Biographical and spiritual disruption in chronic illness

Narrative, identity and faith work in kidney dialysis patients

A thesis submitted for the degree of Doctor of Philosophy

by

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Research Question

How do renal dialysis patients respond to biographical and spiritual disruption? What is the impact of kidney disease and chronic illness on faith, as described in patient narratives?

Abstract

The six-year study explored whether biographical and spiritual disruption may have both negative and positive aspects – a disturbance or challenge may lead to positive as well as negative consequences. A chronic illness model was derived from the literature: good health, illness disruption, expression and evaluation, role recovery and resolution. The model was tested through a theoretical coding process against narrative interviews. Field data was used to analyse types of disruption response – peak, trough, progressive and regressive.

Twelve narrative interviews were coded using narrative, theoretical and disruption-response coding. This led to a revision of the illness model, now seen as a sequence of disruption and response cycles. Faith subjects also recounted faith stories about struggle and survival. Faith practice and observance was interrupted by illness. Patients' initial response was disorientation, but responses stabilised over time to a consistent pattern – the learning response.

Key areas of study were learning effective illness responses, resolving disruption cycles, pursuing role recovery, expanding faith, and disclosing and processing suffering. Three general conclusions about chronic illness were formed – that chronic illness involves learning, that it requires different kinds of chronic illness work (narrative work, emotion work, grief work, identity work and faith work), and that it creates a specific kind of narrative quest, whose purpose is to define the subject's role and resolve the chronic illness story.

People with long term conditions often work hard, they deal with repeated disruption, they learn new roles, they construct survival stories, and learn ways of resolving each disruption stage. The study suggests a view of long-term conditions different from the accepted picture of progressive decline. It suggests that individuals become more resourceful, more skilled and better able to deal with suffering and loss as their illness progresses. With faith subjects, faith grows and adapts to face the challenges found in living with illness and apply faith to each new situation.

Introduction

Biographical & spiritual disruption in chronic illness

i Research question

This study began by investigating biographical and spiritual disruption, and asking what impact chronic illness had on faith. Its final conclusion was that chronic illness subjects create an illness narrative which defines the roles and responsibilities illness entails, and then recounts how this role was enacted. This involved difficulties and setbacks, learning and illness work; but in general, the illness story is progressive – it shows how the subject carries out the task that has been set. This conclusion does not answer the research question in a direct way, but instead grows out of the study process and the way it developed. Clearly there were intermediate stages and other questions and answers which arose, before this end point was reached.

Biographical disruption in chronic illness has been studied by sociologists for thirty years, but spiritual disruption has been widely overlooked. The term spiritual disruption is not a standard term in sociology, but will be used in this study to denote a disturbance to the individual's normal pattern of belief and practice, and the changes that result. The term 'spiritual' is used in an inclusive sense to refer both to recognised religious faiths and also personal spiritual beliefs. The study explores whether biographical and spiritual disruption among dialysis patients may have both negative and positive consequences – a disturbance or challenge may have positive as well as negative results.

The research question has two parts:

1. How do renal dialysis patients respond to biographical and spiritual disruption?
2. What is the impact of kidney disease and chronic illness on faith, as described in patient narratives?

The first question focuses not on describing what kinds of disruption are encountered, but on the individual response to these. The approach has therefore taken as read that kidney patients in common with those with other long-term conditions experience extensive biographical disruption (McGee & Bradley 1994). Spiritual disruption on the other hand has not often been described, although G Williams touches on it (1984). The descriptive data set out in this study is derived from chaplain-patient interactions within the Living Well Programme (LWP) (Appendix A) and patient interviews (Chapters 4 & 5).

The second question could have been put the other way around and have asked ‘What is the impact of faith on kidney disease and chronic illness?’ This would then have meant describing what faith is, and how it is used by those with chronic illness. But the basic approach taken to answering question two was observational (Section 3.1), and took faith and spiritual belief in their ordinary everyday sense, without delving into first principles. This allowed the study to address and describe the faith behaviour of interview subjects in a straightforward way, and observe how their faith responded to, adapted, changed and was affected by chronic illness in different ways.

ii Chronic illness and the critique of the biomedical model

The sociology of illness has offered different alternatives to the mind–body dualism of Descartes (1644) which became foundational for biomedical thought. Recent trends toward holistic mind-body integration in fact reflect the much earlier stance of orthodox Christianity on inseparability of body and soul (ibid p 3). Bendelow (2009) points out that the medical profession has allowed the holistic view to gain ground in areas of illness where there is either no clinical explanation, or there is no cure. These areas include old age, chronic illness, anxiety disorders and degenerative illnesses such as cancer and chronic obstructive pulmonary disease (COPD) (ibid p 25). Chronic patients undergo severe treatment regimes, knowing that at best these will only hold the illness in check. This then creates a demand for lifestyle or quality of life enhancement. Frank (2010 p 121) calls this the ‘illness as normality’ model, where progress can only be made in ordinary life – the illness world is fixed and unchanging.

This study and the Living Well Programme in which it was set uses the holistic approach, mind and body or body and soul concept as found in Orthodox Judaism and early Christianity. This approach resulted from the team’s experience with long term kidney patients who were experiencing suffering and distress. There was no way that the ‘spiritual’ component could be separated out from the deprivation and loss which characterised their whole lives – both had to be addressed. A similar phenomenon was observed in palliative care, when ‘total pain’ was described by Cicely Saunders in the 1960s as loss in every aspect of one's being (in Clark D 2000). The study did not seek to set out a full theological or theoretical treatment of this theme. It merely suggested that a practical consequence of this approach is that a person's faith cannot then exist in a separate 'spiritual' realm disconnected from ordinary life. Instead faith constantly interrogates and explores lived experience (including illness), in order to make sense of it and give it meaning.

iii Context: Spiritual care provision in the NHS

Spiritual care is provided in hospital by chaplains of various faiths, and recognises that illness disrupts the person's normal faith practice and may also affect their beliefs. Beyond this, chaplains also care for those whose lives have changed profoundly, as a result of chronic or terminal illness, who need support in coming to terms with such changes.

Spiritual care is provided within the NHS as part of the NHS basic charter to respect religious faith and dignity of patients (DoH: The Patients Charter 1991). Spiritual care research has hitherto focused on efficacy, end of life, spirituality versus religion, multi-faith and multi-cultural issues and patient perspectives (Neuberger 1998, Robinson, Kendrick and Brown 2003). Spiritual care in a hospital environment splits into two broad areas: acute medicine, and end of life and palliative care. The latter has expanded considerably over the last twenty-five years; since the hospice movement first took the lead in offering a different kind of care at end of life (Clark 1998). This in turn has fed back into the way spiritual care is offered within palliative care in mainstream hospital settings (White 2006).

A large proportion of the patient population now experiences chronic illness. Chronic patients take up 50% of hospital beds, 70% of healthcare funding and 30% of GP appointments (DoH 2010). This can be viewed negatively as a huge drain on NHS resources – or positively as an opportunity to look into a new approach to care, so that chronic patients' treatment can be planned and managed without 'blocking up' the healthcare system.

Chronic illness poses a different set of challenges for spiritual care. Since Talcott Parsons (1951) first described the 'sick role', where patients meekly acquiesce to the treatment prescribed, society has changed, and patients have found a voice. The transition from an acute setting to a hospice (palliative) setting represents a major culture shift (Clark 1998). There is a recognisable difference between the way spiritual care is carried out in each setting, which mirrors differences of practice among chaplains and other professions in the healthcare team (Bolen 1996; Cobb & Robshaw 1998). Palliative care offers a ‘whole life’ approach to care, which in time may spill over into chronic illness. This would mean that the implications of the illness for patient’s lives outside of hospital could also be considered alongside clinical factors.

This study was set in a large, regional renal department in South East London which is typical of many regional centres. The kidney disease trajectory described in it offers a number of specific challenges for spiritual care. The illness involves a heavy treatment burden: either dialysis three times a week, or a transplant, which involves a high level of hospital attendance for monitoring, medication and medical supervision for the rest of one’s life. In either case, the illness will affect the patients’ lives in a major way, with regular hospital visits, surgery and inpatient stays (Chambers, Germain & Brown 2004). This distinguishes kidney patients from other chronic sufferers of diseases such as multiple sclerosis, Parkinson’s or diabetes, who will also experience major life changes, but will spend proportionately far less time in hospital, and manage most of their treatment at home or in the primary care setting.

The effect this has on clinical and spiritual care of kidney patients is twofold. Firstly, there is sustained contact over time allowing supportive relationships to be built. The kidney patient will continue to attend the (same) specialist hospital over many years (Chambers, Germain & Brown 2004). Secondly a whole life approach to the illness is possible: spiritual care may seek to address the biographical and spiritual disruption that affects all chronic patients, and it becomes one of the resources used to respond to this disruption.

iv. Social reality of dialysis – the patient experience

What is life on dialysis actually like? Dialysis involves filtering the blood of waste products by pumping it through a machine. This requires an access line into the patient’s vein. At first a temporary line can be used, but in longer term a fistula is required, a procedure which involves minor surgery. In dialysis treatment, two needles are inserted into the fistula three times a week, leaving the patient with limited movement of the fistula arm for at least three hours while they sit on a chair or lie on a bed.

Two kinds of dialysis unit were found in the hospital setting. The first in the hospital itself was a ward provided with rows of hospital beds. This was used for the frailest dialysis patients with other medical conditions which meant that a doctor needed to be present. The layout did not encourage activity or interaction between patients. The second kind was the satellite unit situated outside the hospital, often in converted premises. This had rows of reclining dialysis chairs arranged in bays of four or six. Patients recline or remain upright, can read, watch TV, listen to music on headphones or go to sleep. In this layout, there is generally more conversation and interaction in the satellite unit.

The satellite unit at the local Kidney Treatment Centre had a comfortable waiting area. More chat and interactions occur in the waiting area than inside the unit. Most patients are brought by hospital transport, which often drops them early and may be late taking them home. This extends the four hours on dialysis machine by up to two hours either side, an hour's journey plus an hour's waiting, making an eight-hour round trip. Two or three patients may regularly share one run and driver – this creates interaction and solidarity. The unit itself was provided with 'free' TV. This has an isolating effect – patients may instantly put on head phones, switch on and isolate themselves from their surroundings. Hot drinks are brought round on a trolley as well as biscuits or toast.

Some dialysis patients are still working, and may bring laptops into unit and work whilst dialysing. This likewise minimises interaction, and enables individuals to ignore the illness world they are in. There is also the option for an elite group to have a haemodialysis machine at home. They must first train in the unit on 'self-care', putting oneself on and taking oneself off the machine, and be fully competent in dealing with alarms and malfunctions supported by a help line.

Staff interact with patients in mainly functional ways – calling them in, weighing them, showing them to chairs, setting up machines and putting patients on dialysis machines. There are many experienced dialysis nurses who have worked in the unit for many years. Some units work twelve hour shifts – there are two daytime shifts of four hours plus change-over, plus an evening shift for people who work during the day. Patients spend their time on dialysis mainly reading, sleeping or watching TV. They are given hot drinks with toast or biscuits. There is also internet access.

The social world of the unit operates in a particular way. Patients have a choice: they may greet others, chat, catch up with family news and so on. There is a core of stable long-term dialysis patients who talk, are sociable and know each other. But these tend to be the older long-term patients; for them the unit is their social world, they do not go out much. Other patients do not interact. Hay (2005) reported half of patient starting dialysis were age 65 and older, and many experienced depression and powerlessness and so interacted little with others. Hooper (in Mcgee & Bradley 1994) identifies disengagement from social life and role changes as common among haemodialysis patients.

Another important distinction is between temporary and permanent residents. Ideally dialysis should be a temporary solution – transplant is the best long-term prospect for kidney patients. For younger adults who are basically fit, dialysis is a stop-gap until the lengthy process of preparation for transplant is complete. If individuals know they are on the transplant list, they need not bother to engage with the dialysis setting – they are just passing through. But the subjects of this study were all long-term dialysis patients – their medical conditions made it very unlikely they would ever get a transplant. The complex loss of future life potential experienced at the outset of chronic illness applies to the latter group, but not the former. The first will expect that once they get a transplant, life will continue as normal.

The dialysis unit then offers a shop window on kidney disease and a whole range of different situations and responses. The beginner may look at the frail elderly people on dialysis who after many years are in steep decline, and be unnerved and upset. Equally they may be other people who attend dialysis unobtrusively, make little fuss or noise, yet are living busy active and normal lives without advertising the fact.

In the reflexive section describing how dialysis patient react to a chaplain visit (3.12), the issue of disclosure is discussed. The issue of disclosure and genuine communication between patients was significant – it depended on whether a supportive culture existed where those having difficulties could express their needs and emotions. Here it seemed more common that patients in difficulty became withdrawn, and closed themselves off. Hooper & Cohen (in Chambers et al 2004) state that dialysis patients are afraid to express even minimally negative feelings toward family or staff. White (2004) reports that dialysis treatment impairs personal and family life of the patient. The culture of the unit influences which stories can be told, and may promote general rather than personal topics. Stories about family, weddings and holidays or trips out were readily told. The staff influenced this culture; if they restricted their communication to clinical matters, this set a pattern. If they themselves showed interest in patients' lives, this too had a knock-on effect.

The dialysis unit then presented a complex social reality. Some patients entered into the social interaction readily and willingly, others were isolated either through choice, or because they found the setting difficult and hard to tolerate. Any visitor to the unit would notice which patients were talkative and communicative, and which kept themselves to themselves. The same applied to staff-patient interaction. Staff related easily to those patients who were doing well, chatting and giving them friendly attention. Other patients, who had not adjusted as well and were experiencing difficulties, were more demanding toward staff, and displayed negative reactions such as poor cooperation, rudeness and non-compliance. Staff protected themselves from over-demanding patients by keeping their distance. Each patient then seemed to choose the level of participation or non-participation which suited their circumstances.

v. Biographical disruption, the Living Well Programme

Biographical disruption is a core concept in the sociology of health and illness, and describes the interruption of many aspects of normal living caused by chronic illness (Bury 1982). Its impact is described by Becker (1997) as follows:

> An illness is a major disruption to one's biography…one's sense of wholeness on which a sense of order rides disintegrates. One must reconstitute that sense of wholeness in order to regain a sense of continuity (1997, 39)

Spiritual disruption has not yet been widely used as a working concept – the nearest to it is perhaps spiritual pain or distress in palliative care, though this has a different meaning. In this study, spiritual disruption is taken to mean any disturbance in faith and practice that results from chronic illness, and produces change.

The study of LWP data and patient narratives formed the backbone of this study. Life course interviews and studies are done within many different disciplines and fields of research (Eakin 1999). They usually require sustained involvement and a commitment from participants. The resulting text belongs to the narrator as well as the researcher, and can be used and developed in various ways. Because the context of the study allowed sustained contact with research subjects over time, there was other field 'data' beside research interviews – informal meetings, casual conversations, review of progress against lifestyle targets and so on (Silverman 2005). The study therefore uses field data as well as full length interviews, and the use and significance of this additional data is discussed in Chapter 4 and 5.

Much narrative work has been done studying patients' stories, and how these define identity (Hurwitz et al 2004, Garro 1994, Kleinman 1988). The social scientist will see identity as mainly defined through social roles and performance (Charmaz 1983, Elliott 2005, Eakin 1999). The study of narrative is used to structure and analyse patient interviews, using formalist narrative theory initially. Paul Ricoeur's post-structuralist theory of narrative (Ricoeur 1988) was also a key influence, offering a philosophical view of life, ends and purposes and the changing self which spans the divide between religious and secular approaches, and explores the destiny and meaning of persons (White 2002). The study observed how subjects use faith during long term illness to provide a framework of meaning. The unstructured narrative interviews allowed them to describe the role of faith in their own response to illness.

The Living Well Programme (Guy's and St Thomas' Hospital 2007–2014) was a self-management and coaching tool for use with dialysis patients in Guy's renal department. It used work done in Stanford University Chronic Disease Self-Management Programme (Lorig et al 2006), and offered a life review and coaching programme for kidney dialysis patients which is described in more detail in Appendix B. Patients' own life reviews were used as indicators of their life practices and commitments. They were described in past, present and future time, which enabled them to plan life recovery targets. The patients in the sample in this study were all participants in LWP.

vi. Research aims and objectives.

The principal research aim was to observe illness processes, identify biographical and spiritual disruption in LWP and patient narratives, record their responses to these, and analyse the responses using a narrative framework. The secondary aim was to understand the impact of chronic illness on faith and patients’ response to this, as described in patients’ own narratives.

The research objectives were:

1. Identify patients who have experienced biographical and spiritual disruption from LWP participants.
2. Observe and record patients’ responses to biographical and spiritual disruption, including how disruption was managed, and whether it was followed by attempts at life and role recovery.
3. To better understand biographical reconstruction (life and role recovery) after illness disruption, and observe how this may be achieved in chronic illness.
4. To record evidence of faith demand, faith work, faith responses, changes in belief and practice, and faith work resulting in spiritual growth or change.
5. To present findings that describe the processes and life impact of chronic illness to assist further research, and enable practitioners to develop specific spiritual care and life recovery resources for this patient group.
6. To provide a theory base for the Living Well Programme, which would inform its future development.

vii. Chapter summaries

Chapter 1 sets out the basic dilemma of chronic illness – that it is indeterminate, unresolved and potentially endless. It introduces four different narrative models of chronic illness (Section 1.1) which are used throughout the study. The primary model; the narrative quest, is a progressive model moving forward to resolution. But chronic illness can also be seen as repeated disruption cycles with no ending or resolution (model ii), as an augmented narrative which expands to contain disruptive events (model iii) and as an account of illness which is lived out in two different life worlds, good health and illness (model iv). The tension between these models is a key theme throughout the study.

Chapter 2 builds up a model of chronic illness using a narrative structure based on Labov’s (1967) four-part model (Section 1.1), but adds an extra stage, life and role recovery. The tension within the story plot derives from the initial disruptive illness event, which results in losing the good life one once had. Chapter 2 reviews the four narrative models and then describes the primary model in detail (Sections 2.2–2.6). Model (iii) augmented narrative is illustrated by describing faith work, the work subjects do to expand their faith to take account of illness and suffering (Sections 2.7– 2.8), so that it continues unbroken through crisis times. Subjects may recount an illness world of suffering and dislocation (model iv), but barriers are also present which prevent disclosure.

Chapter 3 outlines theoretical positions referred to in the study. Longitudinal qualitative analysis (Saldana 2003) was used in analysing patient data from participants in the Living Well Programme. Narrative method was used to analyse and code unstructured narrative interviews from a sample of 12 patients (9 faith, 3 non-faith subjects). The primary theoretical illness model built up in Chapter 2, the five-part narrative quest, was used to devise a theoretical coding for narrative interviews. The research aims and objectives are outlined, together with ethical issues and approvals. The narrative analysis method used (Flick 2002) interprets data as social construction (Bruner 1987) rather than a chronological reconstruction of events.

Chapters 4 and 5 present the interview data which forms the core of the research. Chapter 4 uses narrative enquiry and describes the twelve study interviews in four groups: it analyses the plot structure, the roles of the narrator and how the story is told. Chapter 5 describes the narrative analysis and five stage coding process. The codings used were narrative coding, theoretical coding, disruption-response coding, illness work coding and progressive learning coding. One narrative from each group is analysed in more detail to illustrate links between faith and action, disruption and response, to describe how new life stories are created and how some subjects live in two different worlds, health and illness.

Chapter 6 reviews the key issues raised by the data analysis, and their impact on the theoretical model put forward in Chapter 2. The primary model, the narrative quest, did not take account of repeated disruption events, and the impact of repetition on modifying patient responses. The problem of resolution in chronic illness is discussed and a solution suggested. The primary model is revised and redefined as a role quest rather than an activity quest, where subjects define the responsibilities they take on during illness for themselves. Chapter 6 discusses how subjects may inhabit and move freely between the life worlds of health and illness, and also how narrative life worlds are disclosed so that they express and contain suffering.

Chapter 7 reviews the research question, the research aims and method and discusses limitations and generalisability. It lists the main conclusions of the study which were that chronic illness subjects progress, they take on a specific role and responsibilities, they learn, they create an illness plot which can be sustained, they do many kinds of illness work, they manage disclosure and they create counternarratives describing suffering. These positive conclusions are at odds with the generally accepted picture of the dialysis trajectory, which suggests a negative response to illness followed by progressive loss and decline. Chapter 7 explores whether the study sample consisted of exceptional able survivors, who might not have been typical of the group as a whole. But it concludes that in fact the study subjects had all at an earlier stage responded negatively and been disabled and disoriented by the illness. This led to the study's conclusion about progression in chronic illness: these dialysis patients progressed from an initial negative response, through a learning and exploration stage, to a positive and active response to the illness.

Chapter 8 looks at the potential for further research. It outlines two follow up studies with kidney and cancer patients (8.3 and 8.4). One of these, the KPA trial (8.3) specifically targets patients who are struggling on dialysis, and so will provide valuable information as to whether the study findings may be replicated in a different sample group. It discusses practical applications of the study both for kidney patients and for others with long term conditions.

Appendix A sets out the data gathered about LWP participants included in the study. As well as the interviews (Chapters 4 and 5) field data was gathered about patients' life activities and the impact of illness over time. An important finding arose as a result of the interval of up to two years between LWP data sets and interview recordings. By comparing these, it was observed that these subjects had made significant progress during this period in managing disruption and addressing life recovery on their own without any expert intervention, supporting the learning hypothesis. Appendix B reviews the Living Well Programme in the light of the study findings and makes suggestions for further development

viii. Contribution: Learning response, chronic illness work, the narrative quest

The study describes how chronically ill subjects describe and respond to their illness. Dialysis treatment and disruptive illness events generate disruption and recovery cycles, which create the opportunity for learning and recovery work. Other kinds of chronic illness work are also observed – narrative work, emotion work, grief work, identity work and faith work. Narrative work is part of the narrative quest of chronic illness, which is to recount how the individual learns to become increasingly more confident and adept at managing life disruption and planning and engaging in life and role recovery tasks.

A key study finding concerned repetitive disruption, the way chronic illness consists of a string of repeated setbacks and disruptive events, which have to be dealt with in turn. The study findings are surprising here, since one might expect that many patients would be worn down through this process, and so lose their motivation to fight back. But the study suggested the opposite occurs. The sample group became more skilled and adept at managing disruption, and used this ability to enable life and role recovery. The subjects in this study gave top priority and effort to defining the role they wished to enact during illness and to carrying this through.

This study was itself located within a new development programme, the Living Well Programme, which is described in Appendix A and had over a hundred participants. The study findings were not available at the time the programme was running. But now an opportunity exists to interpret the study findings and apply them to the LWP framework in two ongoing follow up studies during 2017- 2018 (see 8.3 and 8.4). There is also a national initiative to encourage activation among dialysis patients using a specially designed patient activation measure (PAM) (Hibberd 2007). The experience gained from LWP will be relevant here, since it suggests that qualitative factors outweigh quantitative in studying activation, and that it is not the amount of activity that counts, but its value in relation to the patient's own life goals.

ix. Impact of chronic illness on faith: Implications for spiritual care

Faith is a free resource in healthcare, and offers the potential for sustaining hope during long term illness. Faith groups work as support networks, and care for the sick is a normal duty in this context. Betty, quoted in Gareth Williams (1984) insists that she is in God's hands, and so remains serene and untroubled by illness. But contrary to Williams' anecdote, Betty's reaction was not seen in the faith subjects in our study, who generally experienced the same life losses and emotional disruption as others did. In addition, they needed to understand their illness in the context of their religious faith.

For faith subjects, expanding the faith world to include illness was seen as a vital gateway to rebuilding the faith story. Here the believer who has long term illness works out and redefines what is required of them by the faith they hold, so that there remains a specific calling and responsibility that gives meaning and fulfilment to life. But these do not exactly mirror and imitate the pattern of faith observance and activity followed in good health. Instead, the illness world is seen as a new and different context for faith and practice – here too faithful living may take place in different forms.

Observing and describing the impact of chronic illness on faith revealed two distinct processes at work: the effect on belief itself and the impact on observance. There seemed to be two distinct tasks to be addressed. The first was to expand or interpret faith, and apply it to the illness situation, so that it became a useful resource. The second was to maintain links with the faith group, attend worship when possible, and continue an active role. This would enable the individual to participate and receive fellowship and support – but this became more difficult as they became less active.

The illness narrative often contained an individual faith story. Chronic illness poses faith challenges and so people reach out for faith. But at the same time their contact with a faith group is reduced when they become ill. The faith story documents individuals' struggles as they work out what their faith requires of them during illness. The study highlighted chronic illness work and especially faith work. This suggested that the spiritual carer, rather than offering 'care' (pastoral care, concern, sympathy, advice) needed to help the patient do the faith work that was needed, to relate their faith to the world of illness. The particular faith work that patients undertook is described in the study interviews, and shows how they were able to discover and engage with new forms of prayer, observance, worship and spiritual experience which fitted better with the limitations of illness. The faith story itself became a witness to the unbroken chain of believing which the person had kept up even through periods of isolation and difficulty.

A key theme that emerged during the study was disclosure, and in particular the disclosure of suffering. Could a faith community receive, understand, and share in the suffering of its members who had chronic illness? This proved problematic, since the chronic illness world lay outside the experience of many faith group members. In a faith group that strongly emphasised healing, patients might not disclose their suffering, if the culture privileged stories about healing and victorious faith. The subject might then be more likely to reveal suffering and spiritual pain to a chaplain or spiritual carer in hospital context, rather than to their own faith group. Particular narrative passages in interviews offered a window into the person's world and into the suffering they experienced; these served to express and contain the suffering, which became part of the narrative.

x. Impact of study on chronic illness research

The wider significance of this study within the field of chronic illness is that it suggests that learning occurs naturally and spontaneously during chronic illness in particular patients, using their own efforts. Observing and studying these patients showed that they improved their responses and became more skilled and adept over time. The observation of chronic illness work including emotion work, grief work and faith work also suggested that patients had considerable potential to reflect on and evaluate their situation and work at the complex emotions and losses the illness caused, so as to avoid being burdened by these. They had then gone on to improve their prospects for good survival and adaptation.

This research study suggests a different approach to understanding dialysis patients and those with other long-term conditions. Most other studies have focused on quality of life, noting that this invariably declines during progressive illness. This study suggests that even though the illness trajectory is downwards and quality of life reduces, dialysis patients learn effective illness responses, work through the complex emotions and losses that chronic illness brings, and create illness stories which recount their personal and individual way of dealing with chronic illness. The work they do represents a substantial achievement. The fact that it goes unrecorded in the clinical setting may result from a culture, where only the factors that produce change in clinical outcomes are published and recorded. But even though the work patients do does not change the clinical outcome of progressive illness and decline, it has a fundamental impact on how they respond and live with long term illness. It allows them to build for themselves illness stories which restore a sense of agency, identity and pride, and also, for those with faith, enables them to apply their faith in resourceful and creative ways to the illness world in which they live.

Chapter 1

Literature review

Chronic illness: the untold, unfinished story

1.0 Introduction: The untold story

> *'As these mundane discomforts accumulate, they take over everyday life. They become all an ill person has to look forward to. And one day, after many days with nothing else to look forward to, that person changes… She has been worn away, and she doesn't care any more. Among caregivers this change is called burnout. Ill persons also burn out. Some may continue in treatment but only because they don't care enough to stop. Those who do stop treatment are the ones who still care about how they live: they are willing to live a shorter time, under circumstances that they hope will be more of their choosing.'*
>
> (Frank 1991, p 140)

Arthur Frank's '*At the will of the body'* (1991) describes his own experience of cancer. In the final chapter he discusses the remission society, those who live on under the burden of chronic illness. The passage above describes how the illness may gradually wear you down, until you lose the will to live. This process of attrition, which Charmaz (1991, p 9) calls 'interruption, intrusion and immersion', is what the chronically ill experiencing kidney failure most dread.

But this is not the story that is told to dialysis patients at the outset, nor is it told by patients in this study. Patients are told initially that dialysis is a straightforward routine which can be done at home or in hospital; it will not interfere with activities of daily living; and the patient can look forward to a full and active life. The patients in the study tell courageous and resilient stories of adaptation and adjustment, fighting back as the illness progressively takes its toll and limits their lives. Here then are competing stories about life on dialysis: which of them is true?

This study used mixed methods (see Chapter 3) – narrative and longitudinal qualitative research. It recorded and analysed patients' own illness stories about how they responded to the various stages of illness. It is based on long-term dialysis patients, who often have other serious health conditions, and so cannot go on to receive transplants. The medical advice they are given, carry on living as normal, conflicts with published medical research data documenting the profound psychosocial impact of end-stage renal disease (McGee & Bradley 1994, p 3), which indicates that dialysis patients' quality of life consistently deteriorates over time. Patients cannot expect to go on living normally, even though they often attempt to do this at first.

This is an observation and analysis study, which grew out of an intervention programme. The particular programme was the Living Well Programme (LWP), which monitored patients' attempts to self-manage and deal with the impact of the illness on their lives through a process of life reviews and follow-ups. The programme offered patients no additional resources, other than those already available to them within the healthcare system and community. It worked simply by recording what they did, and comparing this with what they had done before, the targets they had set themselves, and noting progress.

Both LWP and this study share a common grounding in narrative method. The study used full length narrative transcripts (illness narratives), while LWP used a more structured narrative matrix – a life review of physical, mental, social and spiritual aspects of patients' lives over time. In both cases the aim was to compare patients' lives before and during illness, and to document their hopes for the future. The goals however were different. LWP wanted to record past, present and future (planned) life activities as a way of helping a patient to balance and prioritise current activities. The study used illness narratives in a different way, to study the responses to chronic illness which patients learned and developed, which were described through a sequence of illness episodes. This it was hoped would offer a theoretical foundation to a key premise of LWP, that chronic illness subjects learn and develop competence as illness progresses, and themselves have the capacity to manage their lives within the limitations of illness.

Arthur Frank has studied published illness narratives extensively and derived from these a typology of how people react to serious illness. Frank's own cancer story quoted above led to the '*Wounded story teller* '(1995), an in-depth account of many published illness narratives, often by cancer patients (no kidney patients were represented). In this book it becomes clear that illness stories have a powerful impact. They not only tell us about heroic struggle, desperate resistance and deep pain; they also show how the story was formative and perhaps transformative for the author who is the patient. The patient lives out the story she tells. Mishler (1999) and Langelier and Peterson (2003) explore further the performance of narrative in daily living to express identity. Frank develops the theory of the potential of stories further in '*Letting stories breathe'* (2010). Here he argues against classification and rigid analytical method, urging instead that stories explain themselves – you have to wait until you 'get it'. From the perspective of chaplains and others who care for long-term patients, illness stories are a rich resource, with potential to lead to better communication and particular understanding of the patient's world.

Returning then to the dialysis setting, using stories might be a way to get inside the patient's world, and begin to understand the ups and downs of a life limiting illness, from which there is no escape. But immediately there is a problem: this seems to be a world without stories – no stories are being told. Stories, Frank says, work well to connect people, by giving them a stock of foundational narratives which they can use and develop (2010). They call individuals into groups, and they call on groups to assert common identities. There are cancer survivors' groups, cancer survivor stories and self-help and support groups. But kidney dialysis patients do not seem good at story-telling, or at creating collective identity. The new patients do not hear the stories recounted by the old timers. The staff do not listen to stories about patients' daily lives – they may be too busy. This appears at first to be a story-less world.

What then is the story that is not being told? Frank's quote about decline and burnout may be relevant here. Looking round the unit, plenty of possible examples may catch the eye. The newcomer sees the signs, but would rather not know. In fact. many of those who come in, switch off and sleep through dialysis lead active and busy lives: but one would not know it. Another of Frank's questions (2010, p 81) 'What is the force of fear in the story and what animates desire?' is relevant. The fear of the illness is due to its destructive potential, its future progressive impact on people's lives. The desire in the illness is for escape, which usually means getting a transplant.

What then of the authorised story, that dialysis patients can and do live active and productive lives? The participants in the study, all at different stages of the illness, will show that this is partly true, but it requires much hard work and effort. They recount their stories to the researcher, which they have also shared with others, stories which work generatively in the way Frank describes.

1.1 Building a story: Four narrative models of chronic illness

The study method is grounded in narrative theory which is combined with longitudinal research methods (3.1). Chapter 1 will outline four different approaches to narrative found in the literature and will relate these to four narrative models. The first, the primary model for the study, the five-part narrative quest, is described fully in Chapter 2. The four models are introduced below.

Model (i) the five-part narrative quest is described in 1.1–1.3. It is based on a narrative framework based on Labov's four part formalist structure (1967): orientation, complication, evaluation and resolution. Bury (1982) and other writers on biographical disruption and Frank (1995) follow this pattern, where a settled state is disturbed and is then reconstructed or stabilised. Bruner (1990) suggest that we become the stories that we tell about our lives: the narrative quest then creates a new story incorporating illness.

Model (ii) disruption and response cycles uses Ricoeur's (1992) idea of concordance and discordance, and suggests that life is a mixture of harmonious and disruptive events to which the individual must respond. The task of a life story is to integrate these disparate events and combine them into a single unified plot, which describes a consistent character.

Model (iii), augmented narrative is based on Root (in Hauerwas & Jones 1989) and introduces a different narrative concept in which a life story must be expanded to contain disruptive events, such as chronic illness. Soelle (1975), Moltmann (1975), and Pannenberg (1985) extend the idea of expanding narrative to include overcoming the estrangement caused by suffering, illness and adversity.

Model (iv) living in two different narrative life worlds is described in 1.7–1.9. Felman and Laub (1992) describe the life world of holocaust victims, and the enormous problems created in trying to express and communicate this world to others. Arlie Hochschild (1983) describes how people manage their stories and their emotions in response to social situations, where the social world dismisses or discourages certain stories and certain kinds of emotional expression. Walter Brueggemann (1995) sets this in a faith context within the Judaeo-Christian framework of covenant, a particular faith world that is ordered and regulated by God's command, and contains sin and suffering. Brueggemann's faith world is one where the faithful need to find a voice to express their pain and hurt when experiencing adversity.

The four narrative models illustrated from the literature are summarised in the table below.

Table 1.1.1 Narrative models of chronic illness

Narrative model title	**Description**	**Literature Chapter 1: sections**
Five part narrative quest	Good health, illness, expression and evaluation, life recovery, resolution	1.2 Bury, Williams & Williams 1.3 Frank
Disruption response model	Repetitive cycles of disruption and response	1.4 Ricoeur
Augmented narrative model	Narrator expands life story to include disruption suffering and loss	1.5 Root & Hauerwas 1.6 Soelle, Moltmann & Pannenberg
Living in two different life worlds	Life worlds of health and illness are separate and distinct: each places different obligations on the illness subject	1.7 Felman & Laub 1.8 Hochschild 1.9 Brueggemann

There are two broad approaches when using narrative method in research: narrative analysis and narrative enquiry. Frank (2010) says that he 'follows Catharine Reissman in believing that there is not, nor should there be, any method of narrative analysis, if method is understood as a prescribed set of steps that the analysis should follow' (2010, p 72).

Frank goes on to describe his dialogical method of interpreting narrative which he terms socio-narratology which will be referred to later. But the study method adopted initially here was narrative analysis (Silverman 2005, Flick 2002, Wengraf 2001) which is used extensively in medical sociology research, especially when focusing on patient perspectives. Wengraf (2001) distinguishes between ‘told story’ and ‘lived life’ and his method seeks to uncover the differences between the two. For some theorists including Frank, this would seem a pointless pursuit: it is generally accepted that narratives are fictions or constructions which emplot, represent and construct reality in many different ways (White & Epston 1990). Nevertheless this study needed to observe the course of chronic illness and kidney disease, including various interruptions and crises, in some detail. Therefore, the patient narratives studied were analysed in two different ways:

1. As a relatively accurate account from the patient’s perspective of what happened at illness onset and thereafter, including key events, crises, and the subject’s reactions to and interpretations of these events.
2. Using a formalist narrative model, to analyse the way the illness narrative is constructed to follow a specific story plot, which the narrator has chosen.

The first analysis would enable comparison of the typical illness trajectory different subjects experienced. For dialysis patients the treatment regime is standard and varies little, as are the usual range of physical problems and side effects associated with it. But the response of patients to this treatment process would be found to vary widely. The second analysis would uncover the patients preferred response strategy, the characteristic way they reacted to the illness. This approach would uncover rich data and in-depth accounts of patients’ emotional and faith responses to crises during illness. Later in the study in Chapter 6 after detailed analysis, the five-part narrative quest model was revised from a recovery quest to a role quest, where the role the narrator chooses and describes generates learning and illness work (6.3)

This study works with patient stories using narrative as a discipline. In the basic formalist narrative approach (Labov 1967), the story plot is condensed down into four or five elements: orientation, complication, evaluation, resolution and (sometimes) coda. Narrative theory has developed considerably since Labov’s simple scheme, which used work by Propp (1968) and Greimas (1982) on Russian folk tales. Structuralist and formalist narrative thinking was at its height in the 1960s. Later developments of narrative theory became more sophisticated and complex under influence of postmodernism (Lyotard 1984, Genette 1988, McQuillan 2000). But in this study the basic formalist narrative structure is adequate, since in essence illness stories are simple in form: a stable state, good health, is disrupted by a dangerous threat, serious illness: the response to that threat and its resolution forms the substance of the story plot.

In this study of illness stories, the way the narrator describes the complicating event (illness onset) throws light on how disruptive it was, and how it impacted on her life. But in addition, the narrative will include the narrator's own evaluation. Events will be described as calamitous, difficult, routine or extraordinary using expressive description. Important events will be described in great detail, less significant ones in brief outline.

Chapter 1 therefore will explore literature about chronic illness from a narrative perspective. It shows how the literature illustrates at least four different approaches to describing chronic illness. Each of these is related to a narrative model, see Table 1.1 above. One of these, model (i), is developed to form the theoretical basis for the study, a five-part model of the chronic illness process. The other models (ii) to (iv) will be discussed further in Chapter 4 and 5, and will be used to amplify and compare with the primary model.

1.2 Studying illness stories: Biographical disruption: Bury, Williams and Williams

This section reviews the study of illness stories by medical sociologists. The biographical disruption debate is described and analysed. It represents an important starting point and setting for the study, and allows spiritual disruption to be introduced by analogy, to explore whether it works in a similar way.

1.2.1 Michael Bury: biographical disruption

The biographical disruption debate summarised by Julia Lawton in her retrospective article (2003) offered a useful starting point for the study. At first it was intended to use Bury's term (1982) as a cue or reference point. Biographical disruption was a well-known idea in medical sociology; but most writers apart from G Williams (1984) had hitherto ignored the spiritual aspects of disruption. These are described in the study narratives and suggest that faith subjects undergo the same kinds of life disruption as others do, and in addition experience the disruption of their patterns of faith observance and practice.

Bury (1982) and Charmaz (1991) offer textbook models of the effect of chronic illness on patients' lives. Michael Bury's 'biographical disruption' model is well known in the literature and has been cited many times over the past 25 years. It has been critiqued by Williams (1984) and Williams S (2000) on the grounds that biographical disruption is only part of the process, or is a normal aspect of life.

Bury's term is nevertheless much cited and useful in stating an obvious truth – that chronic illness interrupts whether temporarily or permanently the life course, seen as an ordered narrative. How the life course thus interrupted is described is important. When first person narrative is used, then it is likely that the story will be told differently each time, depending on the hearer. In narrative theory (Labov 1967), stories need interruptions and crises; they then become part of the story, the plot continues until the next crisis arrives. A narrative critique of Bury's idea would then argue that a life story is simply a sequence of disruptions, or change-events, which the subject responds to. The negative value judgment implied in the term 'disruption' is soon lost, as other disruptions follow. Disruption becomes normal. Williams G (1984) shows that the sequel to biographical disruption is biographical reconstruction. Williams S (2000) suggests that not all chronically ill subjects experience disruption, and that change is normal.

Bury's 1982 article offered a common-sense approach which remains valid. Bury says that chronic illness involves a recognition of the worlds of pain and suffering, which are normally only seen as distant possibilities. This is true – but only for a short time. Chronic illness is a different life world which is strange, unfamiliar and threatening at first, but then becomes familiar. The new arrival dips into it, and then hurries back to normal living. There is some immediate disruption and inconvenience, but there is also hidden away a much greater burden of potential damage to future life plans, which is not immediately apparent. Bury says chronic illness does not 'break out', it 'creeps up' (1982 p 170). Recognition and disclosure may be delayed.

The study itself began from Michael Bury’s straightforward definition of biographical disruption, as a situation ‘where the structures of everyday life and the forms of knowledge that underpin them are disrupted’ (1982 p 169). Chronic illness represents a critical situation, Bury asserts, which has three aspects: it disrupts taken for granted behaviours, it disturbs normal explanatory systems, and it generates a response mobilising resources in facing an altered situation. Using Bury’s definition as it stood, the term spiritual disruption was coined by analogy, with the word ‘spiritual’ being interchangeable with faith. This led to spiritual disruption being defined as a situation where the everyday practices of faith and the faith systems that underpin them are disrupted. The consequences are threefold: it disturbs taken for granted faith behaviours (attendance and observance), it disturbs normal faith based explanatory systems, especially those concerning pain and suffering, and it generates a faith response that mobilises faith resources.

These definitions gave a convenient starting point for the study. Bury’s definitions married well with the other starting point, formalist narrative theory (see above), which also gave a straightforward outline of a simple narrative plot. The intention at this early stage was to focus more on spiritual disruption, since other writers had covered biographical disruption in detail. But as the study progressed it began to develop and challenge accepted views of biographical disruption in chronic illness, by introducing the idea of disruption and response cycles.

Bury concluded in his study that this disruptive experience throws into relief the cognitive and material resources available, and the key forms which explanations of pain and suffering in illness take in modern society. Faith is one such explanatory system: but it too has drawbacks which are highlighted below (1.9). Bury mentions the deep involvement of medicine in reorganising the disruptive experiences of chronic illness, which involves social control; a dialysis patient’s treatment regime is strictly controlled. But the evidence of this study is that medicine has withdrawn from involvement in ‘reorganising disruptive experiences’, leaving this to others to handle. Now the practical management of personal troubles and affliction is much more likely to fall to the patients themselves, sometimes assisted by a chaplain, psychologist or social worker.

Bury’s work then was foundational for the study of biographical disruption, and enabled others to build up a specific literature. In this debate, how the illness story was constructed (narrative plot) was less important than dealing with the disruptive effects of illness.

1.2.2 Gareth Williams: narrative reconstruction

Gareth Williams (1984) takes Bury’s work a step further, and looks at the consequences of biographical disruption. He is concerned with how illness arises, and specifically how illness narratives offer plausible accounts of where the illness came from. In narrative terms this is emplotment – there has to be a connecting thread that links up different events. Narrative reconstructs a sense of order from fragmented events. Quoting Musil, Williams says

> What they like is the orderly sequence of facts because it has the look of necessity, and by means of the impression that their life has a course, they manage to feel somehow sheltered in the midst of chaos. (Musil 1979 p 436)

But Williams says order cannot always be sustained against the chaos. For him, narrative reconstruction represents the workings of the discursive consciousness. It includes explanations, acts of interpretation, the narrative restructuring of profound discontinuities. Life has a course; the self has a purpose or telos. Narrative imaginatively reconstructs the past so that it has meaning or purpose for the present (1984 p 179). But the relationship between self and the world changes: the biographical telos has changed too.

The concern about finding a ‘cause’ for chronic illness is rarely found in kidney patients – there are plenty of medical explanations for kidney failure. Instead, narrative reconstruction concerns reconstructing the self, life plans, ends and purposes. Williams’ framework also fits very well with faith: the same discontinuities and breaks are present, the same need to find a faith thread which ties it all together. Quoting MacIntyre (1984) he says

> The narrative of their life has become unintelligible to them, it lacks any point any movement toward a climax or telos. (MacIntyre 1984 p 202)

Only Williams addresses faith. He describes two subjects – one is Gill who loses her faith, the other is Betty who keeps it. Describing Betty’s faith, he says:

> There are some situations in which the central meaning of life is defined by some transcendent principle…. Where God is the Cause or Unmoved mover, the individual may be liberated from the burdens of narrative reconstruction… (1984 p 193)

Here I disagree with Williams – Betty is untypical, this study will show that faith subjects experience spiritual disruption too. They then perceive that there is an urgent need to reconstruct the faith story, not in order to discern a cause, but in order to find a new way of living faithfully with illness. Williams' conclusion after meeting Betty is that

> The secular search for cause and meaning or what Alasdair MacIntyre (1984) has called the 'narrative quest' is redundant, because the cause meaning and purpose of all things is preordained by God. (ibid 193-4)

Again, this statement is not supported by this study. The study participants all remain faithful, but struggle at first to find a new calling (injunction), to replace the many active roles they had before. Faith remains constant, but practice has to be quite different, and must be rediscovered. Because Betty did not see herself as the author of her own narrative, Williams asserts, there was nothing to reconstruct or explain. But the essential role of both self-narrative and faith narrative is to link the subject with the telos and describe how the life plan (faith plan) is worked out through the story. None of the faith subjects in the study who had kidney failure at first knew what to do, and how to respond. It became clear to them later, often after a struggle. Betty's blind certainty here is untypical of the general response found in faith members. In fact, the study shows a much greater convergence between biographical and spiritual disruption than Williams' account suggests.

1.2.3 Simon Williams: a postmodern critique

Simon Williams' critique (2000) of biographical disruption is complex. Williams takes us forward into the postmodern world of fluid identities, and writes from its perspective of a flexible narrated self, founded on many different narratives. He also refers to other modes of thought – disability studies, new ideas about the self and body.

Williams agrees with Bury that coping is perhaps best seen as a cognitive process whereby the individual learns to tolerate or put up with the effects of illness (2000 p. 44). Coping also involves maintaining a sense of meaning and value in life, in spite of symptoms and their effects (Bury & Holme 1991). Like Bury and Holme, Williams distinguishes styles of coping. He refers to the disruption of ‘taken for granted assumptions and behaviours’, and to ‘explanatory frameworks’. He states that response to disruption involves mobilisation of resources and practical consequences (2000 p. 43).

Bodily constraints need to be located in practices and discourses. Following Bourdieu (1984) he distinguishes two different modes of adjustment: accommodation, becoming more flexible, and active-denial, whereby illness is opposed through increasing engagement in everyday activities. In other words, adjustment and adaptation are in many cases the normal response to disruption. Where denial occurs, the response is a driven attachment to the life practices of good health, to which the subject is deeply committed.

Williams expands his argument that adjustment is normal, and refers to Cornwell’s ‘Hard earned lives’ (1984), which highlights the cheerful stoicism and pragmatism of East-Enders who refuse to worry or complain. This attitude is learned from a harsh environment. Similarly Pound et al (1998) discover that 70, 80 and 90-year-olds find their experiences have equipped them with considerable skills which enable them to deal with crises successfully. Older people see illness as inevitable in old age, and meet it with a greater sense of acceptance. This is frequently seen in dialysis patients in this age group, as Bury himself stated:

> They are severely restricted physically, yet never bored. Their housing is deficient yet it does not seem to worry them – they have got used to it. (1991 p 159)

Williams asserts that the opposite of biographical disruption is biographical reinforcement. Strauss and Corbin (1988) see three stages in identity work: defining and redefining the self, refocusing of direction, and integration. There is a parallel with the idea of augmented narrative – the self-story is augmented and enhanced so that it now includes suffering and loss, and also with the idea of narrative re-emplotment, creating a new story plot. Williams asserts that most lives follow a narrative thread defined by everyday happenings and routines; when major problems occur in their social world their identity is bound to be threatened (1984).

Simon Williams is not challenging the entire theoretical construct of biographical disruption, but is rather questioning its significance. Disruptive events frequently happen during chronic illness – they are normal and predictable. This study analyses many types of response, and also how these develop and become stronger and more effective. This would also explain the competence of the 'old old' (Bury & Holme 1991), and the skills of the East-Enders in Cornwell's study (op cit). Williams is correct in stating that the response to disruption cannot be prejudged – each individual responds differently. What this study has shown is that responses themselves form a narrative which is generative – people will continue responding in the way that they have learnt works best.

Williams concludes that biographical disruption has analytical utility and explanatory potential – but it is ultimately redundant. Biographical disruption implies a shattering of our taken for granted assumptions about our bodies and ourselves and the world. Other possibilities are that illness may already be a central part of our biography e.g. from early childhood (augmented narrative). Williams' alternative to biographical disruption is biographical continuity and biographical reinforcement. The life story is rewritten to include living with illness, and so becomes part and parcel of everyday life. For Williams, illness may be normalised or problematised; for haemodialysis patients it becomes the new normal. But the healthy life they had before with its rewards and fulfilment was also normal. They do not have the opportunity, flexibility and energy to create multiple identities and biographical reappraisals: instead they invest huge effort in reconstructing and regaining the stable identity forged in good health.

The detailed outline given in Sections 1.2.1 – 1.2.3 of the biographical disruption debate reflects its central position in medical sociology. The study accepts in general terms the major contribution this debate has made to understanding chronic illness and serious illness in general. The criticism made here is that because the debate does not use narrative theory, it is careless in its terminology. G Williams in asserting that biographical disruption leads to biographical reconstruction is actually confusing two different things. First life disruption can be followed by life recovery and resumption of normal activity. Second illness disruption interrupts the life story, which then is reconstructed with a number of possible different plots. This may describe resumption of the normal activities of good health, or may instead tell a different story about a new different life lived in the illness world. This distinction is important, since in chronic illness change may be overwhelming or it may be manageable, depending on the framework of meaning the subject gives to it, and hence how the illness story is emplotted.

1.3 Structuring illness narratives: Frank: chaos, quest and restitution

Arthur Frank has specialised in the study of illness narratives, using narrative method to understand illness better. The illness stages he defines start from chaos (disorder and disruption), then move on to quest, the search for meaning, and lastly restitution, the restoration of a pre-existing order.

1.3.1 The wounded story teller: Frank

Arthur Frank's book '*The wounded story teller* '(1995) is seminal for this study in that it offers a theoretical model of illness narratives, derived from published stories written by patients. This power of expression puts these patients at the top end of the scale in terms of articulation and description. Like Ricoeur (1992), Frank takes an ethical view of the self. For Frank the key question is - how to live a good life while being ill?

Recounting an illness story is a powerful act. That is, it places the narrator and subject in a position of control. At first sight chronic illness may seem to be no more than a sequence of disastrous happenings, which wound, batter and submerge the helpless subject. But now the narrator takes control, and shows how at every turn the subject survived, came through, was resilient and resourceful, and fought back. Frank's basic model – chaos, quest, restitution – was influential in the five-stage model put forward in this study (Section 2.1). In this section Frank's understanding of the self as a narrator who is also a moral and ethical agent is discussed. Frank addresses the key themes that are central to the study of a moral and ethical view of narrative identity. Frank asserts that the story teller (narrator) engages in moral action.

> The ill person who plays out Parson's sick role accepts having the particularity of his individual suffering reduced to medicine's general view. ...The post-colonial ill person wants her own suffering recognised in its individual particularity; 'reclaiming' is the relevant postmodern phrase. (Frank 1995,11)

> As a post-colonial voice the story teller seeks to reclaim her own experience of suffering. As she seeks to turn that suffering into testimony the storyteller engages in moral action. (Frank 1995,18)

Reclaiming a voice is certainly a key feature of the ethical self – but there are soon many competing voices all jostling for attention. Moral struggle during illness has two aspects: one to live out or live up to a plan or narrative, large or small, particular or general, the other to choose or construct that narrative. 'What can be lived up to' implies a moral value, an ideal of performance. In Victorian times suffering might have been borne nobly and bravely, today the focus is more on the unique individual response, a particular personal struggle. But the issue especially for people of faith is that the ideal of noble or brave performance can no longer be lived up to, leading to a profound sense of failure. For Frank suffering has a moral purpose:

> Moral purpose of reading is to witness a change of character through suffering; change equals moral duty. Auto mythologies can become stories to reassure the healthy that just as author has risen above illness, they too can escape (Frank 1995,135)

The nature of the moral duty or purpose which suffering may fulfil is not stated. 'Rising above' implies stoicism, or the obligation to fight back. Being immersed, reaching rock bottom, losing control, simply being carried along is perhaps the fundamental illness experience – one of total helplessness. In acute illness this might come when one wakes up in intensive care after a road accident, unable to move. In chronic illness it is less dramatic, more like a gradual process of attrition, which one can do nothing about.

Frank's narrative model – chaos, quest, restitution – is seminal for this study. But it does not in fact reflect the reality of chronic illness, where restitution (or recovery of former life pattern) is not a realistic goal. Instead the study model uses the term resolution, which implies that the quest for life recovery can be resolved at a particular perhaps half way stage, by accepting a particular outcome which includes gains and losses.

1.3.2 Letting stories breathe: a socio-narratology (Frank 2010)

Frank's more recent book, *Letting stories breathe* (2010) offers a comprehensive account of narrative enquiry as an interpretive method. Frank describes the capacities of stories – how stories breathe, how stories teach people who they are, how stories connect people. A key question is who is holding their own in the story. This implies that a basic function of the illness story is to show that the subject really is coping and managing – a story plot about the competent self. Asking how stories help people to remember who they are is important in illness: the remembered story is often the story of good health, contrasted with the story of who they are now.

Asking ‘what does the story make narratable’ suggests that there are accepted norms of what can be told. Discussing trouble, Frank asks ‘Who is troubled by something, who ought to be troubled, and who has the narrative resources to tell a story about being troubled?’ (ibid p 28). The introduction for this study described the dialysis unit as a place where few stories were told. Perhaps the patients learn that all their stories are the same, and so are not worth telling. Narrative resources include energy, opportunity and the availability of a sympathetic listener. A narrative may not be told because it contradicts an authorised narrative, which says that the dialysis allows one to continue with normal living. Frank also asks ‘what is the effect of people being caught up in their own stories?’ (ibid p 78). This is a vital question when examining faith stories, which have strong authority, and may be difficult to challenge.

In an important development, Frank suggests that his illness narrative typology (chaos, quest, restitution) could be extended to a further type, the ‘illness as normality’ narrative, which is often found in diseases involving long term deterioration. ‘Life is lived around the illness, accommodating it as necessary, but ignoring it as much as possible. Claims are often made to be living a normal life despite the illness. Meaning is sought not in the illness itself, but in life around the illness’ (ibid p 121).

This has major implications for the study since the focus of the illness story changes completely. The determined fighter/survivor plot is often found in long term illness, and focuses totally on describing the fight against the illness, beating the system and generally resisting all the unpleasant physical effects the illness has. This battle is set in the illness world. But Frank’s new type suggests that this battle is unimportant, or cannot be won. Instead the real battle takes place in the life world of good health, where the ill person fights hard to hold her own. Is this the same as the carry-on-with-life-as-usual story, which suggests that dialysis need have no impact on normal living? It is not the same, since here too, there is decline: the patient is not able to sustain all normal activity as before. But what it suggests is that it is in everyday activity that success and failure in chronic illness is measured over time. So long as there is activity in and access to the world of healthy living, the subject's life has value: if this disappears, then it does not.

Finally, Frank recounts how groups tell people what their stories ought to be (ibid p 135). He adds: 'Recovery groups cannot be imagined without the recovery narrative – life spiralling downward, hitting bottom, ceasing denial and giving up control, finding some higher power that changes behaviour' (ibid 136).

This is close to a faith or conversion story that can only be told to a group who hold the same belief, that this is how it should be. A faith story can only exist and be told in the context of, or as a counter to, an authorised narrative (Hervieu Leger 2000). In this study faith subjects describe how the authorised faith story runs out, and then has to be reconstructed by the subject by accessing new elements and resources of faith relevant to the illness situation. This personal faith narrative may later be adapted to suit the authorised story.

1.4 Emplotting the story: Ricoeur: concordance and discordance

Paul Ricoeur is a modern philosopher of some stature, who developed a systematic theory of narrative (*Time and narrative* Ricoeur 1984-88). This is used here as an authoritative source with which to compare the different ideas about narrative already outlined. Whilst Frank's approach is more empirical, recounting and analysing illness narratives to understand their meaning, Ricoeur is more systematic, developing narrative concepts within a philosophical framework into ideas of how life is, and should be lived.

Ricoeur's narrative structure and terminology were found to be valuable in this study, because of their broad scope and systematic approach. They emphasise that life practices and purposes are universal themes, not restricted to people of faith. The good life was thematised by patients as an ideal lost world, which they wished to recover. For Ricoeur, concordance and discordance are both part of life. Ricoeur offers a developmental approach to story-telling: stories are recounted, elaborated and told over and over again (mimesis 1, 2 and 3). This differs from Frank who argues that one story is followed by another different story. For Ricoeur, the life story is always developing and changing, but must be a unified whole, incorporating all the concordant and discordant aspects life brings.

Ricoeur offers an ethical philosophical treatment of the self in a narrative frame. Ricoeur's headings, taken from '*Oneself as another'* (1992) offer a systematic evaluation of the narrated self. 'Concordance and discordance' (1992,141) mean that a life story is always made up of favourable and adverse events. The 'good life and the good self' (1992,158,179) reflect the ethical aspiration to live well, and the desire to recount a self that has a worthwhile life project. The 'power to act' (1992,316) is a key ethical component of the self, which is never a helpless object. Even inactivity is an act. The 'self stripped bare' (1992,168) is the irreducible self, after discordance and disruption have taken away the props – adversity may undermine character and plot. 'Ascription, imputability and responsibility' (1992,295) are at the heart of the ethical self – the self takes responsibility for life events and circumstances which he does not choose and would not have wished for. 'Attestation and witness' (1992,302) refer to narrative as witness – the story carries a moral weight and impact when recounted (see Felman and Laub 1.7 below). Discussing practices and 'life plans, ends and purposes' (1992,157,177), Ricoeur suggests that life plans are normative. Every individual has a life plan and purpose, whether explicit or implicit. These may be entirely personal, and have no reference to religion or community.

'Injunction, being enjoined' (1992,350), means for Ricoeur that life has a purpose beyond survival, beyond the self. Referring to the 'other who calls' (1992,352), he is getting closer to a spiritual or religious framework; but equally this could simply mean living for a greater purpose, something outside oneself. The importance of Ricoeur's ethical thought here is that he asserts that life has purpose for everybody, regardless of religious affiliation. If that purpose is removed, there may not be a reason for living.

