to collect information based on observation. This method was thus not used in the current study.

ii) Interview Administered Questionnaires

These questionnaires allow for an opportunity to clarify misunderstandings and elaborate the meaning of questions and it also allows for carrying out observations during administration of the questionnaires. It is an appropriate means for participants with reading or language difficulty. Disadvantages however include difficulties collecting data from a widely dispersed sample. Interview- administered questionnaires tend to be time consuming and there is the additional risk of interviewer bias affecting the responses provided by the participant (Oppenheim, 1992). Due to the nature of concepts to be investigated in this study and the

type of participants i.e. elderly with possible low literacy skills, questionnaires developed had to be interview administered to allow for effective use with a wide range of participants. This study used interview administered questionnaires in phase 3. This allowed participants to have any misunderstandings clarified in order to respond appropriately. Phase 2 was used to develop questionnaires to be used in Phase 3 of the study.

4.3.3 Standardisation

Standardisation is defined as: a process of taking an assessment and developing a fixed protocol for its administration and scoring, then conducting psychometric studies to evaluate whether the resultant assessment has acceptable levels of validity and reliability (Laver-Fawcett, 2007).

Crocker and Alyina (1986) outlined 10 steps in preparing a standardized scale

1) Identify the primary purpose for which test scores will be used

2) Identify behaviours that represent the construct or define the domain

3) Prepare a set of test specifications

4) Construct an initial pool of items

5) Have items reviewed

6) Hold preliminary tryouts

7) Field test items of the large sample representation

8) Determine statistical properties of item scores

9) Design and construct reliability and validity studies

10) Develop guidelines of administration , scoring and interpretation

(Crocker and Alyina 1986: 66)

In the current project not all of these stages could be implemented due to difficulties in recruiting sufficient clients. Other studies have used self-designed questionnaires based on much less development and validation, than the above recommended process, for example the MS Self-efficacy Scale (Schwartz et al, 1996). The MS self-efficacy scale was developed from the Arthritis self –efficacy scale, and 14 of the 20 items from the original scale were retained/modified to be appropriate for MS and another 10 items included to reflect MS symptoms. Psychometric testing involved administering the questionnaire on 141 participants alongside standardized tools measuring related constructs: the Kurtzke expanded Disability scale, Sickness Impact Profile and the Ryff Happiness Scale.

A standardized scale is expected to possess following attributes:-

1) Reliability

2) Validity

3) Responsiveness to change

4) Sensitivity

5) Specificity

i) Reliability can be defined as: "the extent to which results are consistent over time and an accurate representation of the total population under study" (Joppe 2000: 1). There are 3 aspects of reliability: Inter-rater reliability, test retest reliability and intra session reliability. Inter-rater reliability refers to the degree of agreement between more than one raters (the person taking the assessment) on the same phenomenon. Test retest reliability is related to reproducibility of the results on subsequent testing. It is used to measure consistency of the tool on different occasions (Bowling, 2002). Test retest reliability was carried out on the adapted questionnaire and will be reported in the results chapter.

ii) Validity- Refers to the extent to which the scale is able to measure what it is designed to measure and legitimate conclusions made from the scores (Sim and Wright, 2000). Sim and Wright (2000), describe four forms of validity: Face validity, content validity, criterion-related validity and construct validity. Face validity refers to an investigators' view on the relevance of the questionnaire (Bowling, 2002). "Face validity is concerned with the extent to which data appear to be valid, in the eyes of either the researcher or the subject" (Sim and Wright, 2000: 125). In assessing face validity the questionnaire is judged subjectively on its usefulness, relevance, appropriateness, and clarity (Bowling, 2002). Content validity assesses the extent to which the measure assesses the characteristic or domain to be measured in the most balanced and full way possible (Bowling, 2002). Sim and Wright stated the following regarding content validity: "Content validity is concerned with the scope of a tool: the extent to which it taps the full domain of content of a concept or phenomenon" (Sim and Wright, 2000:126). Face validity of the adapted questionnaire in the current project was done using health professionals' opinions. Criterion validity refers to assessment of a measure based on its correlations with another measure which is accepted as the gold standard or another scale in which validity has been established (Bowling, 2002). In this project, the new, adapted SE questionnaire (Psychosocial Adaptation Self-Efficacy Questionnaire -PSE) was administered alongside the General self-efficacy questionnaire (the accepted gold standard). Results showed a strong correlation between the PSE and General self-efficacy questionnaire. See results chapter 5 for details of this.

4.3.4 Method of Adaptation of a Self-Efficacy Questionnaire for Stroke Survivors in Kuwait

As mentioned previously, semi-structured interviews from Phase 1 were used to both explore the experience of stroke and rehabilitation in the Kuwaiti context, and then to develop the

initial pool of relevant themes for the questionnaire. These themes were then used to choose statements from a pre-existing self-efficacy scale used for people living with chronic illnesses.

Relevant items for the questionnaire were obtained by 2 methods

1) Review of other self-efficacy scales used in disability research

2) Themes from semi-structured interviews of stroke survivors in Kuwait receiving physiotherapy in Phase 1

From the review of existing scales, appropriate items were compared to each other and to information from the participant interviews to see which were most representative of the Kuwaiti participants' own accounts. Items in pre-existing scales that the participants did not refer to were excluded. Further items were excluded after informally assessing the relevance of items with therapists when assessing the face validity of the questionnaire.

Review of Self-efficacy Scales Used in Disability Research

A literature search was conducted to identify appropriate standardised measures of self-efficacy that might be adapted for patients in Kuwait. Self-efficacy scales were assessed on the following criteria below in addition to targeting the five major themes identified by the interviews.

- Reliability

- Easy to use

- Validity

- Sensitive to change

- Suitability in different environments

Search Strategy

To find the scales currently being used by researchers to measure self-efficacy, the following databases (AMED, CINHAL, PsycInfo, Medline) were searched using the terms self-efficacy, stroke rehabilitation, neurorehabilitation, measurements and questionnaire. Reference lists of self-efficacy studies in neurorehabilitation were also searched to obtain references for questionnaires used to assess self-efficacy. Scales assessing falls and balance self-efficacy were excluded because the main focus of this study was psychosocial recovery. The following measures of self–efficacy were identified in the literature, all were obtained and scrutinized.

a) The Generalised Self-Efficacy Scale (GSE)

The Generalised Self-Efficacy Scale is a 10 item questionnaire created to assess self-efficacy beliefs and the ability to cope with different stressful situations in Life (See appendix 4 for copy of scale). It was developed in 1979 by Mathias Jerusalem and Ralf Schwarzer in Germany. Since then it has been translated into 26 different languages and used in different types of research in health, psychology and social behaviour. It is usually self –administered but in some cases participants can be assisted in filling the questionnaire and explanation of the statements. Schwarzer and Jerusalem (1995) report a significantly high internal consistency. They reported Cronbach's alphas ranging from 0.76 to 0.90 in samples from 23 nations. (Schwarzer and Jerusalem, 1995). Test retest reliability was assessed by Schroder et al (1998) on 246 Cardiac surgery patients, r= 0.67. denoting fair test rest reliability. This scale has been shown to be reliable, valid and possesses high stability (Leganger et al. 2000; Schwarzer, Mueller, & Greenglass 1999). It has been used as an indicator and predictor of quality of life after life changing events (Jerusalem and Schwarzer, 2004). This scale has been used in health research in investigating self-efficacy in chronic pain patients (Asghari et

al, 2001). The GSE has been examined for use on individuals with arthritis (Barlow, Williams and Wright; 1996). Kennedy, Taylor and Hindson (2006) used the GSE in investigating the benefits of sports activities in 35 individuals with spinal cord injuries. However, the use of this scale in neurological research is limited and it can been critiqued as being too general because it does not relate to specific situations or behaviours and lacks sensitivity in assessing change of self-efficacy in specific life circumstances.

b) Strategies Used by People to Promote Health Questionnaire (SUPPH)

This is a 39 item questionnaire devised by Lev and Owen (1996). The SUPPH was developed for patients on haemodialysis and cancer patients thus its items do not specifically target the needs of stroke patients such as functional limitations or difficulties with returning to social activities. Participants report their confidence in carrying out self care activities. The original SUPHH was divided into 4 subscales: Coping, stress reduction, making decisions, and enjoying life. The questionnaire involved rating statements in the 4 subscales on a 5 point rating scale: 1 (very little confidence) to 5 (quite a lot of confidence). An example of a statement in the stress reduction subscale is: "I have confidence in my ability to keep my stress within healthy limits" (Lev and Owen, 1996). The SUPPH is reported to possess good psychometric properties in patients on haemodialysis and those undergoing cancer chemotherapy (Lev and Owen, 1996). Cronbach's alpha internal consistency reliability for the overall SUPPH score was very high, 0.93 initial testing and 0.95 at retest. Test retest stability coefficient was 0.94, the retest was done after 2 weeks. Validity of the SUPPH scale was assessed by administering it along side the following validated scales: the Revised Grief Experience Inventory (RGEI) and the Health Behavior Scale (HBS). The SUPPH correlated positively with the HBS (r=0.61, $p < 0.001$) and negatively with the RGEI (r= -0.38, p <

.01). Thus indicating that increased self-efficacy was related to more positive health beliefs and less reported grief.

The validity and reliability of using this scale in neurological research has not been assessed. Robinson-Smith et al (2000) used a modified version of the SUPPH in evaluating the relationship between self-care self-efficacy, functional independence, quality of life and depression in stroke patients. This modified version however was not tested for reliability and validity but was simply a change in terms to refer to stroke patients.

c) The MS Self-efficacy Scale (MSSE)

Schwartz et al (1996) developed and validated the MS Self-efficacy Scale (see appendix 7). These researchers identified the absence of a valid scale specifically for patients with multiple sclerosis. This is an 18 item scale that emulates the format of the Arthritis Self-Efficacy scale (ASES). Subjects are asked to rate on a scale of 10-100 their confidence in performing activities related to psychosocial and physical independence. 14 of the original 24 items were adapted directly from the Arthritis Self-efficacy Scale and an additional 10 items specifically to coping with multiple sclerosis was added. The 18 items are divided into two main subscales: Function and Control. An example of an item from the function subscale: "How certain are you that you can walk on flat ground?" And an example from the control subscale is: "How certain are you that you can control your fatigue?" Pearson's correlation coefficients were used to assess test-retest reliability, and intercorrelations between subscales. Schwartz et al (1996) assessed the psychometric properties of this scale. One hundred and forty-one individuals with MS filled out a questionnaire pack containing the MS Self-efficacy Scale, the Expanded Disability Status Scale, the Sickness Impact Profile and the Mastery subscale of the Ryff Happiness Scale.

The MSSE was reported to be both sensitive and specific, meaning that it was able to pick up subtle changes in self-efficacy and possessed high internal consistency and test retest reliability. The researchers reported high test re-test correlation (r=0 .75) on the whole questionnaire. The Function and Control subscales also presented with high test retest correlations: (r=0.81) and (r=0.62) respectively. In assessing intercorrelations between subscales, function and control subscales were modestly but significantly correlated (r=0.32). In discussing the MSSE, Schwartz et al concluded that it was a reliable, stable and valid measure of self-efficacy for MS patients. However this scale has not been tested on stroke patients or found to be reliable or valid for stroke patients nor validated for use in non-Western cultures.

d) The Liverpool Self-efficacy Scale

Airlie et al (2001) developed and assessed the psychometric properties of a scale to measure self-efficacy in patients with Multiple Sclerosis. The scale was developed from a literature search which was carried out to identify themes associated with impact and adjustment to MS. Semi-structured interviews were also carried out with 10 patients aimed at identifying themes related to the impact in MS. Themes identified included lack of independence, low self worth, loss of personal control, fear of the future and the burden of MS. Themes from the literature search and interviews were used to construct a preliminary 22 item scale in which subjects were asked to rate on a four-point scale their level of agreement with each statement. The scale was then assessed for acceptability and ease of completion on 10 subjects.

Examples of items on the scale include:

1) "Since my diagnosis was confirmed, my life has been beset with difficulties over which I have no control"

2) "I often feel helpless when dealing with my difficulties"

Respondents were asked to score each item on the following four point scale:

1-Strongly agree

2-Agree

3-Disagree

4-Strongly disagree

Psychometric properties of this scale were evaluated on 100 patients with MS attending a specialist MS clinic. To assess construct validity, the scale was assessed along side Barthel Index and Rankin Scale (a measure of dependency) which have been previously validated. The following other scales were also administered alongside the scale being assessed: The Hospital Anxiety and Depression Scale, Rosenberg Self Esteem Scale, Mastery Locus of Control Scale and Stigma and Impact Scale. At the time of this study there was no validated MS self-efficacy scale to assess it against. This scale was identified to be positively correlated to the self esteem measure, Barthel score and Mastery Locus of control scores. It correlated negatively with anxiety and depression and the Rankin scale scores. These results were used to report the criterion validity of the scale.

Reliability was assessed in two ways. Firstly, using a test-retest method and secondly, the internal consistency of the scale was assessed using Cronbach's alpha. Test-retest reliability correlation coefficient (r) was 0.79 and Cronbach's alpha was 0.85, indicating high reliability. Its application to stroke patients has not been demonstrated.

e) The MS Self-efficacy Scale (Rigby et al, 2003)

The MS Self-efficacy Scale is a 14 item scale developed specifically for use with MS patients (different from the one outlined earlier). (See appendix 7 for copy of questionnaire). Open ended interviews with 15 individuals attending an MS clinic, were used to generate items ensuring a patient focused approach was adopted. Each participant was asked how MS had impacted on their lives and the interviewer explored their reported feelings and difficulties. Interviews were then transcribed and thematic analysis was carried out.

Psychometric analysis of the MS self-efficacy scale was conducted with 142 individuals diagnosed with MS. Validity was assessed by administering the scale along side these other scales: The Control Scale of Schwartz et al's MS Self-Efficacy Scale (MSSE), Hospital Anxiety and Depression Scale (HAD), and the Dispositional Resiliency Index. Validity was also established by asking health professionals working with MS patients the relevant of items of the scale and if they thought there were items missing. Rigby et al report the scale as possessing high internal consistency (Cronbach's alpha=0.81) and test re-test reliability ($r=0.81$, $P<0.001$).

Regarding validity, since the scale was developed from interviews of MS patients, the authors anticipated it possessed high face validity. This was confirmed from feedback from respondents and health professionals working with MS patients. Scores from the scale correlated significantly ($r=0.64$. $p<0.0001$) with scores on the Schwartz et al MSSE scale, indicating some concurrent validity. Scores from this scale correlated negatively with depression scores (HAD) ($r= -0.707$, *p < 0.001*).

Examples of items in the scale include:

1) I am confident when meeting new people and going to new places

2) Planning for the future helps me to cope with my illness

3) I can keep my MS from interfering with time spent with my friends and family.

Respondents were asked to rate each item on a 6-point Likert scale ranging from 'Strongly Disagree' to 'Strongly Agree'. Six items were phrased negatively and responses had to be reversed. A copy of this scale can be viewed in appendix 7.

f) Chronic Disease Self-efficacy Scales (Lorig et al, 1996)

This is a collection of 3 scales: Self-Efficacy to Perform Self-Management Behaviours, General Self-Efficacy and Self-Efficacy to Achieve Outcomes Scales. These scales were developed at the Stanford Patient Education Research Center. Internal consistency of the various subscales was high, and ranged between 0.77 and 0.92 and test retest reliability of the various subscales ranged between 0.72 and 0.88 (Lorig , Stewart , Ritter et al, 1996). Assessment of the validity of these scales has not been documented. A copy of the questionnaire can be found in the appendix 7.

4.3.5 Summary of Self-efficacy Scales

Six self-efficacy scales relevant to psychosocial recovery in neurological rehabilitation were identified by the literature search. However, none of these were developed specifically for stroke patients. Items in all of the scales were reviewed and compared to themes raised by participants from the semi- structured interviews in Phase 1 of this study. Similar items were covered by most of the scales, however the Chronic Disease Self-efficacy Scales appeared to cover all the issues raised by participants in the Kuwait sample of Phase 1. Hence this was adapted to be used in this study. The adapted scale was named Psychosocial Adaptation Self-efficacy Scale (PSE). Details on how items were chosen can be found in chapter 5.

Testing the Validity and Reliability of the Adapted Self-efficacy Questionnaire

A small study on health professionals was carried out to assess the relevance of the questionnaire items. Participants were physiotherapists working at the rehabilitation facility in Kuwait. Approval to handout these questionnaires was given by the head of the facility. All participants were volunteers and had the right to decline participation.

The questionnaire was amended with tick boxes under each item for therapists to assess informally whether or not they thought the items were relevant given their experience of working with stroke patients. Completed questionnaires were returned within 3 hours and brief discussions held with therapists regarding their comments about the relevance of the items. 13 questionnaires were handed out and 11 returned filled. Results of this study can be found in chapter 5.

An exploratory pilot/validation study was also carried out. The adapted self-efficacy scale (PSE) scale was administered on 10 patients (see the table below for details of participants) via interview to compare its results with the generalized self-efficacy scale (GSE) which is a validated, reliable measure of self-efficacy. The same information sheet, and consent form and procedures of the wider study (which will be described in the following section) was used. Some participants from this pilot study were used in the wider study if they were available (mainly female participants).

Test-retest reliability was assessed by presenting the scale to a group of participants on two occasions. The time between test and retest varied from one participant to the other (between 1 and 7 days) with a small sample of 8 participants. Results can be found in chapter 5.

Table 4.1: Demographic data of the Validation

Patient No	Age	Gender	Time since stroke	Type of stroke	Side of weakness	Nationality
001	60	Female	2 months	Infarct	Left	Kuwaiti
002	60	Female	3 months	Infarct	Left	Kuwaiti
003	65	Female	8 months	Infarct	Right	Kuwaiti
004	50	Female	1 month	Infarct	Left	Kuwaiti
005	83	Female	1 month	Infarct	Right	Kuwaiti
006	64	Female	1 month	Infarct	Right	Kuwaiti
007	55	Male	4 months	Haemorrhage	Right	Egyptian
008	62	Male	3 months	Infarct	Right	Egyptian
009	72	Male	6 years	Infarct	Left	Kuwaiti
010	75	Male	8 months	Infarct	Left	Kuwaiti

4.4: Phase 3- Relationships between Self-Efficacy, Life Satisfaction and Religious Faith in Female Stroke Patients Living in Kuwait

4.4.1 Introduction

The aim of this phase of the project was to investigate the relationships between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait. As mentioned previously, the literature review highlighted the lack of research on self- efficacy and religious faith with regard to the stroke patient, especially within an Arabic context. The initial two phases explored the experiences of stroke patients which were used to adapt a self-efficacy scale for participants in Kuwait.

The following questions were addressed by phase 3:

Among female stroke patients living in Kuwait,

1) Is self-efficacy related with life satisfaction?

2) Is life satisfaction related with religious faith?

3) Is self-efficacy related with religious faith?

4) What is the best predictor of life satisfaction (variables assessed were: psychosocial adaptation self-efficacy, general self-efficacy, religious faith, time since stroke, and age).

4.4.2 Study Design:

A cross-sectional study design was carried out to investigate the relationship between self-efficacy, life satisfaction and religious faith. This study design involved the collection of data at one point in time on a number of cases. Advantages of the cross-sectional design include the ability to detect patterns of association between variables at a given point in time, this study design however is unable to show cause and effect relationships. In other words, although an association between variables can be identified, there remains an ambiguity regarding the direction of inferences about causality. Cross-sectional research designs are criticized as having poor internal validity because of the difficulty in establishing causal direction. Other study designs that can be used in such a study include longitudinal design. This includes collection of data on variables more than once along the course of time, for example, at one months and then 3 months later. This design allows for inferences to be made regarding causality. Disadvantages of longitudinal research designs, however, include increased cost and time for subsequent measurements as well as sample attrition (Bryman and Teevan, 2005). A longitudinal study design was not used in this study due to difficulties locating participants after the first assessment. It was also not needed to answer the research question.

4.4.3 Participants

A total of 40 patients with confirmed stroke admitted into the inpatients facility and those attending out-patient physiotherapy sessions at a large Rehabilitation Hospital in Kuwait participated in the study. In line with the local population, Kuwaitis made up 55 % of the study sample (22 participants) and Non Kuwaitis made up the remaining 45% (18 participants). The Non-Kuwaitis were of the following nationalities: Indian, Lebanese, Philipinos, Iraqi, Egyptian, Bangladeshi, Bedouin, Ethiopian, Sudanese, Iranian, and Saudi

Arabian. There was a wide variation in age in the main study sample ranging from 30-73 with a mean of 55.3 years and a standard deviation of 10.28. Participants were all female due to difficulty recruiting male participants and because experience of Muslim women under-researched. This also helped to ensure homogeneity and to reduce variation in the sample. Inclusion and exclusion criteria were the same as those used in phase 1 of this project. Inclusion and exclusion criteria were as follows:

4.4.4 Inclusion criteria:

- Recent stroke patients attending outpatient physiotherapy

- Diagnosed with a cerebrovascular accident or stroke on CT scan.

- Stroke patient (as mentioned above) with cognitive functioning and speech adequate for participation.

4.4.5 Exclusion criteria:

- Patients unable to give consent due to cognitive deficits

- Patients with expressive and receptive aphasia following stroke

- Patients with other neurological conditions i.e. multiple sclerosis, Parkinson disease, peripheral neuropathy etc

- Patients with previous documented psychiatric history.

4.4.6 Ethical Considerations:

Ethical permission was initially obtained from Brunel University. Based on this, permission was obtained from the physical therapy department at a rehabilitation hospital in Kuwait, in line with local practice. Information sheets and written consent forms were translated to

Arabic and made available to participants before recruitment to participate in the study. All questionnaires were identified with reference numbers in order to ensure confidentiality. Patients were reassured that their participation/ refusal would not affect rehabilitation. Patients unable to give consent due to cognitive difficulties were excluded from the study.

4.4.7 Recruitment:

Patients were approached before or after their physiotherapy session by their physiotherapist to seek their permission to voluntarily participate in this study. The information sheet was explained to them and they were informed about their right to withdraw and that their rehabilitation would not be affected by their willingness to participate or withdrawal from the study.

4.4.8 Procedure

Participants were interviewed with a panel of the main researcher and a translator (this was a neutral person, neither a relative nor their own physiotherapist). Despite having the questionnaires in Arabic, it was found that the translator was at times required to re-read questions for the participants and clarify the meanings of questions. Some participants required scenarios and explanation of how to rate their beliefs and life satisfaction on a scale of 1-10. Clearly this introduced some variability in administration but was necessary in order for patients to understand the questions and also followed social norms of interaction operating in this culture. The following scales were administered:

1) The Psychosocial Adaptation Self-efficacy Scale (adapted from the Chronic Disease Self-efficacy Scales): This was adapted for use in this study. See phase 2 in this method chapter for more details.

2) The Generalised Self-Efficacy Scale (Schwarzer and Jerusalem,1995)

3) Single item life satisfaction measure (10-point rating scale)

4) Santa Clara Strength of Religious Faith Questionnaire (Plante and Boccaccini 1997).

These will be described in more detail below

4.4.9 Assessment Instruments

i) The Psychosocial Adaptation Self-efficacy Scale (PSE)

The Psychosocial Adaptation Self-efficacy scale (adapted from the chronic disease self-efficacy scale) was developed for this project from interviews with stroke survivors living in Kuwait, and the themes were used to identify relevant items from the Chronic Disease Self-efficacy Scales (CDSES). The process of reliability and validity testing of this scale was reported in the previous section. This scale is made up of 8 items regarding psychosocial self-efficacy which participants have to rate their level of confidence regarding. For example: "how confident are you that you can deal with the frustration of your disability /disease". Level of confidence is then rated on a scale of 1 (Not at all confident) to 10 (Totally confident). The total score from the 8 items represents the participants' psychosocial adaptation self-efficacy. Cronbach's alpha was acceptably high, indicating internal coherence. (Cronbach's alpha= 0.78).

ii) Single Item life Satisfaction Measure

Participants were asked to rate on a scale of 1 to 10 how satisfied they felt with life at the moment. "1" denoting: not satisfied at all and "10" denoting: very satisfied. Other studies have used a single measure such as this in assessing life satisfaction post-stroke (Osberg, DeJong, Haley et al, 1988).

iii) The Generalised Self-Efficacy Scale (GSE)(Schwarzer and Jerusalem, 1995):-This scale was described previously in the section regarding self-efficacy scales identified in the literature.

iv) Santa Clara Strength of Religious Faith Questionnaire (SCSROF)

This is a 10 item questionnaire designed to measure strength of religious faith. It was developed by Plante and Boccaccini in 1997 to be used to assess religious faith regardless of denomination or affiliation (see appendix 4). Participants are asked to indicate their level of agreement (or disagreement) for each of the 10 items. Four options are provided 1 (strongly disagree), 2 (disagree), 3 (agree) and 4 (strongly agree). Examples of items are: 'My religious faith is extremely important to me', and 'I look to my faith as a source of comfort'. Plante and Boccaccini (1997) reported some evidence for the reliability and validity of the scale. Internal consistency of 0.95 (Cronbach's alpha) and split half reliability of r=0.92 was reported. Validity testing against the Duke Religious Index (DRI) showed a correlation of between 0.71 and 0.85 on the different subscales of the DRI indicating high convergent validity (Plante and Boccaccini, 1997). Further psychometric testing of the SCSROF confirmed that the scale possessed good internal consistency with an alpha coefficient of 0.93 (Lewis, Shevlin, McGuckin et al, 2001).

Freiheit, Sonstegard, Schmitt et al (2006) conducted a psychometric evaluation of this scale. Their study involved 124 undergraduates from a catholic university. SCSORF was found to be internally consistent (alpha =0.95). On convergent and discriminant validity SCSORF correlated strongly with a standardized spirituality scale (r=0.76, p less than 0.01) and with religious behaviour (r=0.61, p less than 0.01) (Freiheit, et al, 2006).

v) Data Analysis

Choice of Parametric Statistics

Arguments exist in the literature regarding the use of parametric tests to analyse ordinal data. Many research textbooks advocate non-parametric statistics with the use of ordinal data (Bowling and Ebrahim, 2005; Lewis-Beck, Bryman, Liao, 2004), however some researchers claim that parametric tests are robust and can withstand some deviation from expected parameters including the use of ordinal data, and that they are more powerful (e.g. Cohen, 2001; Portney and Watkins, 2000; Armstrong, 1981). Traditionally, parametric tests are used when the following criteria are met: 1) Ratio and interval data 2) normal distribution of data 3) appropriate sample size, 4) scores in different groups have homogeneous variances. Some researchers express arguments against the use of parametric tests for ordinal data in stroke research, claiming that only non-parametric methods are appropriate (Duncan, Jorgensen and Wade, 2000; Roberts and Counsell,1998; Sulter, Steen and De-Keyser,1999). On reviewing outcome measures used in stroke trials, Duncan et al (2000: 1435) stated the following: "Because most of the outcome data are ordinal and are not normally distributed, nonparametric statistics should be used". However the reasons for this stance were not elaborated upon. Similar statements were made by Roberts and Counsell (1998). They regarded the use of parametric statistics on ordinal data in stroke trials as incorrect, arguing that ordinal scales should not be treated as continuous scales as the intervals between the points on the scale are not necessarily equal. This continues to be an ongoing debate.

Historically, the two stances on this debate are the: 1) Stevens-Siegel position and 2) Nunnally position (Nunnally, 1978). The Stevens–Siegel position argued that there is a direct link between levels of measurement and statistics. Thus non-parametric statistical analyses

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are more appropriate for nominal and ordinal data while data measured by interval or ratio levels should be analysed by parametric tests (Stevens, 1946). Nunnally (1978), on the other hand, questioned these strict rules and stated that there is no harm using parametric statistics for ordinal data. He demonstrated the robustness of parametric tests when dealing with ordinal data despite violations of assumptions. This view point is supported by other more current researchers (such as Armstrong, 1981, Cohen, 2001). Cohen (2001: 309) concluded the following when reviewing the use of parametric tests in ordinal data in dentistry: "(1) Parametric tests are sufficiently robust relative to typical violations of normality; (2) presumed statistical prohibitions against the application of parametric methods to ordinal data do not actually exist; and (3) 'ordinal' dental indices have sufficient quantitative meaning to be considered quasi-interval."

Song, Jerosch-Herold, Holland et al (2005) reviewed statistical methods used for analyzing Barthel Index scores (an ordinal scale) in post-stroke intervention. They reported that 45 of the 100 studies identified used non-parametric tests while 16 used parametric tests on scores derived from this scale. Computer simulations showed that the parametric methods had similar type 1 error rates and statistical power when compared with the non-parametric methods. This indicates that non-parametric tests were not necessarily superior or more appropriate than parametric tests when dealing with ordinal data such as Barthel Index scores.

Lutgen and Bostrom (1995) stated the following conclusion regarding this argument about the use of parametric tests for ordinal data: "It is unlikely that this controversy in measurement theory will be solved in the near future. Therefore, it is important for readers of research to be aware that differing opinions exist, these opinions often are formed by the

discipline of the researcher and/or the school that the researcher attended, and that there is no right or wrong opinion." (Lutjen and Bostrom, 1995:10)

Other studies reported in the literature review chapters of this thesis have used parametric tests in dealing with similar data. For example, Robinson- Smith et al (2000) investigated the relationship between self-care self-efficacy, functional independence, quality of life and depression post-stroke. Data were further analysed with Pearson correlations and hierarchical multiple regression. Haslam et al (2008) also used Pearson's correlation with similar questionnaire data from 53 participants. Likewise, Hartman-Maeir et al (2007) also used Pearson's correlation with similar data from 56 participants. In the review of studies investigating factors associated with life satisfaction post-stroke, 10 of the 20 studies identified used parametric tests when dealing with ordinal data. Mindful of this debate, parametric tests have been applied in the analysis reported next. Nevertheless, nonparametric Spearman's correlations were also carried out and are reported in appendix 8. Only when contrasting results were obtained, are they identified in the text.

The SPSS version 12 was used for all analysis. Descriptive statistics were used for all variables. The internal consistency of each instrument was examined used Cronbach's alpha. Pearson's correlations were used to evaluate the association between self-efficacy, life satisfaction and religious faith. Independent t tests were used to assess differences within the sub groups of the study sample.

Multiple linear regression and stepwise multiple regression were used albeit in an exploratory way, to identify the most significant predictor of life satisfaction, out of the

variables measured. Full details and rationale behind use of these tests can be found in the results chapter.

4.5: Phase 4- Exploring Health Professionals' Views of the Influences of Culture on Stroke Experience in Kuwait

4.5.1 Introduction

The aim of this final phase of research project was to explore health professionals' views of the clinical implications of the findings of earlier phases of the research, and to explore their perceptions of the influence of culture on the stroke experience in Kuwait. It is possible that issues held as important to patients might not be the same issues that health professionals become aware of during their work with patients during rehabilitation. Practical/ clinical implications are often drawn from research findings but this phase helped to assure that clinical implications were explored explicitly with health professionals working in the field.

4.5.2 Setting and Participants

Following ethical approval, the study took place at a rehabilitation facility with outpatient stroke rehabilitation services in Kuwait.

Only health professionals volunteering to participate were included. 14 health professionals with stroke experience working in Kuwait were interviewed. Only 12 of these interviews were used in the analysis. The recordings of the other two were poor and resulted in difficulty hearing the speaker. Details of the 12 health professions can be found on table 7.1 in chapter 7.

4.5.3 Method:

Semi-structured interviews were carried out with 12 health professionals with current/ recent stroke rehabilitation experience in Kuwait. The technique of snowballing was involved in recruiting participants. The researcher is a physiotherapist who has been working in stroke rehabilitation in Kuwait. Local health professionals working at a rehabilitation centre were informed about the study verbally, and then given full written information (including main interview questions) if interested in participating. They gave written consent. Permission was given by the centre to access staff in this way (see appendix 3 for letter). Further recruitment occurred through participants letting other colleagues know about the study. They too were provided with full information and given written consent if interested in participating. Snowball sampling is considered adequate when there is no clear sampling route or frame (Mason, 1996) as was the case in Kuwait, as there is no special interest group or other forum for contacting a range of health professionals. The interviews took place in a quiet room at the Institute or at a suitable public location (for anyone working outside of the Institute). Interviews were conducted in English and took 45 minutes to one hour. All participants were informed of the aims of the study, their right to withdraw at any time, and that all interviews would be tape recorded and confidential. Written Consent was obtained prior to beginning the interviews.

i) Ethical Considerations:

   a) **Ethical Approval**: Ethical approval was obtained from Brunel University. Approval was also given by the head of the Rehabilitation Institute.

   b) **Informed Consent**: As mentioned above, all participants were qualified health professionals (physiotherapists, speech therapists, occupational therapists or nurses)

who were provided with written information about the study, had time to consider whether or not to participate, and signed consent forms prior to participation.

c) **Participants' Rights**: Participants were informed that they were under no obligation to participate, and could withdraw from the study without giving reasons, and without affecting their standing at the Institute. They were also notified of their rights to copies of the results of this study on completion.

d) **Confidentiality**: Participants were identified by a code number. Names and other identification details e.g. address, were kept separate from the data. All participant records used in the study were stored in a secure place and information stored in a computer had a secure password access. Participants were assured that any quotations from interviews would be kept anonymous.

ii) Interview Guide

Participants were explained the aims of the study and the results obtained in Phase 3 regarding self –efficacy, life satisfaction and religious faith. 'Self-efficacy' was explained to therapists not familiar with this term. All interviews were conducted in English.

The following main questions were used to guide the semi-structured interviews:

a) My study showed that self-efficacy was a significant contributor to life satisfaction - how do you understand this relationship, and how can this be applied clinically?

b) In your experience, what are the most significant challenges faced by stroke patients? (Explore physical/ functional, psychological and social changes)

c) How have you addressed psychosocial issues during rehabilitation in the past?

d) In your view, what influences quality of life and life satisfaction in stroke patients?

e) Does culture have an influence on the stroke experience and rehabilitation process (why and how?)

f) My results did not show a relationship between religion and self-efficacy and life satisfaction. Are you surprised and why? What did you expect?

4.5.4 Data Analysis

Interview transcripts were analysed with thematic analysis. Steps used were the 6 steps as described previously. Second coding by supervisor of a proportion of the transcripts was also carried out to ensure trustworthiness of the data and analysis. Findings from this Phase will be reported in chapter 7 and 8.

4.5.5 Trustworthiness in Qualitative Research

The concept of rigour is important in any kind of research. It ensures that the methods and findings of the research can be trusted. Bowling (2002: 118) refers to rigour as the following : "minimising contamination and enhancing the accuracy of the research process, the collection of data in an objective manner, the systematic collection, analysis and interpretation of data, the careful maintenance of detailed research records, the use of additional research methods to check validity of the findings…" Research is said to be worthless without rigour (Morse, Barrett, Mayan et al, 2002).

In qualitative research the concept of "trustworthiness" has been viewed as a substitute for reliability and validity (Morse et al, 2002). This concept was initially introduced by Guba and Lincoln (1981) with 4 main criteria: credibility, transferability, dependability and confirmability.

Credibility can be described as: "the issue of 'fit' between respondents' views and the researcher's representation of them" (Tobin and Begley, 2004: 391). Guba and Lincoln (1989) described credibility in terms of recognition of experiences from the descriptions provided thus ensuring that the descriptions provided are faithful representations of the participants views. This criterion can be demonstrated by member checks, peer debriefing and prolonged engagement. Member checks involves the returning of text and results of analysis to participants to ensure that their experiences were adequately captured (Koch, 2006). Other methods to ensure credibility include persistent observation and audit trails (Tobin and Begley, 2004).

Transferability refers to how generalisable the results of the study are to other similar situations (Tobin and Begley, 2004). Guba and Lincoln (1989) describe transferability as the 'fittingness' of results of a project.

Dependability can be demonstrated by conducting an audit trail which includes reflexivity. The process of decision making is thus documented alongside side a critical self analysis of the researcher during the project (Tobin and Begley, 2004).

Confirmability is described as being: "concerned with establishing that data and interpretations of the findings are not figments of the inquirer's imagination, but are clearly derived from the data" (Tobin and Begley, 2004: 392). The researcher clearly outlines how integrations of the data were derived (Koch, 2006). Confirmability is said to be demonstrated when the other criteria i.e. credibility, transferability and dependability have been established (Guba and Lincoln, 1989). These issues have been readdressed in the discussion chapter.

In phase 4 of the study, trustworthiness was established by second coding of a proportion of the data, which ensured that data analysis was carried out appropriately.

Chapter Summary

This chapter presented the research methods used in this project. Four phases were involved in this project, firstly aiming to explore the experiences of stroke patients in Kuwait and secondly to adapt a self-efficacy scale relevant to their experience. Thirdly, the associations between life satisfaction, self-efficacy and religious faith were investigated with the most significant predictor of life satisfaction identified. The fourth and last aim of the study was to investigate the perceptions of culturally diverse health professionals on cross cultural influences on rehabilitation in Kuwait and issues such as life satisfaction, quality of life and challenges experienced by the stroke survivor.

The whole project involved the use of a mixed method approach i.e. quantitative and qualitative research methodologies were combined. This provided a rich source of varied data from stroke survivors and the health professionals working with them. The next four chapters present the results of all phases of the project.

Chapter 5

Chapter 5

Results of Phase 1and 2

Adaptation of a Self-efficacy Scale for Stroke Patients in Kuwait

The aim of phase 1 was to explore the subjective impact of stroke on the life of patients in Kuwait through interviews. The themes from these interviews were subsequently used in the adaptation of a self-efficacy scale for stroke patients living in Kuwait. As reported in chapter 4, semi-structured interviews were carried out with 15 individuals with a diagnosis of stroke living in Kuwait. Eight of these were female and the others male. Thirteen of these interviews were carried out with the assistance of an interpreter who translated the interviewer's questions and the participants' responses from Arabic into English and the remaining two were fully in English. A full description of the procedures of phase one can be found in the methodology chapter. Table 5:1 shows the profile of the participants. All participants were married and living with family.

Table 5.1: Profile of Study Participants

Identification Initials	Age	Nationality	Religion	Stroke Onset	Side of brain affected	Co-morbidities
Mrs FS	46	Kuwaiti	Muslim	2002		Hypertensive
Mrs NM	52	Kuwaiti	Muslim	2006		Hypertensive
Mr FD	69	Kuwaiti	Muslim	2003		Hypertensive
Mrs SH	57	Kuwaiti	Muslim	April 2006	Left	
Mrs SK	59	Iranian	Muslim	April 2005	Right	Diabetic and Hypertensive
Mrs NA	60	Kuwaiti	Muslim	Feb 2006	Right	Osteoporosis, diabetic, Hypertensive
Mr MS	70	Kuwaiti	Muslim	Feb 2006	Left	CVA 1999
Mr KM	64	Kuwaiti	Muslim	May 2004		
Mr MY	67	Kuwaiti	Muslim	2006	Right	CVA 1999, 2002
Mrs MA	67	Kuwaiti	Muslim	2005	Right	Hypertensive, CA breast
Mr MU	64	Kuwaiti	Muslim	2000	Right	hypertensive
Mr NM	49	Kuwaiti	Muslim	1996		Hyperlipidemia, hypertensive
Mr KD	80	Kuwaiti	Muslim	2001		
Mrs MN	45	Indian	Hindu	May 2007	Right	
Mrs LT	50	Indian	Christian	2008		Diabetic

Thematic analysis was carried out on all interviews to identify concerns regarding the impact of the stroke on their lives as described in the methods chapter.

Eleven recurring themes were initially identified. These were: nostalgia, speech, dependency, mood changes, changed role in family, social isolation and withdrawal, physical disability, changes in family relationship, fears, beliefs about future, opinions about rehabilitation. These themes were then grouped into the four main themes with subthemes as can be viewed

in the table below. Finer details about each of the themes and subthemes will be discussed later in the chapter.

Table 5.2: Themes and Subthemes for Stroke Survivor Interviews in Kuwait

Themes	Subthemes
Physical and Speech Difficulties	-Speech difficulties -Dependency -Physical difficulties
Social changes post-stroke	-Change in role within family -Family support -Social withdrawal and isolation
Psychological Changes	-Mood changes -Nostalgia
Perception of Rehabilitation	-Improvements made with rehabilitation -Views about the patient's and therapists' role in Rehabilitation -Perceptions regarding rehabilitation services

Four main themes were identified, as shown above. Although they are described here in turn, they were highly interconnected in the participants' experiences.

5.1: Physical and Speech Difficulties

These were the most talked about issues by the patients as judged by the volume of transcript. Three subthemes were identified: speech difficulties, dependency, and physical disability.

5.1.1 Speech

Participants reported a variety of speech difficulties. The following quotations from the translator reflect patients' awareness of their speech difficulties.

> Interpreter: "Her tongue becomes thick heavy but not affect her relationship with family" (Mrs NM, 52yrs).

In the above quotation, the interpreter explained that although Mrs NM acknowledged her speech difficulties, she believed it did not affect how she related with her family (or she might have needed to reassure herself or the translator that family relationships had not been affected). Other participants mentioned further problems in addition to speech difficulties and described how the change in speech had affected their lives.

> Interpreter: "Hand movement, hand function affected, heaviness of her tongue, heaviness of the lower limb, she cannot walk too much." (Mrs NA, 60yrs).

Mrs NA described a similar heaviness of tongue as did Mrs NM who also explained the effect it had on her outings.

> Interpreter: "She becomes angry and anxious, she feels like her way of speech is not normal so she doesn't like to go out." (Mrs NA, 60yrs).

The interpreter was not relaying the participants' responses verbatim but translating the meaning of the responses to the questions. However, the use of "heaviness of tongue" perhaps reflects a cultural description of patients' perceptions of their difficulties. The quotations also reveal other physical difficulties that will be discussed in other sections of this chapter. It is worthy to note that the third quotation reflects the problem of social withdrawal which the participant attributed to her speech difficulties.

Another participant expressed her pride with the improvement in her speech with therapy, which she connected with working with a speech therapist:

"My speech was affected but in the initial stage I got a speech therapist working with me and with speech therapy got better. The speech therapist thought that I had recovered with an amazing speed." (Mrs MN, 45yrs).

In addition to abnormal feeling of the tongue, another participant mentioned difficulty stopping laughing:

"Means getting my mouth dry and the tongue also, I am feeling thickness on the tongue. And if I start to laugh I can't stop that is the – if anybody saw me that they will think I am mad, like that I will laugh, I can't stop, this another difficulty for me." (Mrs LT, 50).

In the quotation above Mrs LT alludes to others labelling her and perhaps rejecting her due to her difficulty in stopping herself from laughing. She expressed the possibility of being labelled as "mad" by others. This implies that some of the sequelae of stroke could carry negative social implications.

The main speech difficulty expressed by participants was the heaviness of the tongue, which is probably due to poor control of muscles controlling the tongue due to the stroke. This was associated with speech difficulties which in turn caused some anxiety and social withdrawal. However, speech therapy was experienced as helpful in some cases. Speech difficulties were mentioned by females only. The male participants interviewed did not raise this issue.

5.1.2 Dependency

Participants voiced their frustration with having to be dependent on others for basic care and other daily living activities.

> Interpreter: "She stays at home nothing to do. Before she did everything independently. Now some work she cannot do. Before she drove but now. No. Her husband brings her here". (Mrs FS, 46yrs).

In this quotation, the participant expressed her difficulties with not being able to do things independently. There is also the sense that because she cannot drive and is dependent on her husband she has to stay at home. Thus, she communicates a sense of boredom and frustration. The next participant elaborated on this experience by describing her perceived loss of adult status:

> Interpreter: "She told me I am depressed. She feels like she has lost something. Now she feels like a child." (Mrs SH, 57yrs).

The association with feeling like a child, the loss of adult roles or status, and being dependent has led to perceived depression as expressed in the quotation above. Psychological issues such as depression will be discussed in more detail in other sections.

The dissatisfaction with being dependent was expressed by most of the participants. Specific activities like washing and dressing were considered the most difficult to deal with.

> "I feel my complete world has changed. I am not even able to nurse my own self. I am not able to dress up myself , I am not able to take a bath myself , and I feel very embarrassed somebody else doing these things for me because these are very personal to everybody. And I don't like it." (Mrs MN, 45yrs, interview in English)

Mrs NM expressed the embarrassment associated with dependency on others for private things such as hygiene. Similar difficulty with bathing and dressing is expressed in the quotation below:

> "My daughter wants to go, she is married, her husband wants her there, newly married only three months and maybe this month end she will go. I told her go, no problem, I can manage - before - but till now she is giving me bath because I can't clean everywhere and I told her maybe end of this month I can do myself bathing also, this is my problem, big problem wearing clothes, everything". (Mrs LT, 50,   English interview).

Dependency and the feelings of being a burden to other members of the family are expressed in the quotation above and in the other statements by participants. Having to depend on other family members also meant less freedom to go out and led to isolation at home. Comments about dependency were made by only female participants, male participants did not raise this as an issue despite mentioning difficulties with physical function.

5.1.3 Physical Difficulties

A variety of physical difficulties were mentioned such as not being able to use the hand or whole arm, balance difficulties, and problems with walking.

> "I am experiencing difficulty with my hand because I can't comb, I can't brush, but toilet I can manage now. I can now - before one and a half month very much difficult for me." (Mrs LT, 50)

Interpreter: "Walking independently, does stairs but unable to use right hand". (Mrs FS, 46yrs)

In both quotations above, participants mentioned that their current difficulty was the use of their hands. While mobility improved, residual difficulties were related to hand function. However, other participants mentioned difficulties with walking.

Interpreter: "He can do everything but cannot walk like before and cannot use left arm as before. But he can do everything; He has to go slowly, using his left hand for shaving, ADL is a little difficult. Social activities, shopping are like before, praying like before." (Mr KM, 64yrs).

In this quotation, although the translator said that the participant mentioned difficulty walking and using his left arm, he still insists that he can do everything and life is similar to prior to the stroke. It is unclear whether these claims reflected a denial of his disabilities, or an eagerness in the interview to appear to be coping well, or the experience of being able to compensate with his unaffected side. This could also possibly be an issue specific to his male identity. All survivors mentioned some physical disability associated with having a stroke. Mobility challenges were the most voiced problems. Participants with affected upper limbs also mentioned difficulties performing activities of daily living such as washing and dressing themselves.

5.2: Social Changes post-stroke

Three main social issues were mentioned: change in role in family, family support and social withdrawal and isolation

5.2.1 Change in Role in Family

Change in role in family was a subtheme identified as one of the major social changes post-stroke. Participants voiced concern that they believed that since the stroke their role within the family had changed. Concerns with an inability to care for children and support the husband were expressed by the participants, especially younger female ones.

> "It has affected my life completely and I am shattered. I am not able to participate with my children as I use to do before, they love my cooking, and I am not able to cook for them. I am not able to do what I could do for my husband before; in fact he is the one who is doing things for me now. Luckily, I have a very understanding and caring husband. And I cannot participate with school games with my children". (Mrs MN, 45yrs)

In the quotation above, Mrs MN uses the word 'shattered', this is a strong, emotional word with highly visual connotations of breaking apart, to express the changes that had occurred in her life since the stoke. She also expresses the loss of engaging in activities with her family. This further highlights the loss she expresses.

> Interpreter: "She has three children and it has affected her ability to take care of them". (Mrs FS, 46yrs)

The change in role from taking care of others in the family to being the one cared for is evident in the last quotation. The role of these women as the care provider in the family

appeared to be a source of satisfaction and self worth. Not being able to perform this role was expressed to have a significant impact on their satisfaction. The emotional dimension of the experience was much more clearly expressed by those who could speak English. With the Arabic-speaking patients, lack of depth regarding the emotional dimension of the stroke experience could either be attributed to participants not revealing this dimension to the translator or the translator not relating these views (perhaps linked with cultural taboos, as will be discussed later). Male participants did not comment on their change in role since the stroke.

5.2.2 Family Support

Family support was identified as another important subtheme regarding social changes since the stroke. This related to the time and effort that participants perceived was spent by family members providing encouragement and assistance to the stroke survivor.

While some participants mentioned some reduced family support, the majority expressed an increase in family support and visitation since being discharged from hospital.

> Interpreter: "She has only one friend and the relationship is as before. With her family supporting her, she has good family support." (Mrs FS, 46yrs).

In the quotation above, the interpreter related Mrs FS's report that she has good family support. However, due to the language barrier further details on what this support entailed was not determined. Mrs MN in the quotation below elaborates on what family support meant in her situation.

> "He (her husband) is very supportive of me, he's like: I have to get you better. I'll do anything to get you better. The way he supported me, the love and affection. He never

treated me like a burden. He supported me in everything, whatever I wanted to do. He tried to do things that would make me happy. He always tries to do thing around me to involve me. The children also, he would tell no we cannot do this without mama. We would do only when mama is there. He tries to make me feel important. The children have given a lot of love, affection and support." (Mrs MN, 45yrs)

The support from spouses, children and other family members was expressed as being valuable post-stroke. Mrs MN mentioned the importance of not being treated like a burden and being involved in activities in the home, maintaining her role as mother.

However, some participants felt that other relatives did not appear to show the concern they expected.

"My sister is here but she is not even - I don't know, not calling me or asking about me. When I had a job I myself was calling everybody, I informed them I am doing this... likewise my son, he said if I didn't call them nobody will know I am in this condition, this is my condition." (Mrs LT, 50)

Mrs LT in the quotation above makes a comparison between her actions when she was well and in employment to those of her relatives now. She expresses how she showed her concern for others by telephoning, however since the stroke other relatives have not reciprocated by enquiring about her. However, Mrs LT mentioned the support given by her children:

"my children helped me a lot……(this) means for caring for me and, you know, financially also they are helping me a lot, only they are here to help. ... They were feeding me when I was in the hospital and now I told them, you know, after one month I told them I can finance myself and so. They were feeding me like a baby, they two are here for me to help financially and personally." (Mrs LT, 50)

Mrs LT expresses her desire to be independent, however she regrets having to rely on her children both financially and physically. She also mentioned her need to finance herself and not rely on her children. Perhaps this reflects her desire to be viewed as an adult and not a child. Some participants did not regard receiving care as problematic:

> Interpreter: No, (*relationships*) getting better. Getting more care from his family and friends. (Mr KM, 64).

Most of the participants expressed the increase in family support since the stroke. They believed that this helped them to remain encouraged and motivated to persist despite their difficulties. However some participants mentioned negative changes in family relationships since the stroke. Mr NM mentioned blaming his wife for the stroke and her reduced care of him. Assistance was provided by his daughter. Mr MY mentioned a similar reduced care from his wife despite having increased visitations from other family members. He also added a concern with his reduced sexual relationship with his wife.