Ricoeur's ideas and key concepts appear again in section 2.5 below, where they are used to construct a theoretical framework for illness, disruption and recovery, which will be used to analyse the data gathered for the study. This will be used in preference to the theoretical scheme derived from the 'biographical disruption' debate, outlined above in sections 1.2.1 and 1.2.3, which itself include a number of writers and sources. Ricoeur offers a consistent philosophical approach that can be applied to all the study subjects, those with and those without faith. He avoids many of the difficulties of the disruption debate. Disruption (concordance and discordance) is normal and an essential component of the life story. The subject has the power to act, takes responsibility for his actions, witnesses to and attests to the grounds of his actions. Self-constancy, being true to self is fundamental; but there is also injunction: the self is called and enjoined by the other or others, other people, society and by implication, God.

Using Ricoeur's ideas overcomes a key difficulty of the biographical disruption debate which attempts to describe illness and disruption without being specific about the central role of the values, beliefs and life practices which illness disrupts. These life practices and purposes crucially are translated into a life story which is interrupted by illness. Recreating this story is not just about recovering activities, but is vital to life itself. It may involve creating a totally new life story with a different story plot. Ricoeur's 'life practices ends and purposes' (see Section 2.3 below) may have to be modified in the new life story. The study refers specifically to religious faith, which Ricoeur avoids, so reference must also be made to literature about faith in relation to illness and suffering, and how this is dealt with. Here disruption will carry a different meaning, and relates more to ideas of sin, alienation and estrangement (Section 1.6) as well as the disruption of the core relationship between God and the believer, where suffering can be seen as abandonment (Soelle in Section 1.6).

Ricoeur's narrative account of dislocation and reorientation then becomes integral to explaining the way subjects remake and reapply ends and purposes including faith, after biographical disruption. Each person has the choice of continuing to accept the authorised faith story, which values acceptance and endurance, or through bold exploration and faith quest come to a new understanding of faith, which offers new resources of hope and grace (gifts) within suffering. Members of faith groups then have a narrative choice: they can recount their illness story using the traditional framework of faith, or they can choose to adapt and expand the baseline story, using personal experiences encountered during illness.

1.5 Augmenting and expanding the story: Root and Hauerwas

This section describes how narratives may be augmented to include discordant events, and how particular scriptural stories become symbolic saving stories in which the reader is implicated in some way.

1.5.1 Michael Root: augmented narrative

Augmented narrative refers to the process whereby stories are enlarged and expanded to absorb new and often discordant events. Discordant events occur which threaten to overwhelm the story plot, and destroy its main character. But if the story plot can be expanded to accommodate the untoward event and manage the outcome, then the plot may be stabilised. Applied to chronic illness, the discordant event is a threat to life as lived in good health which is embodied in a specific life story which is now threatened. But there may be a new story which contains part of the previous story about good health, but also describes how things worked out during illness.

Michael Root's essay, 'The narrative structure of soteriology', comes within a collection of contributions by narrative theologians inspired by Hauerwas and Jones (1989). Root's essay is chosen since it describes a very specific process that has central importance to the argument advanced here. This describes the concept of augmented narrative. Put simply, a story unfolds in a straightforward way until suddenly a foreign or alien event occurs, disrupting the whole story. The remainder of the story then describes how this awkward event is dealt with and processed, until it is absorbed into the story. The narrative is augmented or enlarged so that the uncomfortable and inassimilable happening becomes part of the story's fabric and plot; a disruption and resolution story, mirroring what might happen in chronic illness.

Root's description of this is in theological language, but the process is similar in a secular context as well.

> Soteriology: there are two states of existence - a state of deprivation (sin, corruption), - a state of release from that deprivation, plus an event that produces a change from first to second state, an event that transforms first into second. This gives sufficient conditions for a narrative. (ibid p 263)

Root here is describing a narrative plot: first a state of deprivation such as illness, then a transforming event, then a state of release from deprivation, for example healing, as in the many healing miracles found in scripture. This simple process might suggest that Root is only interested in narratives about healing and liberation. But his theory also describes another more subtle way in which stories may bring about change and transformation.

> Theologians show how the Christian story has a particular kind of relation to the reader's life and world. The story is the story of the reader's redemption. The stories of Jesus and of the reader are related… within a single larger story. The story is of good news because redemption follows from the primary form of inclusion in the story. The task [of salvation] is to show how the reader is included in the story. (ibid p 266)

Here then the reader can identify with a character in the scripture story, and appropriate that story for themselves. Retelling the story in an augmented form that brings out a particular interpretation is the key to salvation, meaning and new life. This means that stories can be artfully retold, so that the meaning is enlarged, altered or reframed to suit a new and different context.

> Saving interpretation of the Christian story must play off, utilise and shape, patterns that do or can exist in the reader's life that are like redemption – typically deprivation/release, a story of Jesus who is repaying a debt, freeing captives etc (ibid 274).

The basic two stage process Root describes is a simple and fundamental one - a state of deprivation (sin, corruption), a state of release from that deprivation, plus an event that produces a change from first to second state. Its relevance to chronic illness is clear: deprivation and the hope of release are two central features of such illness. The illness deprives a person of freedom and enjoyment. Treatment, pain control or therapy offer relief, and hence potential to enjoy again that of which one was once deprived. In its theological application, it describes sin and corruption, that which spoils or degrades the relationship with God, and redemption, that which restores it. But the saving event or transformation might also be a treatment breakthrough such as a transplant, or an epiphany or change of heart, leading to a different attitude. But this may not be the only outcome possible: it may be that the illness may be re-described, so that it is itself the place and setting for salvation, that is, salvation is found within the illness world in a way that transforms it.

This study suggests a five-stage model of the way faith and identity may be reconstructed in chronic illness, in Section 2.3 below. Root's method is the key: the reconstruction must include a full and adequate evaluation of loss and disruption. Once this is done and the disruption has been absorbed and accepted, further disruption will not then pose the same threat – reconstructed faith now includes an account of pain and suffering, which paradoxically allows both suffering and faith to co-exist.

Stanley Hauerwas is a post-liberal theologian who following Frei (1974) employs narrative methods to examine sacred scriptures. Hauerwas uses biblical narratives to inform who we are as individuals and communities and what we intend to become. He argues that stories may be expanded and adapted, but all relate back to a founding tradition. This expanding of stories may apply to chronic illness, where a new unexpected episode may occur, quite different from what went before: this then becomes part of the story plot.

Hauerwas' essay on Watership Down (1981) is a classic of narrative interpretation, where he analyses how the different rabbit communities in Adams' children's story are formed by the stories they tell about their founding hero-rabbit (Adams 1975). More seriously in *A community of character* (1981), Hauerwas rejects liberalism's story that tradition is outdated and unnecessary. Ignoring tradition severs our vital connection with the resources of faith we inherit from the past. Hauerwas accepts like Ricoeur that the story becomes a life plan, but one that is still in the making.

> The self as story organizes resources for a coherent life plan. We are not formed primarily by the rules we hold, but by the stories and metaphors through which we learn to intend the variety of our existence (1981 p 71)
>
> Our metaphors and stories entice us to find a way to bring into existence the reality that at once should be but will not be unless we act as if it is (ibid p 73).

This last sentence about bringing into being a reality that should be, but is not yet, eloquently captures the paradox felt by those who passionately believe they will be healed, even though it has not happened yet.

Hauerwas' treatment of the biblical passion story is central to his understanding of faith. He sees the cross not as a detour but as the only route to God's kingdom, the place where the kingdom is found. Illness, passion and suffering are not obstacles which get in the way of faithful living, but are integral to the journey. This combined with Root's idea of augmented narrative offers a new definition of what an illness story is.The illness story describes, expresses and includes the full weight and burden of suffering which the illness has brought about, and contains it within the faith system. Living faithfully within suffering becomes an integral part of the life of faith.

1.6 Stories about suffering, alienation and exile: Soelle, Moltmann and Pannenberg

All illness includes suffering, which is different from pain. Pain can be treated and alleviated, but suffering has to be endured and undergone. Puchalski (2006) quotes Cassel (1982), who understands suffering as a threat to our personhood. Cassel insists that the alleviation of suffering (as well as pain) is part of the warrant of medicine. But Hyden (1997, 46) asserts that 'patient narratives give voice to suffering in a way that lies outside the domain of the biomedical voice'. Suffering 'becomes our passion in the deep double sense of the word' (Soelle 1975 p.125). Chronic illness includes repetitive and routine suffering which can be predicted – it will happen again. Processing and absorbing suffering becomes a key task for the chronically ill, which they must learn if they are to survive. A core function of the illness story is to express and describe suffering, which otherwise would remain mute and voiceless. Recounting suffering gives the sufferer a voice, and also enables them to describe how the suffering was endured, absorbed or overcome.

Suffering is universal, but spiritual pain is a specific condition found in faith subjects, who suffer specifically within the realm of their faith. For example, they feel that God has abandoned them or he is far away, or they feel that life is unjust, or that God is indifferent to their plight. Dorothee Soelle in *Suffering* (1975) describes the attitude of modern society to suffering as apathy:

> Insofar as the experiences of suffering the *pathai* …of life are repressed, there is a corresponding disappearance of passion for life and of the strength and intensity of its joys. (1975 p 36)
>
> An inability to perceive suffering develops not only one's own, through indifference, but especially the suffering of others. (ibid p 38)
>
> People stand before suffering like those who are colour-blind, incapable of perception…The consequence of this suffering-free state of well-being is that people's lives become frozen solid. Nothing threatens any longer; nothing grows any longer…nothing changes. (ibid p 39)

Soelle develops the notion of passion and suggests that passion can be the gateway for action. In her table 'Suffering and language' reproduced in Table 1.6 below, she sets out the three phases of suffering. This table informs and corresponds closely with the three middle stages of the five part model in Sections 2.4-2.8 below.

Table 1.6 Suffering and language (Soelle 1975 p 73)

Phase 1	**Phase 2**	**Phase 3**
Mute	Lamenting	Changing
Numb explosive		
Speechless	Aware, able to speak	
Moaning	Psalmic language	
Animal like wailing	Rationality & emotion communicated together	
Isolation	Expression, communication	
The pressure of suffering	The pressure of suffering	The pressure of suffering
Turns one in on himself	Sensitises	Produces solidarity
Autonomy of thinking	Autonomy of experience	Autonomy of action
Speaking and acting lost	(can be integrated)	Produces change
Objectives cannot be organised	Objectives utopian (in prayer)	Objectives can be organised
Reactive behaviour	Active behaviour	
Dominated by the situation	Suffering from the situation	Helping to shape the situation
Submissiveness	Suffering	
Powerlessness	Acceptance and conquest in existing structures	Acceptance and conquest of powerlessness in changed structures

Whilst Phase 1 is characterised by numbness and powerlessness, Phase 2 uses expression and communication within existing frameworks and structures. In Phase 3 expression leads on to organising, action for change and conquest of powerlessness. Soelle's table sets out clearly a process which is later used in the study's narrative chronic illness model (Section 2.3) in Stage 3: Expression and evaluation. The choice she offers of speech, expression or remaining silent is illustrated later in the study. Clarke A (2004) discussing situational analysis includes mapping silences as a tool – she suggests that subjects retreat into silence for protection. In Section 1.7 below, testimony as a form of expression depends on power and authorisation - who can speak? What can be told in private may not be admitted publicly. Secondly, expression can be modified: examples will follow where faith stories concerning suffering are adapted for specific audiences. The progression from muteness to expression to action mirrors the study's five-part model, where expression precedes recovery and resolution.

Soelle describes suffering as work and concludes that

> The capacity for love is strongest when it grows out of suffering…It has become more independent of the fulfilments that come from the outside: it is more unconditional. The sufferers have no more to lose at the hands of fate: they are through with the God who is understood as an alien being who controls everything. They have everything to gain, not as a gift given from outside but as a change within themselves, the strength of the weak. (1975 p 126)

Soelle sees mute, voiceless suffering and apathy as negative, and sees instead a different choice, speaking out, which leads to inner change and new strength. Her work is important here, since the study encountered a setting in which suffering was not voiced, and remained hidden. Understanding how this came about then became a key task for the study. Although all the subjects seemed to be reticent to speak about their suffering, faith subjects experienced a different kind of barrier, presented by faith, which inhibited their speech. Certain faith groups teach that suffering and illness can and must be healed, and therefore those who suffer feel ashamed and inadequate, and so cannot speak out. This particular faith understanding can be actively challenged by showing that suffering is part of God's creation, and part of normal living.

Jurgen Moltmann is another theologian who has developed a particular understanding of suffering. He leads the 'Pain of God' theologians who since World War 2 challenged the traditional view that God does not suffer. Echoing Soelle, he describes Western society as an officially optimistic society.

> This God is power, and only successful faith makes an impression…From this perspective, those who suffer are sick: those who weep and mourn show no stamina. The world has nothing more to say to us. It does not touch us… We become hard in the give and take of life. (1975 p 71)

Moltmann (1965 & 1974) follows Abraham Heschel (1936) who named the theology of the prophets as a theology of pathos. God takes man seriously, Moltmann argues, to the point that he suffers from the actions of man and can be injured through them.

> Man corresponds to the pathos of God…He is angry with God’s wrath. He loves with God’s love. He suffers with God’s suffering. He hopes with God’s hope. In covenant with the God of pathos, man steps outside of himself, takes part in the life of others, and can rejoice and suffer with them. (1975 p 76)

Here Moltmann offers a different, more collective version of the story of suffering than Soelle. In her version, the story expressing suffering liberates the sufferer to act for change on their own behalf. But Moltmann sees the story as a story shared between God and his people, which offers solidarity, community and hope.

Pannenberg (1985) by contrast offers an understanding of man’s suffering as leading to isolation and alienation, which is itself a major theme in sociology as well as theology. The majority of people in society are healthy, and so the chronically ill become a marginal group. The healthy majority may feel sympathy and compassion for particular illness groups, such as people with cancer, MS and ME, but this may depend on how strong the voices of these specific groups are. From a social perspective, suffering as opposed to specific illnesses and conditions is not an issue for public debate, but stays in the private realm. The sociologist Hervieu Leger (2000) found that

> The question of meaning that comes to the fore in extreme situations – where there is suffering, where there is death – is more than likely to receive a subjective individual response. (2000 p 93)
>
> In order for meaning to have an effect, there must be at a given point the collective effect of meaning shared; meaning that is individually constructed must be attested by others, it must be given social confirmation. (ibid p 94)
>
> Sickness calamity failure and death, once such scourges, are no longer resigned to as an inevitable part of human life, and are seen as appalling injustices and reversals to self-realisation. (ibid p 96)

The chronically sick long for their suffering to be recognised and affirmed: but society does not wish to hear about this subject, since it is reluctant to address the reality of suffering and its everyday impact on people’s lives.

Pannenberg (1985) distinguishes between alienation and estrangement. Sickness and sin are equated in the Old Testament, and occasionally in the new. Although such notions now seem irrelevant to a scientific worldview, they still have currency in some religious traditions. Sickness is perceived as wrong, and the opposite (deprivation) of the state of shalom or peace with justice, which God intends for his people - it creates a barrier. Sickness whilst not being sin can then be said to alienate people from the life of God, if they see this life as being connected solely with health and wellbeing.

Pannenberg argues that sinners are estranged from God. But there is also alienation as when the self is found in an alien or hostile environment, in which it is not allowed to develop. Sickness includes being estranged from one's normal healthy self, or from one's sick and non-functioning body. Sickness may be an experience which could encapsulate the definition of estrangement that Pannenberg offers:

> The profundity of the term estrangement lies in the implication that one belongs essentially to that from which one is estranged. (1985 p 282)

The story plot of illness may then be like a story of journeying into a strange country, being exiled, and longing to return home. This story plot expresses well the dislocation, loss of identity and belonging that the study will explore further below. In stories of exile, the exiles have two choices: settling down making the best of things and adapting to their new environment, or else retaining distinctive identity, and focusing all their efforts on escaping and returning home. This choice is influenced by whether the exile itself is seen as tolerable and sustainable, or as insufferable and profoundly wrong.

Soelle, Moltmann and Pannenberg offer crucial insights on how to read illness stories in the light of faith. Soelle shows that suffering happens, and is contained within the love of God. Moltmann urges that God too suffers, and so becomes involved in man's own suffering. And Pannenberg uses biblical images of exile and alienation to describe the estrangement experienced by those who suffer. This theme appears in faith stories about illness, where at first the illness world is seen as dark and alien compared to the bright and fulfilling world of good health: but in the end God is found to be present in both worlds.

Those with chronic illness live in two different worlds, the worlds of health and illness, and are able to move freely between them. If they did not do this, their estrangement from normal life would be complete. But as will be seen, some subjects who are housebound and live very restricted lives retain a vitality and interest in the world outside, and keep in touch with it in many different ways.

1.7 Stories that cannot be told: Felman and Laub: crises of witnessing

Section 1.3 asserted that recounting an illness story is a powerful act, because it places the narrator and subject in a position of control. But the introduction observed that the dialysis unit seemed to be a place without stories; patients were reluctant to talk much about their experiences.

Witness and testimony are specific kinds of narrative genre. *Testimonio* in the Latin American context usually refers to political testimonies in situations of oppression (Jara & Vidal 1986). Testimony is also a specific term used to describe religious testimonies, where faith members stand and testify within the faith group, usually about a dramatic faith event. Holocaust testimonies are another unique genre, where testimony is buried for a long time, because there is no one available or willing to hear them. Their relevance here is that they underline the conditions needed for testimony: a supportive group of hearers, who will receive and validate the narrator’s experience, and are capable of absorbing the impact of those experiences.

Felman and Laub’s work (1992) with holocaust survivors showed that finally telling their story gave survivors freedom and release, but had a profound impact on hearers. The burden was transferred. Carrying and then releasing a burden of this kind can be done in two ways. Firstly, the burden can be passed to a qualified professional trained to accept it. Or in the religious sphere, the burdens of both pain and guilt can be transferred through the sacramental process of confession and forgiveness. The chronically ill experience a burden of deprivation and loss: recounting this in narrative form both expresses and defines the loss, making it part of the accepted structure of the story plot.

Testimony itself requires the presence of a hearer that is capable of accepting the burden of the testimony offered. Shoshana Felman (ibid) describes how a class of students involved in recording holocaust survivor testimonies became unable to function, because of what they had heard. She also describes the lightness and release of a person after testifying.

> He experiences his decision to speak up as profoundly freeing; his own sudden realization of the magnitude of his burden of silence and its dead weight on himself and on his loved ones comes to him surprisingly at once as an exhilarating unexpected liberation from his nightmares. (ibid p 46)

This extreme example illustrates a more basic point. The power to speak is dependent on the power, strength and readiness of another to listen. The act of speaking (witnessing) has the effect of recovering one's own story, and so being true to oneself.

> There was no longer any other to which one could say thou in the hope of being heard. (ibid p 82)
> Loss of capacity to be a witness to oneself is the means of annihilation. (ibid p 82)
> Repossessing one's life story through testimony is itself a form of action and of change. (ibid p 83)

Fellow sufferers may not themselves possess the power to be witnesses or listeners, since they too are implicated in the same shared and maybe death-denying consciousness. Nor is there any deep sense in the chronically ill of collective action flowing from collective identity – all may suffer alone. Felman and Laub's work therefore has profound implications for understanding the story of chronic illness. Holocaust testimonies were themselves the result of cultural change. In the post war years, survivors wanted to forget: society was not particularly interested in what they might say. But fifty years later, cultural consciousness about holocaust commemoration grew and grew. This put pressure on survivors to disclose what they had suffered.

In the next section Arlie Hochschild's work on managing emotion is discussed. Its relevance here is that, where there is no powerful censorship system in place preventing patients from disclosing their experiences, especially those of hurt, pain and suffering, if it happens it must be the result of self-censorship. They have no right to complain, they are lucky to be alive, their suffering is rather routine, mundane and predictable, no one would really want to hear about it. The study narratives will therefore be examined carefully to see whether resistance and counter narrative appears as a theme, below the surface.

What then are the stories that are not being told on the dialysis unit? Are these all horror stories, suggesting that life on dialysis is not worth living? The stories in the study will show that this is not so: but the truth is more complicated than the official version. Life on dialysis involves pain and disruption, success and failure, a long struggle. The stories themselves illustrate and witness to the courage, tenacity and resilience of their authors. They are honest and moving, not glossing over the pain and difficulty. The fact that they are often not recounted or transmitted means that many dialysis patients live in a lonely world, without solidarity, where collective knowledge of suffering is never shared.

1.8 Managing stories: controlling self disclosure: Hochschild

The subject of Arlie Hochschild's book ‘*The managed heart* ‘(1983) is the management of emotions by airline staff. Goffman (1969 & 1981) describes how social actors stage performances of desirable selves to preserve ‘face’ in situations of difficulty. Hochschild extends the theme of managing how the self is presented to the management of difficult emotions by airline staff. This may seem distant from the present subject, but its content had a seminal effect upon the direction of the study, as a result of an imaginative link between emotional labour, Hochschild's primary focus, and the notion of managing emotion, managing illness stories and managing faith stories, and how they could be told.

Hochschild’s basic premise is straightforward. She observed that Delta airlines staff felt anger at passengers who behaved badly; but in order to survive in their jobs they had to mentally detach themselves from their feelings, and were trained to do so (1983 p 17). What can happen to us, Hochschild then asks, when we become estranged from our feelings? We use the mechanism of gift exchange.

> We pay tribute to each other in the currency of the managing act. We pay, overpay, underpay, play with paying, acknowledge our dues…Gift exchange: muted anger, conjured gratitude and suppressed envy are offerings back and forth from parent to child, wife to husband, friend to friend and lover to lover…I shouldn’t feel so angry we say. (ibid p 18)
>
> Trying to feel what one wants expects or thinks one ought to feel is probably no newer than emotion itself. A worker may withdraw emotional labour and offer instead a thin crust of display (ibid p 20)
>
> The show of feeling has a robot quality. (ibid p 23)

So what about faith? Might the same kind of things be happening to faith subjects? Faith after all has a strong emotional element, together with a heavy component of obligation and authority – I ought to feel thankful, joyful, prayerful, forgiving and so on. Why might this be important in chronic illness? Because we suffer, we feel hurt and wounded, and so may experience anger and resentment. This makes faith more difficult to sustain – it may then have that 'robot quality' Hochschild describes, because the subject no longer feels loyal, grateful and prayerful because of the hurt experienced, and is only acting and pretending. Pretence is of course debilitating: faith is now effectively disabled, and can no longer provide any real inner strength or resilience. True faith demands freedom of expression, emotional accounting and honesty about concealed and troublesome feelings, which may threaten its existence and effectiveness. Hochschild discusses feeling rules:

> We can offend against a feeling rule when we grieve too much or too little. (ibid p 64)
>
> When my husband died I thought I should feel a great sense of loss and grief. Instead I found a sense of freedom at being able to do as I pleased. (ibid p 66)

The feeling rules that may be broken are feelings about life. We ought to feel thankful, blessed and confident, religion tells us, and in hard times we must be resilient and persevering. But emotions are also reliable indicators and signals of the way things really are, and therefore if ignored can have psychological consequences. Faith then, just like the corporate airline employer, is an authority system, which describes how we ought to think, feel, believe and act. It too uses sanctions, but these consist of approval or disapproval of thoughts feelings and actions, rather than threats to employment.

It is in the realm of expectations that faith and emotion work come together. Emotional life is attuned to expectations of love, gratitude and fulfilment in satisfying relationships. Faith too has this expectation, that the life of faith will result in fulfilment, that godly living has its reward. In relation to God there should be reciprocity, with our love for God being answered by signs of God's love for us. When this does not happen there is disappointment and hurt, which may be life-long. A key task of chronic illness for the faithful is then to give voice to the sense of anger, hurt and injustice and find healing. It is then possible to live again without rancour, and explore the possibilities of another life in a new way.

Hochschild's idea of emotional labour or emotion work gave rise to the concept of faith work which is set out later in this study (Section 6.8). There are two aspects to faith work. The first is close to Hochschild's 'emotional labour', and its task is to work through emotions of hurt, anger and betrayal which exist in the subject's relationship to God, as a result of illness.

Without such emotional labour, no further progress is possible. The second kind of faith work is different, and involves the work of searching, renewing and adapting traditional faith to the world of chronic illness, so that it may be once more vital and effective. Faith work as evidenced in the study narratives is described in Section 6.8 below.

Hochschild’s work also underlines how subjects actively manage both their feelings and also the stories they present. The study found that disclosure of emotions and stories about faith struggles were difficult for faith subjects to recount - perhaps they felt they should not have been feeling the way they did. This reflected the role of the faith system and social group in preferring one kind of story to another.

Hochschild’s ideas highlight and illustrate a key theme of this chapter, which is recounting, disclosing and witnessing to suffering. It is reinforced by Dorothee Soelle (1975), who suggests that describing, naming and witnessing to suffering in some way reduces its hold over us, and leads to change.

> The way [liberation] leads out of isolated suffering through communication (by lament) to the solidarity in which change occurs. (ibid p 74)
>
> If people are to move from passive endurance to suffering that can humanise them in a productive way then one of the things they need is language. (ibid p 75)

What then is the suffering that is peculiar to chronic illness, that is vague and difficult to define, yet impacts on the present everyday reality of the sick person? It is the suffering that has not happened yet, but we know will occur. It is the anticipated loss of much of what we like and enjoy doing, and the many commitments we value. Facing this particular kind of suffering needs courage, but also a measure of defiance. It has not happened yet, so until it does, we will continue to make the best of every opportunity and every moment.

1.9 Story telling as finding a voice: complaint, hurt and lament: Walter Brueggemann

Stories can include both testimony and confession. Gabriel (2004) discusses confessional discourse and says it enables a victim to become a survivor. He quotes Foucault (1977) who describes confessional discourse as a ritual which redeems, exonerates and purifies. But Gabriel argues this has changed in late modernity to a powerful assertiveness. The victim is now enabled to become a survivor through the magic of finding a voice and having their voice heard (2004.179).

Walter Brueggemann, a post-liberal narrative theologian, goes back to the Old Testament and sets suffering within the framework of the covenant between God and the believer, which is itself called into question by disruptive life events. Brueggemann takes up Ricoeur's analysis in his discussion of the Psalms (1995). He uses the five stages of grief described by Kubler Ross (1969) to underline how protest and lament take specific forms.

Brueggemann describes how Ricoeur has had a dialogue with Freud and psychoanalysis, which results in a displacement of the traditional hermeneutic of faith.

> Ricoeur argues that these two hermeneutics are both essential and must be seen in a dialectic of displacement and recapture. Consequently, the first task, displacement – cannot be separated from the second task, recapture of meaning in interpretation. This alternation of relinquishing (*deprise*) and recapture (*reprise*) is the philosophical basis of the entire metapsychology. (ibid p 18)

Brueggemann identifies lament as the natural response to displacement. Speeches of surprise, dismay and disappointment arise because the speaker never expected this to happen to him or her (ibid p 19). He cites Psalm 88 as a psalm of desolation, where every hope is abandoned. But then he says the suffering person or people discover that they belong to a community bound to and cared for by God. They discover that the world has a new coherence, that the 'devastating hopelessness of lament is not finally appropriate for the way life is.' (ibid p 22)

> Thus the two parts of the lament – one of which looks back in anger and chagrin, and the other forward in hope – correlate with our two hermeneutical postures. (ibid p 24)

The important feature here is the move from anger to hope is achieved via expression.

> Persons and communities are not fully present in situation of disorientation until it has been brought to speech. One may in fact be there but absent to the situation by denial and self deception… It is likely that one will continue to assume the old now discredited dysfunctional equilibrium that is in fact powerless. (ibid p 28)

The Bible story that best illustrates disorientation and reorientation is the Job story (ibid p 20). Job dares to complain about his sufferings to God. His friends urge him to accept the 'old equilibrium' which says that Job must be punished. In the new orientation that follows, Job is lifted up out of his prison of suffering, and sees the world in a new way through God's eyes. But the story also shows how risky and dangerous Job's complaint is, and how it evokes general condemnation in the social setting.

In the previous section, Hochschild explored the social mechanisms which work to limit and control disclosure of emotion. But Brueggemann's work as a post-liberal theologian has a different focus. In '*The psalms and the life of faith*' (1995) Brueggemann describes how the psalmists voice their grief, hurt and anger at the way their lives are going, the injuries their enemies are inflicting, and the pain, sickness and trouble they have to endure. Brueggemann describes this outpouring as faithful covenant address. That is, it is authorised and acceptable to voice complaint and hurt to a covenant partner, on the grounds that God has an interest in and duty of protecting his own people. Brueggemann develops this further, pointing out that whilst particular psalms are clearly desperate cries for help (Psalms 13, 22 and 130), it is not always clear what concrete answer was given. Nevertheless, the psalmist invariably closes by expressing confidence that his cry has been heard, and that God will be faithful and fulfil his side of the covenant.

The lament psalms have resonance for those facing chronic illness, who may feel abandoned and betrayed by a God who appears to be absent, and has not answered their prayers for help. But Brueggemann's focus is not only on the question of answers, but more especially on the right to give voice and be heard. He argues against a religion of control, which suppresses legitimate grief and anger. Instead the voice of suffering represents a real and potent force, which tells the truth about the way life is and demands to be heard.

> Where the cry is seriously voiced, heaven may answer and earth may have a new chance. The new resolve in heaven and the new possibility on earth depend on the initiation of protest.
> (ibid p 111)

The psalms are an early example of the marginal voices of those who suffer that insist on their right to be heard. In '*The prophetic imagination'* (Brueggemann 1978), these voices are opposed to the politics of numbness and apathy, and insist that pathos or passion must be expressed. Here Brueggemann follows Soelle in urging that the 'real restless grief' of those who suffer must find a voice. The God they address is in turn a God of mercy and compassion, who pays regard to the poor, needy and dispossessed.

In more recent times marginal voices have established their own powerful right to be heard, as the politics and sociology of gender, disability and race has developed and come of age in a secular context. But Brueggemann's powerful contribution is to insist that believers too have a voice, which can be raised in protest and urgent entreaty. He does not see passive acceptance as a particularly religious attitude, and argues that God too suffers and is deeply implicated in human suffering. Stage 3 of the study model, expression and evaluation, first allows for the release of feelings such as angry protest, and then a more dispassionate evaluation of how change could happen, leading to a process of negotiation.

Relating this process to chronic illness, the parallels are clear. Chronic illness appears unfair and unjust to the believer, and undermines the settled world of faith and practice, obedience and reward. The narrative life world of chronic illness (Section 1.1) is an unsettling, uncomfortable place. The believer may cry out to God in complaint, but does not know if their complaint will be heard – and it may not be authorised or approved by the faith group. So the complaint is not voiced, or not openly expressed. But the dynamic of self-censorship that then comes into play is the same as that observed by Hochschild in Section 1.8 above. Here there is deep anger and deep hurt. Where these feelings are managed and suppressed, the believer may become dysfunctional. Faith may be effectively disabled by anger and hurt, and become of little use. It is only after speech, expression and reorientation, Brueggemann argues, that the new orientation becomes visible and accessible; grace and hope are restored.

1.10 Summary: Core concepts

Table 1.10: Summary of chronic illness models

Narrative model - title	**Description**	**Literature Chapter 1: Sections**	**Core concepts and issues**
Five part narrative model	Good health, illness, expression & evaluation, life recovery, resolution	1.2 Bury, Williams & Williams 1.3 Frank	Achieving life recovery, finding resolution in chronic illness (7.9)
Disruption response model	Repetitive cycles of disruption & response	1.4 Ricoeur	Taking responsibility, retaining agency, disruptive impact on life plans, identity (5.2-5.9)
Augmented narrative	Narrator expands life story to include suffering and loss	1.5 Root & Hauerwas	Open and closed narratives. Faith world prefers settled order; living with disruption &

		1.6 Soelle Moltmann & Pannenberg	dislocation not envisaged (5.3 5.8)
Living in different narrative life worlds	Life worlds of health and illness are separate & distinct. Expression, understanding & disclosure difficult to achieve across social boundaries	1.7 Felman & Laub 1.8 Hochschild 1.9 Brueggemann	Expression & disclosure transfers burden. Faith subjects manage and restrict disclosure, all patients modify narratives to avoid disclosing suffering (6.9)

The first part of this chapter has explored the stories that are told about illness in the literature. Formalist narrative theory sets out a clear pattern for a story plot – orientation, complication, evaluation and resolution. A complete illness story usually ends with cure and recovery. But chronic illness does not seem to meet the basic requirement of this plot structure, since it is unfinished and unresolved. The study investigates further how subjects would resolve this indeterminate story plot. The disruption cycle model (Ricoeur 1.4) would become important at interview analysis stage (Section 5.2) when the illness stories showed just this kind of repetitive sequence. Root's augmented narrative model (Sections 1.5, 1.6) would become crucial for faith subjects when facing reality of suffering and the emotional labour this entailed (Section 6.7 and 7.11). Narrative life worlds (Sections 1.8 and 1.9) have important symbolic meaning: the remembered 'good life' of good health is part fact, part myth. The life world of illness is threatening and disordered at first, but later becomes more predictable. Linde (1993) sees creating coherence and predictability as a key task during illness. Finding an expressive voice to describe and order the confusing experience of chronic illness is a challenge requiring clarity and skill.

Chapter 2 will explore how an illness story of this kind may still be emplotted and given a tellable structure, even without a finite ending. Stories recount change, threat, danger, the unexpected, the impossible, and the difficult situations that get worse or are overcome. Suffering that is stable, predictable and ongoing with no let-up does not make a good story. But suffering too can change: what at first seems chaotic and unbearable may later be ordered and sustainable. The sufferer may receive a gift or secret – that is, a new and surprising way is found, whereby suffering can be borne, new life discovered and new possibilities explored. This then may have the makings of a story, one that can after all be told.

Sections 1.6, 1.7 and 1.9 explored the life world of suffering in a faith context: seeing it as a barrier separating the sufferer from God, a buried cry that the sufferer does not dare to express, and an angry complaint which the sufferer uses to begin to negotiate a more equitable outcome. In Section 1.8 Managing stories, Hochschild’s well known work about disclosure was extended to narratives about faith: faith subjects too manage disclosure, and only recount those parts of the story that fit with orthodox faith. In the next chapter the empirical concepts outlined above will be drawn together to build a narrative model (Section 2.3) of the chronic illness process, which will be used to address the interview data.

Chapter 2

Constructing the story of chronic illness

2.0 Introduction: What kind of story is chronic illness?

This chapter sets out the theoretical framework within sociology and pastoral theology which is then used throughout the study. Section 2.1 begins with Parsons' sick role and discusses its applicability to chronic illness. Section 2.2 describes the sociology and theology of emotion and how feelings are communicated inside a specific social world. Section 2.3 describes the primary study model which was developed, used and modified throughout the study. It is based first on the literature outlined in Chapter 1, and draws from existing narrative models found in that literature (Section 1.1). The primary model selects from the four stages already identified by other authors and adds a fifth, the expression/evaluation stage, to give a logical sequence. It also draws from longitudinal data and experience gained in the first three stages of the Living Well Programme, on which the author and team had been working during the study. This basic narrative model is intended to reflect how able narrators recount illness as they experience it, and how they structure their illness accounts so as to give them a framework of meaning. This model will then be tested on the study interviews using narrative analysis and enquiry.

Within medical sociology, chronic illness stands between acute illness and terminal illness in terms of severity and impact. Acute illness includes the possibility of recovery, but from terminal illness there is no cure or release. Yet improvements in medical science have led to prolonging the lives of those who are terminally ill in dramatic ways. Chronic illness too is inescapable, yet it does not have the same immediate emotional impact. It is likely to shorten life, and so contains a deferred threat. The social response to chronic illness diagnosis is muted and ambivalent: in social discourse some sympathy may be voiced. 'What a shame,' people might say, 'yet maybe Bill will still have a few years of active life left to enjoy.' The normal response to news of loss or misfortune is modified, because the loss has not occurred yet – it is a loss of potential.

Illness stories and especially published illness stories are a genre, a particular kind of story, which builds specific expectations. 'He got ill, he had the usual treatment, he got better again', does not really make a story. Things that are normal and go to plan are unremarkable:

it is not worth writing about them, or even spending time recounting them in detail. An illness story, therefore, is expected to contain an element of drama and suspense: things did not go according to plan, there were all kinds of setbacks, but in the end the hero survived. Within the four classic types of drama first described by Aristotle (1997) and later Frye (1957) tragedy, comedy, satire and romance, various types of endings and outcomes are possible. If it is a tragedy, there will be no happy ending: yet the drama consists in the many twists and turns by which the hero dodges and delays the tragic fate that awaits him. The tragic hero always has options and strategies for escape, often choosing the wrong ones: otherwise the story might have little interest.

The ancient writers knew that the struggles of men and women to do battle with and try to overcome cruel fate had endless dramatic possibilities, and a ready audience, since such struggles were mirrored in the real lives the audience led. Today medicine has improved dramatically: but this means that we live in a remission society (Frank 1995), full of people who might have died, but did not do so. Instead they live on, but often their lives are limited by the conditions they have. Do we really want to hear their stories, about coping with pain and limitation, about lives that are so much harder than our own? Would we not rather hear the story of an illness survivor who through courage and endurance got through the bad times, and was able to live a fulfilled and active life, thereby giving hope to other sufferers? Narrative, which stories can be told, is constrained by the rules of social discourse and what people may wish to hear. Stella, as Arthur Kleinman reports (in Good et al 1992), keeps recounting her chronic pain symptoms: she longs for her pain to be legitimised, even though it cannot be treated. But none of the doctors wish to hear her story, because they can find no way of treating her pain.

Central to this study is the practice of attention, of accurate observation of and listening to a particular patient group who, as was stated in Chapter 1, are not very vocal, do not draw attention to themselves, and do not always hold their own. This chapter sets out a method for observing and modelling chronic illness and its effects. Chapter 3 will describe the methodology for analysing their illness stories, and defining the special features of these. The study shows that these individuals are able to make themselves heard in the right circumstances, with an attentive listener or researcher. But what is it that makes their stories interesting, dramatic and recountable, or on the other hand uninteresting and easily ignored within the social setting?

Charmaz has done work on the moral worth of chronic illness sufferers, and has noted that the more incurable they are, the less worth they have: they are damaged, dysfunctional people with no potential and so have little value (Charmaz 2005). A century ago the terminally ill may have been viewed in exactly the same way; but since then there has been a revolution in Western society, and the dying have high status, and can make large claims on time and resources. Dying, more than chronic illness, has been legitimised as a suitable cause for concern, research and funding. This study does not address this wider disparity, but can briefly point to specific factors within the setting studied, which might result in the subjects there not being heard.

There is a treatment hierarchy within kidney care: all kidney patients are not the same. This is not based on clinicians or staff preferences – all patients are given the same attention and quality of care – but on a kind of hierarchy inherent in the treatment possibilities within the illness. The best long-term treatment for kidney disease is transplant, and within kidney units the transplant team have the highest status. Transplant operations are like heart operations and cancer operations: they are difficult, sometimes dramatic, and have life transforming potential. They elicit interest and concern from social circle, family and friends, particularly when there is a live donor involved. And the stories told about transplants, whether successful or unsuccessful, are often dramatic too, and full of suspense. Nobody knows if it is going to work, until it happens.

Below this in the treatment hierarchy comes short term dialysis, which provides a stop-gap, until a transplant kidney becomes available. The dialysis process is the same for all patients; but those who expect to get a transplant do not have to engage with the long-term issues and loss of life potential in the same way, because they hope to escape soon. And finally come the long-term dialysis patients who, for whatever reason, are not suitable for transplantation. They may have other conditions, be too frail or simply rule themselves out, because they are unreliable and will not follow a treatment regime consistently. This group are therefore similar to those with other long-term conditions that result in progressive decline.

Kidney dialysis has been available for fifty years or more, and has not changed much in that time. Technical improvements are constantly being made in machines, which become smaller and easier to operate, allowing the patients to operate them at home on their own, if they wish, with suitable training. The stories that are current in kidney magazines often concern these improvements, since they enable patients to travel, do sport and generally achieve far more than they could before. The folk heroes are therefore the able and active, and the high flyers. The underachievers and those who hate being on dialysis are often unreported. A key concern of this study therefore became the impact of the social setting of the dialysis unit, and also the faith group, on how stories are told. The story's tellability will depend partly on its content, and partly on the dominant narratives that are current within the setting or institution.

2.1 Illness as social state: the sick role - defining responsibility

Sickness affects social roles: the sick person may stop working for the time being, until they recover. Chronic illness affects one's responsibilities to society in the longer term, as one's ability to fulfil the roles and responsibilities one had before diminishes. Parsons (1951) first described the sick role, and defined it in terms of deviance – illness was unmotivated deviance for which the individual could not be held responsible. The sick person was absolved of many of the roles and responsibilities he had had in normal life. Crucially chronic illness was excluded from this sweeping definition, since the chronically ill normally wish to continue with normal living as much as they can.

Chronic illness is generally regarded as providing a particular clear case of the non-applicability of Parsons sick role for by definition, these conditions are not temporary, and the sick person cannot be expected to get well. " Maximum functioning is achieved if patients are encouraged to continue their normal social role as far as possible" (Kassebaum & Bauman 1965). Freidson (1970) modified Parsons theory using Lemert's social reaction theory (1974) – the labelling approach, where illness defines the individual's new status. At first individuals may resist being labelled; but later they may accept the label, as it allows them to accept less responsibility. Secondary deviance occurs when the individual re-organises his or her self-perception to match the new role and socially defined expectations.

> "The mechanism which transforms primary into secondary deviance… is a change of identity and acceptance of a deviant social status as a result of other people's responses to the individual rule breaker." (Morgan. Calnan & Manning 1985.52).

Freidson also wrote that chronic illness bestowed unconditional legitimacy which involves permanent exemption from normal role obligations (which this study challenges), and some additional privileges occurs when illness and impairment are believed to be incurable. Goffman's classic work on stigma and identity (1963) discusses the management of stigma, discreditable attributes and discrediting attributes by disabled people, and also the decision about what to disclose.

Managing information about the failing: to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie: and in each case to whom when and where (Goffman 1963 in Morgan Calnan & Manning 1985,65)

Goffman identifies three strategies – passing, covering and withdrawal. Passing involves attempt to conceal a discredited attribute, covering involves trying to reduce the significance of the stigmatising condition, and withdrawal involves opting out of a social situation if a benefactor is lacking, or if passing or normalisation proves too difficult.

The stigma connected to different kinds of chronic illness is related to their visible effects. Kidney patients may not look any different at first, but there may be noticeable physical changes later on. These may prompt the individual first to decline, then later to accept a deviant social status, once they can no longer pass as normal. Goffman's characterisation of stigma as 'spoiled identity' is telling – what has been spoiled may not be appearance, but life potential: this person can no longer do all the normal things they could do before. Key themes within the study narratives will be firstly disclosure, revealing the loss of normal functioning with the stigma this entails, and secondly role recovery, the ability to recover, redirect and reorganise one's life, showing that one is still an able, competent and normal person.

Critics of Goffman point out that stigma bearers are not powerless victims, but exercise some control over these processes. They manage things and use defensive manouevres (ibid 69)

> Goffman's people are both other and self stigmatised and forever doomed. The basis for this dilemma or self contradiction lies in the fact that those stigmatised are apparently wedded to the same identity norms as normals, the very norms that disqualify them (Gussow and Tracey 1968)

Freidson (1970) suggests that change of identity and acceptance of a deviant social status is the result of other people's responses to the individual rule breaker. But the study suggests that dialysis patients themselves wish to be seen as normal and capable, and can often pass as just that. But over time the patient may choose to accept the deviant status (or sick role) in response to serious irreversible life disruption: the patient can no longer manage to fulfil normal roles. Here then the sick role is individually, not socially determined. Dialysis then is an ambiguous state in which the patient may choose or not choose to fulfil normal social roles. Freidson seems wrong in linking legitimacy and curability. Both cancer and kidney disease are long term chronic conditions within which treatment options offer different degrees of normal functioning. The patient may choose to function right up to the ceiling of what is physically possible, or well below it – it is their choice. Section 2.8 below suggests that the patient's illness story will itself describe at what level the person wishes and intends to function.

Uta Gerhardt's work (in Williams & Calnan 1986) on narratives of normality echoes Goffman's critics in that it points out that patients 'account for' their experiences and activities by presenting themselves as competent social actors' (Mishler 1981). Gerhardt refers to patient careers and says

> Patients prefer careers if they can – careers represent optimal patterns of status achievement or status sequences (1986 143)
> A growing number and proportion of surviving patients reach a biographical constellation that is a survival optimal patient career... combining a functional transplant with full time employment (ibid 143)

But Gerhardt is wrong in suggesting that only those patients who reach the 'optimal' patient career status represented by say active employment may work to balance and resolve treatment against other life activities. The study will show that dialysis patients do this all the time, and it is not just those who work who seem to maintain a good quality of life. Anyone may strive to rebalance illness disruption against life activities, however restricted these may be. Discussing the illness career as a process of progressive deterioration Gerhardt quotes Goffman (1963) and Scheff (1966)

> Illness is a career perspective. [Chronic] sickness where a stigma manifests itself in a role that must be taken and draws the person into a spiral of losses (Goffman 1963)
>
> The sick role entails a career of progressive deterioration of the self (Scheff 1966)

She goes on to discuss how personal identity can be preserved when practically all social worlds of a patient are jeopardised (Morgan 1988). Again, this study takes a different view of identity using Ricouer's notion of imputability (2.3 below), that is, taking responsibility for a life that one had not chosen or wished for. A social definition of the self is restricted to the value society places on the sick person (Charmaz 1983); a spiritual definition sees the person as able to define identity and self-worth through creating ends and purposes (Ricoeur 1992) or having a specific calling and responsibility towards a creator God (Barth in Anderson 1892). Sickness, loss or deprivation does not diminish that value. The notion of imputability and taking responsibility includes an active assertion of one's own value as a spiritual being, over against the value others might place on the sick person.

Here Morgan's (1988) study of home dialysis patient's is relevant. In the seventies and eighties, many patients dialysed at home (there were no other facilities), and most went back to work. This is an example of the social imperative Parsons (1951) described in the sick role: 'The sick person's duty to recover, and the chronic patient's relentless effort [duty] to approximate recovery or avoid deterioration as long as possible'. Sick people have an obligation to be useful and contribute, live normal lives and do their best. Renal replacement therapy (RRT) was not universal, and was offered selectively to those who could fulfil these requirements. But then later facilities expanded, until the present day, when there is an unquestioning acceptance of the right to stay alive; RRT is offered to all patients, including those who have multiple conditions making them unable to work or even go out. From today's perspective, the duty of the patient to justify their treatment by recovering and doing useful work seems moralistic and ethically untenable. Yet vestiges of this idea are still found, where because dialysis is expensive and time consuming, patients feel that they must make the best of things and not complain. They are 'lucky' to be alive.

Using the concept of the patient career, Morgan describes an initial positive stage, the return to 'normality', where patient adapt to treatment and resume normal living. But later he says

> At first the patient did not notice it [dialysis] or got used to it. How many feel like this after ten years or more? How much had this (apparently acceptable) new normality been tainted by the development of unpleasant side effects…? It is possible that what was once seen as the routine of new normality has become relentless drudgery with the passage of time (1988, 221)

Morgan here observes a normal feature of progressive chronic illness – balancing treatment symptoms and life activities is an ongoing process. The balance that works at first will not work later. The patient will be helped to manage clinical side effects, but balancing life disruption is up to them. If they can learn this skill early, they can use it to rebalance activities as the burden of the illness changes.

The limitation of the ‘occupational rehabilitation’ process Morgan describes is that few patients achieve it or can sustain it. Instead the study argues that instead of a socially determined priority (usefulness), patients set their own priorities based on individual life goals. In a situation where the big battle cannot be won, choosing small attainable targets provide a sense of purpose and self-esteem. The illness story stretching over years has the function of describing a protracted struggle which itself gives life meaning and purpose – the battle with the illness. This is not the same thing as Parsons duty ‘to approximate recovery or avoid deterioration’ (op cit) which is socially determined. Instead it is a moral and ethical duty to the self, to be true to oneself and one beliefs. This determination to continue and not give up is a personal choice, but also has a social outcome. Other patients too have to make this choice, and can be influenced and learn from particular individuals who show outstanding perseverance and endurance.

Williams and Calnan (1996) also discuss responsibility – the patient feels responsible for accomplishing as much normality as he or she can muster. Quoting Gerhardt they suggest that

> If the patient is to ‘deserve the gift received, then he or she is morally obliged to prove it by accomplishing as much of a return to normality as possible (1996,19)

Here chronic illness is seen as a complex web of moral imperatives where patient careers define their legitimacy by what they can achieve. This study suggests that the social pressure to achieve, whilst certainly present, is less important than the patient’s own creative desire to build a continuous and coherent illness story describing and reinforcing their own enduring identity as both survivor and sufferer. This identity includes racial and ethnic elements:

Morgan (2015) describes how members of minority ethnic groups wait longer for kidneys, and so are overrepresented on the dialysis unit.

Baruch's work (1981) on moral tales studied parents' responses to children's diagnoses of serious medical conditions. Parenting is a moral issue: parents wish to show that they acted reasonably, consistently and competently, even though the child's condition was not diagnosed as early as it could have been. Baruch suggests there is

> The appearance of two worlds or realities, one of which is occupied by the health professions and the other by parents. The rules and standards which guide the conduct of the former are often alien and inaccessible to parents, whereas their own rules are shared in common (1981:288)

This suggests that the parents' viewpoint is easily reinforced by the membership group – normal parents, who always want the best for their children. But transferring this idea to specific patient groups in chronic illness is more problematic. Gerhardt above suggests that patients wish to be seen as competent social actors. Baruch states that parents provide situated accounts to display their competence (1981:277). His parents invoke the normal responses common to all parents of taking care and being responsible. But this 'normal' or normative way of behaving may not be accepted or articulated by the patient group. Some dialysis patients wish to take responsibility for their lives, others do not. The clinical view that dialysis patients 'should' live normally may be contested by patients who argue that this is not possible.

Parsons' sick role gave patients the right to be absolved of responsibility. Freidson (1970) wrote that chronic illness bestowed unconditional legitimacy too; he is surely wrong because chronic patients, as Gerhardt (1989) says, wish to be seen as normal and take responsibility for themselves for as long as they can. The progressive illness model put forwards in this chapter (Section 2.3) suggests there is a continuous process of taking on and giving up role responsibility over the course of the illness, based on trial and error - what can be managed, and also on which responsibilities are seen as vital and non–negotiable.

2.2 Sociology and theology of emotion : communicating feelings within lifeworlds

The sociology of the body and embodiment necessarily includes as well as physical attributes of the body its emotional life and its feelings. Crossley (in Willliams, Gabe & Calnan 2000) describes Habermas' theory of communicative action and says this enables the rational regulation of emotion in the lifeworld.

> [In] Habermas (1987) communicative rationality, it becomes possible to think of emotions as having the potential to be either rational or irrational …. Emotion is rooted in the communicative praxes which are constitutive of the lifeworld (2000:278-9)

In the lifeworld of illness, members set norms of conduct and behaviour, including the obligation to comply with treatment. All members find these onerous and difficult, but will nevertheless not condone non-compliance in others. A key role of lifeworld members is to monitor and regulate emotion – allow disclosure, set moral norms (Baruch 1981), respond to deviance and offer support, approval and disapproval.

As was seen above (Introduction Section iv) the dialysis world does not function as a communicative lifeworld. There is no collective story, there are no moral tales about how doctors and staff routinely ignored the feelings of dialysis patients who were understandably stressed and upset by their treatment. Crossley suggests that

> The danger for the individual is that their conduct ceases to be understood at that of a reasonable and responsible moral agent. This may be attractive to some individuals if it allows them to avoid culpability for their actions, but it is nevertheless a form of dehumanisation and disempowerment… The danger is that areas of conduct are torn loose from the fabric of the lifeworld.. (op cit 2000: 283)
> The life world and its members are effectively disempowered in this respect, as a limit is set to the range of behaviours which are accountable to and controllable by them (2000: 283)

The result is that noncompliance and deviance by members are referred to experts and to specialised forms of technical intervention.

Constructing a coherent narrative of illness will include the expression of a range of emotions, pain hurt and suffering and which would normally be a common currency for members of the lifeworld. Where this is absent, it suggests some form of censorship or control, which may come from authority or from members themselves, who prefer to be seen as capable and competent. This prevents them from building an authentic illness story.

> Cultural impoverishment undermines an individual’s capacity to construct a coherent narrative about their self and world. They are alienated from the types of knowledge that they need to construct a satisfying and legitimate story about their self (Crossley 2000:289).

Disclosure of emotion became a key theme in the study. The reluctance of patients to express their feelings of anger and disappointment about the deprivation they were experiencing grew partly from their wish to present themselves as capable persons, but also from a reluctance to ‘open the door’ to a whole range of negative feelings, which might then be overwhelming. The study subjects used their recorded illness narratives to describe and contain difficult emotions in expressive and assertive ways, which voiced and legitimated the suffering they had experienced.

Williams & Busby (in Williams Gabe & Calnan 2000) discuss the politics of disabled bodies and begin with rehabilitation models which were seen as rather static and reductionist. By contrast Bury (1991) suggested that research should explore meaning by charting the consequences of the illness or by examining the significance of the illness to the individual.

> Rather than looking at what people say it looks at the way in which they say it, or how their understanding of their illness or disability is constructed (Bury 1991,172)
>
> The emphasis in this kind of work is to explore the nature of lay knowledge people with chronic illness or disability develop and what they use it for (Williams 1984, 153)
>
> Three kinds of sociological analysis are described – empirical, epistemological (lay knowledge), and ontological – the sense of pain and loss described in patients own terms (Bury 2001: 175)

Theological reflection (Green 1990) is another perspective, which sets illness within a faith framework, a personal quest for meaning and truth. This quest works within a social frame, the faith group, as well as outside it, when the faith member searches the faith tradition to find the resources he needs for himself.

The lifeworld of faith contains a particular membership group which also sanctions and enables a specific emotional world that expresses the faith, hope and love that grow out of the believers’ relationship with God. The problem for members who have long term illness is when their own emotional world is so radically different from that of the main group, that it can no longer be expressed. This leads to alienation and exile (see Section 1.6 above), which may yet be overcome, if the individual finds the opportunity to witness to their experience as a genuine faith experience in spite of its radically different nature and content, so that it is accepted as authentic.

2.3 Emplotting the story: a five-part narrative model of chronic illness

Narratives describe events, responses and emotions. An illness narrative is not a clinical history: it is set within a lifeworld that sanctions particular kinds of emotion and expression. The primary model used in this study is derived from the literature but significantly adds in an extra stage – evaluation and expression. This includes making value judgments about the illness in its social context; but it also allows the narrator to record their emotions, how they felt after each disruptive event both then, as it happened, and now, as they look back on it.

This section describes how the primary study model, the five-part narrative quest, evolved from the literature. Sections 2.4 to 2.8 will describe how this model works in detail. Later on, the model would be tested against the study data in Chapters 3-5, and examples found to illustrate how the model worked out in practice. In addition, it was found that there were other kinds of narrative structure present, model ii to iv (see Section 1.1 above), but these shared similar characteristics. The main distinction between them lay in how the story plot would apportion responsibility onto the narrator, the story's main subject.

Before this study began, the Living Well Programme had already been working with dialysis patients for some time. It became clear that the main priority for many of these patients was life recovery – but what did this mean? They knew that recovery defined as cure was not possible: they would not get better, but would go on living with the illness. Their illness story centred then on their ability firstly to live life normally as far as possible; and secondly, to get back some part of what they had before, the active and rewarding life style they had once enjoyed. This creates a possible story plot. The good life is lost, and it seems cannot be recovered. But surprisingly and after many struggles, the subject gets back a part, although not all, of what he had valued before. The long struggle for recovery is balanced out and resolved, when the subject decides he has done enough. Whilst there remains some regret for the life now gone, which cannot be recovered, the struggle has eventually produced a life that is still worth living.

This story plot illustrates one way of resolving the chronic illness story, which otherwise continues as a story of 'unending work and care' (Strauss and Corbin 1988) which is never resolved. A variant of this story plot, model iii, is one where the subject perceives the struggle to get back what they have lost as difficult or impossible. Instead they experience a dramatic life change, which involves leaving behind the old story and beginning a new one. This section describes different kinds of illness plot found in the literature.

Several authors have referred to three-stage processes for chronic illness within the literature search for this study. Frank (1995) proposed chaos, quest and restitution, and Brueggemann orientation, disorientation and reorientation. These variations are set out below in table form:

Table 2.3.1: Processes within chronic illness found in the literature

	Good health	**illness**	**transition**	**resolution**
Bury		disruption		resumption
Williams		disruption		narr. reconstruction
Brueggemann	orientation	disorientation		reorientation
Charmaz		interruption	intrusionimmersion	
Frank		chaos	quest	restitution
Ricoeur		displacement	interpretation	recapture
Labov	Orientation	complication	transition	resolution
Soelle		numbness	expression	action

Frank (1995) refers to chaos as opening to faith. He devotes a chapter to testimony, but places it at the end, thereby assigning it to the role of narrative with hindsight (coda), recounting a tale of travail and suffering maybe long after the event. The model in this study draws from the sources and models accessed in the literature, but adds an extra stage – expression and evaluation. This stage includes the work of creating and recounting an illness narrative that includes expressive and reflective material. The orientation, complication, evaluation, resolution scheme is well founded in the literature of formalist narrative (Labov 1967, Propp 1968).

Table 2.3.2 Constructing the story of chronic illness from the literature.

Health	**Illness**	**Reflection**	**Transition**	**Resolution**
Literature based model				
orientation	disorientation	evaluation	adaptation	reorientation
Study progressive five-part model				
Good health	Illness & disruption	evaluation	life recovery	resolution

This model can be broken down so that it describes both biographical and spiritual disruption, following the same basic steps.

Table 2.3.3 Biographical & Spiritual disruption in chronic illness: a five-part narrative model

Biographical disruption				
Good health	illness & disruption	expression & evaluation	life recovery	resolution
Spiritual disruption				
Good health	spiritual disruption	expression & evaluation	faith recovery	resolution

Table 2.3.2 and 2.3.3 above set out the five-stage narrative model, with separate variants for biographical and spiritual disruption. In the model above the transition from disruption to resolution passes through two similar parallel but separate tracks. Good health is followed by illness disruption, expression and evaluation, life recovery and resolution. The story of good health is the starting point and baseline, the stable state then disrupted by illness (stage 2). Disruption must also be evaluated and interpreted (stage 3), before moving on to recovery stage (stage 4). The life/faith recovery stage corresponds to Frank's quest stage, indicating that recovery here is a quest, not a finished state. Both life and faith recovery are experimental stages, involving specific recovery attempts that are not all successful. The resolution stage (stage 5) is reached when by trial and error a balance is reached between recovery and loss, success and failure, which becomes stable and acceptable to the subject, and is the best that can be achieved for now. This resolution story corresponds to Frank's notion of subjects 'holding their own' (Section 2.9), and is a dynamic rather than static balance, open to successive revisions as circumstances change. The new illness story that accompanies resolution is in effect the story of the quest/recovery process that led to resolution: without this process, resolution would never have been achieved. Elements of the five-stage model are all found in the literature (evaluation in Labov, recovery/quest in Frank), but are combined here for the first time.

The question that arises is, are there two different narrative plots here, one for life and one for faith; or are the two so similar that they can be treated as a single five stage process? The study treats the five stage process as similar in both cases. In the narrative coding described in Chapter 5 separate codes are used as follows: ID and SD, illness disruption and spiritual disruption; LR and FR, life recovery and faith recovery. The close similarity between the two tracks also suggests that in the world of chronic illness, conventional boundaries tend to break down. In therapeutic terms this is a whole life approach, a whole life story. The faith subject suffers the same kind of life disruption as the non-faith subject. Both faith and non-faith subjects wish to recover valued life activities. The spiritual carer may discover that the ‘spiritual’ impact of the illness cannot be separated out from the life impact in any meaningful way.

2.4 Life in good health

The next five sections describe the five parts of the narrative model of chronic illness in some detail, and discuss the theoretical foundations of each part. Beginning with life in good health may seem surprising, since this is a study about chronic illness. Nevertheless the ‘good health’ story has a specific role and function to play in the narrative model. It is no longer a factual account of the life a person used to live, before illness struck. Instead it describes a lost world, one that now becomes idealised and precious.

Dialysis patients often said to the chaplaincy team, ‘I just want my life back’. This in a nutshell describes the heart of their struggle and their quest. They simply want to get back to where they were before. This deep desire, this longing for the life once lived, was expressed by many of the dialysis patients, who participated in the LWP programme. The practical answer for the patient was to carry out the LWP life review, a detailed breakdown of life activities (physical, mental, social and spiritual) by the subject in past, present and future time frames. This enabled the LWP team to make some simple comparisons, firstly between activity levels in the past, before illness occurred, and in the present, during dialysis treatment. Normally this showed a substantial drop in activity. The second comparison was between activity now and activity anticipated in the future. The latter often included all the activities that had been lost, and those the subject wished to recover. This required making value judgements about which activities which life goals were most important. How might such value judgments be made?

Clearly subjects in wanting to recover the life they had lost were not just speaking about the taken for granted freedoms a healthy body provides. Instead they meant all the fulfilling and enjoyable emotional, social and spiritual engagements that their lives had provided. This in turn would mean defining the ‘good life’, a goal, end or purpose, which would neatly define the direction their lives had taken. This life goal would normally be contained explicitly or implicitly in the person's life story. But the foundational principles for setting life goals would be different for those with faith and those without.

The pragmatic solution adopted by the study, to find common ground, was to turn to an acknowledged authority, the philosopher Paul Ricoeur, and make use of his definitions of good life, life practices, ends and purposes. The study began (see Introduction) with a particular interest in spiritual disruption and faith. But the study model, derived primarily from secular writers on chronic illness, is not based on faith alone. Instead, it takes religious faith as one possible explanatory system a subject may use, in framing their illness narrative, which in turn gives them a framework of meaning, and defines the ends and purposes they live by. By adopting Ricoeur's framework (see Section 1.4), the good life can be defined in broad terms as either a social, philosophical or theological construct.

Ricoeur's work as a philosopher of narrative (1984) is authoritative and comprehensive. A key feature of it is his treatment of experience as 'concordance and discordance': life events are diverse, some are in accord with one's life plans and purposes, and others are discordant and disruptive. Ricoeur's work '*Oneself as another*' (1992) is a primary source for this study. It explores the idea of sameness and difference – the self must have sameness and identity (idem) to be stable, but also must respond and adapt to change (ipse). Ricoeur situates the self within the concordance and discordance of life events, with real life made up of harmony and discord. In Ricoeur's narrative frame, concordance and discordance are terms used to describe firstly a narrative unity where all fits together (concordance), and secondly a narrative with discordant and disruptive elements. Ricoeur then states there can be concordant discordance, a narrative that can encompass discordant and conflicting elements. In earlier structuralist narrative theory, the definition of disruption can be narrowed down to narrative categories. In Labov's framework (1967) described above (orientation, complication, evaluation, resolution), the disruption is the complicating event, the event that will not fit into the stable situation (orientation) first described. In fairy stories, the evil intruder appears, creates disorder, and then is usually conquered and destroyed by the hero of the story. But in chronic illness the intruder is here to stay, and so a different strategy is needed.

Chronic illness involves a different kind of intrusive event, one that is permanent, but also episodic – disruptive events occur over and over again. The disruptive presence of an alien power (illness) in the narrative affects a number of areas in the patient's life. Here the categories used derive from Ricoeur (1992) as he explores the identity of the self:

- 'Concordance and discordance' (1992,141) –a narrative unites disparate elements into a coherent whole.
- 'The good life and the good self '(1992,158): clearly some part of this must be lost, due to the limitation of illness.
- 'The power to act' (1992,316): this is diminished by illness, one's actions determined by others (e.g. doctors and nurses).
- 'Practices and life plans' (1992,157): similar to the good self, but here a life plan or project may be a key part of identity – a business enterprise, a promising career, a lifelong hobby.
- 'The self stripped bare' (1992,168): deprived of vital roles and relationships, the self is stripped down to its core minimal identity (sameness).
- 'Ascription and imputability' (1992,295): the self, accustomed to define itself by actions and achievements, is now defined by a new role, that of patient/sufferer.
- 'Attestation and witness' (1992,302): the self attests to its core identity and ongoing self-narrative, which now focuses on overcoming the threat posed by illness.
- 'Injunction - the Other who calls' (1992,352): even when a person is ill, there remains the call of the other: the partner, the community, the conscience, or God. Faith work here involves rediscovering or reconstructing this call, and finding how it can be carried through in the new situation.

Ricoeur's cluster of concepts on the theme of the good life affirms the narrative unity of a life which will include concordance and discordance, and assaults on the integrity of the self, which must be resisted. They will be used in this study to define aspects of a good life, from the perspective of an ill person, which is now seen as lost, but may still be recovered. Ricoeur concludes:

> The good life is, for each of us, the nebulus of ideals and dreams of achievement with regard to which a life is held to be more or less fulfilled or unfulfilled. (1992 p 179)

From the perspective of chronic illness, the fulfilling life of good health has now been replaced by the unfulfilling life of illness. Changing this involves reviewing the ideals and dreams that led to the good life that was, and is now lost, and modifying these to suit the new world of illness.

2.5 Illness and disruption (Biographical & Spiritual Disruption)

The second stage of the narrative model is illness and disruption. The literature review highlighted stories about disruption, chaos, discordance, suffering, exile, hurt and lament (Sections 1.2-1.9). For Bury (Section 1.2), biographical disruption involved not just disruption to life patterns and routines, but also to explanatory systems. Spiritual disruption involved estrangement and alienation (Section 1.6) in two ways: the subject was physically less able to attend and participate in faith activities, and so became estranged. And secondly the subject experienced God as absent, since he no longer intervened to give the rewards and blessings that had been experienced in good health.

Frank’s chaos, quest, restitution model suggests that disruption is experienced as simply chaotic: life lacks any order, coherence or predictability. The illness subject is only able to describe it in hindsight, after they have moved on, and can now describe how it felt, giving it expressive form. In the study narratives (Chapters 4 & 5) subjects can still describe in vivid detail the exact circumstances of illness onset and diagnosis, which often occurred many years before. These accounts capture the dread, dismay and horror of discovering that one had organ failure, and the black shadow this cast over the future.

The disclosure of moments of dismay, fear, shock, anger and disbelief may be controlled and later edited out (Section 1.8). The dialysis regime has a brisk and business-like approach, and seeks to establish disciplined treatment routines as the new normal. The general appearance is of individuals getting on with business as usual. There is no looking back or dwelling on the cruelty or unfairness of what has happened. But if the narrative is to be complete, accounts of disruption, deprivation, hurt and dismay somehow need to be recovered and recorded, since these spontaneous reactions are profoundly true. They reveal accurately how the person really felt and responded, whether with anger, dismay, fear or numbness and shock. Once these were recovered in the study narratives, it became clear that subjects who presented as star survivors had often been devastated or dumbfounded in the beginning. Their evident competency had only been acquired later on.

How and why do dialysis patients suffer? Clearly there will be pain, weakness, limitation and inconvenience, but that is not the same as suffering, since such things can in time be endured and got used to. Dialysis patients suffer because of the arbitrariness and unfairness of chronic illness, which strikes some but not others. They suffer because their future, the life they might have had, is stolen from them and may never be recovered. They suffer because in society individuals who have an incurable illness are stigmatised (Charmaz 1983, Goffman 1990). They suffer through isolation and alienation (Section 1.6), because the world they inhabit is cut off and ignored within social discourse. The narrative life worlds model (Section 1.10) suggests that this world is not authorised, recognised nor validated and so is not readily described. The spontaneous negative reactions of those who learn they are to join this group indicate that they understand only too well the full implication of what it means for them, and the lives they will now lead.

The Illness and Disruption (ID) stage is a critical point, when after a period of inaction the patient begins to respond. The impetus for this will be the need for survival, self-preservation and the will to fight back. Patients may do this in an uncoordinated unplanned way at first, but later will begin to manage disruption better and reorganise their lives. It is clear that illness onset and diagnosis is a chaotic period, particularly if the patient has to begin dialysis urgently and immediately. This period may include deep rooted emotions, fears and complex reactions, which are hidden beneath the surface and not disclosed. Once the patient has moved on into active coping mode, it may nevertheless be possible to recover and record what these reactions were, as an integral part of the story.

2.6 Expression and evaluation

Expression and evaluation is the third stage in the narrative model. In fact, narrative evaluation occurs throughout any story; the narrator often comments on events as they go along, giving a personal evaluation of what is happening. The reason it is included as a separate stage in the model, is because of the need for evaluation of future life potential, after the disruptive life impact of illness has been described. Here it is vital that the nature of various losses is carefully evaluated to distinguish those that are recoverable and irrecoverable, before any life recovery work is begun.

Stage 3, expression and evaluation, is in many ways the most difficult and complex stage of the narrative process. It requires both honest expression of the subject's feelings about the illness, and also a rational evaluation of the life potential that remains. There could be two ways of doing this. The first would be to do a catalogue of life activities, before and after illness, and work out what might be recoverable, based purely on a practical judgment – what can I still do? The second way would be much less objective and practical, and instead ask the question, what am I still committed to? This would then list all the commitments and obligations one once had, and review them in the light of the question, what must I do now? This becomes a question of role and responsibility, and for the person of faith is linked to injunction and calling, What am I called to be? Because this second list does not begin with what is now practical and achievable for the individual, it is likely that some of the obligations listed may be hard to fulfil. Also, there remains the question, what do others require of me? As Gerhardt (op cit) points out, patients prefer careers, both so that they can have the satisfaction of performing a useful role, and also so that others may seem them as useful and normal.

Mapping out an illness career requires that the patient must first have done some emotion work in the sense that Hochschild describes (1.8 above). The pain and hurt may remain, but it must be managed so that the patient can make wise decision about their illness career. Turning back to the literature, Kleinman (in Good, Brodwin & Kleinman 1994) provides a graphic account of the extremes of emotion to which chronic pain sufferers are driven. The subjects in his study are classic chronic pain subjects: they suffer from conditions such as tempero-mandibular joint disorder (TMJ). Here chronic pain is pervasive and persistent, but also inexplicable. For these subjects their pain stories are both expressive vehicles, to get others to understand how much pain they are in, and also explanatory stories, to explain how and why the pain occurred.

Kleinman describes the case of a particular patient Stella Hoff, who says this:

> I could be dead or quadriplegic. As it was I was totally totally stunned. I sat there and shook. And that started the whole process. Four years of pain, surgeries, casts….and now this constant pain…And me, us – our lives are ruined. (ibid p 175)

It is at once clear that Stella is an intelligent and perceptive person, who insists on being heard. A doctor comments that 'When I see her name on the list of patients for the day, I feel on edge myself' (ibid 177). Later Stella says:

> Do you believe in evil?...Suffering is an evil. I mean suffering that has no meaning, that brings nothing good with it. There is a spiritual side of my pain. That is what I mean by evil. My spirit is hurt, wounded. There is no transcendence. I have found no creativity no meaning in this, this entirely horrible experience. (ibid p 179)

Stella is included here as an example, in contrast with many dialysis patients, of a highly articulate, expressive patient who has narrative competence – she can describe how she feels, in a way that makes doctors and other listeners very uncomfortable. But Stella's pain and Stella's story are not resolved. Her pain just continues. Because she is articulate, Stella is able to communicate her pain, and perhaps this may give her some small relief. But Stella cannot resolve her pain, and nor can anyone else do this for her. Kleinman in summarising Stella's predicament describes how she fights back:

> She turns even her spiritual crisis into an assault on the dehumanising and language of a treatment system that addresses neither ethical nor teleological questions. She resists the inappropriate extension of biomedicine into… the domain of deeply intimate human experience that calls for compassion and witnessing. (ibid p 182)

Stella tells her story as she does so that someone may hear it and legitimise it – yes, this is really happening to her. But clinicians cannot fit her story in to a clinical model, because her pain although intense cannot be fixed. The ethical and teleological question the system is not addressing is - where is this treatment going, is it actually helping, is it worth it? This is the basic problem in all long-term conditions, which involve pain, suffering and deterioration. There is going to be suffering of some kind, which cannot be remedied. Is there a story which can be told that can somehow explain, justify or set this suffering into some accepted framework of meaning? Such a story can transform, can somehow make the suffering 'worth it'. The courageous survivor accepts pain; life recovery provides symbolic moments of joy and fulfilment, which balance out the pain. The very old describe pain as normal and inevitable. But Stella has no story inside which to 'frame' her pain.

Turning then to dialysis patients, severe, untreatable chronic pain is seldom the issue; instead the problem hinges on balancing the treatment burden, time, symptoms, loss of energy and motivation, against the opportunities that remain for living a normal life. Their pain does not scream out: instead it is dull, monotonous and unremarkable. Frank (2010) calls this the 'illness as normality' narrative that is often used by people with illnesses involving deterioration. Meaning is sought not in the illness, but in life around the illness. Routine pain and deprivation is acceptable, if there is still life – meaning, vitality and purpose. Therefore the illness story about the life that can be lived in spite of illness is a powerful source of self-authorisation and legitimation.

2.7 Life recovery and faith recovery

The fourth stage of the narrative model engages with life recovery and faith recovery. As was noted in Section 2.4, dialysis subjects' one simple wish is to recover the lives they had before. Life recovery and faith recovery are included together in this stage, though they are different in some respects. Faith recovery is a misleading title if it is taken to mean that faith has somehow been lost, and needs to be found again. This did not occur with any of the subjects studied. Instead faith recovery implies a process of reengaging and refocusing faith within a different situation and life world, a process which is described below as 'faith work' (Section 6.8). The experience gained from LWP suggested that a powerful desire for life recovery was widespread and universal, especially among younger patients who had their lives before them: it was impossible not to engage with this, and harness this desire in some way. It was also a powerful motivator: yet it carried the danger of disappointment and disillusion, if the expectations raised proved to be false and unrealisable. The structure of the narrative model and in particular stage 3, expression and evaluation stage (EE), offered an important safeguard: evaluating life potential involved a realistic understanding of the limitations the illness imposed.

It was therefore vital to have a clear understanding of what life recovery in chronic illness involved. Life may be recovered, but it will not be the same life. The life described in stage 1, the life once lived in good health, has disappeared and is gone for good. Instead what is now on offer is a different life, one that is immensely more challenging, difficult and painful, and yet also contains the potential for moments of joy, satisfaction and a sense of achievement. The important and far-sighted choice the chronic illness subject has to make is therefore whether to continue with the quest to recover the old life, which is likely to lead to pain and frustration, or whether to explore this new and different kind of life, and to discover what potential it too holds.

Translating this picture into faith terms, the analysis suggests that hope for the future is both gift and choice. Brueggemann (1991,167) argues that ‘God hopes powerfully for every human person’, that is, he intends a future life of faith and hope. The good life that is faithful living involves the ends and purposes prescribed by the faith tradition, together with the satisfaction and rewards, disappointments and failures this entails. This may be recovered, but it will be a different kind of life. It will also be much more challenging and difficult than the settled world of faith in good health, lived out in the faith community, and involving observance, participation, fellowship and particular roles and rewards. In that world, duties and responsibilities, rules of conduct and observance were all clearly laid down and defined. But now the faith member finds herself isolated, unsure of their role, and whether the same complex set of requirements still applies, now she is ill.

But the choice for the faith member is subtly different in one respect. The ‘good life’ of good health which the subject longs to recover, but cannot, is unforgiving and makes few allowances for frailty. The pace is fast, and the sick person must keep up or fall by the wayside. But faith groups are committed to compassion and concern for the weak. They therefore make allowances, modify the rules and do all they can to accommodate those who are sick or frail. This then allows for participation at a reduced, less active level, and enables the sick person to remain part of the fellowship. But in doing so they may unwittingly discourage the sick person from doing faith work, taking responsibility and engaging actively with the new setting in which they find themselves.

Life recovery, now understood as a new adventure, exploring the life potential within chronic illness, is an empirical process, and works by learning, trial and error. Inevitably the good life, the quest for the lost world, remains a powerful force. Activities and roles that were valued remain a high priority and will once more be attempted. Only when such attempts fail will other less demanding substitutes be considered. The modified model outlined in Section 6.3 below suggests that role adaptation follows life recovery: life patterns are adjusted and balanced to suit the new roles that are undertaken. But this process is itself dynamic and requires skill and foresight. Choosing the right activity balance also takes account of unexpected disruption and setbacks, so that the balance remains sustainable.

2.8 Resolution: new life story, new faith story

One of the key themes of the study would turn out to be the search for resolution. Narrators look for ways of creating resolution. Outcomes and endings are important; they permit one episode to end and the next one to begin. An illness story can be constructed that does not actually lead to cure or a specific medical outcome. Instead the plot may hinge on a change in perception, or a change in circumstance which transforms the way the subject experiences the illness. The quest for life recovery described in the last section may itself contain much good story material – plans and goals, setbacks, victories and defeats. Yet the story plot needs to be more than just a collection of episodes with variable outcomes; the plot must have a progressive structure and move on towards some definite conclusion. The study will suggest that there is a particular art and skill in creating an illness narrative out of chronic illness. The narrator knows that there is a distant ending, which for the present remains deliberately hidden and out of sight. Instead the narrator creates goals, targets and milestones much closer to hand, and easier to reach. These create episodes each with its own drama and action, giving the story structure and articulation. Once the next milestone is reached, there is a sense of achievement, and a pause for reflection.

Arthur Frank in the final chapter of '*The wounded storyteller'* (1995) describes such a moment, when the narrator of the illness story sits on a cliff, watching sea-birds and porpoises and is transfixed. In this moment: he has arrived and is truly happy. But this ending requires that the subject abandons the original quest, or sees it in a different way. The losing and finding story must in the end find something. What is found may be quite different from what was intended, but must be valuable and important enough, that the seeker is prepared to give up the long battle, take a rest and be content. The experience of working with LWP patients prior to the study suggested that often, they were delighted with some relatively small success or improvement, which they had achieved using their own efforts. This suggested that the illness had worked in such a way as to destroy their own sense of agency and control, to the point where they had lost all confidence, and so had stopped trying. Rebuilding such confidence through small achievements could then offer a kind of resolution – I cannot do everything, but I can still do something.

2.9 Conclusion: the power of a story

This chapter has described and developed the five-part narrative model of chronic illness shown in Chapter 1, Table 1.1.1. This was developed from models found in the literature

(Sections 1.1 – 1.3) based on work by Frank, Ricoeur, Bury, Williams and Williams. Essentially this model proceeds in a logical and orderly sequence, one step at a time. Disruption occurs, but it is carefully evaluated. Plans for life recovery are made and carried through. Eventually a positive outcome results when, even though not all the planned recovery has happened, a balance is achieved; the subject is content that she has done all she possibly could. But what if reality is much less orderly, much more chaotic and unpredictable? It might well be that subjects do not evaluate disruption carefully, do not plan recovery sensibly, or may not have the energy to attempt it at all, and so may never achieve any acceptable kind of resolution.

In Section 2.6, two kinds of evaluation of life potential were described – a practical kind, which evaluated activities against resources available, taking account of the limitations of illness; and a moral or ethical kind, describing one's life's purpose, and setting out the commitments and responsibilities that one should fulfil during illness. The second kind of evaluation would, it seemed likely, be used by those with religious faith. But the study would go on to show that other subjects too preferred the second kind of evaluation. They would choose a story plot that would define their own individual response to illness, and the commitments, roles and values that they would continue at all costs. This represented for them, and for the faith patients who also made a moral choice of illness role, a high-risk strategy: there was a much greater chance of failures and setbacks, than if an illness role was chosen which was simply the least risky and most practical in the circumstances. But the reason that subjects chose such a role, and carried it through, was that they were utterly committed to it: this story had power because it had integrity, energy and purpose, and therefore could sustain setbacks and failures and still carry on.

This chapter has set out the theory base and primary study model in some detail. In Chapters 4 and 5 the model is applied to the study data, where it is found that the reality of chronic illness is more complex, chaotic and disorganised than a neat theoretical model might suggest. Nevertheless, examples are found of patients (Group 1) who do organise their illness story as a progressive narrative quest. When choosing which illness role to take on they make a moral choice, choosing to take on specific responsibilities defined by their faith story or self-story. Other narrative structures (Groups 2, 3 and 4) would be found that would define responsibility differently. The value then of using models lies not in creating rigid structures and then expecting real life situations to mirror such structures in a precise way. Chronic illness is a shifting world of change, confusion and unpredictability. This is why patients create illness stories which give structure, meaning and purpose to a disorganised reality. The researcher’s task is to discern these hidden structures, and how patients use them to help rebuild their lives.

Chapter 3
Research methodology

3.0 The research problem

The research problem arose in a dialysis unit where chaplains began visiting patient regularly to offer spiritual care. They discovered that spiritual care could not be offered in isolation; these patients had far reaching needs relating to how to adapt to life on dialysis. The spiritual component could not be separated from the whole life situation. It was also clear that while many of these patients had religious beliefs, their faith and their faith group were not offering much help with the spiritual issues they faced.

This situation gave rise to the Living Well Programme which was a coaching and self-management tool for dialysis patients, offered by a team of up to ten chaplains and volunteers in four dialysis settings over five years (2007-2012). About 100 dialysis patients participated in the programme: it is described in Appendix A. Unusually, the LWP did not offer patients additional resources besides some coaching time and regular follow-up visits. This meant that once the patient had done a life review and set recovery targets, all the work was done by the patients, with periodic progress reviews. The chaplains in the team did of course have their own expertise in spiritual care, which they employed when needed, but this was not the foundation of the programme. All the knowledge and learning about how to live with this difficult treatment came from patients themselves.

The research study set out to observe these patients as they grappled with the physical, emotional and spiritual issues of living on dialysis, and record their responses. It was assumed that in a situation of deprivation and scarcity (these patients got little help), these patients would learn the best way to survive the life impact of this treatment, and that this knowledge might be recorded and shared. It could then form the theory base from which the programme might develop. Alongside this, it was also clear that conventional spiritual care responses used by chaplains did not work well with this target group. Chaplains normally offer spiritual reassurance, prayers and sacraments, and cover the temporary gap created by illness, when patients cannot access religious observance and support from their own faith group. But here the relationship with the faith group seemed part of the problem. The faith group did not seem to understand the impact of chronic illness on faith, and how this affected their members.

The research process therefore had two separate goals. The first was to observe illness processes and patients' ways of responding, to find out what worked best for these patients. The second was to focus on the spiritual impact of chronic illness, and to observe how the group used their faith in responding to illness. Again, this knowledge would be gained mainly from direct observation, rather than from referring to other sources, such as spiritual care literature.

3.1 Research method: longitudinal data, narrative analysis & enquiry

Chapters 1 and 2 described the initial literature search and the theory building process that followed. This chapter examines implications for the study method and describes the research method used. This was an observation study, and observed dialysis patients over several years, producing different kinds of data. The Living Well Programme involved meeting patients and observing their progress, normally over a six to twelve-month period. This generated longitudinal data about their lives on dialysis, including life reviews and progress charts (see 3.12). Then two years later research interviews were carried out with twelve subjects: these were studied using narrative enquiry methods, then analysed and coded using narrative analysis.

The study therefore used mixed methods –longitudinal data and then narrative enquiry and analysis. The overall timescale during which patient observation occurred was three to four years, making this a longitudinal study, whose aim was to observe chronic illness processes as they occurred over time, and chart patients' progress through illness stages.

3.2 Methodology Framework 1: Using longitudinal data in qualitative research

Saldana (2003) describes longitudinal qualitative research as a process that studies change over time, and offers various definitions of change, including 'a succession of differences in time', 'a disturbance in one or more systemic forces that cause change', and 'a continuous unending stream of events…because life is nothing else but movement, motion and change' (2003:9). He cites narrative enquiry (Clandinin & Connelly 2000) in which selected writers have 'played influential and significant roles in the development of narrative enquiry as it relates to temporality and change'. Quoting Pettigrew (1995) he encourages analysts not to gloss over or reduce the conditions of change to a single variable or grand theory:

> 'The task is to explore the complex haphazard and often contradictory ways that change emerges, and to construct a model that allows for an appreciation of conflicting rationalities, objectives and behaviours.' (1995:93).

This suggests that longitudinal research normally uses mixed methods and draws on a variety of data and sources over time. An interview study would not strictly be longitudinal because, even when the interviews covered a whole life course, a long period, there would be no comparative data to track change over time. This study is longitudinal since, even though the primary data source was life course interviews, subjects also consented to LWP data being used which had been gathered before (see Appendix A). The time scale was important (see 3.12). There was that a significant gap of 18-24 months after subjects completed the LWP process and before they did their narrative interviews. This meant that progress and change between LWP and interview could be documented during a period when subjects were receiving no expert help.

Saldana cautions against using a single model. He suggests instead a series of framing questions, descriptive questions and analytic or interpretive questions (2003: 63-64). The framing questions include asking what is different from one pool of data to the next, which changes occur over time, and what contextual and intervening conditions appear to affect participant changes over time. Recording change is important: he suggests observing what the dynamics of participant change are over time, and making preliminary assertions about participant changes as data analysis progresses. Turning to descriptive questions, these concern what increases or emerges through time, what is cumulative through time, what kind of surges or epiphanies occur, what decreases or ceases, what remains constant or consistent, what is idiosyncratic, and what is missing through time. The analytic and interpretive questions Saldana suggests are which changes interrelate, which changes through time oppose or harmonise with natural human development or constructed social processes, what are participant or conceptual rhythms, and what is the through-line of the study.

In one sense, any study of chronic illness must use longitudinal methods, to track the changes that occur over the long course of illness. Saldana's questions are all based on a single hypothesis, that there exists a definitive life story or life history, which sets out the facts of the case: this can then be examined to find the answers. But as Wengraf points out (Section 3.8.2 below), there are in fact two different stories, the told story and the lived life, and the two are not the same. Whist Wengraf's BNIM method (2001) sets out to highlight the differences between the two, narrative enquiry would instead focus on the told story, the account the subject gives, and ask why the story is being told this way. The facts, the clinical history, may exist and could be pieced together from clinical records, but this is not the subject of either narrative analysis or enquiry in qualitative research. Saldana's questions do make allowance for some subjective elements, and the idiosyncratic: participant changes may include attitudes, and he mentions 'surges and epiphanies' and participant conceptual rhythms. His 'through-line of the study' seems to represent a development through time, the way the researcher and participant view and summarise the changes that have occurred. This then is not that different from the concept of 'story plot' used in narrative studies. One concept in particular became important in the study – that of cycles: chronic illness consists of disruption-response cycles, repeated disruption event that have to be dealt with in turn.

This study uses process models to depict actual processes that occur in the field. These may be similar to Saldana's through-lines. In fact, he gives a succession of diagrams (2003: 68, 77, 81 103) which depict and represent change processes in a graphic way. These are not theories or hypotheses but are used simply to help understand the process that the researcher is describing. The four narrative models set out in Section 1.1 are process models: the five-part progressive narrative quest (primary model), disruption response cycles, augmented/new narrative plot, and living in two different narrative life worlds. These are developed throughout the study, with the primary model being the baseline model that is explored first and compared with the study data. These four narrative models all offer different ways of describing change as follows:

(i) Change is orderly and progressive: one event leads to another, and follows a specific story plot.

(ii) Change is random and disruptive. Chronic illness presents a succession of unwelcome uncontrollable changes, which have an unpredictable, often negative effect.

(iii) When major change occurs, the story plot may change as well. The old story no longer works any more, but another workable plot is created instead.

(iv) Change is fluid and negotiable. People live in different narrative life worlds and move between them. Two story worlds are described - the good health world and the illness world: they exist alongside each other and individuals move between them.

The primary model, the five-part narrative quest was the foundational model for the Living Well Programme: patients could, using their own efforts, respond effectively to illness disruption and create an illness story documenting how they did this. But within the hundred or more participants in LWP it was clear that there were other stories here: which could not be ignored. Chronic illness had had a massive disruptive impact on a person’s life, and had destroyed most of the activities, ends and purposes which they held important. Chronic illness had changed everything, career, family, leisure and social life. Now life centred around another story, managing the illness, which became an all-consuming task. Or again chronic illness was a secret, disturbing world where the person went to receive treatment, before returning to normal everyday existence again. Other kinds of illness story therefore existed alongside the primary progressive model. But as Saldana (op cit) suggests, there is no grand theory that can explain the complex nature of reality. The solution adopted was to allow the models to exist side by side as different ways of looking at change.

3.3 Methodology framework 2: Narrative theorists and Frank

Narrative medicine as a branch of medical thought has developed over the last ten or twenty years (Hurwitz et al 2004). Charon (2001 & 2006) suggests that bio-ethics is doubly informed by narrative theory, through doctors developing narrative competence within the practice of medicine, and through the increasing narrative commitments of its ethical sphere. As Charon points out (in Hurwitz 2004, 27) narrative ethics is grounded in feminist studies, post-colonial studies, phenomenology and liberation theology; but makes little direct mention of spiritual and religious themes. The methodology outlined below begins with formalist narrative theory, and then uses Ricoeur’s work as a philosopher of narrative to provide an ethical framework.

3.3.1 Formalist theory: Labov and the Russian school

The formalist school of narrative theory (1910-1930) studied narrative in literature and folk tales and argued that similar structures are found in everyday spoken and written narratives

(McQillan 2000). Labov & Waletsky (1967) invented a basic narrative coding based on studies of drama, novels and folk tales:

[A]	[abstract]
O	orientation
CA	complicating action
E	Evaluation
R	Resolution

Section 1.1 referred to the early structuralist theories of narrative, and Section 1.3 described Frank’s own narrative model of illness (1995) which draws on these. But there are a number of limitations in Frank’s scheme which make it difficult to apply to chronic illness. Firstly, Frank argues that the chaos stage – overwhelming disorientation - cannot be described. In Labov’s story structure, complication is central and is described in detail, and evaluation is a separate stage. It may follow the disruption event (complicating action) directly or may continue as a separate parallel strand throughout the narrative. Either way, this evaluation process is vital and indispensable; the narrator lets slip chance asides, which reveal his feeling and reactions; other protagonists offer comments and interpretations in conversation. The study argues that spiritual evaluation (faith work) is the key to a considered faith response to disruption. Labov’s scheme is therefore used in preference to Frank’s, whilst recognising the latter’s significant contribution.

Within the history of modern narrative theory, Labov and the Russian School (Propp 1968) represent early founding fathers, whose theories may now be seen as a little outdated. Their basic simplicity is the simplicity of the folk tale – good and bad, black and white, a happy ending. Between 1930-1950 later theorists engaged with narrative and history and also with European philosophy, and saw the beginnings of structuralism: 1960 to 1970 was the high point of structuralist narratology (Greimas 1982). The decade 1980–1990 saw the emergence of poststructuralism with important works by Lyotard (1984), Ricoeur (1984-1988) and Genette (1986). The study draws on early formalist narrative theory (Propp 1968) and then poststructuralist theory (Ricoeur 1988).

Labov’s basic narrative scheme outlined above is straightforward and so is suited to chronic illness. Illness narratives have exactly this simple character, the disruption of a stable situation – good health. There may of course be no clear resolution or happy ending. But

Labov's four-part structure has the merit of clarity: to it can be added the notion of narrative augmentation (Root 1989) and narrative reframing (Goffman 1986), so that the essential development of the story lies in the evaluation process as much as in the sequence of events. Ricoeur's work comes from a later period when the postmodern condition (Lyotard 1984) and its relation to human identity had already begun to be discussed. Ricoeur in '*Oneself as another*' (1992) rejects the fluid postmodern self, and suggests that constancy and consistency is a vital component of the self (idem and ipse), whilst it goes through many life stages and changes. This is a key issue in chronic illness, where identity is challenged: this makes Ricoeur a vital source.

3.3.2 Choice of narrative method – analysis versus enquiry

There are two contrasting approaches within narrative method, both extensively used.
The first approach, narrative analysis, uses techniques such as discourse analysis and conversation analysis (Ochs and Capps 2001) to carry out exhaustive studies of texts. These techniques require a very accurate text, transcribed according to a particular convention, so that pauses, interruptions and overlaps can all be noted, and the meaning of the text discerned. Narrative analysis addresses narrative texts, coding them in various ways, and so revealing plot, character and evaluation.

Narrative enquiry (Clandinin & Connelly 2000) on the other hand studies transcribed narratives to find structure and themes and asks questions like 'Why is this story told in this way?' 'How do the plot and characters change and develop as the story unfolds?' 'What is this narrative seeking to accomplish?' This approach looks at the narrative both as a whole, and also through its constituent sections (narrative episodes, complication, evaluation, resolution). It does not on the whole study the text line by line and word by word. This approach uses Ricoeur's and other theories of narrative (1984) to discern coherence structures, moral evaluation, narrative voices, and counter stories.

This study used both approaches, narrative enquiry in Chapter 4 and narrative analysis in Chapter 5. Narrative analysis was the core method and it was applied to all the study data (fieldwork and narrative interviews) to reveal the impact of adverse life events on the life story and on the faith story. But first the basic structure and content of both life and faith stories needed to be established and recorded in a concise way using narrative enquiry

(Chapter 4). Two of the narrative models the study uses, augmented narrative and narrative life worlds, may be said to belong to narrative enquiry, since they view a narrative as a whole and consider the purpose it serves. Narrative enquiry also discusses how subjects construct, elaborate on and modify their stories, in accordance with particular story plots, and whether these stories can then be used as reliable data.

3.3.3 Narrative analysis and coding

Chapter 5 describes the narrative analysis and coding process which was done in five stages: narrative and reflection, theoretical coding (five-stage primary model), disruption-response coding, illness work coding and progressive learning coding. The first two stages were derived from the literature. Schutz and Haupert (in Flick 2002) suggest a simple method of coding into narrated events and subjects' reflections on these events. Theoretical coding is a standard qualitative research method (Silverman 2005); here the five-part narrative quest stages were coded against the interview data.

The remaining coding stages 3-5 grew out of the analysis and further conceptual development (reflexivity). The primary theoretical model (the five part quest) seemed too tidy and complete to fit all cases – chronic illness is about disruption and discontinuity. The disruption response model (ii) was then developed – it described chronic illness as a continuous process of disruption and response (coding stage 3). Whilst this description made no mention of progression, this model still allowed for the possibility of learning – responses stabilised and improved over time. Two key concepts emerged from the analysis process, learning and illness work, and so two further coding stages were added to test these concepts against the data. This proved positive: the results are shown in Section 5.8 below.

3.4 Research aims and objectives

3.4.1 The principal research aim was to observe illness processes, identify biographical and spiritual disruption in patient narratives, record their responses to these, and analyse the responses using a narrative framework. The secondary aim was to understand the impact of chronic illness on faith and patients' response to this, as described in patients' own narratives.

3.4.2 The research objectives were:

1. Identify patients who have experienced biographical and spiritual disruption from LWP participants.

2. Observe and record patients’ responses to biographical and spiritual disruption, including how disruption was managed, and whether it was followed by attempts at life and role recovery.
3. To better understand biographical reconstruction (life recovery) after illness disruption, and observe how this may be achieved in chronic illness.
4. To record evidence of faith demand, faith work, faith responses, changes in belief and practice, and faith work resulting in spiritual growth or change.
5. To present findings that describe the processes and life impact of chronic illness to assist further research, and enable practitioners to develop specific spiritual care and life recovery resources for this patient group.
6. To provide a theory base for the Living Well Programme, which would inform its future development.

The eventual scope of the research was expanded to explain further observation that patients create illness narratives which define the specific roles and responsibilities which patients carry out. These narratives also contained detailed accounts of suffering and loss which were not generally disclosed in the setting, but formed counternarratives which described and validated the patient’s identity as sufferer, and witnessed to the reality of their experience.

3.5 Research setting

The dialysis unit at Guy’s hospital comprises one ward and a number of satellite units, each with four shifts – Monday, Wednesday, Friday and Tuesday, Thursday, Saturday, both morning and afternoon sessions. The basic shift is four hours on dialysis, with extra time for putting the patient on and off the machine. The six satellite dialysis centres are located around South East London. Patients generally begin at Guy’s, and those with no complications are transferred to satellite units which are managed by nurses.

The haemodialysis machine removes waste products from blood. The basic technology is now 50 years old. It is being improved all the time by lighter, more portable machines. Operation is improved and simplified so that it becomes easier for patients to dialyse in their own homes. The process requires an intravenous access line. Preparatory surgery is needed prior to dialysis, firstly to insert a temporary line, and then to insert a fistula in the arm, a

device allowing regular access into the vein. Some patients choose to dialyse at home, and are trained to operate a machine for themselves. For many patients, dialysis is a transitional stage whilst they are waiting to receive a transplant. But for some a transplant has been ruled out for medical reasons, perhaps because of other accompanying health conditions.
Horne & Weinman outline the psychological impact of dialysis treatment (in McGee and Bradley 1994). They describe the self-regulatory model of illness which describes representation, coping and appraisal, which is based on in-depth interviews. Here the patients' own representation of illness profoundly influences their response to it. The method used in this study using patient narratives works in a similar way.

The chaplaincy team offers spiritual care to in-patients throughout the hospital. Kidney patients traditionally were seen during in-patient episodes – normally when preparing to start dialysis or to receive a transplant. Spiritual care at these times normally focuses on the procedure in hand – getting through the operation and its aftermath. By introducing regular visiting on dialysis wards at Guy's, the focus of spiritual care was shifted to normal living. Out-patients are not institutionalised in the same way as in-patients. Dialysis is an interruption in the process of normal living, and patients are more ready to discuss life concerns from the outside world. The spiritual issues encountered by dialysis patients include seeking meaning and connection and a sense of a self beyond personal loss (Chambers, Germain & Brown 2004).

Although the research literature offers many studies into measuring quality of life for kidney dialysis patients, (Joyce in McGee & Bradley 1994) only a tiny handful of rehabilitation programmes are described that address this issue. The medical establishment has shown substantial interest in measuring quality of life (QoL) in kidney patients, since it is an additional way of measuring the outcome of a treatment process. But if asked whether poor QoL is a medically treatable condition, the answer is likely to be no. Quality of life includes social, recreational, psychological and spiritual factors, which are not amenable to biomedical treatment. Yet paradoxically much of the poor QoL observed in kidney patients in LWP was found to be due to physical factors – chronic pain, poor mobility, eyesight loss, loss of energy and motivation (LWP Stage 1 Review 2008).

The setting, the dialysis unit at Guy's, was a permanent treatment centre for some dialysis patients, a transitional setting for others. Patients with other conditions that require medical attention, patients with hypertension and poor mobility, have dialysis at Guy's where there is a doctor present. Other patients move on to a satellite unit after the initial adjustment period, when they are coping well with dialysis and a space becomes available. Some patients after a period on the waiting list receive kidney transplants and no longer require dialysis. For the Living Well Programme, the disadvantage of the Guy's setting initially was that there were a disproportionate number of long term, less able, less mobile dialysis patients present, who were limited in what could be achieved in improving QoL, as compared with an 'average' setting. The programme later moved out to satellite units as well. Some of these more limited patients however showed a great interest in and appreciation of the Living Well Programme, possibly because they did in fact have very poor quality of life. The characteristics of this population had an impact on the study. The twelve interview subjects selected were all drawn from this long-term population (those unlikely to have a transplant) – patients that had been seen by the researcher and chaplaincy team over two or three years and were therefore well known to them. The setting therefore facilitated the formation of long term relationships and sustained observation of subjects over time.

3.6 Ethical issues

The ethics submission was made to Combined Research Ethics Committee (COREC) in March 2008. The researcher was asked to attend the committee in person accompanied by his academic supervisor to answer questions. The areas of concern were confidentiality, the chaplain/researcher role and patient consents. The committee was unclear about how the chaplain might separate the research role from the giving of pastoral care, sometimes to the same patients. In response the researcher stated that the data to be used for research would be of the following kinds:

1. Living Well Plan (dated) which the patient had specifically agreed could be used for the research study
2. Interview transcripts which the patient would have approved, and been given the opportunity to amend or omit any sensitive material.

Whilst there might be other confidential information that the chaplain might know in his professional capacity as chaplain, this data would not find its way in to the research study. The 'chaplain as researcher' role is explored further in Section 3.11.1 below.

The Living Well Programme had been through a separate ethics submission in 2007. In the opinion of the Ethics Committee Chair it had not required full ethical consent, being a service review. The review would aggregate patient feedback responses and show tables of lifestyle targets chosen and achieved, without revealing information about individuals. The ethics submission proposed that this LWP information be used as background data for the research study, since it provided valuable information about the level of disruption found in this patient group. This was accepted. Another level of consent would however be required for patients who, having completed Living Well Plans, subsequently offered to become research subjects, and do narrative interviews. These patients would receive the research project information sheets, and sign consent forms after reading this information.

3.7 Sample selection

The nature of the study required theoretical and purposive sampling (Flick 2002, Silverman 2005). The subject of study was biographical and spiritual disruption, defined as disruptive life changes which also affect faith. The eventual research area was expanded to include the role and responsibility of those with chronic illness. The following subjects were initially excluded from the study:

- People of no particular faith (either before or after illness onset)
- Chronically ill people who report no disruption, either biographical or spiritual.

Stage 1 of the data collection process analyses the LWP sample group [n=50] to determine how many experienced biographical and spiritual disruption. Using LWP as a screening tool in this way also enabled subjects to be selected as a theoretical sample, from a set of listed categories: see Section 3.12. The sample pool consisted of all dialysis patients attending two dialysis units in Guy's hospital. In the two dialysis wards the number of patients available were 4 x 30 = 120 and 4 x 15 = 60, that is 180 patients. This excluded patients on night time dialysis (20-30 patients).

In this study the second question focuses on the impact of chronic illness on religious faith, so the range of suitable research subjects for this part was limited to those with self-reported faith membership. In the overall population at large, the numbers of members of faith group members in the 2001 census was 46 million or 77% of the population (all faiths). In 1991 in a UK population of 57 million 66% of these described themselves as Christian, but only 11%

were active attenders. In 2001 this had changed: 71% described themselves as Christian; but the number of active attenders remained around 10%, with all non-Christian faiths at 5% and no religion at 15% (Office for National Statistics 1994 & 2004).

These figures show that there were big numbers of ‘nominal’ non-observant faith members within the population who had some faith background, and might therefore be likely to turn to faith in a crisis such as illness or bereavement. Turning to the specific patient population in the study, if it followed the national pattern, out of a pool of around 100 patients one might expect 70 to describe themselves as Christian: but of these only 10 or so might be active attenders. But the trust catchment area is very diverse, and has a high proportion of black (African and Afro-Caribbean) ethnic groups, which have a greater proportion of active Christians, as well as many Asian patients who were Muslim, Sikh and Hindu. Therefore the number of ‘committed’ faith members in this group was higher. Although trust policy is to record the religion of all patients, gathering this data in hospital is notoriously haphazard and patchy.

The traditional method for distinguishing between nominal and active members is faith group attendance. But this method was not reliable with our study group, since many claimed to have strong faith, but were no longer able to attend because of illness or poor mobility. The study relied on self-reported faith commitment, to identify committed members. The study focused in particular on two aspects of faith: belief and practice. The latter may conventionally be read as church attendance, but in practice could be measured in other ways, in particular the extent to which faith is applied in real life, for example in dealing with the problems of illness.

The Living Well Programme was used as a means of pre-selection from the 180 people available on dialysis units. Those volunteering for the programme tended to be motivated and articulate – able to describe and discuss their illness and situation, and have some motivation for improving their lives. Because the LWP coach team who were recruiting participants were mainly chaplaincy staff (chaplains, trainees and volunteers), this could have led to a preponderance of religious people volunteering. In fact in LWP stages 1 and 2, the ratio between religious and non-religious participants was about 50-50. For the purpose of this research, it was mainly religious subjects that were of interest; but three non-religious subjects were included for interview to offer balance. This group would help explore the link between a strong self-story and developing effective life recovery strategies.

The possible number of committed faith members from a pool of 200 patients might only be 20 in line with national average (10% - see 3.7.1). But there might be others with nominal affiliation whose faith (belief and practice) had changed as result of illness disruption. These would also be of interest to the study. A theoretical sampling process would seek to identify individuals from each of four categories for further study and interview, based on life and faith gradients – progressive, regressive, peak and trough gradients (see Appendix A).
The longitudinal data (LWP) showed that the study sample all moved through different response levels, responding negatively at first, then going through a learning stage, and eventually responding positively. The sample did not include any subject whose faith had been unaffected – mostly the effect had been positive and adaptive. There were no subjects who had lost faith. But the narratives studied gave ample descriptions of the problems the illness posed for faith members. These are discussed in detail in Chapter 5.9.

A purposive sampling approach is based on the need to identify which patients would best meet the aims of the study. This is different from the theoretical sampling method outlined above, whose main aim is to support a theoretical model of the interaction between illness, disruption and faith. In the end it was decided to use theoretical sampling, in order to substantiate the primary study model. Subjects were chosen that were able to recount very extensive biographical and spiritual disruption, together with their responses over time. This decision influenced the analysis and coding method. Stage 1 coding separated disruption episodes and patient responses, stage 2 coding used five-part model theoretical codes, stage 3 coding examined all disruption responses for consistency or change.

Appendix A (LWP) describes how representative participants were selected for interview in three groups. In section 3.11, reflexivity and reactivity, strategies are described for dealing with confounding and incongruous data.

3.8 Methods of data collection

The methods of data collection used in the study were longitudinal data (contact sheets, LWP life review forms) and semi-structured narrative interviews.

3.8.1 Appropriateness of methods chosen

Many qualitative studies have been undertaken using research interviews. This study is different in that it used both longitudinal fieldwork observation (contact sheets) and research interviews, and combines fieldwork with the study of narrative texts. This is appropriate for the study subject, which explores the relationship between biographical and spiritual disruption over time, and the way disruptive life events affect religious faith.

Patients with religious faith will normally be able, depending on their tradition, to narrate an account of their faith story, including initiation and upbringing, joining a faith community and any significant events or faith crises along the way. Narrative theory states that all narrative is construction (Holstein & Gubrium 2000). Events are selected and described to suit a narrative plot. In a faith narrative, specific events would be used to illustrate how the narrator's faith had helped them in specific situations, or how they perceived that God had intervened to allow certain things to happen. The problem therefore with faith stories from a research perspective is that they could be dismissed by a critical non-believing reader as a selective and one-sided view of events.

There is a research literature on spiritual care from the USA (Koenig 2002) which suggests strong associations between faith membership and good health, and describes positive and negative religious coping. Koenig (2008) found an association between religious affiliation and longevity, but also one between religious struggle (negative religious coping) and greater mortality. The latter group felt that God or the faith community had abandoned them, or that faith in God made no difference. This could be similar to spiritual disruption: but the small sample of subjects in this study who experienced similar negative responses initially went on to rebuild their faith later. Here after initial spiritual disruption, a faith quest was initiated. Faith was reframed and refocused, and this led to specific responses and behaviours which led to better outcomes. But if subjects had only been contacted once, during a spiritual disruption episode, the later positive faith response would not have been recorded. This suggests faith responses need to be studied over time. The study sample (n=12) was too small to generalise or challenge the findings about negative religious coping from the USA.

3.8.2 Two part narrative interviews

Wengraf (2001) sets out in detail a worked out narrative analysis method called Biographical Narrative Interpretive Method (BNIM). The basic diagram of the analysis process has two arms – ‘told story’ and ‘lived life’. Here the key aim of the narrative analysis is to compare the narrated story contained in the biographical interview text, with any data that can be ascertained about the subject’s real life, and then compare the two. Narrative theorists might criticise this method as missing the point – a narrative is not meant to be true, it is meant to offer a rich text that is full of subjective interpretation and meaning.

It was nevertheless decided to use a modified version of the Wengraf BNIM method, as it suited the two kinds of data available to this study. The ‘told story’ is represented by the narrative interview; the ‘lived life’ data comes from the Living Well Plan and contact sheets, which set out clearly the practical issues the patients were facing in living their lives. Wengraf’s narrative interview model has three parts (2001 p.119).
Subsession 1: Initial elaboration of story round topics
Subsession 2: (same day) Extracting more story from the topics
Subsession 3: Questions arising from preliminary analysis of subsessions 1 and 2

In sessions 1 and 2 only SQUINS (single questions inducing narrative) are allowed. In session 3 the interviewer may pose questions generated by the study and ask about topics not mentioned before.

The study version of this design is as follows:
Interview part 1: Biographical illness disruption narrative: 30–40minutes
Interview part 2: Faith story 20-30 minutes
Interview part 3: Identify links between 1 and 2 and summarise; 5 minutes
Total time: 50-70 minutes, depending on patient’s energy and stamina

In interview part 1 the basic question was: ‘Tell me the story of your illness’. In part 2 the question was ‘How has illness affected your faith?’ For non-faith subjects the second question was changed to, ‘What has sustained you and kept you going through your illness?’ Part 3 might include questions about the Living Well Plan, the kind of disruption the patient experienced, and what role faith played in the response. Part 3 was an overview and summary of parts 1 and 2. The location for the interviews was the dialysis unit.

The narrative interviews used a semi-structured narrative approach (Wengraf 2001). There were two interview questions prepared beforehand. 2A and 2B were alternatives for faith and non-faith patients:

1 Tell me about what it has been like, living with this illness.
2A Tell me about your faith and spiritual life during your illness.
2B Tell me what has kept you going during your illness

The reason for this order was to allow the subjects to recount faith as part of their life/illness story, if they wished, before focusing particularly on this aspect in the second question. In the event, many of the subjects produced a single lengthy composite narrative, which included faith and faith responses. There was then no need to separate out the second faith question.

3.8.3 Interview analysis: five stage coding

Twelve research interviews were carried out: average length between 3,000 and 6,000 words. The interviews were analysed using three sets of codings, as follows:

1. *Stage 1: Basic narrative coding, Narrative and Reflection (N & R)*: narrative episodes (N1 N2 etc. numbered); reflection and evaluation (R1, R2 numbered). This separated out action and evaluation in a straightforward way.
2. *Stage 2: Chronic illness coding.* This used the five part coding developed in Section 2.1, the primary progressive model: faith in good health GH, illness disruption ID, evaluation/expression EE, life/faith recovery LR, resolution RN. The results of the two coding processes are given in the table in Ch 5.8
3. *Stage 3: Disruption – response coding* (Section 5.12). This was added later as an inclusive coding and coded every kind of disruptive event (disruption cycles), in order to capture all response types.

The results of the three-stage coding process are shown in Table 5.8.1. Three stage narrative coding: results table. The disruption response coding (Stage 3) was added later (see Section 5.2), in order to examine how responses might develop and change over time.

The first stage narrative coding showed that interviews contained between 13 and 27 narrative episodes describing disruption events, and between 6 and 26 reflective passages, giving the subjects comments and evaluation. The second stage theoretical coding broadly substantiated the model. This is discussed further in Section 5.2 below. The third stage coding went back over the interviews of four key respondents, who had described extensive and repeated disruption. The purpose of this third stage was to review all these subjects' responses, to see if, given the levels of disruption they had experienced, their responses had been right first time, or whether they had developed and become more effective over time. The results of Stage 3 coding are shown in more detail by using examples of disruption response coding from four key respondents.

Data was analysed and provisional conclusions were developed from coding stages 1-3. This lead to further theory work around redefining narrative quest as a quest for responsibility, which led to learning and illness work. Two more stages of coding were added as follows:

4. *Stage 4: Illness work coding*: the illness work hypothesis needed to be tested to identify all the types of illness work described by patients. Seven types were coded: emotion, grief, evaluation, identity, faith, recovery and resolution work
5. *Stage 5: Progressive learning*. The learning hypothesis needed to be tested by coding the different types of learning described in interviews. The codings were initial response (ir), modified response (mr), exploration (exp), communicating learning (com), taking on responsibility (rsp), and receiving reinforcement and affirmation (rnf)

3.9 LWP Data – Appendix A: summary of method and results

Full details of LWP data and findings is found in Appendix A. Here, a short summary is provided. The primary data source was the LWP life reviews, which were themselves narrative in format, with columns for life activities in past present and future. The analysis of this data was done to derive gradient based on activity levels, both for life and faith activities. These would show whether activity increased (positive gradient) or decreased (negative gradient) as a result of illness, and also what the subject expected to happen in the future. A patient's typical life gradient would be negative – lots of activity before illness, less after illness onset, and even less in the future. But some patient's gradients and especially young people showed a different pattern, with activity declining after illness but then bouncing back in the future, expressing their strong wish to achieve life recovery.

Faith gradients showed a different pattern: an initial response to an adverse event such as illness was often increased faith activity, showing how faith becomes a valuable resource in adversity. But some faith subjects did not show this pattern. They responded to illness and managed the disruptive life impact, but faith did not seem to play a key role in their response. Later however their faith was used as a positive and vital resource – a delayed reaction. This suggested two different kinds of faith response - an immediate fight back response and a delayed response, based on reflecting on and processing the impact and losses caused by illness, and then framing a more individual faith response which adapted faith practice to the illness world.

The LWP data gave a specific insight into two different typical faith responses to illness (Groups A and B). It also led to the inclusion of a third kind of response (Group C). This was not a faith response at all, but rather a powerful life story or survivor story, which the person used as their foundational response to illness. This often used a key trait or theme from the self-story, such as always fighting back or always being determined and resourceful, and using this strength to provide hope and endurance during illness. This then was another kind of secular 'faith story', which subjects used in the same way as religious people – to generate a personal illness story, which both documented the survival process, and also described the key skills, principles and sources of hope and strength needed to survive.

This third group drawn from the substantial number of non-faith participants in LWP did in fact change the outcome of the study, as described in Section 3.11. Instead of the key aim of the study being to see how faith might be used as an effective resource during chronic illness, the focus changed to how faith stories and life stories, including survivor stories from non-faith subjects, played a vital role in documenting, guiding and resourcing an individual's survival and behaviour. This further led on to studying how faith responses and illness responses generally came to be formed, developed and improved over time. Illness then becomes a set of skills and competencies as well as a set of beliefs, faith in oneself or faith in God, which grew and developed, until the person became a skilled and competent survivor. Chapter 6 and 7 explore further the reasons why this process has not been recognised or recorded before. Chapter 8 suggest how further research may be needed to establish whether the research findings can be applied to chronic illness more widely.

3.10 Narrative interview analysis: limitations of method

The choice of interview analysis method was narrowed down to two alternatives, Schutz and Wengraf from which Wengraf was chosen, but in modified form. Schutz and Haupert (in

Flick 2000) suggest a background case note – brief summary of biographical details, followed by a sequential analysis. Wengraf (2001 p 239) suggests an analysis sequence called DARNE (description, argumentation, report, narrative, evaluation) which he points out corresponds closely to Labov and Waletsky's original narrative structure (1967). The correspondence is shown below.

Labov & Waletsky	DARNE method
Abstract	Report
Orientation	Description
Complicating action	
Events and actions	Argumentation
Climax	Narrative
Resolution	
Evaluation	Evaluation

The DARNE method did not in fact add anything to Labov, and is less clear. Labov's complicating action and climax are missing: but these are key for identifying disruption. It was decided to keep to Labov and Waletsky as the basic narrative structure, with which specific texts would be compared.

Biography, self-disclosure and recounting in-depth stories about one's own life require a level of commitment, trust and engagement with the listener which goes beyond everyday conversation. But once the obstacles (natural reticence, revealing personal information) are overcome, the illness story is an absorbing topic which will generate a continuous narrative lasting an hour or more. This is an effective, indirect way of eliciting information about a person's faith journey as well as their biographical history. If the faith journey matters and has had an impact, it will be integral to the narrative as told.

Reissman (1993) allows the reduction and re-transcribing of a text into an essential narrative core by editing out non-narrative passages, that is, evaluation and comment. This ignores the value of comments and asides which describe the narrator's point of view, as well as interpreting events from a faith perspective. Reissman is here discounting the most valuable feature of narrative text: by evaluating and commenting on events, the narrator is revealing their subjective standpoint, and also maybe their religious faith.