While the majority of the participants reported increased social support, one woman reported being lonely and two men reported reduced care from close family members like their wives.

5.2.3 Social Isolation and Withdrawal

Social isolation and withdrawal was a subtheme identified in most of the participants interviewed.

This theme is related to keeping away from the public, staying indoors and not wanting to participate in social events like in the past. Participants mentioned the reduced desire to go

outdoors. Feelings of shame and dependence appeared to be associated with their choice to withdraw from the community, not only mobility problems. The following are examples of statements made by participants.

> Interpreter: "she told me she feels sick. Isolated from the people. Sit at home. Always depends on others. What's life if she is not able to do things for herself. Before she was able to go outside, visit, able do things for herself but now people do things for her." (Mrs SH, 57yrs).

As mentioned previously, dependency was closely related to social isolation. Lack of functional ability to get outdoors independently led to isolation, as expressed in the quotation above.

> "Even if my friends come over or if they invite me but I don't feel like going. There is no social life..". (Mrs MN, 45yrs).

Mrs MN expressed her choice to isolate herself from her friends since the stroke, although she did not clearly say why this was so. Mrs LT, on the other hand, did not express concerns about being alone during the day:

> "I am here alone from morning till 4 o'clock, maybe 5 o'clock like that. I am managing myself, not feeling too much difficulty because myself I am trying, I am not sick, I can do like that I am improving. Myself, I am saying I don't have any problem", (Mrs LT, 50).

In addition to dependency, reasons that participants gave for social isolation and withdrawal were also the lack of facilities for disabled access and toileting in Kuwait. Mrs MN was able to elaborate on both these issues:

"There are times that we want to do out (outdoors) but can't go because the place is not wheel chair accessible. Kuwait is not made for wheel chair people. Very few automatic doors and few ramps and I cannot walk on uneven surfaces. I miss my outings with the children, on the beach… (Mrs MN, 45yrs)

"I get embarrassed because every house has a different toilet seat. The height of the toilet seat matters. Then I need help with toileting so I have to ask my husband to come along with me into the toilet and I don't feel that it's decent enough to do that in a party. Or I take my nurse with me who can help me with the toilet. So I don't like to go. I am withdrawing kind of." (Mrs MN, 45yrs)

Male participants were more open about their social isolation than other issues such as dependency or change in role within the family. The following statements were made:

Interpreter: "He feels a little bored, feels like he is in a half prison and is afraid to fall down". (Mr MU, 64yrs).

In the quotation above, Mr MU expressed his hesitation to go out into the community due to fear of falling. He openly expressed feeling imprisoned and bored due to social isolation. Other male participants voiced different reasons for social withdrawal and isolation.

Interpreter: "He says if I go outside my friends will become very sad, If I have enemies, seeing my situation they will be happy. So it's better for me to stay at home" (Mr KD, 80 yrs).

The interpreter explained that Mr KD believed that his disability would upset his friends however it would also excite his enemies. He gives the impression that he believed his

enemies would gloat at his misfortune of having a stroke. To avoid the possibility of being ridiculed and upsetting his friends, he chose to stay at home and not engage with the community. It might also reflect a cultural perception of "enemies" and illness which is prevalent within the Kuwaiti culture.

Social isolation and withdrawal was a commonly voiced challenge by the stroke survivors. Feelings of embarrassment were attributed to dependency. Also, lack of toilet and other accessible facilities contributed to their choice to stay at home. Social stigma associated with disability was another reason for isolation and withdrawal. Fear of falling was also mentioned as a reason for social withdrawal.

5.3: Psychological Challenges

Two main psychological issues were mentioned as affecting the participants since the onset of the stroke. These were challenges with mood, and nostalgia.

5.3.1 Changes in Mood

Participants expressed changes in mood, such as feeling low, lack of interest in relationships, being more emotionally sensitive and somewhat aggressive.

The following quotations were made expressing the mood changes that participants experienced.

> Interpreter: "She told me her mood has become very bad. Shouting, nervous, she don't want family to talk to her, she likes to cover herself and sleep, her mood become very low and she is not interested in talking to them. Before she was like the leader in the house now she feels like a patient." (Mrs SH, 57yrs).

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According to the translator, Mrs SH expressed the negative change in her mood and thought that some of this could be attributed to the change in her perceived role. She emphasised her lack of desire to interact with family perhaps due to the difference in the way they related with her: "like a patient". This could possibly mean being viewed as helpless and requiring care which she dislikes so much. The comment about 'covering' may also imply that she feels or wishes she was invisible.

Other participants expressed that they had experienced an increase in emotional sensitivity i.e. being more labile in mood.

> Interpreter: "she is more sensitive... it has affected her mood but she tries to interact with people" (Mrs SK, 59yrs)

> "Cry, no, no, there is no problem I can stop, but I will cry if I saw something, sad thing, I will start to cry. If anybody say anything to me I will start to, I can't hold, I am feeling my chest, you know, it will break like that, feeling too much. Before also I am like that, very tender hearted, but now more than that, I can't bear anything before. (Mrs LT, 50)

In the quotations above, Mrs LT makes a lot of contrasts between the former and current self, although she asserts that she retains some control – that she *can* stop crying.

In addition to increased emotional sensitivity, another participant expressed an increase in anxiety:

> Interpreter: "Anyone talk about a problem around her she will think about it. She thinks that her brain is open, anything around she thinks about it. There is no specific

problem with her family. She always says she thinks her brain is open." (Mrs NA, 60yrs).

The translator reported that Mrs NA expressed that issues discussed by her family caused her to think a lot. Perhaps Mrs NA found it 'safer' emotionally to worry about others than herself. It is possible that her stroke made her anxious and that she felt better able to cope with the stroke by focusing on worries about her family.

Depression was also mentioned as being related to loss of role as a mother:

"I am so depressed about it…..They want me to come and watch their [children's] games. They won Gold and Silver medals but I haven't been able to go there to see. What kind of a mother am I? I can't be there to share their happy moments." (Mrs MN, 45yrs).

In the above quotation Mrs MN expressed strong feelings of self-doubt about being a good mother, and sense of being excluded from happy moments with the children.

Changes in mood expressed included low mood, increased emotional sensitivity, increased anxiety and depression. Participants mainly associated these emotional responses to their change in perceived role in the family which were valuable to them. Expression of mood changes was mostly from female participants. Male participants rarely disclosed challenges in this area. Mr NM mentioned he was depressed initially but had now accepted his situation. Other men did not elaborate on these issues.

5.3.2 Nostalgia

Nostalgia was a subtheme identified in some of the interviews. This related to thinking about the past before the stroke and making negative comparisons with their current state. Participants mentioned the desire to return to how they were before. The use of the word "normal" was observed in a few of the interviews. There appeared to be a constant unfavourable comparison with how they were prior to and after the stroke. The following quotations reflect this:

> Interpreter: "She wants to be like before. Return back to normal... She gets bored. She is doing the same things everyday and she wants to become like before" (Mrs SH, 57yrs).

Mrs SH in the above quotation expresses the experience of boredom because of a new daily routine. It is possible that before the stroke because of her physical capabilities, she was able to do a variety of activities, however, some of these activities are no longer possible. Similar expression of the desire to return to normal was voiced in the quotation below.

> Interpreter: (*participant was describing the aim of rehabilitation*) "To become normal as before. Return to normal life. There has been a lot of improvement from before". (Mrs FS, 46yrs)

In addition to expressing her desire to return to normal with rehabilitation, Mrs FS proudly emphasised that a lot of improvements had been made in rehabilitation so far. She highlighted returning to normal life, which probably meant her previous lifestyle including how she interacted with other people. Mrs MN also mentioned this, not only returning to perceived normal functioning but being able to "pursue a normal life". She stated:

"Just to be able to pursue normal life like any other individual....Like able to do activities of daily living, your normal cooking routine, your normal sitting down with the family. Now the family looks up to me, if mum can't do that. If the children want to go there, dad will say we have to see if mum can, will she be comfortable or not…..Like going to a movie hall, we haven't seen a movie together in ages." (Mrs MN, 45yrs)

Mrs MN seemed to see herself as a 'brake' on family activities, and stopping them (her family) from taking part in activities. When asked about their aims in rehabilitation, participants mentioned the desire to return to normal as their goals, rather than any specific functional goals i.e. specific things they wanted to be able to do. Perhaps this reflects a misunderstanding of rehabilitation and the belief that they would return to their pre morbid state. But this may also be an understandable goal early on in the recovery process, when people still hang on to 'restitution' narratives (Frank, 1995) that the stroke will only be a temporary interruption to their functioning and lives. Comments regarding a desire to return to normal were made only by female participants. Male participants did not disclose their views on this area.

5.4: Perceptions of Rehabilitation (mainly physical therapy)

This main theme related to participants' experience and perception of rehabilitation, mainly physical therapy. Participants were asked how they were getting on with physiotherapy. The general perception of rehabilitation was positive. Three subthemes were identified under 'perceptions of rehabilitation'. These were further grouped as: Improvements made with

rehabilitation, views about the patient's and therapists' role in rehabilitation, and perceptions regarding service and facilities.

5.4.1 Improvements Made with Rehabilitation

The majority of the stroke survivors interviewed were pleased with the positive changes they had made with rehabilitation. The following quotations give an example of the improvements that they attributed to rehabilitation:

> Interpreter: "Her speech is better, her hand is becoming stronger, her leg is becoming stronger. Before she was depressed but now her mood has changed". (Mrs NM, 52yrs).

The interpreter conveyed the improvements voiced by Mrs NM, these included improved speech, function of arm and leg and improved mood. She had attributed all these changes to the rehabilitation service she was receiving. Other stroke survivors also mentioned functional improvements:

> Interpreter: Since starting physiotherapy she can now stand, she can move in the water......she is doing home exercises. She likes her Physiotherapist so she does her exercises. During the weekend when she goes home she walks to the toilet with assistance (Mrs SK, 59yrs)

Mrs SK conveyed her recovery and compliance with physiotherapy because she liked her therapist. She also sounded excited about the recovery she had made with physiotherapy. Male participants also mentioned improvements they had made:

> Interpreter: "He feels he is getting better, he had physiotherapy at home and massage, ...He has confidence in his physiotherapist" (Mr MU, 64yr).

Mr MU expressed his belief that he had made progress but attributed his progress to his therapist and not his active participation in therapy.

As mentioned previously, participants welcomed changes they had made with rehabilitation, however there was a sense of dependency on their therapists. This will be elaborated in the following section.

5.4.2 Views about the Patient's and Therapists' Role in Rehabilitation

Participants believed that rehabilitation had helped them to improve. However, some participants believed their role in the process was a passive one. The following quotation reflects this:

> Interpreter: "The doctor told him that physiotherapy will help. He doesn't believe he has a role to treat himself. He believes that's the physiotherapists' role. Our God gives us many people to treat us". (Mr FD, 69yrs).

Mr FD in the above quotation expresses his belief that the process of recovery in rehabilitation is the therapist's role. He mentions his doctor telling him that physiotherapy will assist him in recovery however possibly took that advice literally to mean his own personal role was limited. He also mentions his view that the therapist is God's provision to enhance recovery. It is possible that such views could lead to Mr FD not being as active as he could during rehabilitation, and also highlights that rehabilitation was being placed in a religious context.

> Interpreter: "She believes she will get better with physiotherapy. She says why she comes from home". (Mrs SH, 57yrs).

Both these quotations above reflect the trust in physiotherapy to help in recovery post-stroke. However, there was somewhat of a passive approach to rehabilitation expressed by Mr FD.

Perceptions of rehabilitation amongst participants were mainly one of a passive approach with emphasis on placing the responsibility for their recovery on the physiotherapist. One participant felt that the physiotherapist was provided by God for their recovery. This perhaps reflects lack of awareness of the personal active role needed to facilitate recovery or may reflect a cultural norm. It could also reflect a different cultural perspective based on religious beliefs regarding faith and the role of therapists, one that is different from that of the Western world as will be discussed in chapter 9.

5.4.3 Perceptions of Services and Facilities

Lack of rehabilitation services in Kuwait was expressed by a participant. It is interesting as it reveals a perspective from a participant with both professional expertise and experience of services elsewhere.

> "I feel there is such a lack of rehab services over here. The services are poor over here. I went to the hospital and the doctor said I don't need therapy, I have to do home programme. I am a professional, if I could do it myself I wouldn't go to the rehab hospital. Even though I am a professional, I need help in doing things. I am very upset with the attitude of the doctor." (Mrs MN, 45yrs).

Mrs MN being a physiotherapist herself by profession was disappointed with the services in Kuwait. In addition to this, she had been taken abroad for treatment during the early stages

post-stroke and this may have led to her dissatisfaction with services in Kuwait. Other stroke survivors did not comment on the quality of rehabilitation services in Kuwait.

5.5: Kuwaiti /Non Kuwaiti Differences

As the research was concerned with stroke experiences in Kuwait, comparisons were made between Kuwaiti and non Kuwaiti participants to identify possible differences in their experiences of stroke and stroke rehabilitation according to cultural background. However, this comparison is necessarily limited as the Non- Kuwaiti group was made up of only 2 participants (both of Indian origin). Two main differences were identified: issues regarding return to work/finances and religious beliefs.

5.5.1 Return to work and Finances

One of the differences between the Kuwait and Non- Kuwaiti participants was the expressed desire to return to paid employment and the financial strain caused by the stroke among the latter group. The following statements were expressed by a Non- Kuwaiti:

> *"Question- when you think about the future, what are you worried about?*
> Worried about my – see, I have a loan, a bank loan, you know, and in between the bank called me, they are going to legal action. If you didn't pay 500 now they will go for legal action. I don't know from where I will collect this money for my use, for bank." (Mrs LT, 50)

Mrs LT described the challenges with having to find funds to pay off her bank loan, and she went on to describe the difficulties of not having a job in the quotation below:

> "I can manage everything......, my thought is family wise I am not being able to finance, you know, only few money problem, I can manage but the main thing is my life if I go (back to India) – if I don't have a job, this is the question,....its difficult, I am trying to get a new job here in Kuwait". (Mrs LT, 50).

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Mrs LT although mentioning challenges with finances, emphasised that she was managing with "only few money problems". It is possible that this reflected some embarrassment discussing the issue of finances. She was hesitant to express the possible impact of being without a job. A similar concern about returning to paid employment was expressed by Mrs MN, another non-Kuwaiti.

> "I am a physiotherapist by profession; I was to start a job in October last year. But I don't think I can start my work now. I don't know if I'll ever go back to being a physiotherapist. It's rather late for me in life to train for an alternative profession. But you never know". (Mrs MN, 45yrs)

Poor finances and a desire to return to work were expressed by these two non-Kuwaiti participants but not by the Kuwaiti participants. Both of the non-Kuwaitis spoke English and it is possible that due to the presence of the interpreter such issues were not raised among the Kuwaitis. However, Kuwaiti stroke survivors are known to have financial aid from the government. Such aid is not available for expatriates, which makes sense of the voiced concerns by the two Indian stroke survivors. The concern with return to work could also be associated with being younger. However, younger Kuwaiti participants of a similar age did not voice these issues.

5.5.2 Religious Beliefs

Religious beliefs were identified as an important influence on their experiences of stroke in the majority of the Kuwaiti participants, both male and female, especially when asked about the future. Most of these participants believed that their future was in God's hands and that their condition would improve. All Kuwaiti participants were Muslim.

Interpreter: "She hopes to be better, doesn't think about the future. It's in God's hands. She doesn't think about the future. Whatever Allah (God) decides." (Mrs NM, 52)

Mrs NM expressed that she refuses to think about the future. There was a sense of abandonment in God's hands and that whatever happens would be accepted. Similar views were expressed by others:

Interpreter: "I am talking about how he feels about the future. He tells me I have a good future. He is going to Germany …He tell me he is not depressed, he has hope in God who gives health to recover. (Mr MY, 67yrs).

The interpreter related Mr MY's positive view about the future to his belief that God was in charge of recovery. A similar view was expressed by Mr KM.

Interpreter: "He doesn't worry about the future, next year. Because he says this is from our God." (Mr KM, 64yrs).

 Mr FD in the quotation below expressed a direct link between accepting disability and religious faith.

Interpreter: "He is unable to use his upper limb for activities of daily living. He accepts his disability because it is coming from God... He trusts God. It's in God's hands." (Mr FD, 69yrs).

Although Mr FD was unable to use his upper limbs in ADL, he expressed trust in God as helping him in accepting the disability. It is possible that trusting in God is an effective coping mechanism for Mr FD, thus preventing him from focusing on his loss of function.

In the quotations above, the issue of accepting disability due to religious beliefs is evident. Perhaps a lack of acceptance is interpreted as implying a lack of trust in God and lack of faith. During the interviews, it was evident that voicing trust in God was the socially appropriate response to give as opposed to questioning the reason for their disability. Expressed religious beliefs as reported above were distinctive to the Kuwaiti participants. The Indian participants did not mention faith issues to the same extent, judged by the amount of reference and emotional emphasis on religious issues as did the Kuwaiti participants.

5.6: Male/ Female Differences

Comparisons were made between male and female participants to identify experiences unique to each gender. Transcripts of female interviews were more in-depth than those of male interviews amongst the translated Kuwaiti interviews. Male participants were evidently less willing to express their difficulties. This could either be because the researcher was female or of a different culture. It is possible that male participants would have disclosed more to a male Arabic speaking researcher, and this is an issue that will be discussed in the Limitations section of the Discussion chapter. Expressing the impact of change in role, as highlighted previously in this chapter, was mainly from female participants. Male participants did not voice the change of their expected role or the impact it had on their lives.

While female participants voiced mood changes such as depression, anger and anxiety, male participants did not express such concerns. It is uncertain whether or not the men experienced emotional change. Non-disclosure could possibly due to not wanting to be perceived as weak. It is also possible that they didn't want to disclose these challenges to a female interviewer. Female participants also mentioned speech difficulties, however this was not mentioned by male participants. The research method cannot reveal whether there were objective changes

in speech and whether the males were less affected. But non-disclosure of speech problems may indicate that challenges regarding speech were more important to females than men.

Regarding relationships within the family, female participants mentioned increased support from family members, however some felt (and regretted) that they were dependent on their husbands and others for social outings. Such dependency (for social outings) on spouses and relatives were not voiced by male participants. Two male participants mentioned reduced care (personal care) being provided by their wives (instead being provided by servants). This may have indicated that they expected their wives to provide care post-stroke, however females did not have such expectations of their husbands.

5.7: Self-Efficacy and Control Issues

The main aim of this phase was to obtain the most salient themes in order to adapt a self-efficacy scale for the specific use with stroke survivors living in Kuwait. Through exploring the impact of stroke on their lives and their experience of rehabilitation, a number of issues important to stroke patients in Kuwait were identified. Self-efficacy issues were mainly expressed when discussing religious beliefs and perceptions of physical therapy as reported above. Expressed religious belief gave the impression that control for most participants was external i.e. in God's hands, however this was mainly with the Kuwaiti participants and not the two Indian participants interviewed. Kuwaiti participants also expressed the view that the role of the therapists was to "get them back to normal". There was confidence in the therapists to achieve this goal, which perhaps reflects another form of belief in external control i.e. in the health professional.

5.8: Results of Phase 2

Adaptation of the Chronic Disease Self-efficacy Scales

From the results of the semi-structured interviews in phase 1 of this project as described above, the following 5 psychosocial issues were highlighted as needing to be addressed by the self-efficacy scale to be adapted:

a) Concerns about the future

b) Mood changes

c) Relationships with family and friends

d) Changes in social outings and recreational activities

e) Self confidence related to issues mention above

Items relating to psychosocial adaptation were chosen from the 3 main scales making up the Chronic Disease Self-efficacy scales (Lorig et al, 1996): Self-Efficacy to Perform Self-Management Behaviours, General Self-Efficacy and Self-Efficacy to Achieve Outcomes Scales (see appendix 7 for copy of full scales), and the MS Self-efficacy Scale (Rigby et al, 2003). Items chosen were able to address all the issues listed above, this indicated that they were applicable to Kuwaiti stroke patients. The initial adapted scale contained the following items and was named the Psychosocial Adaptation Self-efficacy scale (PSE) (see Figure 5.8 below):

Figure 5.1: Initial PSE Scale

A) General Issues

1. How confident are you that you can deal with the frustration of your disability/disease?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can manage your symptoms so that you can do the things you enjoy doing?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

3. How confident are you that you can keep symptoms from interfering with your sleep

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

4. How confident are you that you can cope in the future?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

5. How confident are you that you can overcome your difficulties ?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

B) Obtain Help from Family, Friends Scale

1. How confident are you that you can get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

c) Social/Recreational Activities Scale

1. How confident are you that you can continue to do your hobbies and recreation?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

D) Control/Manage Depression Scale

1. How confident are you that you can keep from feeling sad?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can keep yourself from feeling lonely?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

E) Thought Frequency Scale

Please rate how often you have the following thoughts:

1) I often feel a failure in the things that I try to do

   Never 1 2 3 4 5 6 7 8 9 10 Always

2) I feel embarrassed in public places

   Never 1 2 3 4 5 6 7 8 9 10 Always

3) I am a burden to my family and friends

   Never 1 2 3 4 5 6 7 8 9 10 Always

4) There is really no way I can solve some of the problems I have with my disability / disease

   Never 1 2 3 4 5 6 7 8 9 10 Always

5.7.2 Assessing the Relevance of Items in the Adapted Self-Efficacy Scale

A small study on health professionals was carried out to assess the relevance (face validity) of the adapted questionnaire items. Participants were 11 physiotherapists working at the rehabilitation facility in Kuwait. Approval to hand out these questionnaires was given by the head of the facility. All participants were volunteers and had the right to decline participation.

The adapted questionnaire was presented with tick boxes under each item for therapists to indicate whether or not they thought the items were relevant to Kuwaiti stroke patients. Completed questionnaires were returned within 3 hours and brief discussions held with therapists regarding their comments about the relevance of the items.

Results:

13 questionnaires were handed out and 11 returned filled. Table 5.3 shows the results per item.

Item A3 received the highest number of "not relevant" ticks. On further discussion with the physiotherapists, they felt that this item suggested that patients could somehow alter their symptoms in their sleep. The item was further explained to them but many thought that the phrasing was unable to bring out the intended meaning.

Item C1 was rated by 4 therapists as being "not relevant". On further discussion with them they felt that C1 was a repetition of C2 and they made the suggestion having only one, either C1 or C2, with the preference being C2.

Table 5.3: Relevance of Questionnaire Items to stroke patients in Kuwait as Rated by Therapists

Item No.	Item relevant	Item not relevant	Comments
A1	10	1	
A2	8	3	
A3	6	5	item unclear, rephrasing required
A4	10	1	
A5	10	1	
B1	10	1	
B2	10	1	
C1	7	4	Same as C2
C2	8	3	
D1	9	2	
D2	9	2	
E1	11	0	
E2	9	2	
E3	10	1	
E4	10	1	Too strong a statement
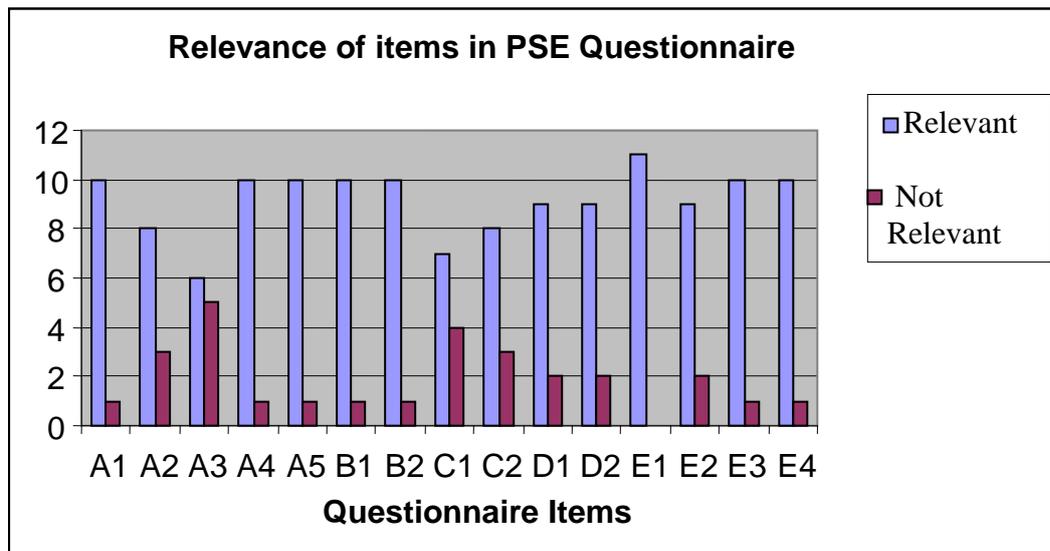
Figure 5.2: Bar Graph Showing Relevance of Questionnaire Items to stroke patients in Kuwait as Rated by Therapists

A group of 4 therapists felt that item E4: "There is really no way I can solve some of the problems I have with my disability / disease" was too strong a statement and would give a patient prone to depression further negative statements to ponder on.

For the second version of the questionnaire the following 3 items were therefore removed.

A3: How confident are you that you can keep symptoms from interfering with your sleep?

C1: How confident are you that you can continue to do your hobbies and recreation?

E4: There is really no way I can solve some of the problems I have with my disability and disease

The depressive thought frequency subscale was later removed from the final questionnaire due to time limitations to validate it and because it had a different response format to the rest of the questionnaire which was potentially confusing.

Summarising, the final version of the Psychosocial Adaptation Self-efficacy (PSE) Scale was therefore an adaptation of the Chronic Disease Scales. Results from semi –structured interviews identified 5 main psychosocial issues relating to self-efficacy which needed to be addressed during stroke rehabilitation: concerns about the future, mood changes, relationships with family and friends, changes in social outings and recreational activities, and self confidence.

Assessing the relevance of chosen items in the questionnaire by stroke therapists was an important aspect of the study and it helped to reduce repetition of ideas. It was also able to provide the scale with some face validity. All the items chosen to be included in the final

questionnaire were considered to be relevant by all participating therapists who returned their questionnaire.

Below is the final version of the PSE used in this project:

Psychosocial Adaptation Self-efficacy Scale

Please rate your confidence to carry out the tasks mentioned in each statement on the scale provided.

Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

1. How confident are you that you can deal with the frustration of your disability/disease?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can manage your symptoms so that you can do the things you enjoy doing?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

3. How confident are you that you can cope in the future?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

4. How confident are you that you can overcome your difficulties?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

5. How confident are you that you can get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

6. How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?

    Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

7. How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?

      Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

8. How confident are you that you can keep from feeling sad and lonely?

      Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

5.7.3 Testing the Psychosocial Adaptation Self-efficacy Scale using the Generalized Self-efficacy Questionnaire

Standardisation is defined as: a process of taking an assessment and developing a fixed protocol for its administration and scoring, then conducting psychometric studies to evaluate whether the resultant assessment has acceptable levels of validity and reliability (Laver-Fawcett, 2007). In order for results from an adapted scale to be accepted, a process of standardisation also known as validation is required. Whilst it is recognised that larger samples are required, practical limitations on sample recruitment meant that it was only possible to conduct preliminary checks, before the main study took place. In an exploratory validation study, the PSE scale was administered on 10 patients via interview to compare its results with the generalized self-efficacy scale (GSE) which is a validated, reliable measure of self-efficacy, as described in the Method chapter. The same information sheet, and consent form and procedures were the same as used for the wider study as explained in chapter 4. Some of the participants (female only) from this validation study were subsequently included in the larger study sample (findings of which are reported in the next chapter).

Data were collected from 10 stroke survivors receiving out-patient physiotherapy (6 female and 4 male). Age of patients ranged from 50-83 with an average of 64.6 years. Time from

stroke ranged from 1 month to 7 years. Table 5.4 shows the descriptive statistics of GSE and PSE scores of the 10 subjects.

Table 5.4: Descriptive Statistics for Validation Study

Descriptive Statistics

	N	Range	Minimum	Maximum	Mean	Std. Deviation
PSE	10	22.00	18.00	40.00	33.1000	7.26407
GSE	10	46.00	29.00	75.00	59.2000	15.89235
Valid N (listwise)	10					

Analysis of the correlation between the total GSE and PSE Scores of all 10 subjects with the use of Pearson's Correlation showed that these two scores were positively correlated ($r= 0.68$; $p<0.05$), thus offering some criterion validity to the adapted PSE Scale.

Reliability Study

Test-retest reliability was assessed by presenting the adapted PSE scale to a group of eight participants on two occasions (Two of the original 10 participants did not return questionnaires at Time 2, thereby leaving a sample size of 8). The time between test and retest varied from one participant to the other (between 1 and 7 days). Spearman's rho $=0.84$ ($p=0.009$). Due to the small sample size of eight participants (less than 10) Spearman's correlations were carried out.

Summary of Preliminary Validation of the Psychosocial Adaptation Self-efficacy Scale (PSE)

Criterion validity was established by assessing the scale (PSE) alongside the validated General Self- efficacy Scale, and finding a significant correlation in the two sets of scores. Face validity was strengthened because items were chosen based on themes raised by stroke patients themselves living in Kuwait. This was further confirmed by physiotherapists working in this country in stroke rehabilitation, rating the relevance of each of the items to stroke patients, as described above

The reliability of the Psychosocial Adaptation Self-Efficacy Questionnaire (PSE) was established via test retest reliability. This was shown to be very high by presenting the scale to a group of participants on two occasions, a few days apart. The PSE scale was identified as a relatively brief, easy to use measure of self-efficacy. The next chapter presents results investigating the relationship between self-efficacy (measured with both the Generalised Self-efficacy Scale and the Psychosocial Adaptation Self-efficacy Scale), life satisfaction and religious faith in stroke patients living in Kuwait.

Chapter Summary

This chapter reported the results from phase 1 and 2 of this project involving qualitative interviews for the adaptation of a self-efficacy questionnaire for stroke patients living in Kuwait. Four major themes were identified in the semi-structured interviews of 15 stroke survivors living in Kuwait. Thirteen of these were Kuwaiti (6 female and 7 male) and the interviews were carried out with the use of an interpreter. Two of the participants were of Indian origin (both female) and the interviews were carried out in English. The four themes

identified were: Concerns with physical and speech difficulties, social changes, psychological changes and perceptions of rehabilitation. All participants reported concerns with a variety of physical difficulties and speech changes post-stroke. Physical changes included difficulty with walking, balance changes and difficulty with upper limb use. "Heaviness of the tongue" was reported as a speech difficulty and this was experienced as having some impact on social outings. Participants reported social changes such as withdrawal, change in their role in the family and changes in family support as occurring since the stroke. Social withdrawal was expressed as due to being dependent on others and lack of facilities such as ramps for wheelchair use and appropriate door width. Social stigma and shame was also expressed as a reason for social withdrawal and isolation. Psychological changes mentioned included negative mood changes and feelings of nostalgia for a 'normal' life or self. Stroke survivors wanted desperately to return to "normal" and some reported being depressed due to their feelings of loss of dependency and other changes post-stroke. Perceptions of rehabilitation were mostly positive as participants believed in the necessity of physical therapy for recovery. However some expressed that the main responsibility for recovery was on the therapist, without active participation on their part. There was also the expressed belief that the therapist was provided by God to aid in recovery.

Gender differences were apparent, mostly regarding change in role in family, with females expressing regrets about this change much more than men. Other gender differences included expressing psychological challenges and communication problems. These were mostly or entirely expressed by female participants. Differences were also noted between the Kuwait participants and Indian participants, although the latter were few in number, so interpretation is necessarily cautious. These differences included expressed religious beliefs and financial/return to work worries. Kuwaiti participants did not voice concerns regarding

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finances and finding alternative employment, perhaps linked to available government support for stroke survivors. Religious beliefs expressed by the Kuwaiti participants appeared to have a role in their self-efficacy. Commonly expressed responses were to trust in God, acceptance and hope for the better in the future, all of which might limit their self-efficacy for achieving specific task goals. Findings in this chapter will be compared to existing literature in the discussion chapter (chapter 9).

The main issues raise in this qualitative phase of the research were used to adapt the Chronic Disease Self-efficacy Scales for use with stroke patients in Kuwait. This ensured that items were relevant to the experience of stroke in Kuwait. The adapted scale was named the Psychosocial Adaptation Self-efficacy scale (PSE). The next chapter will present results on the relationship between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait.

Chapter 6

Chapter 6

Results of Phase Three

The aim of phase three was to investigate the relationship between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait. Forty questionnaire packs were completed in full and therefore included in the data analysis. Four questionnaire packs were not completed in full, this was due to time constraints as participants had to leave the department straight after their physiotherapy sessions and were unable to complete the whole pack. Uncompleted questionnaire packs were not analysed. All participants were recruited from both the in-patient and out-patient physiotherapy departments. Details of the recruitment procedure can be found in chapter 4. This chapter reports the results of the analysis done during phase 3 on the 40 completed questionnaire packs.

6.1: Profile of the Phase 3 Study Sample

Only female stroke survivors were used in this phase of the study. This also helped to ensure homogeneity and to reduce variation in the sample.

6.1.1 Age

There was a wide variation in age in the main study sample ranging from 30-73 with a mean of 55.3 years and a standard deviation of 10.28.

6.1.2 Time since stroke

Time since stroke in months was between one month and 131 months. The mean time was

27.2 months with a standard deviation of 37.3.

Table 6:1 shows the descriptive statistics related to age and time since stroke for the study

sample.

Table 6.1:

Descriptive Statistics of Age and Time since Stroke

	N	Mean	SD	Range	Min	Max
Age	40	55.30	10.28	40	33	73
Time Since Stroke (Months)	40	27.22	37.31	131	1	132

6.1.3 Type of stoke

Of the 40 participants, 33 (82.5%) had a stroke due to an infarct while the other 7 (17.5%)

had a hemorrhagic stroke.

6.1.4 Side of weakness

Twenty three (57.5%) of the 40 participants had a left sided weakness and 17 (42.5%) had a

right sided weakness.

6.1.5 Religion

Thirty six (90%) of the study sample were of the Muslim faith and 4 (10%) were Christians.

6.1.6 Nationality

Kuwaitis made up 55 % of the study sample (22 participants) and Non Kuwaitis made up the remaining 45% (18 participants). The Non-Kuwaitis were of the following nationalities: Indian, Lebanese, Philipino, Iraqi, Egyptian, Bangladeshi, Bedouin, Ethiopian, Sudanese, Iranian, and Saudi Arabian.

6.2: Descriptive Statistics of Phase 3 Study Variables

6.2.2 Total General Self-Efficacy Score

The Total General Self-Efficacy score (GSE) ranged between 12 and 40 with a mean of 31.65 and a standard deviation of 7.49. Table 6:2 shows the descriptive statistics of all the main study variables including the GSE. The lowest score possible on this scale is 10 and 40 is the maximum score possible. A higher score denoted a higher general self-efficacy. Figure 6:1 shows the frequencies of the GSE score. The distribution shows a positive skew indicating more participants rated their self-efficacy as being above average.

Histogram

Mean =31.65
Std. Dev. =7.489
N =40
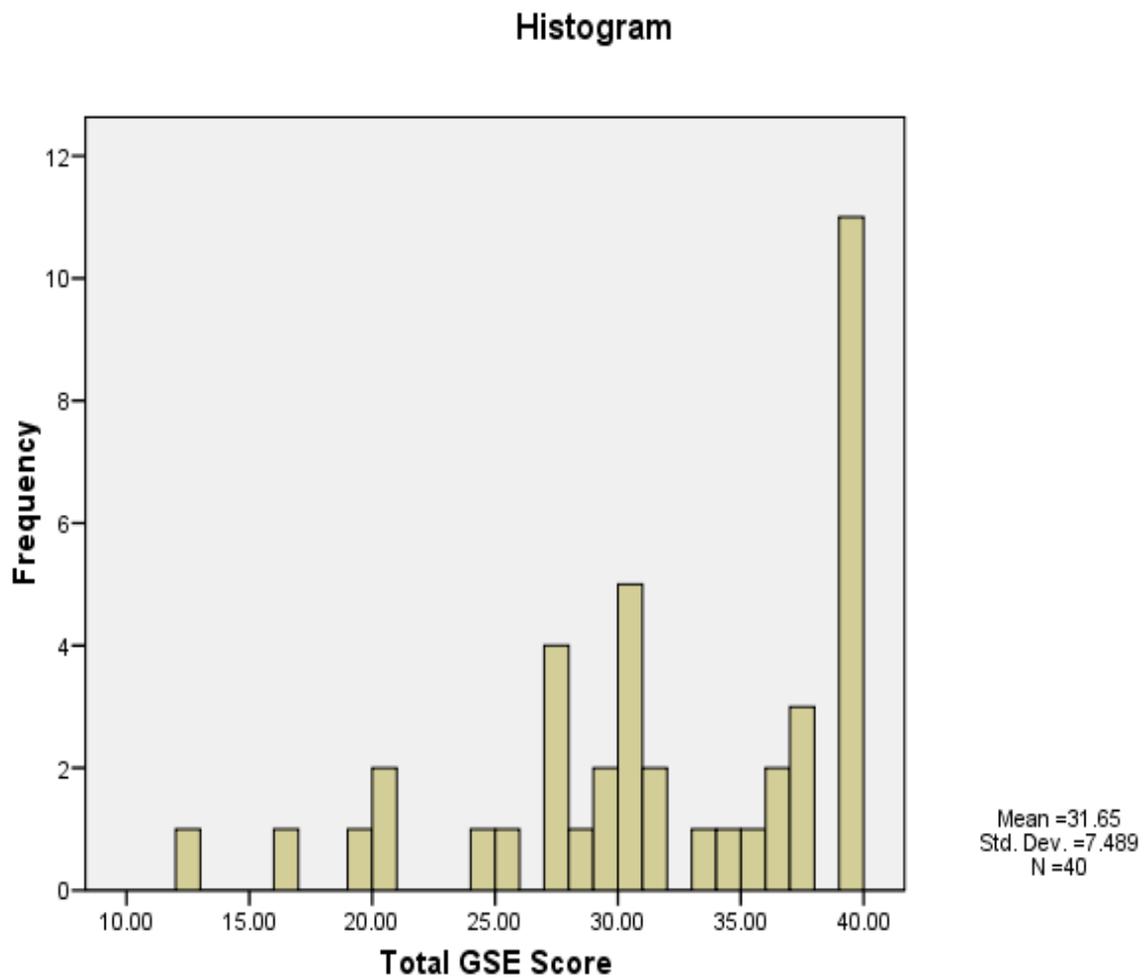
Figure 6.1: Histogram of the distribution of the GSE Score for 40 Female Stroke Patients

Table 6.2:
Descriptive Statistics of Main Study Variables

	N	Min	Max	Mean	Std. Deviation
Total GSE Score	40	12.00	40.00	31.65	7.489
Total PSE Score	40	27.00	80.00	64.08	15.75
Life satisfaction Main measure	40	1.00	10.00	6.73	2.80
Total Religious faith Score	40	25.00	40.00	36.72	3.81
Valid N (listwise)	40				

Key of abbreviations
GSE:- General self-efficacy (possible scores 10-40)
PSE:- Psychosocial self-efficacy (possible scores 8-80)
Life satisfaction (possible scores 1-10)
Total Religious faith score (possible scores 10-40)

6.2.3 Total Psychosocial Adaptation Self-efficacy Score (PSE)

The PSE score ranged from 27 to 80 with a mean of 64.08 and standard deviation of 15.75.

The minimum score possible on this scale is 8 and 80 is the highest possible. Higher scores

indicated higher self-efficacy. A mean of 64 indicates that self-efficacy scores of this study

sample were high, relative to the scale range. This was also demonstrated with the

distribution of the PSE score, which is positively skewed as can be seen in figure 6:2.

Histogram

Mean =64.08
Std. Dev. =15.75
N =40

___
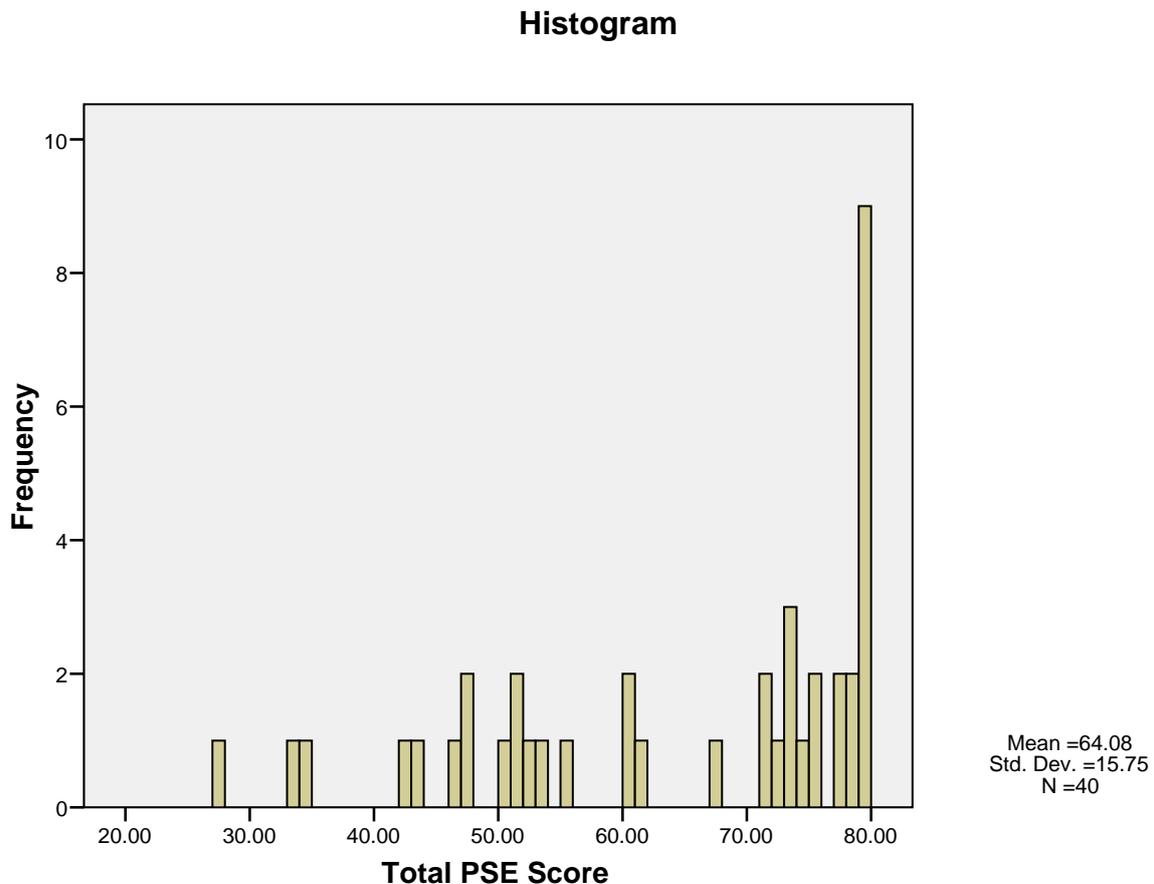
Figure 6.2: Distribution of the Total Psychosocial Adaptation Self-efficacy Score (PSE) for 40 Female Stroke Patients

6.2.4 Life Satisfaction Measure

Life satisfaction was assessed by a single item in which participants had to rate how satisfied they were with their life at the moment on a rating scale of 1 to 10 with 1 denoting "not at all satisfied" and 10 denoting "Very satisfied". Scores from the sample of 40 ranged from 1 to 10 with a mean of 6.73 and a standard deviation of 2.80. From Figure 6.3, a bimodal distribution is seen with high frequencies at score 5 and 10, thus suggesting that the single mean is not an appropriate summarising measure for this sample.

Histogram
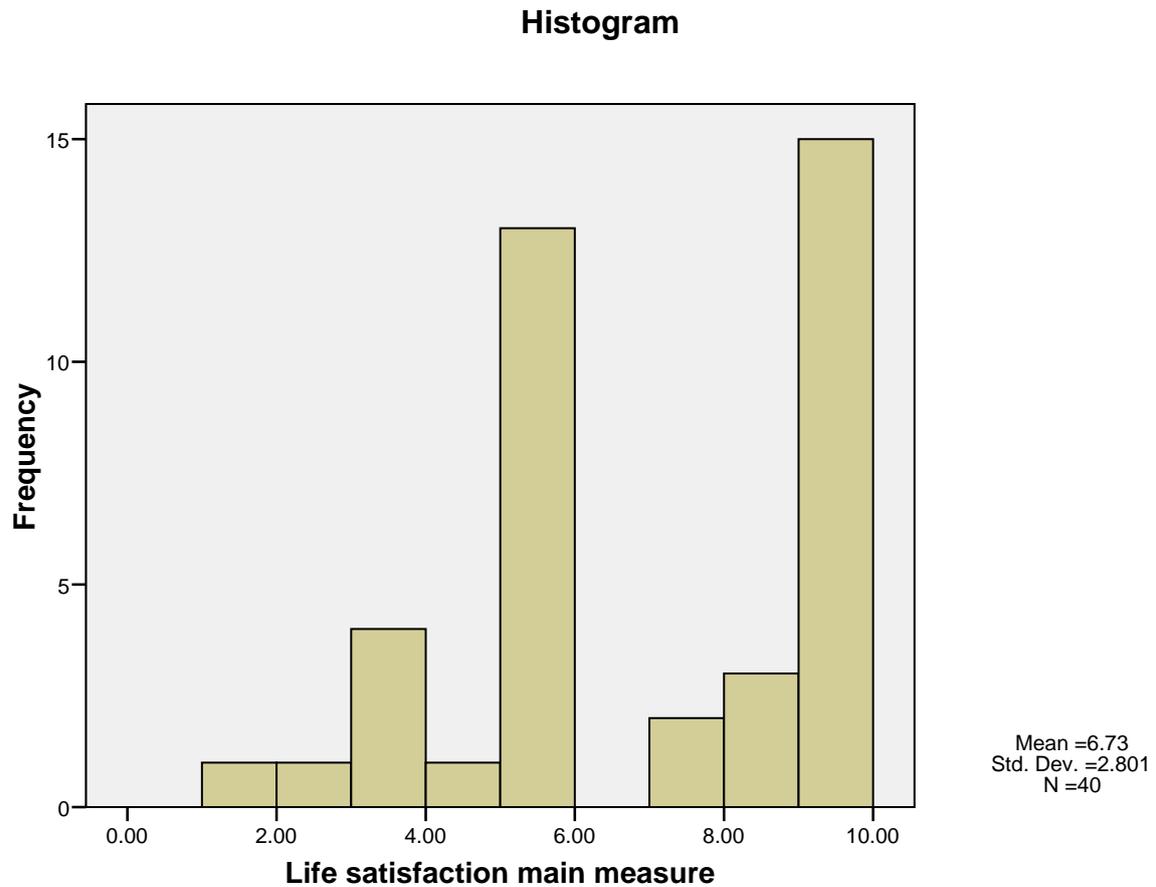
Figure 6.3: Distribution of scores of Life satisfaction Measure for 40 Female Stroke Patients

6.2.5 Religious Faith Scores (Santa Clara Strength of Religious Faith Questionnaire: Plante and Boccaccini 1997).

Religious faith (SCSROF) scores ranged from 25 to 40 with a mean of 36.72 and a standard deviation of 3.81. Figure 4:4 below shows the distribution of the religious faith scores. The lowest score possible on this 10 and highest possible is 40. A higher score indicated higher

religious faith. In the study sample there was a low standard deviation (3.81) indicating clusters of scores with minimal variability. This is also evident in the figure below (fig6:4).

Histogram

Mean =36.72
Std. Dev. =3.809
N =40
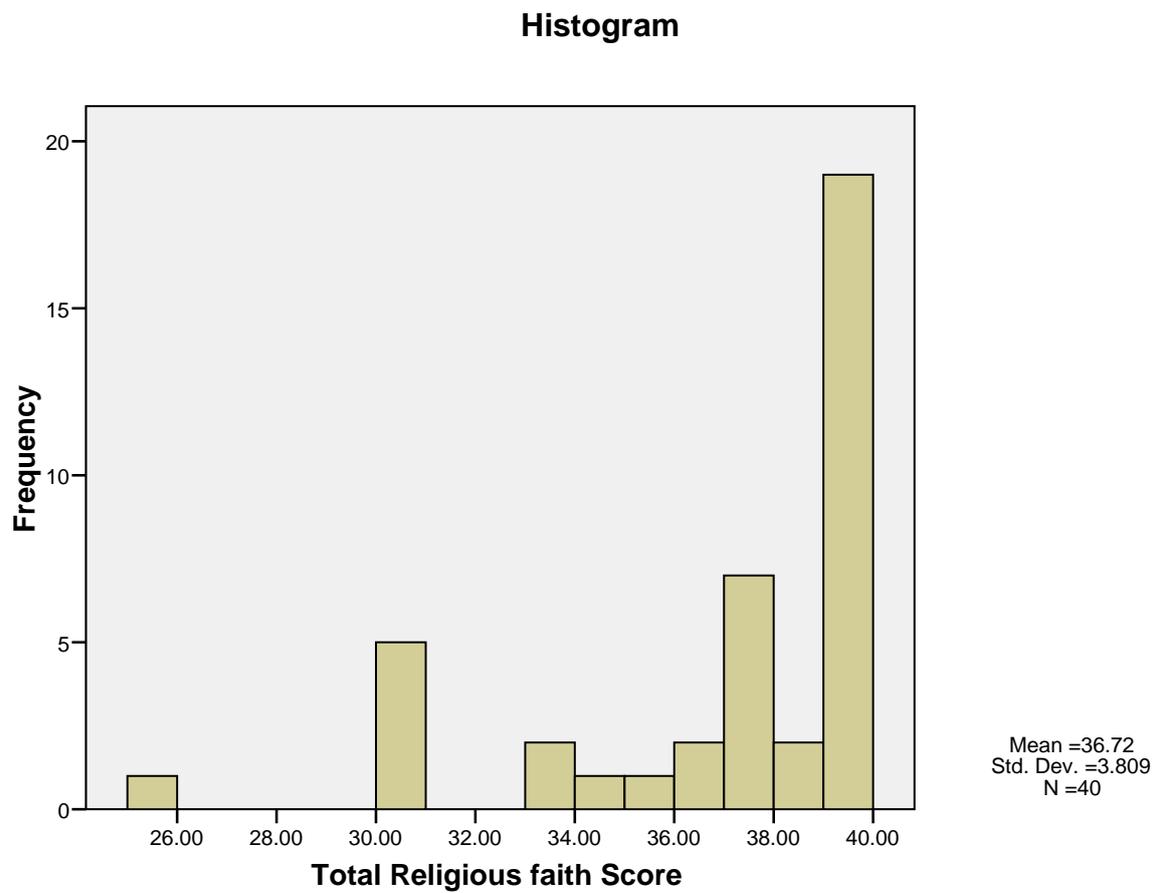
Figure 6.4: Distribution of Religious Faith Score for 40 Female Stroke Patients

6.3: Descriptive Statistics of Kuwait and Non Kuwaiti Sub Samples

Comparative analysis was carried out to identify any differences specific to Kuwaiti participants as this provided an insight into a culture not previously investigated in the past. As approximately half of the sample originated elsewhere, although they lived in Kuwait at the time of the study, checks were made regarding whether their scores on the various questionnaires differed or not. The group was split according to their nationality: Kuwaiti nationals and all other nationals (called the Non-Kuwaiti subgroup). There were 22 participants in the Kuwaiti subgroup and 18 participants in the Non-Kuwaiti subgroup Table 6.3 shows the descriptive statistics of the two subgroups (Kuwaiti and Non Kuwaiti). Mean age in the Kuwaiti sub group was 58.7 while the mean age in the non-Kuwaiti subgroup was 51.1, indicating a difference in age between groups. Independent T Test carried out identified a significant difference in age between both groups (t = 2.48; p=0.018). No significant differences were identified between time since stroke in the Kuwait and non Kuwaiti subgroups, using an independent t test. Independent T-test (a parametric test) was carried out despite the skewed distribution of the variables and the use of ordinal data for consistency with the rest of the results presented in this chapter. In addition to this some researchers claim that parametric tests are robust and can withstand some deviation from expected parameters and that they are more powerful (Portney and Watkins, 2000). The use of parametric tests for ordinal data was discussed earlier in the methods chapter. Non parametric test- Mann-Whitney was also carried out for comparison and thoroughness. Results confirmed a significant different in age between the two subgroups (p= 0.015).