3.11 Validity and reliability

3.11.1 Qualitative research and validity

Qualitative studies based on small samples have high validity but low reliability or generalisability (Elliot 2005). In general, qualitative research does not seek statistical validity – the sample numbers are too small. This study sought to enhance reliability by reviewing data from a wider number of patients (n= 60) from whom the eventual twelve interviewees were chosen, on the basis that they were fairly typical of the larger group reviewed. Extreme cases or nonconforming or confounding examples were not chosen for interview.

An obvious question regarding objectivity might be, would not patients with religious faith tend to over report or overstate the importance of faith in their lives? Would not the researcher (a chaplain) tend to seek out examples of faith application, and thereby introduce bias? But chaplains as opposed to faith ministers have an obvious working familiarity with the difficulties and disruptions faith members experience in times of illness and crisis. Their normal practice involves observing and recording these accurately, so they can be addressed through spiritual care. In this case the researcher was recording the difficulties subjects had with applying faith, and the personal solutions they worked out over time.

Clearly the concept of the researcher as impartial observer has been effectively dismissed – all researchers have bias and work from a specific interpretive standpoint. Mehan (in Silverman 2010, 211) refers to anecdotalism as a specific danger in ethnographic studies, where research selects specific anecdotes to support a finding, whilst excluding others. The subject of this study, spiritual disruption, might well ring alarm bells in faith circles, where authority figures might insist that ‘true’ faith cannot be disrupted. In fact, the study had a reassuring outcome for the faithful, since it would suggest that spiritual disruption leads on to faith quest and faith work, which eventually strengthens faith, and makes it more practical and relevant. But this cannot be shown to happen in every case – there will be exceptions. Examples of widely differing interpretive frameworks are found in the MA dissertation ‘Spiritual needs of renal patients: a narrative approach’ (Watts 2004), which included a survey of staff who surprisingly showed a much more negative and pessimistic view of chronic patients’ situations than did the patients themselves. While patients dealt with illness one day and one step at a time, staff recalled all their case experiences over time. They saw the illness trajectory as a continuously downward slope, and saw patients as people with little future to look forward to. But patients involved in LWP were quick to come up with targets and plans for the future, which for them created hope and purpose. Not all of these plans however would be realised.

The study was able to compare the interview data with data gathered from LWP earlier. The comparison between these two sources (see 4.2) was fundamental in generating the progression hypothesis (7.3), that chronic patient progress through response levels. The progression hypothesis could also have been generated from the interview data, since patients themselves reported how they had progressed. But this earlier data was important to corroborate this finding.

3.12 Reflexivity and reactivity

3.12.1 Chaplain as researcher – ethical issues

The hospital ethics committee composed mainly of consultants had difficulty in accepting the notion of the chaplain as researcher. In clinical practice, clinicians work separately from researchers. Researchers may be evaluating new treatments, and it may be years before these can be used on ‘live’ patients. Nurse practitioners and nurse consultants on the other hand often carry out research using their own practice as a source of data. There are two possible causes for concern. First, is the chaplain abusing his position of trust by doing research? Clearly patients tell chaplains their troubles, and these matters are confidential. Sometimes the chaplain will refer on to a colleague, e.g. a psychiatrist or counsellor, but again the case history remains confidential within the team.

What was being disclosed in the research was the story of an illness as described first in the LWP data and second in the research interview. The patient gave consent, was able to see all the personal data included before publication, and could delete any personal data he/she did not want included. The case history would be anonymised, and often reduced down, so that only salient details relevant to the research topic were included. Through this method the chaplain discharged the duty of confidentiality.

Second, where the research topic concerned religious faith, would the chaplain exaggerate the importance of the faith dimension in order to justify his professional work? This study observed faith in the same way as clinicians observe the progress of a specific illness. The chaplain does not have a precise instrument, a faith thermometer, but it is of vital importance to him/her to know what is happening in the spiritual dimension. This is most often done intuitively – posture, demeanour, and body-language offer tell-tail signs (Lyell 2001). This study suggests that spiritual disruption is an observable phenomenon which is linked to biographical disruption. Where major disruption to the body and the social world occurs, faith as a settled state may also be disturbed – faith and life are closely linked. The subject may show signs of spiritual distress and unease, which have no physical causes.

3.12.2 The role of chaplain as researcher – a reflexive account

This section offers a personal reflection on the role and impact of a chaplain visiting the dialysis unit regularly, and also the specific issues of combining researcher and chaplain role. The author had already become a regular visitor to the unit as part of his pastoral work and was known to patients. This role was shared with others (chaplains, trainees and volunteers) when the Living Well Programme was in progress, so each unit and shift would then have a regular chaplaincy visitor. For example, a black Christian chaplain from the Pentecostal faith might visit a ward on which a number of black patients were present. The latter would respond to the chaplain exactly as they would to a religious minister in their own local culture, which has a high prevalence of black Christians, and treat him with some respect. The author, a white Anglican minister, would also benefit from this response, being accorded the same kind of respect. In the same way, members of other religions also show respect to ministers from other faiths, based on their own custom and practice.

But committed, active members of faith groups only constitute 20% of trust population – the majority of trust patients are not active and some not religious. Their response to chaplains might then range from indifference to hostility, where they are seen as having a purely religious role. But this was not the norm in the dialysis units which were the settings for this research. A pattern had been established of regular chaplain visits in an open plan layout of beds or chairs, where a visitor was conspicuous and visible, and it would be clear who was visited and who was not. It would then be very obvious if the chaplain was singling out religious patients and spending time with them. But here a different pattern had been established, based on visiting all patients, unless they refused a visit, and setting an agenda which extended well beyond religion, and included impact of illness on patient’s lives.

Chaplains work within a practice base defined by the literature (Robinson Kendrick & Brown 2003, Lyall 2001), and work under a code of professional conduct (NHS England 2015) They are trained to deal with the trouble and distress experienced by their own faith members, and this can often be extended to other patients also present in the ward setting. In a large hospital, there will be a therapy team, counsellor, clinical psychologists and others who will share in this task. But the chaplains in the hospital where the study took place had a distinctive way of working. They followed the traditional practice of general ward visiting rather than waiting for referrals.

The chaplain visiting a dialysis unit took on a specialised world with its own specific characteristics. She could adopt a text-book approach, searching hard for signs of spiritual distress and using specific spiritual resources of prayer and scripture. There was a demand for such spiritual work – many dialysis patients were not well supported by faith groups. Or the chaplain could adopt a more generalised role as a mentor, coach and befriender, able to listen to people's troubles without any overriding religious agenda. The author worked within both these role descriptions.

Social science research recognises different kinds of knowledge – firstly that acquired by gathering research data, where a researcher comes in and carefully observes a social situation, always staying inside the role of detached observer (Silverman 2005). Other researchers by contrast may be participant observers, keep fieldwork diaries, and Miles & Huberman (1977) suggest that they must keep any pre-structuring of the study approach to a minimum, and use a naturalistic method. Social science and action research also recognise participant observers, those embedded in a situation as actors and participants, who gather data reflecting their own personal experiences. Here the chaplain was both a participant and an observer (Silverman 2005). His role in caring for dialysis patients preceded any research involvement, and his personal experience reflected an appreciation of the complex experience of the research subjects, some of this confidential, and not recorded within the research data itself.

Webster J (2008) quoting Lynch (2000) lists six types of methodological reflexivity: mechanical reflexivity, substantive reflexivity, methodological reflexivity, meta-theoretical reflexivity, interpretative reflexivity and ethno-methodological reflexivity. The last three concern taken for granted assumptions, non-obvious alternatives, embodied practices, and accountable states. The study would observe the embodied practices of the setting the dialysis treatment unit, even though these were not the subject of the study, which was more to do with patients' lives outside the unit. These practices had the effect of patients not talking freely about their lives, and in particular not discussing what had gone wrong, and the many difficulties they were experiencing. Reflecting on his role, was the chaplain in some way accountable and responsible as a witness, to represent patients' sufferings and difficulties, to be some kind of champion and advocate? As a researcher, of course, he had a different obligation - to record truthfully what he saw, but in a confidential way. But this reflective process led to the question, what lay behind this reluctance to disclose? Was it a harsh regime or some kind of self-censorship? In the end he concluded that it was the patient's themselves who restricted their disclosure out of self-interest. They did not wish to present themselves in an unfavourable light, as this might reduce their chances of receiving a transplant.

How then might the conflicts within the chaplain's reflexive role as researcher be summed up? He may be a witness to suffering through hearing confidential accounts, which he cannot disclose. As research these accounts can be recorded as data. But as chaplain, his role must also be to help that person to find a voice, to express their experience in their own authentic way, so that their pain may be alleviated. But the choice is theirs.

The researcher's role in relation to different cultural and ethnic groups could also be clearly seen. The LWP team included four other chaplains (three male, one female) all of whom were black; black Christian patients were a large group within the setting. Black chaplains then benefited from a normally positive response from black patients, especially church members. The one female chaplain (Nigerian) was commonly addressed as 'Auntie' by black patients, and younger female patients would discuss personal problems freely with her, which they would not have discussed with the (male) researcher. But the researcher, a white Anglican minister, did not encounter any resistance from black patients, who treated him in a similar way to their own ministers. When talking to patients of different faiths (Muslim, Hindu, Buddhist) it was noticeable that these patients were less likely to express feelings such as hurt and dismay than others did– these faiths expect a high degree of acceptance in the face of suffering from their members.   It was also easier for the researcher when discussing for example the issue of prayer for healing to take a different view, from that taken by patients own faith group.

To sum up, the researcher needed to be sure that his normal role as chaplain offering specific kinds of spiritual interventions did not interfere with his role as researcher. Before the research started, the chaplain and team had already ‘broken the mould’ of being exclusive providers of spiritual care, by offering the Living Well Programme on the unit to anyone, and so becoming familiar to patients in that role. It was then much easier to frame the research as a study around life impact of dialysis, although it included the spiritual dimension as well. The researcher’s specific role as ordained minister (and authority figure) came into play when patients reported either lack of support or wrong teaching about healing and chronic illness coming from their own faith leaders. This information was important for the research. The researcher was able to deal with this as chaplain by offering pastoral support, and also giving an alternative scriptural view of the meaning of suffering and healing, and how this could be worked out in faithful ways.

3.12.3 Selecting participants to avoid bias

A major focus of the study was to establish, observe and understand the phenomenon of spiritual disruption, which has not been described before and therefore could be contested. Using theoretical sampling nine subjects who experienced spiritual disruption in different ways were studied. To show that spiritual disruption is a common or at least observable phenomenon in this patient group, a greater number of cases might have been needed. But the same phenomenon had also been observed in the wider study group within LWP (n=36). The LWP setting might have favoured recruiting faith subjects, and among these those of strong faith might have been more motivated to participate in the study. The second study question was neutral - What was the impact of chronic illness on faith? But the interview subjects who mostly appeared at first sight to have strong faith, in fact recounted many struggles, obstacles and difficulties in their faith journey, which they had had to overcome. This made them ideal subjects.

The importance of building evidence for spiritual disruption in chronic illness lies in implications for further research (Chapter 8). Whilst it was only possible to interview Christian subjects for this study, members of other faith groups (Muslim, Hindu, Buddhist) participated in LWP. It was clear from their LWP data that they also experienced disruption at the practical level – worship attendance, prayer, fasting etc. as a consequence of illness. No members of these other faith groups were enrolled in the study– the subjects might not readily have wished to disclose the spiritual disruption they experienced (potential stigma) to a minister from another faith. Clearly if spiritual disruption is found across faiths, then it would strengthen the case for studying it and analysing its causes.

3.12.4 Reactivity: adapting study design as work proceeds

The study might have introduced spiritual disruption as a core interpretive concept and then created a standard measuring tool for use in spiritual care. In fact, the study proceeded in a quite different direction. It took biographical and spiritual disruption as everyday facts associated with illness (Williams S 2000), and instead focused on patient responses. The disruption events that occur for kidney patients are standard and repetitive, but the responses are varied and different.

The study also reacted to an unexpected finding (Section 5.8) which appeared to question the study model (Section 2.3). The five-part narrative model described how in theory a patient would pass through all five stages in order to process and evaluate disruption and achieve eventual resolution. But the finding about disruption–response cycles appeared to undermine the model – there is no fixed point of resolution in chronic illness, disruption is continuous and ongoing. Eventually this was resolved by combining two differing viewpoints (Section 5.8), and seeing the process as a continuous sequence of responding to and resolving each disruption cycle, and then moving on to the next.

The data capture was reviewed at the following key stages:

1. After analysis of fieldwork data from LWP contact summary sheets. These provided good evidence for biographical disruption and some evidence of disruption to faith observance.
2. After recruitment of interviewees. Information about them would already be available (contact sheets). Comparing these would indicate whether the interviewees were representative of the wider group.
3. After interview transcription and analysis, in case more interview data or data coding were needed. In the event additional stages of coding were added to find out about consistency of disruption responses, illness work and learning. Coding stages 4 and 5 were added to evidence illness work and learning responses.

An example of reactivity occurred in Chapter 4. The LWP data analysis produced an interesting set of results which depicted different patterns of response, as evidenced by LWP analysis (Diagram 4.2.1 below p.119). This might have led to further investigation of interview subjects in terms of quick and slow, immediate and delayed responders. But in fact the interview data (Sections 4.2 – 4.6) revealed other information which was more significant for the study. The narrative coding showed the predominance of disruption cycles, and the theoretical coding showed the scattering of five-part narrative codes throughout the interviews, indicating a sophisticated and continuous activity- processing disruption throughout illness trajectory. These findings lead to a key finding of the study, that patients work continuously to manage and mitigate disruption, and also often to achieve life recovery wherever possible.

The scope and direction of the study did in fact develop and change considerably as work went on, indicating reactivity. A key shift in perception came about after the twelve interviews were analysed and results reviewed. As well as the importance of the disruption cycles finding, another result was the convergence of the narrative quest, in faith and non-faith subjects. The subjects with no religion were found to be engaged on their own particular ‘life quest’, that is, the quest to integrate the illness into their own life story, its ends and purposes, in a way that preserved their life goals. This finding based on a small sample had major implications, since it suggested that the illness responses being studied might be found in all dialysis patients, irrespective of faith affiliation.

The study began by criticising previous published work which measured quantitative QoL losses for chronic patients in ever greater detail, without exploring or researching qualitative ways in which patients mitigated and responded to these losses. Joyce in McGee and Bradley (1994 p 43) cites MEDLINE entries that mention QoL as an index term. In 1990 there were 10,000 such publications and about 1000 additions were being made each year, mostly showing negative results. Joyce points out that ‘many methods of assessing quality of life can be criticised because they fail to allow for the positive aspect of quality. There is a general need to extend the sensitivity of methods for measuring quality of life at the positive end of the scale’ (ibid p 45). The study methodology outlined above sought to redress this balance, using qualitative methods to show how patients respond to QoL losses in creative and resourceful ways.

3.13 Chapter Summary – developing a responsive study method

The chapter sets out how the study methodology grew out of the research problem. It began with the problems that patients were experiencing in living with dialysis. It then moved on to exploring the extensive literature about chronic illness, and also the topics of life goals, role and responsibility during illness, and finding meaning in suffering, all covered in the literature of philosophy and pastoral theology.

The study constructed a process model of chronic illness derived from the literature (2.3). It then found from data analysis that this did not exactly correspond to patients' experience: for them chronic illness did not divide into distinct stages, but was a continuous process of disruption and response. The study method reacted to this - the study moved on and, using narrative enquiry, developed further concepts and theories about the chronic illness process, including chronic illness progression, learning and illness work which grew out of studying illness narratives as a whole, their direction and purpose These were tested against the data in further coding stages.

The study drew on two separate sources of data, gathered over time: LWP data (see Appendix A) and interview data. Initially no consistent picture emerged from these two sources. The LWP programme had focused on life recovery: the results achieved showed that patients could make modest improvements in QoL when used as a measure of activity. The interview data produced a more complex picture: disruption and response, gains and losses. Because disruption always continued and occurred in an unpredictable way, there was no certainty that gains would not be overtaken by losses.

A breakthrough occurred when the study discovered from plotting theoretical coding against the time line that patients continued to work at evaluation and life recovery even during periods of major loss and life disruption, when they had little time or energy to spare. This suggested that illness work and recovery work was not motivated by a need to achieve results, but came from a different source – a profound sense of threat to the self-story or faith story, an existential threat to individual identity which had to be resisted at all costs and in every circumstance. This observation led on to the study of the subjects' illness story plots, which described exactly the type of survivor role they had chosen, which they then carried out consistently throughout the many disruption episodes described.

Chapters 4 and 5 will describe the interview data in detail, and the process of theory development that followed, after narrative enquiry and analysis of data was completed.

Chapter 4

Research interviews – overview of contents, and story structure

4.0 Introduction

Section 1.1 outlined two different approaches to narrative study – narrative enquiry and narrative analysis, which are also discussed in Section 3.3.2. The first looks at narrative structure and plot, and asks why the story is told in a particular way, and what is its particular purpose. This approach is followed in Chapter 4. Chapter 5 uses narrative analysis and describes the five-stage coding process applied to the twelve study interviews.

Chapter 2 asked the question, what kind of story is chronic illness, and described the primary progressive models of narrative structure applied to chronic illness and found in the literature (2.3). Chapter 4 gives an overview of the contents of the twelve narrative interviews, which are divided into four groups, which correspond to the four narrative models used in the study (1.1). Each group tells the story in a different way. The first group tells a progressive story about how the subject learned to live with the illness. As each episode develops it is clear that the narrator is gaining in knowledge and experience at dealing with the many challenges of illness. The second group tell the illness as a sequence of disruptive episodes. The drama and suspense in the story comes from not knowing how the hero is going to get out of the fix he is in each time – but that a way out usually presents itself. The third group tell how one story, good health, ends and another one, long term illness, begins. The fourth group manage to live in two worlds, health and illness, at once, constantly moving from one to the other.
Each of the story plots chosen presents its own challenges - subjects work hard to maintain their chosen particular story line. The positive, progressive story plot can be hard to maintain during an illness that is characterised by progressive decline. The pragmatic disruption response plot requires energy and ingenuity to resolve each disruptive event as it occurs. Replacing an old story with a new one requires all the effort that starting again requires. And living in two worlds requires a high degree of dexterity and flexibility, when moving from one to the other.

This chapter explores ways in which subjects become caught up in the narrative structure they create (Frank 2010), and will show how patients invest much time and effort into creating and continuing their illness story plots and roles. Once they have chosen a particular narrative, a way of responding to the illness, they become deeply committed to it, and continue to respond in a consistent way, working hard to maintain the story plot. In this way they use the experience, learning and hard work that has gone before – this enables them to become more adept at managing and resolving the disruptive illness events that continue to occur. Why patients do this is discussed in more depth in Ch 6 – it seems that each patient has their own distinctive and characteristic way of responding to the illness, a kind of specific patient identity, which becomes reinforced with practice, learning and experience. In this way they are able to present themselves as competent and capable survivors (cf. Gerhardt op cit), and their stories provide the evidence to back this up.

4.1 Outline of Interview Process- interview schedule and interview method

The narrative interview process can be summarised as follows. Narrative interviews were carried out according to the method outlined in Section 3.8. Twelve subjects were interviewed; interviews lasted between 45 and 75 minutes and were carried out on dialysis wards. Some interviews were highly expressive, and developed narrative episodes spontaneously. Others were less expressive – subjects needed continuous prompting. In one case the subject had little energy to talk, and so the interview was shorter than the rest. The first three stages of coding used were narrative coding (narrative and reflection N & R), theoretical coding (five-part narrative quest) and disruption response coding. Two further stages of coding were added – chronic illness work coding and progressive learning coding. A detailed description of the five-stage coding process and analysis with diagrams is included in Appendix D.

Interviews were conducted on dialysis units. The subjects were seen a week or two before interview, patient information sheets were given (Appendix E), a verbal explanation offered and consent forms taken. During the interviews subjects were dialysing; this meant the interviews could be interrupted by machines alarming, coffee trolley arriving and medical staff checks. These interruptions are ignored in the transcripts.

The interview schedule with dates is shown in Table 4.1.1 below. The interviews took place between 19.4.11 and 9.7 12 and ranged from 3000 to 7000 words. Interviews were transcribed in question (Q) and patient answer (P) form and numbered in short paragraphs. The interviews were semi-structured and in two parts. In the first part, the subject was asked to recount the story of their illness. In the second part, they were asked about the role of faith during their illness, or for no- faith subjects, what had kept them going.

Table 4.1.1 Interview Schedule

Name	No	Date	Transcript	Word Count	Interview Analysis
Sophie	D11	29 7 11	*	3311	*
Sheila	D4	24 1 12	*	6061	*
Joanne	J5	18 7 11	*	3075	*
Winston	P3	6 8 11	*	6270	*
Tom	D7	10 12 11	*	2587	*
Dawn	D13	19 4 11	*	7009	*
Faith	D19	5 8 11	*	4085	*
Doreen	D12	24 2 12	*	2708	*
Laura	D6	18 3 12	*	3910	*
Bob	D5	5 4 12	*	4101	*
Peter	J7	9 3 12	*	6725	*
Terry	G1	9 7 12	*	5100	*

This chapter therefore establishes and illustrates the four models described in 1.1, whilst recognising the complexity of lived social situations – each individual and setting is unique. The narrative models each represent a story structure which is recognisable and allocates specific roles and responsibilities to the story subject. In none of the models does Parsons 'sick role' actually hold good – the subject is constantly striving in one way or another to fulfil the responsibilities of the illness role that they have chosen. But sometimes the story may break down or grind to a halt. It does not move effortlessly from one stage to the next, but stops short or is interrupted, while the subject works hard in order to overcome a major obstacle.

The order and format of Chapter 4 illustrates the narrative models in turn (Groups 1-4). In Chapter 5 the narrative data is re-examined to find specific kinds of illness work that is accomplished successfully, and also of progressive learning where the subjects' initial response is later modified. This further analysis is particularly important, since it may provide a clue as to how successful learning in chronic illness takes place, and conversely why learning and illness work is sometimes unsuccessful or incomplete.

4.2 Summary of findings from LWP (Appendix A)

The LWP produced significant amounts of qualitative data about patient's lives. The twelve interview subjects were selected from 36 LWP participants whose Living Well Plans were on record and had been updated over time, as described in Appendix A. The analysis of this data was exhaustive and thorough, and took a long time. It looked at different patterns or gradients (life and faith gradients) which recorded levels of life and faith activity over time. These suggested that some patients responded to illness by increasing activity, a fight back response, whilst others needed a time of reflective reaction to process the change events, regroup and then responded later. The research question asked how patients responded to biographical and spiritual disruption. The time taken to respond was not originally thought significant, but proved to be so later. Looking at faith responses, it seemed likely that those who took longer, benefited from taking time to reflect and working out more specific responses, rather than using traditional ready-made faith formulae.

Appendix A describes three different responses to disruption: life disruption accompanied by a strong positive faith reaction (Group A), and life disruption accompanied by faith disruption or delayed faith response (Group B). Group C patients had fluctuating and variable L and F responses. For Group A, disruption and adversity mobilise faith – a 'fight back' response. A good example is Tom's L&F gradients on p.234 top, Diagram A2.2.1. But for group B, no obvious faith response is found at first – but this may happen later, after the person has worked through the faith issues involved. Examples of Group B response are shown in Sheila and Winston's life L and faith F gradients on p. 234 bottom. Table 4.2.1 shows the different L and F gradients recorded for study participants

Table 4.2.1 **LWP Data**: Life L and faith F gradients recorded for 12 study subjects

	Group A p.237		**Group B p.238**		**Group C p.239**	
	Life disruption	*Active F-response*	*Life disruption*	*& faith disruption*	*L & F disruption*	*fluctuates*
	L	F	L	F	L	F
Tom D7	Progressive	Progressive				
Dawn D13	Progressive	Peak				
Sophie D11	Trough	Trough				
Peter J7	Progressive	Progressive				

Laura D6	Trough	Peak					
Joanne J5			Regressive	Stable			
Winston P3			Trough	Trough			
Doreen D12			Peak	Trough			
Faith D19			Trough	Trough			
Sheila D4			Trough	Trough			
Bob D5					Trough	Trough	
Terry G1					Trough	Trough	

The conclusion of Appendix A (A5) were that all patients experienced both biographical and spiritual disruption. Some Group A had a strong active faith response, others Group B did not at first, but this occurred later on as described in interviews. Group B patients provided very good evidence for the learning response – Section 7.3 conclusion 4. which was a central finding of the study. Group B patients experienced major faith disruption, but worked through this using faith work, and achieved a positive outcome over time.

The greatest contribution to the study made by LWP data was to offer a comparison between descriptions of patients' lives taken first from LWP, and then up to two years later from the research interviews. The LWP life review dates are all shown in the interview schedule. There are significant differences. Some LWP subjects, particularly Dawn, Joanne and Bob, (Group 1) are very far from expressing the 'confident survivor' stories that appear later on. It seems that, instead, they are still at the early 'learning' stage of illness response, where different responses and coping strategies are tried out with mixed success. Table 4.2.1 lists the key differences found between LWP and interview results.

Table 4.2.2 Comparison between faith responses in LWP and in interviews

	Positive F responses LWP	Positive F responses in interviews
Dawn D13	11	18
Joanne J5	9	19
Winston P3	5	17
Sheila D4	-16 (neg responses)	25
Faith D19	5	7

The tables focus on one variable, positive faith responses, showing how these changed and became more positive over a two-year period. But the researcher’s renewed contact with subjects at interview stage produced an impression of significant progress not just in faith but also in general confidence for the future and ability to tackle illness disruption.

This finding can be interpreted in two different ways. First it could be used to support LWP as an intervention programme, by suggesting that this was where the learning process started. The past-present-future format of LWP highlighted life activities that had been lost, and enabled participants to target areas for recovery, so initiating chronic illness work. But this might be overstating the impact of LWP since, in the two year-gap, participants had largely worked on their own, without help. The second interpretation is that learning and recovery is a spontaneous, near universal response, both to illness and to other forms of adversity. It is normal to want to recover and to take action to recover what is lost; it would be abnormal to accept loss without response or resistance. In the second interpretation, the subject would only fail to resist or respond because, at the time of crisis, their resources were depleted, they had no power, strength or opportunity to respond and act, or they had not learnt the specific skills that were needed.

The latter may be a plausible explanation for the ‘delayed action’ response observed above among dialysis patients within LWP. There may often be a six month or longer period of disorientation following diagnosis, during which treatment is begun and normal routines are interrupted. The subject then finds they have unwittingly lost key activities – work, social contacts, and leisure activities, which they must now work hard to recover.

In summary, the LWP data gathered did not on its own provide the answers to the research question. It did nevertheless add valuable longitudinal data which lent strength to the learning and illness work hypotheses, which suggested that patients continuously learn and work to recover from the disruptive impact of chronic illness, using their own efforts. It also suggested that patients move from an initial negative response level (L1) to the illness, through a learning process (L2), to an eventual positive response level (L3). The fully developed illness story plot describes this progression, but may not itself appear in its final sustainable form until after the learning stage is complete.

Section 4.3 Narratives Group 1: the progressive narrative quest

Section 1.1 set out four narrative models of chronic illness. The primary model (i) for the study is the five-part progressive narrative quest. This was based on recovery and restitution models adapted from the literature, and suggests that patients respond to chronic illness in a progressive quest to recover the life they had before or, if this proves impossible, to recover whatever they can, until a point of resolution is reached. The three Group 1 patient interviews illustrate this process very clearly.

Dawn's story is one of multiple tragedies and crises in her own life, through a series of difficult illnesses, and in her family, through untimely bereavements. Dawn is an accomplished story teller and a pillar of her church; she is responsible for youth mission and stands up and gives testimonies. This is a story that has been retold and reconstructed on different occasions. The narrative unity of the story comes about because of the way each crisis appears to be another step towards a specific destination - Dawn's journey from nominal faith to born-again believer. Here the climax to the story comes with a spiritual experience Dawn has had, which reassures her of God's love and presence. But this is not a healing miracle; the healing process has a long way still to go, with more medical reverses still to come.

Because this narrative is reconfigured according to a specific plot (the faith journey), it is made to appear more concordant and unified than it probably was. In reality Dawn has experienced major disruption to her life again and again. At the same time, it appears from her evaluations that she could see a pattern, destination or ending in view: she refers to herself as having been saved for a reason. In her story which is dramatic, well expressed and emotionally rich, the disruption has been ironed out to give a narrative unity. This also allows a specific self-narrative to come out. Even in hospital while the body is under attack and is wasting away, and the family are fearing for her life, this survivor story continues to unfold (P23-24)

Q19 And your family were all gathering round?

P23 They were all round. My Mum said when she first saw me on life support she was so scared, my skin had gone charcoal black, and they had me wrapped in foil

Q20 So it was a scary time for them?

P24 I do remember, Yes, and I do have flash backs. I can remember different members of my family standing round the bed and crying and saying, ‘Come on girl you can do this you can get through this’. And that was as far as it goes.

Dawn’s story has an interesting feature which is found also in Faith’s story (4.6). Dawn has so many amazing escapes that she becomes convinced that there must be a reason or purpose for this – she has been saved to do something - P27.

P 27 And that was the first time I felt that God had saved me in order to do something. There was more than what I was doing that I had to do. I don’t know what it is, but I still feel that to this day. And I feel like there was something he saved me to do – I don’t know what it is, but I’m open to suggestions. You know… so that was in 2004.

This is reinforced when other healthier family members, two brothers, die unexpectedly. But there is no sign yet of what that special task may be. But the very sense of hope and expectation is itself a powerful theme of hope for the future, which expects that life still promises new tasks and new challenges. Clearly Dawn is constructing a strong faith narrative, where God’s purpose may well be demonstrated through her survival and her responses. But she also has moments when she wishes to escape from being ill, and just relax, forget and be normal [P89].

Q68 So when you’re telling the story you’re reliving it in your head and it brings back some of the pain?
P89 Absolutely. I forget. It’s very strange. There’s another friend of mine called Samantha who is actually a dialysis patient as well, and she’s got diabetes and all sorts of other things wrong with her. And we talk all the time. and she’s one of the people I’ve kept in contact with from Hammersmith. And we say things like, do you get the feeling that even though we’re ill, we don’t behave like were ill? So we actually forget that we’re ill. You really do, it’s very strange. You adjust your life to what you have to do. Sometimes Mum says you need to go home and get some rest and I say, I feel fine. So you forget that your actually sick – and to me that’s a blessing as well.

This reflects the intensity and exhaustion of Dawn’s long struggle against different illnesses, and the need to leave behind the heroic role.

Joanne’s story starts within the faith group after she experienced kidney failure, and the church have prayed for her healing. Her faith group’s efforts lead her to frustration and despair. She assumes she is worthless, and that it is her fault that she is not healed (P3 – P8).

P3 It was really good, I had faith in God, so I was a regular church goer. Yes, very active in the church.

Q4 Same as you are now or different?

P4 Same as now. Even more now

Q5 So how long ago did it start?

P5 11 years now. So while the illness passes I was not active in the church for quite a long time. I wasn't very active in the church for four years. I hardly went to church because I was not well enough to go. So partly that was a physical thing that I was not well enough

Q6 Was there also a spiritual thing that you did not want to go?

P6 Not really, not exactly. I didn't have the zeal

Q7 Do you mean motivation?

P7 Yes

Q8 So something had happened?

P8 Because I felt uncomfortable, expecting a quick answer to my prayer. A lot of people were praying for me.

Although a capable mother of four children, Joanne has become helpless in the home, and no longer functions in her mothering role. Joanne's turning point comes when she prays that she may be able to improve her life in small steps. This is a radical change: instead of rejecting the illness, and asking God to remove it, she prays for strength to live with it. There follows a series of small but significant achievements. She can go up the stairs again, move around the house, reach the kitchen and begin to cook for the family. Later Joanne returns to church, which she has not attended for a while, and starts to participate. Gradually a reactivated faith gains momentum and she asks if she can help to man the 24-hour help-line. She discovers a gift for this, as a result of her experience with her own troubles. Later she takes charge of the church bookstall, a responsible position. Now Joanne gives a regular testimony which recounts how her faith brought about this transformation. Although this is not a conventional healing story, she asserts that she still believes in healing, and that God will heal her completely one day. But Joanna's real secret is in discovering the power of faithful action to improve her life. Her narrative has power, since it gains momentum as it goes on.

Joanne has come back into church in a prominent role and so can recount an authentic salvation story. Joanne also uses her story in public testimony in church. She shows a 'before and after' picture of when she couldn't walk and when she could, and is willing to describe how she was planning at one point to end her life in despair. Nevertheless, she still has times when she is not well enough to participate in an active way.

Bob by contrast does not have an active faith, yet constructs his narrative plot with reference to what the good life represents for him. Bob was brought up a strong protestant Christian in Scotland, with a strict code of behaviour. Having left home at sixteen to make his fortune, his story has a powerful survivor plot – Bob always falls on his feet. Part of the reason for this is that Bob always sticks to the principles of good and fair conduct he learnt as a child. He does a good day's work, and is always considerate and polite. Bob is known as a model patient in the unit, and shows new patients in the pre-dialysis clinic how it is done. The downside of the survivor story is that it cannot go on for ever. Bob becomes more vulnerable when he discusses his own heart attack, and the death of his partner. But his fall-back position is a moral one: he has always stuck to the rules of good conduct he learnt from his father, and this will see him right (P10, P26, P40).

P10 By this time I was back at work. The irony of all this was, an old boy like me, I can go through all this and get back to work. If I can do this, and do what I did before, so can you. Get your head round the fact that you are going to be on dialysis for the rest of your life, and do something about it. And that is my story to this day.

P26 I took on from my church upbringing, how a good Christian would behave. And to this day I still consider I'm a better Christian without a church, than a lot of people who go to church… I see them on the train on Monday mornings these people are more like animals, not Christians to me.

P40 Not the fear of God, but of damnation. Like um… That goes along with my family as well. My father would always say don't ever do anything to disgrace the family. Do not. Be a man – whatever. Hold your head up. That is stuff you're stuck with. You try. Very difficult in today's circumstances to live like that.

Bob and Laura's stories (4.5) show that those without committed faith can still find meaning in chronic illness. Both have strong principles and firm life plans, which for them provide a powerful incentive to survive and make the best of life. Their stories suggest that a powerful self-narrative may work in exactly the same way as a faith story.

The Group 1 interviews described above illustrate the main characteristics of the primary study model (i), the progressive narrative quest. For Dawn and Joanne illness is a faith journey: their faith grows and expands to meet the challenges that come along. For Bob it is a self-narrative about character, following the moral values he learnt from his father as a child.

These stories are difficult to sustain – progression requires consistent performance and achievement. The main kinds of illness work done by these subjects are emotion work, evaluation work, recovery work and resolution. If the quest is not to become a never-ending search for more life recovery, subjects must limit the work they do to what can reasonably be achieved.

4.4 Narratives Group 2: Skilled Survivor Stories

The three narratives in Group 2 have the same kind of story structure as Group 1. They recount how the illness began, how life was disrupted, and how the subject responded. But these stories show no grand design, overriding faith plot or purpose. The authors' essential task during illness is to survive, to live to see another day, and to carry on. These stories then seem more relaxed and pragmatic: there is no mission to fulfil, and the subjects are more relaxed about setbacks and failures. This kind of empirical response might be associated with non-faith subjects like Terry, who have no life mission to fulfil. In fact, Tom and Peter are both Christians who attend church regularly. But their faith is based on steady routine observance, which is ongoing. For them illness is not so much a faith struggle as a steady battle with the practical problems of survival.

Tom is an older man of Nigerian origin who has travelled extensively and had an important position as a government employee. His illness has separated him from his family, who still live in Nigeria. Born a Muslim, he has a Christian wife and family, but remained a Muslim himself until five years ago, when he had a conversion experience. Tom is a double amputee and has had long spells in hospital. As a relatively new believer, he reads his bible avidly and makes frequent notes, raising challenging faith issues. In his research interview, he refers to both Job and Jeremiah as men who suffered but challenged God, protesting that they did not deserve to suffer as they did. Tom finds this difficult, possibly as a consequence of his previous Muslim faith, which did not permit questioning God's providence.

As an exile and living a life of some deprivation, Tom never complains and remains always eager to discuss faith matters. Perhaps most of all the patients in the study, he displays active faith work, eager to discuss bible passages, which highlight issues around undeserved suffering and making sense of this. In the following passage Tom likens himself to the character of Job in the Old Testament, and refers to keeping his integrity (P43 – P46).

P43 Still my faith didn't change that I would be healed. And up till now, I still believe that I'm going to walk, that I will be healed, that I will walk on my legs, on prostheses.

Q44 What is the main thing that you hope and pray for – walking, kidney failure?

P44 My kidney, my ability to walk Three things I pray – good health, knowledge and strengthen my faith. Like the faith of Job –

Q45 Do you think you're a bit like Job?

P45 I want to be like Job

Q46 You' re already a bit like Job, because you have had a lot of affliction. Do you identify with that story?

P46 Yes, I identify with that story. I read Job two times. I didn't want to change my integrity. That was his thing - I keep my integrity.

For Tom integrity means standing up straight, accepting what you have given and never losing your faith. Interestingly, Tom's narrative of suffering refers to chastisement, that is, he believes that suffering may be a consequence of sin. This means that like Doreen he accepts the identity of a sufferer without protest, and so turns his attention to making the best of living with it.

After a spell of depression, Peter is living in a residential home, and describes some of the frustrations of life there. But he also shows considerable self-awareness: he made the decision to go there through loneliness, and can see that in spite of the restrictions, he is still better off. Discussing other residents' behaviour, he recounts how he stops and says a prayer for them, and now better understands the troubles they face. Peter has reached a stage of resolution through his own hard experiences. He can own his illness story, and accept that it has brought him to a present situation which, though not ideal, can give him the security and care that he needs. Peter has the ability to recount and as an old sailor he is a practised story teller. He tells his illness narrative in a dramatic and often melodramatic way, setting out each crisis in graphic detail. This shows that he controls, owns and guides the story – and greatly enjoys telling it. And although some of the events are unpleasant and distressing, his telling of them makes them interesting to hear. Taking responsibility for Peter means saying yes, this is my life, this is how it was. Peter's return to active faith membership happens in a step by step ordinary way through the kindness of the church members (P42- 44).

P42 I was taught by nuns and then I was taught by Savarian brothers and they were very good. And then he [the priest] said, if you can't get in during the week… by that time he was single handed so he wasn't having a mass every day. So he said come on Sunday morning and receive communion. So I did. And I had a feeling of relief. I sat there most of Sunday I had a look at papers and at football on television and in between I was thinking to myself this seems right.

Q43 You felt you had come home again?

P44 I was becoming part of the flock. I could stop after mass and have a chat with people, they wanted to know how I was, and whether there was anything they could do.

And I think I started saying to them a prayer wouldn't go amiss, and they said all right. A couple of them said to me, and I still see them now, they come up to the home today. The husband does, the wife has the family to worry about. And they said to me you're in our prayers every day. And I actually thought that I could feel it. I don't know, because quite honestly your supposed to. But you tend to look at these things in a different light.

For Peter, belonging and attending provides him with the social support he urgently needs. As well as kidney failure and a transplant, Peter has gone through a year of clinical depression, for which he received specialist treatment and recovered. Although he finds it more difficult to talk about this than his other illnesses, he nevertheless describes it in a matter of fact way, which is detached and factual. One of the contributing factors was loneliness: Peter describes how he begs to be hospitalised to relieve his loneliness. In the end, the solution is for Peter to move into a residential home, where he will always have company. Peter describes how he is reluctant at first to associate with the other residents and come out of his shell. But eventually, because of his good relationships with the staff and helpers, he steps out again into the outside world. This is beautifully described in the bank manager story, where Peter goes to see his bank manager, discovers he still has money, and reasserts control over his financial affairs. Peter also joins the events committee, helping to organise events for the residents.

Terry is an actor whose life has been changed radically by a stroke and by kidney failure. He uses his story telling skills to recount the many scrapes and near misses in his life and illness to his friends, using drama and humour. His story begins at school where he was bullied, and so learned to use words to defend himself (P54).

P54 I think I had to survive in school. Now there are bigger risks and bigger consequences now. Because school is always a sheltered place, but you learn everything. When you say, you survive - if someone is about to hit me, you either dodge or you hit, pre-empt it or run, you hit, you hit them back, or you talk them down. I would always talk them down. I try to. I would knock them down. I would knock them down with words. The weapon of the words. I'm not a big person a big hitter, but I can talk people down.

Terry is never looking for pity: instead he incorporates each new reversal into a carefully constructed illness story, which illustrates how he survives each new crisis, using his wits and innate resourcefulness, which is reminiscent of the classic ‘Trickster’ character in narrative (Cortazzi 1993). Terry’s story telling offers two different insights. First Terry always takes responsibility for dealing with the impact of each disruption event; and second, Terry uses his story as a survival manual and survival chronicle in many episodes. His friends eagerly await the suspense and drama of the next instalment, which does not disappoint them.

Terry’s stroke affected his speech. After intensive speech therapy, he starts to take small radio roles; he also begins teaching drama students which he enjoys. His other creative outlet is oil painting, and he has a busy social life (P24-26).

P24 Loads of friends – never had a problem with that. I’m fairly popular

Q25 Even though you had the stroke and were out of action for six months?

P25 They call me the terminator. It’s a survival thing – I’ll never die they say. But I’m fairly upbeat most women/people would say. I’m fairly, quite funny and they like me to be around for social events. Not that I try to be. And I think I have to be. I think I would have gone under if I had not had that sense of humour.

This excerpt highlights Terry’s performance role as a story teller – he keeps his friends entertained, recounting the many scrapes and near misses he has been in. But there is no heroism here: Terry hates pity, and wishes his survival skills to be seen as normal.

The three Group 2 narratives described above have all the characteristics of the disruption response narrative model (ii). Disruption events keep on occurring, and the subject responds in resourceful ways. All three subjects live alone, and so are used to telling their stories to outsiders whom they enlist as supporters. The main illness work Group 2 undertake is identity work and recovery work – the stories are carefully crafted, disruption is usually followed by recovery. The narrative plot builds the recovery story not so much through progression (the subject becomes more skilled) as through survival – the subject always comes through somehow.

Section 4.5 Narratives Group 3: Dramatic Life Change

The Group 3 interviews recount stories of sudden dramatic life change, where serious illness has a sudden and decisive impact. This means that normality, living the old story, is no longer a realistic possibility: a new story (augmented narrative) must be found instead, which accommodates the drastic change that has occurred

Doreen is a blind Jamaican woman, who we encountered as a new dialysis patient looking lost and bewildered. The noise of machines and people and the unfamiliar environment were all a major challenge as she could not see what was going on. Doreen was recruited late into the research programme after another participant (Dot) dropped out. Doreen's story of kidney failure is only one of a number of losses and disruptions which she has had to overcome. Becoming blind was maybe the worst of these – but she had already lost her parents at an early age and coped with moving to a strange country. Doreen's narrative is mostly staccato and confined to brief question and answer. But there are three descriptive episodes. In the first, the taxi driver episode, Doreen is the centre of a row about being dropped off in the road, which is witnessed by the other passengers (P60 - 63).

Q60 I've heard that before. Do you get angry?

P60 Sometimes, sometimes. One time I get very angry because the driver only take me and he leave me right there by the gate. He didn't take me in. The next time it was the same one. I said you have to take me to the door. He said no, I don't have time for that. And I was mad, everybody was mad – they chucked him out anyway.

Q61 There were some other patients with you?

P61 Yes there were. I said to them, he must take me back inside, everybody was there.

Q62 So you stood up for yourself?

P62 Yes. I said I didn't want him to leave me there, anything could have happened.

Q63 I'm sure it is part of their job.

P63 Sitting in the back, no no no. When we get back, they say it <u>is</u> their job to take patients to the door. But it was only one.

The second descriptive episode concerns Doreen's three-year-old grandson, whom she cares for at home and loves dearly. Both these episodes illustrate Doreen's strength as an assertive and capable person. The third episode is her account of the 'white stick course' – she is learning from an instructor to walk alone with a white stick, in spite of opposition from husband and son, who would prefer her to stay at home.

Q70 Is there anything else you would like to do on your own? When you have finished the white stick course, will you be able to go out on your own?

P70 That's what I am aiming for. Go out for a little walk in the park

Q71 Do you think the family will let you?

P71 Joe say no way. But I'm determined. I am very determined.

Q72 Perhaps the first time they can watch from behind until they are happy

P72 That's what the guys said. They can let you walk there, and you can watch her.

Describing bible stories that she likes, she mentions Job and the woman who touched Jesus' garment – both characters who suffered a lot, but overcame. Doreen is therefore very clear both of her own identity – a person who suffers hardship – and her response – endurance and faith. Her faith narrative too is that God will heal her; but she avoids the impasse encountered by Joanne and Faith, by saying that he will do this in his own time, for he does not give his blessing all at once.

Doreen's account of her belief that she will be healed is a very practical one. She admits that she still gets low and down (P38), but then she calls on her faith, prays and sings and this strengthens her – faith work in action (P35-42).

Q35 What were you praying for at that point?

P35 To see again

Q36 Were you praying for a miracle? But it didn't happen

P36 But I still believe it will happen one day.

Q37 Ok

P37 I am so happy now you know

Q38 But what did that do for your faith then?

P38 It gave me more faith. Sometime I feel very much down and I start singing, praying and I feel much better, happier in myself

Q39 So who helped you most at that time?

P39 My husband and the people in my church and family

Q40 They were good, they supported you?

P40 Yes. Even now they have something special at church, they come and get me. I don't get left out. They make me feel like I can see

Q41 You knew them all before. So how long do you think it took you to recover – you were depressed for three weeks

P41 It take me about two months

Q42 That's not long really, for something like that.

P42 I just say to myself, if the Lord will it, that's it. Why do you get stressed about it and making more problem? That is more stress.

Doreen here provides a pragmatic solution to the tension between active membership of a Pentecostal church with its teaching about healing, and the reality of chronic illness. Healing will happen in its own time.

Laura's story goes back to the discovery of a rare syndrome in her childhood which leads to organ failure – sight loss, kidney failure and bone and joint problems. Diagnosed at 13, she survives schooldays with a mixture of courage and resourcefulness. Later she has a kidney transplant, and is able to live away from home in a residential centre for disabled children as a student and helper. Her crunch point comes when her kidney transplant fails, and she is no longer able to live away from home independently. The struggle for independent living that many young adults with chronic illness experience is made more poignant by her having already experienced some independence, and then lost it again.

Laura does not believe in God, because she says that if she did, how could he be so unfair? Her story reveals that she has a moral view of life, and feels that you must always be the best you can be. For herself this meant helping other children with disabilities, which she has done when well, but can now do no longer. Laura displays the characteristics of resourcefulness and easy acceptance found in those who have lived with illness for most of their lives since childhood. Laura's school day stories illustrate her instinctive taken-for-granted resilience.

Q13 So you were already a bit different because of your eyesight. And then you got the kidney failure. Did that make it better or worse or harder in terms of your reactions to it?

P13 Do you know something, I never, I didn't have a reaction to it. I just accepted it, I had no reaction at all, it was like I cried, it was like, just another thing I had to do.

Q14 It wasn't the end of the world?

P14 No because as soon as I was at home, I asked to go back to school. I just wanted to get back to school in the January. The school wanted me to go back once or twice a week, until I got settled in. But I wanted to go back. I didn't realise how low on energy I was, until I got back. I hadn't realised how much energy I did need to be at school. The school were quite helpful. If I wanted to sleep they let me sleep, or if I wanted a rest.

Q16 So what happened after that?

P16 I went on to do child care. I got a distinction in that, I got a hundred percent. And then I went on to level three, where you can be a supervisor. I'd done that for six months and then I had to leave to have my hip replacement. And that meant I was off, away for eighteen months from college. And when I returned I had to start the course all over again

Q17 What was that like?

P17 I was quite up for it. I couldn't believe I was only twenty, and I had had a double hip replacement. But I chose to have it – I could have waited until later. But I couldn't cope with the pain.

Later, Laura goes on to get a job in a home for disabled children, which she loves, but then her transplant fails

Q29 So that was when your transplant failed, just when you were going to get this job…?

P29 It was awful, that was a big blow, that was quite upsetting and shocking like everything was coming crushing…

Q30 You'd put a lot of effort into the training and the new job?

P30 I was like…I was in disbelief at first that it was failing. I was telling them it wasn't. I said, no it's not. I was telling them it wasn't, it can't be - I am taking all my medication. All I was trying to…I didn't want it to be failing, because I had such a good life with the transplant. In the early days I had problems with it, the hip and the shoulder being done - but in my eyes, they weren't serious…But I didn't want it to end, I didn't want it to be failing, because I had such a good life with the transplant. I didn't want to go back on dialysis.

P31 And in the end when they told me I couldn't go back on PD dialysis either, I had to do haemo, that was it. That was worse than being told the first time I had to do dialysis. It meant that I couldn't do my dialysis at home. I couldn't put myself on because of needles. Because the words 'I can't' weren't in my dictionary. You can't do this, you can't do that

P32 Every other word that I was getting told, you can't wash your hair any more Laura, because you have got a line. That was it. That was when my whole world came crashing down.

Laura's initial story plot, using her own experience to help others, becomes impossible when her transplant fails, and she has to return home. Over time she creates a less ambitious story, which involves chatting to the lonely elderly people on her dialysis shift.

Sophie's story is a simple one, involving both kidney disease and a difficult heart operation. Its dramatic character arises from the fact that her specialist tells her that her operation only has an 8% chance of success: yet she goes ahead anyway, drawing on her Christian faith. Once the operation is successfully over there follows a slow recovery process, with a loss of voice and mobility. This leads to two more 'small miracles', learning to talk again and recovering mobility, which Sophie loves to recount (P39 – 42).

Q39 So were there any special moments when you felt you had a spiritual experience or that God was with you during your illness?

39 Well, he's always with me, because he is the one that pull me through, because I said to people, my time wasn't up yet, he wasn't ready for me see, and he pull me through and that is one of the reasons why I continue my faith.

Q40 And have you ever been asked to give a testimony or tell people what happened to you?

40 I tell people everyday, everyday I tell people, up till Wednesday - there was a lady downstairs in reception, and when I told her my experience, she said no I can't believe it, you're a very brave lady. But I like to tell people what I went through, coz I said I got no fear, I like to spread the news and let people know the way I feel about it and how I pass through that.

Q41 And what do you tell them about, do you tell them about the 8% chance?

41 I tell them everything, I tell them about the 8% chance, I tell them about the intensive care, I tell them about the time in hospital and I tell them all my experience. You have to open and let them know everything.

Q42 Are you happy now in your life? I know you always look forward to the family, especially your grandchildren, don't you?

42 I'm happy because I'm so blessed, and the healing power's in me. I have my family around, it made me fell a lot better. I'm not down, sometimes in the home I was a bit low, but now no, I'm very happy now, very happy.

A further sub-plot concerns Sophie's housing. After her serious illness, she is placed in a residential home, which she dislikes and wants to live independently again. Eventually she succeeds in moving into sheltered housing, where her grandchildren can come and stay. This narrative involves major biographical disruption, but here faith is recounted as seamless and pivotal. Sophie describes how she likes to repeat her story, especially at church where it provides a testimony to faith overcoming obstacles. The discordant element, the long slow recovery and loss of voice, is minimised so that the story appears simple and straightforward. Here the re-authoring process involves a significant shift in identity. Sophie now is no longer just the sick person, who has survived a difficult operation and recovered. She is someone much loved by God, she has received a near miraculous escape from death. Now she has balanced her need for some support with having the independence, so she can see her family. The testimony she recounts achieves a narrative unity which is convincing and powerful, as well as giving resolution for Sophie herself.

These Group 3 narratives illustrate how for those whose illness is severe and life changing, the primary task is to create a new story plot to replace the plot of good health. The primary loss here is freedom of action. Doreen asserts her freedom to go to the park, Laura longs for the freedom she had when living independently, Sophie escapes from the residential home so she can have her grandchildren to stay. The Group 3 narratives describe how a new story is created. Augmented narrative (Root 1989) suggest the life story is expanded to include adverse events. For Doreen blindness and dialysis does not alter her faith attendance and practice. Laura still has the resilience she had at school, and applies it to the many setbacks she experiences as an adult. Sophie uses her miracle story to build a new identity as a faithful witness.

The illness work done by this group is grief work, faith work and recovery work. All three have serious physical limitations and so recovery is difficult; but they are very determined and access whatever help they can get.

Section 4.6 Narrative Group 4 : Living in two different worlds

In the Group 4 interviews the subjects live in two different worlds, health and illness, and move between the two. This allows two different story plots to continue side by side, and prevents the disruption and distress of the illness story spilling over into the normal world of healthy living, at least for a time. These subjects have responsibilities in both worlds, and so work very hard in both. They try to contain disruption and suffering and distance it from normal living – but eventually this strategy becomes unsustainable, as the illness story interrupts and overwhelms the story plot of normal living.

Sheila's story begins when she leaves home and her catholic upbringing, and begins life alone. Soon after a failed relationship, she finds herself as a single mother, struggling to survive. She sees an advert in a local newspaper for a fringe church and rings the number. So begins her search for a faith community, somewhere she can belong and feel accepted. She finally succeeds at the fifth attempt – but four churches could not give her the understanding she needed (P21-P25). Before this she renounces her faith, then changes her mind

P21 No I ended up months later looking for a church, and ended up going to St John the evangelist in Penge.

Q22 So that was the next one?

P22 So when that happened, when he let me down and I couldn't get released from the flat, and I hadn't started dialysis yet, and my Mum had died as well - she died in Nov 2008. And I was pretty distraught, and I got every Christian book I had and tapes, got it all together ready to sling it all out. And I renounced my faith in God and said I didn't believe he was there.

Q23 So you threw them all away?

P23 I got ready to. I had them in the hallway. This went on for a month or so. Even as I said it, I felt totally cut off, like I'd never felt cut off before. I felt for the first time what isolation really meant. And it hurt me because of what I said to God (pause) and it hurt me because I felt the distance.

P24 Then a couple of months later I got my head round everything, and I was talking to my brother Keith who is a very devout Christian. And he said, 'How's it going?' And I said, 'I have said sorry to the Lord but I don't think he's having any of it.' I said, 'I know I have hurt him.'

P25 I then gathered up everything I had put in the hallway, and put it all back on the bookshelf again._ I started going to a church in Penge.

Spiritual disruption for Sheila, now an evangelical Christian, consists of the huge gap between the way the world and her life should be, according to her faith, and the way the world really is, which includes illness and kidney failure, problems with housing and relationships. Encouraged by church friends, she begins to attend healing meetings, and is devastated when the hoped-for healing does not occur (P61-63).

P61 So in a desperate attempt I went there again in the March, and I said, I had prayer healing here before, and nothing happened, I wasn't healed. They said, maybe that's not Gods intention for you, for you to be healed physically - which I was really upset about, I was devastated. And then of course by that time it was Oct 2009, I started dialysis, and everything that could have gone wrong went wrong in the first three months.

Q62 Yes. And of course you hated the idea of going on dialysis – like failure?

P62 Yes I hated it. I hated the noise of the machines. I remember the first time, the nurse who was quire curt with me, and I remember the lights and all this strange feeling of sitting there - these people, all gawping at each other. It was horrible. I still remember it today. I feel for anybody new to dialysis.

Q63 You can always pick them out. Was that the worst thing so far –going on dialysis?

P63 The worst thing was not being healed of the kidney failure at Central Hall Westminster, being told I would not be healed. No - the worst thing was definitely renouncing my faith. That was the worst worst. The second worst was Methodist central hall. The third worst thing was starting dialysis.

Balancing life on dialysis with the demands of work and social life becomes increasingly fraught. At a certain point, she decides she has had enough, and asks the medical team to book her a place in a hospice so she can withdraw from treatment, die and go to heaven. After changing her mind, she focuses her faith on healing ministry, and attends healing events – but without success. Sheila's interview coding shows the highest score for spiritual disruption of any of the sample. The assumption that disruption can be both positive and negative does not seem to be born out in her case – it is profoundly negative. For other subjects, disruption may lead to a faith experience or a different understanding of faith - perhaps the switch from miraculous healing to finding strength and comfort. But Sheila clings tenaciously to the healing script, and rejects the illness outright as being against God's purpose for her.

Sheila's repeated attempts to find a church where she feels at home is a kind of dogged faith work. Even when she is unsuccessful she tries again. She asserts that nevertheless, in spite of setbacks, she is still a member of God's family, and in her strong self-narrative insists that once healed she wishes to want to use her life for good, to serve God and be a good example (P56). But Sheila is also convinced that it is her fault when she is not healed, that she has let herself down, and that 'the enemy' is holding her back.

Faith's story begins in childhood with sickle cell trait. She has treatment throughout her schooling, but it disrupts her exams and other activities like sport and drama. She nevertheless responds to it without complaint, and at 18 starts a business course. Her symptoms improve, and from 18 to 30 she lives a relatively normal young adult life. She also becomes a born-again Christian and member of a lively church. Then her kidneys begin to fail (26-28).

26 Then I had some pain, I ended up in hospital. The doctors were telling me that now, you need dialysis. So the kidney failure had arrived – not good

Q22 Not good at all

27 I just couldn't believe it. I had thought I had another thirty years to do what I wanted. My sickle cell crises were reducing. I thought, finally I am going to be healthy. You just started to live life.

28 And that was taken away from me. And that night I was in bed; and this was quite devastating. I just cried and all my friend would come in, and I just thought no way, it's a dream, I can't believe what was happening to me …and then…it wasn't a dream, it was happening to me. That was it, you know? Then my friends came over and prayed. My Mum came and spoke to me and all that. And all the prayer kept me going back all the time. All the while I never really thought that someone could have something happening to them like that. I never did anything wrong to anyone, I never drink, I never smoked. It didn't make any sense.

At age 30, Faith is diagnosed with kidney failure, which comes as a profound shock. At or near the same time her father, who is medical director of a hospital, dies in Nigeria. Both these losses seem irreversible and unfair. Faith's interview expresses well her struggle to come to terms with them. Central to her struggle is her experience of ten year's freedom as a young adult, which she now feels she will lose totally. In contrast to her easy-going acceptance earlier of sickle cell disease, she feels that this blow is profoundly unfair (P53-57)

Q40 One thing I noticed from your telling the story: after you got the kidney failure you really asked questions it sounded like you felt it was quite unfair like coming after everything else?

P53 Yes I did. I didn't think 'why me?' because I mean – what, should it be somebody else? But I did ask why

Q41 Were you angry with God?

P54 I was angry with God…I didn't feel angry, I just couldn't understand. I mean what did I do wrong? It just doesn't make any sense to my life. I had been very ill. Was I being punished? I can't think of anything I did wrong. You know, I mean, I was kind to people and friends and old soldiers and stuff like that…It just doesn't make any sense.

Q42 Is that still there, or has it gone away?

P55 It's gone away… it's still there. I was praying. Sometimes when you are thinking things, how long can life go on like this for? Just when you think things can't get any worse… Two years ago, I was walking, and then my hip starts again, and now I can't even walk any more. Now, I have to be wheeled around in a porter's chair all over the place. And at weekends I am stuck at home, with no wheelchair and I can't even go very far.

P56 It was this thing - I thought all the suffering that I did was supposed to be so that there was going to be something great. I didn't die - all the time even the doctors thought I was going to be dead. And when I had a coma, they prepared themselves the family and so on - but I didn't die, I came back alive.

P57 I thought that the whole point was so that I was - that I need to be alive to do something great…What happened to me? So it would all be like a distant memory.

Later on, Faith is hospitalised and placed in intensive care with a kidney complication. After a long spell in hospital she recovers but remains weak. At age 35 she is living at home with three carers a day, and her Mum looking after her overnight. Her challenge now is to recover a measure of independence. She remains a faithful Christian, but she cannot attend church very often. For her, faith offers reassurance but not practical ways for her to improve her life. It may be that her loss of freedom was so great a blow, that she cannot recover the confidence to take action, and take the first steps to reassert a measure of freedom and self-agency, once her physical condition has improved.

Winston was brought up in a catholic family, but alone among siblings acquired a strong and deep faith. This lasts throughout his life, through many crises and wrong turnings. Winston's life plan often seems to have gone completely wrong; yet he attributes reversal to God's calling him back to the right path. For this reason, spiritual disruption is pervasive in Winston's account. It is also clear his wife's untimely death from cancer affects him deeply (P46, P49).

P46 … because whatever happened to the left kidney eventually happened to the right kidney too.

Q49 How did you react?

P49 It's no good railing at these things - there was nothing I could do. I felt my life had stopped. Jenny could not quite understand. I seemed to be taking it on the chin, she was getting very angry - why should it happen to me? I couldn't quite understand all this pain, because there was nothing I could do. So that was how I felt about it. It did upset me. Not necessarily the spoken word, but it did.

Winston sees his life story as one of wrong turns, mistakes and reconstruction. His active faith allows him to reconstruct the story from a faith perspective as a pilgrimage plot – learning through adversity. Winston's career has many ups and downs and led him away from his early interest in Catholic faith. Spiritual experiences play an important role in Winston's story – not as miraculous interventions, but simply as messages from God, telling Winston that he is not abandoned or alone as he faces suffering. As a patient, he has had many hospital admissions and seems always to come through against the odds. His own quiet testimony is that God loves and cares for those that are his. His life has achieved resolution, in that there is now no further need to prove anything. He is much in demand as a mentor and helper for those in trouble.

For Winston as a child, the ‘other’ is first of all God. But also, his mentally ill mother is another demanding other to whom he is unfailingly loyal. His life story contains many conflicting loyalties – the RAF, the firm, his wife, the church, his business, which interact and compete with his loyalty to God. Over time his faith story develops so that his priorities are rearranged and ordered, so that an overall unity of purpose is achieved. (P75).

Q75 Can I go back to then, when I met you. You were a very convinced Catholic. You had this strong faith, even though you had been through a lot. Going back in the story you were just an ordinary catholic you went to church once a month. Very nominal. What do you think happened in between?

P75 I suppose my faith was tested. Prior to that my faith was childlike and naive. I grew up with it as a child, I took it all for granted. Before that when you were young it’s different. I was very fortunate I loved Jesus. For me just following Jesus, doing the things he asked me to do was good enough for me. I hadn’t been tested. I felt a bit like the prophet Job. There was wave after wave after wave. I couldn’t get up, before the next wave came. I ‘d found myself wondering, why me? But I didn’t say that without faith. I prayed a lot to get strength to get through, for what was coming. I couldn’t understand. I prayed, please get me the strength to get through.

As with Sheila the many disruptions and setbacks in Winston’s life generate faith struggles and faith work. This he finally resolves by discerning an overall story plot, where God is in control and uses disruptive events to create learning and strengthen faith.

The Group 4 narratives described above link to study model (iv) recounting separate narrative life worlds. There are two key features. First the lifeworld of illness exists alongside the life of good health. Winston in his story often moves between the two – God is encountered mainly within illness. Second the life world of illness contains intense suffering, which is disclosed and expressed in vivid language. Sheila’s description of her plans to abandon her faith (P23- P25) is graphic and intense. Faith’s description of her response to kidney failure (P26-28) also captures the shock, anguish and disappointment she feels. There is a sense that this anguish is never resolved, and so it spills over into her daily life.

The chronic illness work described by Group 4 subjects is intense – they all work hard, but recovery is still out of reach. Only Winston achieves some resolution, when years later he finds a new role as a wise mentor within his faith community. Sheila does faith work and recovery work, but evaluates the illness as unintended and unjust, and constantly struggles against it. Faith too does emotion work and grief work, but her grief persists at a deep level, and she is not strong enough to fully participate in faith community activities.

4.7 Summary of narrative enquiry into interviews and LWP Data

In Chapter 4, the key themes of the study begin to emerge from the interviews, using narrative enquiry. The study began by looking for narrative structure, to confirm work in the literature suggesting narrators order narratives in specific ways for particular ends. This is particular evident in faith stories, where reality and life events are seen through the prism (interpretive system) of religious faith, and so the narrator describes events through that particular interpretive frame. But this is not just true of faith stories. Survivor stories can be based on faith or on self-belief: in either case events are described so as to illustrate how the subject used specific survival skills (including faith) to win through. In literature about narrative theory, the plot is a construction (White & Epston 1990), a way of ordering events retrospectively to fit a certain pattern. This is clearly seen in the five-part narrative quest: the life story begins in good health, is interrupted by illness whose impact is then evaluated, before the individual goes on to life or role recovery, which may not be entirely successful but can be resolved at a particular point. But other narrative structures were also found. Narrative theory is about a tale that is told: most stories have a beginning a middle and an ending. But the stories told here were not over yet, the narrators were still intensely involved in the struggle to survive, in an illness where the future outcome is uncertain. But their stories and the way they tell them show consistency and continuity, they describe a particular way of dealing with chronic illness that the author has chosen. As each episode unfolds it becomes clear that the plot is generative and determinative: it structures what happens next. This is not just a plot that happened in the past, a convenient and engaging way of recounting a set of events that happened at a particular time, to make an interesting story. This plot is life changing and life enhancing – it determines how this person will act now and act in the future, in a consistent way.

Chapter 4 then establishes the narrative role-quest, illness work and progressive learning as key themes for the study. Subjects commit to a story plot which places specific roles and responsibilities on the subject/narrator. The subject then is prepared to enact this plot through future illness episodes, and to do illness work to ensure that the story is maintained against disruption and adverse events. The subject also learns to become more skilled in carrying through the specific responsibilities the story describes.

Chapter 5 will describe the five coding stages using narrative analysis. These were designed to explore and understand the four study models and interview groups. It will then go over in greater detail one interview from each group and examine in detail the illness work described and the learning that is accomplished in each one.

Chapter 5

Interview Analyses: coding, illness work and learning

5.1 Introduction – interview analyses

Chapter 4 outlined the study interviews and their contents and the different story structures that patients used following a narrative enquiry method, which grouped the interviews according to narrative structure (four models). A key outcome of chapter 4 was to show how subjects commit to specific narrative plots which then influence action. The subject has described their own way of dealing with illness which is then used and developed further in present and future time. This chapter describes the interview analysis process, the different types of coding used and the results that were derived, and looks at four interviews in more detail.

In the study timeline, the narrative analysis process came first, directly after interviews were done. Following the original methodology, a narrative model (the progressive narrative quest) was drawn up from literature, and this was tested by coding the interview data using theoretical coding. The results showed that the theoretical model (the progressive quest) did not fit with all the data: other kinds of narrative structures were present. The study reacted to this finding using narrative enquiry, and asking the question 'Why is this story told in this way?' (Frank 2010). Narrative structures were first studied by taking the narratives as a whole using narrative enquiry (Chapter 4). Then after describing four kinds of structure and plot, these are further analysed in Chapter 5 to break down these structures into their component parts.

The interviews were initially coded in three stages as follows. Stage 1 coding used narrative and reflection (N&R) codes, Stage 2 coding used the five-stage progressive narrative quest coding (GH ID EE LR RN) and Stage 3 coding used disruption-response coding applied to faith responses (F and NF). Stage 1 coding showed there were from 13 to 31 separate story (disruption) episodes in the interviews. Stage 2 coding found the five theoretical stages were found in all the interviews in fairly even distribution. The third stage coding found between 24 and 33 different disruption responses in the interviews. This led directly to model (ii), the disruption response model of chronic illness.

At this stage the coding process (stages 1 & 2) was being used to substantiate the primary study model. It showed that the theoretical model needed to be modified - it did not fit all the cases found in the data. There followed a process of theory development, further coding (Stages 3-5) and then the formation of a modified theory about the narrative quest defined as the quest to construct an illness plot which defined the subject's role and responsibility during illness. This was then tested by coding Stages 4 & 5.

5.2 Stage 1-3 coding: narrative and reflection, theoretical coding, disruption response coding

Initially two kinds of narrative coding were used; then later three more were added. The first two coding stages, narrative and reflection and theoretical coding to establish the five-part primary model, were done early on. This established that the five-part model as a structure could be clearly found in some of the study interviews (group 1), but not in all. This led to further exploration. The third stage coding was in fact a reduction and simplification of the primary model to just two stages, disruption and response, a structure that would be present in any illness. The special feature of chronic illness is that disruption and response is cyclical and repetitive. In dialysis, treatment is repeated three times a week and the typical complications that occur also repeat over time. Responses can then be developed and learned until they become habitual. This might represent a kind of resolution – disruption is normalised and responses become automatic.

The disruption response coding was done on five out of twelve interviews and focuses specifically on faith responses. The details are given in Table 5.8. This analysis led to an interesting finding that strong faith subjects were not always faithful. The coding looked at all responses and found that early on in the illness, faith subjects also used non-faith responses, for example empirical and pragmatic responses, and their responses were not consistent. But later, faith responses were established and became consistent and normative. This suggested an important finding, that patients respond randomly and experimentally to illness at first, trying out different responses, and then learn which responses are effective.

This finding was discussed and developed in early drafts of discussion chapters. It proved particularly important in discussing faith responses, since the idea of faith subjects 'working out' answers for themselves was counter to much traditional faith teaching, which works on an authority system, where the faith tradition dictates the right course to follow. But in fact, this learning hypothesis seemed to make sense, and be supported by other research (Lorig et al 2006) which had already established how chronic patients learn to manage clinical aspects of illness.

5.3 Stage 4 and 5 coding: Illness work and the learning hypothesis

The study developed key concepts, the role quest, progressive learning and illness work, from initial stages of narrative enquiry and analysis, which were used to explain how subjects had managed to construct and develop sustainable illness narratives which defined their own roles. This chapter tests these out and re-examines particular interviews to see where these are found. Coding Stages 4 and 5 code narrative interviews for illness work types and learning stages. Examples of this process occur in life recovery - the patient loses roles and activities as illness progresses, and must evaluate which activities are lost for good and which are recoverable. He then plans to recover some life activities, and may be successful in some cases, but not in others. A substantial amount of experimental work is done in testing boundaries and learning what can be done within the limitations of illness.

The idea of illness work, the work that patients have to do in dealing with the disruptive consequences of illness, arose in Chapter 4.7 where patients were found to work hard both to create a specific story plot and illness role, and then to maintain a particular survival strategy through different disruption episodes. This chapter explores in more detail how patients consistently carry out illness work using their experience and resources, learn from the results, and also modify their illness responses over time as learning occurs. Coding stages 4 and 5 results are described under the four interviews analysed in detail.

5.4 J5 Joanne interview analysis: illness work and progressive learning

A basic outline of Joanne's interview was given in Chapter 4.3 above (excerpts P5-12 and P51-52). Joanne came through with Dawn as one of the 'stars' of Group 1, and her story showed a remarkable reversal and transformation from despair and immobility to an active and influential role in her church. In this section her interview is analysed in more detail, using stage 4 and 5 coding to show where illness work was done and how critical learning occurred.

The coding process Stage 4 defined seven types of illness work: emotion work, grief work, identity work, faith work, evaluation work, recovery work and resolution. Stage 5 coding defined seven kinds of progressive learning: initial response, modified response, exploration, re-evaluation, taking responsibility, communicating learning and reinforcement/affirmation. Joanne's coding scores are shown below in Table 5.4.1

Table 5.4.1 : Stage 4 & 5 coding results – J5 Joanne

Stage 4: Illness work coding	Abbrev	J5 scores	Stage 5: Progressive learning coding	Abbrev	J5 scores
Emotion work	em	3	Initial response	ir	3
Grief work	gr	2	Modified response	mr	3
Identity work	id	3	Exploration	exp	2
Faith work	fw	5	Re-evaluation	r-ev	2
Evaluation work	ev	4	Taking responsibility	rsp	1
Recovery work	rec	7	Communicating learning	com	3
Resolution	res	2	Reinforcement/affirmation	rnf	4

The coding results show that Joanne engaged in all the kinds of illness work described, with the most effort going into recovery work and faith work. In the learning scores, Joanne scored highly in communicating learning and reinforcement – this reflected the importance of her giving her testimony in church, recounting all she had learnt. This in turn led to recognition and affirmation from other faith members, and particularly those experiencing similar difficulties.

Turning to the key stages in Joanne's interview, the interview begins during the period when Joanne was already ill and on dialysis. She was a church member, but she did not attend regularly as she describes (P5-10).

Q5 So how long ago did it start?

P5 11 years now. So while the illness passes I was not active in the church for quite a long time. I wasn't very active in the church for four years. I hardly went to church because I was not well enough to go. So partly that was a physical thing that I was not well enough

Q6 Was there also a spiritual thing that you did not want to go?

P6 Not really, not exactly. I didn't have the zeal

Q7 *Do you mean motivation?*

P7 Yes

Q8 *So something had happened?*

P8 Because I felt uncomfortable, expecting a quick answer to my prayer. A lot of people were praying for me

Q9 *So what answer were you expecting?*

P9 Yes I was expecting to be a lot better emotionally and physically and so on

Q10 *Were you expecting healing?*

P10 Oh yes definitely. I was expecting healing. That's what I meant, even spiritually and emotionally. I was very down at the beginning.

Before her illness Joanne was a regular church goer, very active in church (P3)' This changes with illness, and the conflict she experienced because the prayers were not working. This showed itself in moodiness and withdrawal (P11-P13).

Q11 *How did that show? Were your family and friends aware of it?*

P11 I was a bit moody, I wasn't as friendly, I didn't really want to talk. I just want to withdraw and I didn't want to read my bible either.

Q12 *You stopped reading the bible?*

P12 I stopped reading the bible. The only thing I did was pray, though not as much as I used to.

Q13 *So was anyone able to help you?*

P13 Oh yeah, I got some support from my church. And from others as well. Then there was this older lady I talked to, Margaret and I talked to you and you were the first one I was able to talk to.

The illness work Joanne does here begins with her inner withdrawal from church – her evaluation that their recipe is not working. The next task is to find other sources of help which she finds in the hospital – both from nurses and LWP team. There follow some pressing practical issues – because of her weight gain she could not get upstairs into the house (P15-16).

Q15 *The bit I remember was you had to move out of home, because you couldn't get up the stairs*

15 Oh yes, my stairs I couldn't enter the house. That was part of what made me an emotionally depressed person. I have children and I couldn't be with them.

Q16 *I remember the bad moment was when you stopped running the family. Being a mother was very important… You were away from home for how long?*

16 I was away for quite a long time away. For the initial first couple of years, I was hardly able to go inside the house, and then even when I do go home it was like, how I ended up in hospital like every week.

Joanne’s primary task initially was physical (recovery work). Until she could recover her mobility she could not function as a mother. Recovering mobility and resuming family activities led to an emotional turn-around (P20-21). But before this came her suicide attempt (P22-26)

Q20 So you had good family support. So in terms of faith, what happened to turn that around?

20 One or two things I started to do by myself. My faith started to grow I read my bible I prayed more

Q21 Can you think of a particular moment when it changed?

21 It was a gradual change. What made that better was when I was able to spend more time with my family, then there was an improvement as a result. I was able to go into the house, I was able to spend more time around my children. So that I was able to turn my emotions around.

Q22 That was your central role as a mother - once you could do that, your self-confidence improved?

22 Initially at the beginning I actually decided to commit suicide.

Q23 I remember you told me - I was very surprised

23 Oh yeah, I was that low. I felt like I as was another child in the house. I just couldn’t do anything. I was just in despair. I just felt like a body, like a child.

Q24 What was it - the helplessness?

24 Yes, I felt like a body another child

Q25 In terms of your Christian faith did you feel that God had abandoned you?

25 Well at that time I just felt it seemed that - well it seemed like the world was so bad he wasn’t answering anyone, including myself or anybody’s prayer for me. It was not going anywhere.

Q26 So that was the low point. So what happened to get you out of that?

26 What happened was I talked to one of the nurses here. They started getting onto my health, and the role with my children, my children are young, and I was able to get to walk and start getting an improvement. I was able to look through their homework for them, talk to them, that was like…So that I was able to do that was like a sign - the achievement situation had come back, like tolerable.

Joanne’s inability to function as a mother led to despair. The church’s response (prayer) was not working. Then Joanne discovered she could act and take responsibility for motherhood tasks again. Joanne’s power to take initiative and to act independently returned. This led on to another major step – the vow (P30-32), the outcome of Joanne’s faith work.

Q30 I remember talking to you about the night line, the help line- what made you start that?

30 Well gradually my health improved, because of the vow I made to God - if he healed me, I would work for him, I would evangelise people.

Q31 So OK you did a deal did you?

31	Oh yes absolutely

*Q32	That's interesting.. I remember I thought you'd be good at it*

32	I made a deal - if you are able to take me from this useless faith, I will say I make useful service, I will actually work and encourage other people, other people suffering. I found the call centre, and I tried to discuss which ways I could actually work in the church, and which way I could manage at the beginning. I just felt that answering the phone, I could manage that.

Whilst Joanne's return to motherhood was instinctive and natural, the faith work she does leading up to the vow was more complex. She says 'if you are able to take me from this useless faith' (P32), meaning faith without action and without results. The work that Joanne plans to do is helping others, yet this work will also in fact rebuild her own faith and faith identity, making her once again a useful and respected person in her church. Joanne goes on to discover that the illness world is full of tasks and opportunities. The learning she has done links faith to action – she uses her own experience of suffering to help others in distress. It is only when Joanne starts to act in faithful ways that her self-confidence returns (she had felt a failure), as she learns how to help others.

Joanne's faith background is in a church strong in tradition and authority. Joanne is working out her own faith solution, is challenging that authority, but it is accepted once it is seen to work. There are a couple of interview passages where Joanne refers to her faith work in terms of a process of questioning and reappraisal (P43 and P52).

*Q43	And how did your understanding of faith change - is it the same or is it different?*

P43	Its gone back to before the illness. Before the illness I was really faithful, and I was very strong in my spiritual life. After it became shaky and I was thinking, is certain things true, is certain things real - then you ask questions. But then I think I begin to ask questions, and then I think I began to pick up again, it brings me now to where I was thinking better, and to have even more faith in God

*Q52	And do you tell them you nearly gave up?*

P52	I tell them my stories. I tell them where I have been. I even tell them I once tried to commit suicide. And I tell them if I had committed suicide then, I would not be enjoying what I am enjoying now. And they are not to give up too soon, they must have hope. You know, be patient. You know, some times I think I was saying, is God real, I was saying, is this really a merciful God? All this kind of people, shouting and praying and praising. Nothing was happening. Then gradually I said to myself, I saw things happening, that I was able to do more.

Stage 5 coding of Joanne’s interview, progressive learning, showed even distribution across the learning codes (Table 4.2.2). More than any other subject, Joanne scores high for communicating learning and reinforcement. She regularly gives testimonies and others tell her how this has helped them – her learning is passed on (P51).

Q51 And what sort of response do you get when you give your testimony?

51 Oh people come up they congratulate me. I have actually seen people then, I’ve seen people that actually stayed in the faith, because of improvements they see in me. They come to say – ‘I am still here, but I was on the verge of giving up. Your testimony was for me.’

Later in her story, Joanne has become a star, something of a celebrity in her church. It might then be easy to overlook how she was in despair at first, and had to work incredibly hard to carry out her vow, and make herself useful to others in crisis, instead of focusing on her own trials and hardships. Joanne’s high scores for recovery work and faith work reflect a huge effort, which took place over a number of years.

Joanne’s interview is given in full in Appendix C1. Her story is remarkable both as a survival story and also as a faith document. Of all the participants, Joanne was best able to discern and exploit the specific opportunities the illness world gave for Christian service and witness. To do this, Joanne had to work very hard, learn new skills and show sustained commitment.

5.5 G1 Terry interview analysis – disruption response: ingenuity and creativity

Table 5.5.1: G1 Terry – Stage 4 & 5 coding

Illness work coding	Abbrev	G1 scores	**Progressive learning coding**	Abbrev	G1 scores
Emotion work	em	4	Initial response	ir	6
Grief work	gr	6	Modified response	mr	6
Identity work	id	7	Exploration	exp	2
Faith work	fw	0	Re-evaluation	r-ev	5
Evaluation work	ev	3	Taking responsibility	rsp	2
Recovery work	rec	8	Communicating learning	com	2
Resolution	res	3	Reinforcement/affirmation	rnf	3

Terry's narrative interview was described in outline in Section 4.4 (excerpt P24-26). Terry's narrative is a classic 'trickster' story, in which Terry survives by his wits. The story begins at school, where Terry was bullied, and he works out that he cannot win by force, and so uses words, ridicule and resourcefulness to survive.

Terry's interview begins with dialysis onset and then his stroke. He coped well with home dialysis, but found the stroke traumatic because he lost his speech, which made him as an actor feel totally useless. He worked very hard at speech therapy, making remarkable progress (recovery work) and also revisited his former workplace at the BBC as he describes in P8-10.

P8 No I was making noises, not making any sense. That was when I was in high dependency. Then I was taken to ICU, then I was on a stroke ward – in Brighton this was. I was then released and went home. I still obviously was on dialysis. And I started to get all those big deliveries.

Q9 You were still doing PD at home?

P9 I tried to get up to London. I could talk, I had a lot of speech therapy. But even when I wasn't too good working, I would go back up to London to BBC to see my work people. To make me feel I was still, you know still worth … you know it was my worth really. So it's got better and better – but I can't remember things now.

Q10 So that was January and you got to August with the transplant: so were you mobile by then?

P10 Yes fine, perfectly mobile, walking around – I was starting to speak better. I still had the speech therapy. I had certain problems, talking and remembering.

Terry's plan was to go back into doing radio parts, and start with monologues. He managed the first, but with others he made mistakes, and decided to come off the books with the agent. Terry's strategy then changes, and he takes on teaching work and also paints as a creative outlet (learning - modified response). Terry is a sociable person and he has a group of loyal friends. He describes how his friends enjoy hearing about his narrow escapes, P24-26.

Q24 What about friends and social life?

P24 Loads of friends – never had a problem with that. I'm fairly popular

Q25 Even though you had the stroke and were out of action for six months?

P25 They call me the terminator. It's a survival thing – I'll never die they say. But I'm fairly upbeat most women/people would say. I'm fairly, quite funny and they like me to be around for social events. Not that I try to be.

And I think I have to be. I think I would have gone under if I had not had that sense of humour. Then trouble is, I had a girl friend who was a bit of a psychotherapist. When I became ill I was quite self-deprecating, which I don’t care [about]. I would tell people what was going on and then make jokes about it. And she would say no you mustn’t do that, it’s not good for you. You’re masking things. You’re an actor for God’s sake.

P26 And I would say, no it’s not true, it’s not the point. I’ve had a lot of people say, and I’m quite good psychologically, if I make a joke about me, and they say Oh bless, and I don’t like that – I don’t care. I don’t want that. A lot of people want me to be upset with my situation, so that they can then feel they can rescue me. There’s a lot of rescuers around. So I get that frustration. I have a lot of frustrations - that’s my buzzword today.

This excerpt show how Terry is able to ‘perform’ his story, engage his audience and get positive reinforcement. It also shows that Terry is self-deprecating and resists any form of pity – he hates ‘rescuers’ (P26), and takes pride in not needing help. Terry’s girl friend is registered blind and is also an actor, and they share the same evaluation of their disabilities (P38-39).

P38 She’s got a very healthy attitude about all that. She lost both her eyes when she was thirteen, which I think if I was going to have diabetes at thirteen, I would be hell of a lot worse. I can’t remember anything before that, whereas she went through it. She also lost her father - she’s had quite a life

Q39 She’s a survivor?

P39 Yes, she gets depressed sometimes. Sometimes a couple of prozacs can help. I think I’ve…She says I’ve helped - quite positive. If I was to say to her I’m so sorry, anything like that, she would go mad. And the same if she said that to me. If people say I’m brave, I’m tempted to deck anyone who says anything like that. As far as I am concerned that’s how life is.

Later in the interview Terry is asked directly whether as a survivor he gets better at it (P54-55). In his long response he goes back to the bullying at school, when he used words as weapons. He then later uses the same skills, humour and laughter, to defuse situations in the army (TA), and now uses them as he recounts his illness.

Q54 The survival thing - is it always there or do you get better at it?

P54 I don’t think you need to, if you’ve gone through. I think I had to survive in school. Now there are bigger risks and bigger consequences now. Because school is always a sheltered place, but you learn everything. When you say, you survive - if someone is about to hit me, you either dodge or you hit, pre-empt it or run, you hit, you hit them back, or you talk them down. I would always talk them down. I try to. I would knock them down. I would knock them down with words. The weapon of the words. I’m not a big person a big hitter, but I can talk people down.

P55 I can get people when I even when they’re drunk, I can knock them down. I’ve been in a pub and I would say, come and have a drink, and I would calm them down quite well. When I was in the army I did the army TA thing, I would be at camp and there used to be fractions, and I would go in and have to be a bit of a mediator, and defuse things. And I'm quite good at that. And I learnt that from school – how to make someone laugh. It's a huge thing: you can get rid of it, if you can make someone laugh Your weapons can be made of rubber. You can't be angry at someone when you are laughing. And I love that, I love comedy.

Terry is realistic about the pressure on him to keep on performing. But at the end of the interview he resolves the situation explaining how his confidence is derived. He describes recounting to his Dad how he failed his A Levels, P70-74.

P70 Exactly and I think that's happened quite a lot in my life. But as soon as I got those results which was in India and I said its UN, and my Dad said, No, what, is it really? And I said, No, that's it - that what it is. And my Dad said, What? What are you going to do? Which was an interesting question. Not - Right what we'll do is… No - what are you going to do? And I said, right, I'm going to be an actor. Straight away.
Q71 So you knew?
P72 And then he said, You're going to be an actor? Why do you think… And I said well I've been acting the last two years and probably for the rest of my life – it's perfect and I did. And he feels terrible, that I've had a stroke: he has to worry about it. I don't - I have to get on.
Q73 In the theory there is something about loving the damaged person you don't seems to have a problem with that.
P73 Everyone thinks that at some point I'm going to break down – My God, I've lost enough. I think if that was going to happen, it would have happened by now.

Terry describes how his Dad worries, and then says – 'I don't - I have to get on' (P72). The implication is that if he stopped to worry, he might fall apart. As when earlier in the interview when Terry describes resisting pity, his survival depends on bracketing out the emotion work which occurs below the surface, as Hochschild describes, in order to get on with the task of survival.

5.6 Group 3 Laura interview analysis – creating a new life story

Table 5.6.1 D6 Laura : Stage 4 & 5 coding : Illness work and progressive learning

Illness work coding	Abbrev	D6 scores	Progressive learning coding	Abbrev	D6 scores
Emotion work	em	4	Initial response	ir	2
Grief work	gr	4	Modified response	mr	3

Identity work	id	2	Exploration	exp	2
Faith work	fw	0	Re-evaluation	r-ev	4
Evaluation work	ev	7	Taking responsibility	rsp	4
Recovery work	rec	3	Communicating learning	com	3
Resolution	res	4	Reinforcement/affirmation	rnf	2

Laura is included in group 3, since her life story falls into two parts. As a child and young adult, she was an extraordinary achiever, overcoming the limitations of a rare condition. Her learning, exploration and the praise and reinforcement she achieved were evident. But this now is in the past, and Laura has to adapt to a life of restriction and limitation. It is clear that her natural instinct towards challenge and achievement will not change, but she may have to accept fewer results and rewards.

Laura's story was described in outline in Section 4.5 (excerpts P13-17 and P29-32). In P13-17 her interview describes having kidney failure and then losing her eyesight in school. Laura does well in school in spite of these handicaps, and goes on to do even better in college, where she works with blind children. Laura's story begins early in school, when she is diagnosed with a rare condition – nobody knew how serious this was (P2-3). Laura was picked on in school, but she overcame this by having a loyal group of friends (P8). Laura's incredibly positive response to her illness diagnosis is shown in P13-14.

Q13 So you were already a bit different because of your eyesight. And then you got the kidney failure. Did that make it better or worse or harder in terms of your reactions to it?

P13 Do you know something, I never, I didn't have a reaction to it, I just accepted it I had no reaction at all, it was like I cried it was like, just another thing I had to do.

Q14 It wasn't the end of the world?

P14 No because as soon as I was at home, I asked to go back to school. I just wanted to get back to school in the January. The school wanted me to go back once or twice a week until I got settled in. But I wanted to go back. I didn't realise how low on energy I was, until I got back. I hadn't realised how much energy I did need to be at school. The school were quite helpful. If I wanted to sleep they let me sleep, or if I wanted a rest

Laura continues to be a highly motivated student, even though she has to stop and restart her studies to have two hip operations (P16-17)

Q16 So what happened after that?

P16 I went on to do child care. I got a distinction in that, I got a hundred percent. And then I went on to level three, where you can be a supervisor. I'd done that for six months and then I had to leave to have my hip replacement. And that meant I was off, away for eighteen months from college. And when I returned I had to start the course all over again

Q17 What was that like?

P17 I was quite up for it. I couldn't believe I was only twenty, and I had had a double hip replacement. But I chose to have it – I could have waited until later. But I couldn't cope with the pain.

Laura lives independently for five years studying and helping children with disabilities, which fulfils all her ambitions. She also learns to take responsibility becoming head of student union (P22-24).

Q22 So you enjoyed your student days?

P22 Yes it was really good. I got the best of both worlds. The fact that I was independent, I was living away from home, I really enjoyed it. I was there for five years. It was a long time.

Q23 So were you working with children?

P23 Yes I was. I used to go in the day time and in the evening. I went up to the school, they had children with other long term medical conditions as well, other disabilities. So I used to help them. So it meant that I got my other qualification with helping with children with disabilities on top of my normal child care qualification, because I did it in my own time, which helped. It meant I was always busy, but I didn't mind that.

Q24 So you had a specialist skill as well?

P24 Which was going to help when I wanted to go into an appointment. In my last year I was head of student union, so I had to go to a lot of governors' meetings as well, so I and a lot of responsibility, and a lot of fund raising which was good.

This phase of Laura's life ends when she graduates and goes home – and then her transplant fails (P29-32 quoted in Ch 4 above). Laura uses a number of vivid expressions to describe her feelings at this moment. This was 'a big blow', it was 'upsetting and shocking', my world 'came crashing down'. Laura responds with denial – 'I didn't want it to end'. She understands that the implications of starting dialysis again are that she will lose her independence and all her plans for independent working and living.

Laura's shocked reaction is in sharp contrast to her story so far, when she has accepted operations, emergencies and hospital treatment as a matter of course. Her basic response was to get back and get on (recovery work), and while she was in education this worked well.

There now follows for Laura a lengthy time of evaluation (high illness work score) during which she grieves for her loss and evaluates what life still holds (P55-56).

Q55 What is your inner something that keeps you going?
P55 I always try to think about the positives all the time
Q56 I can see that you're a positive person
P56 I always try to see that there's a light at the end of the tunnel. It's got to be so that you go through all this bad stuff for a reason, to get to the good stuff.

Laura describes battling for survival as the only way to get to 'the good stuff'. For her there must always be a goal, a challenge to work towards. At the end of the interview, it is clear that Laura the fighter is still there (P69-71).

Q69 So what was the biggest disappointment – not being able to use the skills you learnt, child care and specialist skills. Is there a way you can still use those?
P69 I hope so. If I can get a transplant. Otherwise it will have been all for nothing
Q70 So you're on the list?
P70 Yes, I have been for three years
Q71 There's no medical reason why they can't give you one?
P71 They'll give me one. Yes - the next big thing is, I want to work.

Laura is very definite she has no religious faith – it would be impossible she feels to reconcile this with all the suffering she has experienced. But she carries out her belief in 'being the best you can be' by talking to many frail elderly patients on the ward, most much older than her, and sharing their troubles.

5.7 Group 4 Sheila – living in two worlds

Table 5.7.1 D4 Sheila: Stage 4 & 5 coding : Illness work and progressive learning

Illness work coding	**Abbrev**	**D4 scores**	**Progressive learning coding**	**Abbrev**	**D4 scores**
Emotion work	em	5	Initial response	ir	3
Grief work	gr	7	Modified response	mr	3
Identity work	id	4	Exploration	exp	5
Faith work	fw	11	Re-evaluation	r-ev	5

Evaluation work	ev	9	Taking responsibility	rsp	4
Recovery work	rec	4	Communicating learning	com	3
Resolution	res	1	Reinforcement/affirmation	rnf	4

Sheila's story is challenging and difficult. She probably works harder than any other subject in the study, particularly at her faith work – but this does not lead to an eventual resolution. Instead, because of Sheila's conviction that she will be healed through the power of prayer, she is constantly angry and frustrated when this does not happen, yet she keeps on trying. Sheila lives in two worlds, the world of work and social life and the world of illness, and works very hard to hold her own in both. Sheila's illness work codes show that she does a lot of faith work and evaluation work. Her learning scores indicate she is strong on exploring faith and healing and consistently re-evaluates outcomes.

Sheila's story was described in Section 4.6 (excerpts P21-25, P61-63) where she leaves home as a single mother, then struggles to survive. She contacts a church and begins a long faith quest.

P10 So I rang up and said I am feeling really lonely really low, things are going to change with my partner, I am struggling financially etc. The next thing I knew someone came to visit me, and asked me would I like to come to a Christian fellowship in Sydenham, just near where I was living.

P11 So they picked me up, and it just so happened they were running an Alpha course at that time. It must have been autumn. I went on Holy Spirit weekend with them. And it was the first time I witnessed people falling about, being hit by the Holy Spirit, falling asleep, laughing, crying. But nothing happened to me.

Sheila's new faith provides her with social support and community – but she is consistently misunderstood, and moves from one church to another, only finding a church that understands her needs at the fifth attempt. But when her mother dies, she is grief struck and decides to renounce her faith (P22-25 quoted above in 4.6). Two years later Sheila is on dialysis but hates it; her fistula fails and she decides to withdraw from treatment (P29-31).

P29 So the faith has been up and down. In Jan 2010 my fistula failed and I had only been on dialysis three months and I wanted to end it all. I tried to get in touch with a nearby hospice. But I didn't get on with the doctor who was there.

P30 And they said OK, you live in Shortlands you'll be closer to another hospice and so I went there. And that's when I met their social worker. She came to my house actually.

Q31 Is she the social worker there?

P31 Yes, she’s a nurse/social worker, a consultant nurse. Of course at the time I wanted… I think Robert must have called you. I said I wanted the priest to pray over me, somebody called. I don’t remember how you came in to it.

At each crisis point Sheila is insistent, articulate and demanding, confronting doctors, nurses and chaplain. Here the chaplain put her in touch with the one church where Sheila had settled and they gave her emergency support. In time Sheila accepts the dialysis treatment, becomes more compliant, learns to do self-care, and is placed on the transplant list (P35-36).

P35 I had neighbours upstairs who made an awful lot of noise, I wasn’t sleeping well, I was struggling at work, I was working for a very demanding partner, who wasn’t very sympathetic about what I was going through. It was a bit of a dark time. I thought when I moved it was going to be easier.

P36 At end of 2010, I got myself trained to do self-care. got the nurse to train me. I thought then things were looking up. And I moved house in Oct 2010, and I though this is it. Jan 2011 they found a match, on the paired kidney scheme, the date was scheduled for 20 May.

At the same time Sheila’s close friends in her church suggest she goes for healing prayer at a special healing event (P40-44). This is unsuccessful, so Sheila tries another very experienced healer.

P40 We went along, and I was a bit sceptical because there was a woman, a lot of people falling on the floor before the worship songs had even started. And I thought give over – you’re going to put people off, if you start doing things like that.

P41 I went up for prayer to the minister who was delivering giving his healing stories and asked him to pray for me. And he left me in the hands of three other people. They were falling about – it was explained to me that they may have been experiencing some of the pain I had. I have to say that the pain that I had in my neck area and my hip – that’s all vanished. But the kidney failure I still have – I’m still on dialysis.

P43 And now I’m wondering if come the 10th of December whether I will be healed or not.

Eventually Sheila has been to three or four healing meetings in the period before her transplant is due. Sheila blames the lack of results on herself (P49-50). Sheila has shown intense determination, first in finding a church, with many failed attempts and then in seeking healing, without success. The interviewer asks her what kept her going – it was her determination to find God (P51-53).

Q51 What strikes me you have been very determined, although you didn't have great success in fitting in …you kept on going back

P51 I kept on going back for a beating

Q52 What made you keep on going back?

P52 Because I knew that somewhere somehow there would be people like me, there'd be broken people, who God is…I was determined. All I wanted was to get God basically, and I would do whatever I could to get him.

Q53 And did you? Was there ever a time when you felt you'd achieved that?

P53 No I'm still not sure if I have. I know Jesus loves me. I understand.

Sheila's story could have been a classic progressive faith quest – she hit a low point, she turned to faith, and her prayers might have been answered. Sheila does experience moments of deep faith and is also supported by a strong fellowship. But her evaluation and interpretation of her faith experience seems flawed – she dictates a particular solution. Sheila is deeply troubled that she does not have the assurance that other Christians she knows possess (P56-57).

P56 I still wish I could hear Him like other people say they hear him talking to them. I wish that I could. You see if I'm to stay alive John I want to do something good, I want to do good, I want to be a living example and not get carried away in myself. If I'm to be healed of this disease then I want to use it for good, not for my own ego, but for God's ego.

P57 I'd love to be an example. But how do I greet all those other people out there who need to be healed? Like Rowena who's dying of MS and has had lots of problems… when there so many people out there better than me, better Christians, who are suffering like Simon, who's got cancer and two beautiful kids – why me and not them?

Towards the end of Sheila's interview, there are signs that Sheila has learnt from constant setbacks that she will not get the answers to her prayers that she wanted. She describes the emotional cost of repeated disappointments (P79-80).

Q79 What have you found in faith in God, faith in Jesus, that helps you get through?

P79 There are times of calm, there are times of peace. And it makes you forget just how awful sometimes it has been. You remember but it doesn't hurt you and affect you as bad as it used to, when you recall it.

Q80 Have you found any kind of spiritual strength that you didn't know you had?

P80 Yes, I suppose I have because its deepened my hope in Christ. It's given me more hope. I actually think I am calmer than I used to be

Sheila is now also able to focus on her fears about the transplant – but she is also able to envisage Gods protection over her during any danger (P85).

Q85 Moving forward from that, so you've got the possibility of a transplant in Feb- how will you deal with that in terms of your faith?
P85 I will still be scared I will still be hoping that Christ will be with me every step of the way. And did have a dream once when I was at a low ebb: he was talking to me and he told me not to be afraid because he would be there at the other side. And I was kind of hoping that I was going to sink into oblivion then - but it didn't happen.

Sheila's story is important because she acted out and disclosed her pain in obvious ways, which led to her receiving help and eventually at least containing if not resolving some of the anguish she felt. The other subjects in the Group 4, Winston and Faith, were less open – their pain continued to exist below the surface, but they would not disclose it. Sheila truly represents Brueggemann's description of lament (1.9) – an insistent, loud and confident voice, demanding to be heard (cf. Stella, Kleinman's patient in Good 1994), by both God and others. Other patients do not have this confidence – they feel their pain is illegitimate, unreasonable and maybe shameful, they fear those who hear may think worse of them for not being stronger; or worst of all, they fear it shows that they have indeed been abandoned both by God and by others.

Sheila then as the bold confident and articulate sufferer is unusual, perhaps highly exceptional among dialysis patients, who normally disclose little. Dialysis patients have no shared, authorised collective discourse about suffering, such as other patient groups have created. Her example may be useful in the follow up study of patients reacting badly to dialysis, who display their negative responses in round about ways – through non-compliance, hostility and negative behaviour, yet rarely recount the profound suffering they undergo.

5.8 Coding Stages 1-5 – results and overview: reflexivity & reactivity

The results of all five stages of narrative coding are summarised in Table 5.8.1

Table 5.8.1 Summary of narrative coding Stages 1-5 - results

Group	**G1**			**G2**			**G3**			**G4**		
Subject code	J5	D13	D5	G1	D7	J7	D6	D12	D11	D4	P3	D19
1 Narrative/ reflection												
Narrative (N)	14	19	17	26	17	31	18	18	13	27	24	14
Reflection (R)	10	14	17	26	10	15	14	8	9	22	12	6
2 Five part narr. quest												
Good Health	2	1	8	**14**	4	2	6	1	2	1	6	10
Illness & Disruption	9	7	6	12	3	14	6	6	5	**18**	5	11
Expression & evaluation	3	6	11	**17**	7	12	6	6	9	8	8	12
Life Recovery	7	8	4	8	12	12	4	**13**	11	8	5	4
Resolution	4	4	2	2	3	3	2	4	4	2	0	0
3 Disruption - response												
Faith responses (1)	7	11								12	5	0
Non-faith responses (1)	8	4								3	11	5
Faith responses (2)	12	7								13	12	7
Non-faith responses (2)	1	2								3	5	7
4 Illness Work												
Emotion work	3			4			4			**5**		
Grief work	2			6			4			**7**		
Identity work	3			**7**			2			4		
Faith work	5			0			0			**11**		
Evaluation work	4			3			7			**9**		
Recovery work	7			**8**			3			4		
Resolution	2			3			4			1		
5 Progressive Learning												
Initial response	3			6			2			3		
Modified response	3			**6**			3			3		
Exploration	2			2			2			**5**		
Re-evaluation	2			**5**			4			**5**		
Taking responsibility	1			2			4			4		
Communicating learning	3			2			3			3		

Reinforcement/affirmation	4			3			2			4		

The results of each stage of the coding process are set out in the table and explained below. The narrative analysis evolved over time and reacted to the data as it was analysed. In the original method planned (Section 3.3), only two stages of coding were envisaged, narrative coding and theoretical coding, to substantiate the five-part progressive quest. But the distribution of stage 2 coding results found that they did not fit into a clear five stage sequence. Joanne’s coding diagram (Appendix C3) showed a scatter pattern, suggesting that the response pattern was continuous – subjects were reacting to disruption all the time as it occurred. This led directly to the disruption-response cycle model (model ii) as a concept. This was a much simpler model, which depicted chronic illness as simply a repetitive series of disruption cycles, a kind of endless treadmill, with no apparent plot, meaning, structure or ending.

This pessimistic analysis did not however fit with the picture of the narratives derived from narrative enquiry in Section 4.7 above. A key finding of Chapter 4 was that subjects create a script, a story plot, which defines their role and their preferred way of responding to the illness. This plot at first arises from past events describing the way the subject responded to illness at the start, and began to make progress. It is then projected into the future: the subject must now enact the responsibilities and roles the plot describes. But the illness is unpredictable and limits or undermines the plot and the role the subject has chosen. This leads to learning, to damage limitation and the hard work of recovering and sustaining the story plot.

Here then was a different way of looking at illness narratives. If they were made up simply of repeated disruption cycles, then subjects might respond to disruption events in an ad hoc and pragmatic way, recovering what they could, and letting the rest go. But these disruption events in fact constituted a threat, a danger, an affront – they threatened the person, their role, their identity and their faith in a fundamental way.

This meant that the subject is always working, always enacting and performing the illness story they have chosen – there is never any time off, since this activity is fundamental to survival and identity. After the theoretical coding process was completed, the five-stages of coding were plotted against timelines (disruption response coding Stage 3) for four subjects, and this showed that the four continued to work hard at recovery even after severe disruption events, when they had little energy left.

The original theory model derived from the literature did not then fit the data derived from studying dialysis patients. But instead the narrative enquiry and analysis process produced a different theory model which seemed to fit better with the observed data. This second theory was that subjects with chronic illness create for themselves illness narratives which describe specific roles and responsibilities which they then enact and sustain. This process is difficult and arduous and can easily be undermined by further adverse illness events. The subjects respond by learning, by finding more effective responses, and by doing different kinds of illness work.

The theory building stage then grew out of the analysis process to form a different theory from the one used to design the theoretical coding process (Stage 2). This then led to the reflexive question, what kind of coding process might be used to substantiate the new theory and evidence it from the study data? The theory was formed using narrative enquiry (Chapter 4) – why did the subjects tell their story in this particular way? But if the outcome of the story plot and the role it defined was learning and illness work, then these should be clearly visible in the study interviews. This was then tested by coding stages 4 and 5, illness work and progressive learning. The coding results in table 5.8.1 show that all the categories of illness work and progressive learning chosen were found consistently in the four interviews recoded – one from each group. The only exception was faith work, because two of the four subjects chosen did not have any particular faith.

5.9 Summary of interview analysis and coding stage

Section 3.2.2 above describes the two types of narrative study method – narrative enquiry and narrative analysis. The study used both, the first to capture the overall thrust of the narratives in Chapter 4, and the second to evidence different quest stages and different kinds of work patients were engaged with in Chapter 5.

Chapter 4 described how subjects construct illness stories and choose a specific narrative plot. This plot explains how they responded to illness initially and guides and determines future responses to disruption. Frank (2010.139) describes ‘the fundamental question of narrative habitus: who gets caught up in which stories, with what effect…’ Because subjects are ‘caught up’ in a particular narrative, they become totally committed to it, and continue to act out this specific plot so long as they can. The narrative then becomes a survival manual and a learning record, which is then added to, applied and revised in each successive episode.

Chapter 5 describes the five-stage coding process used for narrative analysis. The first two stages of coding were used to establish the primary five-part narrative model (2.3). In this progressive story plot the subject becomes more adept over time, always working at life recovery. Next came the pragmatic survivor plot (disruption response model ii) where the subject wins some and loses some, and is satisfied with whatever can be recovered. Both these plots place responsibilities on the subject to fight back as best they can - an ongoing struggle. Model iii removes this responsibility – the old life story can be written off, as can the responsibility for recovery. Instead the subject begins again, and redefines the life responsibilities he chooses to take on, so that these may be more practical and suited to the limitations of illness. But the final ‘two worlds’ plot once again places heavy responsibilities on the subject, who now has to ‘keep up’ and meet the demands placed on him in both life worlds.

The coding process produced a set of neat, orderly results as shown in the table above. At this point it was important to review the data to see what else was present. Did the data show up any unexpected or confounding features, which did not fit into the theoretical framework the study had set out so far?

Organising the study narratives into four groups by narrative plot suggests that these narratives are in some way standardised and fit exactly into a theory model. In fact, the illness narratives being studied, were varied, open, indeterminate and incomplete, and were still being recounted by patients, with no certain ending. The narrative models built from theory by contrast had a much more definite and resolved structure. The primary study model for example seemed to suggest that patient could work through all five illness stages consecutively, in a logical way, until resolution was achieved – but this rarely happened in practice. There therefore appeared to be a disconnect between tidy theory and messy, confusing reality. How did the study resolve this?

In essence this conflict and contrast was itself a vital key to understanding patients experience – the way they respond to illness. It was precisely the indeterminacy, uncertainty and unpredictability of chronic illness that constituted its greatest threat: as Illich points out (1977), meaningless, unstructured and random suffering is for humans unbearable. The illness narratives primary purpose is therefore to give a predictable order and structure to an unpredictable illness world. The order is created by the story plot.

Another important finding from Coding Stage 4 was how hard the study subjects appeared to be working. A general picture from the literature (Tsay Lee & Lee 2005) might suggest dialysis patients are listless, inactive, apathetic and depressed – but not these patients. This observation at first came from observing faith work - the work faith subjects did as they grappled with the faith issues the illness presented, and applied these to daily living. The nature of faith is such that it transcends time and circumstance – faith members will continue to work at and apply their faith in past, present and future time (Barth 1982, Moltmann 1967). But the non-faith subjects had just as clear an idea of their life goals and purposes, how they wanted to live, and worked tirelessly to make this happen in spite of the illness. It therefore seemed important to describe and analyse the illness work that patients did, and see how this might fit with the theory base of the study as it evolved.

The learning hypothesis, Coding Stage 5, was a logical development both of the primary progressive model – patients needed to learn how to manage the illness better – and of the disruption response model. Because disruption is so frequent and repetitive, its impact would be cumulative and quite soon overwhelming (Charmaz 1991, Ricoeur 1992) – unless patients were learning all the time how to manage it better. But there seemed to be another aspect of learning which was less obvious. The primary model (2.3) suggested that patients move in stages from disorientation and inaction to a point where they deal effectively with most of the disruptive impact of the illness – but this might seem too good to be true. The illness is progressive, so there will always be new and increasingly difficult challenges to face. But learning includes learning to deal with failure and loss, which is an inherent part of chronic illness, together with its emotional impact. The learning hypothesis therefore must include emotional learning, which takes account of failure, for example failed life recovery attempts, and the emotional impact of these. This results in accepting losses, targeting achievable goals, and conserving scarce energy.

Good evidence for illness work and progressive learning was found in the interview coding process. Did this then solve the conflict between theory and practice - where the real-life stories studied did not at first appear to fit exactly into the theory model proposed? This was perhaps seen most obviously in models (iii) augmented narrative and model (iv) living between two life worlds. In augmented narrative the illness crisis is so far reaching that any idea of recovering the previous life story is lost. Instead a new different life story living with the illness is begun. But letting go of the first story is letting go of the self, as expressed through its many core activities, and may lead to a profound loss of identity, grief and suffering (Ricoeur 1968). In model (iv) the life world of illness is seen as hostile and dangerous, and the subject works hard to continue to live and work as much as possible in the normal world of good health. The illness world threatens all that is important to them - the freedom to act, work, and have a social life. But as they are forced to spend more and more time in the illness world, they experience grief, alienation and suffering (Pannenberg 1985).

5.10 Summary of data stage

The data stage of the study in Chapters 4 and 5 has analysed the interview data alongside the theory base set out in Chapter 1.1 and 2.3. It found that the evidence did not support the theory in its original form, which suggested that patients progress through five illness stages, (good health, illness and disruption, expression and evaluation, life recovery and resolution) in a clear, ordered and sequential way. Chronic illness is made up of disruption cycles each of which may contain all these stages, but they are not clearly defined and separated. Instead the patient in each cycle uses expression, evaluation and recovery skills learned in previous cycles to respond to further disruption.

The theory building process began in Chapter 4 described the narrative quest in a different way. The purpose of the illness narrative was now to define how the subject responded to illness, and to develop that response into an ongoing story plot, creating a role that the subject could sustain. (Gerhardt 1986 Frank 2010). Enacting and sustaining this role involved progressive learning and illness work, which were evidenced from the study narratives in coding Stages 4 and 5.

But the data analysis also found data that did not exactly fit within this mainly positive and constructive interpretation, that patients could indeed construct consistent illness stories which defined their roles, made sense to themselves and others, and gave the illness meaning. But all the interviews contained clearly defined crisis episodes which vividly describe an illness crisis – bad news, an emergency admission, a dangerous operation. Dawn’s TB diagnosis and Doreen’s failed operation to restore her sight are examples. These stories contain heightened language and emotional expression, and often describe times when the person has no control over events, and may experience great fear, distress and uncertainty. These story episodes do not in any way fit into a ‘progressive’ illness plot: they simply describe vividly the reality of fear and danger, and the complex emotions the persons feel as they lose control of events. Similar in kind are the reflective passages which come after a crisis a tragedy, for example Faith describing the death of her father, or Dawn the deaths of her two brothers. How could this have happened? Why did it happen to them and not to me, they ask? There is no clear answer.

Data Chapters 4 and 5 then offer a contrasting story. On the one hand there is ample evidence from the interviews and analysis that subjects have indeed constructed a continuous and consistent illness story, which has a clear plot, and describes well the narrator’s own specific response to the illness and the role they took on. On the other hand, within all the narratives there are accounts of suffering, crisis and distress which stand alone. This is the raw, harsh irreducible reality of chronic illness, which cannot be altered or changed (Soelle 1975, Strauss & Corbin 1988). Chapters 6 and 7 will explore further the relationship between these two kinds of data, and whether they can be integrated within the study’s theoretical framework.

Chapter 6

Discussion – reviewing the data: theory development

6.0 Introduction: reviewing theory and data

The narrative enquiry and analysis process described in Chapters 4 and 5 yielded very positive results. All twelve of the study participants had produced detailed full-length illness narratives. They had emplotted these illness stories in different ways according to their own response to the illness, and the role they chose to take on. Their stories showed a high level of consistency and continuity: even though there were crisis and interruptions, the stories continued on, with a consistent plot. The stories contained progression. Most subjects were unsure at first, but over time became more skilled and competent in dealing with the illness. Chapters 4 and 5 then create a picture of dialysis patients as competent actors and narrators, who had learnt how to live with a difficult illness, and still fulfil their own life choices and objectives in some way. Ch 7.5 will discuss how this emerging picture differs from the normal description of dialysis patients found in the literature, and gives possible reasons for this.

How did the data findings from Chapter 4 and 5 compare with the theory base of the study in Chapters 1 and 2? Chapter 1, the untold unfinished story, suggested that the uncertainty and indeterminacy of chronic illness (no cure) made it a difficult story to tell. But the study subjects had overcome this problem by describing how, whilst the illness had remained the same, they had become better at dealing with it. The five-part progressive narrative quest (2.3 – 2,8) described a patient progressing through five consecutive stages, as they learnt to manage disruption, evaluate life potential and plan and engage with life recovery. Inevitably this ideal model was not visible every time in the data. But some patients' illness narratives (Group 1) did show the key feature of this plot, the progressive quest: the subjects progressed towards a better adaptation to their illness, became more skilled and were able to enact the role they had chosen. Other patients chose different plots (Groups 2, 3 and 4); but having done this and described an illness role, they were also successful in carrying it through. The only exceptions were the Group 4 subjects, living in two life worlds, who found that meeting the demands of both worlds (conflicting roles) became hard to sustain.

Although not all the study subjects chose the progressive quest plot, they all recounted sophisticated illness narratives with a continuous plot which carried on through many episodes. Their stories about chronic illness were not confused, disorganised and chaotic, as one might expect; instead they created order and continuity, counteracting the unpredictable and disruptive nature of the illness. The illness narratives communicated feelings and described suffering and loss: the research format (recorded interviews, confidentiality) seemed to enable more open disclosure than was normal in the setting. Disclosure was carefully managed: the faith subjects were careful to present themselves as faithful believers, even though they had had times of despondency and despair.

This chapter takes forward the theory building process. Starting from the interview data, it discusses specific examples which generate concepts leading to the seven main findings in Chapter 7 – progression, role responsibility, the learning response, chronic illness work, sustainability, containing suffering and counternarrative.

6.1 Theory development – core concepts, narrative structure

A process of theory development occurred during the data analysis. Firstly, the goal of the narrative quest was redefined as a quest for role responsibility, not life recovery. Just as the theoretical debate about the sick role (2.1) remained unresolved, so also illness subjects were presented with an open question – what role might they now have? This would be worked out in the illness story they chose. Examples of specific roles the study subjects took on were Joanne’s help-line role, Dawn’s youth minister role, Laura’s children’s worker role, Terry’s teaching role and Peter’s events organiser role.

Secondly the repetitive disruption response cycle process observed uncovered the learning response – patients learned more effective illness responses over time. This learning process was observed in more detail through an extra coding stage (Stage 5: Progressive Learning coding), which uncovered the various kinds of learning that took place – modified responses, communicating learning, exploration, taking responsibility and receiving reinforcement. The redefined narrative quest for role responsibility had a specific consequence – patients undertook illness work of different kinds so that they could continue to fulfil the role they had undertaken. Two kinds of illness work were observed during Stage 4 coding – emotional and intellectual work (emotion work, grief work, evaluation work, and faith work) and active physical work – recovery work and resolution (balancing recovery work against resources to achieve a stable outcome)

The focus of the data analysis process therefore changed from its original objective, testing the primary five-part narrative quest model, to testing and refining the narrative role quest model, including studying the impact of the role quest observed on patient behaviour, in particular in the learning response and in different kinds of illness work.

6.2 Emplotting chronic illness - defining the task

Chapter 2 built up a model of chronic illness based on literature. This was tested against the data. The model was based on Labov's story structure – orientation, complication, development and resolution. The story plot hinges on resolving the complication (disruption) in a satisfactory way. In the case of chronic illness, the complication/ disruption can never be resolved; the illness will not be cured or go away. Therefore, a different task is needed as the goal of the story plot. This task may be to absorb the impact of the illness, reorganise one's life and go on living as one did before. Alternatively, the task may be to accept that the old life has gone for good, and illness requires a different way of living. In either case a story plot can be constructed, recounting how the subject did indeed rebuild her life, step by step, or describing the many difficulties and setbacks she encountered. The subjects learn to respond more skillfully, and so a survival story role develops about the skilled survivor who conquers each successive challenge.