To reduce the chance of type I statistical error which is common in multiple tests of significance, p value was reduced to 0.01 (Coolican, 2009). Results of the other comparisons at this level of significance can be seen below.

Table 6.3 Descriptive Statistics of Subgroups based on Nationality

Nationality		N	Min	Max	Mean	Std. Deviation
Kuwaiti	Age	22	33.00	73.00	58.73	10.10
	Time since Stroke (Months)	22	1.00	132.00	32.61	45.46
	Total GSE Score	22	12.00	40.00	31.95	7.83
	Total PSE Score	22	33.00	80.00	68.32	13.70
	Life satisfaction Main measure	22	3.00	10.00	7.23	2.86
	Total Religious Faith Score	22	36.00	40.00	38.41	1.44
	Valid N (listwise)	22				
Non Kuwaiti	Age	18	34.00	68.00	51.11	9.10
	Time since stroke (Months)	18	1.00	72.00	20.64	23.62
	Total GSE Score	18	16.00	40.00	31.28	7.26
	Total PSE Score	18	27.00	80.00	58.89	16.90
	Life satisfaction main measure	18	1.00	10.00	6.11	2.68
	Total Religious faith Score	18	25.00	40.00	34.67	4.75
	Valid N (listwise)	18				

Key:
GSE- Generalised self-efficacy   PSE-Psychosocial adaptation self-efficacy

6.3.1 General Self-Efficacy Scores between Groups

Mean total GSE in the Kuwaiti group was 31.95 and in the non-Kuwaiti group 31.27. Fig 6.5 gives a visual representation of total GSE scores between both groups. Mean total GSE scores are similar in both groups. A T test carried out did not identify a significant difference between both groups (t = 0.28; p= 0.78, 2-tailed). Mann-Whitney test showed similar results (p=0.60).

Total GSE Score
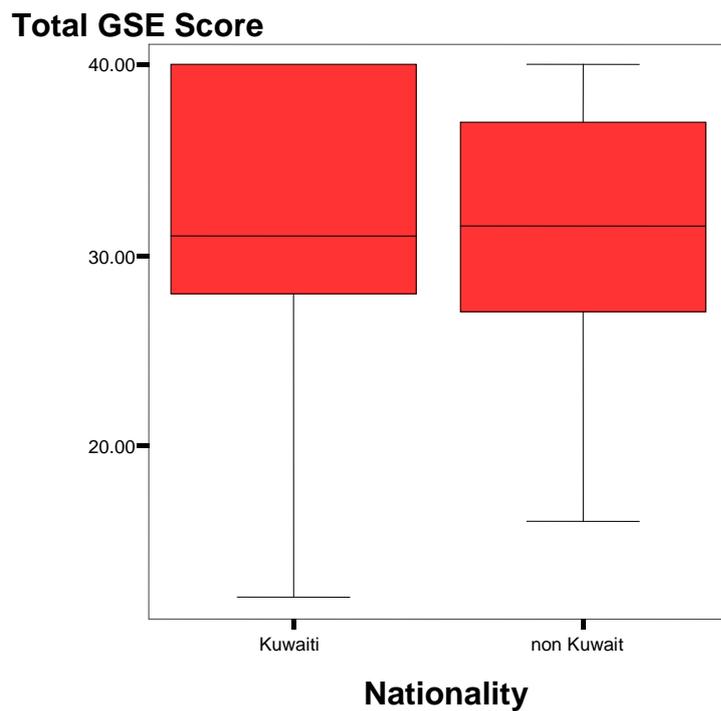
Figure 6.5: Box plot showing GSE of Kuwaiti and Non Kuwaiti subgroups

6.3.2 Psychosocial Adaptation Self-Efficacy Score between both Subgroups

Mean total PSE in the Kuwaiti group was 68.31 and in the non-Kuwaiti group 58.88. Fig 6.6
gives a visual representation of total PSE scores between both groups. Mean PSE was higher
in the Kuwaiti subgroup and showed less variability than among the non Kuwaiti group.
However, an independent groups T test carried out did not identify a significant difference
between the groups (t= 1.95, p =0.059). Mann-Whitney test showed similar results (
p=0.070).
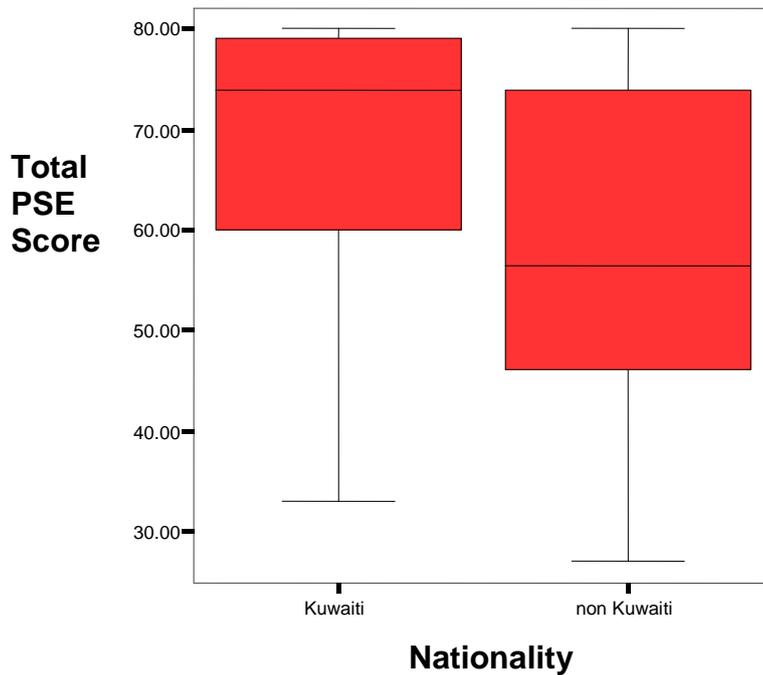
Figure 6.6: Box plot showing Total PSE of Kuwaiti and Non Kuwaiti subgroups

6.3.3 Total Life Satisfaction between Kuwaiti and Non-Kuwaiti Subgroups

Mean total life satisfaction in the Kuwaiti group was 7.2 and in the non-Kuwaiti group 6.1.

Fig 6.7 gives a visual representation of total life satisfaction scores between both groups. Life

satisfaction was somewhat higher in the Kuwaiti subgroup than in the non Kuwaiti group.

However, the difference observed was not statistically different (t= 1.26, p= 0.21). Mann-

Whitney test showed similar results (p=0.20).

Total life satisfaction Score

Nationality
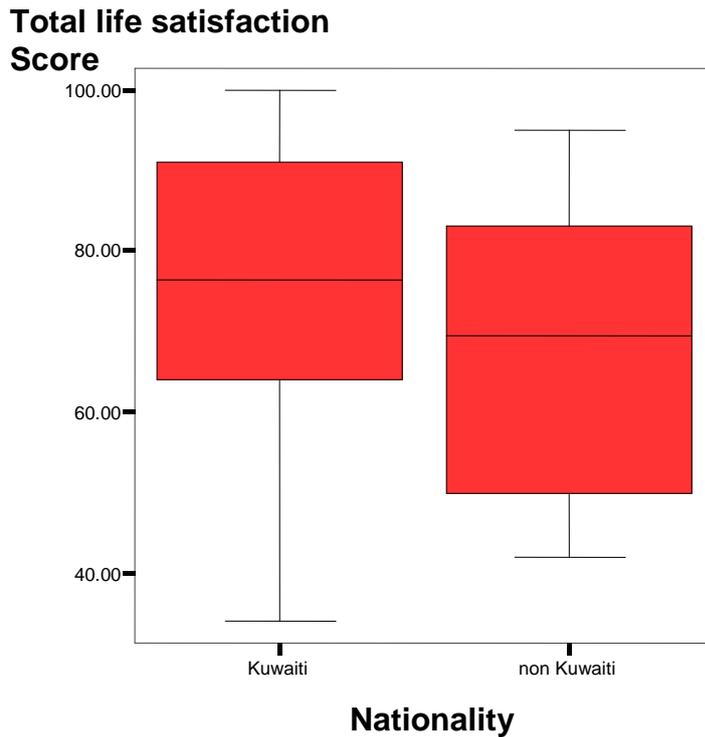
Figure 6.7: Box plot showing Life Satisfaction of Kuwaiti and Non Kuwaiti subgroups

6.3.4 Total Religious Faith Scores Amongst Kuwaiti and Non Kuwaiti subgroups

Mean total religious faith score in the Kuwaiti group was 38.4 and in the non-Kuwaiti group 34.66. Fig 6.8 gives a visual representation of total religious faith scores between both groups. Religious faith scores were higher in the Kuwaiti subgroup than in the Non Kuwaiti group. The Non –Kuwaiti group showed more of a variability in scores while in the Kuwaiti group scores appeared clustered towards the highest score. This suggest a higher and more universal commitment to their religion (Muslim faith) among Kuwaitis. T test identified that the difference in the measure of religious faith between the Kuwaiti and non Kuwaiti group was statistically significant (t = 3.5; p = 0.001). This indicated an increased "strength of religious faith" amongst the Kuwaiti group. Mann-Whitney test showed a significant difference at (p< 0.05) but not at p.<0.01(p=0.026)

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Total Religious faith Score
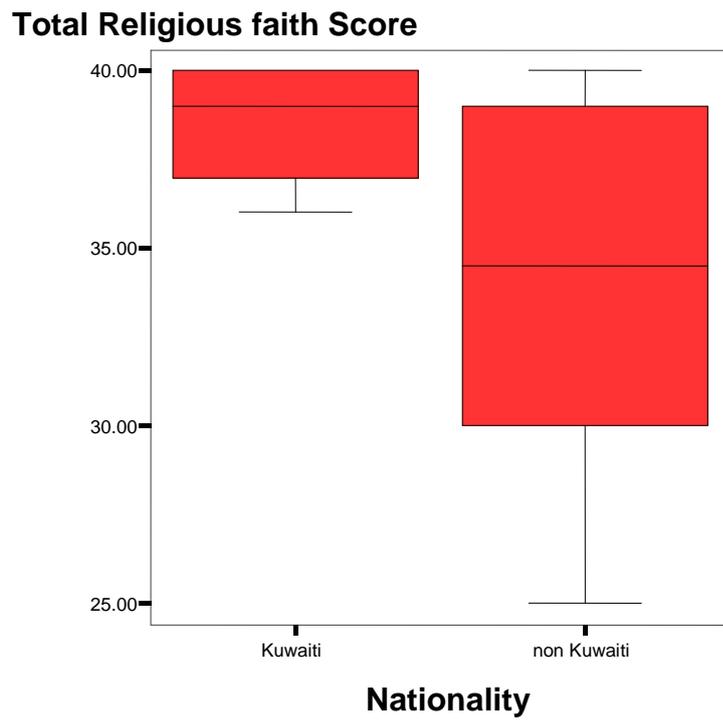
Figure 6.8: Box plot showing Total Religious faith Scores of Kuwaiti and Non Kuwaiti subgroups

6.4: Correlational Analysis of the Phase 3 Study Variables

6.4.1 Choice of Parametric Statistics

Pearson's correlation which is a parametric test was chosen instead of Spearman's correlation (non parametric test) despite the use of ordinal data in measuring self-efficacy, religious faith and life satisfaction. The argument regarding use of parametric tests for ordinal data has been discussed in chapter 4. Nonparametric Spearman's correlations were also carried out and are reported in appendix 8.

6.4.2 Results of Correlational Analysis

One of the aims of the current project was investigate the correlations between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait.

Although not an aim of the study, scrutiny of the data revealed that there were age differences in the Kuwaiti and Non Kuwaiti samples. Analysis was conducted to identify if age was associated with any of the variables as age differences might confuse the patterns among the variables of interest. Results of correlational analysis using the Pearson correlation coefficient showed that age of the participant was only correlated with total Religious Faith Score (older participants reported higher religious faith scores ($r=0.36$, $p= 0.021$). Time since stroke was not correlated with Self-efficacy scores (GSE and PSE) or with life satisfaction scores. Generalised Self-efficacy scores (GSE) were significantly positively correlated with Psychosocial Self-efficacy scores (PSE) and life satisfaction. Religious faith was not correlated with any of the main study variables: GSE, PSS and life satisfaction. Table 4:4 shows the various correlation coefficients amongst the variables. Below is a more detailed description of the relationships between the variables. To reduce the chance of type I errors

with multiple testing, p value was reduced to 0.01 (Coolican, 2009). Spearman's correlations were also carried out for comparison and thoroughness, and with awareness of the debate about the appropriate choice of tests for nonparametric data, as discussed in the methods chapter (chapter 4). Results of the Spearman's test can be seen in appendix 8, where similar results were obtained with the exception of the relationship between age and religious faith.

Table 6.4: **Correlations** between the Phase 3 Study Variables

Key of abbreviations
GSE:- General self-efficacy
PSE:- Psychosocial self-efficacy

Correlations

		Age	Time since stroke (Months)	Total GSE Score	Total PSE Score	Life satisfaction main measure	Total Religious faith Score
Age	Pearson Correlation	1					
	Sig. (2-tailed)	.					
	N	40					
Time since stroke (Months)	Pearson Correlation	.035	1				
	Sig. (2-tailed)	.831	.				
	N	40	40				
Total GSE Score	Pearson Correlation	-.163	-.047	1			
	Sig. (2-tailed)	.315	.774	.			
	N	40	40	40			
Total PSE Score	Pearson Correlation	.164	.096	.657 **	1		
	Sig. (2-tailed)	.313	.556	.000	.		
	N	40	40	40	40		
Life satisfaction main measure	Pearson Correlation	.071	.249	.452 **	.658 **	1	
	Sig. (2-tailed)	.665	.121	.003	.000	.	
	N	40	40	40	40	40	
Total Religious faith Score	Pearson Correlation	.364 *	.158	.089	.114	.187	1
	Sig. (2-tailed)	.021	.330	.584	.484	.247	.
	N	40	40	40	40	40	40

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

Age of the participant was significantly positively correlated with religious faith, albeit at the 0.05 level (r=0.364) (p=0.021). Age did not correlate positively or negatively with any of the other variables analysed. This was an important issue to identify, in order to control for age in other analysis.

The GSE Score and PSE Score

The Generalised Self-efficacy score (GSE) was significantly positively correlated with the Psychosocial Adaptation Self-efficacy score (PSE) r=0.657 (p=0.0). This indicates a high correlation and offers some validation of the PSE Score developed specifically for the stroke patients living in Kuwait.

The GSE Score and Life satisfaction Measure

The Generalised Self-efficacy score (GSE) was significantly positively correlated with the life satisfaction single measure r= 0.452 (p=0.0).

The GSE Score and Religious Faith

Correlational analysis did not identify any significant relationship between Generalised Self-efficacy score (GSE) and religious faith score.

The PSE Score and Life Satisfaction Measure

The Psychosocial Adaptation Self-efficacy score (PSE) correlated significantly with the life satisfaction measure r= 0.658 (p=0.0), and indeed showed a greater relationship than the Generalised Self-Efficacy scores.

The PSE Score and Religious faith Score

No significant relationship was identified between Psychosocial Adaptation Self-efficacy score and religious faith r=0.114 (p=0.48)

Correlations between Variables with Age Controlled

Correlational analysis reported above showed that age was associated with religious faith.. With age controlled for, similar results were still obtained regarding the relationship between PSE and life satisfaction. However, the relationship between GSE and PSE was stronger with age controlled (r= 0.70, p =0.0). Table 6.5 shows the results of correlational analysis with age controlled for.

Table 6.5: Correlations between Variables with Age Controlled

Correlations

Control Variables			Total GSE Score	Total PSE Score	Life satisfaction main measure	Total Religious faith Score
Age	Total GSE Score	Correlation	1.000			
		Significance (2-tailed)	.			
		df	0			
	Total PSE Score	Correlation	**.703**	1.000		
		Significance (2-tailed)	**.000**	.		
		df	37	0		
	Life satisfaction main measure	Correlation	**.471**	**.657**	1.000	
		Significance (2-tailed)	**.002**	**.000**	.	
		df	37	37	0	
	Total Religious faith Score	Correlation	.162	.059	.174	1.000
		Significance (2-tailed)	.326	.720	.289	.
		df	37	37	37	0

Key of abbreviations
GSE:- General self-efficacy
PSE:- Psychosocial self-efficacy

6.5: Comparative Analysis of Kuwaiti and non-Kuwaiti subsamples

Further data analysis was carried out to compare results of the Kuwaiti sub- sample with those of the non Kuwaiti sub- sample. This was carried out to identify any differences or associations specific to participants originating in the Kuwaiti culture and to determine whether immigrants to the culture were responding similarly or differently. Table 6.6 shows the correlations between variables for each subgroup separately.

Table 6.6: Correlations between study Variables amongst Kuwaiti and Non Kuwaiti subgroups

Correlations

Nationality			Age	Time since stroke (Months)	Total GSE Score	Total PSE Score	Life satisfaction main measure	Total Religious faith Score
Kuwaiti	Age	Pearson Correlation	1	-.234	-.061	.148	-.027	-.317
		Sig. (2-tailed)	.	.295	.787	.510	.904	.150
		N	22	22	22	22	22	22
	Time since stroke (Months)	Pearson Correlation	-.234	1	.061	.041	.236	.111
		Sig. (2-tailed)	.295	.	.788	.856	.290	.623
		N	22	22	22	22	22	22
	Total GSE Score	Pearson Correlation	-.061	.061	1	.714**	.290	.281
		Sig. (2-tailed)	.787	.788	.	.000	.191	.205
		N	22	22	22	22	22	22
	Total PSE Score	Pearson Correlation	.148	.041	.714**	1	.495*	-.067
		Sig. (2-tailed)	.510	.856	.000	.	.019	.766
		N	22	22	22	22	22	22
	Life satisfaction main measure	Pearson Correlation	-.027	.236	.290	.495*	1	.034
		Sig. (2-tailed)	.904	.290	.191	.019	.	.880
		N	22	22	22	22	22	22
	Total Religious faith Score	Pearson Correlation	-.317	.111	.281	-.067	.034	1
		Sig. (2-tailed)	.150	.623	.205	.766	.880	.
		N	22	22	22	22	22	22
Non Kuwaiti	Age	Pearson Correlation	1	.513*	-.391	-.042	.028	.504*
		Sig. (2-tailed)	.	.030	.108	.870	.911	.033
		N	18	18	18	18	18	18
	Time since stroke (Months)	Pearson Correlation	.513*	1	-.359	.080	.223	.147
		Sig. (2-tailed)	.030	.	.144	.752	.375	.562
		N	18	18	18	18	18	18
	Total GSE Score	Pearson Correlation	-.391	-.359	1	.649**	.686**	.013
		Sig. (2-tailed)	.108	.144	.	.004	.002	.959
		N	18	18	18	18	18	18
	Total PSE Score	Pearson Correlation	-.042	.080	.649**	1	.807**	-.040
		Sig. (2-tailed)	.870	.752	.004	.	.000	.875
		N	18	18	18	18	18	18
	Life satisfaction main measure	Pearson Correlation	.028	.223	.686**	.807**	1	.156
		Sig. (2-tailed)	.911	.375	.002	.000	.	.537
		N	18	18	18	18	18	18
	Total Religious faith Score	Pearson Correlation	.504*	.147	.013	-.040	.156	1
		Sig. (2-tailed)	.033	.562	.959	.875	.537	.
		N	18	18	18	18	18	18

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

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6.5.1 Correlations within the Kuwait Sample

In the Kuwaiti sub sample, generalised self-efficacy (GSE) correlated significantly only with Psychosocial adaptation self-efficacy (PSE) and not with life satisfaction contrary to the full sample correlations. Pearson relation co-efficient between GSE and PSE was 0.71 (p=0.00). PSE, however, correlated significantly with life satisfaction r= 0.495 (p= 0.019).

6.5.2 Correlations within the Non Kuwaiti Sample

In the Non-Kuwaiti sub sample, Generalised Self-efficacy (GSE) correlated significantly with both life satisfaction and psychosocial self-efficacy. Age correlated significantly with both total religious faith score and time since stroke in months. In both the Kuwaiti and Non Kuwaiti samples, GSE and PSE scores were significantly correlated in a positive manner. PSE scores in both sub groups were also significantly correlated with the life satisfaction measure.

In comparing sub-sample correlations to those of the whole sample the following similarities were found:

-The positive relationship between age and religious faith identified in the whole sample was only identified in the Non Kuwaiti subgroup.

-The positive association between the GSE and PSE scores identified in the whole sample was also identified in both Kuwaiti and Non Kuwaiti subgroups offering some further validation of the adapted measure.

-The positive association between GSE and the life satisfaction measure identified in the whole sample was only identified in the Non Kuwaiti subsample and not in the Kuwaiti sub sample.

-The positive association between the PSE score and life satisfaction measure identified in the whole sample was also identified in both Kuwaiti and Non Kuwait subsamples

-The lack of association between religious faith and the other variables (except age) in the whole sample was also identified in both subsamples.

Table 6.7 shows the correlational analysis for each subsample with age controlled for. This was carried out because previous analysis showed a significant positive relationship between age and religious faith scores. Similar results were obtained and the relationship between GSE and PSE was stronger in the non Kuwaiti sub sample when age was controlled for (r =0.69, p= 0.002).

These correlations identified that although both subgroups were similar in correlations regarding PSE, life satisfaction and religious faith, differences were present regarding relationships between age and the GSE score. In other words, apart from age and GSE score, both subsamples could be put together and analysed as one whole sample reflecting reported life satisfaction, psychosocial adaptation self-efficacy and religious faith in female stroke patients living in Kuwait.

Table 6.7: Correlational Analysis with Age Controlled

Correlations

Nationality	Control Variables			Total GSE Score	Total PSE Score	Life satisfaction main measure	Total Religious faith Score
Kuwaiti	Age	Total GSE Score	Correlation	1.000	.732	.289	.277
			Significance (2-tailed)	.	.000	.204	.225
			df	0	19	19	19
		Total PSE Score	Correlation	.732	1.000	.505	-.022
			Significance (2-tailed)	.000	.	.020	.925
			df	19	0	19	19
		Life satisfaction main measure	Correlation	.289	.505	1.000	.027
			Significance (2-tailed)	.204	.020	.	.908
			df	19	19	0	19
		Total Religious faith Score	Correlation	.277	-.022	.027	1.000
			Significance (2-tailed)	.225	.925	.908	.
			df	19	19	19	0
Non Kuwaiti	Age	Total GSE Score	Correlation	1.000	.688	.758	.265
			Significance (2-tailed)	.	.002	.000	.304
			df	0	15	15	15
		Total PSE Score	Correlation	.688	1.000	.809	-.022
			Significance (2-tailed)	.002	.	.000	.933
			df	15	0	15	15
		Life satisfaction main measure	Correlation	.758	.809	1.000	.164
			Significance (2-tailed)	.000	.000	.	.530
			df	15	15	0	15
		Total Religious faith Score	Correlation	.265	-.022	.164	1.000
			Significance (2-tailed)	.304	.933	.530	.
			df	15	15	15	0

6.6: Multiple Regression Analysis of the Predictors of Life Satisfaction

The second aim of Phase three of this project was to identify the most significant predictor of life satisfaction. Multiple linear regression (MR) was used only as an exploratory means to investigate predictors of life satisfaction. MR is usually used with larger samples to predict a dependent variable using a set of several independent or predictor variables (Portney and Watkins, 2000). Due to the low number of participants in this study i.e. 40 participants, MR was chosen as an explorative tool and findings will be confirmed by further research with larger samples following this doctoral project. Similar studies have used hierarchical multiple regression in analysis of such data with a similar sample size (Robinson- Smith et al: 2000). Hartman-Maeir et al (2007) also used multiple regression with similar data on 56 participants. But it is acknowledged that the recommended number of participants is a minimum of 50 cases plus 8 cases for each independent variable (Tabachnick and Fidell, 1996). Although many authors advise a large sample size for multiple regression, there is some difference in practice. Harris (1995), for example, recommends a sample size of **50 + p** (number of predictive variables) (cited in Coolican, 2009).

Multiple linear regression, in addition to being used to predict a dependent variable as mentioned previously, can be used to better understand clinical phenomena by identifying factors related to it. Step wise multiple regression can be used to identify those variables making the most valuable contribution to a given relationship (Portney and Watkins, 2000). In this study, stepwise multiple regression was carried out after multiple linear regression for

thoroughness to hone in on the variable most important in predicting life satisfaction among stroke patients living in Kuwait.

6.6.1 Multiple Linear Regression

The Multiple linear regression analysis involved entering five variables into the model: age, time since stroke, GSE score, PSE Score and total religious faith score. Table 6.8 and 6.9 show the results of the multiple regression analysis. Adjusted R-square was 0.405 .This indicates that 40.5% of variability in life satisfaction was predicted by the model with all five variables. Further results identified that amongst the five variables entered into the model age, time since stroke, GSE score, PSE Score and total religious faith score, only PSE score predicted life satisfaction. Standardized Beta coefficient for the Total PSE score was 0.619 (p=0.002). The Standardized beta coefficient represented the relative weight of the variables in predicting life satisfaction (the dependent variable). This meant that about 60% of the prediction of life satisfaction could be attributed to psychosocial adaptation self-efficacy.

Table 6.8: Summary of Multiple Regression Analysis

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.694[a]	.482	.405	2.15998

a. Predictors: (Constant), Total Religious faith Score, Total GSE Score, Time since stroke (Months), Age, Total PSS Score

Table 6.9: Results of Multiple Regression Analysis predicting life satisfaction

Model		Unstandardized Coefficients		Standardized Coefficients		
		B	Std. Error	Beta	t	Sig.
1	(Constant)	-3.012	3.682		-.818	.419
	Age	-.020	.040	-.073	-.495	.624
	Time since stroke (Months)	.013	.010	.176	1.382	.176
	Total GSE Score	.012	.068	.032	.176	.861
	Total PSE Score	.110	.032	.619	3.446	.002
	Total Religious faith Score	.083	.101	.113	.821	.417

a. Dependent Variable: Life satisfaction main measure

These results demonstrate that psychosocial adaptation self-efficacy was the only significant predictor of life satisfaction in the sample tested.

6.6.2 Stepwise Multiple Regression

Stepwise multiple regression was carried out with the use of fewer variables to identify which variable made the most valuable contribution and to test the strength of prediction with fewer variables, a number better justified by the limited sample size. This involved adding new variables in each successive step. The criteria for adding a variable was that its partial correlation was the highest of all the other variables and the test of its regression coefficient was significant (Polgar and Thomas 2000). Three models were thus constructed. The table 6.10 shows the summary of all three models, each of which test the predictive power of a selected variable or group of variables.

In the first model, only PSE was entered and R Square was 0.418, indicating that PSE accounted for 41.8% of variability of life satisfaction scores. In the second model, GSE was added (PSE and GSE) and religious faith was added to the third model (PSE, GSE and

religious faith). The results showed that PSE was the most significant predictor of life satisfaction. GSE and religious faith did not make any significant contribution to the prediction of life satisfaction. The table 6.11 show the coefficients of all three models.

Table 6:10 Summary of Stepwise Multiple Regression Models, predicting life satisfaction

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.658[a]	.433	.418	2.13718
2	.658[b]	.433	.403	2.16452
3	.668[c]	.446	.400	2.16967

a. Predictors: (Constant), Total PSE Score

b. Predictors: (Constant), Total PSE Score, Total GSE Score

c. Predictors: (Constant), Total PSE Score, Total GSE Score, Total Religious faith Score

Table 6.11: Results of Stepwise Multiple Regression Analysis predicting life satisfaction

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	-.771	1.433		-.538	.594
	Total PSE Score	.117	.022	.658	5.384	.000
2	(Constant)	-.924	1.617		-.572	.571
	Total PSE Score	.113	.029	.635	3.865	.000
	Total GSE Score	.013	.061	.035	.215	.831
3	(Constant)	-3.826	3.584		-1.068	.293
	Total PSE Score	.111	.029	.624	3.778	.001
	Total GSE Score	.012	.062	.032	.197	.845
	Total Religious faith Score	.083	.092	.113	.908	.370

a. Dependent Variable: Life satisfaction main measure

From the table above, it is clear that only Total PSE made a significant contribution to predicting life satisfaction. Total GSE in model 2 had a beta coefficient of 0.035 indicating a

small predictive effect on life satisfaction and this was also not significant (p=0.83). In the third model, total religious faith had a beta coefficient of 0.113 with a p value of 0.37 indicating it did not make a significant further addition in predicting life satisfaction.

This result demonstrates that only total psychosocial adaptation self-efficacy (PSE) was a predictor of life satisfaction in the sample tested. However, the limited sample size means that this finding should be viewed with caution, an issue that will be returned to in the Discussion.

Chapter Summary

This chapter reported the findings from Phase three of this project. This involved a quantitative analysis of the relationships between self-efficacy, life satisfaction and religious faith in female stroke patients living in Kuwait. This chapter also aimed to present exploratory multiple regression analysis to find the most significant predictor of life satisfaction post-stroke, from among the variables measured.

Results showed that the General Self-efficacy Scale (GSE) and psychosocial adaptation self-efficacy scale (PSE) were significantly correlated (in the sample overall, as well as the Kuwaitis and Non-Kuwaiti subsamples), offering some validation of the PSE scale. Correlational analysis using Pearson's coefficient showed that both Psychosocial Adaptation Self-efficacy and General self-efficacy were positively correlated with life satisfaction. In other words, higher reports of self-efficacy were associated with higher reports of life satisfaction. However, psychosocial adaptation self-efficacy (PSE) showed a stronger association with life satisfaction, indicating the relatively greater sensitivity of this scale. Religious faith was not associated with any variable except age. Comparative analysis of

Kuwaiti/ Non-Kuwaiti subsamples was carried out to further identify any cultural associations in the data. This analysis showed that the relationship between age and religious faith was only present in the Non Kuwaiti sub group and not in the Kuwaiti sub group. However, controlling for age in the correlational analysis yielded similar results regarding the associations between PSE and life satisfaction, and a stronger relationship between GSE and PSE in the Kuwaiti group. In the subgroup analysis, GSE was not significantly associated with life satisfaction in the Kuwaiti subgroup. However, both PSE and GSE in the Non Kuwaiti group were significantly associated with Life satisfaction. This indicates that the Psychosocial adaptation self-efficacy is probably a more sensitive measure than general self-efficacy for both native and immigrant members of the culture.

Multiple regression analysis identified that Psychosocial Adaptation Self-efficacy (PSE) was the most important predictor of life satisfaction. General self-efficacy and religious faith did not contribute significantly in predicting life satisfaction. However it must be noted that the sample size was small and further research on a larger sample is required to confirm findings.

Chapter 7

Chapter 7

Results from Phase 4 (Part 1)

The aim of phase 4 was to investigate the perceptions of health professionals who treat stroke patients in Kuwait regarding issues such as their perception of patients' quality of life, life satisfaction, and cultural influences on the stroke experience. Health professionals interviewed were from a variety of cultural backgrounds thus providing an opportunity to investigate how they perceived the influence of culture on stroke recovery and rehabilitation in Kuwait. This also provided an opportunity to discuss their perception of the results of Phase Three of the study regarding the relationship between self-efficacy, religious faith and life satisfaction in female stroke patients living in Kuwait. This last aspect will be discussed in the next chapter (Chapter 8).

Sixteen health professionals with experience working with stroke patients were approached for inclusion in the study (this was explained in more depth in the methods chapter). Two of these declined participation because they were not able to free up time in their diaries to attend the interviews. The remaining 14 health professionals were interviewed and the narratives transcribed. On reading through the transcripts only 12 of these transcripts were included in the thematic analysis. The other two were incomplete due to problems during audio recording. Ten of the participants were female and two male. Of the 12 included, one was a speech and language pathologist, another was an occupational therapist, three were nurses and the remaining seven were physical therapists. Table 7:1 shows the background of the 12 health professionals interviewed, pseudonyms are used to identify each person, for a

qualitative study such as this participant size is 12 is deemed appropriate to achieve data saturation. All interviews were carried out in English.

Table 7.1: Profile of Health Professionals

Pseudonyms	Age (in full years)	Nationality	Profession
Katie (HP01)	45	American	Occupational Therapist
Anna (HP02)	28	German	Physical Therapist
Andrea (HP03)	40	Canadian	Physical Therapist
Smitha (HP04)	30	Indian	Physical Therapist
Aylne (HP05)	47	Philippine	Nurse
Matt (HP06)	40	Canadian	Physical Therapist
Ahmed (HP07)	27	Kuwaiti	Speech and Language Therapist
Khadeja (HP08)	45	Kuwaiti	Physical Therapist
Helen (HP09)	38	Malaysian	Nurse
Mohammed(HP10)	42	Kuwaiti	Physical therapist
Deepa (HP11)	45	Indian	Nurse
Grandesa (HP14)	29	Philippine	Physical Therapist

The following seven topics were discussed relating directly to the questions asked:

1) The perceived role of the therapist in stroke rehabilitation

2) Perceived challenges the stroke patient faces from the therapist's view

3) Factors believed to determining quality of life in stroke patients

4) Perceptions of life satisfaction post-stroke

5) Perceived effect of culture on rehabilitation and stroke experience in Kuwait

6) Clinical application of results of the Phase 3 study regarding self-efficacy and life satisfaction

7) Perceptions regarding religious faith and relationship with life satisfaction and self-efficacy.

This chapter will present themes identified on the following 4 topics: Factors believed to determine quality of life in stroke patients, perceptions of life satisfaction post-stroke, perceived effect of culture on rehabilitation and stroke experience and cultural differences believed to affect rehabilitation in Kuwait. As mentioned previously, the next chapter will present themes related to therapists' discussions of the results of the Phase 3 study and the associations they perceived between religious faith and the other variables.

7.1: Factors Perceived by therapists to Determine Quality of Life in Stroke patients

Six subthemes were identified from the analysis of the 12 interviews regarding the issue of quality of life post-stroke. These were function and dependency, relationships, personal values, treatment and rehabilitation, finances, and lifestyle. Table 7:2 shows the subthemes related to perceived factor determining QOL in stroke.

Table 7.2: Subthemes of Perceived Determinants of QOL and Life Satisfaction Post-Stroke

	Major Themes	Minor Themes
Quality of Life in Stroke	1) Function and dependency 2) Relationships 3) Treatment and rehabilitation 4) Personal values 5) Finances 6) Lifestyle	
Life satisfaction post-stroke	1) Faith and spirituality 2) Adjustment and new perspective 3) Goals and function 4) Self –reflection	1) Pleasurable activities 2) Public reaction 3) Rehabilitation and environment

7.1.1 Function and Dependency

Health professionals interviewed expressed views indicating that function and dependency were very important in determining quality of life (QOL) after stroke.

The following was expressed by a speech and language therapist:

"Quality of life is, well of course when they got the stroke as a result they lost some skill sets, they lose some recognition probably, so obviously they will lose independency and I think this is a big part of quality of life, independency. " (Ahmed, Kuwaiti)

In the quotation above the speech therapist associated independency directly with quality of life. He also acknowledged the loss of functional ability and some cognitive functions e.g.

recognition. The mixture of both physical and cognitive losses was described as having an effect on quality of life.

Other therapists expressed the following regarding quality of life.

> "a stroke patient most probably will walk but everybody in the street will see him and they will say he was having a stroke, it will be seen directly that you are having problem and this is it, he can do many of his functions but in a non - appropriate way, this is not quality of life. To feel that you are nearly normal and this is a good quality of life". (Mohammed, Kuwaiti)

Mohammed associated quality of life directly with quality of movement. He referred to a patient walking in a "non appropriate way" as reflecting a poor quality of life. The idea of 'normal' ensuring a better quality of life could possibly be related to cultural influences which stigmatises disability. The idea that the people in the community will view the functional difficulty negatively adds to the perception of a poorer quality of life.

Poor quality of life was described by some of the health professionals as related to dependency and loss of family roles:

> "if they can help their family, they can work and then they can play their role, their function, with their family, their community then I think these all thing can help, it can improve their quality of life, whether then they would be at home, bedridden and they cannot do anything without help, and that will be a lot more trouble". (Helen, Malaysian)

Helen contrasted the patient's ability to perform their role in the family versus being totally dependent on the family as a significant factor in determining quality of life. Being able to

earn money and fulfil a role in the community was viewed as improving quality of life. A similar view was expressed in the quotation below. In addition, the quotation below mentioned the possible emotional problems associated with dependency.

"So the quality of life is really very bad and they are not able to do them anything for themselves, and that manner really hurts". (Smitha, Indian)

Function and dependency were mentioned by all the health professionals interviewed as being the most important factor determining QOL in stroke. Several expressed fear of dependency when asked to place themselves in their patients' shoes. In addition to this, quality of function and perceived difficulty in performing tasks by onlookers also seemed to be perceived as being important.

Interviewees also indicated that severity of the stroke in relation to disability affected QOL in the following quotations.

"So as a result quality of life depending again on the degree of the stroke is significantly impacted, it's pretty much your functional role in the world and how you interact with it and to a greater or lesser degree that has suddenly been altered and that takes some adjustments (Katie, American)."

The therapist here explained her perception of what she felt about QOL. As interaction and function in their world was seen as a description of QOL, it would thus be affected to different extents by the severity of the stroke and associated disability. A similar view was expressed in the quotation below:

"I think the type of disorder and the severity that's a big, that's an important factor or determinant of quality of life because sometimes you may, if you lose a finger it's not

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like you lose a whole like hand, the whole arm or both of your feet. So I think the

type and severity of the disorder will determine the quality of life." (Ahmed, Kuwaiti)

Function and dependency appeared to be a major perceived determinant of quality of life

across the various cultural backgrounds of the participants. Poor quality of life was

associated with increased dependency and severity of disability.

7.1.2 Relationships

Relationships with family members and others within the community were also discussed as

extensively as the impact of function and dependency on determining quality of life. Good

family support was expressed as helping with depression and loneliness while poor family

support could lead to depression. The following was stated:

"I think their family play important role because especially when they go straight to

house, -- to your home, so if you have a good family that can support you and then

you are feeling that you are not alone or you are not struggle alone with what you are

having. So by the family -- by helping from the family, you can recover, of course the

family can motivate you that you need to do physio, you need to eat good diet and all

these things and then these all can help because I think some -- if you don't have a

good support from the family and then you feel very depressed and de-motivated

"(Helen, Malaysian)

In this quotation, the health professional expressed her view on the importance of good

family support. Motivation to adhere to physiotherapy, and a good diet was thought to depend

upon the family however, the quotation also highlighted what happens if that support is not

present.

"This is the second main factor, relatives. Of course, the person supports somebody, if a person -. For example, you fell down somebody try to – you feel, you think, okay, very good, we have somebody like that. So always the human beings depend on other human beings and the human beings just like this, they ignored him, they feel something very, why he has ignored me like that, this is the only psychological apart from our therapy". (Smitha, Indian)

In this quotation the therapist mentioned her observation of normal human relationships and the need to have support when we fall metaphorically. She mentioned how without this support or when the person with a stroke feels ignored this can affect him or her psychologically.

Words spoken by relatives were also mentioned as determining QOL. Negative words, including those suggesting the person being a burden, were seen as contributors to a poorer quality of life:

"Okay, but if the relatives are really very bad and they are keep on telling, you are problem to us, it makes him depressed". (Smitha, Indian:8)

Family relationships were expressed as having an impact on quality of life. Support provided, attention given and words spoken were perceived to either motivate the patient when positive or increase the risk of depression when negative. This appeared to be a subtheme mainly discussed by Eastern health professionals interviewed i.e. Indian, Malaysian, Kuwaiti and Philipino. The Western therapists (Canadian, American and German) highlighted that family relationships were a big part of rehabilitation in Kuwait and mentioned ways in which it

supported and hindered rehabilitation. This will be discussed in the section on cross cultural differences.

7.1.3 Treatment and Rehabilitation

Access to good treatment and rehabilitation services was voiced as another important issue in determining QOL after stroke. The following statements were made regarding this:

"We need to see like this, usually with a good treatment, usually we can improve our quality of life. Let's say like if the country has a good system, good facilities and good healthcare system then if the patient can get all the facilities, the treatment and also the patient willing to do it (Helen, Malaysian).

Interestingly the health professions perceived that available resources in the country of Kuwait and access to good treatment and patient willingness to engage in therapy are important in determining QOL.

"Treatment, it's not physiotherapy treatment only, it's also the medical treatment"….. (Smitha, Indian)

"And he has to take care everything in a proper manner, I mean on and off time, the tablets, the medicines what he has - what the doctor prescribed for him and he has to follow our treatments like one hour we are doing and he have to do by himself in home, home program like that, so these things also give him a better quality in life". (Smitha, Indian)

Again, the above quotation mentioned the need for active participation in therapy by the patient by carrying out home programmes as well as being compliant to other prescriptions by the medical and rehabilitation team in facilitating QOL.

Some of the health professionals felt that Kuwaiti patients had access to better treatment and rehabilitation by going abroad for treatment and were then able to bring back equipment to manage at home on return from their treatment abroad.

> "Yes everybody goes abroad and they are mainly caring for them, then sort of better treatment they are going, but - and comparatively, I am comparing between India and this Kuwait people, of course, they are having money and their – if initial stage when they found out this is a stroke they immediately goes to London or of course the government is helping them. So their quality of life is really very good because they have some experimental braces in a proper manner, not like just what we handmade like that, no, but they are getting a very proper braces, other things and they are getting a good treatment with some great training. -(Smitha, Indian)

The perceived difference between Kuwaiti patients and patients in India was highlighted in the quotation above. She discussed the ability of Kuwaiti patients to travel to Western countries to get better care and "proper" equipment as opposed to handmade equipment possibly used India. Access to help from the government is also a difference that could impact QOL when comparing Kuwaitis with other nationals within and outside Kuwait.

The skill, attitude and care of the physiotherapist were other issues related to treatment and rehabilitation that were voiced as determining QOL:

> "I think it will depend most of the times on us as physiotherapists, if we work with them in a good way that will give them good quality of function, this is one fact". (Mohammed, Kuwaiti)

"And the other side is we as physical therapists are aiming that our patients have normal function (quality of function) not just to do the functions, yes, If its just to do the function we can do our job fast and finish, but if we concentrate that he will walk with good hip flexion and with heel strike, without deformities". (Mohammed, Kuwaiti)

The therapist above suggested that physiotherapists have a role in determining the QOL of their patients by how they deal with the patient. He highlighted that aiming to increased quality of movement for example during walking and taking time to ensure optimal function and movement would increase QOL. In this quotation, Mohammed tried to emphasize the importance for the therapist to ensure that good quality of function is obtained. Achievement of the task alone, although quicker to obtain, should not be the main focus of the therapist. He made a direct association between quality of movement and quality of life.

Treatment, rehabilitation and the therapist were expressed as important in determining QOL in stroke patients living in Kuwait. Access to good quality therapy was seen as dependent on available resources in the country or access abroad to obtain such care. Expatriate therapists perceived that Kuwaiti patients had a better quality of life due to their access to health care and rehabilitation abroad. A Kuwaiti therapist mentioned the importance of the quality of rehabilitation received and quality of movement aimed for in helping enhance quality of life post-stroke.

7.1.4 Personal Values

QOL was also described as being determined by what the individual who has experienced the stroke perceives as important. The following views were expressed:

"Again, it goes back to the values and the belief systems and what's important to them. Yeah, it's something so personal like as I said you think you know and you have to ask them, you have to say – you have to probably get to ask the family since you don't know, what's important to that person. Again, the language barrier is huge. It's very hard to meet prompt sometimes. Here is something their whole entire health … what's important to them and then from there you think about the quality of life." (Andrea, Canadian)

The therapist above highlighted the importance of understanding patient personal values as this in her opinion affects quality of life. She also mentioned the difficulty obtaining such information when language is a barrier.

"If I had lost my, if I am a young stroke and sexual activity is really important before and my wife now doesn't think of me the same way then, I can't put my arm around her the way I am used to, she can't deal with that, then certainly that will affect me". (Matt, Canadian)

The importance of sexual activity for a young stroke patient and difficulty relating to the spouse can be an issue that would affect QOL.

"Yeah, I mean, sometimes its communication, sometimes its hearing, sometimes its vision, depending on what they place for most value in. If I can get around my wheelchair and still see perfectly well I make -- some people are okay with that, I wouldn't be, you know some people that, you know, they are not so bad in their mind. I am glad they can still hear, talk, and see and will cherish a kind of fun. If they will be that way then, their quality of life won't suffer that much". (Matt, Canadian)

In the above quotation, the importance of identifying what the patient places value in was expressed, including the ability to continue with activities they enjoy despite losses in other aspects of function.

Personal values were mentioned as important determinants of QOL in stroke patients mostly by the Western health professionals. The difficulty in obtaining this information is present when there is a language barrier however, this information can aid in identifying solutions or replacements for losses experienced. It is possible that Western therapists have more attunement to the concept of patients' personal values and beliefs. Matt mentioned 'fun' associated with personal values as being important in quality of life. This reflects a patient-centred view of illness, quality of life and rehabilitation. A Kuwaiti therapist mentioned in her critique of rehabilitation in Kuwait the tendency for local therapists to plan the same programmes for all patients without taking their personal values into consideration. It is possible that the issue of personal values in rehabilitation is a Western concept.

7.1.5 Lifestyle

The way the stroke patient continues to live his/her life after stroke was expressed to be another factor that determined quality of life.

> "For me in a very basic sense quality of life is being able to freely interact with your world and do the things you like and want to do that after stroke is significantly inhibited...... So quality of life for me is enhancing the way a person interacts with the world, choose to make it more effective and make it more efficient, to make it a little bit more like the way it used to be or even better in some respects" (Katie, American).

QOL is perceived by this American therapist as being determined by the stroke survivor's ability to continue doing activities and being able to freely relate either via communication or through movement with the world, according to the above quotation. She also added the role of an occupational therapist in facilitating this interaction with the world to promote QOL in patients. Other therapists also mentioned the need to return to premorbid lifestyle and to interact with the world.

> "How well they can come back and perform their roles back again, how well they can come back and lead the normal life again, (change) all your bad habits, change your lifestyle and do normal exercises or and keeping themselves healthy and fit and being able to do all other activities normally" (Deepa, Indian).

Changing negative aspects of one's lifestyle and returning to pre- stroke roles were expressed by the quotation above as being important in determining QOL. A similar view of retuning to pre stroke life and roles is mentioned in the quotation below.

> "Some people recover I think about 80 to 90%, some people may be less than that, but at least the interesting thing about stroke is as long as they can return to their life, maybe not fully as before, but at least they can help themselves – if they can help their family, they can work and then they can play their role, their function, with their family, their community then I think these all thing can help, it can improve their quality of life". (Helen, Malaysian)

Ability to interact with society and deal with obstacles were significant issues related to adjusting to a new lifestyle post-stroke mentioned by some of the health professionals.

"If you are - these patients are not able to interact with their society, people around them; this is not a very good quality of life, and sometimes some of these patients they will avoid interacting with other individuals because they are having these problems, this is not a quality of life "(Mohammed, Kuwaiti).

Degree of social participation was expressed by this therapist as influencing QOL. Perceptions of social sigma specific to the Arabian culture could be responsible for this. This will be discussed in more detail when reporting results on cultural differences and will be explored further in the Discussion.

Lifestyle post-stroke was mentioned as being related to QOL by health professionals of different backgrounds. Degree of social participation was viewed to be an important aspect of lifestyle post-stroke

7.1.6 Finances

Available funds were expressed as being an important determinant of quality of life by only two of the health professionals. The following statements were made:

"I mean it is like totally the economical position of the patient "(Smitha, Indian).

The therapist above expressed her perception that the financial standing of the stroke survivor was an important factor in determining QOL.

" if not especially if they are in a difficult situation like financially they may feel that they are a burden to their family and they may undergo more depression, and the family is to play a vital role here not to just, you know, giving them, not just showing the patient that he is a burden to the family". (Aylne, Philippine)

Finances appear to be related to dependency and associated depression in the quotation above.

> "Quality of life, well, I can say they are financially stable....." (Aylne, Philippine)

Interestingly, respondents mentioning finances were from India and Philippines. Western and Arab health professionals did not mention the effect of finances on QOL except in regard to obtaining better treatment abroad as mention previously. A Kuwaiti therapist mentioned finances as one of the differences between Kuwaiti patients and those of other nationalities living in Kuwait.

> "Like I said, foreigners they usually come and stay alone or they have limited
>
> resources, but here in our country, between family and government supports paying
>
> for them, so many things are being done for them. But the foreigners, they have
>
> limited resources." (Khadeja, Kuwaiti)

 Therapists agreed that finances were important in determining quality of life post-stroke.

7.2: Life Satisfaction Post-stroke

Participants were asked whether they thought quality of life and life satisfaction were the same concept and what they believed determined life satisfaction. The generally expressed view was that life satisfaction, although related to quality of life, was a separate construct.

> "I think it can be very different because obviously there are some people who have
>
> had severe strokes that aren't able to be physically functional, but they have
>
> emotionally worked through and resolved the issues and come to a point of

satisfaction and perhaps even enjoy a better quality emotional life through awareness of things they may not have been aware had they not slow down enough from the impact of the stroke to notice some things "(Katie, American)

In the quotation above, Katie explained how a stroke survivor can report higher life satisfaction despite perceived poor quality of life due to difficulties functioning physically. Interestingly she used the word 'emotional quality of life' and associated this to life satisfaction. This concept of emotional quality of life wasn't expressed in the same way by other health professions and could possibly be related to Western concepts of health involving physical as well as emotional dimensions. She also expressed that increased awareness of certain life issues promotes life satisfaction. Life satisfaction is thus seen as related to acceptance of the current situation while quality of life is viewed as related to physical functioning. A somewhat similar view of acceptance related to life satisfaction was expressed in the quotation below.

"It's different……Life satisfaction is related to accepting - the patient is accepting what he is having, okay, it might not be 100%, it could be 80%, 90% or sometimes 60%, 40% of the normal function but he is happy, satisfied, he is enjoying his life and he is living, this is satisfaction. On the other way some patients who are normal with 100% function, they are not satisfied, satisfaction is something occurring from inside". (Mohammed, Kuwaiti)

In the above quotation not only did the therapist mention the need for acceptance to achieve life satisfaction, but he also pointed out that even people with full function may not be

satisfied, thus satisfaction is a subjective internal process that cannot truly be assessed by onlookers.

"No, actually not necessary that life satisfaction and quality of life is the same. It can be, I mean, it can be both ways, it can be okay – you are satisfied with life and you have a good quality of life. It can be qualitatively life is ok. You are stress out, you are a chain smoker and you continue with smoking and you say okay I am satisfied with what I am doing, but actually you are not satisfied in your inner self......" (Deepa, Indian)

The nurse expressing her view above argued that patients may rate positive life satisfaction but their quality of life might be poor due to bad health habits such as smoking. Life satisfaction and quality of life were thus not perceived as the same. She mentioned that they are related however, there is a subjective "qualitative" element associated with life satisfaction, however quality of life perhaps can be quantified regarding health habits and other indices.

According to most of the participants, QOL was perceived as being related to functional ability and good health, while life satisfaction was thought related to happiness and acceptance. The following quotation expressed the perceived association between satisfaction and happiness.

"Yeah, if you are satisfied, it's simple if you are satisfied then you are happy. (Ahmed, Kuwaiti)

"Life satisfaction, you can have money, you can have everything you want, but you still not satisfy with your life, you know, what I mean, because some people they have a lot of money, but they still not satisfied with their life. But when you are talking about quality of life in stroke patient, I would say they want to regain their health and of course, if they regain their health they might be healthy, of course when they have health, usual as before. For me if I look at life satisfaction it has a different aspect."
(Helen, Malaysian)

In the above quotation, QOL was related to regaining good health post-stroke, while life satisfaction although perceived as different was not clearly defined.

All the health professionals interviewed expressed the presence of a difference between life satisfaction and quality of life. However, clear descriptions of life satisfaction were not always provided. While QOL was said to be related to function and good health, life satisfaction was described in terms of its subjectivity, happiness and related to acceptance of their current situation post-stroke. Although participants expressed similar views regarding the difference between quality of life and life satisfaction, the issue of accepting disability was emphasised more amongst the Kuwaiti and Malaysian participants and not so much amongst the Western health professions. It is possible that this could be related to religion with acceptance of disability the expected religious response within the Islamic faith. This will be discussed in more detail in the next chapter.

Factors believed to determining life satisfaction in stroke patients

Four major sub themes were identified regarding factors determining life satisfaction. These sub themes were the following:

1) Faith and Spirituality

2) Adjustment and new perspective

3) Goals and function

4) Self reflection

Three minor themes were also identified. These were termed minor themes because for each only one participant mentioned them as being important in their perception. Although they were important subjectively for that person, they were not widely endorsed by the sample. It's important not to 'dismiss' statements as 'only' from one person as the qualitative approach accepts that each person's lifeworld is different and may enrich understandings of a phenomenon..

1) Pleasurable activities

2) Public reaction

3) Rehabilitation and environment

7.2.1 Major Sub themes on factors determining life satisfaction in stroke patients

1) Faith and Spirituality

Religious faith and spirituality were the most talked about issues related to life satisfaction. Health professionals mentioned that faith and spirituality helped with finding satisfaction, peace and comfort post-stroke. The following quotation demonstrates this.

> "Life satisfaction, I think when a patient believes in something bigger than themselves and they can trust in a being bigger than themselves. I think this can provide a source of motivation and source of comfort, source of connection." (Katie, American)

In the quotation above the therapist mentioned the possibility that belief in a higher force can be a source of motivation and comfort. Other therapists believed that faith was the most important issue regarding satisfaction.

> "I think his belief, his faith is really the most important factor for him, otherwise he will not be happy no matter what you have done for him, maybe he can walk but he will look at the small, small things. 'No, I am walking like this',." (Mohammed, Kuwaiti)

In this quotation the therapist indicated how lack of appreciated of gains made during recovery could be associated with religious faith. He also went on to explain the Arabian belief that illness is an opportunity to develop a closer walk with God but he was also suggesting that the person has to put thoughts of divine punishment out of his mind in order to take this accepting attitude.

"I think it is mainly coming from inside the patient, we outside can help little bit push him but it something coming from inside. He is believing in Allah that this disease was not his fault, it was coming from Allah, so he will believe in this and he will accept and he will take this as opportunity to be near God and to go to more praying, more doing good things this will give him life satisfaction but not if he will just feel, "oh, what have I done, what wrong things I have done that Allah has put this, which is wrong." (Mohammed, Kuwaiti)

Religious faith and spirituality were identified by the health professionals as being important in determining life satisfaction post-stroke. Similar views were made by therapists of different cultural backgrounds. This perhaps suggests that the perception that faith and spirituality could influence life satisfaction is not specific to only certain cultures. Or it might reflect their awareness of the prevalence of such beliefs in Kuwaiti culture.

2) Adjustment and New Perspective

Health professions expressed the belief that having a new perspective after stroke was an important determinant of life satisfaction post-stroke. This was perceived to include having a new way of looking at themselves and the environment post-stroke

"I think for some people it (life satisfaction) is coming to grips with something deep within themselves, knowing themselves so to speak a little bit better, perhaps even the ability to change one's perception about something (Katie, American)

The importance of the patient being able to identify change and the therapists' role in facilitating this was expressed as a determinant of life satisfaction.

Acceptance of ongoing functional problems was identified as being necessary to adjust to a new life post-stroke and develop a new perspective. The following quotation highlights this point.

> "They need to accept their problem first and if they accept their problem they will try to compensate, adjust their lives according to their disability and then they will be at least satisfied. I don't want to say happy, but at least satisfied and that will determine (life satisfaction)." (Ahmed, Kuwaiti)

Ahmed expressed the need for stroke survivors to accept their disabilities in order to use what they have left and be satisfied with life .

> "Okay, if you have a disability, if you lost your arm, you need to accept your problem like, okay, I lost one arm, but I – first of all, I am still alive and I have my other arm. Then they need to adjust their lives like probably learn how to use one arm instead of both the arms. Learn how to eat with one hand and then if they could adjust their routine or their life that's acceptance." (Ahmed, Kuwaiti)

Adjustment and gaining new perspectives post-stroke were identified as important in helping the stroke survivor move on and begin a new life. Health professionals believed that life satisfaction was determined by how effective this process was.

3) Goals and function

Life satisfaction was believed to be related to achieving goals. These could be personal goals, or functional goals set during rehabilitation.

"I think that is - I mean whatever I set as an objective, as a goal is being attained, I think I will be satisfied. (Aylne, Philippine)

Putting herself in the patients' shoes, Aylne expressed the importance of achieving set goals in facilitating life satisfaction.

Both life satisfaction and QOL (discussed previously) were perceived to be related to independence, itself seen as dependent upon recovery of function.

"Life satisfaction is, if I improve my movement like what makes me feel more independent, as an example that I can sit now, that I could not do before and that is also a higher quality. So it's like if the graph for quality goes like this, the life satisfaction also increases." (Anna, German)

In the above quotation, the therapist used the example of achieving sitting post-stroke. She expressed that an increase in functional ability would cause an increase in quality of life and life satisfaction also.

A similar view was expressed in the quotation below:

"Their life satisfaction is …Well, I cannot tell maybe for the answers because I have not been in that situation you know, but of course their quality of life will be - these are inter-related, right, they won't be satisfied because they are bedridden, they cannot function as expected from a normal human being and their quality of life is affected because of their situation and even in their capability to be functional in the society is not being attained". (Aylne, Philippine)

Goals and function seem to be the point at which both quality of life and life satisfaction appear to overlap in the views of the therapists interviewed. The health professionals tended to talk about both issues together when trying to explain how function can relate to life satisfaction. There also seemed to be some confusion about these concepts/ experiences and what influences them. These ideas were hard to formulate and express and the participants seemed to struggle when answering.

4) Patients' Self Reflection and awareness of own needs

Health professionals expressed the increased tendency for stroke survivors to think more deeply about meaning of life, values, relationships and the world at large and felt that this was a determining factor for life satisfaction. The following statements were made:

> "I think it [stroke] causes people to look introspectively and to examine the way they interact with life and the world and relationships and I don't think that always happens for a person automatically. So in some respect and for some people I think it can enhance that part of their life even though the physical aspect perhaps is not as capable. (Katie, American)

In this quotation, the therapist suggested that introspection might enhance certain aspects of the patient's life even in the presence of physical difficulties.

Another therapist expressed the view that finding meaning for yourself post-stroke had an influence on life satisfaction

> "Finding some kind of meaning for yourself, whatever that is" (Matt, Canadian)

The occupational therapist elaborated more about introspection:

"I think actually this is something independent from faith whether a person believes in a particular religion or God or not because many people who are really involved religiously don't necessarily know themselves. I think it's very easy as human beings to project and focus on something outside of ourselves, so I kind of see that as a separate thing from looking inward and really seeing who we are and why we believe, what we believe, whether we have a faith or not, why we choose certain reactions to things or perhaps they are automatic and we don't choose them. (Katie, American)

Katie made a comparison between religion and introspection, with the latter being more in tune with knowing self and understanding personal reactions. Interestingly, this focus on meaning and self-knowledge that comes from some of the Western therapists, perhaps this relates to the Western world view.

Understanding one's self, beliefs and what makes one happy was perceived to determine life satisfaction by the quotation below:

"Each person has his own belief, needs, happiness, you know, things that makes you happy doesn't make me happy. The thing that makes me happy doesn't for sure make you happy. For example, I think, again depends on each patient and talking to them and understanding their needs and helping them to reach that." (Khadeja, Kuwait)

In the quotation above the health professional emphasised the need to understand the patients' personal need and the therapist's role in helping them achieve that (which still gives a more passive role to the patient). However, the therapists considered that the patients themselves had to know these personal needs for themselves before communicating them to the therapist.

7.2.2 Minor Themes

These were themes inferred from the accounts of particular health professionals which they viewed as vital concerning life satisfaction.

1) Pleasurable Activities

Loss of pleasurable activities was mentioned by only one therapist as being important to decreasing life satisfaction.

> "I would still -- for me to lose physically, my abilities, you know I derive a ton of pleasure from exercise, running, activities, sports, you know, so my physical abilities give me a lot of pleasure." (Matt, Canadian)

He went on to elaborate on the importance of recreating something meaningful and pleasurable to get satisfaction back in situations where previous pleasurable activities were no longer possible.

> "For me it would be a complete shift because I would have to find something completely new that brings me pleasure because for me the first thing I think that when I want to do something for me, would be to go and run or workout at the gym or swim or play volleyball or play a sport, you know, hockey. And, so without those I would have to learn how to, I have to recreate something that was meaningful and pleasurable to get satisfaction back". (Matt, Canadian)

It was interesting that a Western therapist was the one emphasising the importance of pleasurable activities outside of home and work roles. This might reveal cultural values and assumptions, connected with the biopsychosocial approach to rehabilitation.

2) Public reaction

One of the community therapists mentioned how public reaction could have a negative effect on life satisfaction.

> "when a person goes abnormal they (the public) are just looking like: why she is doing like this? ......Even when we go outside, if we find some people walking with waggling gait or circumduction gait, with some other gait you can see, automatically we think: oh, he is poor, but these things make them have a less confidence in themselves. (Smitha, Indian)

Some therapists thought that perceptions of public disapproval may cause the stroke survivor to withdraw from public places. This was expressed in the quotation below.

> "These are all the main things that stroke patients are facing, they don't want to go in the public even though they are walking nicely, they can hold the stick, but even though somebody coming immediately, come and help them that also some people they don't like when others immediately come and help them, to hold them, please don't they'll say" (Smitha, Indian)

Smitha also expressed the possible dislike of help by the stroke survivor. This could relate to being perceived as weak and helpless, which are stigmas associated with disability.

3) Rehabilitation and Environment

Rehabilitation was viewed as an important part of the life of stroke patients and thus the location and environment of rehabilitation was perceived to play a role in determining life satisfaction.

"Yeah, I think who is around you. I mean, if you are in – I think it's different if you have your rehabilitation in your own house than, you know, in a kind of home, elderly…(Anna, German)

"If you are in a place where you feel yourself comfortable then your rehab will be better, your mood is different. ..... the peace is what you get from the environment like how it looks, the building, the room, and the people around you. (Anna, German)

Comfort in the rehabilitation facilities and behaviour of the people around was expressed as important for satisfaction.

7.3: Cultural Issues Related to Kuwait

The following themes were identified regarding cultural issues specific to stroke rehabilitation and recovery in Kuwait from the health professionals' perspective.

1) Family involvement

2) Education

3) Prevailing attitude of stroke

4) Patient goals

5) Dependency and presence of maids

6) Social stigma (social outing public reaction)

7) Finances

8) Religion

7.3.1 Family Involvement

Family involvement was the most talked about issue related to the culture in Kuwait. Extended family is practised in Kuwait with children, parents, grandparents and in-laws typically living in the same house. The following statements were made:

> "the family is around them and very often they live in a household again with extended family. So they don't feel estranged from the family because they are not in a separate location and getting to the family or having the family come to them is not an issue. So in the Kuwaiti culture I actually see that very much as positive that they have extended family, not only very often right in the same household but they are for support and they are for interaction and there it's part of their daily life motivation." (Katie, American)

In this quotation the advantages of extended family in the Kuwaiti culture was mentioned as provision of support and motivation. A similar view is expressed below.

> " they practise extended family, you know, they are supportive with one another, I guess, as we have seen them coming in and they are always there beside them, and yeah, they are good family" (Aylne, Philippines).

In this quotation, the nurse explained how in hospital family members are always with the patient. Family involvement is not only specific to illness situations. It was expressed that it was normal for people to age with their families.

> "People get older here at home anyway in their family, that's the big difference to what's happening in Germany." (Anna, German)

The therapist interviewed made a comparison with her culture in Germany where people typically age without living with extended family.

"Family and friends were viewed as a social network to assist the patient in recovering. So when a person gets a stroke, the whole family even friends have to be involved in the problem. They create like a network or something to assist him and even if he recovers, he still gets the help." (Ahmed, Kuwaiti)

The issue of family providing a support group and important for encouragement was explained by other therapists also.

"Family is the key really, you know, if you have close family ties, of course, there is - that could be one of the key of the recovery of the patient, their encouragement and circle of support. ... As far as we have seen here in Kuwait they have close family ties . (Aylne, Philippine)

In this quotation the nurse points out that in Kuwait she has observed close family relationships.

Other advantages of having family support were that it can aid in carry-over of therapy gains. In the quotation below, the therapist explained:

"really the support of the family especially daughters or the son being there for their parents is a blessing and it really affect the parents....So if that daughter believe in what you are doing, importance for her mother, she will go back and tell her, "no mom, you have to cycle, no mom we have to walk, no mom we have to do this sit to

stand 20 times a day" so she will do it. But imagine if that person didn't believe in this who will encourage like this, 'you have to do it' ". (Khadeja, Kuwaiti)

She also highlighted the importance of the family members to believe in the therapist and the programme prescribed. The family members can then encourage the patient to do the same activities out of the structured therapy times. Some disadvantages were also mentioned regarding extended family and increased family involvement. A therapist working in the community described battles with the family regarding providing care and having to work to gain the trust of the family.

> "The intrinsic respect, patients they respect you, they assume you know what you are talking about whereas here they assume you know nothing in the beginning and it's just the way it is because they can shop around, they can hire whoever they want. So you have to earn the respect a lot more, you have to get them to buy into what you are saying and that takes time, when you first see them, it can take six months trying to get them to buy into what you are saying." (Andrea, Canadian)

She further explained why this is often the case in the community setting.

> "Where as it's just an assumption that you know what you are talking about if you are licensed is working in the hospital chances are you are not going to do things that are not right. But here sometimes it's respect from the male family or family members first, I mean, I have to dress differently depending on who I am seeing on a given day, so that's the cultural issue. (Andrea, Canadian)

In the quotation above, the therapist mentioned how a therapist working in a hospital would get more respect because of the assumption that they mostly know what they are doing. She

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also mentioned an issue of gender bias in getting respect from family members. She also seemed to reflect in the previous quotation on the issue of *buying* care , that perhaps this affects trust and adherence to treatment as people can 'shop around' to get a therapist who says what they want to hear.

Other disadvantages mentioned were that the family could slow down progress by helping too much and removing the opportunity to learn. The next quotation reflects this.

"In Kuwaiti culture, the family get involved too much and they sometime restrict the therapy, sometimes you teach the client to do something and the family are like "yeah come daddy you know this, come on do it, no that's wrong". They get involved like too much, and support is good but if it's more than normal - it's not good for the patient because he will become totally dependent.".. (Ahmed, Kuwaiti)

Ahmed emphasised that family involvement can infantilise the patient and discourage independence. A similar idea about the dangers of helping too much was expressed by Matt.

"Occasionally people will overprotect after an injury in general, certainly with the stroke there is a scenario where often people will want help too much. For example with getting a cup to drink from and just like with the child we can often do everything for them. So if they don't spill or something that looks easier for them, but then by doing so you are never giving them the opportunity to practice or the opportunity to learn something." (Matt, Canadian)

Perceptions of family involvement were mostly positive. Extended families were expressed as being a source of support, encouragement and motivation. A few disadvantages mentioned

related to a lack of respect towards physiotherapists working in the community and over-helping the patient hence increasing dependency. The perceived advantages and disadvantages of family involvement were shared amongst the various culturally diverse health professionals.

7.3.2 Education

Both Kuwaiti and Non Kuwaiti health professionals mentioned that lack of education made a difference in dealing with stroke in Kuwait. Some Kuwaiti therapists compared their experience with foreign patients they had worked with both in Kuwait and abroad. The following statements were made:

> "Because some of them [families] they are not well educated, they feel that if you get stroke and …your cognition gets impaired, they think that he is psycho or crazy or something, so that's why they hide them from others and they don't want to do anything about it. (Ahmed, Kuwait)

Due to lack of education about stroke and its associated problems, families and patients were observed sometimes to withdraw from the public. In addition to this, the health professionals considered that hearing negative experiences of other people encourages demoralising perception about stroke as expressed below:

> "I feel because of their knowledge is limited and hearing of other people who had the same incidents and is crippled. So they think this is it, since you have this you are crippled and the assistance has to be there from somebody else." (Khadeja, Kuwaiti)

Lack of education about stroke was also perceived to be the reason for less emphasis on rehabilitation. The need for doctors and nurses is widely accepted in the society but rehabilitation is somewhat of a new concept.

> "So I think particularly with the stroke patients it seems there is not a very great awareness for the need of rehabilitation, it almost seems like there is more of an acceptance of "We need the critical medical people, you have to nurse them back to health so that they can breathe and they can move and they are not sick", but when it comes to the more physical functional aspects there doesn't seem to be a great awareness or emphasis on that". (Katie, American)

The Kuwaiti speech and language therapist expressed that some patients did not understand the long term nature of rehabilitation and thought it was like medication. Some patients were considered to have unrealistic expectations of rehabilitation due to lack of knowledge.

> "Some of them think that rehab is just like medication, you get it once or twice and then you are back to normal life. So they don't understand that therapy sometime takes months or even years and it may benefit or may not. So most of the people here thinks that, they ask me how many, like how many visits if they have stroke patients and they are like how many sessions do we need to get them to his old level, just like before the stroke and I'm like we don't know, we need to evaluate him, we need to see the progress and I cannot give you specific times just like if you are taking medicine or something, take the medicine for a week or two weeks and then stop it and you should be fine, we cannot do that in therapy." (Ahmed, Kuwaiti)

Unrealistic expectations especially among young stroke patients are expressed below. Also the interesting idea that money can *buy* recovery.

> "you get some of these younger stroke who say well I would finance you, everything is going to be okay and I am going to be a 100% again and then sort of saying well you are not because you plateau and so this is the most *we can get you to* and again it doesn't matter if you all the money in the world to access the equipment, this is all I can do for you, so making them realize their condition. (Andrea, Canadian)

In addition to a lack of education about the need of rehabilitation and unrealistic expectations, a therapist explained that some patients believed that all they needed from therapy was massage. This could indicate both an expected passive attitude towards rehabilitation and lack of awareness of what rehabilitation entails.

> "They are just lying on the bed and they would tell the nurse to do some work for them and they will tell the physiotherapist to do some massage, of course, massage is contraindicated, I feel so in stroke, but they want to do some massage for them, they want to feel relaxed." (Smitha, Indian)

The need to educate and explain more was identified as being important in Kuwait.

> "The role as the physio don't change, it might if there is any language barrier, you have to – that is different, you might get lost in translation and yeah, and I'm explaining more here to patients that I had to do at home, yeah, explaining more, convincing more." (Anna, German)

In the previous quotation the therapist made a comparison with her home country Germany and felt that in Kuwait due to lack of education, she had to explain and convince the patients

more during therapy. For those with experience of clinical practice elsewhere, educational level of stroke patients and their families was perceived as an important issue differentiating therapy in Kuwait from other parts of the world. Lack of education about stroke and rehabilitation was perceived to be related to reduced appreciation of rehabilitation services or unrealistic expectations.

7.3.3 Prevailing Attitudes Regarding Stroke

Similar to lack of education, health professionals reported a distinct theme; a prevailing negative attitude regarding stroke amongst Kuwaiti stroke patients and their families. The main attitude was that the stroke survivor was sick and should remain at home and rest. Some believed that stroke signified end of life.

> "Its end of life over here, do you know what I mean? In the West, it's kind of – it's something that can happen and because they can be managed you can still get a pretty good quality of life. That's how I see most of my patients in the West. Here, it's like oh no they are sick, they need to stay in bed.....whereas when you see stroke as an event and actually we have this window of time where we want to really work and get her up in moving, you know, They ask: why does she have to be mobilized, she is so old, let her be".. (Andrea, Canadian)

The common attitude that no further recovery was possible was also reported.

> "After they are getting the stroke these people, I mean the Kuwaiti people, they feel I don't get recovered anymore so they feel like that, so they always lie in the bed, they don't want to do any work. I mean this is the main part and they just want to lay, lay, lay so because of that I mean they have two servant maids and one nurse here just to look after them, so they just eat, have some tablets, that's it." (Smitha, Indian)

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In this quotation, the therapist explained her experience whereby stroke survivors stay in bed and are looked after by nurses and house maids because of the attitude that they will no longer recover. They can do this because they have maids, and therefore the social context rather reinforces the sick role.

A Kuwaiti therapist expressed the prevailing attitude of society regarding stroke and that patients refuse to work hard on their therapy because of pity from relatives.

> "There is a blockage and it happened somewhere in your brain and poor one, underline poor, hundred lines on the poor, poor, poor, he is crippled. They don't want to work hard and for this to happen they have to work very hard". (Khadeja, Kuwaiti)

A similar view regarding refusal to work hard was expressed by an Indian Physiotherapist.

> "I mean, Kuwaiti patients they don't like to work at all, I am sorry to tell this, but really they don't like to work, only the young who is very younger they are really cooperative and they are doing their level best. But the people who are really very old patient, for example maybe 60s even 50s also, they got stroke they don't - they are just lying on the bed and they would tell the nurse to do some work for them" - (Smitha, Indian)

> "There doesn't seem to be a lot of motivation for and perhaps this is age related too, perhaps this plays a little bit mentality that they are older anyway, I don't know."(Katie, American)

Health professionals expressed that the prevailing attitude of Kuwaiti stroke patients was that stroke was the final end of life with no recovery possible. Thus, patients took a passive approach to therapy, and motivation to work hard in rehabilitation was perceived to be low. There was also the widespread notion among patients that increased age meant that they did not have to work hard during therapy. Statements by the health professions could be regarded as rude and implying that patients are to blame for their attitude in rehabilitation, however it is possible that the whole social context is one that separates the sick from the well, and that reinforces the dependence of older people.

7.3.4 Patient Goals

The predominant view was that when compared to stroke patients in Western countries, patients in Kuwait did not typically have personal goals for activities they would like to achieve with rehabilitation.

> "They don't, and I am not talking only about the stroke patient and -- not that my patients…, they are not motivated to -- they don't have anything…,examples of goals: I want to walk again, I want to go skiing, I want to travel, or I want to do this and that. It's very difficult to get something from them what they want to reach;. (Anna, German)

A therapist mentioned that stroke patients in Kuwait were less bothered by not being able to do certain activities.

> "So in that respect they don't seem to be as bothered by not being able to, for example, cleaning their house or go shopping because there is someone to do that for them whereas in the States people do that for themselves for the most part. So many

of their basic life needs are met by someone else, so there is not as deep or a compelling reason to be functional" (Katie, American)

In the above quotation, the therapist makes a comparison with patients in the US where patients have to do certain self-care activities themselves. In Kuwait, however due to the almost universal presence of maids, patients appear to be content with an inability to function independently. The issue of dependency and presence of maids will be discussed later in this chapter. Also there seems to be a more restricted view of activities. Those mentioned are all activities of daily living whereas leisure activities seem to have less meaning. This view was confirmed by the same therapist below:

"I think more people in my experience in the States, for example, are seem to be more affected by their inability to participate in certain activities, where extracurricular activities here in Kuwait among locals do not seem to be high on their list of priorities." (Katie, American)

The notion of greater contentment with disability in stroke patients in Kuwait was also expressed by another therapist (as noted in a previous theme).

"Technically, I would say that people are okay with some loss in Kuwait, easier than they would be in North America. Most people in North America will not quit until I can get this absolutely close to perfect as possible. Here there seems to be a more, there seems to be greater contentment with some loss and being okay with that." (Matt, Canadian)

In this quotation, he made a comparison with his own culture of North America and suggested that in Kuwaiti there is more acceptance of certain losses.

Due to the perception that patients in Kuwait perhaps have different view of goals, a therapist working in the community described adjusting her programme to meet their expectations.

> "You know what, here is an example, I have gotten a lot more probably slower. I have broken down the goal in many, many factor versus cutting to the chase….Yeah, and knowing when to stop and knowing that it's not a wasted visit if you just move her arm five times that was great, that was fantastic .. and it's not that simple, but you've got to really, really break down the steps" (Andrea, Canadian)

Relatively limited patient goals were mostly expressed by Western therapists from the US, Canada and Germany as a cultural difference in dealing with patients in Kuwait. The drive to overcome disability did not appear to be as strong as they had experienced in their own country. This could be due at least in part to the presence of maids, which will be discussed in the next section.

7.3.5 Dependency and Presence of Maids

Dependency and the presence of maids was expressed by both Kuwaiti and Non Kuwaiti health professionals as a cultural difference between dealing with stroke patients in Kuwait and in other parts of the world. The therapists thought that dependency in Kuwait (amongst Kuwaitis) was not viewed as a problem.

> "So when a person gets a stroke, the whole family even friends have to be involved in the problem. ....They are surrounding all the time while in other cultures…. and dependency is not a big deal for him because whether or not he recovers the whole family will be with him." (Ahmed, Kuwaiti)

"Yes, As I told you, I mean, here it's okay to be dependent on someone else. For example, I told you our religion focuses on taking care of our parents. The more you take care of them the more you have better chance to go to Heaven, it is related. Since you believe in God in order to get his satisfaction you have to care for your parents. The main thing He (God) always asks us to do, take care of our parents. So here, the family, I mean, old person they will try to help them. So here, it's okay for the patient to be dependent, not the other way, independent, but in the foreign country because they don't have this, they have to work very hard to reach to the independency. "(Khadeja, Kuwait)

In the quotation above the therapist explained that encouraging dependency stems from their religious beliefs. Caring for relatives is viewed as offering better chances to go to heaven. She also mentioned that in other countries patients have to work hard to achieve independency while in Kuwait dependency is accepted.

Another therapist expressed another reason for acceptance of dependency, namely the presence of assistance for caring , with paid staff available for caring for children and performing other activities. Hence the loss of function might not have such a great impact when compared to someone without such paid help.

"Here in Kuwait people are more familiar with dependent relationships. So people that clean for you, people that cook for you, people that can let your children for you and that certainly plays a big role in the loss, sense of loss, that people here probably experience less loss than they were – say a female that had a stroke with young kids. If the nanny could bring the baby to them, then they could hold them still and the nanny gets their food ready and helps them feed" (Matt, Canadian)

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A Kuwaiti therapist also explained her belief that certain social attitudes encouraged dependency.

> "I think the mentality of the society is the ones that encourage them to be crippled. Oh, poor one, oh don't give them too much exercise physically, so they always focus on their problem. They will likely be dependent on others and here especially our society it's so, I mean, they like to help but sometimes too much help doesn't help fix it, you know, what I mean. So, for example, they have maid, so okay the maid will do things for her." (Khadeja, Kuwaiti)

She also expressed her view that the presence of maids encourages disability and makes the point that helping doesn't always help the stroke survivor to recover. This therapist elaborated further by comparing Kuwaiti patients with non Kuwaiti patients living in Kuwait. Her view was that non Kuwaiti patients, because of lack of help from family or maids, achieve independency to a greater extent than Kuwaiti patients.

> "I mean, see this is the thing not like foreigners. She knows that she has to depend on herself to do her stuff, her children won't help her, she doesn't have maid or, you know, assistance to come home and do things for her so she has to depend on herself." (Khadeja, Kuwaiti)

Dependency and the presence of maids were expressed by all the health professionals interviewed as a difference between Kuwaiti and non Kuwaiti patients both living in Kuwait and abroad. Access to funds to hire nurses, and domestic helpers was thought to contribute to this lack of need to recover independence in addition to the prevailing attitude of accepting aging and anticipating poor recovery post-stoke.

7.3.6 Social Stigma and Isolation

Isolation due to social stigma associated with disability was expressed as a cultural characteristic that therapists had experienced in Kuwait. The following quotations express this viewpoint:

> "For some, they become ashamed of the problem.....Yeah, some of them, like they want to hide it they don't want to tell anyone about....I don't know, it's a cultural thing." (Ahmed, Kuwaiti)

> "Just, you know, they had the stroke so they look different and some they want to cut themselves off socially. It could be either way, … they want to cut themselves socially or they want to have everyone visit. (Andrea, Canadian)

There is the indication from the above quotations that because of visible effects of the stroke, patients and families may feel ashamed and thus choose to hide the patient from society. The patient is cared for by the family so isolation is mainly from the general public, the stroke survivor is thus enveloped and hidden *within* the family.

The issue of "saving face" appears to be expressed by the therapist interviewed as the quotation below shows.

> " So initially they all want to cut everyone off because they don't want to be seen as weak - and in Canada people want to have that social network, they want to have that social support." (Andrea, Canadian)

In this quotation she made a comparison between patients in Canada who want to have a social network whereas in Kuwait they avoid the public in order not to be perceived as being weak.

In addition to social stigma associated with stroke disability, depression associated with stroke was also described as a socially undesirable topic.

> "Assessing someone for depression or even suggesting depression is such a taboo topic, heavy debate." (Andrea, Canadian)

> "No, I find, I can't ask out right if are depressed, it sounds sad. Okay, so I put it into different terms. Have you thought about the medical management, ah no no, she got her faith, she pray, she reads the Koran everything will be fine, that's how they deal with depression . (Andrea, Canadian)

A Kuwaiti therapist mentioned that in Kuwait disabled people do not go out due to negative public reaction and lack of assistance to help them go outside.

> "For example, suppose that you are a hemiplegic patient and you are not going [to the]community, not living in the community. If, for example, in our culture we are not seeing people with disabilities going through life, okay. ....nobody is willing to take care of him and because, you know, if he has to go to the market to buy something from the supermarket, he need somebody with him." (Mohammed, Kuwait)

He also seemed to imply that disabled people's lack of visibility makes people unaware of disability issues. Family members appear to require a lot of encouragement to take the stroke survivor outdoors. A community therapist explained:

"The family here they want to hide mummy in the closet with all her care. They want the best care, but they don't want to take her out. So even if we get the equipment, even if we get custom wheelchair which is meant to go outside of the house, they need encouragement to do that and a lot of time they do come around, they take them in the garden, take her down the street it's okay, that had to be ..... so that's huge for the patient. (Andrea, Canadian)

Lack of facilities for the elderly was mentioned to be one of the reasons for the reduced social outings of stroke survivors.

"Many times, here we don't, for example, [have] places where these elderly people with these kinds of disabilities like the stroke where they are getting together and talking to each other. If they were talking to each other they can say, "yes, yesterday I went to that place and I have done this, this and the other person tell yes, yes" and they will talk to each other and they will push the patient and he will be more independency in his life, even the function, level of function is the same, but now he is coming to the community, he is living; he is enjoying his life with various aspects, but all the time in the house" (Mohammed, Kuwait)

In this quotation above the therapist expressed appreciation of a possible social facility like a stroke club where patients can get together and share experiences, however because this is not available stroke survivors stay at home. In addition to this, the therapist felt that two other

reasons could contribute to patients' reduced social outings, namely the physiotherapists not practicing mobilising in a real setting and lack of preparation of the environment i.e. access equipment like ramps and doors for wheel chairs.

"One thing we are as physiotherapists responsible.... Yes, I will say, if we will stop our rehabilitation and just making the patient to be able to walk inside the gym, but we did not take him to walk outside, how he will walk, I am sure he will not walk because he did not practice it, but if we will take him to walk outside on the grass, on uneven surfaces where he has go one stair up, down and he would do all these things, we can help them to be involved in the community. (Mohammed, Kuwait)

"This is one part.. ourselves and other things could be related to the environment. Are we preparing the community, the environment, outside environment to receive these patients or not? If these patients, for example, were in wheelchair, okay, and they have stairs what they will do? They will stay outside, they will not go but if we...if the environment was prepared for them they can go." (Mohammed, Kuwaiti)

The social stigma of disability was expressed as being related to reduced social participation by stroke survivors in Kuwait, In addition to this, lack of facilities, lack of rehabilitation in real settings and limited access to equipment were also mentioned.

7.3.7 Finances

Access to finances for treatment abroad, equipment and paid staff was mentioned as a characteristic of stroke experience specific in Kuwait. Finances have been discussed earlier in

relation to QOL and are re-visited here as a cultural characteristic which therapists thought distinguished Kuwait and non-Kuwait experience of stroke.

"Yes everybody (Kuwaitis) goes abroad and they are mainly caring for them, then sort of better treatment they are going, but - and comparatively, I am comparing between India and this Kuwait people, of course, they are having money and their – if initial stage when they found out this is a stroke they immediately goes to London or of course the government is helping them (Smitha, Indian)

Smitha in the quotation above, expressed that patients in Kuwait, due to funds being available, have access to rehabilitation abroad. She made a comparison with her home country India, where access to such care might not be possible due to lack of governmental support.

A Kuwaiti therapist also supported this belief. She mentioned finances as one of the differences between Kuwaiti patients and those of other nationalities living in Kuwait.

"Like I said foreigners they usually come and stay alone or they have limited resources, but here in our country, between family and government supports paying for them, so many things are being done for them. But the foreigners, they have limited resources." (Khadeja, Kuwaiti)

Kuwaiti patients were perceived to have advantages due to family and governmental financial support and access to treatment abroad as mentioned earlier.

7.3.8 Religion

Religion was expressed as an important aspect of life in Kuwait and the health professionals thought it had an effect on attitudes towards rehabilitation. Some therapist believed that Kuwaiti patients perhaps placed more responsibility on God than patients in some other cultures.

> "Yeah, in some ways, there is more responsibility to God here than there is at home. Say, for instance I could become lackadaisical about rehab, because it's up to God anyway whenever I try to do my best in therapy, doesn't matter, I mean they are going to recover or not, Insha'Allah. So that kind of potential attitude doesn't mean everybody has that but if there is that sense of, God dictates everything so much so that I don't even have to try or that nothing I do is going to matter, then there could be a bit of a more laxed approach to the therapy whereas in North America most people would feel like God helps those who helps themselves kind of an attitude." (Matt, Canadian)

In this quotation, the therapist made a comparison between belief in God in Kuwait and in North America. There appeared to be the perception that patients in Kuwait believe that since God is in control they have less responsibility in their rehabilitation. However, the health professionals coming from North America, perceived that a different attitude is taken, one that involves the patient taking an active role in rehabilitation.

A similar fatalistic view from patients in Kuwait is expressed in the quotation below.

> "sometimes we have to point it out to them, sometimes it's not intrinsic it's not... Again, because "life is meant to be this way so why should I aspire to anything else" you know what I mean. "God wanted it this way so I don't have to do it". So therapy

is a huge deal for some of these people, actually work toward the goal, so that's the different way of life." (Andrea, Canadian)

Interestingly this therapist explains how therapy might be difficult for some patients due to the belief that their disability is God's will for them.

A nurse explained that stroke may be seen as a challenge in Islamic countries like Kuwait.

" some people say that it's not like a punishment, but it's the challenge for you. This is some sort of challenge for you from the God and then that's how you take it." (Helen, Malaysian)

Religion appeared to be an important factor in rehabilitation of patients in Kuwait, according to these health professionals. More in-depth answers were provided regarding how they thought religion affects psychosocial recovery post-stroke and these will be discussed in more detail in the next chapter.

Chapter Summary

This chapter presented results from the first part of phase 4 of this project. The aim of this part was to explore health professionals' perception of quality of life, life satisfaction post-stroke and their perception of cultural characteristics peculiar to stroke survivors and rehabilitation in Kuwait.

Quality of life and life satisfaction were perceived to be similar but not identical constructs by the health professionals interviewed. Quality of life was expressed as being more related to function and good health, while life satisfaction was perceived to be related to feelings of happiness and acceptance of the new situation post-stroke. Six main subthemes were

discussed as perceived determinants of quality of life post-stroke, these were: Function and dependency, relationships, personal values, treatment and rehabilitation, finances and lifestyle post-stroke. Western therapists placed more emphasis on personal values than the other therapists. This may be indicative of a different world view based on their background, including their education in the biopsychosocial approach to rehabilitation, as will be discussed in Chapter 9. Determinants of life satisfaction discussed included faith and spirituality, adjustment and new perspective, goals and function, and self reflection. Minor themes mentioned included the impact of pleasurable activities, public reaction and rehabilitation/environment.

Health professionals interviewed discussed eight main cultural characteristics related to stroke experience and rehabilitation in Kuwait. These were family involvement, education, prevailing attitude to stroke, limited patient goals, dependency and presence of maids, social stigma, finances and Muslim religion.

Chapter 8

Chapter 8

Results of Phase 4 (Part 2)

Health Professionals' Views on Phase 3 Results and Clinical Applications

The main aim of the latter part of the interviews in phase 4 was to explore the perceptions of the health professionals regarding the results of phase 3 of this project and how these results could be applied clinically. Health professionals were explained the results of the study and they discussed whether they felt the results were expected or not, and their interpretations of the findings.

8.1: Comments on Relationship between Self-Efficacy and Life Satisfaction

The results of the current project indicating a positive relationship between self-efficacy and life satisfaction was reported to be expected by the health professionals interviewed. All of them voiced that they were not surprised with the results. Reasons which they thought responsible for the associations were given:

> "I think it is expected. When the person from inside wants to do something, he will try anyway, he will do the exercises, he will do his best and he will add something and it will help because, yes, (he says to himself) I will do this and when he will

succeed in doing he will get more satisfaction, I have achieved something, I think they

are correlated with each other." (Mohammed, Kuwaiti).

In the above quotation, the therapist viewed self-efficacy as a willingness to achieve the best,

an internal determination that would cause the patient to try to succeed in the task at hand.

Achievement of the task is what causes satisfaction in Mohammed's point of view. A similar

view was expressed in the quotation below.

"Well, very much because what that communicates is that someone is very internally

motivated and if you are internally motivated to enjoy life, to be satisfied with life, to

find the positives in life, to enhance your life you are obviously going to live a much

better quality life. If the person doesn't have that basic innate ability to motivate

themselves and find those positives and those points that inspire them and give them

life satisfaction obviously that is going to affect the rehabilitation, it's going to affect

their attitudes for rehabilitation which translates ultimately into their ability to

participate in a satisfactory way in life and to function in life, both mentally,

physically and spiritually so self-efficacy is very, very important." (Katie, American)

Katie viewed self-efficacy as a type of internal motivation, which enables one to view life

differently and see the positives thus a more positive report of satisfaction. She also pointed

out how lack of self-efficacy and associated satisfaction will affect participation in

rehabilitation and functioning post-stroke.

A few therapists expressed the view that self-efficacy was the same as positive thinking and

was related to achieving goals and faster recovery, thus its association with life satisfaction.

"Yeah, I think if you think positive that you will achieve this goal, no matter how hard you have to work for this you will be, you are more satisfied, because you are doing something to have a change and in the end if you are achieving this goal you are more satisfied." (Ann, German)

"I think it's quite correlated, it should be correlated; there is a relationship between both because no matter what other might do for you - if you don't have that inner that inner determination, the strength within you, faith within yeah, I want to be better or I want to do this. I think it's that person's positive approach helps him to recover faster than everybody else doing the treatment. No matter what others may do but if you don't have the positive thinking that I should be okay or if it's like, oh never mind, let them do, if you are not strong enough, I don't think that we will be able to help them." (Deepa, Indian)

In both quotations above the health professionals mentioned the need for positive thinking which they understood self-efficacy to be associated with. They both mentioned the personal nature of it and how it assists in rehabilitation to achieve the set goals. Goal achievement appears to be a perceived mediating factor between self-efficacy and life satisfaction, according to these health professionals.

"I think if your feeling is that you can do it, and like let's say if you cannot walk because you have one side weaknesses and you believe inside your, I mean, self-efficacy, you have a belief that one day you can walk as before and then you try to achieve it with all the facilities, treatment, and all these things. And if one day you recover and then you are satisfied with your life, you know what I mean, so I think

they are related. If they recover, of course, it can contribute to satisfaction." (Helen,

Malaysian)

Although goal achievement was considered to cause satisfaction, it was also pointed out that in cases where initially patients had high self-efficacy and goals were not achieved, this could lead to depression.

 "...but if they try hard and because of the some factor they cannot heal or they cannot regain what they have before, then they will feel depressed instead of satisfied with their life......" (Helen, Malaysian)

"They cannot achieve what they want, so this will make them more depressed rather than satisfied. So it always has a positive and negative relationship." (Helen, Malaysian)

The quotations above highlighted that both positive and negative consequences can result from high self-efficacy, based on whether or not patients' goals were achieved.

Matt pointed out that it should not be assumed that only those patients with high self-efficacy are satisfied, because those with low self-efficacy could be satisfied with their lives also.

"They are rare, but there are people that think that I can't really change it that, I am okay with that. So they can – I think they can be satisfied too, but I think it would be more common for people to want to be able to change it and if they could they would be more satisfied, yeah, I agree but I wouldn't shock me.... (the reverse)" (Matt, Canadian)

Although most therapists found meaning in the positive relationship between self-efficacy and life satisfaction, the above quotation reflects that it is also possible that in situations where patients feel they cannot change anything but have accepted their situation to also rate highly on life satisfaction despite low self-efficacy scores. No cultural differences were identified among the health professions regarding their understanding of the obtained relationship between self-efficacy and life satisfaction.

8.2: Clinical Applications of the Relationship between Self-efficacy and Life Satisfaction

Eight sub themes were discussed regarding how these project results can be applied clinically to enhance self-efficacy and life satisfaction among stroke patients. These sub themes were: Identify change, Providing Incentives, Environment and therapy, Awareness of individual differences, Providing examples, Motivating and encouraging patients, Setting goals, and Education. In discussing these eight areas, health professionals appeared to offer conflicting perspectives on control, ranging from their role as the professional in charge of providing care/rehabilitation, to their desire for the stroke survivor to participate in the process. These issues will be highlighted as the subthemes are discussed.

1) Identify Change

Many of the health professionals interviewed expressed the belief that life satisfaction can be enhanced by identifying and demonstrating change to patients, which will increase self-efficacy and satisfaction. The following statements were made:

"Yeah, by showing them their good results, discuss their improvements and if they are not improving, we can use other techniques [to] probably reinforce them." (Ahmed, Kuwaiti)

The quotation above also pointed out the need to identify alternate ways to increase self-efficacy and satisfaction in situations whereby observable signs of improvement are not present.

"Again, just showing people where they where and where they come and they have to say oh yeah we started in last February or we started in October...." (Andrea, Canadian)

"I might use goniometric measurement to show change and write it down and bring it up in front of them every time and say last week you were 35 degrees of elbow flexion and this week you are 50 and this week to 55. At last you have made a whole 5 degrees..... The person that's intrinsically motivated would probably not need to do that, I would just have to show them once that they felt a little different and for them it might be that I point out, you know, you notice you are touching your head now when you reach up, and when they realize that that's all they would need, and it would be more important to them than me cheering them on with the goniometer, that's all." (Matt, Canadian)

Therapists pointed out the need for some objective measurement. In both quotations above, participants suggested the use of time or an objective measure of impairment and disability to identify change. Similar views were expressed in the quotation below. Health professionals

pointed out that patients themselves do not always see the small gains they make in rehabilitation and require their therapist to point these out and celebrate them.

> "We have to show them that they are succeeding because, you know, sometimes with these cases we are not seeing big changes in a short period of time, but we can see small changes. Can we make our patients see these small changes that they are really improving? Yesterday, you were not lifting your ankle, you are not able dorsiflex, but today there is some flicker, there is improvement, yes, please. Now we can work on this, yes, this is something, we have achieved it, we can work" (Mohammed, Kuwaiti)

Identifying change was expressed as a vital aspect of enhancing self-efficacy and increasing life satisfaction. In situations where change is not measurable, the need to identify another means to reinforce self-efficacy is required. The possibility of negative changes and loss of self-efficacy during rehabilitation was not mentioned by the health professionals interviewed.

The health professionals' statements clearly indicated that identifying change was within their control, however this could then be used to facilitate increased self-efficacy of the stroke survivor. Identifying changes was a strategy described by health professionals from all the different cultural backgrounds.

2) Providing Incentives

Providing patients with some type of incentive or reward for participation in rehabilitation and goal achievement was suggested to help increase self-efficacy and life satisfaction.

> "So every time they do something encourage them, give them an incentive, something like that, something to make them feel happy, yeah, you have done, you are going to achieve it, come and try. (Deepa, Indian)

"If somebody has a trophy room, I would probably need to give them lots of extrinsic rewards. I would need to show them on a measuring tape what they did or a video tape, or give them lots of feedback in their face, cheerleading awards and lots of tangible goals that they can see and be reminded of. For the person that is motivated within or doesn't require the trophy room, he is okay with knowing what they are capable, what their past achievements were and that was good enough. They don't need the fuss around and that person who is going to be more rewarded by his success on a personal level then me cheerleading for them. So just being aware of that and the differences in personality, and you know, you catered to the best you can. (Matt, Canadian)

The need to identify what a patient would regard as an incentive was emphasized in the above quotation. Identifying change might be an incentive; however other patients might want more tangible rewards of their achievements. The speech and language therapist mentioned the use of food items liked by the patient as rewards. Other therapists mentioned that in physical rehabilitation, rewards might be doing activities enjoyed by the patient. Providing incentives appeared not to be related to cultural backgrounds as both Western and Kuwaiti therapists mentioned various types of incentives. However, Western therapists suggested enjoyable activities as incentives more than the therapists of other backgrounds. Similar to the previous subtheme, in deciding upon and providing incentives, the health professional statements indicated that they took the role of the person in control of the rehabilitation relationship. They regarded this as a positive control to increase motivation and cooperation of the stroke survivor.

3) Environment and Therapy

Health professionals also mentioned that the setting of rehabilitation and quality of therapy helped in increasing self-efficacy and satisfaction.

"..and we should also show that we have the facilities, "we will help you with this, if you need this we will do this". So I think the whole package, of course, we can do in the clinical care.. if we motivate them, give example, have a good rehabilitation centre with all the exercise program and all these thing, that's what help them to recover." (Helen, Malaysian)

"The other thing is to let her environment boost her, help her more not just from herself but with the others, this will increase her also power to work harder and give more, this is what I mean. (Khadeja, Kuwaiti)

The environment and rehabilitation facilities were seen as being able to increase self-efficacy in stroke patients. Patients seeing appropriate equipment were thought to feel they are receiving the best care and this could increase their self-efficacy. Khadeja also mentioned the social environment and the possible effect of others to increase self-efficacy.

4) Awareness of Individual Differences

The view that each patient is different and must be treated individually was mentioned. Therapists mentioned that their role included being aware of what the patient is going through.

"Sometimes you have to try to be read between the lines a little bit, but again these awareness as I think all help us to appropriately motivate a patient, I don't think we have to be supernatural in some respect. I think we can only be expected to do the

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best we can, but I think being conscious, being aware and being present with each individual patient is important." (Katie, American)

"So just being aware of that and the differences in personality, and you know, you catered to the best you can." (Matt, Canadian)

Other non Western therapists also commented on awareness of the patients' own feelings and needs, and tailoring rehabilitation to meet these needs. Khadeja expressed the following :

"I always say, get the patients involve, let them go back to their normal life. Go deeply, see what the patient really need. The thing is we don't discuss the goals really, one-on-one with the patient, what exactly you want to go back to, focus on that and miracles will happen, I believe that's one" (Khadeja, Kuwaiti).