By what process did the study subjects come to emplot their illness narratives? The story plot did not emerge on day one in its final form. These stories all begin with confusion and uncertainty. This suggested that there were two stages in creating an illness story: the early stage, where the illness onset dictates events, and the subject has no control over them; and the second stage where the narrator creates a story plot, decides on his role, and responds to illness in a consistent way. The first stage is uncomfortable and disorienting for the subject, who seems helpless to begin with. Creating a story plot grows out of an exploration of the illness world to see what possibilities it has, a learning process – and the new story plot reflects what the subject now believes they can do.

6.3 Finding a role– redefining the narrative quest

The original five-part quest model had a pragmatic and adaptive basis – that life activities should be based simply on what could be managed within illness. The evaluation stage was seen as vital here – life activities would be carefully evaluated and divided into those that could be continued and those that could not. It assumed the patient was a rational individual, who would only undertake tasks that were suitable, sustainable and practical during illness. But this assumption proved to be false. Patients invest emotional capital and moral value in activities that are important to them, and seek to resume them, whether this is practical and achievable or not. There follows a difficult learning process, finding out what can and cannot now be done. If the patient discovers that all the things he tries to recover are now impossible, he has reached a dead end.

This observation led to reconsidering the goal of the narrative quest. The quest at its heart is a quest for worthwhile action and participation, a quest for value, worth and identity – linked if possible to the values the individual is already committed to. But in fact, roles are flexible and adaptable – they need not be exactly the same roles as the subject carried out before (although this is what most patients would like). In Joanne's story her recovery began with her resuming domestic tasks – she could be a mother again, and care for her family. Only later did she take on responsibilities in the church. Roles also progress and develop, starting with caring for oneself, then caring for others. Doreen derived enormous pleasure from caring for and being helped by her young grandson aged three.

If then the narrative quest is redefined as a role quest, and not a performance/activity quest to determine which activities the patient should undertake during illness, then this offers much wider possibilities and choices. It is likely that over the course of a long-term illness a patient will carry out different roles, more active ones at first, more limited ones later. It also allows the subject to 'turn down' responsibilities which they feel they cannot fulfil. In the dramatic life change model iii, the narrator decides that none of the old roles are possible any more – a new life story has now begun with different roles and responsibilities. Dawn and Joanne are fortunate in that they are offered roles in the church that use their particular skills and experience. Other subjects are less gifted than they, and so do not find ready-made roles to fill. But they can choose to follow a career as a patient, as Terry does, and surprise and delight their support group by how much they can still achieve. Peter finds a new role in the old people’s home on the events committee. Bob becomes useful by demonstrating how to use the dialysis machine to new patients on the pre-dialysis clinic.

Redefining the narrative quest in this way then makes sense of other observations from the data. Some patients (Joanne, Terry) work extremely hard to find new roles and take on more responsibility. Others like Faith, Sonia and Tom are more relaxed – they are doing as much as they can manage. Resolution occurs when the role demand is consistent with time and energy available. Sonia, once she has her sheltered housing unit, is content to look forward to weekly visits from family. But the role quest also has risks – not all roles are suitable, practical and achievable, the patient may choose roles that are too onerous and cannot be sustained.

6.4 Enacting the story - chronic illness work

Whatever plot the subject has chosen, the patient must now work hard to enact and sustain it. Much is at stake here. The story plot in essence sets out to show that the subject is a worthwhile, conscientious and capable person, who in spite of their illness fulfils their responsibilities to society and to others (Gerhardt 1996, Morgan 1988). This is not easily done and requires commitment and dedication. The data suggests that chronic illness work is present in all the accounts studied – all are committed to the story they have chosen, and work hard to sustain it.

What then were the types and variations of illness work found? Stage 4 coding discovered emotion work, grief work, evaluation work, faith work, recovery work and resolution work. The first three were ‘invisible’ kinds of work, mental or emotional processes which nevertheless had to be done, before any action towards recovery could start. Examples of these were Faith’s grief at her father’s death, and Dawn’s grieving process after the death of two brothers. As Hochschild (1983) demonstrated, negative emotions disable and confuse, preventing effective functioning.

Other kinds of work were done which were incomplete, interrupted and unsuccessful. Choosing and sustaining an illness story requires experience skill and knowledge. Among the patients studied, Winston and Sheila in particular kept on getting it wrong. Winston made disastrous business and career choices, Sheila’s faith quest constantly meets obstacles and setbacks. For them learning meant emotional learning, learning from loss and disappointment, learning to re-evaluate their life potential in a different way. The narratives have periods when the story stands still: the illness work needed in order to progress to next stage has not yet been done.

6.5 Learning from experience - the learning response

Many different kinds of learning were observed from studying the data. Coding stage 5 identified initial response, modified response, exploration, re-evaluation, taking responsibility, communicating learning and reinforcement. The subject’s initial illness responses were later modified. Choosing a story plot and a role required exploration of the illness world, and the opportunities it contained. Loss and damage caused by illness disruption led to emotional learning. Failure in selecting and carrying out sustainable recovery tasks led to grief work and re-evaluation. Specific examples of learning included Peter’s response to depression when he sought company and companionship by moving into a care home. Faith moves into her own bungalow in her twenties so she can live independently, but later needs carers to help her with daily tasks. Tom longs to walk again on his prostheses, but learns eventually that the effort required makes him too exhausted.

Communicating learning was observed in only a few subjects (Joanne and Dawn) who recounted their stories in a public way to their faith groups. This allowed them to receive reinforcement and affirmation. But it is likely that other subjects recounted their stories in less public settings to friends and significant others, and so received affirmation in another way.

The study observed that the dialysis unit was not an active learning environment, where learning could be shared. This seemed to stem from the basic requirement which patients set themselves that their illness stories should present themselves as capable and competent persons in the public domain. But their illness stories also contained accounts of disappointment, failure and suffering. Learning from these experiences formed a major part of the learning and illness work patients did. They found ways to express and limit the negative impact of suffering and loss. The open description and expression of crisis moments helped subjects to own the suffering as their own, part of their life now as a patient. But this learning could not be passed on except in a protected, confidential and safe situation.

Spiritual learning also occurred and was described in interviews. Dawn describes studying scripture with her mother, as they shared the spiritual pain of family bereavement. Winston through a variety of personal spiritual experiences at times of crisis learnt that God had not abandoned him: this helped him though his times of despair. Tom describes how from reading about Job in the bible he learnt how a person might retain integrity and self-respect during affliction. Patients learnt through faith work to perceive the illness world in different way, as a place of spiritual experience and opportunity as well as a place of danger.

6.6 Sustaining the story plot – progression

The basic narrative structure used in the study (1.1) requires that the story plot moves forward: there needs to be development and progress, the story must move on. Subjects create progression in different ways. They begin by recounting their helplessness at initial diagnosis, and then describe their growing level of skill at managing disruption. Alternatively, the illness is so destructive that nothing can be saved; beginning again from nothing is also a powerful story, as the narrator starts to build a new life from scratch. In the ‘living in two worlds’ story, the subject is walking on a tightrope, always balancing conflicting requirements. But even here progression is possible, since the subject may be able to scale down commitments in one world, in order to focus more on the demands of the other.

Sustainability is another aspect of an illness narrative. Clearly in long term illness, short term gains are of no value, if they are quickly cancelled out. The study subjects seemed able to make careful choices and invest energy in those activities which were sustainable. Doreen commits to attending blind groups because they arrange to collect her and bring her home. Peter re-joins the catholic church knowing that this will offer him long term pastoral support. Sonia moves to sheltered housing which will provide her with some independence as well as support. Faith is a member of a church cell group who help her through her illness crises.

Sustainability is clearly the most difficult aspect of the chronic illness story to achieve. The disruption response cycle continues, one disruptive event follows another. Why then are subjects not simply overwhelmed, to the point that they give up as Charmaz (1991) suggests? Even Dawn, a high achiever, treasures the particular times when for a moment you forget that you are ill – the burden is lifted. Religious faith contributes to sustainability by virtue of a different time scale and perspective. But most of all faith legitimises and validates the experience of suffering and loss, and places it inside the context of faithful living. Most major religions account for suffering and place it within a framework of meaning. This helps the sufferer to understand that that his experience is not pointless and meaningless, but is an integral part of human existence.

Although they did not always win, the study subjects found ways to sustain their stories through setbacks and crises. The skilful survivor must shrug off a setback and move on. Narrators recount small wins with relish: Doreen's victory over the cab driver, Peter's trip to the bank manger to put his financial affairs in order, Sonia's fight to get a sheltered housing accommodation and Tom's continuing battle to walk upright on two artificial legs – these small victories have immense significance, and contribute to sustaining a progressive story plot.

6.7 Expressing emotion - containing suffering

Expressive accounts of suffering were found in most of the narratives. The study data also showed that subjects seemed isolated in their experience of suffering, which they were reluctant to disclose. Culture and society give special privileges and respite to the grieving and accept their need for solidarity and support. Chronic illness at its heart is an experience of suffering and loss – people may survive only if they find validation, acceptance and support of their role as sufferers.

The narrative framework of the illness story offered a specific structure within which accounts of suffering were set. Expressive and detailed descriptions of crisis events are a key feature of the narratives and are an essential part of the stories. These descriptions were expressive and emotional, alive and raw – their emotional impact remained powerful. It did not appear that the subject had in some way 'processed' the suffering, so that it had now lost its impact.

Ricoeur (1992) suggests that in a tragedy. the story plot may overwhelm the character, who can now no longer control events. But here it seems that accounts of suffering exist alongside a progressive story plot which the narrator sustains. The plot may be interrupted, the crisis occurs and then the plot resumes again. The narrator cannot prevent either the suffering or its impact, but can then go on living, taking responsibility for those aspects of life over which she still has control. The narrator takes on and includes these crisis events in her story. They are not described as unfair, outrageous or disastrous, but are recounted as they happened. Ricouer's term imputability (ibid) describes taking on a story, perhaps an experience of suffering, which one did not wish for – but it happened and is recounted truthfully. The narrator is able to contain the impact of suffering because the story plot has sufficient strength and momentum, to continue and carry on.

Examples of vivid accounts of suffering were Dawn's experience of the family visiting her in hospital when she nearly died. Faith's response when hearing of her father's death. Winston's account of his wife's death from cancer, and Doreen's account of the failure of the operation to restore her sight

6.8 Re-evaluating responsibility - faith work

Faith work was described in the interview accounts and recorded in Coding stage 4 (5.3 and 5.8), faith subjects had to deal with aspects of sustaining their belief and practice, which the illness made more difficult. This included practical aspects of attending worship, fulfilling faith responsibilities and participating in the faith community. All of this was made more difficult by the illness and the reduced energy and mobility they experienced. At the heart of the problem lay a conventional definition of faith, which prioritised attendance and observance – faith as performance, lived out in the context of a faith community made up of mainly healthy active people

The faith members in the study approached the problem in two ways. Some through life-long habit placed a high value on observance and membership. They also tried to keep up with faith responsibilities and commitments as much as they could. The difficulty with this approach was that in time they would find this increasingly difficult, and might then see themselves as second class members, not really performing as they should. Examples here were Tom, Patrick, Doreen and Sonia, all regular church goers. The other approach was to re-evaluate for oneself the requirements of one's faith as they applied to illness, and then redefine one's own responsibilities. Faith groups did not offer much help here. If a person was sick they were quite happy to exempt them from attendance and other tasks – but this was not what study members really wanted.

Joanne and Dawn were able to redefine for themselves what faith in chronic illness might mean. Joanne's problem was that her faith group had expected her to be healed, which left her with a sense of failure, which her vow to serve God was able to redress. Dawn had not been an active church member, but came to faith during illness through her mother. She learnt to trust and depend on God during a number of illness crises. Sheila too encouraged by church members pursued faith healing with great determination, and was devastated when this did not happen.

These stories showed two opposite reactions from faith groups. The first was to absolve the long-term sick of responsibility, whereas in fact they wished to retain responsibility as long as they could. And the second was to place an impossible burden on them, the requirement that they should be miraculously healed, which led to severe distress and disappointment. But faith subjects showed both maturity and ingenuity in the way they dealt with these pressures. Firstly, they re-evaluated their faith deciding that if it was worth anything, it had to provide help and strength during illness. They found for themselves valuable resources in scripture, prayer and in real life accounts of those who had turned to their faith during times of suffering. Secondly both Joanne and Dawn gave testimonies in church about their faith experiences, which described how their faith had helped them overcome severe illness crises. Their stories were celebrated by the church, giving them support and encouragement from other members.

Tom, a convert to Christianity from Muslim faith, had read the book of Job twice and strongly identified with Job's affliction. But he had a real problem with Job's complaining attitude – Job frequently protests to God that his suffering is unjustified, whereas Tom's faith background suggested that acceptance must be the only faithful response. For these subjects, faith played an important part in containing suffering. Brueggemann (1.9) sees disclosure complaint and expression of suffering as a core part of the covenant relationship between God and the believer. If he is right, then believers have a responsibility to disclose and account for their suffering to God and others, so that their faith may be applied to all of life. Scripture stories about suffering involve the reader, who may relate these to personal experiences. Moltmann (1.6) discusses suffering and hope where suffering engenders and produces active hope, which affirm belief in salvation. Root (1.5) describes the process of salvation as an event which removes deprivation. Here the deprivation is not the deprivation of good health, which cannot now be changed, but the deprivation of God's blessing and presence which suffering had seemed to suggest.

Faith then provided a life line for those subjects who were able to apply traditional faith within their new situation. The result for them was a different kind of faith, born out of wilderness and exile, which was able to dispense with observance and performance when these were no longer practical. They showed a pioneering and innovative approach to faith, exploring the illness world as a place of opportunity, and found there many people who were in desperate need of faith resources. But most of all, they helped themselves by recreating a new faith pattern which allowed them to take responsibility for themselves and act in faithful ways. Joanne and Dawn both succeeded and were recognized by their faith groups as people with outstanding faith, who had endured suffering, and so could help others.

6.9 Counternarrative – the hidden story

Section 6.7 above explained that the illness story contains the suffering it describes without resolving it or diminishing its impact. The study has also shown that patients manage disclosure – they do not readily reveal the suffering they have experienced, when this may be seen as abnormal. Dialysis patients are accustomed to live in an environment where suffering is not easily disclosed. This creates a specific tension within each individual – who am I really: the story that I tell about myself in public, the capable, competent person, or the story that I may tell myself and a few trusted others, the person who suffers, and sometimes experiences despair? For the religious person, this tension is just as great. Am I the dutiful, observant and righteous person that my faith group observes, or am I in fact the person who suffers, who sometimes doubts, who sins and falls short of the responsibilities that faith requires of me?

Within the study narratives this tension was most clearly seen in Sheila’s story. Sheila constantly tried to live up to a faith story which she saw devout Christians she knew living out. They seemed serene, together, confident and untroubled, whereas she constantly battled with illness and its disruptive effects, and so failed to live up to the high standards her faith required. Most of all, Sheila refused to accept suffering; it was wrong, against God’s plan, contrary to the blessings that faithful believers should expect. This meant that Sheila was rejecting a part of herself, the suffering person, and so was in constant conflict.

Nelson (2001) defines counter stories (counternarratives) as those which position themselves against master narratives found in our culture that summarise socially shared understandings, in this case society’s beliefs about chronic illness. Individuals may tell their own personal counternarrative in different ways. It may be a hidden story which they tell only to themselves or perhaps a few trusted others. Or it is told publicly in which case the person is positioning himself as a rebel against the accepted position. Terry in the study told a counternarrative about the unpredictable and resourceful survivor. Terry also refused to engage with suffering, because he would not accept the pity and concern that society wishes to bestow on sufferers.

What then is the function of these counternarratives - who are they for? They represent a conflict, certainly, but in the end, who is right – which is the real story? Human beings as social actors create narratives of normality about themselves. As Goffman observed (1990) they manage and conceal the spoiled identity which society imputes on those who remain ill, and will not be cured. But do they believe these stories they tell? The study suggests that they do not accept the story and role which society has made for them, but instead create the own counternarratives and roles which they passionately believe in, which sustain them throughout their struggles.

The resourceful survivor story is a good example of a counternarrative that is acceptable, because it confounds normal expectations that this person will just get worse. But can a counternarrative about underserved and prolonged suffering ever be acceptable? In the end the question does not matter, if the person has already engaged with, taken on and lived with this role, and knows that this is who they now are. This is the truth – whether other people can accept it, or would rather recoil from it and ignore it, is now down to them. In the context of faith, the believer is transparent – God knows the thoughts of his heart and also witnesses the way in which he suffers. This then is the ground of faith – God accepts me as I am, sick or well, whole or scarred. This is the foundational moment, whether enacted through self-acceptance or through religious faith, when the person understands who they now are and accepts it. The crisis of witnessing the study discovered involved the struggles the study participants experienced to reveal who they were, in a setting where this was hard to do. Yet their stories which were highly developed, consistent and well-crafted showed that they had against the odds achieved this in this difficult environment. These stories were not improvised and put together for the researcher in an ad hoc way – they had existed long before, and had sustained and guided their tellers throughout their illness.

6.10 Summary of Discussion Chapter 6

The discussion chapter has reviewed the main theoretical concepts and found close connections to the study data. Illness narratives are carefully emplotted and allocate specific responsibilities onto the subject who is also narrator. These will reflect the subject's life goals, and also the life potential the subject still foresees as achievable. The literature base for the study covered the key themes later explored – narrative reconstruction, disclosure, responsibility, identity, narrative continuity and building a consistent self-story. The theological literature used in Chapter 1 (Barth, Moltmann, Hauerwas Pannenberg and Brueggemann) focused mainly on man's calling and responsibilities before God in the life setting and social situation, and the nature of suffering. Hochschild's work was enlarged and expanded further to include not only emotion work, but also faith work and the many other kinds of work done in chronic illness, in order to enact the role chosen by the subject. Disclosing suffering emerged as a consistent theme. The study identified a number of factors in clinical and faith settings preventing disclosure. Responsibility in chronic illness (the sick role) was reviewed again, now seen as a careful and conscious choice by the subject only to take responsibility for what could be managed.

Reconsidering the research question suggested that instead of two separate parts, the two questions were closely related. Biographical and spiritual disruption meant interrupting the self-story and faith story. Rebuilding and reconstructing these formed the key task of chronic illness. The impact on an individual's faith was no different from the impact on an individual self-story which threatened the core values and activities that constituted identity.

Faith was different in one respect, as it involved responsibility to a higher authority (the faith group, God). But in Ricoeur's interpretation The Other who enjoins (1.4) also represented a complex set of obligations which had the same effect. the sick person needed to find a way to engage with these obligations and decide which could be met. The disclosure of suffering described in narrative data was done in a sophisticated and expressive way. These descriptions had a special purpose, to truthfully record and frame the experience presented, in a way that did them justice and accurately represented the individual's pain.

Illness narrative involves the performance of the chosen illness plot in successive episodes showing continuity and progression. Enacting the roles described required illness work of various kinds which often went well beyond the requirements of survival. The energy and motivation for this work was drawn both from the individual and from the social setting (friends, family, faith group) toward whom the performance was directed.

Chapter 7 will describe how the quest of chronic illness was resolved by the study's participants. Resolution for them meant balancing the demands of survival alongside enacting the role they had chosen. Because this role was often demanding, it could not always be sustained easily. But subjects showed adaptability and resourcefulness in adapting their chosen role to the limitations of their illness.

Chapter 7

Conclusion

The narrative quest of chronic illness: resolving the story

7.1 Research problem, research setting and research aims

The research question had two parts: How do renal dialysis patients respond to biographical and spiritual disruption? What is the impact of kidney disease and chronic illness on faith, as described in patient narratives?

Any research study has a context and setting. This study arose in response to a practical problem in a specific setting, a dialysis unit. The spiritual care team were visiting the patients there regularly, and found it was not possible to provide spiritual care in isolation. Patients had a wealth of problems concerning their illness, its life impact and emotional and spiritual consequences, which were all interlinked and could not be separated. From this demand came the Living Well Programme, which used a life review form to record patient's life activities before and after illness, assessed life potential and set targets for life recovery during illness. The research aims and objectives of the study were listed in Section 3.4.1 and 3.4.2, and included a practical aim to enable practitioners to develop specific spiritual care and life recovery resources for this patient group, and to provide a theory base for the Living Well Programme, which would inform its future development.

The story the study uncovered was both encouraging and unexpected. These study subjects work and learn; they create inspiring illness stories as well as tragic ones. They have hope, they rebuild faith, they suffer, but are able to contain this suffering and carry on. They had all been through depressing times and had had rock-bottom experiences, but had come through. How do they do it? They have courage, they have self-belief, they have special skills, they create a unique illness story, they build a role for themselves, and enact that role. They work extremely hard. They learn, they become more skilled, they resolve disruption events, letting go of what is lost, and focusing on what is still possible. They are archetypal survivors – but their stories are not celebrated or widely known, because just as they learn new skills and become more expert, at the same time the illness progresses and wipes out all the progress they have made.

These then are survival stories, but with a different twist. The point of a survivor story is that the hero survives against impossible odds, wins through and comes back to tell the tale. These survivors also tackle difficult obstacles, face suffering and pain, live to the limit that the illness permits, but then finally lose the battle. What is the point, the observer may ask? Why do they not simply give up – it will get you in the end? But this is the point – some do give up, and so live a life of bare survival, a joyless and bleak existence. The subjects of this study made a conscious choice, to continue to fight, even though they could not actually win. They decided it was better to live the very best one can, be the best you can be, as Laura said, rather than to lie down and give up. It takes a different kind of courage to fight on. These survivors do not take impossible risks, climb mountains and scale rapids. Instead they know when to fight and when to let things go, how to conserve precious energy, how to choose carefully the goals to pursue, selecting those they know they can manage.

7.2 Reviewing the study method

The study worked by observing and modelling illness processes, and examining and analysing them using the study data (LWP and narrative interviews). This analysis produced concepts – the story plot, the disruption response cycle, the learning hypothesis, chronic illness work, faith work, different narrative models, role responsibility and so on. Ideally these different concepts might have been combined into a single definitive theory about chronic illness, but the study's aim was not theory building for its own sake. Instead its purpose was to build a framework for helping patients with chronic illness, using data from patient's own stories, which showed how they themselves had overcome many problems, and progressed from one stage to the next. They had embarked on a life-long learning process, and this learning was an invaluable resource for themselves and others.

How then might the study help other patients? Following LWP, the chaplaincy team was sponsored by KPA in 2016 to carry out an innovation trial to help patients who were having severe difficulties living on dialysis (8.3). These patients were at the opposite end of the spectrum from the study subjects, who were mainly (now) resilient survivors. But the study showed that they too had started from the bottom – their response at first had been entirely negative, they had been listless, apathetic and unmotivated, and had at times given up hope.

The study therefore puts forward as its theory base first the five-stage narrative quest, and then the amended version, the narrative role quest which describes the role the narrator takes on within the illness story plot. The notion of quest suggests search, exploration and progression – the narrator may not find the role they are looking for straight away, but finds it eventually and then acts it out. The notion of progress and progression in chronic illness is vitally important especially for those having difficulty. If it can then be shown, simply and clearly, that patients can and do move from one level to the next, and then the next – then there is hope. Patients are not simply ‘stuck’ in whatever stage of illness response they find themselves in. Instead, they can and do move and make progress, using their own efforts and obtaining help when they need it. This alone would be a sufficiently important finding to justify the study.

This central finding stands in contradiction to much of the available literature on dialysis patients. This chapter explores the reasons for this in Section 7.5 Generalisability, and accepts that the study sample is relatively small (LWP n=36/100, Interviews n=12) , so further work may be needed to reinforce this central finding.

7.3 Study conclusions: observation, describing and analysing illness processes

This was an observation study based on fieldwork, longitudinal data and narrative enquiry and analysis. The outcome of such observation is not so much a list of theoretical findings but rather a detailed description of processes: what happens, how things work, how patients overcome difficulties, how they get from one stage to the next. This can be illustrated in the approach to the second part of the study, which explored the impact of chronic illness on faith. This charted the subjects’ faith responses and experiences, how they questioned and rethought their faith, and applied it to a new, very different life situation. No attempt was made to answer the theological question, what does religion have to say about chronic illness? Instead, the answer is provided by describing how the subjects did faith work, used their faith to deal with their illness, and modified and adapted it in different ways.

An observation study sets out to observe and record what is happening in the study setting. This inevitably means that the study may come across and observe people, events and behaviours that are unexpected, unrelated to or have only an indirect bearing on the research question. The findings about disclosure in the study are of this kind. How do people respond to the disruption caused by illness? They suffer the consequences, both in physical terms and in the impact of their lives. Whether they choose then to disclose their suffering is another issue, but it is relevant. Disclosure is part of the response, and has consequences: without it their suffering may never be alleviated or addressed.

Table 7.3.1 below sets out the main topics, headings and areas of observation undertaken, the concepts and theories that arose from them, and the hypotheses these generated, which were discussed in Chapter 6.

Table 7.3.1 Observation results: How do patients respond to chronic illness?

Topic	**Observation**	**Process**	**Concept**	**Theory**	**Hypothesis**
1. Response types: L1 – L3 progression	3 basic levels of response were observed: negative neutral & positive (L1-L3)	Responses L1-L3 occurred in sequence. Study subjects moved through all three levels L1 to L3	Chronic illness represents far-reaching loss of future goals and life plans. Negative initial reaction is normal	Initial negative reaction is overtaken by fight back response. Patient explores life potential & life recovery	***Progression*****:** L1 to L3 progression is the normal trajectory. Patients achieve this unaided & describe this process in personal illness story
2. Illness narratives: early stage (L1)	Patients tell stories about their illness (15 -30 episodes)	Narrator recounts events, responds and reflects on them	Events and responses create consistent patterns where disruption dictates response	Illness pattern dictates response & story plot: narrator controlled by events	Illness defines plot & subject's role, which are outside his control
3. Illness narratives: later stage (L2-L3)	Patients form story plot at early stage (L1 or L2) Which define subjects role & responsibility	Story plot is expanded in each successive episode	Story plot defines subject's role & identity, which is consistent	Story plot & role now *determine* subject's actions and responses	***Role responsibility*** Narrator creates story plot: subject works hard to sustain and protect role
4. Repetitive disruption in chronic illness: the learning response	Subjects describe 19-30 disruption & response cycles	Responses improve through repetition and feedback (results)	Disruption response cycles create feedback loop: good responses save energy, reduce losses & build skills	Disruption in chronic illness is continuous & ongoing, & generates progressive learning	***Learning response:*** progressive learning results in improved responses, skills, confidence & hope
5. Creating sustainable story plots	The role & responsibility taken on is one that can be sustained during illness	At evaluation stage 2, pat. evaluates life potential: negative/positive outlook	Story plot describes roles & activities which subject can recover during illness	Plot presents subject as able & competent; tasks described must be achievable, to sustain plot	***Sustainability****:* Because life recovery is arduous & difficult, subject only takes on those tasks he thinks he can achieve

6. Modifying illness story plots	Roles & tasks described in first plot could not be achieved:	Subjects encounter difficulty, loss & failure and modify story plot	Story plots can be expanded to include disruptive events which change the story.	The 'losing and finding' story suggests old life plot is lost; a new plot is created instead	Re-emplotment: The subject may create a new story plot about life with illness
7. Containing suffering – emotion work	Illness onset debilitates and disorientates patient, leading to loss of normal routines & commitments	Negative emotions, grief and loss disable patient and disrupt normal life pattern.	Emotion grief and faith work are essential tasks without which no progress or recovery is possible	The illness story contains episodes of suffering pain and loss which may overturn the story plot	***Containing suffering:*** A key function of the illness story is to express, contain and witness to suffering and loss
8. Faith work	Faith involves responsibility: patient do faith work to discern responsibilities in illness world	Faith sets out duties and obligations for normal living: apply/modify these for illness situation	The obligations of faithful are modified & relaxed; OR a quite different set of responsibilities are taken on	Illness world can be explored as a faith context containing specific challenges & opportunities	Illness may generate faith responses which are different & distinct from those in normal living
9. Chronic illness work	7 types of illness work were observed: emotion, grief, evaluation, identity, faith, recovery & resolution work	Illness work is generated (1) by disruptive events: patient do work to recover loss & restore normality	Illness work is generated (2) by story plot describing role. Subject works hard to sustain role & carry out responsibilities	Recovery work (1) is continued while success is achieved, & energy and motivation are available	***Illness work:*** Illness work is vital for progression from one stage to the next (L1-L3)
10. Disclosure	Some patients did not disclose suffering & loss in dialysis setting or to faith group	Patient manages disclosure in order to protect identity as competent & compliant patient	Model Illness narrative describes how patient copes with illness and continues with normal living	Dialysis patients have an obligation to live normally & productively and justify the cost of keeping them alive.	Self-censorship by individual patients prevents formation of collective consciousness which might lead to action
11 Counter-narrative: attestation & witness	Patient included vivid accounts of suffering in illness narratives	The patient attests to the suffering they experience – attestation of self (Ricoeur 1992)	These accounts suggest that suffering is an integral part of the illness and identity of the sick person	Attestation of self means that patient must recount their own suffering, and find ways to do so.	***Counternarrative*** The absence of a listening and suffering community did not stop the subjects witnessing to their own suffering
Topic	**Observation**	**Process**	**Concept**	**Theory**	**Hypothesis**

The key observations from the study listed in the table are set out below.

1. *Progression.* Three levels of response to illness and disruption were observed: L1 Negative, where patient is disabled and disoriented by illness; L2 Neutral, where

patient explores illness limitations and evaluates life potential, and L3 Positive, where patient creates an illness story plot, which describes, plans and enacts role recovery.

2. In early stage illness narratives, illness events determine subject's responses; these are repeated and create consistent patterns, which generate a descriptive story plot.
3. *Role responsibility*. In later stage more developed illness narratives, subjects create a story plot which defines their role responsibility and their chosen way of responding to illness. This now determines their actions and responses.
4. *The learning response.* Disruption and response cycles were repeated (19-30 observed in interviews), which led to subject developing greater skill and learning more effective illness responses.
5. *Sustainability.* Subjects evaluate life potential during illness and choose to take on a role responsibility which can be sustained within illness limitations.
6. Illness story plots are modified when the roles and tasks first described and targeted could not be achieved; the subject encounters difficulty, loss and failure and builds a different plot.
7. *Containing suffering*. Suffering and loss are an integral part of chronic illness and generate emotion work and grief work, which may disrupt normal life patterns. The illness story serves to *contain the impact* of suffering so it does not overwhelm the story.
8. *Faith work* occurs when the subject applies faith beliefs and practices to the illness situation, modifies these as necessary, and determines which faith responsibilities can be undertaken during illness.
9. *Illness work.* Patients undertook chronic illness work firstly to respond to disruption events and restore normal life patterns, and secondly to enact and sustain a particular role or identity described in the story plot.
10. Some patients did not disclose suffering and loss in dialysis setting or to faith group. Patients manage disclosure in order to present themselves as normal, competent and compliant with treatment routines.
11. *Counternarrative: attestation and witness.* The illness narrative attests to the sufferings the person has experienced. The self witnesses through the story to a new identity as sufferer which the person has taken on. This witness is a counternarrative to the story of normality (10) which the person uses in some social settings.

The observations listed led to defining concepts, building theories and forming hypotheses. The seven main hypotheses arising from the study were the *progression hypothesis* – subjects make progress over time, recording this in the illness story : the *role responsibility hypothesis*, where subjects determine and describe the responsibilities they undertake during illness; *the learning hypothesis*, where subjects learn specific skills and use these to improve responses; *the sustainability hypothesis*, that subjects create story plots and roles that they can sustain; the *illness work hypothesis*, that subjects do various kinds of illness work, so that they can respond to disruption and enact the roles and responsibilities described in the illness story; the *containing suffering* hypothesis, the illness story serves to *contain the impact* of suffering so it does not overwhelm the story, and the *counternarrative* hypothesis, where the person asserts their identity as sufferer over against the narrative of normality they may use in social settings.

The other four observations listed did not give rise to any theory or hypotheses, but were descriptive. They highlighted how illness controls the subject in early stages, story plots can change, faith work may generate distinctive faith responses to illness and how subjects manage disclosure. The seven hypotheses generated by study – progression, role responsibility, learning, sustainability, illness work, containing suffering and counternarrative are expanded below in Sections 7.6 – 7.10, and their implications for spiritual care and patient care are discussed.

7.4 Limitations of present study: Confirming and replicating findings

The findings of the study listed in Section 7.3 indicate that biographical and spiritual disruption was actively addressed by the study group, and that for faith members their faith played a significant part in their response. The limitations of the study that would qualify these conclusions are listed as follows.

- The sample size was small – thirty-six LWP participants (out of 100 total) who completed Living Well plans, then twelve interview patients: not sufficient to be statistically significant.
- The sample may not have been representative of the study group, made up of all dialysis patients: the LWP programme tended to attract the most able and proactive patients in the group.
- The study required a theoretical sample of patients with declared faith, in order to study faith impact. Therefore, these patients might be expected to have stronger than average faith.

- Narrative competence was important in sample selection. Subjects were expected to recall and recount numerous illness episodes in one narrative interview, so had to be capable of sustaining an expressive narrative.
- Sample selection process may have favoured able, articulate and competent survivors.
- There were no participants with weak or lapsed faith, who might have been able to describe why their faith had been inadequate when facing chronic illness.
- Researcher and LWP team mainly consisted of chaplain and volunteer coaches from chaplaincy team. This could distort patients' faith accounts, if they wished to present their faith in a favourable light to other faith members.
- Patients' voluntary participation in LWP suggested that they were the most proactive, positive and motivated in the study group. Other patients who were more negative and passive would not have participated.

The justification for the theoretical study sample of key informants was that part two of the research question about faith was a new research area – no one had researched the impact of chronic illness specifically on faith before. It was therefore necessary to study key informants, a theoretical sample, those with proven faith, and those whose faith stories also recounted the many difficulties and problems encountered during their spiritual journey. The sample was later modified to include 25% of non-faith subjects to provide a basis for comparison. This had a direct impact on the study findings.

As regards sample size, this may not be important in a qualitative study. The number of respondents used provided rich data which complemented each other, and led to a large volume of material to be analysed and coded. The findings have high validity for this group. The criticism in regard to using good survivors has some substance. The findings give an optimistic picture of resilience and developing effective survival responses. On the other hand, these subjects had themselves moved from a low inactive response level (L1) at the outset during LWP to a positive and proactive response level (L3) later, by the time of the study interviews – so they had not always been able survivors, and were able to demonstrate significant progression.

7.5 Generalisability: can findings be generalised across the dialysis population?

The original research question about how subjects respond to biographical and spiritual disruption produced some positive and interesting findings (Chapter 4 and 5). Subjects learn, they develop better responses, they deal with losses as they occur, they seek to resolve an indeterminate illness into distinct episodes, and they devise and pursue a life quest (role quest), to recover what they have lost. Whilst at first this quest may seem unrealistic and impractical, they soon learn to modify and reshape it in a more realistic way, testing out new roles and exploring the life potential of the illness world.

Nowhere in the study's findings did it state that subjects responded to biographical and spiritual disruption by simply giving up, as things got more and more difficult. As explained above, the sample were a determined and articulate group with powerful illness stories, which documented each person's struggle with the illness – these subjects were both good narrators and good survivors. Yet the author's experience and the literature also record that this is not necessarily the general pattern (Strauss & Corbin 1988). Some subjects resist at first, then give up later; others find the illness to be an overwhelming injustice that has wrecked their lives, and so do not make any recovery plans at all, or if they make any, fail to carry them out (Frank 2010).

A mirror image approach to the study findings might then look for subjects who did the opposite: did not learn, did not resolve disruption, did not recover, did not expand faith boundaries, and did not express, process and absorb suffering. Tsay Lee and Lee (2005) describe how patients with end stage renal disease (ESRD) must confront the burden of long term illness and numerous disease associated stressors. The ability of the patients to cope with and adapt to these stressors has an important influence on physical and psychological wellbeing. This suggests that disruption is an integral part of ESRD, but that there is a wide range of response to this burden. It might then be more beneficial and practical to study a representative range, which would include average performers as well as the two extremes of high and low achievers. By studying a graded sample including those in the middle, who might be closer to the able group studied here, it might reveal how responses change over time.

The follow-up trial described in Section 8.3 below divides patients into three response groups: negative, average and positive responders, corresponding to levels L1 – L3 in the study. This study has described how these different response levels come about, and how people move between them. The latter is the most crucial point of all. If response levels are simply predetermined by an initial negative response to the illness which is then fixed, then it may be that that little change is likely to occur, and intervention may be unsuccessful. But if the situation is much more fluid than this, the picture may be different. Because chronic illness is repetitive and progresses slowly, there is ample time to learn new skills and build constructive responses. Conversely because chronic illness is progressive, it seems likely that people move between response groups, and that able responders may become less able responders as illness progresses.

7.6 Progression in chronic illness: progressing through response levels

Progression in chronic illness is an important issue when half the healthcare population have long term conditions (LTC's) which are degenerative (DoH 2010). How may progression be defined when the physical trend is normally downwards? The patient activation measure (Hibbard 2007) derives from research which shows that patients do better when they are more active, but only the more able patients can easily increase activity levels.

The study began with a progressive model of chronic illness which moved from disruption through evaluation to recovery (2.3). This was found to be an oversimplification: disruption is repetitive and continuous: disruption response cycles are repeated so that each time the patient responds with recovery work, and accepts losses as they occur. Progression does not mean improving health-related quality of life, which is based on measuring patients' physical activities using a standard QoL measure. The illness is by definition progressive, so any improvements in QoL are likely to be temporary and reversible. But progression can be achieved in two different ways: first by learning more effective responses, so that the patient becomes more skilled at managing disruption and life recovery (see 7.8). Such learning will not change the downward trend, but will reduce the impact of disruption and increase confidence and hope. Secondly, the patient can progress from simply reacting to adverse events as they occur, and responding in a pragmatic way, to making an overall life plan (the illness story plot), which describes how the subject will respond to disruption and enact the role they have chosen in the future. This does not mean disruption will not continue to occur – but the subject now has a powerful motive for managing and overcoming it.

The second method of progression requires the use of narrative. The patients create their own personal illness narrative (oral or written) which describes progression. They begin at illness onset, and describe how they were devastated and disoriented, not knowing what to do. From this helpless beginning, they move on to learning more about the treatment and exploring the illness world, and eventually progress to the positive activation and life recovery stage, where they work hard at life recovery targets. The revised Living Well on Dialysis Programme (8.3) used this definition of progression. But alongside this process disruption response cycles continue, generating loss of valued life activities, negative emotions, loss and grief. As well as developing positive responses the subject has to contain the impact of these losses using emotion work, grief work, and evaluation work: this is an intergral part of the chronic illness task.

The study developed a more detailed description of narrative progression over time (see 7.3 Conclusion 3). At the early stage the illness dictates the story. Negative events occur frequently and unpredictably: the subject can only react as best they can, and does not know what will happen next. The subject gradually becomes more experienced and capable, chooses more effective responses, discerns when to fight back and when to accept loss – the learning response. The patient tests out what is recoverable and what is not, and evaluates what the life potential within illness may be. At a particular point the subject creates an illness plot which defines the subject's role responsibility – what kind of obligations the person now chooses. This is linked to an evaluation based on the self-story or faith story – that there are certain activities or roles that are of high value, because they are bound up with identity or faith – these must be recovered or saved in some form, if in any way possible.

The subject now has a plan and a role and has chosen a particular narrative plot. The study described four kinds of plot which allocate responsibility in different ways. At this point the subject changes from being helpless – a passive victim – to having some control over disruptive events. The subject will no longer fight back blindly, hoping for the best, but will be selective, choosing when and when not to fight. By enacting the role described in the plot, the subject demonstrates they are a capable person, able to be true to themselves and their beliefs, even when facing difficult circumstances. The illness narrative instead of chronicling events as they occur now becomes generative – it determines how the subject responds, where and when they direct their efforts.

This definition of narrative progression as a process has several advantages for patients. Firstly, it can survive failures, setbacks and disappointment. It is based on an evaluation of life potential or faith potential which may be proved wrong – recovery was just not possible in this area. The evaluation must then be done again to find out what is still left, still possible. The subject must have determination and ingenuity to find the one thing that can be won back, whilst other major losses are all the time occurring. This narrative strategy is also particularly relevant to faith subjects: faith is linked to the responsibility to be true to one's beliefs, and so finding the opportunity for faithful action is especially important to the faith member.

7.7 Role responsibility in chronic illness: the sick role reconsidered

Paul Ricoeur (1992,339) describes the 'Other who calls' and says that injunction, having obligations to one or more others, is part of the human condition. Parsons sick role (1951) freed patients from such responsibility in order that they might be free to get well. But for the chronically ill having a role to fulfil, having commitments and duties to discharge, is life saving and a vital sign of one's ongoing membership of society. Gerhardt and Morgan (1996, 1988) have considered this from the social viewpoint, discussing what obligations society might wish to place on these individuals. In the narrative framework of this study this is reversed, so that the individuals choose and describes the roles they wish to have. Faith might seem be a special case since religion deals with transcendent values, and it might appear that its obligations are universal, not conditional on health or illness. But often faith groups see it differently, wishing to excuse those who are ill, for fear of imposing demands that cannot be met. But the sick person continues to wish to be useful in whatever way they can within the faith group. And in fact, membership of any group works in the same way. A dialysis patient who was captain of the bowls team still went down to the club and helped every week, even though he could no longer play in the team.

Responsibility begins with taking responsibility for oneself. Ricouer (1992, 295) again defines imputability as taking on responsibility for a life which one had not wanted or expected. This is a big step, since this life is painful and demanding, and it might be easier to argue that it is simply too difficult. In section 2.6, two ways of evaluating life potential were discussed: the practical way, simply doing whatever one might have time and energy for during illness, and adjusting this as required; and the moral and ethical way, living life as one should, according to one's personal beliefs or faith commitments. The second route was much harder, yet most study subjects chose it, since it gave them a powerful motive for carrying on and living in the way that they wanted to.

Talcott Parsons (1951) when removing responsibility from the chronically ill in describing the sick role exempted those with chronic illness, and he was right. These patients wish to have responsibility for themselves: they also of necessity have to recover, negotiate, adapt, modify and reduce the responsibilities they take on, as the impact of illness changes.

7.8 The learning hypothesis: a powerful route to fulfilling life potential

The learning hypothesis has already been extensively documented in chronic illness research (DoH 2010, Lorig et al 2006). Here it is extended to cover not just clinical and physical aspects of long term conditions, but also includes learning about managing disruption and life recovery. The learning that was observed in the study was of several kinds – devising and then modifying initial responses, exploring the illness world and its potential, communicating learning, obtaining reinforcement, and reassessing and re-evaluating illness impact. Learning is enhanced through rewards and reinforcement. In the early stages of dialysis learning occurs quickly, and is rewarded by mitigating disruption and pain, discovering better diets, better ways of controlling symptoms, better ways of organising daily routines and so on. The urgent task at first is to handle treatment and reorganise one's life around it. Once accomplished, the next task, that of resuming normal living, begins. It is here that a different kind of learning is needed.

LWP participants often recounted how they wished to resume work, renew commitments, wished to volunteer or do something useful, but the system was loaded against them. Disclosing they were kidney patients closed many doors, and they became discouraged. Learning here meant learning to accept failure and loss, to absorb it and try something else. Terry (5.5) repeatedly tried to get back to work without much success. His solution was a mixture of creative hobbies, part-time acting and teaching. Another LWP participant, a retired actor, found much fulfilment going on theatre trips with former colleagues.

Communicating leaning to other dialysis patients was limited, but faith members Dawn, Joanne and Sophie all gave accounts of their faith story to faith groups, describing the suffering they had been through and the strength they found through their faith. Patients also enjoyed reading books and biographies of people who had overcome difficult circumstances using their faith. Joanne and Winston were the most successful in using what they had learnt: they were both in demand to offer help and counsel to those in trouble.

7.9 Illness work: resourcing and recording patients' own illness work

Illness work is the work patients do to counteract the impact of the illness, and to find for themselves a useful and sustainable role. Coding Stage 4 (Section 5.3) described following types of illness work: emotion work, grief work, evaluation work, identity work, faith work, recovery and resolution work. The study went on to demonstrate how this work came about, what motivated it and how it was sustained.

The initial motivation for illness work was often deprivation: patients had lost the settled life pattern of good health with its fulfilling range of roles and activities, and would work hard to get it back again. The sense of hurt and loss from having something valuable taken away was a powerful motivator, but often did not last. Another motivator was useful learning: recovery work led to learning better survival skills, which made survival easier. But a large part of the work patients did was linked to losses resulting from illness: loss of job role, loss of self-esteem, loss of social life, hobbies and relationships. The initial impact of such losses was negative emotion and grief. Doreen describes how she grieved for two months after her blindness came and then carried on. She had completed her grief work, and was now able to function normally.

The various kinds of illness work observed during the study were described in Chapters 4 and 5. Recovery at first is a normal instinctive response; but patients learn to respond in more sophisticated ways, because not every response works. The study showed that a huge amount of work was going on, often unrecorded. The LWP had had the task of monitoring and guiding the work that patients were doing, reinforcing and encouraging their efforts, and recording their results. This work might also grind to a halt, or be interrupted and then resumed again, because of unexpected setbacks.

A crucial gap occurred (18-24 months) between the subjects' participation in LWP and the research interviews. This showed unexpectedly that most had made substantial progress unaided. This led directly to the illness work hypothesis, that patients are continually engaged in illness work on their own account, to mitigate the negative effect of the illness on their lives. This significantly alters the role of chaplain and other therapeutic disciplines who work with patients and devise therapeutic interventions. As explained above (Introduction iv) kidney dialysis patients located away from a hospital access these specialisms only occasionally – and they are expensive to provide. Instead of devising new interventions, chaplains and others might instead track and record the illness work patients are already doing and where appropriate assist them in achieving it.

In the study setting this would involve a significant revision to the chaplain's role, placing far more responsibility onto the patient and offering a framework in which to record the illness work that they do. At key points such as the evaluation stage, when patients evaluate life recovery potential and set targets, the chaplain would advise and discuss, to ensure that targets set were achievable. But the patient would do most of the work. Another intervention and review point might be sustainability: the patient might be doing extremely well with life recovery, but is becoming exhausted in the process.

7.10 Sustainability in chronic illness – finding sustainable response levels

Finding 5 in Section 7.3 above suggested that subjects evaluate life potential during illness and choose to take on a role responsibility which can be sustained within the limitations of illness. This suggests a careful learning process has occurred, finding out which tasks can be managed and which cannot. The heart of the narrative quest is describing and enacting a role: this must be chosen carefully if it is to be sustained, or else the story plot will fail.

Studying disruption responses in Ch 5.2, it was discovered that some faith subjects did not use faith responses consistently at all to start with – they were bewildered and unsure. Joanne did not embark on her own faith story which defined her role until after three years of uncertainty and confusion. Dawn too would experience many medical crises before her faith work took her in a specific direction. This suggests that subjects search for an illness plot and role over a period of time: when they find one, it is based on considerable experience of illness, and so is more likely to be sustainable.

Such sustainability depends on two factors. Firstly, at evaluation stage, enough trial work must have been done for the patient to have a realistic assessment of feasible recovery targets. These cannot just be a ‘shopping list’ of all activities the patient ideally would wish to recover. Secondly a major cause of unsustained recovery effort is failure and disappointment; the patient tried, failed and then gave up. Funding recovery and overcoming failure requires exceptional resilience: often specific emotional support is needed. This may be especially true when the disappointment is not disclosed – the patient did not wish to admit failure.

The LWP was well placed to provide support for patients’ recovery work. A revised format of LWP would place chaplains and professionals in an advisory or supportive role and patients and patient organisations as prime movers and sponsors (See Appendix A - LWP). But the sustainability hypothesis advanced here is that patients were well able to find sustainable response and activity levels, and adjusted these as time went on. This may mean that during a good period, they may be able to recover and sustain more activity than they had done before. But if disruptive illness events then occur, activity levels will be reduced again.

7.11 Containing suffering: disclosure and witness

One answer to the research question, how do patients respond to disruptive events, is that they describe them: they recount in detail what happened, and these accounts are vivid and expressive, and describe well the emotions the subject felt at the time. In chapter 1.7 the literature discussed the responsibility of being a witness, both that of the sufferer, to recount what happened, and that of the hearer, to receive their witness (Felman & Laub 1992).

How might these illness stories help to contain the suffering which they describe? The particular episodes of crisis, helplessness and pain described in the narratives are not resolved – they stand alone. The narrator recounts them confidently in clear expressive detail – an act of witness. The narrator has moved from being a mute sufferer (Soelle 1975), not understanding the enormity of what was happening, to being an expressive voice, able to record what happened in expressive detail. This requires confidence and strength, together with the knowledge that with hindsight, the suffering did not overwhelm the person, they moved out of it into the next stage of the story, reasserting narrative control. The narrator is a free agent, able to include whatever episodes in the story she wishes to recount, while still holding the story together. Including these stories of suffering and disruption indicates the narrator can hold the story together, in spite of them.

The study showed how there was no shared suffering identity among dialysis patients in the setting, because they were reluctant to disclose what they had suffered. But the study subjects claimed their own suffering identity through their individual stories, which they told to friends, faith members and others – I am a sufferer, this is what happened, this is what I went through. They were able to do this because they had completed the emotion work and grief work that had to be done. Whilst recounting what happened still recalled difficult emotions, these emotions had been expressed and contained, the story had moved on. As Soelle (1975) asserts , claiming and owning one's own suffering is a powerful act, which ultimately allows the person to share their burden and move forward.

The study therefore suggests that individuals may contain their suffering within a developed illness story, even when they are in a setting of non -disclosure, where suffering is not shared. There might then be three different ways of containing suffering depending on the social setting where it takes place. Firstly as here, the individual does this alone, developing their own story, which is only shared confidentially with a few trusted others. Second, there may sometimes be a suffering community of patients where all may recount, all share and all receive support from each other. Thirdly, there may also be another layer of expert professional help and support available which patients can access. This may be needed more if the second layer of mutual support is missing; but also, where there is no culture of openness, patients may never get past the barriers to disclosure and seek specialist help.

This was clearly illustrated in the follow up study (8.3 below) in the chemotherapy unit at Guys where there existed a high level of solidarity among chemo patients, and disclosure by patients and family members was normal. Here chaplains worked easily, listened to countless cancer stories and were able to discern quickly which patients needed extra support. Patients were also more likely to access specialist help as well, since they were open and articulate, quite used to sharing the difficulties and disruption to their lives caused by the treatment – an open learning environment, the opposite in many ways to the dialysis unit.

7.12 Counternarrative: attestation and witness

The contribution of the study then was to observe and record exactly what these patients did, how they managed, how they build their own illness stories and chose roles they could fulfil and sustain. Over time, often a period of years they built up a highly specialised kind of skill and knowledge, and they continued to learn as they faced new challenges. A surprising finding was how little this knowledge was shared – the study has analysed the reasons for this. But in the end each patient is responsible for himself – to survive, to get by, to fulfil his responsibilities to himself and others. The illness stories each person created were specific and individual to themselves – perhaps each person has to find their own way at first, and do so alone.

So who then were these stories for? They were of course told to the researcher – but they existed long before that, and had been told in other formats. Were they designed to elicit sympathy and support from those nearby? This seems unlikely – there was little opportunity in the setting for such stories to be told and be heard. Were they stories intended for the world at large, a kind of witness to suffering and endurance? This too seems unlikely- they were not in the public domain; one subject had been urged to write a book, but said it would be too difficult emotionally.

These stories were created for the subjects themselves. Gerhardt (1996) sees dialysis patient's stories as a social transaction, asserting that this person is competent and normal. Morgan (1988) also starts from a social perspective – is this person worth keeping alive, if they cannot function and be productive and useful? But these stories are in fact answering a deeper question – what am I worth to myself, in my own eyes? Charmaz (2005) describes how the chronically ill have less and less worth to society as time goes on. But Ricoeur (1992,22) says 'credence is also trust….attestation is fundamentally attestation of self ….attestation can be defined as the assurance of being oneself, acting and suffering'. These subjects have heard and understood the ambiguous value society places on them. They have also perceived how their faith group is uncomfortable with their refusal to be cured, so that they might once again be productive members. And so, in the end, these stories are a powerful rejection of all that others say and feel about them, the value that others place on their lives. After a struggle, they have learnt to believe in themselves again, to realise that their suffering is now part of who they are. And so, each story becomes a declaration – this is who I am now: I am still here, I am carrying on, I have learnt how to do this, and I am proud of it. The turning point for them came when they ‘took on’ and accepted all the suffering that came with the illness: they accepted it, and decided that they could still in some way live faithfully and be true to themselves inside the illness. This is in sharp contrast to many around them, who find their suffering unaccountable, disturbing and unacceptable.

The emergence of counternarratives in a difficult situation is not surprising. The cancer patients described in 8.4 below do not need to create counternarratives – their voices are heard, their suffering is expressed and they experience a high level of social support. But these dialysis stories created as personal attestation and witness still need to be told to someone. Terry has a group of friends who love hearing his survivor stories; Sophie loves recounting her 8% chance operation story to anyone she meets. This suggests that whilst major cultural change in the dialysis setting (closer to the cancer model) might be a long way off, small counter cultures of resistance and openness made up of patients and patient groups might be a practical possibility, and might occur spontaneously under the right conditions.

For the faithful there is another deeper question as well – what am I now worth in the eyes of God? This too is a contested question. In the book of Job in the Old Testament, Job’s friends spend 37 chapters trying to convince Job that there must be something wrong with him, because he is ill – it must be his fault. Job stubbornly refuses to accept this, and is finally vindicated. There remain faith groups who give their members similar teaching about suffering, healing and blessing today. But Nouwen (1994) reflecting on the prodigal son story (Luke 15:11-24) asserts that the lost son returns not just to forgiveness, restoration and acceptance – he also returns to responsibility. He takes responsibility for his actions and their consequences, but asks that he may still have a role as servant in his father’s house. The father in response gives him a role that is more important and also much more demanding: he becomes a son again, with all the duties that involves. The faithful who have long term illness also take on not just the suffering which is part of it, but also the responsibility to respond in faithful ways, to be witnesses, and to live out their faith in this different world with its many new challenges.

7.13 Faith in chronic illness: describing & witnessing wilderness faith

The study findings (7.3) suggest that the illness world is a separate faith context containing specific challenges and opportunities. Here illness may generate faith responses which are different and distinct from those found in normal everyday living.

The study subjects generally chose to stay in touch with their faith group, its traditions and observance, as much as they could. This was a sound survival strategy, since the faith group offered them pastoral support, and visited them during hospital stays. Such support and contact reduced the risk of estrangement which patients may experience during periods when they are unable to participate in faith group activities. Among the twelve study subjects three, Joanne Dawn and Winston, rose to prominence within their faith group and achieved positions of responsibility. Dawn and Joanne gave testimonies publicly about their illness experiences and the faith that sustained them.

The world of chronic illness is remote from the normal daily experience of the faith group and may be little understood. Joanne, Dawn and Winston all had specific faith experiences during times of suffering and pain recounted in their illness stories. Joanne and Sheila both became depressed at particular times and said they wished to end their treatment. They later rediscovered faith. Dawn though her mother, Joanne through her vow to serve; Winston from his childhood faith all rediscovered faith through specific spiritual experiences. Their faith could be described as 'wilderness faith' which grew out of times of deprivation and suffering, something different in kind from everyday faith observance in normal living. This faith gave rise to faith work – finding resources in scripture describing wilderness, exile and homecoming, which in turn fed into their faith stories. For these patients then the illness world became the setting for a new and different understanding of faith, as applied to the illness situation and its challenges. This had led to faith work, learning and the ability to communicate such learning to others. Two or three patients were able to take these experiences back to the faith group and recount them as testimony. The new skills and faith insights they had gained were directly relevant and useful in the illness world. Thus it came about that Joanne helped to man the 24-hour telephone helpline for those in crisis, and Winston became a skilled spiritual counsellor for those in trouble. Wilderness faith describes a different faith world which may only be familiar to those who have been there and have also experienced similar difficulties.

The answer to the study question about impact of chronic illness on faith was that it gave rise to faith work. This faith work was needed because there were no straightforward answers to hand, nothing that described exactly what the faithful response to chronic illness might be, and what responsibilities the faith member might take on. In fact, the range of traditional faith answers on offer ranged from seeking miraculous healing to quiet prayerful acceptance without complaining. These answers did not satisfy the study participants, and they worked hard to find their own, without departing from the traditions they had inherited.

The testimonies these patients gave to their churches illustrated victorious faith, faith that wins through. The dark moments they experienced, the moments of abandonment and despair, were most likely not included in these testimonies – their churches might have found these difficult to receive. The chaplain's task therefore is to listen to, receive and accept these 'hidden' accounts of suffering, which have occurred in this strange other world, and affirm and witness that they happened, just as the patient described. The suffering is real, and so also is the strength and faith that these patients received, as they worked hard to discern what faithful living meant for them, in this new and different world. (Watts 2011) The particular wounds and scars they collected on the way may not be visible, but they exist and will remain, as will the new spiritual experiences and faith insights from the wilderness they have received during their journey.

Frank (1991) refers to the Jacob story (Gen 32: 24-30) where Jacob struggles with the angel in order to receive a blessing, and then goes home wounded and limping.

"We have to choose carefully which stories to live with… Jacob's wrestling became a story I lived with as part of my personal mythology of illness. This is what it is to be ill: to wrestle through the long night, injured, and if you prevail until the sun rises, to receive a blessing. Through Jacob's story, illness becomes an adventure." (1991,81)

For these patients, their illness led them a on a different faith journey, a different road, a faith adventure through the wilderness. They too are now witnesses, but not everyone will understand what they have to say.

7.14 Contribution to patient care

The purpose of the study was not just to observe patients as they grappled with a difficult illness, but also to build a knowledge base which might help other patients in their situation. How then may the findings in this chapter help other patients?

The study collected illness stories and analysed them according to narrative theory. The stories used were transcribed from research interviews – a lengthy process, one not possible in everyday practice. Yet illness stories are everywhere – each illness has one, as any chaplain knows – how it started, what went wrong, the operation, the pain and suffering, the difficult recovery. Compared with most healthcare settings, the dialysis unit was an un-storied environment (1.0) – stories were hard to come by, much time had first to be spent building trust and openness.