Khadeja in the quotation above, used the phrase "miracles will happen" to emphasize the importance of discussing goals and tailoring rehabilitation specifically for patients. The idea of being aware of individual differences in order to facilitate self-efficacy was expressed by therapists from Western countries and a Kuwaiti therapist. However Western therapists were more attuned to this.

5) Providing Patient Examples

Showing patients examples of other patients who have improved was said to help increase self-efficacy and improve life satisfaction.

"We can show them to other patients who have recovered that helps a lot. I have seen many patients , I mean, even other disease, you show another patient who have

recovered, who have gone through the pain......., it can help them to develop their

strength, you know, "yes I can do it". If it's possible for that person it's not

impossible for you" (Deepa, Indian)

Deepa described how observing others can empower the stroke survivor to try. Similar views
were expressed by other therapists.

> "The second thing maybe you can show examples of other patient that already are
> successful in, I mean, recovery from stroke. So maybe by looking at this person, this
> patient before you see and you give example, look at this patient, this patient have
> similar like you, but now with the self-efficacy, strong self-efficacy, with the
> motivation, with all the exercise and you can see that this patient is recovered now.
> (Helen, Malaysian)

Providing examples of other patients was expressed as an effective way of enhancing self-
efficacy in clinical practice. This view did not appear to be related to the cultural background
of the health professional interviewed.

6) Motivating and Encouraging Patients

Motivating and encouraging patients were the most mentioned strategies to increase self-
efficacy and life satisfaction

> "Okay, in the clinical practice I think the first thing we need to do is we need to
> motivate the patient maybe..with our program or I don't know, but you would need to
> motivate the patient that they need to have a strong belief that they can do it. They

can do and they can achieve what they want maybe not at the maximum level, but not at the minimum level. At least they will recover something. (Helen, Malaysian)

"Motivate them in whatever we are doing, initially they will be completely dependent on you, but gradually we can help them to become independent. (Deepa, Indian)

The importance of motivating patients, not only in their ability to improve but also in participating in the therapy or treatment being administered was expressed in both quotations above. The importance of encouragement was also mentioned:

"as I mentioned in the beginning I believe our role is to encourage the patient." (Katie, American)

"Yes, basically when we are sitting with these patients and we have to give them a lot of encouragement." (Mohammed, Kuwaiti)

Avoiding any expressions of negativity was highlighted by some therapists.

"We should not express negativity to this patient, we should be always positive in dealing with them that 'you can do, you can do it,' you have experience plus explanation." (Aylne, Philippine)

"Keep them motivating in every step, show that they are needed, show them that they are required, 'you are important', they are so important to everyone around, make them just feel that then show and them that their family is supportive and their family is there for them, keep them happy, I mean, don't let them do any – whatever make them develop a negative attitude or whatever, whatever belief they have, whatever doubt they have, whatever kind of – they are anxious about everything." (Deepa, Indian)

From both quotations above, both therapists suggested avoidance of negativity from the patient and the family would help to increase self-efficacy and satisfaction.

Views regarding motivation and encouragement of patients to enhance self-efficacy do not seem to relate to the health professionals' cultural background.

7) Setting Goals

Working towards a set goal was expressed as important in increasing self-efficacy and associated life satisfaction.

"First, to find out what their goal is and if they have a goal or if they don't, then you might want to show them what can be a goal, not to tell them that should be your goal that is something what -- what can be a goal, just to give example and give them time to think about that. And to list something, what can be done to achieve these goals and, yeah, I wouldn't necessarily give the time that you have to achieve this in this period of time because that's individual, so no pressure, but pressure in the right time if they -- you need to motivate. I think that's the thing what drives and what drives you… motivation." (Anna, German)

In the quotation above, Anna explained that providing patients with options of goals to work towards can invite cooperation and providing pressure at the right time can increase the motivation required to achieve the set goals.

> "I think by breaking down the goals for people. When I show them the things that they've achieved then I find out that their outlook is more positive. When they are lying in bed and they feel like they can't do anything then yeah, I mean, I have a lot of people who don't think life is good, but when we break it down and say okay look at where we were and look at where we have come." (Andrea, Canadian)

Breaking down goals, in addition to being used to plan treatment, can be used to get patients to appreciate the improvements they have made. Thus, this would help with increasing satisfaction, according to several health professionals.

> "Like I said, if you know the patient setting the goals together, it's silly really, to do the treatment same for everybody. Each one has his own goals. If we started like this the patients will come empowered to do the next thing his schedule, not my schedule in his own schedule." (Khadeja, Kuwait)

Khadeja highlighted the importance of individual goals for patients and setting them with the patients. This goal-setting strategy was perceived to increase self-efficacy and motivation.

Setting goals was mentioned as an important strategy to increase self-efficacy and life satisfaction in stroke patients. It was mentioned that goals have to be set with the patient and specific to their individual needs. Such goals guide therapy and help to identify change. However in the previous chapter health professionals mentioned the difficulty in getting patients to list their personal goals.

In this subtheme, health professionals' statements indicated a mutual cooperation relationship with the stroke patient. They highlighted the need for goals to be made by the patient, however also mentioned that they (health professionals) can show the patient what could be an appropriate goal. The patient was therefore viewed as an active participant in the rehabilitation process rather than a passive recipient of therapy.

8) Patient Education

Improving patients' knowledge of stroke and rehabilitation through offering resources, and education by the health professional were voiced as strategies to help increase self-efficacy and life satisfaction post-stroke.

> "A couple of things that come to mind, perhaps if you see a need, offering resources to patients if you feel that they need psychological health I think it's appropriate for therapist to offer resources and again I think education to the extent that the individual therapist is able to educate their patient is important, as I mentioned to help them become more self aware, but again this is going to vary on the ability of some therapists because this is not traditional what we are educating in to a large extent."
> (Katie, American)

Educating the patients specifically on psychological issues was also mentioned as being important.

"Not only, I mean, the physical, but psychological also you need to have a small talk with the patient, so they are motivated ...., they can achieve this. If you have a good self-efficacy, you have motivation in yourself, so this is what we need to do to our patient." (Helen, Malaysian)

"I think we need really to educate them and make them believe that they can do because some people, how much we talk to them also sometimes they will not believe that they can do this, but I think if you really show example and all these they really will believe, but of course, they need to." (Helen, Malaysian)

The importance of educating patients to aid in increasing self-efficacy and satisfaction was voiced by the health professionals interviewed. Education strategies suggested involved talks about the importance of motivation and self-efficacy, recovery and the patients' role in rehabilitation.

This subtheme indicates a shift in perceptions of control among the health professionals. Initially, control in provision of education and educational resources was understood to be with the health professional, however as the quotations above reflect, it was hoped that education would enhance the stroke patients' sense of self awareness and self-efficacy

9) **Other Issues Raised**

In addition to the subthemes mention above, one therapist described the importance of partnering with the families of stroke survivors in enhancing self- efficacy and life satisfaction in clinical setting.

> "There should be partnership, okay, health professionals, families, the patient is the most important in there, how to motivate them, to arouse him that he can do it, he can recover, okay. And family is really important as I told you I have seen that, that wife is always there, day and night, encouraging 'no, you can do' and then you see the result. (Alyne, Philippine)

Similar idea of involving the family was also mentioned by Helen in the quotation below:

> "Psychological, may be we can involve with the family ... at the beginning they will have a depression, so a counsellor, yeah, so that they can have somebody to counsel them and then by doing all this I think this will help them. (Helen, Malaysian)

Helen also suggested that stroke survivors could be referred to a counsellor to help them work through issues surrounding depression, self-efficacy and life satisfaction.

8.3: Association between Religious faith and Self-efficacy/Life Satisfaction

The second set of results from the Phase 3 study concerned the lack of relationship between religious faith and self-efficacy, and between religious faith and life satisfaction. The majority of the health professionals interviewed were surprised by this finding. Only one, however, was not surprised with the results.

The following statements were made:

> "I would expected that the more deeper the person is in the religious faith, you know, their life satisfaction would be better, but I know that always doesn't happen, because I have seen examples on it but it's surprised me that globally you really found that doesn't happen"…..(Andrea, Canadian)

> "Because I think always I really believe that the religion has a big effect on the life satisfaction of any person. (Khadeja, Kuwaiti)

The expectation from the health professionals interviewed was that those with higher religious faith scores would rate higher in life satisfaction. Some gave their own personal experience regarding why they thought the association would be present:

> "You know, when you believe that anything happens to you is from God and always it's for the good of you, even if I have a stroke I would know, I believe strongly that God did this to me or sometimes for a good thing in the long run." (Khadeja, Kuwait)

"They should have a strong faith on yourself, I mean, faith cannot come only from yourself along it has to come from some kind of, I mean, there is a external force, the power has to come from there but it cannot be just your or maybe it can be ....I don't know, I think it's really required, very necessary". (Deepa, Indian)

Interestingly, although the two quotations above are from therapists of different cultures and religions, they both appear to insist, based on personal experience, that belief in an external force has a role in coping during negative circumstances. A similar view was expressed by a Canadian therapist below:

" I personally find it easier dealing with somebody that has a religious affiliation, obviously even easier if it's same as mine, if it's not then I still find it easier because - - but they seem to be more at peace and they seem to be – if they still feel that there is a role for them to play within that scenario then I find them easier to deal with than somebody that has no hope. And there are more people that have no hope, there are more people in the no religion side that would it hard to define hope than those that do have it." (Matt, Canadian)

Matt somewhat equated religious beliefs with hope and lack of religious beliefs as a possible lack of hope. When questioned further on this point, he mentioned that others without religious beliefs probably have a replacement that could create the hope needed for recovery:

"The person that's religious in the same scenario would likely feel that there is some sense of purpose even for that experience, so they would likely have more hope. That doesn't mean that the atheist couldn't find something to get them hopeful and they may have some relationship they want to restore and they are going to fight to get it

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back or they do something rather than religious needs, just easier I find personally, that's all. (Matt, Canadian)

Responses to the project's results concerning religious faith appeared to be based on personal experience. Those without strong religious convictions did not want to comment when asked what they thought. An American therapist, however, had strong views regarding this issue, streaming from her negative experience with religion growing up.

" guess we have to speak here from my personal experience, I actually spent a large percentage of my life very religious and became a little more aware of why I believed, what I believed, made some different choices and decisions in my life and even though I would say today that I am spiritual, I am not religious and –in retrospect, putting myself in those shoes, I think initially having a faith and believing something external to myself from a religious point of view although it's helpful, I don't think its sustaining long term when it comes down to the nuts and bolts of dealing with the effects of a condition like this. (Katie, American)

In this quotation although she acknowledged that religious faith could have a positive role, she was doubtful on its long term sustaining effect in prolonged disability conditions like stroke. She then further explained the difference between spirituality and religion and the importance, in her own perception, of spirituality to satisfaction as opposed to external religious rituals.

"I think ultimate satisfaction in one's life is a deeper more internal process. Now some might argue God is that deeper more internal process and that is quite possible, but if so then I think it's more a pure source than even religion can give it, because again religion tends to be more external, tends to be more based on conditions and

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rituals, this is just a true state of being and understanding and that sounds probably little, a little bit deep but in my personal opinion this is why it is not surprising me, I guess because of the switch I have made in my life from being very faith based and religious based to now being more spiritual based in my own belief." (Katie, American)

Although the majority of the health professionals interviewed were surprised with the lack of association between religious faith and self-efficacy/life satisfaction found in this study, one therapist felt that the results were expected because of the difference between spirituality and religion. Other health professionals offered the following suggestions as to why the association was not identified.

"The other thing is why didn't you see the relation between religion and the self satisfaction or the efficacy, I think because in a way they stop fighting for things and I don't think this is related to religion more or less, but they stop, they stop fighting for their rights for example or doing things". (Khadeja, Kuwaiti)

In this quotation, Khadeja believed perhaps the stroke patients interviewed had already lost hope and given up hence the lack of association noted. Others believed the difference between verbal expression of religion and action could contribute to the lack of association:

"Maybe they are just verbal, they say that religion is the most important thing but they don't apply it to the recovery part" (Ahmed, Kuwaiti)

"For me, if I will believe that what's occurring to me is coming from God, then I will accept that, this is what I believe, this is the real belief. But if you would take the

religion as just doing the activities, praying, fasting and all these things without this belief inside us, what was coming from God for me, okay. This will give him satisfaction, but if it was just movements he is doing, it's just actions" (Mohammed, Kuwaiti)

In both quotations above, Kuwaiti therapists expressed the view that they expected the practice of religion to be associated with higher report of satisfaction. They appear to suggest that perhaps the stroke participants did not apply their religious beliefs and practices (i.e. fasting and praying) to recovery. Other suggestions for the lack of association were expressed:

"Then maybe that is not the proper measurement tool potentially, that we are not asking right questions to determine if they are truly finding any of their satisfaction from their religious background or their religion really isn't that meaningful to them. There is a potential that it's the name only, it's not necessarily a practice or a believed practice. If it's just a practice and it's not a deep down believe that actually influences their life in hard times and I guess it would not really matter."(Matt, Canadian)

The possibility that the measurement tool was not sensitive enough to detect changes in religious faith was a suggestion given by Matt in the quotation above, however similar to the other therapists he mentioned the possibility of a difference between belief and practice of religion and using it in coping and recovery post-stroke.

Three subthemes were discussed regarding the role of religious faith in recovery and rehabilitation from the perspectives of the health professionals.

1) Religious coping and acceptance

2) Fatalistic beliefs

3) Therapists' role with religious issues

1)   Religious Coping and Acceptance

Most health professionals interviewed believed that religious coping helped with acceptance of the new situation post-stroke.

> "Now, what I have noticed probably in regard to a faith based acceptance of their condition is they may work through things a little bit more quickly or a little bit differently than someone who does not have a specific religious belief." (Katie, American)

The acknowledgment that faith based coping can have an influence post-stroke was emphasized in the quotation above. Matt elaborated a bit further on the process he thought was involved in religious coping below:

> "Well, I think if – I felt that there is some sort of supreme being directing traffic or directing the flow of things and the people that seem to feel that way can manage better. So if I have a stroke, I mean, and again it depends on this thing or in God or if they accepted as something given from God, then it's how I am going to be rest of the while. And then if that person cannot blame God and accepted that something given

that, there is going to be grace or some kind of a supreme new direction that seems more hopeful than if there wasn't. (Matt, Canadian)

"So I am religious I will cope with this crippling disease. I am religious I will cope with this terminal *disease* or, anyway it's coping. People, some people - religion help you to cope better than not having any religion and this is what I believe. (Khadeja, Kuwaiti)

A Kuwaiti therapist mentioned that acceptance was a major part of religious coping in terminal conditions in the quotation below. Acceptance was seen as "pure religion". She also emphasized that acceptance was also necessary in disabling conditions such as stroke and thought that religious beliefs helped to achieve this.

"But if you will tell me that cancer patient and he has a strong religion and you will tell him you will die, will he collapse ?, you see, would he go to drugs, would he go and fall and drink? No, he will accept and live the rest of his –this religion, this is pure religion. This is what has pleased you, are you in peace for this thing or do you live peacefully with this decision or this disease, it's a terminal disease. (Khadeja, Kuwait)

Religious instruction was also mentioned to help not only in coping but also in facilitating motivation to continue to work harder during rehabilitation.

"Well, the religion tells us to not to give up, to try harder and harder, to pray and to work until we get the debt down or work done and I think there is the same complex,

if you have a problem, you don't have to give up very easily, try hard, harder and harder until you will get the results you want." (Ahmed, Kuwaiti)

Ahmed was further asked to elaborate on how acceptance helps during rehabilitation:

"No, I mean, it depends on the type of the disability that was just one example, not preventing them from recovering but if you don't accept your problem, you may not return to 100% accuracy. So having faith and having acceptance will help you learning new skills and new ways and becoming more functional." (Ahmed, Kuwaiti)

He explained the importance of acceptance in learning new skills and moving on with life post-stroke as expressed in the quotation above.

The issue of acceptance appeared to be culturally influenced as health professionals from other (non-Kuwaiti) cultures viewed acceptance in more negative terms as fatalism, which they thought prevented active participation in rehabilitation. This is discussed in the next section.

The Kuwaitis interviewed felt this issue of acceptance was a positive aspect of their way of life and a coping strategy they grew up with.

"This is how we are being raised, something bad happens we accept it. We weren't learnt, for example, for a patient, she doesn't know that by working harder she will improve. Again, I am saying to you, it's the education, it's the knowledge, it's the knowing about something in the right way, not just fictions…we are raised to accept things happen as it is. (Khadeja, Kuwaiti)

Although the issue of acceptance can be viewed negatively, Mohammed explained that acceptance is a positive strategy that could lead to increased motivation.

"if they are accepting, they are willing to do something, what I feel is acceptance is a positive way. This is what – not accepting but to just surrender and stop doing anything. Accepting means that I am accepting what I have, that I can do something to improve it. If he will accept his disease, now he will try to see what types of treatments that are possible and he can achieve, maybe his treatments are not so good but he is trying to do something and this is good. (Mohammed, Kuwait)

Interestingly, Helen below who was of the Muslim faith, although non-Kuwaiti, explained the positive and negative effects that acceptance can have on a patient.

"acceptance in the stroke patient, they have negative and positive effect. Because if, at the early stage you say that this is my fate, I am going to accept it. Some of these people they wouldn't do anything, they just accept it, this is what God want me to do. This is going to happen and this is what sometimes demotivate them, but the other side is the positive side. This is what God give me, so even though you work hard, you try hard, but if you are recovered, you are recovered, if you are not recovered, then they will just accept it. So that's why I say sometimes it's positive sometimes it can be negative"(Helen, Malaysian)

Religious coping and acceptance was expressed as a culturally sensitive issue in rehabilitating the stroke patient. While the Kuwaitis viewed acceptance as necessary and a true reflection of their religion, Western therapists generally viewed religious coping and acceptance as different, with acceptance more related to fatalistic beliefs, which will be discussed next.

2) Fatalistic Beliefs

Some health professionals identified that patients could have fatalistic beliefs which they thought could affect their participation in rehabilitation:

> "So some people even though they try hard, but they believe that after you pray, after you do everything but if the condition is still there, then in our belief that this is your fate. You can't do much already because you already do what you can do, but if the fate is already like that, it's like that you can't change the fate. You can try to improve, but if the God willing then, then thank God, but if the God is not willing then it's fate, because I think that's the belief. (Helen, Malaysian)

In the above quotation, Helen suggested that certain religions are associated with fatalistic beliefs and can affect the amount of effort required to make change during rehabilitation.

Matt explained in the quotation below that although fatalistic beliefs can lead to reduced personal responsibility in his opinion, religious faith can be used to fight through the challenges.

> "I think they are able to deflect some of the responsibility or the consequence or allow some of weight of the experience to be placed on their God or God instead of taking it all by saying it's a shame that I have lost this function but it's according to God's will. It seems to make it easier to deal with than if it was just too bad for me, why is there a rain cloud over me, nobody else because, you can also say that God will take you through it, as oppose to I have to fight through it on my own." (Matt, Canadian)

Fatalistic beliefs appeared to be an issue that can limit rehabilitation from some therapists' perspectives. This highlights the importance of education of patients on their role in rehabilitation regardless of religious beliefs.

3) Therapists' Role with Religious Issues

Some therapists expressed the view that health professionals had a role to play in enhancing religious faith if that helped motivate patients during therapy.

> "As they let us and within our college guidelines. In Kuwait there is none, so it's a personal choice as to how far you get involved in it. Where it's (religious faith) helpful, I think you get involved but where it's potentially going to cause problems and it's up to the patient to decide how much we can get involved in that. (Matt, Canadian)

A Kuwaiti therapist pointed out that religion was part of life in Kuwait and could not be separated from rehabilitation. If religion could be used to motivate patients to improve and increase their function and satisfaction then they considered it does have a role.

> "We have to...Most of people even here in Kuwait they are Muslims even some of them but they are still believers, those group of unbelievers they are still minority. We can do many things and this is, I mean religion is not outside the hospital or inside the mosque alone, no, it is living with us in every place and at every time so it is something, I mean, part of our life, we can utilise it to the maximum to help these patients to achieve something, at least not in terms of function but at least of satisfaction, at least trying to do something". (Mohammed, Kuwaiti)

Health professionals mentioned the need to use religious beliefs to enhance motivation during rehabilitation as religion is an important part of life amongst Kuwaiti patients. However caution must be taken as issues of religious coping, acceptance and fatalistic beliefs appear to differ amongst individuals as highlighted in the two previous sections.

Chapter Summary

This chapter presented the results of the second part of the health professional interviews. The aim of this part was to explore the health professionals' views regarding the results of the Phase 3 study investigating the relationships between self-efficacy, life satisfaction and religious faith in stroke survivors living in Kuwait. They were also asked how they thought the results could be applied in the clinical setting from their perspective.

Results regarding the positive association between self-efficacy and life satisfaction were expected by all the health professional interviewed. However it was also pointed out that stroke survivors with low self- efficacy could report high life satisfaction. Goal achievement was expressed as the mediator between self-efficacy and life satisfaction. Strategies to enhance self-efficacy expressed by the health professionals included: identifying change, providing incentives, rehabilitation and environment, providing examples of other patients, encouraging and motivating, identifying individual differences, setting goals, and education of the patient. In discussing these strategies to enhance self-efficacy and life satisfaction, health professionals struggled with identifying who controlled the encounter. Many positioned themselves as in control of goals, incentives and therapy activities, whilst aiming that although they were in control of the rehabilitation relationship, however their aim was to enhance active participation of the stroke patient.

The results of phase 3 of this project showing a lack of relationship between religious faith and self-efficacy and between religious faith and life satisfaction came as a surprise to most of the health professionals interviewed. The majority expressed the view that they had expected to see a positive relationship between religious faith and life satisfaction. Reasons for the lack of relationship obtained included use of an inappropriate measurement tool, and possible lack of application of religious coping in the stroke recovery process despite voiced religiosity by stroke survivors. Three subthemes were identified in discussing their perceived association between religious faith and recovery/rehabilitation. These were: religious coping and acceptance, fatalistic beliefs and the therapists' role with religious issues in rehabilitation. While Kuwaiti therapists viewed religious coping in a positive light and as assisting in acceptance of disability, some Western health professionals felt that religious beliefs caused patients to place responsibility of their progress in God's hands and so not try as much in rehabilitation. These different views may have been shaped by the home culture of the health professionals. Stanhope (2002) describes different allocation of responsibility over symptoms based on cultural backgrounds, with Western cultures more attuned to taking more personal responsibility. These issues will be discussed in more detail in chapter 9.

Chapter 9

Chapter 9

Discussion

The overall research question of the current project was: ''What influences patients' experiences of stroke and life satisfaction in Kuwait?'' More specific research questions were:

1) What are stroke survivors' experiences of stroke in Kuwait?

2) What is the relationship between self-efficacy, life satisfaction and religious faith in stroke patients living in Kuwait?

3) What are the cultural influences on stroke experience and rehabilitation in Kuwait from the health professional's perspective?

Four main phases were involved in this study. The first phase involved the use of semi-structured interviews to explore experiences of stroke amongst survivors living in Kuwait. Themes from these interviews were used in phase two in adapting the Chronic Disease Self-Efficacy scales to produce a scale specific to psychosocial adaptation for stroke patients living in Kuwait. Phase three involved the testing of the Psychosocial Adaptation Self-efficacy Scale, the standardised Generalised Self-efficacy Scale, a life satisfaction measure and the standardized Santa Clara Strength of Religious Faith Questionnaire (SCSROF) on 40 female stroke survivors in Kuwait. The final phase of this project (phase four) involved semi-structured interviews with 12 health professionals from different professional backgrounds working with stroke patients in Kuwait. Topics covered in the interviews included their perceptions of the challenges faced by stroke survivors, any cultural influences and

differences inferred while working in Kuwait and their suggestions about the clinical implications of the results of phase three of the project (i.e. investigations of the relationship between self–efficacy, life satisfaction and religious faith).

This chapter will discuss the findings of all phases of this project. These findings will be discussed under the following headings: Impact of Stroke, Cultural Differences, Results of Phase 3 Study, Clinical Application, Critical Evaluation of this Project, Reflection of the research process and New Contributions to Knowledge.

9.1: Impact of Stroke in Patients Living in Kuwait

Research Question 1: What are stroke survivors' experiences of stroke in Kuwait?

Participants in Kuwait described an experience of stroke involving physical and speech difficulties, psychological difficulties including challenges to and interpretations through religious beliefs, and social changes. These will be discussed in the following sections.

9.1.1 Physical and Speech Difficulties

i) Physical Difficulties:

Reduced balance, difficulty walking, reduced upper limb function and difficulties with activities of daily living were the main physical challenges expressed by the stroke patients living in Kuwait. These results are consistent with those of other studies, both in the Arabic and Western worlds. Al-Orabi (2002) reported similar results in stroke patients living in Jordan. He investigated the experiences of stroke patients in Jordan with the use of semi-

structured interviews, and found that physical difficulties were important experiences post stroke. Unlike the current project, interviews were conducted fully in Arabic and then transcribed. Transcripts in the project by Al- Orabi were then translated to English prior to data analysis. Advantages of this included obtaining rich expressions of the experience of stroke in the native language of the participants. Participants could possibly have expressed more than they did in the current project in Kuwait, where disclosure was limited due to the presence of an interpreter.

Pound, Gompertz and Ebrahim (1998), in the UK, also reported on stroke patients' concerns. Their sample was made up of 40 stroke survivors aged between 40 and 87. Twelve participants of the 40 interviewed expressed difficulties with washing, bathing and dressing. However, for some participants their difficulties were magnified due to the location of the bathroom (i.e upstairs) and difficulty with access, whilst others were waiting for aids and adaptations to be put into the bathroom to make bathing easier. Some participants in the Kuwait sample mentioned difficulty bathing but this was not due to upstairs access or awaiting aids/ appliances, but rather, reflected physical impairments. Fourteen of the participants interviewed in Pound et al's study mentioned difficulties with walking. However, their concerns appeared to be focused on their walking ability rather than the reaction from the public (i.e any felt social stigma associated with an altered walking pattern). This is somewhat different from the results in the current study carried out in Kuwait where social stigma associated with altered walking pattern was expressed by some of the participants and health professionals interviewed. As a further possible limitation making comparison with the current study uncertain, only 49% of the approached target group (40 of 82 contacted) participated in the study by Pound et al (1998) which means that their findings could possibly reflect the concerns of the less disabled stroke survivors.

Similar concerns with physical difficulties, as obtained from the current project, were reported by Murray and Harrison (2004) and by Dowswell, Lawler, Dowswell et al (2000) in the UK. Murray and Harrison (2004) investigated the experience of being a stroke survivor with the use of both face-to-face interviews and e-mail interviews. Ten participants aged between 38 and 81 (mean age was 48.8 yrs) participated in the study. Data were analysed with interpretative phenomenological analysis which yielded a rich interpretation of their experience. Participants expressed concerns with a combination of physical disabilities, cognitive changes and psychological constraints which created a sense of a profound loss of self. The results of their study highlighted the need for post-stroke counselling to assist the acceptance of some of the physical disabilities associated with stoke. It must be noted, however, that participants in their study were 2 years or more post-stroke and were also living in the community rather than attending rehabilitation, hence their experiences might not be generalisable to acute stroke survivors, or those attending rehabilitation. The use of e-mail interviews, although providing time for deeper reflection prior to answering the questions asked, could have created an environment where true experiences could be hidden and responses that were socially acceptable were presented. E-mail also requires typing skills which may be limited among some stroke survivors, leading to thinner accounts. The observation of body language and other non-verbal cues present in face-to-face interviews was not available, hence some of the responses via e-mail could have been misinterpreted.

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Also, with e-mail accounts, it cannot be absolutely certain that it was the individual with the stroke who had responded. As the majority of the participants were aged in their 40s and 50's, it is questionable whether a similar e-mail interview with an older population would be appropriate. Nevertheless, the findings obtained were the similar to those from the face-to-

face interviews in their study. This suggests that e-mail interviews were as able to capture participants' main concerns as face-to-face interviews despite the mentioned disadvantages of e-mail. Results reported regarding concerns with physical difficulties were similar to those presented in this current project.

Dowswell, Lawler, Dowswell et al (2000) reported on the experiences of a group of 30 stroke survivors with the use thematic analysis of semi-structured interviews. Their study was carried out in the UK and participants were aged between 60 and 94 yrs. As with the other studies reviewed previously, and similar to the results of this current project, participants expressed concern over loss of physical abilities and associated loss of social roles. Participants expressed a sense of 'rolelessness' which was a combination of physical difficulties, environmental limitations and psychological changes post-stroke. Participants included in the study by Dowswell et al (2000) were purposely chosen from a larger sample used in a randomised controlled trial. Their results are similar to those of other studies presented previously in this chapter.

In summary, a sizeable amount of literature is present highlighting the physical difficulties experienced by the stroke survivor. Although in the current study, it remains possible that such concerns are highlighted because they are easier to express to the translator, such limitations of expression do not seem to apply to UK studies. Hence, in light of available research, it appears that people's concerns with their physical difficulties post-stroke are not unduly influenced by cultural (or interview) factors. This suggests that physical abilities are important aspects of most occupations, independence and sense of identity, and appear to be highly valued aspects of everyday experience for people regardless of culture, hence mourned when lost.

ii) Speech Difficulties

Participants in this study expressed difficulty with their speech described as "heaviness of the tongue". This loss of motor skill caused some anxiety, and resulted in not only personal frustration but social withdrawal. Pound et al, (1998) reported a similar finding in which thirteen of their 40 participants in the United Kingdom mentioned speech impairments as being difficult to handle due to the negative reaction of others. In further support of the current study's findings, Teasdale and Engberg (2005) reported aphasia following stroke as having negative effects on social relations. An earlier study, however, by Pedersen, Jorgensen, Nakayama et al (1995) reported a lack of association between aphasia and social/physical functioning in the 6 months following stroke. Using multiple linear regression and logistic regression analysis they identified that although initially aphasia had a small non-significant influence on physical and social functioning status during the 6 month period following stroke, this was not present at discharge from a stroke unit. They concluded, perhaps surprisingly, that their results suggested that aphasia might not be important for social or ADL functioning as measured by the Barthel Index and Frenchay Activities Index. It is possible that the scales used were not sensitive enough to pick up changes in function. Speech difficulties were measured by the Aphasia Subscale of the Scandinavian Scale. Three options present were: severe aphasia, moderate and mild, assessed on a scale of 0 to 3. Although significant associations were identified between aphasia and scores from the Barthel Index and Frenchay Activities Index, multiple regression analysis failed to show significant covariation with the Frenchay scores. The authors concluded that this demonstrated that aphasia does not hamper physical functioning and is without consequence to ADL and social functioning post-stroke. These results conflict with those expressed by the participants of this study, and with other personal accounts of people with aphasia (e.g.

Boazman, 1999). The reason for this difference could be in the type of methodology used and the questionnaire tools used in assessment of social function by Pedersen et al (1995), which might have had limited sensitivity or a selective focus. The qualitative nature of this current study allowed the participants to express their own views (although limited by the presence of the interpreter). However, Pedersen et al (1995) used quantitative tools such as Barthel Index (BI), and the Frenchay Activity Index (FAI) to measure social functioning. It is possible that FAI was not sensitive to pick up changes in social functioning including human interaction but rather assessed physical ability to carry out activities. This difference in results probably highlights the need for qualitative analysis of the experiences of patients for they might yield different results than the use of standard questionnaires. For example, the BI measures functional difficulties but not the meaning of such difficulties to respondents, or their compensatory strategies. In this current study, "heaviness of tongue" was reported by three participants, but had a quantitative standardized tool being used this finding would not be highlighted, as this option would not be offered by the questionnaire. In the current study, speech difficulties were linked by participants to social dimensions of stroke. It appears from these findings that speech difficulties (where they affect people after a stroke) are a 'universal' concern, not much affected by culture, although described in ways that are influenced by language (and/or difficulties in exact translation).

iii) **Dependency**

Stroke patients (mainly female) in Kuwait expressed their frustration with dependency on family members for activities of daily living and outings. Dependency, from the stroke survivors' perspective, was associated with feelings of being a burden on the family and isolation due to not being able to go outdoors independently. Other studies have highlighted dependency as a problem expressed by stroke survivors. Pound, Gompertz and Ebrahim

(1998) reported a similar finding with a U.K sample. Twelve of their 40 participants expressed difficulty in washing, bathing and dressing and required help from others to carry out these tasks. The frustration from having to rely on others for personal activities was also expressed amongst their U.K sample. Appelros, Nydevik and Viitanen (2003) reported that one year post-stroke, 37% of their sample of 377 participants in Sweden were dependent. Dependency was assessed using the modified Rankin Scale (MRS). White, Magin, Attia et al (2008) also reported 'feelings of dependency' as one of the main problems reported by stroke survivors. Their sample was made up of 12 community dwelling stroke survivors in Australia. Using qualitative research methods they identified that feelings of dependency contributed to changes in mood post-stroke, which is consistent with the finding of this Kuwait based study. It is possible that women in particular in an Arabic culture tend to be more embarrassed/ shamed by receiving personal care from others in the family. However research in support of this is absent in the literature. A few Western studies have highlighted the challenges women face when their position changes from being the caregiver to being the recipient of care and dependent on others (Dowswell et al, 2000; Kvigne, Kirkevold and Gjengedal, 2004). The issue of change in role will be discussed in more detail later in this chapter. Men in the current study did not express frustration with dependency as did the females. Reasons for this could include not wanting to express such problems to a female interviewer (Patton, 2002) or dependency not being viewed as a problem for men. It is also possible that within their culture receiving care from a female partner or servant might be perceived as being 'normal'. Empirical evidence in support of these interpretations is absent from current literature.

Western studies have reported dependency as an issue for both males and females, however this was not the case in the current project. This could be related to cultural differences in

gender-specific illness behaviour, with men more accepting of receiving care and being dependent than women. In addition to this, men within the Kuwaiti culture might not be expected to perform caring tasks in the home, so dependence is not so challenging to their status in the home. There is also the possible embarrassment of disclosure to a female interviewer. However, these are highly tentative interpretations without solid prior evidence to guide them, and which need further research, as few men were involved in the study and they may have been inhibited by the social context of the interview.

Other physical challenges reported in the literature included incontinence (Burton, 2000). However this was not mentioned amongst the Kuwaiti participants in this study. This does not mean that such problems were not experienced but it is possible that disclosing such problems may not be culturally acceptable. Hence the failure to mention and discuss the implications it had on their lives could be linked to social taboo rather than absence of this common consequence of stroke. Some Western literature has identified stigma associated with urinary incontinence in community dwelling adults and elderly persons (Paterson, 2000; Heidrich and Wells, 2004), but evidence is lacking from Arabic cultures. Further discussion of the potentially limiting influence of the interview context will be found in the Limitations section.

Overall, concerns about physical challenges, and speech difficulties expressed by stroke survivors in Kuwait appear to be consistent with similar reports in other parts of the world. These perceptions of these challenges of stroke appear not to be dependent on cultural influences. Dependency was the only issue in which concerns differed to those reported in Western literature. In the current study, females were more likely to express frustration with dependency than male stroke survivors. It is unknown to what extent this represents cultural

differences in gender roles within the home and gender expectations, or inhibitory social influences specifically affecting the males during the interview process.

9.1.2 Psychological Difficulties

Two main psychological challenges were identified by stroke patients living in Kuwait. These were: mood changes, and nostalgia. Participants described their changes in mood since the stroke such as low mood, depression, being emotionally more sensitive, feeling aggressive, and anxiety. These perceived changes are consistent with those of other studies. Al Orabi (2002) presented results regarding a study of people in Jordan, where the psychological impact of stroke was expressed as frustration, depression and anger. Participants in Jordan were able to express in depth the psychological difficulties they were facing because the interviews were carried out fully in Arabic. Transcripts were then translated to English prior to data analysis. Whilst it is possible that some loss of meaning could have occurred during the translation from Arabic to English, the original interviews enabled fluent accounts.

Other studies from Denmark, UK and the US, have identified psychological problems post-stroke as problems with attention, memory and emotional control (Teasdale and Engberg: 2005). Teasdale and Engberg (2005) investigated psychosocial consequences of stroke in Denmark with the use of a postal questionnaire. Participants had suffered a stroke 5, 10 and 15 years previously. Psychosocial consequences of stroke were assessed with a postal questionnaire in which participants were asked whether or not they thought the stroke had affected their attention, memory or emotional control. This questionnaire was not assessed for reliability or validity prior to use, however it was administered alongside the validated Nottingham Health Profile. Results showed that regardless of the time post- stroke,

psychosocial problems reported included attention, memory and emotional control problems. Disability assessed with the Rankin disability score was identified as the most significant predictor of psychosocial outcome. Due to language barriers with the Kuwaiti participants in the current study, these psychosocial issues were not explored in depth, however interviews with health professions indicated that they had experienced these problems with their patients in Kuwait.

Phenomenological studies into stroke experience have also yielded similar findings to those of this study i.e self-reported mood changes post stroke. For example, Burton (2000) reported anger /frustration, loss of control and hope regarding issues related to emotional recovery amongst stroke participants in the United Kingdom. Burton's (2000) study was made up of 7 stroke survivors who were interviewed initially when admitted into hospital and then follow-up interviews were carried out on discharge. A total of 73 interviews were obtained over 12 months from discharge. Participants described their various experiences at the different stages i.e. initial phase, early recovery, slowing down of recovery and the new challenges they had encountered. Hope, loss of control and anger were described as emotional issues they were struggling with post-stroke which were issues mentioned by stroke participants in Kuwait. Results from Burton's study were obtained from only seven participants, so although allowing for a deeper exploration of experiences as with other phenomenological studies, caution is required in generalising these findings to a larger sample. Participants in Burton (2000) study also mentioned "uncertainty" regarding emotional recovery which was not mentioned specifically by the Kuwaiti participants. "Uncertainty" and "Anxiety about the future" were also themes identified by another phenomenological study by Hilton (2002) carried out in the US. In contrast, in the current study based in Kuwait, when asked about the future, the common response reflected either avoidance of thinking about the future or

trusting in God. This will be discussed in more depth in the Religious Belief section, and may suggest a cultural difference.

Other psychological changes reported in the literature include feelings of helplessness and frustration (Pound et al, 1998). Decreased mood amongst participants in Kuwait was attributed to difficulty with speech, boredom associated with staying at home, and loss of previous function. They did not offer more 'internalised' accounts referring to helplessness, or similar psychological states, and it is unknown whether such concepts are less readily available in Kuwaiti culture or whether the interview process inhibited such disclosure. Similar to the results of this study, Pound et al, (1998) identified that fifteen of their 40 participants in the U.K reported being unhappy. Seven of these attributed their low mood to having to stay at home and the others reported low mood due to being dependent on others, problems with their speech and functional difficulties. However, it must be noted that results of Pound et al (1998) refer to stroke survivors at 10 months post-stroke and might not necessarily be applicable to recent stroke survivors or those more than one year post-stroke. Yet similar results were also reported by White, Magin, Attia et al (2008). They explored mood changes post-stroke in 12 stroke survivors living in Australia at 1, 3 and 5 years post stroke. Four main types of mood changes were identified with the use of semi-structured interviews. These were: feelings of frustration, feelings of reduced self-efficacy, feelings of dependency and feelings of loss. Feelings of frustration expressed were associated with not being able to carry out ADL functions as before or having to take extra time to complete a task which led to anger and increased low mood. Feelings of loss were associated with difficulties with physical functioning, cognitive impairments and speech difficulties as with the Kuwaiti participants of the current project.

Participants in the current study also expressed a desire to return to "normal", a theme referred to as 'nostalgia'. There was a constant negative comparison between how they had perceived themselves in the past and their physical condition now. Doswell et al (2000) also discussed patients' desire to return to 'normal' and the use of previous pre-stroke function as their yardstick of recovery amongst a U.K sample (13-16 months post-stroke). They also pointed out that 'recovery' could possibly have different meanings to stroke survivors and health professionals. In the Kuwaiti sample, physical therapy was consistently viewed as 'helping to return to normal' among both patients and some of the health professionals. It is thus possible that the desire to return to 'normal' is a widespread human need not specific to any specific culture. Other studies have reported on the dangers of such beliefs as stroke survivors were then disappointed when they were not able to return to "normal" i.e. attain their pre-morbid functional ability. Burton (2000) reported on a UK sample of stroke survivors (0-12months post-stroke). Pre-stroke life was used as a yardstick of recovery and the slowing down of recovery during rehabilitation led to feelings of despondency and frustration. Stroke survivors in their U.K sample found it difficult to view modest clinical improvements positively. Similar perceptions were stated by Doswell et al (2000: 514): "Objectively and reliably measured improvements may not be regarded as improvements of any significance by stroke patients themselves". Other researchers have investigated disappointment with recovery (Anderson, 1992; Pound, Gompertz and Ebrahim, 1994). More recently Wiles, Ashburn, Payne et al (2002) reported on patients' expectations on recovery from stroke in the U.K. They reported that patients tended to have very high expectations of recovery that were independent of the expectations or counsel of their therapists. Despite therapists trying to avoid encouraging over-optimistic expectations, patients assumed that their recovery would be full with rehabilitation.

In the current project, the desire to return to normal was not related to the time since stroke. Stroke survivors ranging from a few months to 10 years post-stroke held on to optimistic beliefs that rehabilitation would help them return to normal. However, it must be noted that these stroke survivors were quite recently referred for physical therapy. It is possible that those not referred for further therapy do not hold on to such optimistic beliefs. A similar idea was expressed by Burton (2000) in a U.K study. Stroke survivors still undergoing rehabilitation held on to optimistic beliefs of full recovery, however, these beliefs were reduced once patients were discharged from rehabilitation. Burton (2000) also reported that optimism was highest during the first 2 weeks of rehabilitation when stroke survivors experienced rapid positive changes in their physical status.

This desire to return to normal appears to be similar across various cultures and although highest during the initial acute phases, according to previous evidence, such optimistic beliefs can still continue when the stroke survivor is given an opportunity to engage in rehabilitation to make a change. However, continued optimism may reflect people's general lack of awareness and understanding of stroke and brain injury and its typical long-lasting effects.

9.1.3 Religious Beliefs

Religious beliefs were most strongly expressed when stroke survivors living in Kuwaiti were asked about the future. To this question, most participants expressed trust in God and acceptance of disability. When asked about the future, the immediate response by most referred to trusting in God and not questioning His plan and reasons for the stroke. Some participants reported avoiding thinking about the future because it was "in God's hands". Religious beliefs of this kind (acceptance of fate and avoidance of thinking about the future) have not been identified in other similar qualitative studies looking at experience post-stroke.

Most of the research into the stroke experience takes for granted either secular or Christian beliefs in relation to the stroke experience. This study has highlighted differences in attitudes that may be attributed to religious beliefs in the Muslim context. Previous researchers have reported that Muslims use religious coping more when compared to other groups of people (Loewenthal and Cinnirella, 1999; Loewenthal et al., 2001, Bhui, King, Dein et al, 2008). Of the fifteen participants, thirteen were Muslims and two were of other religions (Christian and Hindu). The responses regarding religious beliefs were expressed mostly by the Muslim participants. However, despite expressing acceptance of disability, participants also expressed frustration and challenges with the stroke experience and an assumption about return to normality in other areas of the interview, so apparently revealing some contradictions in their attitudes.

Other studies have reported that religious faith might help in coping post-stroke. Robinson-Smith (2002) investigated the use of prayer as a coping strategy in eight participants post-stroke. However, her results did not connect the issue of acceptance of disability and avoidance of thinking about the future with religious beliefs, as did the current project. According to Robinson-Smith (2002), prayer was perceived as a source of comfort, strength and help in relieving stress due to the sudden change in life post-stroke. Health professionals in Kuwait in phase 4 of this project, however, did report that they believed religious faith played a role in providing comfort, motivation and inner strength post-stroke. Kuwaiti therapists were able to elaborate on the issue of acceptance of disability and the expressed trust in God that was voiced by the majority of the stroke patients interviewed. They explained that acceptance of disability reflected belief in their Muslim religion and that it is associated (in their experience) with moving on, working hard and learning new skills. However, therapists also reported that they felt patients who accepted their disabilities were

at times unmotivated and uninterested in doing things for themselves. They acknowledged that patients' understanding of acceptance could include avoidance of responsibility and feelings of abandonment, however they thought patients were misunderstanding the meaning of acceptance. Franklin, et al (2007) reported that religious fatalism was associated with higher scores on chronic illness. It is possible that religious beliefs may motivate some stroke survivors to work hard in rehabilitation and direct their attention away from unproductive mourning for lost function. On the other hand, it could demotivate others, encouraging passivity and hopelessness. More detailed case study research would shed further light on such differences in response. The relevance of religious beliefs in rehabilitation and comparison with published literature will be discussed in more detail later in this chapter when discussing the results of Phase three of the study.

9.1.4 Social Changes

Stroke survivors living in Kuwait mentioned various changes regarding the social aspects of their lives since the stroke. Positive changes included increases in family support. Negative changes included concerns with their changed roles in the family, and social withdrawal/isolation post-stroke.

i) Social Support

Social support was, on the whole, expressed as increased, with more visits from family and friends. Al Orabi (2002) expressed similar results from stroke survivors in Jordan. Support from families was expressed as helping to keep participants motivated and encouraged during the process of recovery. Social support and relationships have been well documented in recent studies carried out in Brazil, Canada, and Australia, as a factor affecting quality of life and life satisfaction in stroke patients (Carod-Artal and Egido, 2009; Doble, Shearer, Lall-

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Phillips et al 2009; Teoh, Sims and Milgrom, 2009). Tsouna-Hadjis, Vemmos Zakopoulos et al (2000) presented results indicating that higher levels of family support in Greece was associated with improved functional and psychosocial status post-stroke. This is in support of the expressed experience of the stroke survivors in Kuwait of the benefits of support from their families. Family support appears to be a general need rather than situation- or culture-specific.

It can also be argued that increased family visits may not necessarily imply increased support. It is possible for more people to visit but not necessarily to offer physical or emotional support. In addition to this, reporting increased family support might be a perceived as a socially appropriate answer with participants not wanting to disclose dissatisfaction with the support they were receiving.Two male stroke survivors mentioned the reduced interaction with their wives and disappointment that care was provided by professional carers, however they did mention support from other family members.

Tentatively, from this study, one may question if the nature of support expected could differ amongst people of different cultures. From personal observation, extended family structures are practised in Kuwait, and it is therefore uncommon to see a stroke survivor living alone or in a residential facility. This has implications for expected support. Presence of family members and regular visits from other family members not living in the same home are expected in order to fulfil kinship obligations, however emotional support and instrumental support may not be expected to the same extent as among stroke survivors living in an individualistic culture. It must be emphasised that these issues were not fully explored in the interviews due to language barriers and because experiences of social support were not

included among the main aims of this project. This subject could form the focus of future research.

ii) Change of Role in Family

Change from being the caregiver to being the one receiving care was identified to be challenging in the younger female stroke survivors interviewed. They regretted that they were now unable to care for their children and their husband. More important than the activities they had carried out previously while providing care for the family, was the identity they derived from such a role. Similar concerns were found by Dowswell et al (2000) in the United Kingdom. They stated: "Many stroke patients deeply felt their change in status from 'doers' to receivers, from active to passive. Particularly painful was the inability to help others, which had been a lifetime's role for many and especially so for many of the women" (Dowswell et al, 2000: 513). Kvigne, Kirkevold and Gjengedal (2004) report a similar finding from a longitudinal study of female stroke survivors living in Norway. They reported that female stroke survivors struggle in trying to regain their roles as mothers, wives, housewives and grandmothers.

Male stroke survivors in Kuwait did not mention the change in role as a challenging issue. Without previous evidence, a confident interpretation cannot be offered. Tentatively, this lack of concern with role change may have been because the male participants were older than the female participants and were already in retirement age. In addition to this, caring for the family is mostly a female role in the Kuwaiti culture, with men being the breadwinners, the researcher observed this during her time in Kuwait. Perhaps due to being past retirement, that burden of change in role among the male participants was not expressed/ perceived. In phase 4, Kuwaiti health professionals interviewed explained that due to extended family living and

help from the government, financial burdens were not experienced post-stroke amongst Kuwaiti stroke survivors unlike non-Kuwaiti survivors.

Stroke experience amongst the Kuwaiti participants in this study appeared to be associated with gender roles. Similar results regarding the female role was reported by Kvigne, Kirkevold and Gjengedal (2004) as mentioned previously. There is also the issue of 'hegemonic' masculinity whereby males may not admit to experiences thought to be diminishing of their status as men. It does not mean that they do not have these concerns but will not admit to them, especially to a female interviewer. Lobeck, Thompson and Shankland (2005) reported that male stroke survivors in the UK expressed changes in their identity and having to take on new roles which pre-stroke they would have viewed as not 'manly' enough such as baby-sitting grand-children. No such similar concerns were reported by the Kuwaiti male stroke survivors in the current study.

iii) Social Withdrawal and Isolation

Participants mentioned some hesitation in continuing with social activities and lacking interest in going out-doors. Reasons for social withdrawal included being dependent on family members to take them out and embarrassment about their disabilities. However, this contradicts participants' reports that they had accepted their disabilities due to their faith and trust in God. Some mentioned that they were impeded by lack of facilities allowing for wheel-chair access, and lack of disabled toilets in the community. Reduced social life is consistent with results of other studies (Dowswell et al, 2000; Murray and Harrison, 2004) conducted in Western countries such as the U.K. Reasons for social withdrawal given in these other studies included physical obstacles, fear of falling and personality changes perceived by the stroke survivor. Similar to the comments by stroke survivors in Kuwait,

those in the U.K in the Dowswell et al study mentioned feeling ashamed of their disabled state and not wanting to be a burden on others as other reasons for social withdrawal. However, a major difference between this current study and theirs was the availability of stroke clubs, day hospitals and centres in the UK that offered opportunities for stroke survivors to keep in contact with others in a similar situation as themselves. Offering some further support, Simpson and Redman (2000) reported that the theme of shame and social stigma was prevalent in Arabs (Lebanese), Italian and Vietnamese traumatically brain injured (TBI) survivors and their families. Snead and Davis (2002) reported that amongst brain injury patients in Canada, their attitude towards disability in themselves and others affected their extent of community reintegration. Individuals with TBI who had a more positive attitude toward their disability and acceptance scored higher on quality of life and showed greater community reintegration. Given the similarities between psychosocial recovery in TBI and stroke, it is possible that social stigma could frame a stroke survivors' personal attitudes towards themselves and that this can influence their willingness to participate in social activities. Nevertheless, people with TBI are more likely to be younger and male and such differences may create different social pressures and expectations. Results of studies of TBI experiences cannot therefore be generalised to include stroke. The results of the current project indicate that stroke survivors in Kuwait withdraw socially due to social stigma, inappropriate facilities in the community, and being dependent on others to take them out.

Expressed social challenges discussed by stroke patients living in Kuwait i.e. change in role within the family and social withdrawal, appear to contradict their expressed acceptance of disability and trust in God mentioned in the religious belief section previously. It is possible that this reflects different "faces" of the stroke experience in Kuwait. The possible 'public religious face' in which expressing acceptance and trust in God is socially acceptable seems

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to differ from the 'private face' in which the stroke survivor personally experiences the frustration of physical, speech, and other limitations and social stigma associated with disability. The 'private face' appears to express similar concerns as other stroke survivors in other countries.

9.1.5 Financial Challenges

Interestingly, financial challenges and problems with return to work, were not expressed by the Kuwaiti participants. Returning to work especially for younger stroke survivors is an important factor associated with life satisfaction post stroke reported in western literature (Vestling, Tufvesson, Iwarsson, 2003; Vestling, Ramel, Iwarsson, 2005). Participants living in Kuwait but of non-Kuwaiti origin expressed worries regarding loss of income and desire for replacement employment, however this was not expressed by Kuwaiti stroke survivors. This could either be because discussing such matters with a stranger might not be culturally acceptable or because financial help from the government and family support meant that such concerns did not exist to the same extent as for non-Kuwaitis without government support. Statements from health professional interviews help shed some light on this issue. Kuwaiti stroke survivors were perceived to have access to better rehabilitation abroad and access to equipment on return to Kuwait. This was expressed as contributing to better quality of life and life satisfaction. Financial security thus appeared to assist both in recovery opportunities and optimism regarding the future. Further research is required to explore this issue in more depth. There is limited published evidence on the extent and effects of government financial support on stroke survivors in Kuwait.

9.2: Results of Phase 2 and 3

Research Question 2: What is the relationship between self-efficacy, life satisfaction and religious faith in stroke patients living in Kuwait?

9.2.1 Self-Efficacy and Life Satisfaction in Stroke

Phase three of this study investigated the relationship between self-efficacy, life satisfaction and religious faith, using questionnaire measures. Two categories of self-efficacy were measured: general self-efficacy (GSE) and an adapted questionnaire termed Psychosocial Adaptation Self-efficacy (PSE). Mean Scores for general self-efficacy was 31.65 (range 10-40) indicating a high general self-efficacy amongst the sample of stroke survivors in Kuwait. Scholz, Dona, Sud et al (2002) reported the following mean GSE scores on healthy participants in different countries: Japanese-20.22, Hong Kong Chinese-23.05, Costa Ricans-33.19, Danes-32.19 and French-32.19. The results of the current project indicates an equivalent high mean GSE score (31.65) when compared to results from other countries. Mean GSE was similar between Kuwaiti-born and non-Kuwaiti subgroups in this study (31.95 and 31.27 respectively).

The results of phase 3 of the study identified a significant correlation between self-efficacy and life satisfaction in female stroke patients living in Kuwait, using both measures of self-efficacy. The life satisfaction score and generalised self-efficacy (GSE) yielded a significant positive correlation. The Life Satisfaction score and Psychosocial Adaptation Self-Efficacy correlations obtained were also significant. A stronger positive correlation was observed between PSE and life satisfaction than GSE and life satisfaction, which suggests that the Kuwaiti-adapted scale was more sensitive. It is unclear if this is because the PSE was adapted

for Kuwaiti participants and therefore better tailored to their concerns, or (more simply) because it offered a wider range of scores.

Results by Robinson-Smith et al (2000) in the US support the findings of this research, albeit with different measures. They reported, using a sample of 63 stroke survivors, that self-efficacy correlated strongly with quality of life at one and six months post-stroke. Self-efficacy was measured with the Strategies Used by People to Promote Health (SUPPH) which was not developed for stroke patients. However, 23 items were modified to make it applicable to stroke survivors (this study was reviewed earlier in the literature review chapters). Quality of life was measured with the Quality of Life Index-Stroke Version. Despite their study being carried out in the United States, their results were similar to this research and showed that self-efficacy beliefs were significantly related to quality of life and depression. Robinson-Smith et al (2000) advocated various methods to improve self-efficacy in rehabilitation. This included providing patients with vicarious experience through observing others with similar disabilities achieving similar goals, health care personnel promoting self-efficacy during goal-setting, and self-talk and prayer. The role of health care personnel was mentioned to play an important role in facilitating self-efficacy of patients because of their perceived expertise by the patient (Robinson-Smith et al, 2000). However, it must be emphasized that Robinson-Smith et al (2000) assessed for quality of life and not specifically life satisfaction as in this study. Further discussion of goal-setting will be presented later in the chapter.

Previous studies i.e Hampton and Marshall (2000), Smith et al (1998), and Cicerone and Azulay (2007) provide research on people with other neurological conditions showing the relationship between self-efficacy (especially that related to psychological recovery) and life

satisfaction, in support of the results of Phase three of this study. Results from (healthy) participants without neurological problems have also indicated that self-efficacy is strongly related to life satisfaction. Caprara and Steca (2005) reported that affective and social self-regulatory efficacy beliefs were found to be positively correlated with cognitive and affective components of subjective well-being in healthy adults in Italy. They highlighted that efficacy beliefs regarding management of mood and social relationships had a significant effect on participants' subjective well-being, specifically positive thinking and happiness. Although their study was carried out in Italy on healthy adults, one can see a similarity between their results and these findings from this sample of female stroke patients in Kuwait. The testing of Psychosocial Adaptation Self-Efficacy in this study included questions such as mood regulation and social participation which are similar to the affective and social self-regulatory efficacy beliefs as measured by Caprara and Steca (2005). Although the results by Caprara and Steca (2005) were carried out on healthy adults and thus cannot be generalised to a stroke population, it is interesting to note that similar patterns occur in both healthy and stroke survivors. This suggests that the association between self-efficacy and life satisfaction/subjective well-being might be widespread and not limited to stroke.

Health professionals interviewed in Phase 4 of this study expressed their belief that the relationship between self-efficacy and life satisfaction was expected. Self-efficacy was perceived as being related to inner determination and offering a better chance of persisting with tasks until success is achieved. This view supports Bandura's (1994) theory that self – efficacy can affect behaviour through regulation of motivation. According to his view, motivational, and cognitive processes, work together in moderating behaviour and perceived satisfaction. Since self-satisfaction is related to matching adopted goals, persisting in

achieving one's goals can directly influence satisfaction. Motivation is thus seen as the key to persistence in efforts to fulfil goals.

Life satisfaction was viewed by the health professionals interviewed in the current study to be a result of belief in current and future goal achievement. Goal achievement was thus perceived to be the mediating factor between self-efficacy and life satisfaction. This view was also expressed by Bandura (1994). He theorised that most human behaviour is regulated by thought processes related to goals deemed important to the individual. Self-efficacy is described by Bandura to affect the choice of goals and commitment to them. Viewing oneself achieving goals could possibly result in higher perceived satisfaction in that domain which could influence overall life satisfaction. Lent et al (2005) provided some evidence showing that satisfaction regarding specific goals was related to overall satisfaction. Even without true evidence of success on reaching certain goals, the belief that one can carry out the activity or achieve the goal leads to visualization of successful scenarios which in turn could affect perceived satisfaction. However, poor self-efficacy could lead to visualization of failure and negative reports of satisfaction.

Bandura further explains that especially during managing difficult tasks, self-efficacy is associated with persistence and quality of performance: "Indeed, when people are faced with the task of managing difficult environmental demands under taxing circumstances, those who are beset by self doubt about their efficacy become more and more erratic in their analytic thinking, lower their aspirations and the quality of their performance deteriorates" (Bandura, 1994: 4). However, observing the quality of performance deteriorate could lead to reduced satisfaction with performance in that area. A similar view was expressed by the health professionals interviewed. Therapists pointed out that stroke survivors with high self-efficacy

initially, could later on become depressed if expected goals were not achieved. One physical therapist also pointed out that patients who have accepted their current disability and no longer believe that further recovery is possible may rate their self-efficacy as being low despite rating life satisfaction highly. In other words, although the relationship between self-efficacy and life satisfaction is positive in most cases, there may be patients with low self-efficacy reporting high life satisfaction. Maybe they also de-prioritise certain aspects of functioning/ task achievement as seen with spinal cord injured people who may re-prioritise to reflect what they are capable of, rather than dwelling on what they are not (Weitzenkamp, Gerhart, Charlifue et al, 2000).

Lent et al (2005) also help in understanding the underlying mechanisms involved in life satisfaction and its relationship with self-efficacy. This information helps to explain some of the results of this project. They presented an integrative model of life satisfaction in which domain and global life satisfaction are influenced by different constructs including personality, cognitions (relating to self-efficacy and goal-setting/attainment) and the environment. Self-efficacy is proposed to contribute to goal selection and progress, while the environment is viewed as having the potential to either enhance or reduce self-efficacy. They also proposed that satisfaction with regards to specific goals will be related to global satisfaction more strongly in domains viewed as more important to the individual. Their results showed that self-efficacy and outcome expectations were strongly correlated, and that both were correlated with goal progression and environmental resource, goal importance and domain satisfaction. In addition to this, both domain (academic and social) satisfaction were moderately correlated to global life satisfaction.

The findings by Lent et al (2005), although related to academic and social self-efficacy, are significant to this project because they highlight the importance that satisfaction with specific goals has on overall life satisfaction. They also offer some evidence in support of the social cognitive model of life satisfaction in which self-efficacy, outcome expectation and the environment are all associated with global life satisfaction. It is possible that these associations would be stronger after a distressing event like a stroke in which both physical and psychosocial domains are esteemed as highly important. Further discussion of goal-setting will be presented later in the chapter.

9.3.2 Religious Faith Association with Self-Efficacy and Life Satisfaction

Results of this study failed to show any significant quantitative association between religious faith, self-efficacy, or life satisfaction in stroke survivors undergoing physical rehabilitation in Kuwait. Age was the only variable significantly positively associated with religious faith (mostly Muslim faith). The relationship with age was derived from a post-hoc analysis and the relationship was much weaker when analysed non parametrically. The data indicated that older stroke survivors tended to score higher than younger ones in relation to religious faith. It is possible that with increased age people cling to more traditional religious faith, or alternatively, that they had a more conservative religious upbringing than the next generation did.

In the results of this study, religious faith did not show any significant association with self-efficacy, neither general and psychosocial adaptation self-efficacy, nor with life satisfaction. In other words, both self-efficacy and life satisfaction were unrelated to religious faith, as measured by the Santa Clara Strength of Religious Faith Questionnaire (SCSROF). Although there were no identical studies in the literature to compare these results with, these results are

inconsistent with findings from available literature reviewed in earlier chapters investigating religious faith and health outcomes in general in both Western/ Christian samples and Muslim samples. Weaver at el (2004) identified eight articles in which religious faith had positive associations with coping with illness. Religious faith was also reported to be related to mental health, and happiness in healthy Kuwaiti students (Adbel-Khalek, 2006). Results by Abdel-Khalek (2006) are significant to the current study being researched. Carried out on Muslim university students in Kuwait, it showed that religiosity, mental health, physical health and happiness are all significantly intercorrelated. While religiosity accounted for only 15% of happiness, mental health accounted for 60 % of happiness. This shows that there are other factors apart from religion that could influence mental health to bring about changes in self-reported happiness. Nevertheless, the use by Abdel-Khalek (2006) of a single item to measure each of the four variables causes one to question the validity of the measurement used. For example in measuring religiosity the participants were asked the following: What is your level of religiosity? And were asked to rate it on a scale of 0 (very low) to 10 (very high). A similar procedure was used to measure the other three variables. No investigation was carried out to assess the validity of such a single measure for assessing religiosity. Using such a single measure also makes it difficult to determine what aspects of religiosity the participants are referring to (such as interpersonal religion, religious attendance, or external religiousness). In addition to these limitations, since not carried out specifically on stroke patients, the findings cannot be generalised to include them. The participants in the current project were older, so there may be generational differences. Education could play a role, as perhaps Kuwaiti students feel more able to express private views, or able to challenge the assumptions of elders, and feel less constrained by the norms that may govern older people. Faith may become a more salient issue when people are directly faced with disability/ mortality (Idler and Kasi, 1992; Idler, Kasi, Hays, 2001).

The results of this study were also inconsistent with results of studies investigating certain aspects of religion and recovery in stroke patients in the US. Robinson-Smith et al (2000) reported that prayer had a role in coping post-stroke among Christians. Details of this study can be found in the literature review chapter. Perhaps in this current study, investigating religious faith as a broad concept did not allow for the identification of the associations of certain aspects of religion such as prayer or attendance at religious events. A different method used to obtain data could have yielded different results. Robinson-Smith et al, (2000) used interviews with eight stroke survivors who had already identified that they used prayer as a coping strategy. In contrast, this current study used a validated generic scale measuring religious faith of which prayer was a part. Options in the scale limited responses to strongly disagree, disagree, agree and strongly agree. Perhaps having more of a choice of responses could have yielded different, more nuanced, results.

Giaquinto et al (2007) also presented results in support of those of Robinson-Smith et al, (2000) and in contrast to those of this study. They reported that religious beliefs were associated with lower anxiety and depression scores amongst Italian stroke patients (predominantly Christian). They reported their results to imply that religious beliefs do influence the ability to cope post-stroke. More details of this study are reported in the literature review chapter.

Ai, Peterson, Rodgers et al (2005) also present findings different from those of this study, regarding the association between religious faith and self-efficacy. They investigated the effects of religious faith on locus of control in cardiac patients in the US (predominantly of the Christian faith). Despite looking at locus of control and not specifically self-efficacy, their

results are relevant to discussing the results of this study. Ai et al (2005) described internal control as a type of event-specific self-efficacy, thus making their findings relevant. Results of their study showed that subjective religiosity (assessed with a Likert scale questionnaire) was positively correlated with reduced internal control and increased 'powerful others' health locus of control. This indicated that participants who rated themselves highly on subjective religiosity tended to report less personal control over their health issues. However, the use of prayer as a coping strategy was positively associated with internal health locus of control. This indicated that participants reporting higher use of prayer as a strategy reported higher personal control of their situation. These findings also demonstrate that religious belief and/or practice has no uniform influence on levels of internal control, but that the many facets of religious observance need to be differentiated in research studies into control and self-efficacy.

Reports from research described above, appear to provide some evidence for an association between religious faith (especially prayer) and psychological variables such as internal control, reduced anxiety and happiness. However, results of this current study did not reflect this. Results of this study showed that religious faith was not associated with life satisfaction in stroke patients undergoing rehabilitation in Kuwait. Fry (2000) also presents contradicting findings amongst healthy elderly individuals in the United Kingdom. He reported that participation in spiritual activity, meaning for life and inner peace were strong predictors of psychological wellbeing in the elderly, 85% of which claimed a religious belief (mainly Christian). Spirituality was identified as a significant predictor of life satisfaction in patients undergoing rehabilitation in the US (Tate and Forchheimer, 2002). Tate and Forchheimer (2002), investigated life satisfaction, quality of life and spirituality in cancer and rehabilitation patients. Their study sample consisted of 136 patients undergoing rehabilitation

(spinal cord injury, amputations, and polio) and 72 cancer patients. However, stroke patients were not investigated. It is however possible that spirituality and religious faith might be two different constructs. While Western literature documents a distinction between these two terms (Williams and Sternthal, 2007; Giaquinto et al, 2007), Rassool (2000) mentions that in the Islamic context, the terms "Spirituality" and "Religion" mean the same thing.

Evidence from the literature mentioned above suggests that spirituality and religious faith could be associated with health outcomes and life satisfaction in the rehabilitation of neurological patients. However, the current study failed to identify such a relationship. Below are possible reasons for this lack of relationship in this project.

Possible Reasons for Lack of Quantitative Association between Religious Faith and Life Satisfaction/Self-efficacy

Possible reasons for lack of association include an inappropriate tool being used for measuring religious faith, and contrasting Muslim and Christian religious beliefs regarding control and surrender.

i) Inappropriate Tool for Measuring Religious Faith:

One issue that may account for the lack of relationships is that the Religious faith scores (Santa Clara Strength of Religious Faith Questionnaire) showed much less variability than in other studies. Most participants reported high scores. It is possible that the tool used for measuring religious faith in mainly Christian or secular countries was not sensitive enough to pick up subtle differences in levels of agreement in a predominantly Muslim sample. Or

perhaps it was an inappropriate method of investigating religious faith in patients living in Kuwait. It appeared to the researcher that participants, especially those of the Muslim faith, were conscious about being perceived to be insufficiently religious and perhaps provided the socially acceptable answers to the question posed. During data collection, participants may have felt that they were being personally "judged" by their answers to the questions. Social desirability effects are well understood in social psychology to be a source of potential bias especially in face-to-face data collection (Presser and Stinson, 1998). In this project, the issues may go deeper than social desirability, as there may be a strong conviction that there is no alternative other than being deeply religious and unquestioning of faith. This highlights the possible difficulties in determining the influence of religiosity in cultures where people are expected to have a strong public commitment to religion. A more appropriate method of investigating the religious influences in the Kuwaiti culture might be with the use of phenomenological interviews where participants express their feelings and how they perceive their faith to assist in their recovery. Such an approach might ensure maximum disclosure without the feelings of being judged as on a standardized measurement scale. But this would require probably repeated interviews to establish trust and rapport, and a stronger sense of privacy. However, even with these safeguards, this research method might not suit all participants. If there is a deep conviction that questioning religion is non-Islamic, then people may not reveal any doubts, even if they engage in a more probing interview. Such interviews might only appeal to people who are younger, more educated and more able to reflect on inner experience. Participants may also resist disclosure, in any case, with an interviewer perceived as non-Muslim and therefore possibly suspected to have an intention to criticise their religion.

ii) Religious Beliefs Regarding Control and Surrender

It is possible that religious beliefs influence perceptions of control and surrender despite a lack of association with self-efficacy being found in this study. The health professionals who were interviewed expressed the view that the issue of acceptance could be responsible for the lack of associations observed between religious faith and self-efficacy, and between religious faith and life satisfaction. Kuwaiti therapists explained that within their culture "pure religion" was perceived as surrendering to "God's will". This could possibly be a reason for a lack of association between religious faith and self-efficacy. In other words, stroke survivors with a higher religious faith rating may choose to surrender control to God as a reflection of their faith. However, this possibility does not explain the lack of association with life satisfaction, as it might be expected that those who claimed more acceptance of their condition through belief in God might express higher life satisfaction. Health professionals interviewed felt that there might be a possible difference between belief and action. In other words, despite voicing trust in God publicly, stroke survivors might still privately rate their life satisfaction as being poorer due to their various daily challenges. Studies have identified that Asian, Arab Israeli, Indian and Jordanian women with breast cancer share similar beliefs regarding attributing their illness as "God's will" which differed from those of Western breast cancer sufferers (Ashing, Padilla, Tejero and Kagawa-Singer, 2003; Baron- Epel, Granot, Badarna and Avrami, 2004: Lee, Tripp-Reimer, Miller, Sadler and Lee 2007 and Petro-Nustas, 2001). Western breast cancer sufferers did not invoke religious beliefs to understand their illness. Similar studies have not been carried out on stroke survivors to provide any comparison. Nevertheless, the results of the current project indicate that religious faith amongst stroke survivors in Kuwait might not necessarily enhance life satisfaction or self-efficacy.

iii) Fatalistic Beliefs

Although phase three of this project showed a lack of association between religious faith and the psychological variables assessed, health professionals in phase four identified religious fatalism to have an impact on patients' psychological state and behaviour. Religious fatalism has been suggested to be associated with negative health behaviour and outcomes in the (largely Western) literature. Fatalism can be defined as: "the belief that an individual's health outcome is predetermined or purposed by a higher power and not within the individual's control" (Franklin, Schlundt, McClellan et al 2007: 564). Franklin, et al (2007) reported that religious fatalism was not found to be a predictor of any health variable, however individuals who scored higher on chronic illness were more likely to possess fatalistic beliefs in their study. The results also showed that those who reported higher fatalistic beliefs tended to report their health as being worse that those without fatalistic beliefs. It is possible that fatalistic beliefs might be a means of religious coping for individuals with chronic illnesses. However, it is also possible that fatalistic beliefs can cause the individuals to possess a reduced self-efficacy in self-management of chronic conditions. Ai et al (2005) reported that certain aspects of religious beliefs could be responsible for reduced self- efficacy/personal control. This study has been discussed in more detail earlier in this chapter and in the literature review chapter.

A lack of association between religious faith and psychological variables such as self-efficacy and life satisfaction in this study could reflect possible fatalistic beliefs amongst stroke survivors living in Kuwait. This was supported by interviews with stroke patients and health professionals. Fatalism was expressed as a stroke survivor coping strategy by Kuwaiti health professionals, in support of findings by Franklin, et al, (2007). Western therapists in the current study voiced their concerns that fatalistic beliefs resulted in a lax approach by the

patient towards therapy and avoidance of responsibility to play an active role in rehabilitation. This perceived contrast, may stem from the Western health professionals' own culture and experiences with patients in their own countries who appear (to them) to be more engaged and participative in therapy. Kuwaiti-born therapists, on the other hand, explained the need for patients to be educated about recovery and the need to participate in therapy. A Malaysian Muslim nurse explained that fatalism could have both a positive and negative role in rehabilitation. Its positive role was expressed as being related to acceptance and contentment with disability after trying as best as possible to recover and achieve the set goals. The negative role was expressed to be abandonment (spiritual surrender) and lack of active participation in therapy as mentioned by Western therapists. It is possible that Western health professionals have been educated in client-centred models which emphasise personal worlds, values, motives and active engagement by the patient (Sumsion, 1999). Whereas the patients may only have been socialised into biomedical perspectives with the added complication in Kuwait that the therapist is seen more as a servant than an authority figure. Lack of participation in therapy might therefore not be due to fatalistic beliefs but a cultural belief that they are passive recipients of therapy and hence active participation is not necessary. Fatalistic beliefs and cultural beliefs regarding the patient's role in rehabilitation might contribute to stroke survivors in Kuwait not engaging actively in rehabilitation, but further research is needed.

9.3: Cultural Differences Perceived by Health Professionals.

Research Question 3: What are the cultural influences on the stroke experience and rehabilitation in Kuwait from the health professionals' perspective?

Health professionals interviewed expressed certain perceived cultural differences in the stroke experience between patients in Kuwait and those they had worked with in other countries. What were considered culturally distinctive were discussed in the following eight main areas: family involvement, prevailing attitude of stroke (the sick role), patient goals, dependency and presence of house maids, social stigma, finances and religion.

Other studies have identified behaviour associated with the sick role (Parsons, 1951) as related to cultural differences. The concept of the sick role presents the idea that there are two rights and two obligations of individuals who become sick in our society. The two rights are that (1) The sick person is exempt from "normal" social roles and (2) the sick person is not responsible for his or her condition. The two obligations are that (1) The sick person should try to get well and (2) The sick person should seek technically competent help and cooperate with the physician (Parsons, 1951). Fitzgerald, Mullavey-O'byrne, Clemson (1997), interviewed 86 occupational therapists regarding cultural issues when dealing with patients. Seven important themes were reported: professional values, family roles and responsibility, communication, social behaviour, gender, sick roles and explanatory models. The issue of sick role and social behaviour are similar with the results of the current project.

Health professionals interviewed voiced that family involvement was one of the major differences between rehabilitation in Kuwait and other parts of the world where they had worked. The practice of extended family is a strong feature of the culture in Kuwait, thus it is

uncommon to see a Kuwaiti stroke survivor living alone. Advantages and disadvantages of family involvement were discussed by the health professionals. Advantages included provision of support, encouragement and motivation. Being in a familiar environment, with familiar people, was also thought to enhance recovery. However, it was also pointed out that too much help from family members could lead to further dependency, through reinforcing the sick role. Physiotherapists working within the community (i.e. visiting patients at home) mentioned clashes between themselves and family members on therapeutic goals and style of therapy. Therefore it sounds as though professionals and patients (and their families) might be inhabiting different 'cultures', the therapists focusing on a biopsychosocial model of stroke, whereas the patients and families hold on to traditional medical and maybe religious models. In other words, while health professionals typically understand the importance of physical, psychological and social aspects of rehabilitation, patients and family members tend to focus solely on traditional understanding of the sick role and accept the need for assistance and rest. While family involvement can be helpful in achieving carryover of therapeutic gains, it is necessary to minimize the negative aspect of interfering family members on rehabilitation and 'helping too much'. The need to build a good relationship with family members is very important. Health professionals need to tailor therapy to patient's/ family's model of rehabilitation, whilst also seeking to educate them about the importance of active involvement. This might mean engaging more with the family of the stroke survivor and appreciating their world view.

Lack of education about stroke and rehabilitation were expressed by Western health professionals as a difference between stroke patients in Kuwait when compared to Western countries. Therapists felt that family members and the patients themselves were unaware of the importance of rehabilitation and the possibilities of recovery post-stroke. Lack of

education/awareness was also mentioned to be responsible for limited access to rehabilitation services in Kuwait because the need for rehabilitation was not appreciated to the same extent as other critical medical interventions. Poor educational level of the older generation (i.e. above 50) and lack of education regarding stroke were also said to be responsible for unrealistic expectations from both the family and stroke survivors. Lack of education (amongst the elderly) could also be the reason for the perceived prevailing attitude that stroke is the end of life, as reported by some of the health professionals interviewed. This attitude was reported to be particular to Kuwait when compared to other Western countries in which the health professionals had worked. The stroke survivor is typically viewed by family members as being sick and needing to be left in bed and not made to do any exercises. This further highlights the need for more education of the general public and families with relatives who have had a stroke. Tyson's et al (1999) study (Southampton Stroke Audit) found that patients often complained about lack of information being given to them during stroke rehabilitation, suggesting that stroke patients in the U.K also might not be well informed.

Lack of patient goals and low motivation level amongst stroke survivors during rehabilitation in Kuwait was a perception reported by therapists interviewed. They felt that stroke patients in Kuwait, when compared to patients they had worked with in other countries, were unable to identify specific activities that they wanted to be able to carry out. Two main issues could be the reason for such an attitude; firstly, the attitude towards aging in Kuwait (with expectations that older people will be cared for within the extended family) and secondly the widespread presence of paid assistance (domestic helpers and private nurses).

Dependency was reported to be socially acceptable in Kuwait according to both Kuwaiti and non-Kuwaiti health professionals. However, stroke survivors interviewed did not necessarily agree, as some felt frustrated by their condition and regretted loss of roles. The easy access of maids and extended family living was mentioned to be contributors to an acceptance of dependency from the health professionals' perspective. Help from paid maids is not seen as 'dependency' or as demeaning in any way in the wider culture but as an everyday resource for a comfortable life. However, whilst increasing the physical and emotional comfort of stroke survivors, reliance on paid help could possibly be a hindrance to rehabilitation aims, encouraging passivity. This finding has not been reported in other studies involving stroke survivors, and seems to indicate a potentially important, culturally-specific influence on the stroke experience.

Health professionals interviewed voiced their concerns regarding the effect of social stigma on patients' willingness to engage with the community. Disabilities were expressed as being "abnormal" and led to staring by the public. Stroke survivors felt uncomfortable with this, and so avoided contact with the public. This view is supported by Goffman's (1963) explanations of the need for patients to avoid the public in order to protect their identity. But interestingly, some of the health professionals also had quite negative attitudes themselves, and often used the word 'abnormal' when contrasting patients with their pre-stroke state, or referred to clients in slightly disparaging terms. Other studies have also described social stigma associated with disability, and its role in social withdrawal (Simpson et al, 2000; Dowswell et al, 2000; Snead and Davis, 2002; Murray and Harrison, 2004).

In summary, health professionals interviewed believed that cultural influences on stroke experience and rehabilitation in Kuwait existed in the following areas: family involvement, prevailing attitude to stroke (the sick role), patient goals, dependency and presence of house

maids, social stigma and religion. Family involvement was viewed as being more intense than they had perceived in other countries and led, they argued, to increased dependency. The presence of house maids and availability of privately hired nursing staff was perceived as further contributing to dependency although patients themselves may not regard such widespread support as dependency.

9.4: Clinical Applications of the Findings

In most studies, the researcher draws implications from the data, however in this project, the health professional interviews served as a method of investigating implications of the results with professionals from different cultural backgrounds. Their perceptions served as an invaluable aspect of the discussion of the results. These perceptions will the discussed in this section.

The need to understand the experiences of the stroke survivor in different cultures cannot be over-emphasized. Stroke survivors living in Kuwait expressed difficulties in all major areas of life and these were confirmed by health professionals who were working with them. Interviews allowed the stroke survivor participants to express their own views regarding the challenges they were facing without being forced to answer pre-determined questions as in a questionnaire. Although the use of an interpreter appeared to limit the depth of responses (discussed in the limitations section of this chapter), the information gathered highlights many similarities between the stroke experience in Kuwait and other parts of the world. Concerns with physical disability, speech difficulties, and psychological problems appeared to be similar as reported in the literature. However differences appear to exist in areas such as social support, perceptions of dependency, social stigma and patient engagement. This highlights the need for cultural sensitivity during the rehabilitation of a stroke patient and

when developing a rehabilitation service in different cultures. These include how to communicate effectively with patients and families, understanding the various expectations both patients and family members bring into rehabilitation and how to effectively motivate and engage the patient in rehabilitation.

9.4.1 Physical Disabilities:
Although most patients accepted receiving physical rehabilitation (physiotherapy, occupational therapy and speech therapy), understanding their own role in rehabilitation was somewhat limited. Therapists explained that patients did not fully understand their own role in rehabilitation and that they placed full responsibility for recovery on to the therapist. This highlights the need for more education about stroke and rehabilitation in Kuwait. Stroke survivors who had received therapy abroad mentioned the lack of adequate rehabilitation services in Kuwait (both in terms of quality and quantity). This view was also confirmed by health professionals interviewed. The need for acute emergency health care staff was commonly understood by the government to be necessary. Rehabilitation, however, appeared to be somewhat of a new concept with less emphasis placed on it. This study highlights the need for increased awareness by the government on the necessity of rehabilitation services and the need to extend services that are already available, and to inform the population about their existence (and purpose). This perhaps will prevent stroke patients from seeking treatment abroad, and thus reduce the financial burden on the government sending these patients abroad for therapy. Having better stroke services in Kuwait would also keep stroke patients near their families which is good for morale.

This study also highlights the need for patient education programmes for stroke survivors in Kuwait and their family members. Effective forms of patient education have been reported in Western literature regarding other long- term disabling conditions (Jones, 2006). Barlow,

Williams and Wright (2000) report on the use of a self-education programme in enhancing self-efficacy for the management of symptoms, reducing depression and improving overall health status in arthritis patients. The programme was led by a pair of lay individuals who had arthritis themselves. Results showed that between baseline and the four month follow-up, the intervention group (who attended the education sessions) had significantly higher mean increases in health beliefs, cognitive symptom management and communication with physician. In addition to this, the intervention group showed greater decrease in depression and higher increase in positive mood than the control group. The results of the Barlow et al study showed that the arthritis self- management programme was effective in facilitating self-efficacy and improving use of self management techniques and health status (i.e. fatigue, anxious, depressed and positive mood) (Barlow et al, 2000).

A similar stroke education programme conducted by stroke survivors could provide an important resource for new stroke survivors and their families in Kuwait. Kendall, Catalano, Kuipers et al (2007) present evidence to suggest that educational programmes for stroke survivors might be beneficial. They assessed 100 people with stroke in Australia, 58 of which were randomly assigned to attend the Psychosocial Skill Expansion Programme. This programme was designed to address psychological and social issues related to stroke and was based on the Chronic Disease Self Management course. Participants who did not attend this programme reported declines in functioning related to family roles, activities of daily living, self care and work productivity during the first year post-stroke. These areas of decline were not reported in the intervention group. Their results suggested that the psychosocial education programme could have had a protective role in preventing decline in function. However Skidmore, Koenig, Munin et al (2008) present somewhat contradictory findings regarding the benefits of stroke education programmes for patients. They evaluated the effect of clinical

education programmes on stroke related knowledge with 34 patients. Stroke-related knowledge was in three main domains: risk factors, warning signs and appropriate actions to take if stroke is suspected. Results showed that stroke-related knowledge remained poor after this educational programme. The content of the programme requires closer scrutiny, as perhaps the issues addressed were not deemed as crucial to recovery by the patients. This study highlights the need to target educational programmes to meet the needs of their target audience.

Other studies have reported benefits of educational programmes for patients with other conditions. For example, Barlow and Barefoot (1996) reported the use of a series of sessions to enhance self-efficacy in individuals with Ankylosing Spondylitis (AS). The teaching sessions included providing information about exercise, symptom management and problem solving techniques. Results showed that the intervention group differed significantly from the control groups in self-efficacy and depression scores. However no long-term changes in exercise behaviour were identified. Similar results were reported by Taal, Riemsma, Brus et al (1993) on individuals with rheumatoid arthritis.

Results of the research studies reviewed above regarding self-management of chronic disease provides some evidence for the importance of targeting self-efficacy specifically than educational strategies alone. Some of these strategies should be applied in the management of stroke patients, however research on this is limited (Jones, 2006). Further research is required to establish how to present such self-management programmes to people who may have high levels of religious surrender, and who may not share the same views as Westerners regarding the importance of taking control oneself. In the U.K, self-help is backed up by Department of

Health policy (DOH, 2001). In Kuwait however, the Government has no policy statements on self-help expectations for those with long-term disability.

9.4.2 Psychological Challenges: Results of this study highlighted mood changes and desire to return to normal as the main psychological challenges expressed by stroke survivors. Community therapists explained that depression was treated with shame and embarrassment. Kuwaiti patients and family members tended not to acknowledge depression and viewed it as a reflection of lack of religious faith. This indicated a clash between the professionals' and the lay persons' understanding of depression. This further highlights the need for health professionals to educate families and the patients on depression and other psychological issues. However it may be difficult to shift cultural 'norms' and taken-for-granted ways of thinking due to people's concerns with appearing religious in public (as well as having private religious commitments). In addition to this, acknowledging depression and other psychological difficulties might be difficult concepts to accept within Kuwaiti culture. Provision of resources or providing situations where families and patients can talk to others who have been through similar situations and have passed through their difficulties successfully, may help to reduce the social stigma associated with psychological problems, and would not necessarily conflict with religious commitments. A lack of psychologists working with stroke patients in the community was also noted by the researcher and commented on by health professionals interviewed. In the absence of such professionals, therapists at the outpatient centre could have some training to identify patients with psychological problems and refer them to specialists at the stroke rehabilitation centre. Karasz (2005) reported that ethnic minorities in the US were less likely than their white counterparts to seek medical treatment for depression, this was linked to their understanding of the causes of depression. While participants of European Americans viewed depression in

terms of biological causes, those of South Asians origin viewed depression in terms of social and moral terms that needed to be dealt with self management. Further studies would need to explore the cultural understanding of depression in the Kuwait context and framing referral for treatment in ways that would be culturally accepted.

9.4.3 Social Challenges

Stroke survivors expressed frustration getting outdoors due to physical disabilities and lack of facilities such as appropriate door width, ramps, disabled toileting facilities, and table height at restaurants. These barriers were also emphasised by physiotherapists working in Kuwait. The need to highlight to the government these barriers to access and provide recommended adaptations is paramount. Without adequate facilities, the stroke survivor is unable to access shops and other services and thus remains at home isolated during the day. Previous research has reported that isolation can be related to depression post stroke (Hackett and Anderson, 2005). Health professionals also mentioned the lack of social / leisure activities for stroke survivors in Kuwait. Perhaps culturally, stroke is perceived to be a disorder of the elderly and leisure activities outside the family setting might not be culturally relevant. However, there is definitely a need to develop further services in addition to rehabilitation to meet the needs of younger stroke survivors in terms of social interaction and leisure activity. Perhaps the situation is like the one that prevailed a few years ago in the UK before the Disability Discrimination Act came into being. Since this Act, there has been improved access to public buildings for disabled people and measures have been put in place to improve employment opportunities and prevent discrimination (DDA, 1995).

9.4.4 Enhancing Self- Efficacy during Rehabilitation

Results of phase three identified a significant association between self-efficacy and life satisfaction post-stroke. Psychosocial adaptation self-efficacy had a stronger correlation with life satisfaction than general self-efficacy. Targeting psychosocial self-efficacy during rehabilitation could aid in improving life satisfaction post-stroke. The psychosocial adaptation self-efficacy scale (designed for use in Kuwait) can provide valuable information to direct implementation of strategies to improve life satisfaction in this context. Health professionals interviewed identified eight areas where these results can be applied clinically from their perspective. These were: identifying change, providing incentives, environment and therapy, awareness of individual differences, providing examples, motivating and encouraging patients, setting goals, and education about recovery and rehabilitation (See results chapters for quotations and commentary related to these themes).

The health professionals interviewed mentioned the need to identify functional change by using objective measures to enhance self-efficacy and life satisfaction. It was pointed out that patients themselves do not always notice the changes made during rehabilitation and even when they do notice the changes, they may not appreciate them. Other studies have also commented on this (Anderson, 1992; Pound, Gompertz and Ebrahim, 1994; Doswell et al, 2000). The health professionals emphasized the need to celebrate small gains made and find ways to show the stroke survivors these changes. Other incentives mentioned included rewards for participation in rehabilitation or rewards for achieving set goals. Examples of these could be activities enjoyed by the patient, food or drink items or outdoor activities. These incentives were perceived to help increase self-efficacy and motivation to continue with rehabilitation. However, such suggested incentives might raise ethical issues if patients thought they were being deprived if not making enough change.

The need to ensure that the rehabilitation environment is well equipped was mentioned as another factor that can enhance self-efficacy and satisfaction post-stroke. Providing the stroke survivor with the confidence in the therapist and rehabilitation facility was expressed by both Western and non-Western health professionals as another way to facilitate self-efficacy. Dixon (2007) highlights the importance of a multidisciplinary rehabilitation environment in increasing self-efficacy in neurological rehabilitation. In such an environment, patient concerns are met and information provided.

Western health professionals highlighted the importance of developing programmes specific to the individual characteristics of the patients. This involved getting to know the patients, their likes and dislikes, and communicating with their family members to ensure that therapy is tailored to their individual concerns and personal goals. Although these suggestions reflect sound client-centred practice (Sumsion, 1999; Maitra and Erway, 2006), they also include addressing/ utilising religious commitments, such as prayer habits or having to attend the mosque.

Both Western and non-Western health professionals mentioned that showing patients examples of other patients who have improved might help increase self-efficacy and improve life satisfaction. This can also be known as learning through vicarious experience, defined as learning through the observation of others (Holloway and Watson, 2002). Bandura (1994) explains that observing success of others similar to oneself, which involved determination through various set-backs, increases the observer's self beliefs that they too are capable of achieving the same results. However, observing others similar to oneself failing reduces self-efficacy belief in that particular task. The self management programmes used with patients

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who have chronic disease are based to some extent on vicarious experiences. Lay participants with the chronic disease themselves share their experience of the condition in addition to the standard content of the programmes. This strategy can be used in stroke rehabilitation. Setting up of informal groups of stroke patients will facilitate enhancing self-efficacy through sharing experiences and learning from the successes and mistakes of others (Jones, 2006). Informal groups might be more appropriate for the younger stroke patients in Kuwait who may be keen to understand their symptoms better and comply with exercise programmes and other advice obtained from such programmes. However, its relevance and acceptability with the older generation is questionable. Further research is needed to determine how to tailor such programmes acceptably for older stroke survivors.

Although vicarious experience has not been investigated in stroke rehabilitation, some evidence from cardiac surgery participants helps in the understanding of possible effects of learning from the experiences of other patients. Parent and Fortin (2000) investigated the effect of vicarious experience through peer support on anxiety and self-efficacy in men undergoing cardiac surgery. The results showed that only the experimental group (who had support from other patients who had undergone the same surgery) showed a significant decrease in anxiety during hospitalisation. In addition to lower anxiety, the experimental group also showed higher self-efficacy and reported activity at 5 days and 4 weeks. Results of Parent and Fortin (2000) suggest that vicarious experience such as peer support can help reduce anxiety and improve self-efficacy expectations in patients undergoing cardiac surgery. This finding, although derived from cardiac patients, supports the perceptions of health professionals interviewed regarding the importance of providing patient examples for stroke survivors to help increase self-efficacy during rehabilitation.

Verbally motivating and encouraging patients were the most talked about strategies to enhance self-efficacy during rehabilitation. Health professionals interviewed mentioned the need to express positive words and avoid negative statements regarding the stroke patients' condition. Jones (2006) has also explained the importance of verbal feedback in enhancing patient capability. This feedback can be given by health professionals and family/friends of the patient. Bandura (1994), however, emphasises that it is more difficult to increase self-efficacy by verbal persuasion alone than it is to reduce self-efficacy with negative words spoken. Negative words appear to confirm already existing self doubts and insecurities. This emphasises the need for caution when providing negative feedback and people in general find it easier to be discouraged than to be motivated with words alone.

Bandura (1994) explains that there are four primary sources of self-efficacy which can be targeted during rehabilitation to improve self-efficacy. These include: performance attainment, vicarious experiences, verbal persuasion and physiological state. Performance attainment, also described as mastery experiences, has a direct effect on self-efficacy beliefs. This is when an individual is successful in accomplishing a task thus leading to perseverance in further tasks. While success increases one's belief in one's capabilities to carry out a certain task, failure reduces one's self belief. Lorig and Holman (2003) advocate the use of specific action plans to enhance skill mastery. Health professionals interviewed in this study mentioned the use of objective measures (reported earlier) to enhance skill mastery and identify change.

Goal-setting and targets are regularly used during rehabilitation, however these tend to be focused more on functional rather than psychosocial issues. Perhaps there is a need to include more goals targeting psychosocial issues in the rehabilitation process. Health professionals in

Kuwait interviewed expressed the importance of setting goals to increase self-efficacy during rehabilitation. Goals were viewed as incentives to treatment and also used to plan the therapy and invite cooperation with the stroke patient. Effectiveness might rely on more general education about the active role of the patient in stroke rehabilitation. The issue of goal-setting and patient engagement will be discussed in more detail in the following section.

Self-efficacy can also be developed from interpreting physiological and psychological states (Bandura, 1994). Jones (2006) mentions the great need for the stroke patient to understand issues such as anxiety, depression, fear and how these affect their psychosocial recovery post-stroke. Health professionals interviewed in this study mentioned the need to educate patients and their families on issues regarding recovery, psychological and social issues post-stroke. However, it is difficult to assess how receptive patients and families are to this information at the time of the acute stroke when shocked and having to cope with the suddenness of the condition. However, such education might be more appropriate with chronic stroke patients (more than 6 months post-stroke) and might facilitate self –efficacy amongst both the patient and supporting family members. In Kuwait, presenting such education within a religious framework might increase receptivity and compliance. Further studies around these issues are required.

Goal-Setting and Patient Engagement

As mentioned briefly in the last section, goal-setting can be used as a tool to facilitate self-efficacy in stroke rehabilitation. Goal-setting can be described as a: "a process of discussion and negotiation in which the individual and staff determine the key priorities for rehabilitation for that individual, and agree the performance level to be attained by the patient for defined activities within a specified timeframe (Playford, Siegert, Levack et al 2009:

p.335). Wade (1998) describes it as: "the process of agreement on goals, this agreement usually being between the patient and all other interested parties. The process might include setting goals at various levels and in various time frames"(p.273). Goal planning is another term which is used synonymously with goal-setting. Levack (2006) argues that the above definition of goal-setting/goal planning does not give a true reflection of the process, as not all goal planning involves agreement with the patient. The preferred description of goal planning was "establishment of goals" (Levack, 2006; p740). The word: "goals" can be described as the end result, or aim of one's ambition (Levack, 2006). Wade (1998, p.273) defines the word goal as: "a future state that is desired and /or expected". The general consensus is that goal-setting is crucial in rehabilitation, however it is unknown whether strategies of goal-setting used in Western countries are effective in non-Western cultures. Goal-setting has been reported to facilitate increased motivation and self–efficacy in rehabilitation. However, the majority of the studies carried out on goal-setting have been done in Western countries, with limited information about how transferable these results are in non-Western cultures (Baker, 2001, Dixon, 2007). This topic becomes particularly important in Kuwait given the results of this project indicating that difficulties with goal-setting is an important cultural characteristic specific to Kuwait. In the current project, health professionals expressed the view that Kuwaiti stroke patients struggled with identification of goals during their rehabilitation. In addition to this, wide spread access to maids and paid help was thought by health professionals, to affect the process of achieving basic goals related to ADL. This highlights the need to have a closer look at goal-setting in the literature and identify how best to improve the process in Kuwait with its distinctive characteristics of religious beliefs, access to maids and extended family involvement.

Research studies (in Western cultures) have highlighted the importance of goal-setting in rehabilitation. These include improving patient management and effectiveness of treatment strategies, improved outcomes and identifying benefits from treatment (Baker, 2001). These benefits could include increased performance on tasks, increased satisfaction, increased compliance to treatment protocols and increased morale (Baker, 2001). Other purposes of goal-setting include increasing self-efficacy and motivation during rehabilitation. Dixon (2007) identified goal-setting as one of the strategies to enhance self-efficacy in patients undergoing neurological rehabilitation. Goal-setting meetings were expressed as being important in motivating patients. The following was also highlighted: "These meetings are an important source of information for patients; breaking things down into manageable steps to help patients adjust their expectations and understand the route to recovery" (Dixon, 2007: 235).

Young, Manmathan and Ward (2008) studied perception of goal-setting amongst carers, patients and rehabilitation staff in a neurorehabilitation in-patient unit in the United Kingdom. Content analysis was used to analyse semi-structured interviews with participants. Results identified that goal-setting was perceived as beneficial by all three groups. Benefits included increased motivation, reassurance for the patients, assisting in providing problem solving strategies for patients and careers. Rehabilitation staff expressed their view that goal-setting aided in team work and made practice more focused. Similar results expressed by health professionals in Kuwait suggested that goal-setting could increase motivation and be used for guiding therapy.

There appear to be various aims of goal-setting reported in the literature. The need to highlight specific strategies of goal-setting to increase self-efficacy is paramount. Levack et

al (2006) investigated the use of goal planning in rehabilitation. The aim of their study was to identify the purposes of goal planning reported in the literature and the ways in which goal planning was carried out i.e mode of action. Relevant databases between 1966 to 2004 were searched using key words related to goal-setting, goal planning and goal attainment and 530 relevant articles were identified. From these articles identified, only 123 met the criteria for inclusion in the analysis. They then conducted thematic analysis on articles investigating goal planning in rehabilitation. Four main purposes of goal-setting in rehabilitation were identified: 1) to improve patient outcomes; 2) to increase patient autonomy; 3) to assess outcome of treatment techniques; 4) to adhere to contract, legislative or professional guidelines (Levack et al, 2006). Improving patient outcome as determined by standardized outcome measure was found to involve four mechanisms which were: i) by influencing a patient's level of conscious motivation, ii) by enhancing the specificity of training to meet an individual patient's requirements, iii) by achieving secondary therapeutic effects, outside the scope of the goal itself, and iv) by improving teamwork. Goal-setting to increase patient autonomy was reported to be as a result of involving patients in the rehabilitation process thus facilitating a sense of ownership. Assessing the outcome of treatment techniques was highlighted in three studies as a way to evaluate the success of the rehabilitation programme and was carried out by comparing observed outcome with desired outcome. Documentation of goal planning and/or the extent to which family/patients were involved in the process helped to meet the contractual, legislative and professional requirements.

Studies included in the review by Levack et al (2006) were all carried out in Western countries and it is unknown if these purposes and mechanisms identified are involved in goal planning in non-Western countries. Further studies are warranted in the non-Western context to explore these issues in greater depth. The aim of increasing patient autonomy might not be

consistent with the culture in Kuwait and the understood model of rehabilitation within Kuwaiti families. As evident from the patient interviews, responsibility for recovery post-stroke is placed largely on the health professionals and not on the stroke survivor him/herself i.e. there is little personal responsibility. The majority of patients appear to hold on to the biomedical model of rehabilitation which encourages dependency on the health professional. The shift from a culture of dependency on health professionals to patient autonomy is one that might be challenging for Kuwaiti patients and their families, and they might find it irrelevant within their own cultural context. Facilitating this shift might need to occur in a wider social context i.e. through the mass media and education, and would require a joint effort of all health professionals involved in the rehabilitation. On the other hand, it is possible that providing families with more information about relationships between self-efficacy and life satisfaction might help to encourage consideration of goals/ active responsibility for progress towards goals.

Purposes and understanding of goal-setting might differ between patients, family members, health professionals and funding organisations. Levack, Dean, McPherson et al (2006) interviewed nine clinicians in New Zealand to explore the value and purposes of goal-setting in brain injury rehabilitation. They reported that there was an inconsistent use of the word 'goal' and the purposes of goal-setting differed amongst the clinicians interviewed. The following was stated regarding the many connotations related to the word: 'goal' in the rehabilitation context as identified from the interviews conducted: "These include (but are not limited to) an individual patient's hope or desire, the therapeutic objectives of individual clinicians, the shared objectives negotiated between any number of stakeholders involved with an individual patient's' rehabilitation, a point of reference for outcome evaluation, as well as in some cases a statement of intent for accountability to a health funder" (Levack et

al, 2006b: 1446). Results by Levack et al (2006b) highlight the importance of clarifying the purpose of goal-setting and the meaning of the word 'goal'. They further reported that due to inconsistencies in meaning and purposes of goal-setting clashes between patients, health professionals and funding providers occasionally occurred. Clinicians in this New Zealand study also reported that at times they had different sets of goals, one for the patients and another set for funding providers to avoid clashes between families or funding organisations. These issues will need to be explored in the Kuwaiti context to investigate how to maximize the goal-setting procedure in order to increase self –efficacy specifically, as previous studies have demonstrated that the purpose of goal-setting is not as clear cut as previously described.

Identification of what type of goals enhanced self–efficacy and the rehabilitation process will also facilitate a more effective goal-setting process in the Kuwaiti context. Black and Brock (2010) demonstrated that short-term goal-setting is a valid measure of patient progress in in-patient neurological rehabilitation. Short term goal-setting was found to identify and facilitate review of the rehabilitation plan in patients not progressing as expected. Achievement of goals set at two weeks by the rehabilitation team was identified to predict achievement of goals at discharge and length of stay at the rehabilitation facility. These results may also indicate that the patients achieving the early goals were making a better recovery post-stroke than those not reaching the goals. In which case it may be a matter of how severe their stroke is, rather than any process of goal attainment in rehabilitation. Goals set included items related to health, social domains, communication, mobility, cognition and activities of daily living. However, these goals were set by the health professionals without inclusion of the patient and their family members. This has implications on the generalisability of these results to the Kuwaiti context where family involvement is an essential aspect of

rehabilitation. Regardless, results by Black and Brock (2010) emphasize the importance of setting short-term goals in guiding the rehabilitation process.