A simple prescription and solution to this problem would be – to change this environment, to create a learning environment where patients learn from and support each other, not only with the technical aspects of dialysis but also with practical issues of living with the disruption caused by the illness. This might be possible, though chaplains alone would not be able to bring such a change about. But in a way, this misses the whole point of the study, which showed that these particular patients in this setting, where there was little support, were able on their own to develop sophisticated illness narratives, taking responsibility, containing suffering, creating counternarratives and choosing their own specific path to effective survival. This alone was a huge undertaking – the fact that it happened at all is significant, and particularly that they did it using their own resources with little help. Taking this forward, a possible next step would be for a small scale counter culture of able survivors to form spontaneously, allowing stories to be shared.

Another simplistic response might be, that the study has identified dialysis patients as a needy group, a worthy cause, and that this might then contribute to a campaign by patient groups for better help and professional support for these patients, as they struggle to deal with the disruption to their lives. But again, times are hard, money is scarce, and chaplains would not be able to bring about such a major reallocation of resources. So what other resources might be available?

Patients are a free resource. The study suggests that patients themselves are capable actors and narrators, and devote much time and energy to managing their lives, dealing with disruption and continuing to live with the illness in the best way they can. This goes largely unnoticed since they do not seek help, which is expensive, and generally get by on their own. In the field of spiritual care, the subjects recounted amazing stories of spiritual exploration, growth and formative spiritual experience, which again they initiated themselves and found help from faith members when they needed it – the chaplain's role was simply to affirm and support what they were already doing.

Chaplains have a responsibility to link people with spiritual resources at times when they cannot access those provided by their faith group. The study discovered a different kind of faith experience among faith members who grappled with suffering and alienation, and found their own way to resource and sustain their spiritual journey. Again, the chaplains task was to observe the specific ways in which these patients learnt and grew in faith, offering support and encouragement when needed. For those in continuing contact with their faith group, the traditional pastoral offices, prayers and spiritual support the church offers are normally sufficient. For those who have lost touch and are embarking on a new spiritual journey alone, the journey will be harder, but also rewarding; the chaplain has a responsibility for them too, and must give them what they need to help them on their way.

Chapter 8

Application and further research

8.1 Research conclusions

The detailed findings of the study were set out in Section 6.13 and included progression in chronic illness, role responsibility, the learning response, illness work, sustainability, containing suffering, and counternarrative. These findings suggested that patients with chronic illness undertake different forms of chronic illness work: emotion work, grief work, identity work, faith work, recovery work, and resolution work. The main conclusion described in Chapter 7 was that the primary study model (2.3) represented a particular form of narrative quest with its own special structure, which was derived from the study narratives. Section 7.7 described the role quest where the narrative quest was redefined as a quest to find individual role responsibility during illness.

In Section 7.5 generalisability it was recognised that the study sample were perhaps exceptional – but how exceptional could not easily be quantified. More research work would be needed with a larger sample. An opportunity to embark on this in a small way was offered by Guy's and St Thomas' Kidney Patients' Association in January 2016 who offered a grant to do further work with hard to reach dialysis patients. This innovation trial described below in Section 8.3 would work with those experiencing difficulties on dialysis, and would throw further light on the quest for narrative resolution.

The study suggested that survival in chronic illness, managing disruption and life recovery skills could all be learned: even the most able survivors did not have these skills to start with. If true, it has implications not just for the relatively able and articulate group studied, but also for the whole group, dialysis patients generally, and perhaps also for the less able members who respond in negative ways to dialysis treatment. It raises the possibility that the latter are not struggling just because they have more physical problems, they suffer from health inequalities, or because that their attitude and response to the illness is more negative. It could be much simpler than that - they simply have not learned the skills one needs to live life to the full, within the limitations of each stage of the illness. This conclusion could logically be drawn from the study, but there is no direct evidence here from the other end of the patient spectrum. It would therefore be necessary to test the study findings against this group as well, to see whether the same factors that contributed to the success of the patients in the study were also important for the low achievers, or whether other factors come into play.

8.2.1 Original contribution - understanding illness narratives

The study itself began (Section 1.2.1) with Michael Bury's straightforward definition of biographical disruption, as a situation 'where the structures of everyday life and the forms of knowledge that underpin them are disrupted' (1982,169). Chronic illness represents a critical situation, Bury asserts, which has three aspects: it disrupts taken for granted behaviours, <u>it disturbs normal explanatory systems</u>, and it generates a response mobilising resources in facing an altered situation.

Following Bury, different authors described the processes occurring in chronic illness: see Table 2.3.1 p 72. G Williams identified disruption and narrative reconstruction, Frank identified chaos, quest and restitution, and Ricoeur displacement, interpretation and recapture. The study built up a composite five-part model from these, the progressive narrative quest, Table 2.3.3 p 73: good health, illness and disruption, expression and evaluation, life recovery and resolution. All these models made a positive assumption about recovery (restitution, resolution, recapture), which was not borne out in practice. In addition, they failed to observe and describe another key process that was occurring, which enabled patients to make progress following disruptive illness events – patient work.

Patient work in these progressive narrative models might well have been described as mainly recovery work. But based on Hochschild (1985), other quite different kinds of work were observed: emotion work, grief work, identity work, faith work, evaluation work and recovery work. Hochschild's emotional labour consisted in working though emotions of hurt, anger and betrayal, in staff's relationship with employer and others. But the study found the same emotions in faith subjects in their relationship with God, society or significant others. The importance of emotion work and other kinds of illness work lay in the specific sequence in which they were observed. Emotion, grief, identity, faith and evaluation work all preceded recovery work. In Bury's terms, this work involved reconstructing the 'normal explanatory systems' (1982,169), which illness had disrupted.

The dialysis unit is at its heart a community of sufferers, but one without any collective, authorised voice. Frank (2010) describes the conditions in which a suffering community build it’s own story – how stories connect people (Section 1.3.2). But the study described a community that failed to build its collective story, or mobilise its members to express what they had endured. Why did these illness narratives come out of a setting where many chose not to disclose, and the narrators themselves had not told their stories to their fellow patients? The answer was that these stories were created for the subjects themselves (7.12 p.199) as testimony and as counternarrative to reclaim identity and witness to their own suffering.

The original contribution of the study was then firstly to consider illness narratives in their social setting, and how this influenced the stories that could be told (Frank 2010). Then secondly it focused on individual counternarratives, life stories and faith stories, which arose as a protest and witness ‘against’ the socially accepted story that dialysis patient live normal lives. By creating stories that were detailed, continuous and complete, not omitting any of the suffering that individuals had experienced, they were able to reclaim their identity as survivors and sufferers who could witness to the whole of their illness experience truthfully, as it happened. The labour or patient work that was observed had gone largely unnoticed by researchers. It arose from patients choosing roles within the narrative plot, not because they were manageable or practical but because they constituted identity and were life enhancing. These were often difficult and onerous to carry through, involving immense effort, but rewarding, because they involved being true to oneself and one’s own beliefs.

8.2.2 Original contribution: faith in chronic illness

The original contribution of the study was the discovery and observation of faith work during chronic illness. Hochschild (19985) wrote about the managed heart – how authority does not allow feelings of hurt anxiety or dismay – only the official culture of hope and optimism can be voiced. All faiths have authority structures, which determine how faith members should act, feel and respond. Hochschild’s insight was that a person’s individual feelings did not always respond obediently to the instructions the authorities gave. Chronic illness is a momentous event engendering deep-seated sense of loss, abandonment and isolation. For the faithful, such feelings may be directed against a God who has allowed such a calamity to happen, or they may be directed against a faith group, who do not seem to understand the scale of the crisis that has occurred. The study observed how the emotional component of faith could be disabling and disorienting, so long as the anger and hurt continued.

Beyond this, faith work also had to address a range of practical difficulties concerning belief, observance and responsibilities. Were believers required to continue all religious observances exactly as before, or should they be let off entirely? They did not want such dispensation – they wished to remain useful, but might have to change roles and responsibilities. The creative leap that Joanne and other study members achieved was to realise that the chronically ill lived in a new, unfamiliar world where the range of tasks was totally different – suffering, deprivation and loss were everywhere, faith and hope in short supply. Applying faith to this new setting proved transformative for them, and bore fruit.

Koenig (2002) and Pargament (2000) suggests strong associations between faith membership and good health (Section 3.8.1), and describes positive and negative religious coping. Koenig (2008) found an association between religious affiliation and longevity, but also one between religious struggle (negative religious coping) and greater mortality. This qualitative study challenges Koenig's designation of questioning and struggle as negative religious coping leading to poor outcomes, although the study does not have sufficient numbers to challenge his quantitative results. The study narrative interviews contained many instances of suffering and struggle where patients found new ways to respond, which were entirely different from those prescribed by faith groups, who suggested prayer for healing or patient acceptance.

Counternarrative was also found in faith stories – a different, less conventional approach. Beginning with isolation and estrangement, members worked their way back towards the faith community by telling stories and giving testimony. These were artfully constructed so as to conform to accepted faith language. Instead of miracles, they told of grace, support and comfort during great dangers and crises. They might not mention the anger, isolation and confusion they had experienced, preferring to dwell on their positive achievements and so receive affirmation and support. In their personal spiritual lives, a transformation had also occurred. Though a spiritual experience they disclosed and laid bare all their suffering to God, and experienced acceptance and a new identity so that their illness, instead of being removed, became part of who they were. God would use them in exactly the situation they found themselves in.

The original spiritual care contribution of the study arose from the dialectic between the authority system of the faith group and the position of chaplain as somehow distinct and different, working inside the illness world, rather than within the faith group authority system. This meant that the chaplain was able to encourage the expression of distress, difficult emotions, hurt and ager, whilst assuring patients that these were not a denial of their faith. The dialysis unit then became a good location for faith work, where patient could work through successive illness stages, test new responses and roles and reconsider what their faith obligations might now be.

8.3 Follow up studies (1): Hard to reach dialysis patients

This innovation trial reflects the need to test the study's conclusion against a wider sample. The LWP external evaluation highlighted the presence of hard to reach dialysis patients, who did not participate in different programmes and activities (including LWP) that were available. These patients were the opposite of those recruited in this study, who were generally highly motivated, and wished to work hard for their own recovery. The trial is therefore challenging, since it seems to be attempting a radical turn around, whereas in practice most patients move forward through gradual transitions, one step at a time. Recognising this, the trial proposes to use a transitional approach, by first of all reintroducing LWP in modified version, incorporating the study findings concerning role responsibility. The programme sought to recruit group 1 hard to reach patients; their initial resistance would it was hoped be modified as they built a constructive relationship with the satellite chaplain during regular visits

The strategy chosen was to identify the hard to reach group early on, and use targeted and direct intervention, instead of spreading resources more widely. The bid proposal suggested there were two sub groups within the target group as follows:

- Patients who found living on dialysis very difficult and expressed a strong negative reaction to the treatment
- Patients who were passive in their response, expressed no strong feelings, but did little and had very little to live for.

Direct intervention would require the agreement and cooperation of the individuals concerned. The ward manager would therefore draw up a list of potential participants, and refer these to the satellite chaplain who would then work with these patients. The patients with a strong negative attitude would be known to staff, may well have been referred before, and might be expected to be resistant to intervention. The passive group on the other hand might be more responsive, since they may previously have had little attention. As the programme evolves it may be possible to test both these strategies in different satellite units. The targeted intervention would be evaluated on a case by case basis.

8.4 Follow up studies (2): Cancer Day Centre Trial, Guy's Hospital 2016

The second follow up study moves outside the area of kidney dialysis, and applies the study findings in a cancer day centre setting. The catalyst for this was the building of a new cancer centre at Guy's, containing a major regional out-patients' facility. This led the spiritual care team to review the need for out-patient spiritual care – none is specifically provided at present. The out-patient trial uses the model described in this study to explore whether spiritual care is required across the cancer illness trajectory lasting say one to ten years, with peak demand at individual crisis points. It is also designed to explore whether here too patients learn and do faith work and other kinds of chronic illness work in response to initial diagnosis, which they then use and develop throughout the course of the illness.

This is a service development pilot designed to give information about spiritual care demand in order to set up a new service. It made use of the theory base and findings of this study in the following ways. Cancer patients may share the same characteristics as other chronic patients and can create illness stories, learn effective illness responses and do specific kinds of chronic illness work, using their own resources and initiative. If this is true, then a way could be found using this resource to change currently accepted priorities where end of life and palliative care have a higher priority and attract greater resources than caring for cancer patients across the trajectory.

Initial results from the trial showed that cancer patients are articulate, communicative and proactive, each with a specific cancer story to tell. There is a strong collective identity with shared culture and communication between patients and families. This patient group has energy, commitment and resources and works hard. It has different characteristics from the dialysis patient group, and these would favour the self-help patient directed approach to chronic illness explored in this study.

In the next stage of the trial the team will develop resources to enable narrative work and record learning and illness work with this group. The 12-month review (Jan 2018) showed a specific demand from recently diagnosed chemo patients and from those on maintenance treatment. The first group were engaged in emotion work and grief work following diagnosis. The second group were evaluating the effect of long-term cancer on their lives and pursuing recovery work alongside treatment.

8.5 Impact on Living Well Programme – further development.

The impact of findings on LWP is summarised here, and described in more detail in Appendix A, which is intended for the team members who collaborated on the programme, and those with a specialist interest in doing further work with dialysis patients. A short summary is included here, to show how the conclusions of the study have contributed to patient care in a practical way.

Appendix A gives an overview of the Living Well Programme and restates its basic assumptions. It suggests that modern medicine offers chronic illness patients ample time, but does not suggest how this time may be used. The dialysis population itself was found to comprise a vast range, from patients who were constantly busy, to those who did very little at all.. But it appeared also that these differences between patients were not always due to physical factors. Some patients seemed to manage well on dialysis, whilst others hated it and found its disruptive life impact intolerable.

A central issue for LWP was life recovery, which many active patients seemed to desire above all else. Whilst it was a powerful motivator, the programme had to engage with this task realistically, knowing that not all the individual’s aspirations for recovery would be met. Part of the ‘recovery’ process would consist of dealing with and processing losses. The practical problems that had been encountered with LWP also centred on recovery targets – these were not always achieved. Often no clear end point was reached when the LWP process could be said to be ‘complete’, enabling both coach and patient to move on. The quest for life recovery appeared to be an unending one.

But in the meantime, the research study had been developing a theoretical structure, which would underpin and modify the practical programme. Three key developments occurred which would eventually solve the issue of the (unfulfilled) life recovery quest. First, the study would redefine the narrative quest of chronic illness as a role quest, to find which responsibilities the subject might undertake during illness. Second the study identified four different narrative plots which patients chose, which allocated responsibility in different ways. Third, and linked to this, the study defined different kinds of chronic illness work – narrative work, emotion work, evaluation work, grief work recovery work and identity work. If LWP participants embarked straight away on life recovery without carefully evaluating what roles they could now fulfil and sustain, then recovery work would be likely to fail.

The study demonstrated that the narrative plot and role quest (model i) was the key which led on to the other chronic illness tasks the patient undertook. Often the illness narratives contained emotional expression, grief work and identity work as in model (iii), reconstructing the self-story in different ways. In the LWP context, the life review formed the baseline narrative, which was revised and expanded in subsequent contacts between chaplain and patient.

The study conclusions were very positive for LWP, in that they affirmed the capacity patients have for creating progressive story plots, learning effective responses, and planning and carrying out the illness work they needed to do, as they enacted their chosen role. This could fundamentally change the perception of dialysis patients as a needy group, deserving sympathy, to an active and competent patient group, well able to share their learning and handle the exacting demands of their particular condition.

A key factor in the further development of LWP will be patient demand and the collective patient voice. Looking at a range of long term conditions, it is clear that many conditions (cancer, MS Parkinson’s, Alzheimer’s) have a strong public voice and public profile. This in turn stimulates demand for better services, more research and more funding. The study found that dialysis patients are ‘un-storied’ people, their successes and failures, trials and tribulations do not find ready expression or exposure. Cultural change would need to begin within the treatment centre, where patients could communicate and celebrate their learning achievements, and campaign for more resources. This could then contribute to the wider debate about research and resources for long term conditions.

8.6 Conclusions: Further research

The story of this research project is about more than the study itself. It took place in parallel with the Living Well Programme in which more than 100 patients and 25 coaches took part over a seven-year period (see Appendix A). The study was firstly a theoretical enquiry about biographical and spiritual disruption. But it was also building up a theoretical base for a patient programme, which was already being developed and modified – the two strands continued side by side. Arguably the theory should have come first; but in reality, theory and practice went on as parallel strands, with feedback loops occurring at various stages.

The programme recorded many small achievements as well as some setbacks. It obtained initial funding for a two-year pilot, but no continuation funding followed. The programme finished before the study was completed. As well as answering the research question, the study therefore needed to demonstrate whether there is a sound theoretical basis for an intervention in a dialysis setting aimed at alleviating life disruption and enabling life and role recovery. The contribution of the study to spiritual care was to observe and record faith processes – reactions to illness, faith demand, faith responses, faith work, ways in which faith was challenged and expanded, and how subjects resolved their own faith questions.

The LWP’s basic premise had been that dialysis patients needed intervention, either in the form of expert professional help, or in the form of lay led coaching and mentoring, in order to achieve life recovery. The outcome would then be measured using validated measurement tools, which would measure any changes in activity levels. This was done and it was found that activity levels did not increase overall in long term.

In the light of the study findings, this basic premise needed to be amended as follows. Dialysis patients who face the challenges of chronic illness create an illness story plot which defines the role they wish to take on. They learn new skills and embark on different kinds of chronic illness work, which enables them to enact this role. This work is documented in their own illness story, which forms an account of how they learn to live with the illness. This is itself progressive, and describes how successive disruption events in turn generate more skilful responses. It also describes failure and loss, and the suffering that ensues when valued roles and activities are found to be non-recoverable.

But such losses once evaluated refocus the life recovery process, narrowing it down and selecting only those targets which may still be achievable. The outcome then may well be a reduction in life activities, in such a way that only those activities that can be sustained, are rewarding and give personal fulfilment are pursued. The subject benefits from this process by using less energy and effort, and obtaining more success and better results from the effort that is expended. A further benefit may be a greater sense of control, since the subject has successfully negotiated the narrative illness quest and achieved small wins, recovering what could be recovered, and successfully letting go of that which could not. Overall the outcome may be a reduction in overall activity as measured by a standardised measure such as a validated quality of life measure.

If patients always chose sustainable targets and sensible roles, there might be no need for a programme like LWP. But the research study found that choosing a role was a moral and ethical choice, not a practical one – patients wished to become again the person they had always been, and recover the roles they had had before. When this quest failed, this led to an existential identity crisis – now life had no hope or meaning any more, there was no future left. This crisis needed a trusted other, someone who could help the patient rediscover identity and self-worth, and find a role that made life worth living. Before they could do this, illness work was needed, emotion work, grief work, identity work and faith work, so the person might accept this damaged self and this different life, and so begin to piece together the fragments of their lives to make something new.

LWP then would need to be sponsored and funded by a patient group, who understand from personal experience the risks and difficulties involved and are willing to support those who engage in the programme in the longer term. It may be lay led, since it is offering knowledge and learning derived from patients themselves and uses the skills that they themselves acquire and learn. This in turn may be offered to patient groups and dialysis settings as a framework. The cost to the health care dialysis setting would be mainly administrative, to oversee the scheme, which would be led by patient organisations, with a light touch. There would also be the need for a small resource and information point, a notice board, desk or shelf of resources with displays, so that information and achievement can be passed between patients, peer supporters and volunteers on the unit.

8.7 Reflection: turning theory into practice

Section 7.3 reviewed the course of the research process, and reflected on how the outcome (findings) had been different from what had been expected. This chapter has explored the relationship between theory and practice, and how a research study was conducted in parallel with a live programme concerned with improving dialysis patients' wellbeing. Here too the results were quite different from what had been anticipated, with surprises occurring along the way.

The basic idea of running a theoretical study alongside a practical programme goes against the clinical model, where theoretical research must be completed first, for obvious reasons. But it is found in action research, which seeks to study processes as they occur in the field, whether in healthcare or in education. Here the intention is to improve or modify current therapeutic processes, by observing results and considering how changes might improve outcomes.

LWP offered a background to the study as well as a source of participants. Based on positive assumptions LWP sought to improve quality of life (QoL), and do this through a coaching intervention. When the results were evaluated, no great improvements in health related QoL were found. The qualitative assessment however recorded a high level of patient satisfaction. This showed that the programme had given participants a new sense of hope and fulfilment. This was based on relatively minor gains in life recovery, not big enough to reverse the general downward trend, yet significant enough to have symbolic value, and give hope to participants.

Against this background the study might have been expected to produce mainly pessimistic findings. Chronic illness comprises a sequence of repetitive disruption events, which would be expected to continue to have a negative life impact, and undermine any minor life recovery efforts that patients undertook. But the study findings were entirely different, and emphasised that learning and life recovery took place even in the most difficult conditions, using minimal resources.

The LWP evaluation suggested a contrast between quantitative and qualitative findings. The small-scale coaching interventions that occurred within LWP may have offered hope and generated action for life recovery, whilst not really changing the big picture. But the study findings gave a quite different interpretation. The subjects' illness narratives often spanned a period of years and went right back to illness onset, years before. The narratives reported 19 to 30 separate disruption cycles, most of which were outside the period of the subjects' LWP participation. It was then clear from analysing these narratives that the subjects were already involved in managing disruption, planning life recovery and doing illness work, both before and after they engaged with LWP. What then the programme was doing was observing. recording and harnessing a process that was already in train, part of a much longer narrative quest, which was vital for the participants.

The study findings therefore suggest that patients do not need or do not wait for a programme such as LWP, before they start doing illness work and learning the skills they need. But at different times the narrative quest may falter, roles may change and the quest require reinforcement. LWP provided such reinforcement in the form of personal encouragement together with a written illness narrative or life review, which charted all the progress the subject had made so far, and offered a solid foundation for the future.

If then subjects were already working hard in order to find their own way to live with chronic illness, long before any programme was devised to support their efforts, this suggests two things. First, the will to live, to resist, to fight back and to retain and protect one's life and one's key commitments and beliefs, remains a core part of the human spirit, and will be found everywhere and in all kinds of long term conditions. Secondly it suggests that even where such resistance and struggle against progressive illness is done on one's own, with little social solidarity, support, or group culture of resistance, individuals create counternarratives of suffering and struggle which affirm their own role as those who can experience profound suffering and still come through.

Alongside the study's key findings disclosure, affirmation and witness became subsidiary issues that were also important. The 'untold unfinished story' (Chapter 1) of chronic illness is not told, because no one wishes to hear it. The role of LWP then is not solely to instigate and promote life recovery: patients will do this anyway, though they may need to learn some new skills along the way. Instead the role of LWP is to record, resource and develop a special narrative quest, which the subject has started and will continue on and carry through in his own time and his own way. But this quest needs to be communicated, affirmed, celebrated and supported, so that a new culture of communication and solidarity may develop, in which others can participate both as supporters and also as protagonists, survivors and narrators.

And so the study can end with two vital questions for the future. The first is addressed to dialysis units and all who work in this field:

> *Can the dialysis unit become a social setting which sustains its members and receives, contains, carries and shares their stories and their suffering?*

The second is addressed to the various faith groups to which these patients belong:

> *Can a faith group become a faith community which sustains those members who have long term illness and receive, contain, carry and share their stories and their suffering?*

At present the means to achieve this are not there, and are not in place. The untold, unfinished story has not been recorded or recounted; the listeners are not yet gathered together or ready to hear what are moving and sometimes difficult stories to receive. The unfinished task is therefore to make this happen, either on a small or large scale, so that a true and faithful witness to a complex and ongoing story of joy and pain may occur, and may bear fruit.

REFERENCES

Adams R (1975) *Watership Down*. Bristol, Avon Books

Anderson R (1982) *On being human – essays in theological anthropology*. Grand Rapids, Eerdmans

Aristotle *Poetics* (1997) trans George Whalley ed Baxter & Atherton. Buffalo, McGill UP

Baruch G (1981) *Moral Tales: parents stories of encounters with the health professions* in Sociology of Health & Illness 1981 Vol 3(3), 275-9

Bateson M (1994) *Peripheral visions.* New York, Harper Collins

Becker G (1997) *Disrupted Lives: how people create meaning in a disordered world*. Berkeley

Bellah R (1985) *Habits of the heart.* Berkeley, UCP

Bendelow G (2009) *Health emotion and the body*. Cambridge, Polity Press

Bolen J S (1996) *Close to the bone: life threatening illness and the search for meaning*. Scribner, New York

Bourdieu P (1984) *Social distinction.* London, Routledge

Brueggemann W (1978) *The prophetic imagination*. Minneapolis, Fortress Press

Brueggemann W (1991) *Interpretation and obedience: from faithful reading to faithful living*. Minneapolis, Fortress press

Brueggemann W (1995) *The psalms and the life of faith*. Minneapolis, Fortress Press

Bruner J (1990) *Acts of meaning.* Cambridge MA, Harvard University Press

Bruner J (1987) *Life as narrative.* Social Research 54,11-32

Bury M (1982) *Chronic illness as biographical disruption*. Sociology of Health and Illness 4(2)

Bury (1991) *The sociology of chronic illness: a review of research & prospects* in Sociology of Health & Illness Vol 13 (4)

Bury M (2001) *Illness narratives: fact or fiction?* Sociology of Health and Illness 23(3)

Bury & Holme (1991) *Life after ninety*. London, Routledge

Cassel E (1982) *The nature of suffering and the goals of medicine*. New England Journal of Medicine 11, 639

Census 1991: Office of Population Surveys and censuses Great Britain. London HMSO 1994

Census 2001: Key statistics for urban areas in England and Wales: Office for National Statistics. London TSO 2004

Chambers E Germain M & Brown E eds (2004) *Supportive care for the renal patient.* Oxford, OUP

Charmaz (1983) Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness* 5: 168-95

Charmaz K (1991) *Good days bad days: the self in chronic illness and time*. New Brunswick, Rutgers UP

Charmaz K (2005) *Advancing Social Justice Research*, in Denzin N & Lincoln Y Handbook of Qualitative Research. London, Sage

Charon R (2001) Narrative medicine – a model for empathy reflection profession and trust JAMA 2001:286: 1872-902

Charon R (2006) *Narrative Medicine: Honoring the stories of illness*. New York, Oxford UP

Charon R, *The ethicality of narrative medicine*, in Hurwitz B Greenhalgh T & Skultans V (2004) *Narrative research in health and illness*. BMA, Oxford, Blackwell Ch 1

Clandinin D & Connelly F (2000) *Narrative inquiry*. San Francisco, John Wiley

Clarke A (2004) *Situational Analysis: Grounded theory mapping after the postmodern turn.* Thousand Oaks CA Sage

Clark D (1998) Originating a movement: Cicely Saunders and the development of St Christopher's hospice 1957-1967, *Mortality* 3(1): 43-63

Clark D (2000) *Total pain: the work of Cicely Saunders and the hospice movement*. American Pain Society Bulletin 10(4): 13-15

Cobb M & Robshaw V (1998) *The spiritual challenge of health care*. London, Churchill Livingstone

Cornwell J (1984) *Hard earned lives: accounts of health and illness from East London.* London, Tavistock

Cortazzi M (1993) *Narrative analysis*. London Falmer

Crites S (1986) *Story time: Recollecting the past* in T Sarbin ed. The Storied nature of human conduct. New York Praeger.

Crossley N, Emotions, psychiatry and social order: a Habermasian approach, in Williams, Gabe & Calnan (2000) *Health Medicine & Society: Key theories, Future agendas*. London Routledge Ch. 14

Department of Health (1991) *The Patients Charter.* London, HMSO

DoH (2010) *Improving the health and wellbeing of people with long term conditions*. Central Office of Information

Denzin N & Lincoln Y (2011) *The SAGE handbook of qualitative research 4th edn*. London, Sage

Descartes R (1644) *Principia Philosophae,* trans Miller R 1983. Boston, Kluwer

Eakin P (1999) *How our lives become stories.* Ithaca, Cornell UP

Elliot (2005) *Using narrative in social research*. London, Sage

Felman S & Laub D (1992) *Testimony: crises of witnessing in literature psychoanalysis and history*. New York, Routledge

Flick U (2002) *Introduction to qualitative research*. London, Sage

Ford D (2005) *The modern theologians.* Oxford, Blackwell

Foucault M (1977) *Discipline and punish: the birth of the prison.* New York, Vintage

Foucault M (1988) *The History of sexuality Vol 1 an introduction.* London Tavistock 1.9

Frank A (1991) *At the will of the body.* Boston, Houghton Mifflin

Frank A (1995) *The wounded story teller*. Chicago, CUP

Frank A (1997) *Illness as moral occasion: restoring agency to ill people*, Health 1(2): 131-148

Frank A (2010) *Letting stories breathe: a socio-narratology.* Chicago UCP

Frei H (1974) *The eclipse of biblical narrative.* New Haven & London, Yale UP

Frei H & Hauerwas S (1989) *Why narrative ? Apologetics criticism and the loss of narrative interpretation*. Eugene Oregon Wipf & Stock

Freidson (1970) *A study of the sociology of applied knowledge*. New York, Dodd Mead & Co

Frye N (1957) *Anatomy of criticism*. Princeton NJ, Princeton UP

Gabriel Y in Hurwitz et al (2004) *Narrative research in health & illness*. Oxford Blackwell

Garro L (1994) Chronic illness and the construction of narratives, in Good et al (eds) P*ain as human experience*. Berkeley, UCP

Genette G (1986) *Theorie des genres.* Paris, Seuil

Gerhardt U *Narratives of normality: end stage renal failure patients experience of their transplant options* in Williams S and Calnan M (1996) Modern Medicine: lay perspectives and experiences, London UCL Ch 7

Gerhardt U (1989) *The sociological image of medicine and the patient* in Social Science & Medicine Vol 29(6), 721-728

Glaser & Strauss (1968) *Time for Dying*. Chicago, Aldine

Good M, Brodwin P & Kleinman A (1994) *Pain as human experience*. Berkeley UCP

Goffman E (1969) *The presentation of the self in everyday life.* New York, Doubleday

Goffman E (1981) *Forms of talk*. Oxford Blackwell

Goffman E (1990) *Stigma: notes on the management of a spoiled identity*. Harmondsworth, Penguin.

Gordon T (2001) *A need for living*. Glasgow, Wild Goose Publications

Greimas A (1982) *Semiotics & language*. Bloomington, Indiana UP

Gussow Z and Tracy (1968) *Status Ideology and adaptation to stigmatized illness: a study of leprosy*. Human Organisation 1968 Vol 27(4) p.316-325

Gutierrez G (1973) *A theology of liberation: history politics and salvation*. New York, Maryknoll

Habermas J (1987) *The theory of communicative action*. Cambridge, Polity

Hauerwas S (1981) *Vision and virtue: essays in Christian ethical reflection. Notre* Dame, NDUP

Hauerwas S (1981) *A community of character.* Notre Dame, Indiana

Hay C (2005) *Predictors of quality of life of elderly end stage renal patients*. Ph D, Georgia State Univ

Heidegger M (1992) *The concept of time,* Trans William McNeill. Oxford, Blackwell

Heschel (1936) in Moltmann J (1975) *The experiment hope*. Augsburg, Fortress Press

Hervieu Leger (2000) *Religion as a chain of memory,* Translated by Simon Lee. Cambridge, Polity Press

Hibbard J et al (2007) *Do increases in patient activation result in improved self-management behaviours?* Health Services Research 42(4): 1443-1463

Hochschild A (1983) *The managed heart: commercialization of human feeling*. Berkeley, UCP

Holstein J and Gubrium J (2000) *The self we live by: narrative identity in a postmodern world.* New York, Oxford UP

Hooper J, Psychological care of patients in the renal unit, in McGee & Bradley (1994) *Quality of life following renal failure*. Chur, Harwood AP Ch 12

Hooper J & Cohen L, Psychological and psychiatric considerations in patients with advanced renal disease, in Chambers E Germain M & Brown E eds (2004) *Supportive care for the renal patient.* Oxford, OUP Ch 9

Horne R & Weinman J, Illness cognitions: implications for the treatment of renal disease, in McGee & Bradley (1994) *Quality of life following renal failure*. Chur, Harwood AP Ch 7

Hurwitz B Greenhalgh T & Skultans V (2004) *Narrative research in health and illness*.

BMA, Oxford, Blackwell

Hyden L (1997) *Illness & Narrative*. Social Health & Illness 1997:19(1):48-49

Illich 1 (1977) *Limits to medicine: the expropriation of health*. London, Boyars

Jamieson (2002) *A churchless faith: faith journeys beyond the churches.* London, SPCK

Jara R & Vidal H (1986) *Testimonio y Literatura.* Minneapolis, Institute for the study of ideologies of literature

Jones G (2004) *Blackwell companion to modern theology*. Oxford, Blackwell

Kassebaum G & Bauman B 1965) *Dimensions of the sick role in chronic illness* in Journal of Health & Human Behaviour Vol 6 (1) American Psychological Association

Kleinman A (1988) *The illness narratives.* USA, Basic books

Kleinman A in Good et al (1994) *Pain as human experience.* Berkeley, UCP

Koenig H (2002) *Spirituality in patient care*. Philadelphia, Templeton

Koenig H (2008) *Medicine religion & health*. Philadelphia, Templeton

Kubler-Ross E (1969) *On death and dying.* New York, Macmillan

Labov W & Waletsky J (1967) *Narrative analysis: oral versions of personal experience,* Journal of narrative & life history 7: 3-38

Labov (1973) *Sociolinguistic patterns*. Philadelphia, Philadelphia UP

Langelier K & Peterson E (2003) *Storytelling matters: performing narratives in daily life.* Philadelphia, Temple UP

Lawton J (2003) *Lay experiences of health and illness*, Sociology of Health & Illness,25: 23-40

Lemert E (1974) *Beyond Mead: the societal reaction to deviance*, in Social Problems Vol 21(4) JSTOR

Linde C (1993) *Life Stories: The Creation of Coherence*. Oxford, OUP 1.10

Lorig et al (2006) *Living a health life with chronic conditions*. Boulder, Bull Publishing Co.

Lyall D (2001) *Integrity of Pastoral Care*. London SPCK

Lyotard (1984) *The Postmodern Condition*. Manchester MUP

MacIntyre A (1984) *After virtue: a study in moral theory*. New York, OUP

McGee & Bradley (1994) *Quality of life following renal failure*. Chur, Harwood AP

McQuillan M (2000) *The narrative reader.* Abingdon, Routledge

Mehan H (1979) Learning Lessons: social organisation in the classroom, in Silverman D (2010) *Doing qualitative research* (3rd ed). London, Sage

Mishler E (1986) *The analysis of interview narratives. In Narrative Psychology. The Storied nature of human conduct.* TR Sarbin ed 233-55. New York, Praeger

Mishler E (1999) *Storylines: Craft artists narratives of identity*. Cambridge MA Harvard UP

Moltmann J (1967)*, Theology of Hope.* London, SCM

Moltmann J 1974) *The crucified God.* London, SCM

Moltmann J (1975) *The experiment hope.* Augsburg, Fortress Press

Morgan M et al (2015) *Who waits longest for a kidney? Inequalities in access to transplantation among BAME groups in the UK*. British Journal of renal medicine Vol 20 (1) pp 4-7

Morgan J, Living with renal failure on home haemodialysis, in Anderson & Bury (1988) *Living with Chronic illness: the experience of patients and their families*. London, Unwin Hyman Ch 9

Morgan M, Calnan M & Manning N (1985) *Sociological approaches in health & medicine.* London, Croom Helm

Musil (1979) *The man without qualities,* in Williams G 1984.. London, Picador

Nelson H (2001) *Damaged identities, narrative repair.* New York, Cornell UP

Neuberger J (1998) *Primary care: core values: patient priorities*, *BMJ* 1998.317:260

Nouwen H (1994) *The return of the prodigal son: a story of homecoming.* London, Darton Longman and Todd

Ochs E and Capps L (2001): *Living narrative: Creating lives in everyday storytelling.* Cambridge, Harvard UP

Pannenberg W (1985) *Anthropology in theological perspective.* Edinburgh, T & T Clark

Pargament et al (2000) *The many methods of religious coping*, in Journal of clinical Psychology 56.4, 519-543

Parsons T (1951) *The social system.* London Tavistock

Peterman A & Fitchett G (2002) Measuring spiritual wellbeing in people with cancer: the functional assessment of chronic illness therapy – spiritual wellbeing scale (FACIT SP) *Annals of Behavioural Medicine* 24(1): 49-58

Picker (2013) *Living well programme: evaluation of the pilot at Camberwell and New Cross satellite dialysis units*. Oxford, Picker Institute Europe

Pound et al (1998) *Illness in the context of older age,* Sociology of Health & Illness 20(4): 489-506

Propp V (1968) *Morphology of the folk tale.* Austin Texas, Texas UP

Puchalski C (2006) *A time for listening and caring*. Oxford OUP

Reissman (1993) *Narrative analysis*. London, Sage

Ricoeur P (1984-88) *Time and narrative Vols 1-3*. Chicago, Univ Chicago Press

Ricoeur P (1968) Life: a story in search of a narrator, in Doeser M & Kraay J (eds) *Facts and values.* Dordrecht, Nihoff

Ricoeur P (1992) *Oneself as another.* Chicago, UCP

Robinson S Kendrick, K & A Brown (2003) *Spirituality and the practice of health care.* Basingstoke, Palgrave MacMillan

Root M (1989) The narrative structure of soteriology, in Hauerwas S & Jones L (eds) *Why narrative? Readings in narrative theology.* Grand Rapids, Eerdmans

Rorty R (1989) *Contingency, irony and solidarity*. Cambridge, CUP

Russ, Shim & Kaufman (2005) *Is there life on dialysis Time & aging in a clinically sustained existence.* Medical Anthropology 24(4): 297-234

Said E (1993) *Culture and imperialism.* London, Chatto & Windus

Sanders, Donovan & Dieppe *The significance and consequence of having painful & disabled joints in older age*. Sociology of Health & Illness Vol 24 No 2, pp.227-253. Oxford Blackwell 6.12

Saunders C in Clark D (2000) *Total Pain the work of Cicely Saunders and the hospice movement*, American Pain Society Bulletin 10(4), 13-15

Saldana J (2003) *Longitudinal qualitative research: analysing change through time.* Walnut Creek CA., Alta Mira Press

Saunders C in Clark D (2000) Total Pain the work of Cicely Saunders and the hospice movement, American Pain Society Bulletin 10(4), 13-15

Scarry E (1985) *The Body in Pain: The making and unmaking of the world*. Oxford OUP

Scheff T (1966) *Being mentally ill – a sociological theory*. London, Weidenfield & Nicholson.

Schutz & Haupert, Narrative analysis, in Flick (2002) *Introduction to qualitative research*. London, Sage Ch 7

Silverman D (2005) *Doing qualitative research.* Second Edn. London, Sage

Soelle D (1975) *Suffering*. Minneapolis, Fortress Press

Strauss & Corbin (1988) *Unending work and care: managing chronic illness at home*. San Francisco, Oxford Jossey Bass

Tong et al (2009) Patients' experiences and perspectives of living with CKD, *American Journal of Kidney Disease* 53(4): 689-700

Tsay Lee & Lee (2005) *The effects of an adaptation training programme for patients with end stage renal disease.* Journal of Advanced Nursing Apr 50 (1) 39-46

Tyrrell et al (2005). *Ageing & Mental Health.* Jul (4): 375-9

Watts J (unpublished) *Review of LWP Stages 1, 2 and 4*. London, Guys and St Thomas Foundation Trust

Watts J (2004) *The spiritual needs of renal patients: a narrative approach*. University of Leeds, School of Healthcare Studies, MA dissertation

Wengraf T (2001) *Qualitative research interviewing*. London, Sage

White G (2006) *Talking about spirituality in health care practice*. London, Jessica Kingsley

White J 2004. *Healing the body and soul of the nephrology patient.* Nephrology News & Issues 2004 Jan. 18(2):51-3

White M & Epston D (1990) *Narrative means to therapeutic ends.* New York, Norton

White V (2002) *Identity.* London SCM

Williams G (1984) *The genesis of chronic illness: narrative reconstruction*, Sociology of Health & Illness 6(2): 175-200

Williams G & Busby H, The politics of disabled bodies, in Williams S, Gabe J & Calnan M (2000) *Health Medicine & Society: Key theories, future agendas.* London, Routledge

Williams S (2000) *Chronic illness as biographical disruption or biographical disruption as chronic illness?* Sociology of Health & Illness 22(1): 40-67

Williams S & Calnan M (1996) *Modern Medicine – lay perspectives and experiences.* London, UCL Press

Willliams, Gabe & Calnan (2000) *Health Medicine & Society: Key theories, future agendas.* London Routledge

BIBLIOGRAPHY

(includes titles used in background research but not referred to in main text)

Anderson R (1982) *On being human – essays in theological anthropology*. Grand Rapids, Eerdmans

Bal (1997) *Narratology: introduction to the theory of narrative.* Toronto UTP

Barth (1978) *The Word of God and the Word of Man* Trans. D Horton. Gloucester Peter Smith

Barth in Anderson R (1982) *On being human – essays in theological anthropology*. Grand Rapids, Eerdmans

Bakhtin M (1981) *The dialogic imagination: four essays*. Austin Univ of Texas Press

Barthes R (1986) *The Rustle of language,* Trans Richard Howard. London Blackwell

Bauman Z (1992) *Mortality, Immortality & other life strategies*. Stanford, Stanford UP

Berger P (1967/1991) The sacred canopy: elements of a sociological theory of religion. New York, Anchor

Cassidy S (1991) *Good Friday people*. London, DLT

Gates H (1995) *Thirteen ways of looking at a black man,* New Yorker 23 Oct 1995

Geertz C (1966) *Anthropological approaches to study of religion*. London, Tavistock

Jones G (2004) Blackwell companion to modern theology. Oxford, Blackwell

Kelly and Field (1998) *Conceptualising chronic illness* In Field D and Taylor S eds Sociological perspectives On Health Illness and Health Care Oxford Blackwell Scientific

Kubler Ross E (1978) *To live until we say good bye.* London, Prentice Hall

Levi Strauss (1958 trans 1963) *Structural anthropology*. NY, Basic Books

Liebermann M (1998) *Commitment Value and Moral Realism*. Cambridge CUP

Lyall D (2001) *Integrity of Pastoral Care.* London SPCK

NHS England (2015) NHS Chaplaincy Guidelines 2015: Promoting Excellence in Pastoral Spiritual & Religious Care. (Updated 6 March 2015)

Nouwen H (1992) *The return of the prodigal son.* London, Darton Longman & Todd

Ricoeur P (1970) *Freud and philosophy.* New Haven, Yale University Press Rorty R (1989) *Contingency, irony and solidarity*. Cambridge, CUP

Saunders C (2003) *Watch with me.* Rockford Illinois. Mortal Press

Scarry E (1985) *The Body in Pain: The making and unmaking of the world*. Oxford OUP

Schechtman M (1996) *The constitution of selves*. Ithaca Cornell UP

Stark and Bainbridge (1987) *A theory of religion* New York, Peter Lang

Taylor C (1989) *Sources of the self.* Cambridge, Harvard UP

Vanier J (1988) *The Broken Body.* London DLT

Weber M (1963) *The sociology of Religion.* Boston, Beacon Press

Appendix A

The Living Well Programme: data analysis and results

A1 Introduction

This chapter describes the first part of the data stage of the study, which gathered and analysed qualitative data arising from the Living Well Programme. The LWP provided longitudinal data about patients' lives, how they managed their illness and responded to disruption events. All the study subjects participated in LWP and agreed that this data could be used anonymously, alongside the research interviews

A1.1 LWP as narrative data

The Living Well Programme was described above in Introduction v. The data it generated was important in that it produced first- hand accounts of living with chronic illness over time, and particularly evidence of disruption. The past/present/future narrative format of LWP allowed simple narrative lines or profiles to be plotted, which showed whether the narrative profile was going up or down (progressive or regressive narratives). In earlier stages of LWP, the 12 narrative dimensions (physical, mental, social, spiritual) were aggregated to give an overall 'lifestyle gradient' (L-gradient). In stage 3, spiritual dimensions 9-12 were aggregated to give a 'faith gradient' (F-gradient). The data from earlier stages was also available to do this. This allowed L and F gradients to be worked out for all patients, in order to evaluate whether any relationship existed between L and F scores or patterns.

Identifying how and when disruption occurred was the first step. The narrative profiles of these patients indicate that some experienced dramatic disruption followed by equally dramatic recovery; others exhibited a gradual downward pattern. By looking at peaks and troughs in patients' L and F gradients, different kinds of response and recovery patterns could be observed.

A1.2 Links to theory

The study began by establishing spiritual disruption as an empirical fact. A definition was offered above (Intro iv): spiritual disruption is defined as 'any disturbance to faith and practice that results from chronic illness and produces change'. Disruption can be of two kinds – temporary, when the previous faith belief and practice is restored after a time of disturbance; or permanent, when the previous state is not restored. In this case belief and practice may be discontinued or may be changed in a radical way; such changes may involve loss of faith or renewal of faith.

A1.3 Detailed methodological issues

The methodological issues that arise from studying spiritual disruption are related to description and measurement. Using LWP data, an empirical means of describing disruption by coding life gradients or scores was devised – the largest drop in gradient equals the greatest disruption. This is a relatively simple method based on fieldwork contact sheets, which capture some of the quality of the patient encounter. To give a more in depth view, a qualitative interview and a disruption narrative is required (see Chapters 4 and 5) to capture the original settled state, the nature of the disruption and the response to it. In Section 1.1 formalist narrative theory was used to show that a disruptive event is central to a story plot, and that in everyday narrative structures, disruption is always followed by response and sometimes resolution (ending), through which equilibrium is restored.

A1.4 Mapping disruption using LWP

In this study LWP data was used as a first order tool for mapping disruption – its extent and general impact. The patient’s own narrative (narrative lines under LWP dimensions) identified how serious the disruption was. The past–present comparison showed what activities and roles had been lost; the present/future columns showed the extent of the recovery that was planned and anticipated.

LWP was shown to be an effective tool for mapping out the territory and broad outlines of the biographical and spiritual disruption process. In this appendix its use can be seen in three ways:

1. To observe and record the extent of biographical and spiritual disruption.
2. To group patients in terms of their response to disruption.
3. To define a theoretical or purposive sample for interview stage.

The Living Well Programme asked patients to describe their life activities under 12 headings:

		Past	Present	Future
Physical	Keeping fit/going out			

	Eating well			
	Symptoms and pain			
Mental	Personal interests			
	Doing a useful job/role			
	Emotional wellbeing			
Social	Friends & family			
	Staying independent			
	Housing benefits & care			
Spiritual	Spiritual growth			
	Belonging to a faith group			
	My living well story			

The LWP life review tool contained 36 fields as shown above which when completed described activities in past, present and anticipated future. This was a narrative tool: it did not include any quantitative measures of activity levels. Instead it recorded and coded the subjects' descriptions of activity. For example if there was a lot of material under 'personal interests' before illness, less now, and even less in the future, this would result in reducing scores. As a fieldwork tool it did not attempt to offer accurate measures of activity at one moment, but instead to record broad changes over time. Clearly in the example quoted, personal interests had diminished over time. Similarly, if material about family and friends decreased over three stages, this indicated less activity and therefore less contact.

A key feature of the tool was the future column. To a quantitative researcher this column would be meaningless, since the future does not exist yet, and so cannot be measured. But in chronic illness, planned future activity is a vital indicator of hope and life potential, and is the place where the greatest losses may occur. So recording anticipated future gives a vital insight into patients' outlook.

A2 LWP data analysis: Overview

A2.1 Description of LWP data studied

LWP had developed in twelve-month stages as follows:

LWP Stage 1: 2007-8

LWP Stage 2: 2008-9

LWP Stage 3: 2009-10

The format remained largely unchanged throughout.

The data used for the study was as follows (n =36). Only complete LW plans were used; some LWP participants did not complete all of the sections in the programme.

Stage 1	LW Plans from 10 patients. Complete LWPs from 7 of these patients
Stage 2	LW Plans from 21 patients. Complete LWPs from 16 of these patients
Stage 3	LW Plans from 13 patients. Complete LWPs from 13 patients

The contact sheets summarised the LW Plan data and were the primary data source. The LW Plans were coded by giving plus points for positive statements and minus points for negative statements, so arriving at past present and future score for the 12 dimensions, resulting in 36 fields of data. By comparing past, present and future scores a profile was derived which was termed the lifestyle gradient (L gradient). A separate profile was derived from three spiritual fields (10-12) which was termed the faith gradient (F gradient).

A2.2 Analysing LWP data: introduction

LWP was designed as a pastoral intervention, not a research tool. The data in the life review was used mainly to help patients address life and faith issues. Little analysis of this data was done as part of this process. The main benefit that came from the life review process was to highlight changes and especially losses that had occurred. These in turn had to be evaluated and sorted into recoverable and non-recoverable losses.

But as the researcher looked at the data available, its potential for research became clearer. After developing a coding system and a way of representing disruption graphically as the life gradient and the faith gradient, this gave an instant picture of where the patient stood – see Diagram A2.2.1. Taking the first example Tom, the life gradient clearly shows the dip or trough created by illness disruption. But Tom anticipated that this would be put right and recovered in the future. A link is suggested between a trough (life line L) caused by life disruption and a peak (F line) indicating a strong faith reaction. Winston’s gradient shows some minor life disruption alongside a major faith dip: life disruption is causing a current faith crisis, yet Winston remains optimistic and expects things to improve in the future. Sheila’s L and F gradients show a huge negative dip in both L and F scores: this gave major cause for concern. This was a time when Sheila had really hit rock bottom, and thought life was no longer worth living. These simple diagrams did in fact correspond with the patient's state and outlook, which was known to the researcher as chaplain. They therefore passed the first empirical test of plausibility.

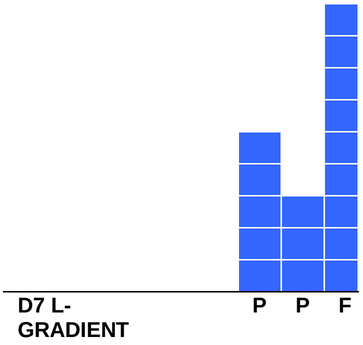
Developing and expanding this L and F coding and scoring system across the sample available (36 patients) proved more complex. The results are shown in Diagrams A2.2.2 and A2.2.3. Diagram A2.2.2 shows patients from stages 1 and 2, Diagram A2.2.3 shows patients from stage 3. The results indicate a wide diversity of L and F responses and patterns, which it proved difficult to generalise and theorise. The following general conclusions were made:

- A commonly found L gradient was the downward regressive pattern: see D1, D12, D21 J1, J5, and J9. This corresponds to most people's view of chronic illness: a steady loss of activity from past, present to future. The opposite pattern, an upward gradient, see D7, D10, D13 was surprising and more exceptional.
- The trough pattern for both L and F corresponds to another basic perception of illness: life before and after (recovery stage) is good, but life dips dramatically during illness: see D2 D3 D5 D6 D7 D8 in stage 3. This pattern clearly anticipates life recovery, in the perception of the patient.
- The peak pattern, see D2 D8 D10 D12 D20 for L and F is interesting since it shows that for some individuals the response to illness is to fight back hard, investing energy and effort, hence the increased life activity levels. The peak pattern of F gradient J1, J4, D1, D7, D13, D15, D21 occurs when the subject's primary response is to mobilise faith in response to life disruption.

Some consideration was given to whether this tool might have a therapeutic application. But in the end it was not developed any further in this way. It was however noted that occasionally dramatic drops occurred between past and present scores (black arrows on diagram), which were a warning sign that the patient might be in crisis. In practice this would already have been noticed through pastoral contact. But this did give the diagrammatic use of gradients some empirical validity.

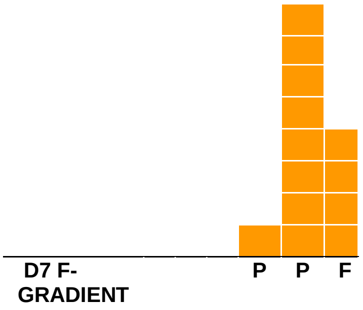
Diagram A2.2.1 Introductory Diagram: L & F Gradients

Tom D7



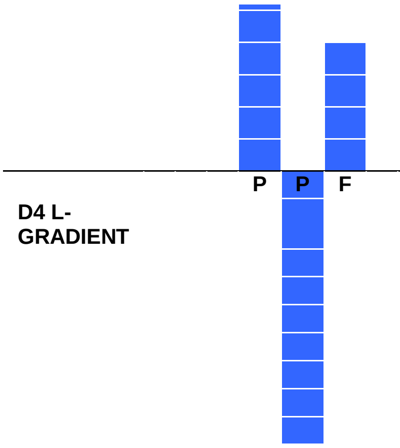
L & F gradients are a means of depicting biographical and spiritual disruption
L Gradient – life (biographical) disruption
F Gradient – faith (spiritual) disruption
Each diagram has three columns – P P F: past, present future
The column height corresponds to past present and future scores derived from narrative coding of LWP life reviews

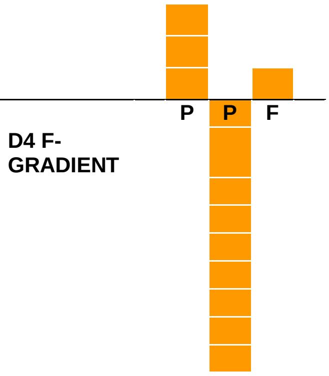
Tom’s L gradient is trough pattern
This indicates reduction of life activities in P present column, caused by illness disruption. The Future F column shows that Tom expects to recover and increase life activity in the future



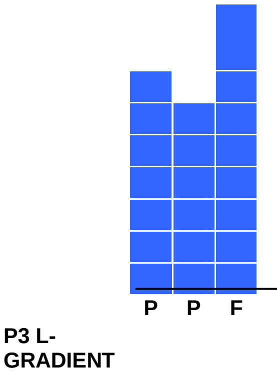
Tom’s F gradient is peak pattern.
This indicates Tom has a strong faith response to illness disruption in ‘present’ P column.
The combination of trough pattern L gradient (life activity disrupted) and peak pattern F gradient (faith activity increased) places Tom in Group A: life disruption and increased faith

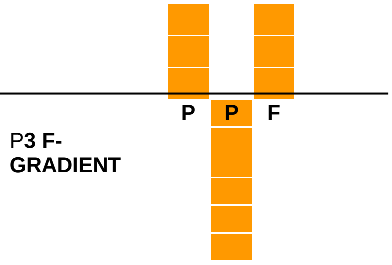
Sheila D4





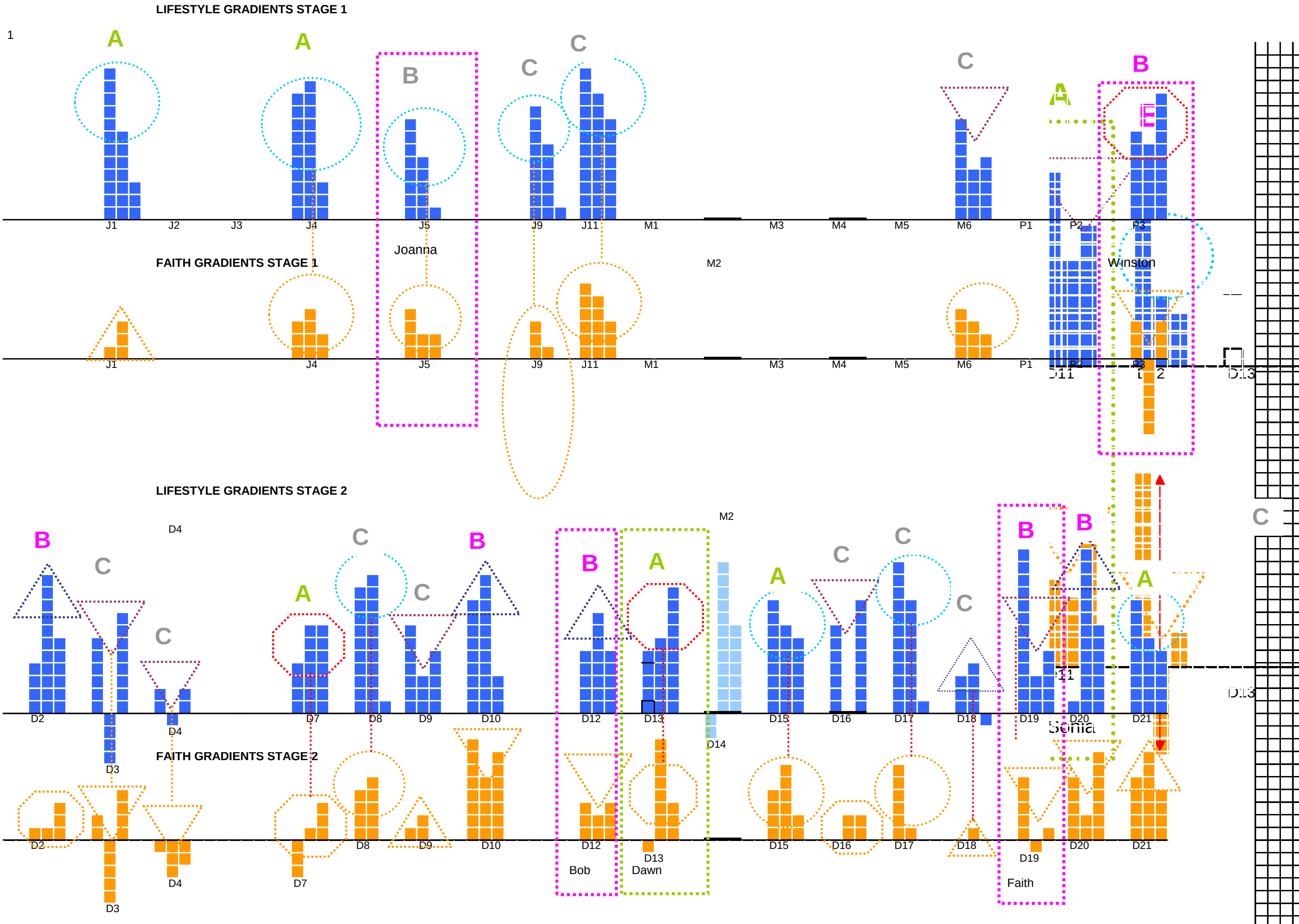
Winston P3





D4 Sheila’s L and F gradients are both trough shaped, with major negative scores in P Present column. This places Sheila in Group B/C: major life disruption paralleled by faith disruption

P3 Winston’s L gradient shows minor life disruption. But the F gradient shows a deep trough. This places Winston in Group B: life disruption and disrupted faith



Stages 1-2
Interview
sample

GROUP A ⬚

GROUP B ⬚

STAGE 1 & 2 data analysis **Grouping by L/F response**

Group A	L disruption and increased faith	[6]
Group B	L disruption and modified/disrupted faith	[6]
Group C	L disruption paralleled by F disruption	[11]

KEY

◯ Progressive Narrative

⬡ Regressive Narrative

△ Peak narrative - peak response

▽ Trough narrative - major disruption

A2.3 Life and faith gradients: observing changes

L and F gradients for all 36 subjects were compared to identify any recurring patterns, and see if there were any changes. The main patterns observed were peak, trough, progressive and regressive for L and F.