There is an increased emphasis on goal-setting in Western countries which has resulted in incorporation of goal-setting into practice guidelines however this has not yet occurred in Kuwait. As mentioned by Levack (2006), goal-setting has recently become a part of contractual, legal and professional requirements, and guidelines. For example the British Society of Rehabilitation recommends active participation of patients in goal-setting and "A Patient Centred Service" is the core requirement in of the National Service Framework for Long Term Conditions in the U.K (Holliday et al, 2007). At the moment, no such professional guidelines exist in Kuwait enforcing, or supporting, inclusion of goal-setting in rehabilitation. However, as health professionals interviewed in this project expressed, there is the understanding amongst themselves (i.e the health professionals) of its importance during rehabilitation. Perhaps inclusion of more information on goal-setting for patients and their families, and contracts regarding goal attainment, might facilitate more active participation in rehabilitation.

Several methods of goal-setting have been identified by studies done in Western countries and it appears that patient centred goal-setting is not easily achieved. Leach, Cornwell, Fleming et al (2010), investigated approaches towards goal-setting amongst rehabilitation professionals (physiotherapists, occupational therapists and speech therapists) in an Australian Hospital. Eight health professionals participated in email interviews in which they were asked to give responses to seven semi structured open ended questions regarding goal-setting in sub acute rehabilitation. Three main approaches to goal-setting were identified: Therapist controlled, therapist led and patient controlled. Therapist controlled goal-setting

involved little or no collaboration with the patient or family members. Therapist led goal-setting involved a collaboration between therapists and patient, with the therapists providing guidance but allowing patients to set goals. The patient focused goal-setting was carried out by only one of the therapists interviewed and it focussed mainly on the patient and their family. Participants also discussed barriers to patient controlled goal-setting. These included: difficulty communicating with patients having expressive aphasia, discrepancies between patient's and therapist's goals and limitations of therapist's time. Increased motivation was expressed as the main advantages of a patient centred approach. This study was carried out in Australia and it is possible that results would be different in Kuwait where patients seem to prefer a therapist led approach. It is also possible that therapists might have described the process they believed they adopted but not the true process that would have been observed on video recording. A similar survey done in the U.K of goal-setting methods used in rehabilitation reported that therapists mostly used a problem-oriented approach as opposed to a patient-centred approach to goal-setting (Holliday et al, 2005). This involved rehabilitation teams defining, formulating and evaluating the goals. About a third (30%) of therapists used goals to measure rehabilitation success, however standardized goal-setting measures were not commonly used. Clinicians revealed that patients were not given information on goal-setting however they were given a written copy of the goals. Patients and families in Kuwait would certainly benefit from being given information about goal-setting and given the opportunity to discuss their own goals with the rehabilitation team.

Some other potential problems have been identified with goal-setting, these include: patients who lack cognitive skills to contribute to the goal-setting process, and difficulty transferring goals set in hospital to community settings (Playford et al, 2009). The issue of transferability of goals set in hospital to community settings becomes more evident in a culture like Kuwait

where patients' roles at home differ from their allocated role during rehabilitation. A stroke survivor might be expected by the therapist during rehabilitation to reach for items independently or carry out other tasks e.g ADL. However, due to the availability of maids and other paid help, such goals might not be regarded as appropriate or even necessary by the patient once they return home. The results of this project highlight the importance of setting goals jointly with the patient and the family to ensure appropriateness and transferability into the community setting.

The results from this current project suggests that goal-setting in Kuwait could benefit from interdisciplinary meetings with both the stroke survivors and key family members, and not only one- to- one goal- setting sessions within physiotherapy treatment time slots as currently practised. However, health professionals would need to understand the different world views of stroke patients and their families in Kuwait and how to engage effectively with them. This might require listening to their concerns and tailoring goals to their major concerns. Some research studies carried out in Western countries have shown that therapists within the rehabilitation context were more willing to engage in goal-setting collaboration than the patients, and some of the collaboration involved persuasion of the patient when they did not share the same view of the problem as the health professional. Barnard et al (2010) reported, from a study that involved audio and video recording of 6 goal-setting meetings with the rehabilitation team and patient, that the interaction was heavily shaped by the health professionals and not the patient. Patients used strategies such as silence or humour to express their disagreement with goals set by the rehabilitation team. Although the team acknowledged the patients' concerns they still pressed on with their agenda without changing the set goals. Similar results were reported by Parry (2004). She analysed the goal-setting interaction between patients and therapists in stroke rehabilitation settings in four U.K

hospitals. Video recordings of 74 treatment sessions (which involved 21 patients and 10 senior therapists) were analysed to identify how goals were set. Only eight goal-setting episodes were captured. Results identified that the majority of the time, problems were identified by the therapists alone, who then set goal accordingly. In only one of the eight sessions did the session begin with the therapists asking the patient to highlight the problems they were facing, and in only this episode did the therapist revise the proposed goals according to the patient's concerns. This article shows that despite the literature available on goal-setting in rehabilitation settings, involving patients is still challenging and complex in the Western context. Reasons for the stroke patients' limited interactions in the goal-setting process highlighted by the researcher include a disparity of knowledge regarding problems associated with stroke and possible recovery (Parry, 2004). These issues/ barriers to patient centred goal-setting could be even more pronounced in Kuwait due to reduced awareness of stroke, rehabilitation and recovery, and the low education level of the older population as expressed by health professionals interviewed in phase 4 of this project. Language barriers in Kuwait between expatriate therapists and Kuwaiti patients could also be a barrier to patient centred goal setting.

Holliday, Ballinger and Playford (2007) provided some recommendations in dealing with the disparity between patient and therapist knowledge of stroke recovery. They interviewed in-patients in neurorehabilitation regarding the goal-setting experience. Their results showed that participants felt they needed more explanation of the causes and progression of their disease to engage actively in the goal-setting sessions. Explanation of cause, nature and progression to stroke survivors and key family members prior to engaging in goal-setting will enhance goal-setting in Kuwait and facilitate cooperation and autonomy of patients and their

family members. This will also increase self-efficacy in both physical recovery and psychosocial adaptation domains.

Levack et al (2009) discussed the issues related to involving family members in goal-setting within rehabilitation in New Zealand. They interviewed nine clinicians working in rehabilitation and identified that while involving family members in goal-setting carried many advantages (i.e educating them on recovery and rehabilitation, reducing chances of future conflicts with family members, and supporting family members to retain hope), family members often created barriers to patient-centred goal- setting. Participants expressed their view that family members often came into goal-setting meetings with their own agendas, expectations and time frame. Family members were said to set goals to address their own emotions which at times were not in agreement with the rest of the rehabilitation team or in the best interest of the patient. The result of this was that rehabilitation professionals avoided interacting with family members when such a clash of goals occurred. The authors thus concluded that in cases where family involvement was thought not to be in the best interest of the patient, health professionals should restrict family involvement. It must be noted that this study was carried out in New Zealand. In a context like Kuwait in which extended family is practised, such a recommendation is not feasible and would not be acceptable within the culture. A more appropriate method of enhancing patient centred goal-setting might have to include some negotiation of goals with key family members even in areas of conflicting interests. Further study is needed to explore the differences between family centred goal-setting and patient centred goal-setting in the Kuwaiti context as it is possible that there might be a great overlap between the two. Families are even more important if the stroke survivor does not go outside the home. Since such a patient is more 'enclosed', there is a greater need of a cooperative approach with health professionals.

There is a need to explore what constitutes active patient involvement in goal-setting and its advantages over therapist-controlled goal-setting. Arnetz, Almin Bergstrom et al (2004) reported that active patient involvement in goal-setting during rehabilitation has positive effects on both treatment outcome and quality of life. Active participation included a patient goal checklist and a meeting with the therapist in which a goal forum checklist was filed by both patient and therapist. This appears to be a method of increasing self –efficacy although not termed as so by the authors. Prior to meeting with the patient for the goal-setting session, the therapist filled out a goal checklist based on findings from the initial assessment. This check list and the patients' goal checklist where then compared and discussed in the meeting to establish goals in the following three areas: pain treatment, physical ability and functional ability. Patients exposed to the active participation goal-setting scored higher on range of motion, strength, quality of care scores than the control group. To what extent these activities boost self-efficacy was not reported however this deserves further enquiry. A key limitation in the present context is that their study was carried out on Rheumatology patients not stroke patients thus limiting generalisability.

Holliday, Cano, Freeman et al (2007) reported that neurorehabilitation patients including stroke patients preferred and benefitted from being involved in clinical decision making in which they engaged in active participation. Their study involved two blocks, Phase A which involved the usual goal-setting while the Phase B in which participants engaged in increased participation goal-setting. This involved the use of a workbook in which goal-setting was explained and participants were given the opportunity to prioritise activity and chose those they wanted to work on. Participants could use the workbook with support from family and friends and then their key worker if necessary. Participants involved in phase B set few but

more relevant goals, and reported a greater sense of autonomy than those in Phase A, however there was no difference in functional outcome between both groups. The results of this study showed that the structure provided by the goal-setting workbook helped participants to identify their own goals and increased personal autonomy (Holliday et al, 2007). This study was carried out in the U.K and its transferability to Kuwait is questionable. Participants in this U.K sample had the ability to read and understand how to use the workbook and appreciate what it intended to achieve. As evident during the semi-structured interviews, participants in Kuwait (especially the elderly) required a lot of help from the researcher in explaining the questions and providing scenarios to enhance understanding of scaling in the various questionnaires. It is doubtful whether they would be able to effectively use a workbook to prioritise their goals, it might be viewed as additional work which they deem unnecessary. However further research into its usefulness in younger, more educated stroke survivors is necessary.

Educating health professionals involved in rehabilitation of stroke patients in Kuwait on how to effectively carry out goal-setting might aid in increasing self-efficacy, motivation and patient engagement during therapy sessions. Bovend'Eerdt et al (2009), describes a practical method of setting goals in rehabilitation that are clear, specific and personal to the patient. This method involves four main parts: specifying the target activity, specifying the type and amount of support required, assessment of performance and specifying the amount of time required to achieve the set goals. These methods could help increase self-efficacy, however further research on the relationship between goal-setting strategies and self-efficacy is required.

The concept of patient engagement in relation to rehabilitation beyond goal-setting has been described as: "Deliberate effort and commitment to working towards the goals of rehabilitation therapy, typically demonstrated through active participation and cooperation with treatment providers" (Lequerica, Donnell, and Tate, 2009: 753). Level of engagement can be observed by how involved the patient is in the therapy session, which can range from high enthusiasm, interest and increased participation, to apathy, indifference and low participation (Matthews et al, 2002). Lenze, Munin, Quear at al (2004) demonstrated that low participation in therapy can be associated with poorer change in functional outcome and increase length of stay in hospital.

Health professionals interviewed in the current project expressed concerns with reduced patient engagement of their Kuwaiti patients, compared with patients they had treated in other countries. Reasons given for this included lack of understanding that active participation was necessary, prevailing attitudes regarding stroke, and family members helping too much. Other barriers to active participation in rehabilitation have been reported by other researchers. Lequerica et al (2009) conducted a survey to explore barriers to patient engagement and suggestions on how these can be overcome in a US sample. Their sample was made up of 199 physiotherapists and occupational therapists. Using a survey questionnaire, participants rated their frequency of encountering 27 potential barriers to patient engagement during rehabilitation. Results showed that fear of pain, depressed mood and difficulty learning new information were the three most rated reasons for poor patient engagement as perceived by the therapists. Other issues such as low educational level, family involvement, language barriers, cultural and traditional beliefs were also identified as potential barriers to patient engagement in rehabilitation. With the use of open ended questions, therapists identified strategies to overcome the potential barriers. These were: making tasks goal oriented,

meaningful and enjoyable, providing education, building rapport with the patient, allowing patient control, involving others in treatment, making therapy more rewarding and allowing for flexibility (Lequerica et al, 2009). It is possible that these strategies would increase patient engagement in Kuwait also, in addition to collaborative patient centred goal-setting with patients and their key family members, as discussed above.

Results of this phase 4 of this project, highlighted that health professionals in Kuwait expressed the view that goal-setting could be a tool to increase self-efficacy and motivation in stroke patients receiving rehabilitation in Kuwait. These views are consistent with Western literature regarding the purpose of goal-setting in rehabilitation (Baker, 2001, Dixon, 2007, Levack et al, 2006). However, the available research has pointed out that there are a variety of purposes of goal-setting and there is need to clarify why goal-setting strategies are being put into to place to avoid clashes between the patient, family members and the rehabilitation team (Levack et al, 2006b; Levack et al, 2009). There is therefore a great need to educate both health professionals involved in rehabilitation in Kuwait, patients and family members about how to conduct goal-setting effectively and, more importantly, its purpose with regard to enhancing self-efficacy. This could include setting goals in which the target activity, type and amount of support required, assessment of performance, and amount of time required to achieve the set goals are specified (Bovend'Eerdt et al, 2009).

Patient centred goal-setting although advocated by many studies in Western literature, might not be feasible in Kuwait in which the model of health care and rehabilitation is dependent on the health professional. Patients may not feel they have the knowledge to set appropriate goals or in some cases may not have the desire to do so. Family-centred goal- setting might be more appropriate in Kuwait to facilitate increased self-efficacy, compliance and follow-

through of rehabilitation aims once the patient returns home. This type of goal-setting would need to occur in a structured meeting with the patient, family members and members of the rehabilitation team. Short team goals might facilitate monitoring of how long term and discharge goals are achieved and highlight the need for these goals to be reviewed. Enhancing patient autonomy was identified as one of the purposes of goal setting in rehabilitation, according to western literature (Levack et al, 2006). In the Kuwait content, this might not be understood as patients and family members hold unto the medical model of care in which dependence on health professionals is encouraged. In addition to this, the prevailing public attitude towards stroke as expressed by health professional interviewed in Kuwait, was that it was the end of life and stroke patients were ill and should remain in bed. With such attitudes, attempting to introduce goal setting might seem inappropriate without first dealing with the negative attitude towards the condition. This would require education of patient and families at both individual levels and through the wider mass media. Other strategies to increase patient engagement in goal setting and rehabilitation as recommended by Lequerica et al (2009) might need to be investigated in more depth within the Kuwaiti context. These included: making tasks goal oriented, meaningful and enjoyable, building rapport with the patient, and allowing patient control.

9.5: Critical Evaluation of the Study

This section includes the following main sections: 1) reflection on the research experience in Kuwait; and 2) a critical evaluation of the individual phases of the research project.

9.5.1: Reflection on the Research Experience in Kuwait

"By three methods we may learn wisdom: first, by reflection, which is noblest; second, by imitation, which is easiest; and third, by experience, which is the most bitter." (Confucius, 551-479 BC)

Reflection and reflexivity are contested terms sometimes used interchangeably in referring to similar processes involving self-awareness analysis during research (Etherington, 2004, Krishnamurthy, 2007, Finlay and Gough, 2003). In the current project, the process of reflection was carried out formally at the end of the project, however it is noted that engaging explicitly in reflexivity throughout the research journey would have enhanced the trustworthiness of the project. Finlay and Gough (2003) use the term 'Critical self-reflection' to "capture both poles of the reflection-reflexivity continuum" (p. ix). In these authors' views, reflexivity is viewed as involving "critical self-reflection of the ways in which researchers' social background, assumptions, positioning and behaviour impacts on the research process" (Finlay and Gough, 2003: p.ix). The importance of clarifying how these terms are used is necessary in order to understand what the researcher is trying to achieve in undergoing any of these processes.

Reflexivity is defined by Horsburgh (2003: 308) as 'active acknowledgement by the researcher that her/his own actions and decisions will inevitably impact upon the meaning and context of the experience under investigation'. Patton (2002) describes reflexivity as a vital aspect of qualitative research because it reminds the researcher to take into consideration the origins of personal cultural, political, social, linguistic and ideological perspectives and the influence of these on the research process. A similar view point is noted by Bryman, (2008: 682): "reflexivity entails a sensitivity to the researcher's cultural, political and social context."

Several researchers have highlighted what they regard as the differences between reflexivity and reflection (Etherington, 2004, Krishnamurthy, 2007, Finlay and Gough, 2003). Etherington (2007) points out that although they are assumed by many to have the same meaning, there are apparent differences. Reflection is: "related to self and improving future practice through retrospective analysis of action. It takes a cumulative body of knowledge that can be used to improve practice" (Krishnamurthy, 2007: 15). In other words reflection refers to translating experiences learnt from one setting or occasion to another. Reflection thus is described as a cognitive process in which past experience is used to change future action. It is often used by professionals to change their practice (Schon, 1983). According to Krishnamurthy (2007), the difference between reflection and reflexivity is related to when the process takes place. Reflexivity, takes place alongside the interaction with the participant, i.e. the researcher constantly evaluating his/her own assumptions and relationship with others and the context (Krishnamurthy, 2007). In reflection, the process occurs before the encounter of the new situation/interaction, after the evaluation of past experience (Krishnamurthy, 2007). Finlay and Gough (2003) provide similar description of the differences between reflection and reflexivity. Reflection is defined as: "thinking about something after the event' and

reflexivity is described as involving: a more immediate, dynamic and continuing self awareness." (Finlay and Gough, 2003; p.ix). As mentioned previously, in the current project, reflexivity was not carried out during the research journey, however reflection on the journey and challenges faced was carried out at the end of the project.

The following is a reflection in hindsight of the experiences encountered during the research process. This reflection is carried out to highlight ways in which the background and experiences of the researcher during data collection and analysis had the potential of influencing the findings obtained. This reflection also helped facilitate a deeper understanding of the culture in Kuwait and the decisions made during the research process that could inform future research projects (a benefit pointed out by Finlay and Gough, 2003).

a) **Beginning the research Journey- Identifying my research purpose**

On reflecting on how I developed my research question, I realised that a combination of personal interest, and results from previous literature guided my research purpose. When I started this project, I was unfamiliar with qualitative research. In fact I was doubtful whether it was indeed 'research'. I didn't have any experience interviewing participants and dealing with qualitative data. The initial plan was to conduct semi-structured interviews to identify issues that would assist in developing a scale to measure self-efficacy as carried out in other similar studies (e.g. Rigby et al, 2003). As the project developed, I found myself interested in not only developing a self-efficacy scale but in hearing the accounts of the participants and highlighting cross-cultural similarities and differences in stroke experience/ rehabilitation. I learnt that qualitative research allowed for investigation of concepts in greater subjective detail (Bryman and Teevan, 2005; Patton, 2002, Denzin and Lincoln, 2000). My overall

research purpose then changed from primarily developing a scale-efficacy scale for people affected by stroke to exploring stroke experience in Kuwait. However, I was aware that this was a broad topic and I needed to narrow it down. Glesne and Peshkin (1992) emphasised the importance of choosing a research topic which the researcher finds intriguing. I had previously spent four years in Kuwait during my physiotherapy degree programme and came across a number of stroke patients and the issue of religion and self-efficacy was a topic I found intriguing and wanted to investigate in detail. Some patients that I came across would say it was 'God's will' for them to be in their current situation and appeared to be content with that. I wanted to explore this in more detail as it was a different view of disability from what I had come across in the U.K. Maxwell (1996) points out that researchers need to be aware of their motives for carrying out a project. These motives then guide the choice of methodology, either qualitative or quantitative, and mode of data collection and analysis.

As a physiotherapist, I believed in the uniqueness of each stroke survivor and the possible influence that religious faith could have on rehabilitation. This stemmed from my personal experience of religious beliefs helping me through difficult situations. I thought I would identify a similar pattern with stroke survivors in Kuwait. Some research articles had identified a relationship between religious faith and stroke outcome, however these were carried out in other countries (Robinson-Smith et al 2000, Giaquinto et al, 2007). These discoveries (i.e relationships between religion and stroke outcome in the literature), were not all known about at the beginning of the journey but contributed to the evolving research aims.

b) Reflections on being an insider/outsider in the hospitals and wider culture of Kuwait

The position of the researcher as an 'insider' and an 'outsider' has the potential to influence both the research and researcher him/herself (Gallias, 2008). Analysing the position of a researcher as both 'insider' in some aspects and an 'outsider' in others can enhance researcher reflexivity (Gibson and Abrams, 2003). On reflection, I am now aware that I was perceived as both an insider and an outsider, which had positive and negative consequences for the data collection with patients and staff. I was perceived as an insider by virtue of my professional identity and having studied in Kuwait University during my undergraduate degree. I was also regarded as an outsider through not being a Kuwaiti (i.e. Nigerian), not being Muslim, and not being employed at the first rehabilitation facility where the research took place. At the start of the project, I wondered how I would be perceived being a non-Kuwaiti and non- Muslim, and whether patients would want to disclose personal reflections about their lives.

Illustrating my relative 'insider' status, on my first day at the rehabilitation facility, I was introduced to the other physiotherapists in the in-patient and out-patients physiotherapy gyms. Some of these therapists were my clinical supervisors during my student days and others were much younger. Some remembered me from our physiotherapy training at the university or had heard about me as I was the only Nigerian graduate from the Physiotherapy programme in Kuwait. This meant that I was not perceived as a complete stranger. These prior relationships helped with ensuring co-operation from the treating physiotherapists of the stroke participants involved in the study. The 'insider researcher' is said to have some shared knowledge with other members of the in–group. This might include access to past/ present history and previous encounters (Gallias, 2008). Such prior knowledge might lead to taking-for- granted certain ways of behaving and responding, which highlights the need to be more

sensitive when conducting research in such a position (Schutz, 1976). For example, therapists and patients made reference to 'God's will' during interviews. I was aware (from prior experience as a therapist) that this might be used to prevent further disclosure and I tried to prompt a deeper response where possible. During the early stages of data collection, there was acceptance by the other therapists which helped in some ways to improve the trust, openness and cooperation of the participants. Such acceptance of me as a known physiotherapist also facilitated open disclosures during the interviews with health professionals.

Being an 'Outsider' is described as not being familiar with the people being researched, a stranger to the setting and experience (Hellawell, 2006). It may also signify something even more than being a stranger, but someone manifesting 'difference' thereby prompting others' suspicion. This has the advantage of allowing the researcher to stand back and see things he/she wouldn't have seen from an insider position. Another advantage of the 'outsider' position is a 'freedom from entanglement' which can provide a somewhat more objective perception than an insider position (Allen, 2004; Hellawell, 2006). However, there is the danger that the researcher could 'go native' after being immersed in a different culture for a prolonged period of time (Hockey, 1993). The term 'go native' refers to a situation whereby the researcher stops noticing differences and loses the critical perspective that can come with greater detachment. On reflection, I became aware that I was perceived as a foreigner by the stroke patients, as I was not dressed in the traditional Arabic way and spoke in English. It was also evident that I was not a Muslim as the majority of Muslim females in Kuwait wear a head scarf. This, I felt, led to suspicion and possibly limited disclosure from the patients, and on occasion distrust when questions regarding religious faith were expressed. As the project proceeded, I also had a growing awareness of my lack of understanding of their culture. I had

to be careful not to say anything during the interviews that might be viewed as offensive, and this may have had the negative consequence of reducing the richness of the data collected.

c) The issue of Gender in Kuwaiti society during data collection

In this section, I am reflecting on gender issues affecting the research process (which I did not have had much awareness about before the study began) and how gender was reflected in the settings in which interviews took place. Reflecting on the influence of gender is recommended by Pini (2005), as this has the potential to influence both the researcher and participants. While sharing the same gender can aid in establishing rapport (Gill and Mclean, 2002), differences in gender between participants and researcher can hinder communication (Patton, 2002). This latter problem may be magnified in a gender-segregated society such as Kuwait's.

Phase one of this project took place in 3 different physiotherapy gyms, one for male patients and two for females (in-patient and out-patient), in a rehabilitation facility owned by the government in Kuwait. Phase 4 took place mostly in a private rehabilitation facility which offered me employment while I completed my data collection. Similar to the government-owned rehabilitation facility, this private facility had two separate gyms for male and female patients. Interviewing in the male gyms of the government hospital was at times uncomfortable as I was the only female there and I recognised that it was culturally inappropriate for males and females to mix freely. I was increasingly aware of this cultural limitation and, particularly upon later reflection, I realise that this concern affected how I engaged with the male physiotherapists and patients. I became aware that there was less probing during the interviews and making eye contact with males was culturally inappropriate. Similar experiences were reported by Al-Makhamreh and Lewando-Hundt

(2008) when interviewing male patients in Lebanon. This gender-awareness and self-consciousness affected the flow of the interview and establishing rapport with the participants in my study. Data collection within the male gym was somewhat rushed due to my discomfort being in a setting without other females and a fear of being culturally inappropriate. Hence the data from the male participants might be regarded as thinner – not just because of the men's unwillingness to reflect on personal experience, or translation issues, but because of the inhibiting influence of the gender context. This aspect of data collection would have benefitted from having another Arabic speaking researcher, preferably female (or male for male patients) to assist me in dealing with the cultural sensitivities relating to social interaction between men and women. These issues also led to my focus on only female stroke patients' experiences in the main questionnaire study.

d) Researching Issues related to Religion in Kuwait

In discussing investigating religion, Walent (2008) states the following: "Given the deep rooted nature of religious and spiritual beliefs, a research effort founded on unexamined preunderstandings (one that is not attuned to its own context) may not only pose a threat to the validity of findings, but may unwittingly result in promoting unwarranted divisiveness and misunderstanding" (p.13). With hindsight, I became aware that I acknowledged my Christian background at the start of the project and also became increasingly aware that my own religious faith could have influenced the research project. There was the awareness that I did not understand fully the issues surrounding religious surrender that was frequently voiced by the Kuwaiti participants. My preunderstanding of the Muslim faith was shaped during my university years in Kuwait and conversations with class mates and patients while on clinical placements. For example, prior to the project I had the impression that Muslim participants in

Kuwait followed strict rules and regulations in adherence to their religion and that personal interpretation was discouraged and that this could possibly have led to experiences of abandonment and passivity during rehabilitation. However, as the project developed, I came to see different ways in which participants internalised their religious experiences and used it to enhance recovery. While some adhered to strict beliefs without questioning, others drew strength from their beliefs and used that to motivate them to work as hard as possible. I had to pay closer attention to the different behaviours and understandings of their faith during the patients' and health professionals' interviews. Lietz, Langer and Furman (2006) share a similar experience when interviewing Jewish participants, they describe the importance of being explicit about one's understandings of religious beliefs when investigating religion.

On reflecting on my experiences investigating religion in Kuwait, I came to understand that reflexivity is important in investigating religion because: "religion involves some of the most deeply and passionately held human beliefs" (Weaver & Koenig, 2006, p.1336). This project would have benefited from the use of a reflective journal especially when dealing with issues regarding religion. During the interviews, I was aware that the translators tried at times to portray positive images of their religion and culture and I suspected that patients' negative comments or doubts were not translated into English. I was able to pick out some of this with my limited knowledge of Arabic. The translators appeared at times to engage in conversations with the patient in Arabic to suppress such doubts or negative comments. Patients were sometimes told to trust in God and everything would be alright. Patients themselves tended to use the term "Ishala (God willing)" to close down conversations on personal issues and thoughts regarding the future. Asking patients to elaborate on these issues appeared to be inappropriate once they had said: "Ishala". On reflection, these experiences highlighted the need to have had another Arabic speaking researcher during the data

collection. These realisations were made at the end of the project on reviewing the difficulties encountered. Such a person, if experienced in qualitative interviewing, would have known how to appropriately ask questions to probe deeper despite the participant trying to close down the conversation (whilst maintaining a respectful context). I was increasingly aware that participants may have believed they had to prove how religious they were by voicing trust in God, and that any expressions of doubts were rarely given the opportunity for further explanation. These observations highlighted the issues of social desirability and its possible influence when collecting data on sensitive topics like religious faith in this cultural context.

Not only interviews but questionnaires raised religious sensitivities, in ways that I did not fully anticipate at the start of the project. For example, I started to perceive that collecting data regarding religious faith using a questionnaire appeared to create the impression among participants that they were being scored on how religious they were. This may have led to their desire to obtain high scores which might have affected the validity of the results, even though the originators of the scale assure people of its acceptability across faiths. Perhaps the use of open–ended interviews might be more appropriate to explore issues relating to faith, although the previous discussion emphasises that there are no straightforward ways of researching religious faith in a profoundly conservative culture such as Kuwait. A trained Arabic-speaking co-researcher, with sensitive understanding of religious faith issues, might be indispensable. An Arabic speaking co-researcher would also have provided a better balance of insider and outsider perspectives which would have helped in gaining more sensitive insights. However this was beyond the resources of a PhD student.

e) Reflections on listening to views from the different cultures in Kuwait

This section will highlight reflection related to researching the experiences of people of different cultures living in Kuwait. From interviewing both patients and staff, I became increasingly aware that Kuwaiti patients had access to better care, equipment and government help to be taken abroad for further rehabilitation. Non-Kuwaiti patients were not provided with these services except the initial admission and rehabilitation.

Non-Kuwaiti therapists of Indian and Philippine origin also described the local Kuwaiti population expressing negative attitudes towards them during home visits i.e. being perceived as servants. My increased awareness of what appeared to be social injustice in the culture that I was studying was very distressing during the last year of my project. While therapists from Western countries were treated with respect, those of third world countries expressed their disappointment in the way they were treated by families of stroke patients when working in the community (making home visits). This awareness could possibly have led to a bias during interviewing non-Kuwaiti health professionals and placing more emphasis on their accounts during data analysis. I tried to deal with this by carefully noting the similarities and differences between accounts from health professionals of Kuwaiti, Western and third world origin.

The above section has outlined some of the reflections on various aspects of the research project in Kuwait. Some of the issues raised related to increasing awareness of my role as both an outsider and an insider, gender issues, emerging awareness of personal prejudices, and an increasing awareness of the different treatment of expatriate patients in Kuwait when compared to Kuwaiti patients. These issues have been highlighted at the end of the project,

however identifying these issues more explicitly during the research process would have influenced some of the decisions made. Through the process of reflection, I became aware of my increasing emphasis on the differences in services available to Kuwaiti and non-Kuwaiti patients and the contrasts in the experiences of different health professionals depending on their home country i.e. Kuwaiti, Western, or from a third world country. Being of a Nigerian (third world) background but having lived and had some of my training in the U.K and Kuwait, I had the opportunity to experience the many faces of rehabilitation experience in Kuwait. However, I was more sympathetic to those who appeared to be at a disadvantage due to their third world origin. This created a potential for some level of bias in my emphasis which I tried to limit by presenting both similarities and differences in the stroke experience gathered from the different groups of participants.

The increasing awareness of the "stories" of participants facilitated my shift from being a quantitative researcher to a qualitative one. I found that the semi-structured interviews helped not just to infer themes for the development of a scale but could give a voice to the experiences of the different groups of people. As I listened to the accounts of my participants, I started to become much more aware of power relationships, inequalities and other salient aspects of patients' and health professionals' experiences in the very stratified society of Kuwait. These issues were previously rather taken-for-granted/ not noticed by me and so unexamined. However, as interviewing progressed during data collection and as awareness increased regarding the plight of Non -Kuwaiti patients in hospitals, these issues became very real and important to me. This project highlights the fundamental feature of qualitative research that attempts to take an 'insider' view (hearing 'participants' voices'). With hindsight, the need for a genuine cross-cultural collaboration became increasingly evident through all the phases of the data collection and analysis, to gain more sensitivity in data

collection, analysis and interpretation. These insights will shape any future project that I become involved with in Kuwait.

As mentioned previously, the main aim of reflection is to gain insight from an experience to change future practice, in this case future research. From these reflections described above, I have learnt the importance of an ongoing documented reflexivity process with the use of a research journal to provide a trail of decisions made, and awareness of my personal influences at every stage of the project. It can be argued that reflexivity is an important aspect of qualitative research especially when exploring cultural differences. Engaging in reflexivity during the project may have facilitated a different set of decisions to be made such as partnering with an Arabic speaking health professional through all the phases.

9.5.2: Critical Evaluation of the various phases

Phase 1 and 4 (Qualitative Phases of the project)

This study has several limitations. The use of an interpreter in the interviews of the Kuwaiti sample in phase 1 was found to result in limited disclosure and limited depth of data. The interviewer was unable to use silence and reflection to gain more depth during the interview. The necessary rapport needed to ensure more disclosure from the participant was obstructed by the presence of the interpreter. There was also possibly some loss of meaning of the questions and answers post-translation. This is evident in the length of translation compared with the amount spoken by the participant. Memory issues when the translator is actually summarising what has been said rather than doing a direct 'transcription' may be influenced by their own cultural bias - e.g. deciding what is important/ admissible to disclose. In addition to this, it is possible that interpreter did not disclose issues that would leave a negative impression about their religion to an interviewer who might have been perceived as a

foreigner. Other studies have highlighted the difficulties using translators and the hesitation of patients to disclose sensitive issues to foreign health care professionals (Julliard, Vivar, Delgado et al, 2008).

As mentioned previously in the reflection section, perhaps richer data could have been obtained had all the interviews been done fully in Arabic. This would have required the training of an Arabic-speaking health professional to carry out the interviews and subsequent translation of the interview transcripts from Arabic to English for analysis. This would also have required training in the whole ethos of the project, including the importance of attention to emotional issues. However, due to limited funds, and initially limited research experience, as a PhD student, this option was not explored and interpreters were used to gain as much information as possible. This was considered acceptable at the time, given that the aim of phase one was primarily to explore stroke experience in Kuwait for the adaptation of a self-efficacy scale, rather than to explore the experiences in depth from a phenomenological or narrative perspective. Squires (2008) reviewed research articles using cross-language methods in qualitative research and reported that of the 40 studies identified, only 6 studies met the recommended criteria for trustworthiness. Squires mentioned that failure to acknowledge the translation as a limitation of the studies, in addition to failure to pilot the interview questions in the participants' language as methodological flaws of the studies investigated. Interview questions in the current project were only piloted in English (not in Arabic), however it is doubtful whether this in itself would have changed the quality of data obtained. Larkin et al (2007) viewed translators as possible collaborators in the research process rather than an obstacle. They advocate working more closely with the translator in development of the interview guide. This could lead to richer, more nuanced data especially regarding culturally sensitive issues like religion. The current project would have benefited

from such an approach i.e. partnership with the translators to obtain richer data. However due to time constraints, and limited experience in qualitative methods at the time, this was not possible.

Trustworthiness in Phases 1 and 4 of the Project

The concept of "trustworthiness" is viewed as the substitute of 'reliability and validity' in qualitative research (Golafshani, 2003). Guba and Lincoln (1981) introduced the following four criteria to assess the trustworthiness of qualitative research: credibility, transferability, dependability and confirmability (These terms have been defined in the methods chapter). A variety of strategies can be put into place to ensure trustworthiness in qualitative research these include: "prolonged engagement, triangulation, peer debriefing, member checking, negative case analysis, audit trail and reflexivity" (Lietz, Langer and Furman, 2006: 444). The current project used second coding of a 25% proportion of the transcripts in both phase 1 and 4 to go some way towards establishing the credibility and dependability of the data collected. A study is said to be credible when the descriptions it presents can be recognised when presented to readers or co-researchers. Another way of establishing credibility would have been by allowing the patients to read and discuss the themes obtained from the analysis (Koch, 2006). This was not possible in the current project because the data analysis was carried out a year after the data were collected by which time the patient participants had stopped receiving rehabilitation and could not be located. In any case, considerable problems with translation and possibly patients' ability to conceptualise some of the themes would have been encountered. A similar sharing of the themes in phase 4 involving the health professionals was planned, however this was not carried out as the researcher was no longer residing in Kuwait. However, it is acknowledged that this would have increased the

credibility and dependability of the analysis of the data obtained. It might have achieved greater elaboration of the themes also.

Transferability refers to the ability of the results to be transferred, or generalised, to other contexts (Koch, 2006). It can also be referred to as "fittingness" (Speziale and Carpenter, 2007), which means the extent to which the working ideas fit the proposed new context. The burden of proof for transferability of qualitative findings is said to be on the user of the research and not the researcher (Guba and Lincoln, 1989). Providing thick descriptions of the research settings and information about participants is recommended to enhance transferability, as the user can then decide whether there is sufficient similarity between the research context and their own contexts (Tuckett, 2005). The introductory chapter of this project outlined the setting and nature of rehabilitation in Kuwait. This would help readers in deciding transferability of results to other similar settings in the Middle East or with Kuwaiti stroke patients living in other countries. Future research could involve investigating the same issues with Kuwaiti stroke patients living in the U.K or with other Muslim stroke patients in surrounding countries in the Gulf region. This would require collaboration with other therapists and researchers in those countries.

Triangulation is another way of establishing trustworthiness of qualitative research. This is described as the: "the combination of two or more theories, data sources, methods or researchers in the study of a topic" (Robert et al, 2006: 44). This method helps to ensure that the phenomenon under investigation is studied in the most complete and thorough way (Speziale and Carpenter, 2007). Triangulation attempts to reduce bias from using a single method i.e. offers an attempt to overcome the weakness of a given method (Tuckett, 2005). It can thus be used to confirm (or disconfirm) findings (or emerging theoretical interpretations)

by giving the researcher information from different vantage points (Speziale and Carpenter, 2007). It was initially described by Webb et al (1966) as an approach which increased confidence in findings by using more than one method (cited by Bryman, 2008).

Two main purposes of triangulation have been discussed by various researchers (Jones and Bugge, 2006; Shin, 1998; Begley, 1996), namely: 1) confirmation, and 2) completeness. Confirmation refers to the ability for data analysis and results obtained in a study to be confirmed by the use of other methods, investigators or data from other sources. Shin (1998) stated the following: "The use of triangulation for the purpose of confirmation has necessitated the identification of data collection instruments or techniques whose strengths and weaknesses are known, and then counterbalancing them to minimize threats to validity" (p.633). This was not attempted in this project. Sim and Sharp (1998), however, argue that confirmation of results with triangulation is difficult. Multiple methods might reveal conflicting findings (Jones and Bugge, 2006). There is also an underlying positivistic assumption that the multiple methods are uncovering 'facts' which can be agreed upon – whereas more interpretativist researchers accept that they have an inevitable influence on the research process, and that multiple methods will not necessarily remove their 'presence' from the research findings. Completeness refers to the ability of triangulation to offer deeper insights about a phenomenon by investigating it with the use of different perspectives and methods. This purpose is said to be of more value in research than attempting to confirm the results (Sim and Sharp, 1998). This form of triangulation was more apparent in this project, through the use of quantitative and qualitative methods to explore religious belief, although clearly this could have been developed more.

Redfern and Norman (1994) outlined the following advantages of triangulation.

-Overcomes the bias of single-method, single observer, single theory studies

-Increases confidence in the results

-Allows development and validation of instruments and methods (confirmation)

-Provides an understanding of the domain (completeness)

-Ideal for complex social issues

-Allows divergent results to enrich explanation

(Redfern and Norman, 1994, p.52).

Denzin (1989) and Speziale and Carpenter (2007) go further than defining the purpose of triangulation, by differentiating four main types of triangulation: data triangulation, investigator triangulation, method triangulation and theoretical triangulation. The overall project reported here used both qualitative and quantitative methods in investigating life satisfaction, religious faith and self-efficacy in the Kuwaiti stroke rehabilitation context, so there was limited methodological triangulation used for addressing the overall research question. Establishing trustworthiness of qualitative research with triangulation, may involve the use of quantitative methods to assess the same phenomena under investigation (Golafshani, 2003; Tobin and Begley, 2004). Other methods like case notes or observations, or focus groups can also be used (Jones and Bugge, 2006; Shin, 1998).

Investigator triangulation has been defined as: "two or more research trained investigators who explore the same phenomenon with diverse backgrounds" (Kimchi et al, 1991:365). Mitchell (1986) defines it as: "a research team or thesis/dissertation committee who have shared interest in the topic under study, as well as diverse perspectives and areas of expertise with regard to the topic" (p.214). An example of investigator triangulation is found in the study by Proot, et al (2007), in which two investigators and peer debriefing during analysis

were used to explore perceptions of stroke patients and health professionals regarding autonomy during rehabilitation. Their study also included the use of data triangulation (data were collected from three different nursing homes) and methodological triangulation. These other types of triangulation will be discussed in the next sections. The current project involved the use of investigation triangulation to a limited degree as the two supervisors offered some complementary perspectives on the data and analysis. A more developed research team would take this further (but this would be unusual for a PhD project).

Data triangulation involves "the use of multiple data sources with similar foci to obtain diverse views about a topic or the purpose of validation." (Kimchi et al, 1991:364) It can also be described as the use of more than one source of data in a single investigation. Three types of data triangulation in qualitative research were described according to Denzin (1989): Time, space and person triangulation. Time triangulation involves data collected at different points in time. For example, different times in a day or different days in a week. Space triangulation involves data collected at different locations or sites. It can be used, for example, to compare decision- making or rehabilitation processes at different sites. Person triangulation involves collecting data from more than one set of individuals or groups (Denzin, 1989). Adamsen and Tewes (2000) carried out data triangulation in a study which explored discrepancies between perspectives of patients on their main problems and corresponding documentation by nursing staff. Triangulation of data from three sources was carried out: patient interviews, nursing records and focus group interviews with nursing staff. In the current project, there was limited person triangulation (i.e interviews with stroke patients and health professionals) but as mentioned before, the purpose was not to confirm the findings from one source but rather to elaborate and enrich the understandings achieved.

Method triangulation "incorporates two or more research methods into one investigation" (Speziale and Carpenter, 2007: 384). It can also be described as "the use of more than one research method or data collection technique (e.g structured instruments, observational and interviews), which are selected because each taps a different aspect or dimension of the problem being studied" (Shih, 1989: 636). The use of different methods is said to help provide a detailed understanding of the phenomenon. Combining qualitative and quantitative research methods is seen as valuable, however can be expensive and in some cases present difficulties in combining narrative and numeric data (Thurmond, 2001). Arguments exist in the literature regarding appropriate ways of combining qualitative and quantitative methodologies. These arguments stem from the belief that methods based on differing ontological and epistemological perspectives cannot be combined (Jones and Bugge, 2006; Begley, 1996). This issue has been discussed in the methods chapter of this project. Some methodological triangulation was carried out in the current project in that both quantitative and qualitative data were collected, to enrich the understanding of the complex stroke experience in Kuwait, particularly in relation to religion.

Lambeth and Loiselle (2008) reported on a qualitative method triangulation in which focus group data were triangulated with individual interview data. This method of triangulation was found to be useful because it helped to produce a richer understanding of the phenomenon being investigated and helped identify individual and contextual circumstances related to the phenomenon. In the study by Proot el al (2007), methodological triangulation involved the use of group meetings with participants, and individual participant interviews. Data collected during individual interviews were discussed and peer debriefing (amongst the two

investigators) was carried out to reduce the possibility of single researcher biases. This, more thorough, approach could be attempted in future research on the current topic.

Theoretical triangulation involves the combination of more than one lens or theory in a single investigation (Speziale and Carpenter, 2007). It can be used to compare rival theories and provide a more complete understanding of an issues being investigated. This type of triangulation is used in either developing theories or evaluating existing theories (Shih, 1998). Denzin (1989) describes theoretical triangulation as useful in testing the usefulness of theories and exploring conflicting theories to offer alternative explanations. Lev (1995) investigated self-efficacy in cancer patients with this type of triangulation. She explored Orem's self-efficacy theory and Bandura's self- efficacy theory combined and was able to design a more comprehensive intervention to enhance self-efficacy using both theories. This form of triangulation was not attempted in this project, as it was more exploratory, being conducted in a context where there was little prior theoretical understanding.

Various types of triangulation could have been included in the current project to enhance trustworthiness. Data triangulation was potentially carried out by interviewing both stroke survivors and therapists regarding the impact of stroke on patients' lives. However, direct comparison of reports from stroke survivors and therapists was not carried out. This might have yielded valuable information regarding the differences between actual experience and perceived experience from the health professionals. The use of focus groups to triangulate data collected from semi-structured interviews from both stroke survivors and health professionals might have increased the trustworthiness of the data collected in this project (Speziale and Carpenter, 2007), but it is unclear whether focus groups are a culturally appropriate way of gathering patients' experiences. Other appropriate ways of establishing

trustworthiness in this project would have been :- 1) maintenance of a more detailed reflective journal during the data collection and analysis phases, 2) Investigator triangulation via a cross-cultural collaboration with an Arabic speaking researcher in both data collection and analysis stages. These two points were not carried out at the start of the project for the following reasons: Reflection was not initially seen as relevant as this project started out being primarily quantitative in orientation, and due to insufficient resources an Arabic interviewer could not be employed.

Critical Evaluation of Phase 2

The use of the Chronic Self-efficacy Scale to develop a scale for the Kuwait population resulted in the development of a scale that cannot be compared directly with results of any other self-efficacy scale. However, criterion validity of the adapted scale was established by testing it alongside the Generalised Self-efficacy scale. Further validation studies are required to assess reliability. The strength of the adapted self-efficacy scale (Psychosocial Adaptation Self-efficacy scale-PSE) is that it was more sensitive than the general self-efficacy scale in predicting life satisfaction indicating that further validation is a worthwhile task. A limited number of participants were used for establishing its validity due to difficulty gaining sufficient participants in a clinical setting.

Life satisfaction was measured by a single item measure. Perhaps the use of a more robust measure of life satisfaction might have provided more insight as what dimensions of life satisfaction are related to self-efficacy. Nevertheless, using a single measure is similar to other studies and also saves on time and energy for the respondents affected by stroke.

Critical Evaluation of Phase 3

Phase 3 adopted a cross sectional design. This meant that causal associations could not be made. Compared to other similar published studies, the Phase 3 study used a relatively small sample size of 40 participants for pragmatic reasons i.e. time available, and difficulty recruiting sufficient numbers of willing participants meeting exclusion and inclusion criteria. Only female participants were used in Phase 3, therefore its results cannot be generalised to include male stroke survivors. The use of self-report measures meant that the possibility of participants being unwilling to report their true beliefs regarding self-efficacy and religious faith cannot be overlooked. There is always the possibility that in order to appear socially acceptable, participants may have rated their religious beliefs as high especially because the questionnaires were administered in an interview and not independently/ anonymously.

The sample size of 40 used in this phase of the study was small especially for the use of multiple regression analysis. Ideally a sample size of 50 plus 8 cases per independent variable is required for such studies, so this aspect of the analysis must be regarded as exploratory and needing further testing with larger samples. Due to difficulties with recruitment in the time available (and the length of time taken by each interview) only 40 complete questionnaire packs were obtained. The Santa Clara Strength of Religious Faith Questionnaire (SCSROF) was found to have limited sensitivity within this current project. However, this was not known before the study.

The role of the researcher as a Christian and non-Kuwaiti working and researching in a different cultural context cannot be overlooked. This may have affected participants' willingness to disclose certain issues, as noted in the reflection section. The background of the researcher could have led to subtle biases during interviewing and subsequent analysis of

the data in all phases of this project. The possibility of taken- for- granted beliefs influencing data analysis cannot be overlooked. An ideal situation could have involved the use of stroke survivors and health professionals in the joint analysis of the data. Although some of this was done in the final phase involving health professionals, this would have presented more in-depth analysis in the other phases as well.

The results of this study cannot be generalized to all Muslims or all stroke patients living in the Middle-east. These results are specifically related to stroke experience in Kuwait with its unique mix of Kuwaitis and expatriates. Further studies are required to investigate the difference in stroke experience between Kuwaitis and non-Kuwaitis as small sample size did not allow for in-depth analysis of this issue.

Despite the weaknesses highlighted above, several strengths can be seen in this project. The use of a mixed methods i.e. qualitative and quantitative research methods, allowed for an in-depth study of self-efficacy, life satisfaction and religious faith in stroke patients living in Kuwait. The strengths of phase 3 include the use of a battery of tools, all validated except for the adapted self-efficacy scale (PSE). Health professional interviews provided an in-depth view of cultural influences and differences and confirmed some of the experiences of stroke patients, whilst highlighting some further issues. Some health professionals could contrast their experiences of rehabilitation in a variety of societies/ cultures. They also suggested some clinical implications of the findings, supplementing the researcher's own views. New findings were successfully obtained from this project which will be discussed in the next section.

9.6: New Findings from Current Project

The literature review conducted in this project identified 20 studies focusing on life satisfaction and subjective well-being post-stroke. Factors associated with life satisfaction as identified in these studies include: social support (both family and external support), living arrangement (i.e. those living alone having poorer life satisfaction), low level of depression, absence of urinary incontinence, reduced length of hospital stay, return to work, meaningful occupations and leisure activities. The majority of these studies were carried out in Western countries with the exception of three studies (one from Japan and two from Israel). It is possible that due to differences in beliefs regarding disability and extended family structures in the Middle East, results from the literature review cannot be generalised to include an Arab population. No study investigating factors associated with life satisfaction post-stroke with a predominately Muslim population was identified in the literature review. The current project presents such results from a predominantly Muslim population living in Kuwait. Self – efficacy, both general and psychosocial adaptation, was found to be positively associated with life satisfaction post-stroke.

Results of this study highlighted the importance of psychosocial adaptation self-efficacy in life satisfaction post-stroke. Significant positive associations were identified between psychosocial adaptation self-efficacy (PSE) and life satisfaction. PSE was also identified (albeit using multiple regression in an exploratory way) as the most significant predictor of life satisfaction among the variables tested. A recent systematic review on self-efficacy in stroke rehabilitation identified the positive association between self-efficacy, quality of life and functional outcome as reported by a few studies (Jones and Riazi, 2010). However, this study is the only project identified to date focusing on psychosocial adaptation self-efficacy.

Stroke survivors in Kuwait mentioned concerns with physical difficulties such as difficulty walking and using the affected upper limb, difficulties with ADL such as washing and dressing, and speech difficulties which were similar to reports from Western literature. However, Kuwaiti stroke survivors appeared to have different views of dependency, not only because of living with extended families but due to the socially accepted presence of maids, drivers and other paid help. This distinctive social context increases the need for cultural awareness on the part of the health professional, in order to be able to provide culturally appropriate care for stroke patients.

This study also provided insight into the Kuwaiti culture and stroke experience which has not been investigated before. The possible influence of cultural clashes between therapists and patients/family during rehabilitation was highlighted. These clashes led to negative perceptions of patient motivation by health professionals which on a long term basis could influence relationships between health professionals and their patients.

The possible role that religion played when working with Kuwaiti stroke survivors was also identified. Although quantitative analysis did not identify any association between religious faith and life satisfaction or self-efficacy, interviews from both stroke survivors and health professionals identified that religious beliefs influence patient behaviour and motivation during rehabilitation. Religion was described as having a significant role in expressed acceptance of disability by stroke survivors. However, it is also possible that the expressed acceptance of disability through faith reflected adherence to social norms. This was implied by contradictory statements i.e. expressing frustration regarding challenges in addition to

voicing acceptance of disability and trusting in God. This apparent contradiction gave the impression of two different 'faces', one a 'public face' with socially appropriate responses and expressing trust in God, and the second a 'private face' expressing challenges and frustrations related to disability. Public religious commitment appeared be deeper than a 'social desirability' effect, perhaps revealing a cultural norm which does not permit deviations from the professed religious belief. This presents a challenge for therapists to work within this framework of belief.

9.7: Suggestions for Further Research

Further research is required to investigate possible gender difference in stroke experience in Kuwait. Perhaps due to language barriers and the presence of a translator, male stroke survivors did not share in depth their experiences of stroke. In addition to this, as mentioned previously, more research is required to understand the differences in experience of stroke and rehabilitation between Kuwaitis and non-Kuwaitis living in Kuwait. The few non-Kuwaitis interviewed in this study, highlighted their concerns with return to work and their finances. The impact of these concerns on their recovery needs to be explored in further depth. There was some indication from the literature reviewed that cultural characteristics could affect the experience of caring for a family member with stroke, the need to study this in Kuwait is paramount as the burden of care is mostly on the family members. Further validation of the adapted self-efficacy (PSE) scale is also required.

In addition to these points, there is a great need to further explore the possible influence of religious beliefs on patient motivation and engagement during therapy in this context. In-depth open ended interviews would be a more appropriate method of investigating these issues related to religion amongst the Kuwaiti population. This would involve the interviews

being carried out by an Arabic speaking health professional, trained to conduct open ended interviews, translation of the transcripts into English, and cross cultural collaboration during analysing the data collected from the interviews. Data analysis with interpretative phenomenological analysis would then be appropriate and would yield a richer understanding of how religion affects their experience of stroke and engagement in rehabilitation. A period of ethnographic observation to such an enquiry will enhance and form a richer multi-method case study of one rehabilitation unit. This would allow triangulation of data, and perhaps the addition of more sensitive multiple analytical perspectives if a Kuwaiti researcher was involved in the data analysis.

Recent studies in the UK by Jones, Mandy and Partridge (2009) have shown that self management strategies such as use of a workbook, can help facilitate self-efficacy post-stoke. Such interventions would need to be investigated in a country like Kuwait to assess their transferability to other cultures. This could possibly be initially investigated with detailed case studies to explore how relevant they are to the needs of stroke patients from Kuwaiti and non-Kuwaiti backgrounds living in Kuwait, and how they can be adapted for an Arabian population (particularly younger stroke patients). Other projects would need to investigate the effectiveness of these strategies on a larger scale.

Further studies to explore goal-setting and patient engagement in the Kuwaiti context will aid in a deeper understanding of how to enhance self-efficacy with the use of goal-setting strategies. This could include video recording current goal-setting procedures, and interviewing health professionals, patients and family members about their perceptions of what motivates their engagement in rehabilitation.

Chapter 10

Chapter 10

Conclusions

This project sought to investigate the experience of stroke and factors associated life satisfaction post-stroke in Kuwait. Specific research questions were:

1) What are stroke survivors' experiences of stroke in Kuwait?

2) What is the relationship between life satisfaction, self-efficacy, and religious faith in stroke patients living in Kuwait?

3) What are the cultural influences on stroke experience and rehabilitation in Kuwait from the health professionals' perspective?

The following main findings were identified by this project:

1) **Similarities and Differences in stroke experience in Kuwait compared to Western Literature**

- Differences in experience mostly related to religious views, finances and perceptions of dependency. Kuwaiti nationals benefitted from better financial support than stroke survivors in other countries (but not non-Kuwaitis). Perceptions of dependency were influenced by the socially accepted reliance on maids and other paid help. Further elaboration appears below in (3).

- Similar to Western literature, stroke survivors in Kuwait mentioned concerns with physical difficulties such as difficulty walking and using the affected upper limb, difficulties with dependency for ADL such as washing and dressing, and speech

difficulties. Psychological changes post stroke mentioned were mood changes and nostalgia, these were similar to reports in Western literature also.

- Social changes experienced post stroke by stroke survivors in Kuwait included concerns with their changed roles in the family (mostly amongst females), and social withdrawal/isolation post-stroke. Kuwaiti stroke survivors mentioned an increase in family support which was not identified in Western literature.

2) Religious faith, despite not showing a statistical relationship with self-efficacy or life satisfaction, is an aspect of the culture that cannot be overlooked

- Quantitative analysis in phase 3 did not show any significant association between religious faith and life satisfaction, or between religious faith and self-efficacy, associated possibly with ceiling effects in the selected religious faith measurement tool.

- Kuwaiti stroke survivors appeared to hold simultaneously two differing attitudes towards stroke-related disability. One was a private one in which they voiced frustration related to physical and psychosocial changes post-stroke, and the second a 'public face' which expressed the attitude that everything was in God's hands and that disability was accepted because they trusted in God.

3) Availability of finances and paid professional support resulted in a culturally distinctive experience post-stroke

- Available finances were another significant area that differed between Kuwaiti and non Kuwaiti stroke survivors. Kuwaiti stroke patients did not mention the difficulties with finances post-stroke unlike non- Kuwaiti patients.

- Health professionals (but not the patients themselves) explained that Kuwaiti patients had access to family and governmental financial support (including opportunities for rehabilitation abroad) and this support was not provided for non- Kuwaiti stroke patients living in Kuwait.

- Available finances also led to the easy access to paid maids, drivers, and private nurses to assist in ADL post-stroke, especially among Kuwaiti patients. Such help was not viewed as inappropriate, but as a taken-for-granted social resource, used by able-bodied people too. However, many of the health professionals interviewed expressed the belief that such professional paid help increased dependency, and reinforced the sick role amongst Kuwaiti stroke patients leading to less active engagement in rehabilitation.

4) Relationship between Self–efficacy and Life satisfaction

- Results of phase 3 of this project showed the positive association between self-efficacy (both general and psychosocial adaptation) and life satisfaction post- stroke. These results were consistent with those of non-stroke studies reported in the literature.

- A stronger positive correlation was observed between psychosocial adaptation self-efficacy and life satisfaction than general self-efficacy and life satisfaction, suggesting that the adapted self- efficacy scale was more sensitive for this project.

- Psychosocial adaptation self-efficacy was identified as the most significant predictor of life satisfaction post-stroke in patients living in Kuwait, among the variables tested.

5) Cultural Characteristics Identified by Health Professionals

- Health professional interviews identified cultural characteristics specific to stroke patients living in Kuwait. These included family involvement, prevailing attitude towards stroke, dependency and access to maids, religious beliefs, and social stigma.

- Western therapists perceived patients in Kuwait as being somewhat less motivated than patients in Western countries they had worked with. Comments by health professionals suggested their awareness of cultural clashes between themselves and the stroke survivor/family.

- Western therapists, arguably because they came from an individualistic culture, expected stroke survivors to have specific goals of what they wanted to achieve and the commensurate drive to work towards these goals. Many Stroke survivors in Kuwait, however, expected the health professional to take charge of their case and make the necessary changes to produce recovery.

- The need to understand the expectations that stroke survivors and their family members bring into rehabilitation that are influenced by their culture is very important. Possible clashes between the values and expectations of family members and the health professionals can be avoided if such issues are understood and strategies put in place to target them.

- Appropriate goal-setting and culturally appropriate patient engagement strategies seem likely to enhance self-efficacy and patient participation in rehabilitation in Kuwait. This would need to involve the family and be relevant to the wishes of the patient.

6) Recommendations for Change in Services in Kuwait

- Interviews with the stroke survivors and health professionals in Kuwait highlighted the need to develop more specialist rehabilitation services for stroke in Kuwait, including an emphasis on recovering psychosocial roles and adaptation.

- Stroke survivors mentioned the difficulty with social outings due to lack of adequate facilities such as disabled toilets, ramps for wheel chairs, and appropriate table heights in restaurants. For the stroke survivor to engage more socially in Kuwait, these difficulties need to be addressed at the broader societal level.

Appendices and References

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Appendix 1:

Map of Kuwait

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Appendix 2

Ethics Approval Documents

(Consent form, info sheet)

Consent Form

Project Title: The Making of a Questionnaire to Measure Stroke Patients' Self Confidence

The participant should complete the whole of this sheet him/herself

Please tick appropriate box

	YES	NO
Have you read the Patient Information Sheet?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Have you received satisfactory answers to all your questions?	☐	☐

Who have you spoken to?...

	YES	NO
Do you understand that you will not be referred to by name in any report concerning the study?	☐	☐
Do you understand that you are free to withdraw from the study: - at any time	☐	☐

Version 1:1
14-03-05

- without having to give a reason for withdrawing? ☐ ☐

- without affecting your future rehabilitation? ☐ ☐

Do you agree to take part in this study? ☐ ☐

Do you give permission for your GP to be notified of
your involvement ☐ ☐

Signature of Research Participant……………………………..…….. Date………………………

Name in capitals……………………………………………………………………

Witness statement

I am satisfied that the above-named has given informed consent.

Witnessed by…………………………………………..Date:……………………………

Name in capitals:………………………………………………………………………

Version 1:1
14-03-05

Brunel
UNIVERSITY
WEST LONDON

INFORMATION SHEET

Project Title:

Stroke Patients' Experiences of Confidence During Rehabilitation

Purpose of the Study:

My name is Onutobor Omu (Tobi for short), and I am a PhD student in Brunel University, Department of Health and Social Care. For this study, I wish to talk to men and women (aged over 18 years) who have had a stroke and are currently receiving rehabilitation. My background is in physiotherapy.

This study aims to explore the following issues:

- ❑ The various experiences that have encouraged you during rehabilitation
- ❑ Your confidence during rehabilitation
- ❑ Factors influencing your goals and progress in rehabilitation

What does the study involve?

The study involves an interview that can be carried out at a time and place that is convenient to you. A friend/ partner can be present if you wish. The interview questions are attached so that you can consider them before deciding whether or not to participate. The interview will be informal and relaxed and more like a conversation around the topics on the interview sheet. It is likely to last for about an hour and will be tape-recorded. You can take this sheet and discuss with your relatives for one week before giving us an answer.

What will happen to my information?

The information given by all participants will remain entirely confidential, and your name will not be divulged to anyone else. The interview data will be kept securely. The final report of the project may include quotations from the interviews but these will be anonymous. No individual will be identified in any way in any report of the project. You will receive a summary of the findings if you wish.

Benefits and risks

You will not benefit directly from your involvement in the project, although I hope that the research will provide useful information to other people who have suffered from a stroke, and for therapists working these patients. Your medical care will not be affected in any way (now or in the future) regardless of whether you decide to participate or not in the project.

The interview is likely to be a positive experience, focusing on your experiences and feelings during rehabilitation, but there is always the possibility of touching upon an upsetting experience in relation to your health. If that happens, I will respect your wish either to proceed with the interview or to end the interview at that point. I will be available afterwards, should you wish to talk further about any difficult issues that have arisen.

Your rights as a participant in the study

Your entry to the study is entirely voluntary. You are entitled to decline to answer any question in the interview, and can withdraw from the study at any time without having to give any explanation. If you decide to participate, you will be given the summary of findings at the conclusion of the project. Also If you decide to participate with your permission I would like to notify your GP that you are involved, this would not affect any treatment you are currently receiving.

Do you have further questions?

If you have further queries, please write to Onutobor Omu at the address below, or phone her at work on 07968727022 or 0208 9317894 after 7 p.m.). Alternatively, you can e-mail: tobiomu@hotmail.com

Thank you – Onutobor Omu

6 Carlton Close, Whitton Avenue West, Northolt, Middlesex, UB5 4LQ

Consent Form

Title of Project: Self-efficacy, Life Satisfaction and Religious Faith in Stroke patients Living in Kuwait

Name of Researcher: Miss Onutobor Omu, PhD student, Brunel University, UK; onutobor.omu@brunel.ac.uk
Name of supervisor: Dr Frances Reynolds, Brunel University, UK; frances.reynolds@brunel.ac.uk

If you have read the information sheet and consent to be interviewed, please show your agreement by ticking the following:

1.	I confirm that I have read the information sheet and understand what I will be asked to do	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without my legal rights being affected, and without having to give a reason.	
3.	I understand that the interview will be audio-recorded	
3.	I understand that all my information will be strictly confidential. If quotations from my interview are included in a report of the study, these will NOT reveal my identity.	
4.	I agree to take part in the above study	

…………..   …………………   …………………………..

Name of participant   Date   Signature

I have explained the nature, demands and foreseeable risks of the above research to the subject.

…………..   …………………   …………………………..
Name of researcher   Date   Signature

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Participant Information Sheet (Phase 4)

Title of Study: Self-efficacy, Life Satisfaction and Religious Faith in Stroke patients Living in Kuwait

Introduction:

My name is Onutobor Omu, I am a physiotherapist and a PhD student at Brunel University, London . My research supervisors are Dr Frances Reynolds and Professor Lorraine de Souza, in the School of Health Sciences and Social Care, Brunel University.

I am currently looking for volunteers to participate in my study.

The study has received approval from the ethics committee of the School of Health Sciences and Social Care, Brunel University

For those of you who work at the Rehabilitation Institute, permission has been given for me to interview you.

Aims of Study:

The aims of this phase of research project are to explore the clinical implications of previous phases of my research with health professionals, and to explore health professionals' views of the influence of culture on the stroke experience in Kuwait.

What it involves:

Participation involves a 45mins to one hour audio-recorded interview regarding your experiences working with stroke survivors in Kuwait. The following main questions will be asked :

1. My study showed that self-efficacy was a significant contributor to life satisfaction - how do you understand this relationship, and how can this be applied clinically?

2. In your experience, what are the most significant challenges faced by stroke patients? (Exploring physical/ functional, psychological and social changes)

3. How have you addressed psychosocial issues during rehabilitation in the past?

4. In your view, what influences quality of life and life satisfaction in stroke patients?

5. Does culture have an influence on the stroke experience and rehabilitation process (why and how, in your view?)

6. In what ways might the cultural background of the health professional be relevant when working with Kuwaiti stroke patients?

7. I will also gather some data about your background, such as your age, nationality, countries that you have worked in previously, and professional background.

Your Rights:

- You have the right to request more information before agreeing to participate.
- You have the right to drop out of the study at any time without giving a reason.
- All information about you will be kept confidential i.e. your name and details will not be passed on to anyone else.
- You will be sent a summary of the results of the study if you request them.

- Participation is entirely voluntary and a decision not to take part, or to withdraw from the study at any time, will have no influence your standing within Rehabilitation Institute

Risks and benefits

- There are no benefits to you from participating in this study, although you may find the interview topics interesting

- Should you feel uncomfortable with any of the questions presented, please feel free to decline answering

- Please ensure that you have your manager's permission before agreeing to an interview in your workplace.

Onutobor (Tobi) Omu

Email: onutobor.omu@brunel.ac.uk
Tel: 67092500

If you would like further information or wish to make a complaint about the conduct of the study, please contact the supervisor, Frances Reynolds
E-mail: frances.reynolds@brunel.ac.uk
Tel: 0044-1895 268826
Address: Mary Seacole Building, Brunel University, Uxbridge, UB8 3PH, UK.

Or the Chair of the Ethics Committee:
Elizabeth Cassidy , Mary Seacole Building, Brunel University, Uxbridge, UB8 3PH, UK.
E-mail: Elizabeth.cassidy@brunel.ac.uk

Appendix 3

Ethics Approval Letters

Student's copy.

Brunel
UNIVERSITY
WEST LONDON

School of Health Sciences and
Social Care
Brunel University, Osterley Campus
Borough Road, Isleworth,
Middlesex TW7 5DU
Telephone: +44 (0)20 8891 0121
Fax: +44 (0)20 8891 8247
Web www.brunel.ac.uk

School of Health Sciences and Social Care

Research Ethics Committee

23 February 2005

<u>Proposer</u>:   **Onutobor Omu (PhD student)**
<u>Title:</u>   **Development of a Self-Efficacy Measure for Stroke Patients: the Stroke Self Efficacy Scale**

The Chair of the School Research Ethics Committee has considered the amendments recently submitted by you in response to the Committee's earlier review of the above application

The Chair, acting under delegated authority, is satisfied that the amendments accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study. Approval is given on the understanding that the conditions of approval set out below are followed:

- You should liaise closely with your supervisor in relation to making further refinements to the Participant Information Sheet. For example, there is no lay title for the project and a participant would have to get halfway down the sheet before realising that they are being asked to participate in an interview. In its present state, the language is formal, yet uninformative. Further, the sheet explicitly state that participants can choose whether to take part or not and the final bullet point should read "you will be sent results of the study if you <u>request</u> them" not "require" them.

- Careful proof reading of the entire documentation is advised before transmission to COREC

- Written evidence of COREC approval is provided as and when available before the study can commence

- The agreed protocol must be followed. Any changes to the protocol will require prior approval from the Committee.

David Anderson-Ford
Chair, Research Ethics Committee
School of Health Sciences and Social Care

The Joint UCL/UCLH Committees on the Ethics of Human Research
(Committee Alpha) **NHS**

1st Floor, Maple House
149 Tottenham Court Road
London W1P 9LL
Tel: 020 7380 9579
Fax: 020 7380 9937
Website: www.uclh.nhs.uk

10 June 2005

Miss Onutobor Omu
Phd Student
Brunel University
6 Carlton Close
Whitton Avenue west
Northolt
UB5 4LQ

Dear Miss Omu

Full title of study: **The Development of a Self Efficacy Scale for Stroke Patient**

REC reference number: **05/Q0502/40**

Thank you for your letter of 06 June 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The Committee has designated this study as having "no local investigators". There is no requirement for [other] Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		14 March 2005
Investigator CV Ms Onutobor Omu		(None Specified)
Investigator CV Dr Frances Reynolds		(None Specified)
Protocol	1:1	14 March 2005
Covering Letter Dr Frances Reynolds		23 February 2005
Summary/Synopsis	1:1	14 March 2005

An advisory committee to North Central London Strategic Health Authority

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Letter from Sponsor David Anderson-Ford		23 February 2005
Interview Schedules/Topic Guides	1:1	14 March 2005
GP/Consultant Information Sheets	2.2	06 June 2005
Participant Information Sheet	2.2	06 June 2005
Participant Consent Form	2.2	06 June 2005
Approval letter from Brunel University REC		23 February 2005

Management approval

You should arrange for all relevant NHS care organisations to be notified that the research will be taking place, and provide a copy of the REC application, the protocol and this letter.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant care organisation before commencing any research procedures. Where a substantive contract is not held with the care organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Notification of other bodies

The Committee Administrator will notify the research sponsor and the R&D Department for NHS care organisation(s) that the study has a favourable ethical opinion.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q0502/40	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project,

Yours sincerely

Miss Carol Morledge
Administrator

Email: carol.morledge@corec.org.uk

Enclosures:

Standard approval conditions

SF1 list of approved sites

An advisory committee to North Central London Strategic Health Authority

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North West London Hospitals NHS Trust
R&D Office
Rooms 013-016, Level 5BB
Northwick Park Hospital

Tel: 020 8869 2011
E-mail: alan.warnes@nwlh.nhs.uk
Website: www.nwlh.nhs.uk/research

NHS Management Approval

To: Miss Onutobor Omu

From: Dr Alan Warnes (R&D Manager)

Date: 16/09/2005

Project: The Development of a Self Efficacy Scale for Stroke Patients (**Reference:** 05/Q502/40)

I understand that you have recently received a favourable ethical opinion for the above project, with the condition that you do not undertake research in an NHS organisation until relevant NHS management approval has been received. I am therefore writing on behalf of the North West London Hospitals Trust to inform you that the project has also been approved by the Trust and may now proceed.

To maintain Trust approval for the above project, all staff involved within it must adhere to Trust and Research Governance Framework requirements (see www.nwlh.nhs.uk/research). As Chief/Principal Investigator you are required to formally advise the R&D Office of **ANY** changes to the project including:

- Any changes to the status of the project, e.g. abandoned, completed etc
- Any changes to the protocol – however minor.
- Any changes to the funding arrangements

You are also required to:

- Notify, in a timely fashion, the R&D adverse Events relating to the Research and the appropriate urgent safety measures taken in line with ICH GCP requirements.
- Ensure that the R&D Office has copies of all annual and final progress reports.
- Ensure all researchers involved in the project hold the necessary expertise required and have Honorary Contracts should they need to.
- Ensure adequate and accurate reporting and monitoring of said project.
- Co-operate with all internal Trust monitoring and auditing procedures.
- Where the Trust has agreed to be sponsor to the project, you should be aware and comply with the required responsibilities.

Failure to comply with these conditions may result in Trust approval being rescinded.

Yours sincerely,

NWLH R&D Approval letter, version 2, May 2005
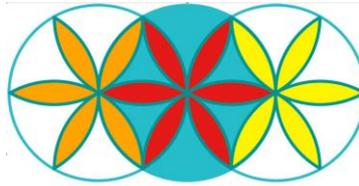
Fawzia Sultan
REHABILITATION
INSTITUTE

Oct 13, 2009

Re: Research Study title: "Stroke and recovery in Kuwait: Exploring patients' and health professionals' experiences." Principle investigator: Onutobor Omu.

This note is to confirm that permission was given by Dr. Elham Hamdan for Ms Omu to conduct interviews with people with stroke, and health professionals at the Fawzia Sultan Rehabilitation Institute in Kuwait. This permission was given under the provision that she follows ethical processes set out by Brunel University (UK).

Regards,

(sent via email)
_____
Elham Hamdan MD
President and Medical Director
Fawzia Sultan Rehabilitation Institute
Amaia Residence Building
Baghdad St., Salmiya , Kuwait
www.rehabinstitutekuwait.com

Appendix 4

Questionnaires used in this project

Generalised Self efficacy Scale

Please rate the extent to which the statements are true.

1) I can always manage to solve difficult problems if I try hard enough.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

2) If someone opposes me, I can find the means and ways to get what I want.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

3) It is easy for me to stick to my aims and accomplish my goals.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

4) I am confident that I could deal effectively with unexpected events.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

5) Thanks to my resourcefulness, I know how to handle unforeseen situations.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

6) I can solve most problems if I invest the necessary effort.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

7) I can remain calm when facing difficulties because I can rely on my coping abilities.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

8) When I am confronted with a problem, I can usually find several solutions.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

9) If I am in trouble, I can usually think of a solution.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

10) I can usually handle whatever comes my way.
   a) Not at all true
   b) Hardly true
   c) Moderately true
   d) Exactly true

Santa Clara Strength of Religious Faith Questionnaire

Please answer the following questions about religious faith using the scale below. Indicate the level of agreement (or disagreement) for each statement.

1 = strongly disagree   2 = disagree   3 = agree   4 = strongly agree

_____ 1. My religious faith is extremely important to me.

_____ 2. I pray daily.

_____ 3. I look to my faith as a source of inspiration.

_____ 4. I look to my faith as providing meaning and purpose in my life.

_____ 5. I consider myself active in my faith or church.

_____ 6. My faith is an important part of who I am as a person.

_____ 7. My relationship with God is extremely important to me.

_____ 8. I enjoy being around others who share my faith.

_____ 9. I look to my faith as a source of comfort.

_____ 10. My faith impacts many of my decisions.

Psychosocial Adaptation Self-efficacy Scale

Please rate your confidence to carry out the tasks mentioned in each statement on the scale provided.

Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

1. How confident are you that you can deal with the frustration of your disability/disease?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

2. How confident are you that you can manage your symptoms so that you can do the things you enjoy doing?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

3. How confident are you that you can cope in the future?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

4. How confident are you that you can overcome your difficulties?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

5. How confident are you that you can get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

6. How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

7. How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

8. How confident are you that you can keep from feeling sad and lonely?

   Not at all Confident 1 2 3 4 5 6 7 8 9 10 Totally confident

Appendix 5

Translated Documents

ترجمة

ورقة معلومات عن المرضى

عنوان الدراسة: الفعالية الذاتية والرضا بالحياة والإيمان الديني فــي المرضـــى المـــصابين بالسكتة الدماغية الذين يعيشون في الكويت.

المقدمة:

أدعى "أونوتوبور أومو"، ومهنتي اختصاصية في العلاج الطبيعي وطالبة للحـــصول علـــى الدكتوراة في جامعة برونيل، لندن. أبحث حاليا عن متطوعين للمشاركة في دراستي.

أهداف الدراسة:

تهدف هذه الدراسة إلى استكشاف المسائل التالية:

- تجربتك منذ إصابتك بالسكتة.
- تجاربك المختلفة التي شجعتك خلال إعادة التأهيل.
- ثقتك خلال إعادة التأهيل.
- العوامل التي أثّرت على أهدافك وتقدمك في إعادة التأهيل.

مكوّنات الدراسة:

تتضمن الدراسة تعبئة استبيانين. وسيكون أحد الأشخاص حاضرا لمساعدتك علـــى تعبئـــة الاستبيان.

حقوقك:

- تملك الحق في أن تطلب المزيد من المعلومات قبل الموافقة على المشاركة.
- تملك الحق في أن تنسحب من الدراسة في أي وقت بدون إبداء السبب.
- ستتم المحافظة على سرية كافة المعلومات الخاصة بك والتي حصلنا عليها، أي أنـــه لن يتم إطلاع الغير على اسمك والتفاصيل الأخرى.
- سوف ترسل لك نتائج الدراسة إذا طلبتها.

تجـــدر الإشـــارة إلى ان إعادة تأهيلك لن يتأثر بأي طريقة بقرارك في المشاركة أو عدم المشاركة في هذه الدراسة.

نموذج الموافقة

رقم المركز:
رقم معلومات المريض الخاص بهذه التجربة:

عنوان المشروع: الفعالية الذاتية والرضى بالحياة والإيمان الــديني فــي المرضـــى المصابين بالسكتة الدماغية الذين يعيشون في الكويت.

اسم الباحثة: الآنسة أونوتوبور أومو

يرجى التوقيع بالأحرف الأولى في الخانة ذات الصلة

١	أؤكد بأني قرأت أو تم شرح ورقة المعلومات لي وفهمت ما هو مطلوب مني القيام به	
٢	أدرك ان مشاركتي طوعية وبأني أملك حرية الانسحاب في أي وقت بدون ان تتأثر رعايتي الطبية أو حقوق القانونية	
٣	أدرك بأنه ستتم المحافظة على سرية كافة المعلومات المتعلقة بي	
٤	أوافق على المشاركة في الدراسة أعلاه	

....
التوقيع   التاريخ   اسم المريض

تم توضيح طبيعة ومطالب وتوقعات مخاطر البحث أعلاه إلى الخاضع للدراسة.

....
التوقيع   التاريخ   اسم الشخص آخذ الموافقة

....
التوقيع   التاريخ   اسم الباحثة

التكيف النفسي الاجتماعي تجاه مقياس الفعالية الذاتية للأمراض المزمنة

يرجى تقدير ثقتك في القيام بالمهام المذكورة في كل عبارة على المقياس المقدم.

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

١) ما مقدار ثقتك لتتمكن من التعامل مع خيبة الأمل في عجزك/مرضك؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٢) ما مقدار ثقتك لتتمكن من معالجة أعراضك بحيث تستطيع القيام بالاشياء التي تتمتع بالقيام بها؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٣) ما مقدار ثقتك بحيث تستطيع التكيف في المستقبل؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٤) ما مقدار ثقتك بحيث تتغلب على مصاعبك؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٥) ما مقدار ثقتك بحيث تجعل عائلتك وأصدقاءك يساعدونك بالاشياء التي تحتاجها (في العمل المنزلي الروتيني مثل التسوق أو الطبخ أو التنقل)؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٦) ما مقدار ثقتك بحيث تحصل على الدعم العاطفي من الأصدقاء والعائلة (مثل الاستماع أو التحدث عن مشاكلك)؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٧) ما مقدار ثقتك بحيث تستطيع الاستمرار القيام بالاشياء التي تحب القيام بها مع الأصدقاء والعائلة (مثل الزيارات الاجتماعية والترفيه)؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

٨) ما مقدار ثقتك بحيث أنك تبتعد عن الشعور بالكآبة والوحدة؟

لا توجد ثقة بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ ثقة تامة

مقياس تكرار التفكير:

يرجى تقدير عدد المرات التي راودتك فيها الأفكار التالية:

١) أشعر دائما بالإخفاق في الأشياء التي أحاول القيام بها

بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ دائما

٢) أشعر بالإحراج في الأماكن العامة

بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ دائما

٣) أنا عبء على عائلتي وأصدقائي

بالمرة ١ ٢ ٣ ٤ ٥ ٦ ٧ ٨ ٩ ١٠ دائما

استبيان سانتا كلارا عن قوة الإيمان الديني

المرجع الأولي: تي. جي. بلانتي آند ام. بوكاتشيني (١٩٩٧). استبيان سانتا كلارا عن قوة الإيمان الديني. علم النفس الرعوي، ٤٥، ٣٨٧ – ٣٧٥

يرجى الإجابة على الأسئلة التالية حول الإيمان الديني مستخدما المقياس أدناه. بيِّن مستوى الموافقة (أو عدم الموافقة) على كل عبارة.

١ = عدم الموافقة بشدة ٢ = عدم الموافقة ٣ = الموافقة ٤ = الموافقة بشدة

_____ ١) إيماني الديني مهم جدا لي.

_____ ٢) أصلي يوميا.

_____ ٣) أنظر إلى إيماني على أنه مصدر الإلهام.

_____ ٤) أنظر إلى إيماني على أنه يجعل لحياتي معنى وهدفا.

_____ ٥) أعتبر نفسي نشيطا في إيماني أو الكنيسة.

_____ ٦) إيماني هو جزء هام لما أنا عليه كشخص.

_____ ٧) علاقتي بالله هامة جدا لي.

_____ ٨) أتمتع أن أكون مع الآخرين الذين يشاركونني إيماني.

_____ ٩) أنظر إلى إيماني على أنه مصدر للراحة.

_____ ١٠) إيماني يؤثر على العديد من قراراتي.

Appendix 6

Example of a Coded

Health Professional's Interview

Extract from Interview HP01

Can you just elaborate on that sort of what you feel as the role of the therapist in stroke we have regarding sort of psychosocial issues?

Regarding psychosocial issue, I do believe it's important for the therapist to be aware of the psychosocial issues whether they would be cultural, whether they be religious, whether they be personality because I think we need to use every avenue available to reach the patient, motivate the patient. I see that motivating the patient particularly in the case of a stroke is really one of the primary jobs of the therapist.

Role of therapist

-aware of culture (HP1:1)

-reach pt with all possible means(HP1:1)

-motivating pt (HP1:1)

-Apply therapeutic technique (HP1: 1)

Other factors

-time we spend with pts limited (HP1:1)

-type of training (HP1:1)

- importance of motivation (HP1:1)

OKay.

In addition, of course to applying therapeutic techniques but from a psychosocial perspective I really see that as being a big part of our job.

How?

It's one thing, for example, to see a patient and have them come in for a limited amount of time)and say, okay, you know, do this, do that, do that. I think we have to take that extra step, perhaps this has a little to do with my training and my background, in fact the Chairman of the Board of the OT school that I went to emphasised psychology, that we had to have almost a minor in it actually, so she felt this was a strong component of the program of overall # probably some of my grounding I think it also though in my - to my personal feelings because we are psychosocial beings, we are not purely mechanical and although the mechanical and the functional aspects are important and have to be there, of course to be able to engage in therapy, motivation is a huge factor. If you are not motivating your patient, more than likely the mechanical things you are doing are going to have very little effect and most likely we will not be carried over. So in that respect I think it's a very critical part of our role, during therapy. –

Okay. How can we do this, how can we achieve this?

I think being sensitive to individual differences, not only the reactions of your patient perhaps cultural background, I think we need to be aware and sensitive on all levels, notice when a patient comes in a mood that perhaps different than their normal mood, notice if our patients tend to be in a state of depression. Knowing what to focus on and what not to focus on, that gets a little bit harder because that comes with skill and practice and working with people, but these things I think we will have a direct influence and more successful outcomes with your patients, not only that individual session but long term.

How we motivate

-sensitive to differences (HP1:1)

Yeah.

What do you feel is the most or are the important challenges faced by the stroke patient?

Because you have already mentioned there are psychosocial issues, so both from your experience what have you seen are the challenges that these people face?
Well, I think some of the challenges as a therapist and we can also talk about the challenges they face, but as a therapist treating a patient there are so many variables. I think the patients, for example, goes through stages, psychological stages as well as physical stages in their recovery, so obviously their functional capabilities, their emotion, their motivations are going to be affected in these phases. I think an another complication is that these phases are long, they are very long unlike an orthopaedic case where it can be a matter of weeks or days even that sort of a change that patient goes on with their life, this can be a very long process and as human beings we seem to be creatures of a immediate gratification and it's very difficult, especially when it comes to your ability to be functional on a very basic level, it's very difficult to be patient with yourself from a patient's perspective. From a therapist perspective, I think we want them to get better, we know it can be a long process, sometimes the challenge is, I think for the therapist of the stroke patient is challenging your patients at appropriate time and trying to push them a little bit beyond their current level. I think sometimes we get stuck in traditional ways of thinking as well and I think if we are working, for example with a patients for a few weeks and we don't see any progress in this particular area, we think okay, well, that's probably not going to get better. When I think sometimes we are too quick to do that, I don't think we are always innovative or creative enough as therapist is to think, okay, how - what else could be influencing this, how can we approach it differently to affect some change, and sometimes I think that means thinking out of the box and beyond our traditional schooling or traditional therapeutic exercises. If something works for that patient and this comes from understanding, again, psychosocial aspects, cultural aspects, you can find a way to motivate that patient to do something that perhaps a traditional approach would not have accomplished then you have done great thing as a physiotherapist for that patient.

Definitely. Can you give me more examples about just thinking out of the box and not being stuck in that traditional way of thinking?
Sure. I would say this is going to depend lots on the cooperation of your patient and the patient family, and perhaps even the countries you practice in. Some countries have more regulations than others and as a therapist in certain places you have to be careful not to overstep your boundaries and scope of practice and we are finding those lines are becoming

more and more blurred especially with the advent of alternative medicine. But one example I can give you is I read a book but I can't exactly remember the name of the – but it was a book - it was written by a neurologist and it was on brain mapping and how - and this also focus on stroke patients but how a patient was able to regain recovery. One particular example I remember is the stroke patient who had a very severe stroke, traditional medical professionals had given up on the patient and two years later the patient was still significantly disabled, the patient could not walk, could not use the left side of his body, speech was affected, so it was pretty severe case and this patient was taken in by his son and the patient was…. and the son not knowing anything about medicine thought, "okay, how does a baby learn how to walk and that way a baby crawls before it walks." And what might have seen unusual or perhaps even cruel to some people was the method that the son chose to motivate his father to be more functional and what he did, he encouraged the father to crawl, to get from point A to point B, rather than jumping in and transporting him from this point to that point, he made his father crawl. As a result of this, a couple of years later his father was able to walk, was able again to speak, was able in a gross way to use his left upper extremity and return to work, I believe he worked as a professor. Now, if someone hadn't thought of that, haven't pushed him in that regard he probably would have lived out the rest of his days with a very severe disability. I am not – I mean I have suggestion, suggesting to make all of the stroke patient crawl, however what this does tell me is that we need to think a little differently, it tells me the human mind and human body is capable of a little more than perhaps we realise. So what am I suggesting by the time, I am suggesting we seek alternative sources of doing things. One example, and there had been studies on this and you could refer to some other, but even for a day, for a 24 hour period if you can get the family's cooperation for a stroke patient not to be able to use their functional arm and make and use the non-functional arm. Now, the first response of the patient might be, I can't but even if they have a minimal amount of muscle function, for example, in their biceps or in their grasp they can bring something to their mouth. They can do it but if they are not forced to do it, it's much easier to not use that limb, let it rest and use your functional limb.

Thinking out of the box
-cooperation of pt and family (HP1:2)
-depends on country and regulations (HP1:2)
-think differently (HP1:3)
-new ways of doing things (HP1:3)
There is a lot of research on that.
There is a lot of research on that and I am a big fan of it because of what I have read about it, because I have seen it, I have read examples of where it works. So I think as therapists, I think even as a profession and as a field we need to expand the way we are approaching stroke patients because I think traditional methods take us only so far and if we are serious about the business of rehabing people, we need to explore every available option basically.

Thinking out of the box
-expand ways of dealing with pt (HP1:3)
-Traditional methods not enough (HP1:3)
-explore every option (HP1:3)
Do you feel that we are limiting our patients in some way?
In some way, but I think we are doing what we know, but medicine is evolving and rehabilitation methods are evolving. So I think this is why professional development is so important, right, because I think we need to expand. I think perhaps therapists in particular our field has gotten to a point, especially regarding neurological development where we

talked a little bit, I think it's time to take that step further. I think medicine is making gains and I think we need to figure out how we can utilise that in the rehabilitation process a little better.

-Professional development important (HP1:3)

I want you to put yourself in the shoes of stroke patients now, you know, and I want you to try and to see what you believe is the world of a stroke patient, what issues do you think are important to them?

I think very basic issues. I think it affects not only the way they interact with their daily life and their ability to bathe and feed and dress themselves again depending on these various strokes, but it affects their personal interaction and then many stroke patients will not be social with the friends that they had before because they are embarrassed, they don't want their friends to see them with their disability, with their inability to function normally like they had before. I think it affects the way they perceive their role in their family, particularly if it is a parent because they are used to do doing things and providing and suddenly they are the ones needing help now perhaps from their kids. So I think there is a significant and a profound change on the dynamics of their interpersonal relationships and I think that very much affects their psychosocial status, and I think that's hard for outsiders to see. I don't think the patient even only shows that but I can only imagine the extent of how that must impact someone that I feel it pretty much changes everything. Now, I think the affect of that can be lessened somewhat if you have a very attentive and supporting family, a support group so to speak but not everyone has that and not even all cultures is that present. So I think that's definitely an aspect over and above the obvious physical incapabilities which are frustrating on a daily basis from brushing your teeth to reaching to the phone to moving from point A to point B.

Challenges the stroke pt faces
-daily interactions (HP1:3)
-self care, ADL (HP1:3)
-relationships (HP1:3)
-Social life (HP1:3)
-Embarrassment/shame (HP1:3)
-their perceived role in family (HP1:3)
-change in dynamics of interpersonal relationships (HP1:3)
-Helped by supportive family (HP1:3)
-Physical incapabilities (HP1:3)

How have you dealt with some of these issues, psychosocial issues in the past in your own experience?

Well, I - as far as interacting with the patient and treating the patient I try to refocus on perhaps gains that they have made. I try to encourage them in a sense that, look, three weeks ago or a month ago or two months ago you were here, you couldn't do this and now you are doing this, so let's keep trying, let's keep working. So, I think channelling, you don't - you want to acknowledge the patient's frustration and I often do. When they tell me how hard something is, okay, yeah, I know it's hard but let's try this and let's work on this, and sometimes if it's a very emotionally overwhelming day for the patient you might have to pause and stop and comfort them a little bit. But I find that rechannelling and refocusing and continuing to encourage and emphasise points of progress, perhaps if they can do one thing better than another thing then we will switch to that thing because then they can see, oh, I can do this. Does that make sense?

Role of therapist (psychosocial issues)
-refocus on gains made (HP1:4)

Yeah, it does.
Okay. I could probably articulate that a little better.

No, that's fine.
Okay.

when you think about quality of life for the stroke patients what comes into your mind, what do you see, what do you target, I guess?
For me in a very basic sense quality of life is being able to freely interact with your world and do the things you like and want to do that after stroke is significantly inhibited. So as a result quality of life depending again on the degree of the stroke is significantly impacted, it's pretty much your functional role in the world and how you interact with it and to a greater or lesser degree that has suddenly been altered and that takes some adjustments. So quality of life for me is enhancing the way a person interacts with the world, choose to make it more effective and make it more efficient, to make it a little bit more like the way it used to be or even better in some respects.

Appendix 7

Self-Efficacy Scales

Chronic Disease Self-Efficacy Scales

We would like to know *how confident* you are in doing certain activities. For each of the following questions, please choose the number that corresponds to your confidence that you can do the tasks regularly at the present time.

> **1. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?**
>
> | Not at all confident | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | Totally confident |
> |---|---|---|---|---|---|---|---|---|---|---|---|

Scales/Items (using the same format as above):

Self-Efficacy to Perform Self-Management Behaviors

Exercise Regularly Scale

1. How confident are you that you can do gentle exercises for muscle strength and flexibility three to four times per week (range of motion, using weights, etc.)?
2. How confident are you that you can do aerobic exercise such as walking, swimming, or bicycling three to four times each week?
3. How confident are you that you can exercise without making symptoms worse?

Get Information About Disease Item

1. How confident are you that you can get information about your disease from community resources?

Obtain Help from Community, Family, Friends Scale

1. How confident are you that you can get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)?
2. How confident are you that you can get emotional support from friends and family (such as listening or talking over your problems)?
3. How confident are you that you can get emotional support from resources other than friends or family, if needed?
4. How confident are you that you can get help with your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?

Communicate With Physician Scale

1. How confident are you that you can ask your doctor things about your illness that concerns you?
2. How confident are you that you can discuss openly with your doctor any personal problems that may be related to your illness?
3. How confident are you that you can get work out differences with your doctor when they arise?

General Self-Efficacy

Manage Disease in General Scale

1. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?
2. How confident are you that you can judge when the changes in your illness mean you should visit a doctor?
3. How confident are you that you can do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?
4. How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?
5. How confident are you that you can do things other than just taking medication to reduce how much your illness affects your everyday life?

Self-Efficacy to Achieve Outcomes

Do Chores Scale

1. How confident are you that you can complete your household chores, such as vacuuming and yard work, despite your health problems?
2. How confident are you that you can get your errands done despite your health problems?
3. How confident are you that you can get your shopping done despite your health problems?

Social/Recreational Activities Scale

1. How confident are you that you can continue to do your hobbies and recreation?
2. How confident are you that you can continue to do the things you like to do with friends and family (such as social visits and recreation)?

Manage Symptoms Scale

1. How confident are you that you can reduce your physical discomfort or pain?
2. How confident are you that you can keep the fatigue caused by your disease from interfering with the things you want to do?
3. How confident are you that you can keep the physical discomfort or pain of your disease from interfering with the things you want to do?
4. How confident are you that you can keep any other symptoms or health problems you have from interfering with the things you want to do?
5. How confident are you that you can control any symptoms or health problems you have so that they don't interfere with the things you want to do?

Manage Shortness of Breath Item

1. How confident are you that you can keep your shortness of breath from interfering with what you want to do?

Control/Manage Depression Scale

1. How confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?
2. How confident are you that you can keep from feeling sad or down in the dumps?
3. How confident are you that you can keep yourself from feeling lonely?
4. How confident are you that you can do something to make yourself feel better when you are feeling lonely?
5. How confident are you that you can do something to make yourself feel better when you are feeling discouraged?

6. How confident are you that you can do something to make yourself feel better when you feel sad or down in the dumps?

Scoring

The score for each item is the number circled. If two consecutive numbers are circled, code the lower number (less self-efficacy). If the numbers are not consecutive, do not score the item. The score for each scale is the mean of the items. For scales of 1-2 items, do not score the scale if any item is missing; for scales with 3-4 items, do not score the scale if more than 1 item is missing; for scales with 5-6 items, do not score the scale if more than 2 items are missing. Higher number indicates higher self-efficacy.

Characteristics

Scale	No. of Subjects	No. of items	Observed Range	Mean	Standard Deviation	Internal Consistency Reliability	Test-Retest Reliability
Exercise regularly	478	3	1-10	6.30	2.70	.83	.86
Get information on disease	478	1	1-10	7.37	2.65	—	.72
Obtain help from community, family, friends	478	4	1-10	6.18	2.42	.77	.85
Communication with physician	477	3	1-10	7.30	2.71	.90	.88
Manage disease in general	292	5	1-10	6.92	2.15	.87	—
Do chores	478	3	1-10	6.29	2.70	.91	.86
Do social/recreational activities	478	2	1-10	6.50	2.65	.82	.84
Manage symptoms	478	4	1-10	5.88	2.40	.91	.89
Manage shortness of breath *(only reported on those reporting shortness of breath)*	280	1	1-10	5.87	2.97	—	.82
Control/manage depression	478	6	1-10	6.51	2.23	.92	.82

Source of Psychometric Data

Stanford Chronic Disease Self-Management Study. Psychometrics reported in: Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions*. Thousand Oaks CA: Sage Publications, 1996, pp.24-25,41-45.

Comments

These scales were developed and tested for the Chronic Disease Self-Management study. We use a shorter, 6-item scale now, as it is much less burdensome for subjects.

References

Lorig K, Stewart A, Ritter P, González V, Laurent D, & Lynch J, *Outcome Measures for Health Education and other Health Care Interventions.* Thousand Oaks CA: Sage Publications, 1996, pp.24-25,41-45.

To download this scale and scoring instructions, right click the link below with your mouse and "Save as" to you hard disk or desktop (for Windows), or double click (Mac):

Download PDF version

Appendix B. The MS Self-efficacy Scale

instructions

For each of the statements below please tick a box to indicate your level of agreement or disagreement, for yourself, at the present time.

1) I am confident when meeting new people and going to new places
2) I find that the things I do during the day make me feel happy and satisfied
3) I sometimes have thoughts about whether my condition will get worse*
4) Sometimes I feel embarrassed in public places*
5) I like not having to (or the thought of not having to) go to work
6) Planning for the future helps me to cope with my illness
7) I can keep my MS from interfering with time spent with my friends and family

8) I have as much independence as I feel I need
9) Sometimes I feel inadequate as a person because of my condition *
10) I often feel a failure in things that I try to do*
11) There are things that I can do to help control my fatigue
12) I often feel that MS controls my life*
13) I can usually do what I want to do when I want to do it
14) I feel that my social life would be better if I did not have MS*

Each item is presented with a 6-point Likert scale, ranging from 'Strongly Disagree' to 'Strongly Agree'. The scores of items marked with an asterisk * should be reversed, i.e., a rating of 2 would be scored as 5. Therefore, a high score indicates an elevated level of self-efficacy.

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Table 2: The Multiple Sclerosis Self-Efficacy Scale (MSSE)

FUNCTION: *As of now, how certain are you that you can:*

1. Walk 100 feet on flat ground?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

2. Walk 10 steps downstairs?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

3. Take good care of your home or yard?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

4. Get dressed or undressed without assistance?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

5. Get in and out of the passenger side of a car without assistance from another person and without physical aids?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

6. Speak clearly to express your needs or ideas?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

7. Write clearly so that others can read what you wrote?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

8. Take a bath or shower without assistance from someone else?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

9. Go on a trip that keeps you away from home for the whole day?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

CONTROL

1. How certain are you that you can control your fatigue?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

2. How certain are you that you can regulate your activity so as to be active without aggravating your MS?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

3. As compared to other people with MS like yours, how certain are you that you can manage your MS symptoms during your daily activities?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

4. How certain are you that you can manage your MS symptoms so that you can do the things you enjoy doing?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

5. How certain are you that you can deal with the frustration of MS?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

6. How certain are you that you can deal with the uncertainty of MS?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

7. How certain are you that you can decrease your fatigue quite a bit?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

8. How certain are you that you can continue most of your daily activities?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

9. How certain are you that you can keep your MS symptoms from interfering with your time spent with friends or family?

10 very uncertain	20	30	40	50	60 moderately certain	70	80	90	100 very certain

Appendix – The Liverpool Self-efficacy Scale

Think about how you have been feeling over the last week. Please read the following statements and indicate the extent to which you agree or disagree with them by circling one answer to each question.

Control subscale
1) Since my diagnosis was confirmed, my life has been beset with difficulties over which I have no control.
2) (R) I feel in control of my life.
3) I rely on others to help me make decisions.
4) Sometimes I feel that my MS controls my life.
5) I often feel helpless when dealing with my difficulties.
6) (R) The way my MS affects me in the future mostly depends on me.

Personal agency subscale
7) I worry about how I will cope in the future.
8) (R) Despite my difficulties, I still manage to cope with daily life.
9) There is really no way I can solve some of the problems I have with my MS.
10) (R) Despite my MS, I can do anything I set my mind to.
11) (R) I am confident I can overcome my difficulties.

Notes: Each question is scored on a four-point scale as follows:

Strongly agree	Agree	Disagree	Strongly disagree
1	2	3	4

For items marked (R) the scoring is reversed.
A low score reflects low self-efficacy.

Appendix 8

Additional results of phase 3

Appendix 8: Additional Results of Phase 3
(Spearmans's Correlation between Study Variables)

Correlations

			Age	Time since stroke (Months)	Total GSE Score	Total PSS Score	Life satisfaction main measure	Total Religious faith Score
Spearman's rho	Age	Correlation Coefficient	1.000	-.021	-.129	.100	.025	.240
		Sig. (2-tailed)	.	.899	.428	.539	.879	.136
		N	40	40	40	40	40	40
	Time since stroke (Months)	Correlation Coefficient	-.021	1.000	-.099	.056	.224	.042
		Sig. (2-tailed)	.899	.	.544	.732	.164	.797
		N	40	40	40	40	40	40
	Total GSE Score	Correlation Coefficient	-.129	-.099	1.000	.621**	.444**	.187
		Sig. (2-tailed)	.428	.544	.	.000	.004	.248
		N	40	40	40	40	40	40
	Total PSS Score	Correlation Coefficient	.100	.056	.621**	1.000	.608**	.081
		Sig. (2-tailed)	.539	.732	.000	.	.000	.620
		N	40	40	40	40	40	40
	Life satisfaction main measure	Correlation Coefficient	.025	.224	.444**	.608**	1.000	.092
		Sig. (2-tailed)	.879	.164	.004	.000	.	.571
		N	40	40	40	40	40	40
	Total Religious faith Score	Correlation Coefficient	.240	.042	.187	.081	.092	1.000
		Sig. (2-tailed)	.136	.797	.248	.620	.571	.
		N	40	40	40	40	40	40

**. Correlation is significant at the 0.01 level (2-tailed).