In stage 2 the gradient patterns are interesting in that mostly these are opposites - peak plus trough etc. Opposite patterns indicate that faith behaves independently from life gradient. The number of peak L gradients occurring in stage 2 is interesting and surprising. The normal pattern of biographical disruption would be that illness creates disruption which would be reflected in a lower or reducing L score. Why might this score go up instead?

Clearly illness triggers a response, for example fight or flight. For some individuals the illness becomes a life project – all available energies are mobilised into fighting the illness. This is indicated by peak L and F gradients. Others will simply adopt a more accommodating strategy, and allow illness to limit their behaviour.

In stage 3 the commonest pattern is trough L gradient plus peak/trough F gradient

Lifestyle gradient	Trough pattern 9 [69%]
Faith gradient	Peak 6 [46%] Trough 5 [38%]

This supports the disruption–restitution narrative for this group – biographical and spiritual disruption is temporary, and is followed by restoration of previous life activities. Stage 3 has an equal split between mirror pattern and opposite pattern (7/6). This may be hypothesised as follows.

Mirror pattern – For some individuals, their faith closely reflects (mirrors) how things are going in their lives as a whole. If life is going well, faith is strong; if things are going badly, faith becomes weaker. Faith here is pragmatic, useful if it works: if not it may be discarded or put on hold.

Opposite pattern – For other individuals adverse events act as a trigger to a strong fight-back faith response. These individuals may be very committed to their faith, and therefore adversity offers a challenge – faith must be effective here as well, if it is to appear worthwhile and strong. The classic fight-back pattern would be one where L gradient goes down, and F gradient goes up in response; or a trough L gradient is answered by a peak F gradient, where faith is mobilised, until the ‘trough’ is past.

A2.4 Grouping of patients by response: group A B C

Having classified L and F gradients by type, specific combinations of these types were also identified separating inverse correlation (group A) from direct correlation (group C) and no correlation (group B). These groups are listed and described below.

Group A	*Life disruption followed by active faith response*		12 subjects (33%)
Stage 1 (1)	J1	Regressive L gradient, peak F gradient	
Stage 2 (4)	*D7	Progressive L gradient, progressive F gradient	
	*D13	Progressive L gradient, peak F gradient	
	D15	Regressive L gradient, peak F gradient	
	D21	Regressive L gradient, peak F gradient	
Stage 3 (7)	D1	Regressive L gradient, peak F gradient	
	D3	Trough L gradient progressive F gradient	
	*D6	Trough L gradient, peak F gradient	
	*J7	Progressive L Gradient, progressive F gradient	
	D8	Progressive L & F gradients	
	D10	Progressive L gradient, peak F gradient	
	*D11	Trough L & F gradients	

In group A, 8 subjects all have peak or progressive F gradients with different L gradients, which indicates that for these subjects disruption triggered an active faith response. The next question then was – how long did this response last? Was it temporary until the crisis was over, then everything returned to normal? Or was it longer lasting, with permanent changes occurring to faith (belief and practice) in response to the new situation? These questions could only be answered by observing these subjects over time. If the initial disruption and faith response was in the past, the subject could be interviewed, and the faith story recorded to detect any significant changes.

There are also patients in stages 1-3 where the opposite has occurred. For some, when the L gradient has gone downward or remained steady, the F gradient has dropped even more and maybe not recovered. Examples are listed below (Group B).

Group B *Life disruption and faith disruption* 9 subjects (25%)

Stage 1 (2)	*J5	Regressive L gradient, stable F gradient
	*P3	Small trough in L gradient, very deep trough in F gradient
Stage 2 (5)	D2	Peak L gradient, progressive F gradient
	D10	Peak L gradient, trough F gradient
	*D12	Peak L gradient, trough F gradient
	*D19	Trough L gradient, trough F gradient
	D20	Peak L gradient, trough F gradient
Stage 3 (2)	*D4	Trough L gradient, trough F gradient

** indicates study interview subject*

In these cases, the F gradient dips further than in the fluctuating group C model. This may mean that the person has found fight back resources (peak L gradient), but faith is not used or applied in this situation – or it may be lost.

The group A subjects all indicated resilient faith, suggesting disruption for them was a trigger for an enhanced faith response. Group B experienced faith loss or major faith disruption, even though they were able to respond effectively to the disruption in their lives. This indicated that some group A and group B patients should be studied in more detail, using interviews - the group A patients to see what it was about their faith that made it respond so readily to the challenge, and the group B patients to see why their faith was of no help to them in responding to a crisis.

This approach would correspond to the purposive sampling method outlined in Section 3.7. Also, the research objective in Section 3.4 was to research into the impact of chronic illness on faith, and use the knowledge gained to enhance spiritual care of these patients. Almost all the cases show changes in faith gradient – there is not a single static faith line. This shows that spiritual disruption leading to change was a common occurrence in this sample.

Group C subjects all support the model in the diagram, showing close correspondence between faith and life gradients. This group represents the largest single group in the study (n=15)

Group C Life disruption fluctuates (up and down) along with faith disruption 15 (42%)

Stage 1 (3)	J4	Regressive L gradient, regressive F gradient
	J9	Regressive L & F gradients
	J11	Regressive L & F gradients
	M6	Trough L, regressive F gradient
Stage 2 (7)	D3	Trough L & F gradients
	D4	Trough L & F gradients
	D8	Regressive L & F gradients
	D9	Trough L gradient, peak F gradient
	D16	Trough L gradient, progressive F gradient
	D17	Regressive L & F gradients
	D18	Peak L & F gradients
Stage 3 (4)	D2	Trough L & F gradients
	*D5`	Trough L & F gradients
	*G1	Trough L & F gradients

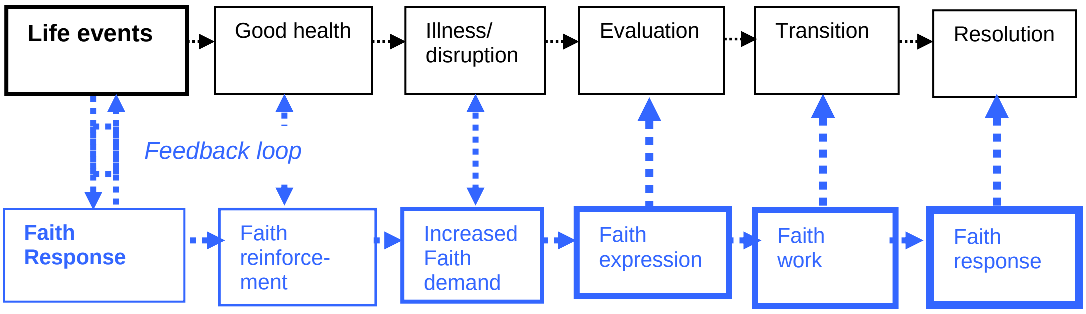
Group C has two sub groups. The first C1 was composed of less active or nominal faith members, who might only turn to faith in times of crisis. The second C2 comprised those with no active faith, but with strong self-belief and self-story which outlined their life goals and purposes. The first group was however of less interest to the study, apart from noting its existence. The second group had a strong self-narrative and purposeful life quest, which for them worked in the same way as a faith story. Three people from this group were later selected for interview.

In this group perhaps the most interesting patients to interview would be those with high future expectations, where disruption is expected to be reversed. The trough patients D3, D4, D2 and D5 and D11 all plan to rebuild life (and faith) in the future. This then is the beginning of the narrative quest (Section 6.7 below) which will explore the possibilities for living with illness, and ways of overcoming its disruptive impact.

A3 Reviewing the model: The faith–life feedback loop

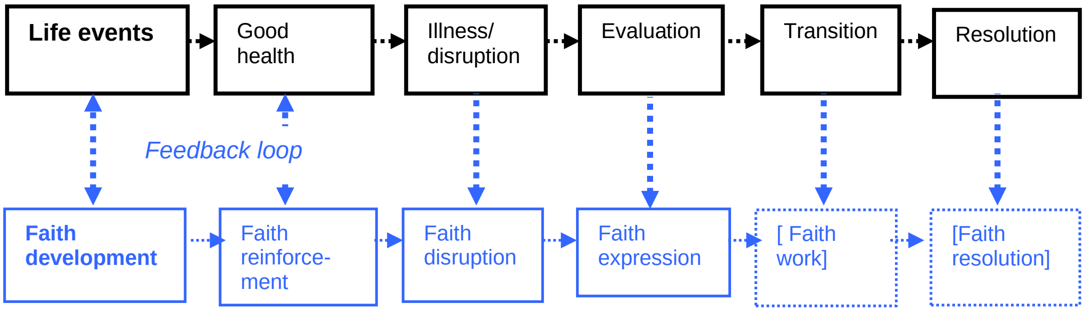
In this section a relationship is suggested between disruption events and life and faith responses, based on the data about L and F responses described above. At first the link between life and faith might appear common sense and obvious: that life events influence faith and vice versa (see Diagram 4.3.1 below). Yet the data above shows faith responses differ widely between subjects. For group A patients with strong faith, life disruption only increases their strong faith responses. Group B patients on the other hand, who also have faith, do not instantly show a strong 'faith reaction'. Disruption to life activity is therefore accompanied by changes in faith activity, both positive and negative. The cases in Group C are all those subjects where the life gradient and faith gradients closely correspond, and changes in one are mirrored by changes in the other. The feedback loop diagrams 4.3.1 and 4.3.2 compare group A and group C patients.

Diagram A3.1 Group A feedback loop



The general picture gained from working with LWP participants was that this feedback loop is present for majority of patients. The intriguing and unexpected discovery here involved group C patients. For these patients faith did not play a major role in their illness response, as they described it. These patients had a residual or nominal type of faith such as that derived from attending church/church school in childhood. Typically such conventional faith is not abandoned, but merely lies dormant until triggered by a crisis. But the findings from LWP indicated that such faith rather than remaining dormant also rises and falls along with life circumstances. For these patients the L line is the driver and generator – and gives impetus to strengthen residual faith when life is positive.

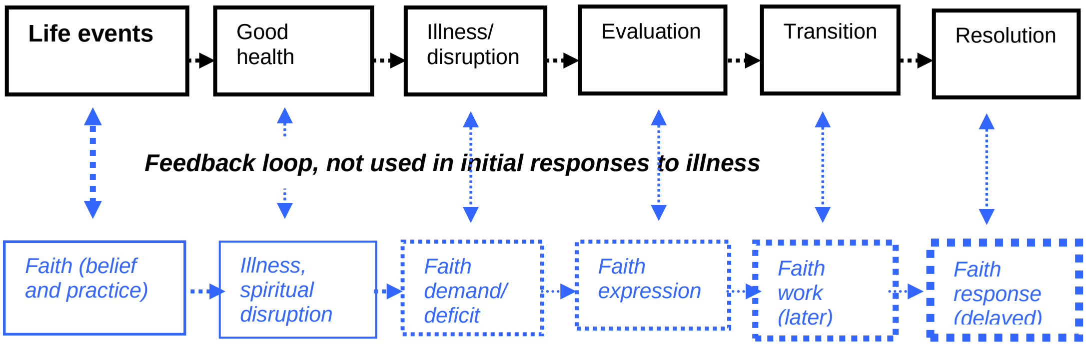
Diagram A3.2 Group C feedback loop



This finding that both positive and crisis life events increase faith response in subjects with nominal faith is important for spiritual carers, as this indicates that such nominal faith remains a potential source of support, which might be nurtured and developed by spiritual care.

For group B (25%) patients on the other hand it seems that the feedback loop does not operate as for the other groups. Some of these patients responded positively and recovered from illness disruption – but faith did not at first play an important part in this. The most likely explanation for this is that the feedback loop is ineffective. Illness onset represents a time of crisis and weakness, which prevents a considered faith response from being worked out immediately. Three strong faith subjects offer evidence for this – D19, J5 and P3, who were all in group B at LWP review stage, but were definitely group A (strong faith recovery) by the time of the interviews.

Diagram A3.3 Group B feedback loop



This group was also important later in the study when the observation of the repetitive disruption cycle (Section 6.4) led to the learning hypothesis – that life and faith recovery is learned over time. Several study subjects (Joanna, Winston, Dawn and Faith) showed this delayed response, which led to a strong resurgent faith response occurring later, after an initial period of exploration evaluation and learning

This suggested that for the faith demand created by illness disruption, the feedback loop may not operate immediately or automatically – the traditional faith system did not provide readily available resources for this new situation. First, new faith resources have to be built up. This was then explored through interviews, and is discussed later in Chapter 6.

A**4** Sampling strategy for narrative interviews

A4.1 Theoretical sampling: types of response

The responses types found through LWP analysis were of three types: groups A, B and C, which were subdivided and described as follows:

Group A	*Life disruption followed by active faith response*
Group B1	*Life disruption and faith disruption*
Group B2	*Life disruption with no immediate (or delayed) faith response*
Group C1	*Life disruption fluctuates along with faith disruption*
Group C2	*Life disruption followed by active recovery response (no faith response)*

Within a small sample it is not possible to suggest specific causal links between the different kinds of disruption being measured. It would nevertheless be fair to comment that illness disruption is also a threat to faith and faith practice, so it would seem possible that a ‘faith response’ would occur directed at limiting the perceived threat (group A). It is more surprising by contrast to find life and faith disruption without any sign of an active faith response (group B). This might be attributed to disorientation or shock, and the need for a period of faith recovery and faith work, before any kind of active response can emerge.

Individual LWP patients were classified as groups A, B and C. The most complex group was group B, where it was not possible initially to determine whether faith was simply inactive, but might recover later, or alternatively might not recover sufficiently to have any impact on life recovery. But it proved possible to revisit four key group B patients at interview stage, after a 1-2 year time interval, by which time their faith response had changed.

The categories (groups) to be studied at interview stage were now revised down to three: patients whose previous faith had been mobilised and strengthened in response to illness disruption (group A), and patients who had previous established faith, but had not yet formulated a faith response (Group B). In addition, there was a third group not previously envisaged, Group C, whose L & F profiles went up and down according to circumstances. This group represents the default or average group: people with some ongoing nominal faith, whose faith did not seem to play an important role in their response to illness. Another variant group C2 consisted of people with little or no religious faith who had a strong sense of purpose in their lives, and used this to manage the disruptive impact of illness.

In relation to the study, groups A and B might appear the most promising for more detailed study, because in these groups life disruption has had the highest (positive or negative) impact on faith. Group C1 on the other hand did not seem to offer much promise for further study. But Group C2 became important and was included, since it was realised that specific kinds of moral agency (life goals) work in the same way as faith, to give purpose and direction during illness.

A4.2 Proposed sampling method

In order to make best use of resources, it was decided to focus mainly on interviewing Groups A and B, according to the method outlined in Chapter 3, but also if time permitted to interview three representative patients from group C2. Group A patients showed a very clear faith impact, – an immediate ‘fight back’ response to disruption. Group B patients were the opposite no immediate response, which needed investigating. Group C, fluctuating faith response, were of two kinds: nominal believers who had some residual faith, and non-believers with their own ethical system. This then led to the initial sample selection for interview as listed below. Group A sample consisted of those with an obvious and immediate faith response, Group B of those with no immediate or delayed faith response. Group C consisted of those with no faith, but a strong life recovery response

Group A patients (5) Inverse correlation, positive faith response – life disruption is followed by enhanced faith response

[D1	‘Sidney’]
D7	‘Tom’
D11	‘Sophie’
D13	‘Dawn’
D12*	Doreen
J7*	Peter

Group B patients (5) Some correlation, negative or delayed faith response – Life disruption and faith disruption occur together.

J5	‘Joanna’
D19	‘Faith’
P3	‘Winston’
D4	‘Sheila’
[D2	‘Dot’]

Group C1 patients (2) Close correlation – life disruption corresponds with faith disruption: both fluctuate up and down together, in a similar pattern.

No suitable interview subjects planned for this group: nominal/occasional believers were not considered to be representative of faith subjects as a group, since their responses seemed random and inconsistent.

Group C2 patients (3) Life disruption is followed by strong recovery response (no faith response)

Patients with no faith who had strong life and self narrative, which provided a specific survivor story plot in response to illness:

D5	‘Bob’
D6	‘Laura’
G1	‘Terry’

[NB. All patient names were replaced by the pseudonyms listed above]

Based on the data above the following sampling process was suggested for interview stage.

1. Interview up to 5 available Group A subjects. The interviews sought to understand the resilience factor, how the ability to fight back and regenerate faith and life comes about.
2. Interview up to 4 Group B subjects (3-6). The purpose was to understand the apparent lack of resilience and resourcefulness and the poor utilisation of faith as a coping resource in this group.
3. Interview 3 Group C2 subjects (no faith) selecting from peak and trough patients where resilience and recovery are present.

This method would generate 10-12 interviews – 12 was initially the preferred number. The data would be analysed and compared. The comparison with non faith subjects Group C2 might expand the scope and relevance of the study, taking it beyond faith subjects only.

A4.3 Changes to interview sample

Some changes occurred during the sample process. Two patients from the original list (Sidney and Dot) dropped out. Five additional patients were subsequently recruited – Peter and Doreen (group A), Doreen Laura, Terry and Bob (group C). The composition of the group C sample, Laura, Terry and Bob, was slightly different from that proposed above. Two out of three had some nominal faith background (family); but all three were non-faith subjects, who had shown strong motivation and self-belief during the LWP process. They were included for interview in order to compare the impact of faith with the impact of a strong non-faith personal narrative, based on an individual's life values.

A5 Overview of LWP as data source

The findings from the LWP data outlined above are summarised below.
Lifestyle gradients and faith gradients proved useful in the research process because they gave an 'at a glance' view of the patients' outlook. A subjective check against what the researcher knew of the patient normally confirmed the picture they provided. There were three main kinds of faith response (A B C) observed from LWP Stages 1-3 (n = 36). No specific causal correlation could be deduced between biographical and spiritual disruption. Some possible relationships were suggested in Section 4.4.1

The conclusions of this chapter can be summarised as follows:

1. Almost all patients in this group experienced both biographical and spiritual disruption. No patients experienced constant undisrupted faith (flat F gradient).
2. For some 33% of patients, disruption was followed by a strong positive faith response (group A).
3. There was a neutral or negative faith response to disruption by 25% of patients (group B). These patients responded positively to disruption, but did not utilise faith as a coping resource initially (possible delayed response).
4. Group C patients split into two groups. In group C1, L and F gradients went up and down in parallel. But in group C2 there was a strong survival response, but no faith response.

It was decided that no benefit would be derived from interviewing C1 patients with nominal faith, since their faith would be largely latent or intuitive, and therefore they would not easily be able to describe and express any evolution or change. Instead group C2 composed of non-faith subjects, survivors with strong self-stories, would be interviewed. This group would help explore the link between a strong self or faith story and developing effective disruption and life recovery strategies.

The chapter offers insights into the impact of chronic illness on faith, and has explored whether biographical and spiritual disruption are linked. It has found that *all* subjects in the sample had experienced both biographical and spiritual disruption, defined as an upward or downward change in L and F gradients. Biographical disruption is consistent with what is known about chronic kidney disease, so it is not surprising it affected all patients. This prevalence of spiritual disruption (no subjects reporting stable/unchanged faith) is an interesting finding, and perhaps would need testing in a bigger sample.

For the largest group, group C 42%, it was found that disruption had affected faith, but had not had an impact on the illness response. In this group the F gradient had fluctuated in line with the L gradient, following life’s ups and downs. This group can be said to have experienced some spiritual disruption, in the sense that they had felt a faith response to disruption events, but it had not been strong enough to influence their overall response. Given the cultural and social factors inherent in religious affiliation, it is not surprising that people do not give up their religion instantly, in response to adversity. Spiritual disruption may have occurred in the sense that this group had residual religious faith (Jamieson 2002), but did not often make use of it, since they were not sure whether it would make any difference.

The finding that for a third of respondents, group A (33%), disruption was followed by an active faith response is encouraging from a spiritual care perspective. There is day to day evidence in acute spiritual care that there is a spiritual response to an illness crisis: physical, emotional and spiritual resources are mobilised in response to e.g. a major accident, an operation or health crisis. It is less well established that such a response is present in chronic illness. But the findings about group A indicate that it was there for these patients. These subjects were followed up over a substantial period of time to prove that the response was indeed long lasting. The longest interval between LWP and interview in the study was three years. During this time it was clear substantial faith development had taken place.

Moving on to the narrative interview stage in Chapter 5, it seemed logical to select representative subjects from groups A, B and C for interview. Yet this chapter (Section 4.4.2) concluded that studying group C1 would not help to answer the research question since the faith shown in that group was largely latent and inactive. But closer study of group C2 subjects showed that whilst not having strong religious faith, they nevertheless had strong life stories, which they used to reinforce their personal survival strategy. This led to the inclusion of three group C2 non-faith subjects in the interview sample. This would have a decisive impact on the outcome of the study, with the result that the narrative quest, that is the quest of the self to fulfil particular life purposes during illness, would be considered alongside the faith quest as a key factor in determining how individuals respond to chronic illness.

Chapters 4 and 5 will describe the in-depth interview process, transcription and analysis of interview results. Within the timescale of this study (completed in 2014), more data became available from the Living Well Programme, but was not included here. Appendix B discusses the impact the study findings had on the theoretical approach and evaluation method for the Living Well Programme.

APPENDIX B
Evaluating and revising the Living Well Programme (LWP)

B1 Theory and practice: developing and applying an evolving theory base

The LWP began before this study started. It was based on the assumptions prevailing at that time about long-term conditions (CDSMP Lorig et al 2006, DoH 2010, Hibberd 2007) which suggested that self-management, self help and patient activation rather than expert intervention were the most practical way to help patients. The study conclusions (7.3 above) at first sight seemed to reinforce this view. They suggest that dialysis patients are able learners, create sustainable illness narratives, define their role responsibility, and work hard to carry out their chosen roles. All this fits well with self-management theory, and suggests that patients have the capacity and learning skills to adjust well to long term illness.

But the study also uncovered a more complex reality. The competent survivor story often turned out to be a ‘narrative of normality,’ based on a desire to present oneself as normal and competent in the social setting. Underneath this there existed a counternarrative about suffering and loss, often undisclosed, which suggested that the competent survivor account was only half the story. The able survivors who participated in the study also told stories about intense personal suffering, past and present, which had not simply been resolved and gone away. This too constituted part of the daily reality of chronic illness.

The five-part progressive narrative quest (2.3) was the starting point both for the research study and for LWP. It was based on the optimistic idea of progression, that chronic patient can and do progress, learn and adapt, whether by their own efforts or by using structured self-help and coaching and mentoring programmes. This was linked to the idea of life recovery: that patients should as far as possible return to and continue with the normal activities and life pattern they had had in good health. But within LWP participants, the success rate for life recovery defined in this way was low; more often, patients found that it was just not possible to continue the life they had led before. Living with chronic illness involved instead a dramatic life change, which was characterised by ongoing unpredictable disruption.

The study therefore included other kinds of illness stories (models ii. to iv.) which were based on different story plots and roles. These roles did not all include the responsibility for life recovery. Model iii. for example was based on letting go of the old life story and beginning a new one. Defining the role and responsibility one wished to take on during illness was then the task of the patient, who now had freedom to take on and discard different roles over the course of the illness. This change altered the theory base of LWP by substituting role responsibility for life recovery. The study also suggested that the developed illness story plot did not emerge until after an extended period of trial and error, which included failed life recovery attempts. Much of the learning observed was learning to deal with failure, suffering and loss, which was an integral part of the illness.

The revised theory base for LWP which replaces the five-part progressive quest is shown in Appendix D, diagrams D1.1 to D1.5. it suggests that there is not one single story told about chronic illness but two. The two separate tracks are the disruption track, which describes illness as an ongoing and never ending series of disruption events, and the recovery track, which describes life and role recovery, learning and progression. The two stories exist alongside each other, and interract in different ways. In the dialysis unit, the recovery story is the normal story told and the disruption (suffering and deprivation) story becomes an undisclosed counternarrative.

A feature of the revised study theory model is that it is much more inclusive. Three new levels of illness response are described (L1 - L3), negative, neutral and positive. The default position from which all patients start is Level 1 – the negative response. All patients begin here – they do not have the skills and experience to manage disruption or reorganise their lives, but in time they may learn. This remains a progressive, optimistic model since it suggests that any patient may over time progress through the three levels (L1- L3), as they learn new skills and develop their own illness story. But this is also a more realistic model, since the disruption track (disruption/ response cycles) always continues. Even L3 patients who have now become able survivors experience severe disruption, and as a result may go backwards for a time.

The revised model can also be applied to those struggling with dialysis (8.3) who may not have developed the second ‘recovery’ track at all. Illness remains for them a continuous cycle of disruption events. But there remains for them a possible way out, since the repeated disruption and response process outlined contains the opportunity of testing and learning different responses, which may lead to better outcomes.

This Appendix describes the evolution of the Living Well Programme through its different stages. It then considers how the programme may be restructured in the light of the study findings, and applied within its current setting, where it is being used to help those Level 1 patients having difficulty on dialysis. A key issue for the programme long-term will be whether to focus on L1 patients only, or whether to involve L2 and L3 patients again. This could produce a better learning environment, where patients at different stages could share their learning and experience.

B2 The Living Well Programme: History and overview

The Living Well Programme began in 2007 and finished in 2014. It took place in Guy’s and St Thomas’ Renal Department. The programme was designed for kidney dialysis patients by the GSTT spiritual care team, and worked in dialysis units in Guy’s, and in two satellite units in SE London. The project team grew from two to ten people within this period. The programme was supported by grants by GSTT Charity through the Kidney Modernisation Initiative (2004-2007), and through a direct grant in 2011 for LWP in satellite units.

The programme had two components: an initial life review, the Living Well Plan, which had 12 dimensions and 36 fields, which the patient worked through with the Living Well coach, a qualified chaplain or trained volunteer. The plan was typed and given back to the patient: it included specific life recovery targets agreed by the patient. The coach then made regular follow up visits, and discussed with participants their progress generally and against the targets set. The programme was described as a self-management and coaching programme, with coach acting as reviewer and progress monitor. No other resources were allocated to the programme: there was no training or rehabilitation budget to help patients learn new skills. The programme cost around £500 per participant per year, compared with the £30,000 cost of dialysis per patient.

The LWP was evaluated externally by Picker Europe (2013), using patient reported outcomes and experience measures and the FACIT measurement tool (Peterman & Fitchett 2002). The evaluation did not record significant overall improvements in health-related outcomes for participants. Yet participants paradoxically valued the programme highly in terms of patient experience, and reported that it increased hope, empowerment and a sense of agency and control. This issue then became central for evaluating LWP as for the research study. How could it be that patients participated in, devoted energy to and reported favourably on a programme that did not improve their health? Was there some other non-physiological factor at work, which was simply being missed, and was not evaluated or recorded?

The 2013 evaluation by Picker gave a sharp contrast between quantitative data, evaluating health outcomes and qualitative data, reporting patient experience. The study findings make this result predictable. The study suggests that the illness story plot and the role it describes represents a vital life line for the subject, recording how they may find a role that gives life meaning and purpose. But focusing on a particular role may not increase activity scores, because patients may narrow down (reduce) the activity range to one or two valued activities.

B3 Implementation: Adapting LWP in light of the study findings

B3.1 Basic structure: life review

The basic form of LWP consisted of a four page life review under four main headings, each with three sub-headings, as follows:

Diagram B3.1 LWP life review

LWP: Name (initials) Date: Coach Review No/date

	12 Dimensions	Past	Present	Future	Targets & review
Physical	Keeping fit				
	Eating well				
	Symptoms and pain				
Mental	Hobbies & interests				
	Job/role				
	Emotional wellbeing				
Social	Family & friends				
	Being independent				
	Housing & benefits & care				
Spiritual	Spiritual growth				

	Belonging to a faith group				
	My living well story				

The initial life review contained 36 fields and took on average 45–60 minutes to complete. The original review became the base document and remained unchanged. The target and review column was completed in subsequent sessions. The life review process took 45-60 minutes plus writing up time. The patient would be seen fortnightly by the coach for 10 minute visits. These would be extended once a month to do an 'LWP review' which covered progress on targets.

The main practical problems with this format were as follows:

1. Time – full life review took too long.
2. Reviews were not always done regularly.
3. The programme was too focused on life recovery targets, and paid less attention to expression and evaluating life potential.
4. The preparatory work in formulating targets (life goals) was not always done.
5. There was no end point when the LWP was 'complete', and hence coach could move on to another client.
6. The life story element (My living well story) was not sufficiently developed or recorded (What kind of story is this?).
7. Chronic illness work (emotion work, grief work, identity work and faith work) had not been done.

The past, present, future, format of LWP lent itself to narrative work. Separate narrative lines could be derived for each dimension, if required, detailing changes. But the format did not lend itself as well to other kinds of work, such as emotion work, grief work, and identity work. Subsequently a new short form of the life review was devised, which had 15 fields: the original 12 living well dimensions, plus three sections to describe the illness story and its life impact. The illness story would then be recounted in three parts: life during good health, life after illness onset, and living with illness in the future.

B3.2 LWP short form: Templates 1-4

The LWP short form (Template 1) was developed to provide a simpler review for the KPA trial, combined with a shorter overall coaching/interaction period. Instead of a whole life focus the short form was intended to take a single disruption cycle (the present) and focus on one presenting problem. The aim would be that patient and coach would solve one life issue, which would give the subject confidence to address other issues as they arose. Focusing on present only would reduce the number of fields and time needed for the review.

The new LWD format shown below incorporates a full revision of LWP incorporating the findings of this study. The four main components are:

LWD Template 1: Life review – short form
LWD Template 2: LWD STORY FORM
LWD Template 3: Patient Referral form – Gateway Programme

LWD Template 1: Life Review – Short form

	12 Dimensions	
Physical	Keeping fit	
	Eating well	
	Symptoms and pain	
Emotional	Hobbies & interests	
	Job/role	
	Emotional wellbeing	
Social	Family & friends	
	Being independent	
	Housing & benefits & care	
Spiritual	Spiritual growth	
	Belonging to a faith group	
	My living well story	

LWD Template 2: LWD STORY FORM

Story 1: Good health	

Story 2: Illness onset: life disruption	
Story 3: Living on dialysis now	
Story 4: Living on dialysis -future (after programme completion)	

LWD Template 3: Patient referral form – Gateway Programme

Patient name	
Patient no	
Staff name	
Date	
Dialysis shift	
Reason for referral	
Satellite Chaplain visits	
Visit 1 (date)	
Visit 2	
Visit 3	
Visit 4	
Visit 5	
Visit 6	
Visit 7 (date)	
Visit 8	
Visit 9	
Visit 10	
Visit 11	
Visit 12	
Chaplains recommendations	
Ward managers comments	

Patient feedback form completed (date)	
Follow up support required	
- fortnightly	
- monthly	
- bimonthly	

The base line resource would be the life review (Short form Template 1). This would be used alongside the LWD story form (Template 2), which would recount how the individual had responded to illness initially and through subsequent disruption episodes up to the present. The main goal of the LWD programme was to record illness work, learning and progression that had taken place, in order to provide patient with reinforcement hope and confidence in the future.

B4 The next stage Gateway Programme: Working with hard to reach patients

The Gateway Programme was a development of LWP, now renamed 'Living Well on Dialysis' (LWD), which focused on those having difficulty living with dialysis. It makes use of basic LWP resources that have been tried and tested, such as the life review, which would be used in shortened form. This would remain the baseline resource which patient and coach would draw up and revise over time.

The Gateway process would start with recording the illness story in abbreviated form. The LWP life review would provide an activity record alongside the illness story. A further goal of the Gateway Programme would be to help patient re-establish links (active, occasional or observer) with the worlds the individual once participated in. Some of these links might be virtual, a flow of information about what was going on, without requiring physical participation.

B5 LWD Gateway Programme – 12 month results Aug 2017

The 12-month review highlighted a key issue found both among LWD participants and in the study– that they had not disclosed the suffering they were experiencing in their lives, nor had they discussed the disruptive impact of the illness with the unit staff. Instead, their response had been to withdraw, become negative and uncooperative, and also non-compliant: they sometimes failed to attend for treatment.

The unit staff had tried to open up discussion with these patients but had been unsuccessful. They were then surprised that the LWD patients had been willing to discuss the pain and distress they were experiencing with the satellite chaplain, who was seen as somehow different from the nursing staff, who had the role of ‘enforcing’ a difficult and sometimes painful treatment regime. The chaplain’s role had then been to defuse anger and stress, and then to further investigate the underlying problems that were causing frustration and loss of hope. A key issue was that many of the patients were living isolated lives: they could not work, and they had no networks or leisure interest with which to fill their time. These problems were longstanding and intractable – they had often lost hope that anything could be done. Given their isolation, the only social setting they had in which to express how they felt was the dialysis unit – and they did this in a negative way.

B6 Evaluation – comparison with study conclusions.

The study defined particular kinds of illness work patients needed to do in order to find a viable means of living with the illness, and creating an illness story. This began with emotion work and grief work, processing the angry response to the deprivation they had experienced. No doubt the sense of anger and injustice some experienced fed into a strong desire for recovery, to get their lives back. The problem for some was that they did not possess the skills or experience for this task. As with physical rehabilitation after a stroke, the patient had to learn new skills from scratch.

The study found that there was little disclosure within the dialysis setting, either patient to patient or patient to staff. The study participants recounted crisis times when they too had experienced suffering and distress, but these accounts were contained within a sustained progressive narrative, which continued on. The crisis times had not derailed or destroyed the story plot that the subject had created. The subjects also described the initial stage of illness, when they too had reacted negatively, and were unable to respond to or deal with disruption to their lives. The solution for them was a period of trial and error, exploring the possibilities of the illness world and finding out what opportunities it might hold. Eventually they had through a learning process discovered activities and roles that they might still fulfil which reduced their sense of isolation and deprivation. This was recorded in their illness narrative which then became a powerful source of self-affirmation, recording what they had achieved.

The absence of disclosure was linked to another constraint – the transplant list, which was the escape route many dialysis patients desired: it gave them hope. To get onto the list and remain on it, they needed to be compliant, competent and responsible, so that they would be able to undertake the complex testing and treatment regime required for a transplant. This then led to a culture of non-disclosure and self-censorship by all those patients who were interested in receiving a transplant. But this culture it seemed had a cost: many patients suffered unnecessary distress when experiencing minor difficulties and disruption within their lives, for which they could have received help and support from other patients or from staff. At the limit, patients who were not coping with dialysis at all would be referred for help (psychologist or counsellor), but these facilities were located away from the unit, so had no impact within the unit.

Placing a satellite chaplain in this setting then had an immediate effect. A much-needed safety valve was now available, and patients were able to disclose life problems and troubles in a confidential way, without fearing that it might reflect unfavourably on their patient record. But in the wider life context, the chaplain could not create for these patients the support networks they needed in order to live more active and meaningful lives. They would have to do this for themselves. The revised study model also showed a lengthy period of exploring and testing out the illness world to test responses strategies and roles and dealing with failures and setbacks. L1- L2 patients who had recently started dialysis would experience frequent failures and disappointments as they pursued life recovery. Support from satellite chaplain would be valuable at this point

The presence of patients on the unit who had been on dialysis for a number of years, and had not reached any accommodation with the illness was a symptom of a long-term problem. Firstly, these patients had not received the help and support they needed early on to learn the skills that living with dialysis required. Secondly, they had then lost hope and become alienated and estranged from day to day contact with normal living. Their only form of social contact was likely to be on the dialysis unit – here it was restricted to contact with other patients in waiting areas and on adjoining machines. These patients then if they did not have a supportive network outside the unit – family, neighbours or friends, found themselves living lives of extreme isolation with little help from the social services system.

The longer solution to this problem would be to intervene much earlier with this group, to help them become more self-sufficient and learning the skills they needed, within the first year or two on dialysis. But where LWD took on long term patients who had not had such help, then it seemed likely that the task was similar to supportive care, helping patient who were living in conditions of social deprivation by giving one to one contact during treatment visits. There would be some patients who would not be able to break this cycle of deprivation, and resume more normal living – these patients would still require ongoing support in long term.

B7 Implications for LWD – innovation programme.

The purpose of the innovation trial was to demonstrate how using modest resources (£12000 over 2 years), an intervention programme might achieve positive results in a patient setting where some patients were experiencing long-lasting and significant problems, and these were not being resolved by existing specialist resources.

The LWD review (Aug 2017) indicated that because of the prevailing culture on a typical dialysis unit, a chaplain visiting weekly would be in high demand as a listener to troubles (disruption track). These could range from minor difficulties in accommodating to life on dialysis to major personal problems and a hostile and negative response to treatment. How might the satellite chaplain then prioritise his time, to achieve the maximum benefit? The target group for the trial was patients with a negative response to dialysis; but other patients would be experiencing disruption as well. Some of this group were patients who had started dialysis recently, others had been on dialysis for over several years and had not adjusted to the treatment.

The current study demonstrated that dialysis patients find starting on dialysis difficult and the life impact disruptive. They find that they suddenly cannot sustain life activities - work, leisure, family, social life, and hobbies which were important to them, because the treatment is time consuming and tiring. They plan to resume these once they have got used to dialysis, but this does not always happen. Nevertheless, the sudden deprivation they experience is a catalyst – they learn, they fight back, they attempt to organise their lives and sustain the activities they value. They also learn quickly how much they can manage and how to prioritise their time. This learning and adaptation window may last for the first year or two on dialysis; after that, it is less likely that sudden change will occur, as patients become accustomed to reduced levels of activity.

The revised study model D5 (Appendix D) shows that the ‘disruption track’ is ongoing – all dialysis patients at whatever stage will experience serious disruption. But L3 patients have had time to develop more effective strategies to manage this. There is then a window of opportunity for the innovation programme at the start of dialysis (L1), when patients are confronting the problems and urgently seeking answers. There is also a willingness to learn and energy to rebuild or adapt life in a sustainable way. The satellite chaplain when encountering patients new to dialysis will be able to distinguish between a normal pattern of life disruption, and an extreme one. But it will remain true that any intervention at this stage is likely to have significant long-term benefits, and build vital skills to prevent problems developing later.

It is much more difficult to obtain positive results with the patients who continue to respond negatively after a long time on dialysis. Their problems concern the whole of their lives, they have experienced extensive deprivation, they may have few resources, they may lack an effective social network. These patients are some of the most needy found in the health care system, and there are no easy answers. In taking on the challenge of working with these patients the chaplaincy team was well aware of the difficulties they faced. They planned to use the experience thy had gained with LWP working with older housebound dialysis patients who lived restricted lives, but had very much appreciated the small changes in their lives the programme had brought about.

The study had observed six core activities dialysis patient undertook – creating a progressive narrative, disclosing suffering, learning effective responses, taking role responsibility, doing illness work and enacting a sustainable story plot. It seemed unlikely that all the LWD participants might achieve all of these, but might in the timescale of the trial undertake the first three, beginning by disclosing suffering. The trial will end in Sept 2018.

B8 Implications of study for LWP as a development programme.

The study produced findings which were different from the generally accepted picture of dialysis patients in the research literature. It depicted the participants as confident, competent, able learners and skilled survivors who had worked out a sophisticated illness story which defined their own response, role and survival strategy. It accepted that this sample did not represent all dialysis patients: there would be others who had not learnt and developed the same skills, nor created their own personal illness story.

What implications do the study findings have for the Living Well Programme? Section B1 above suggests that LWP remains relevant as an evolving development process and theory base. LWD has incorporated the findings of the study, adjusted its priorities, and has continued to work with dialysis patients. The knowledge base within which it operates will now come from patients themselves and the learning and illness work they accomplish. A key role of LWD will be to enable the communication and sharing of this learning more widely, so that patients at different illness stages may access it and use it.

A key finding was that the study subjects had all started at the bottom. At one time they too had been disoriented, deskilled and demotivated, not knowing how to manage the disruptive impact of dialysis treatment on their lives. But they had learnt, they had moved on, they had worked hard and created for themselves a new life story, living with illness, which contained the specific roles and responsibilities they themselves had chosen. This suggest that these patients and others like them, as well as taking on responsibility for their own lives, might also take responsibility for others and have a leadership role as role models, peer supporters and mentors to others who are following the same path.

The particular evolution of LWP recounted here followed a specific path. In its early stages, it enrolled patients on a voluntary basis. It often attracted the more positive dialysis patients who had energy and motivation to work at a self-management programme. It may also have excluded those who were less motivated, less communicative, and those who did not see any point in working for change. More recently since 2016, LWP has engaged with the latter group – the KPA innovation trial described in 8.3. Whilst this trial has also made progress, there is a missing link here. The learning and illness work the study observed is, if the study findings are correct, continuing in this setting and in others, but there is no benefit to other patients. They do not see or hear about the progress patients themselves are making as they move on through different response stages, since there is no means of communicating this. This suggests that any work done toward helping the most needy patients may be missing out on a vital resource, the accumulated knowledge and experience of dialysis patients themselves.

The LWP programme leaders as hospital chaplains were not able to influence the management of communication in the dialysis unit. A change in the culture of units might happen through a top down management process, if this was thought to be beneficial to patients. But also it might occur as a result of initiatives by patient and patient groups, if they saw the benefits of better communication and shared learning between dialysis patients at different stages of the illness trajectory.

The Living Well Programme can therefore continue to help dialysis patients by using the findings of the present study. Its next development objectives will be:

i. To complete the innovation trial at New Cross and publish results
ii. To bring forward proposals to extend the trial to other units, and obtain funding
iii. To broaden the scope of the programme to reengage with L2 and L3 dialysis patients, to support and share their learning and progression
iv. To work with patient groups to bring about better communication and shared learning within dialysis units within the trust.

B9 Summary

Experience with LWD suggested that some patients might be able to create and perform progressive illness stories as the study subjects had done. Three response levels had been identified among dialysis patients on the unit

L1 Negative response: cycles of disruption and deprivation, no learning or progression observed (10%).
L2 Neutral response; exploration, learning, testing boundaries, holding one’s own (75%).
L3 Positive response: patient creates illness story,defines role, carries it out, records progress (15%).

The target group for the trial was L1 patients. This group was further divided into patients who had recently started dialysis and long-term patients. The first were more likely to show improvement, since they were likely to learn more effective responses. By focusing on illness work initially and especially emotion work and grief work, the chaplain could assess the emotional and psychological barriers to improvement. There is the possibility that some patients had themselves given up and could see no future: it was still possible that this small-scale programme could help them, if it was able to bring about small changes

The essence of the research study was to argue that patients have the potential and resources to learn, make progress and find sustainable illness roles on their own. But not all do this: some may have this potential, but are not using it: finding what blocks or prevents them from achieving it would be very worthwhile, and they might then go on to achieve results with only occasional support. Other patients have intractable long-term problems which need skilled professional intervention. The aim of LWD here would be to ensure they got the expert help they needed, even though they might be reluctant to access it. In addition, LWD could provide follow up support on the unit after specialist treatment had been provided.

APPENDIX C1:
Sample Interview J5 Joanne

J5 interview transcript 3079 words
Astley Cooper ward 10.30 am 13 7 11
Stages 1-3 Coding
Stage 1: Narrative Coding (N&R) Stage 2: Theoretical coding (GH ID EE LR RN) Stage 3: Disruption-Response Coding (DR1-DR28)

DISRUPTION RESPONSE CODING
DR1, DR2…
(text underlined)

Q1 We know that chronic illness disrupts life. What we don't know is how much it affects faith

1. For me personally it did not disrupt nor affect my faith. Although at the beginning it just shakes my faith, but I was able to pick it up now

Spiritual disruption
DR1

Q2 Yes

2 I was not very religious because I was occupied with the early stage of the renal failure

Spiritual disruption

Q3 I think I'm going to take it four stages: Good health, the start of the illness, the treatment, and then getting back to normal. So before the illness what was your faith like?

3 It was really good I had faith in God. So I was a regular church goer. Yes very active in the church

GH Faith in good health

N1
Going to church
3-7

Q4 Same as you are now or different?

4 Same as now. Even more now

Q5 So how long ago did it start?

5 11 years now. So while the illness passes I was not active in the church for quite a long time. I wasn't very active in the church for four years. I hardly went to church because I was not well enough to go. So partly that was a physical thing that I was not well enough

DR2

Q6 Was there also a spiritual thing that you did not want to go?

6 Not really, not exactly. I didn't have the zeal

Q7 Do you mean motivation?

7 Yes

Q8 So something had happened?

DR3

R1
Expecting healing
8-12

8 Because I felt uncomfortable, expecting a quick answer to my prayer. A lot of people were praying for me

Spiritual disruption

Q9 So what answer were you expecting?

9 Yes I was expecting to be a lot better emotionally and physically and so on

Q10 Were you expecting healing?

10 Oh yes definitely. I was expecting healing. That's what I meant, even spiritually and emotionally. I was very down at the beginning

Spiritual disruption
DR4

Q11 How did that show? Were your family and friends aware of it?

11 I was a bit moody, I wasn't as friendly, I didn't really want to talk I just want to withdraw and I didn't want to read my bible either

Spiritual disruption

DR5

Q12 You stopped reading the bible?

12 I stopped reading the bible. The only thing I did was pray, though not as much as I used to

N2 Getting help 13-14

Q13 So was anyone able to help you?

13 Oh Yea I got some support from my church. And from others as well. Then there was this older lady I talked to Margaret and I talked to you and you were the first one I was able to talk to

Q14 Was that with the Living Well Plan?

14 No before that just when you were coming on your ward rounds, we talked you were the first person I was able to talk to, and then we prayed you know I found you were approachable. Not only did you pray for me but you were able to pray for my sick son. You remember? Christopher. I was able to ask you to raise him in prayer

Expression/ evaluation

N3 Leaving home 15-17

Q15 The bit I remember was you had to move out of home because you couldn't get up the stairs

15 Oh Yes, my stairs I couldn't enter the house. That was part of what made me an emotionally depressed person. I have children and I couldn't be with them.

DR6

Q16 I remember the bad moment was when you stopped running the family. Being a mother was very important… You were away from home for how long?

16 I was away for quite a long time away. For the initial first couple of years, I was hardly able to go inside the house, and then even when I do go home it was like, how I ended up in hospital like every week

Q17 You had a lot of problems with your dialysis?

17 I literally lived in the hospital. My younger daughter she was young then she called this place 'the doctors house'. When they discussed me, she said 'Mummy when are you going to your doctors house?' She was four then. Oh, there was a lot of things I couldn't do. I couldn't be independent. I was very dependent on my family

DR7

N4 Staying with cousin 19

Q18 You had a friend or relative you lived with?

18 Oh yes I had my family I was staying with my auntie

Q19 When you weren't living at home where did you go?

19 I went to my cousin

Q20 So you had good family support. So in terms of faith, what happened to turn that around?

20 One or two things I started to do by myself. My faith started to grow I read my bible I prayed more

DR8

FR Faith recovery

N5 Gradual change 20-21

Q21 Can you think of a particular moment when it changed?

21 It was a gradual change. What made that better was when I was able to spend more time with my family, then there was an improvement as a result. I was able o go into the house, I

DR9

FR Faith recovery

was able to spend more time around my children. So that I was able to turn my emotions around.

Q22 That was your central role as a mother - once you could do that, your self confidence improved?

N6
Attempting suicide
22-24

Spiritual disruption

22 Initially at the beginning I actually decided to commit suicide.

Q23 I remember you told me - I was very surprised

DR10

23 Oh yeah I was that low. I felt like I as was another child in the house. I just couldn't do anything. I was just in despair. I just felt like a body, like a child

Q24 What was it - the helplessness?

24 Yes I felt like a body another child

Q25 In terms of your Christian faith did you feel that God had abandoned you?

DR11

R2
Despair – no answers

Spiritual disruption

25 Well at that time I just felt it seemed that - well it seemed like the world was so bad he wasn't answering anyone, including myself or anybody's prayer for me. It was not going anywhere.

Q26 So that was the low point. So what happened to get you out of that?

DR12

FR
Faith work

26 What happened was I talked to one of the nurses here. They started getting onto my health, and the role with my children, my children are young, and I was able to get to walk and start getting an improvement . I was able to look through their homework for them, talk to them, that was like…So that I was able to do that was like a sign - the achievement situation had come back, like tolerable

N7
Walking again, helping children
26-28

[Interruption – Lesley: brings pills]

Q27 Yes so there was physical improvement- did you also lose some weight around then?

27 I lost some weight through the illness, through not eating and so on.

Q28 What's important for this is how your idea about God changed, because you felt that before he wasn't answering your prayers?

FR
Faith work

28 Oh it was an interest and improvement in myself.

Q29 So you felt that was an answer . So when did you get back to church?

R3
Faith & church
29

DR13

29 I got back to church after I started to get a lot better physically. Even then when I was going to church, I was not really emotionally involved. I was just going. It was just getting out for a couple of hours instead of being stuck. Just an opportunity of having another place to, get to instead of being stuck in on my own. The spiritual way was not really spiritual. But the more I was going the more happier I felt of being in there. The more happier I felt there, then I decided to have more faith, because I see that my life was different from what it was, so it looked like a time of answered prayer

FR
Faith work

DR14

Q30 I remember talking to you about the night line, the help line- what made you start that?

N8
The vow
30-31

FR Faith work

30 Well gradually my health improved, because of the vow I made to God - if he healed me I would work for him, I would evangelise people..

Q31 So OK you did a deal did you?

31 Oh yes absolutely

Q32 That interesting.. I remember I thought you'd be good at it

DR15

N9
The help line
32-36

FR
Faith work

DR16

32 I made a deal - if you are able to take me from this useless faith, I will say I make useful service, I will actually work and encourage other people, other people suffering. I found the call centre, and I tried to discuss which ways I could actually work in the church, and which way I could manage at the beginning. I just felt that answering the phone, I could manage that

Q33 So you did it all night or just a couple of hours to start with?

DR17

33 I started with a couple of hours, and gradually increased the hours. At the initial stage all I did was answer the phone, take the enquiries down. As time goes on I actually begin to counsel

Q34 So as time went on you became one of the counsellors?

34 I counselled them

Q35 Do you still do it?

35 I still do it now

R4
Encouragement
37-39

Q36 Once a week?

36 I don't even know . Some of them they can phone me, because there are people I still do follow up

Q37 So that was a big thing

37 You know the encouragement from a lot of people even you actually helped me to try and having to try, because I think the other people will actually have a situation worse than me.

Q38 Ok so we have done the illness bit so then it started to improve and we are now on the transition stage. Was there anything the church did?

DR18

Evaluation/
expression

38 The church really supported me they helped me, they helped the family, they helped in the house and spiritually as well. They sit down we pray together, we read the bible together. They encouraged me what to do and what to say or when I was feeling down

Q39 And what point did they start giving you responsibility?

39 After I lost some weight and became a lot more mobile more active and also a lot more alert

N10
The book shop
40-42

Q40 When did they give you the bookshop - was it two years ago?

40 Yes two years ago in 2009

Q41 And what do you enjoy about that?

41 I was able to to run it. I was able to read my books, more spiritual books or magazines. You know we have some breakdown of the bible, to help you understand. We have some spiritual books on the bible. You can read books, so that when you counsel people and you don't know what to say to them and how to counsel them, emotional things. Even for my own personal [growth], it keeps my mind active ,it makes me feel useful and valuable, maybe worthy. Before I was just there, but now it's like my time is occupied. I am doing things I enjoy it makes me a better person

R5
Bookshop reflection- being worthy
41

Resolution

DR19

Q42 So it sounds like it helps you, as well as it helps them.

42 Oh yes

Q43 And how did your understanding of faith change - is it the same or is it different?

43 Its gone back to before the illness. Before the illness I was really faithful, and I was very strong in my spiritual life. After it became shaky and I was thinking, is certain things true, is certain things real - then you ask questions. But then I think I begin to ask questions, and then I think I began to pick up again, it brings me now to where I was thinking better, and to have even more faith in God

R6
Faith questions
43

Faith in good health

DR20

Spiritual disruption

Q44 Could you have helped all those people you have helped before in the way you help them now?

44 Before the illness I would have, because there was nothing to discourage me to shake my faith so I would have

Q45 But what about all that experience now?

45 Yes - Having that experience makes me to counsel better. Where I was coming from and where I am and where I have been I am able to counsel much better

R7
Using Experience
44-46

DR21

Q46 And did you think you found God there in the bad bits ?

46 I think so

[Interruption – tea lady]

47 I am having problem with my knee so I need to go for x ray

Q48 What I was thinking about was how God has worked. You are different now to what you were five years ago. Do you give a testimony in your church?

48 Oh Yes I give testimony

Q49 What do you say?

49 I have it. Do you want I give you a paper – it's gone in one of my magazines.

I used to be in wheelchair and I couldn't stand. I gave the testimony just to encourage people spiritually that God is real. It is good to be faithful, it is good not just spiritually coming to church but to work for him, to work in his family. Just to show how good it is.

I'm okay now I am walking and I can do a lot of things. It is just to try and encourage people, because they are going through the same thing, and they cannot see the truth. They see my

Resolution: new faith story

DR22

N11
Giving testimony
48-51

testimony. So I am trying to do a picture of me in the wheelchair, really big and a picture of what I am now, a picture every day.

Q50 You are the proof?

50 To encourage people spiritually with God and prayer, and he taught me patience and not giving up

DR23

Q51 And what sort of response do you get when you give your testimony?

Resolution: new faith story

51 Oh people come up they congratulate me. I have actually seen people then, I've seen people that actually stayed in the faith, because of improvements they see in me. They come to say I am still here, but I was on the verge of giving up. Your testimony was for me

R8 Reflecting on testimony 52

DR24

Q52 And do you tell them you nearly gave up?

Resolution

52 I tell them my stories,. I tell them where I have been. I even tell them I once tried to commit suicide. And I tell them if I had committed suicide then, I would not be enjoying what I am enjoying now. And they are not to give up too soon, they must have hope. You know, be patient. You know, some times I think I was saying, is God real, I was saying is this really a merciful God? All this kind of people, shouting and praying and praising. Nothing was happening. Then gradually I said to myself I saw things happening, that I was able to do more

Q53 So in the end it needed you to do something. It was God and you. Say a bit about your family and how things are now

N12 Family life 53-55

DR25

53 I used to get really snappy sometimes emotionally but now there is more peace and more understanding. And within the house as well, because I am able to do certain things it frees other people to do things for themselves

Q54 They are growing up now they are getting more independent You still support them?

54 Oh yes

Q55 They come and tell you what they have been doing

55 Oh yes I try to have an open relationship with my children. They can ring up my sons was ringing just now checking on me are you on dialysis

R9 The future 56-57

Q56 We covered most of it what about the future – what do you think the future holds?

56 Looking at where I was, from where I am now, I think the future is going to be even more good.

Q57 So is that there anything you wished for that you can't do?

DR26

57 At the moment I just want to be more active with my mobility… I love working with children, but to work with children you have to be fit, so that's one of those things

N13 Youth work 58-59

Q58 So do you want to be a Sunday school teacher?

58 I get involved with the youth now, to help organise it. So now, they come to talk to me , if they have any problems, they can come to discuss their home like in confidence

Q59 So that's another listening role, encouraging…

59 I'm going - Like today one of my appointments is to do with the youth because some things they want to do , just try and help with them and get it done. I enjoy working with them but there is the difficulty of my diet issue, and my mobility

Q60 Is it a problem for you that you haven't been healed completely?

R10
Healing
60-61

Resolution

DR27

60 Well not really.. I have come to accept and you know I believe I will be healed one day.completely That's my belief , and because of where I'm coming from and where I am now, I have that belief - it gives me that confidence, that I am on the road

Q61 Is it a problem for your church that you haven't been healed?

DR28

61 No they are not worried because they believe it will happen. They encourage me . Now in my spiritual life I am much more stable; they do try and do their part and encourage me, to make space for God, and not to worry.

Q62 What have you got there?

62 My testimony paper

Q63 Can I borrow that and give it back to you?

N14
Written
testimony:
before and
after
62-63

Resolution:
new faith
story

63 Yes of course. Do you see that picture of me there standing, and the wheelchair?

The picture will basically tell its story

Q64 I'll come back Friday and bring your living well plan and the faith story you did before. Its quite along time ago and we will see how things have developed.

64 The living well programme, it really did help me because I was bored - it gave me something to work on

Q65 It was one of the things that sparked

65 It got me going spiritually and to know that when I come to hospital you get this really strong support when you come. It is quite good you really need it as a package, apart from the doctors - you need it as your emotional support

Break 1130 13 July 11 3079 words

Stage 1 Narrative Coding

N	Narrative Episodes	14
R	Reflection & Evaluation	10

Stage 2 Theoretical Coding

GH	Good Health	2
ID/SD	Illness & disruption/Spiritual disruption	8
EE	Expression & Evaluation	2
LR/FR	Life recovery/ Faith recovery	7
RN	Resolution	6

Stage 3 Disruption Response Coding

DR	Disruption Response	28

[Subdivided into F (faith) and NF (non-faith) responses Table 5.8.1]

		First part (early)	Second part
NF	Non-Faith	8	1
F	Faith	7	12

APPENDIX C2 – Sample Interview Analysis

Narrative Analysis J5 interview – 18 7 11 Coding Stages 1-3

Stage 1 – Narrative coding (N&R); Stage 2: Theoretical coding (GH ID EE LR RN)
Stage 3 – Disruption Response Coding (F & NF)

1 Define narrative episodes – remove non-narrative sections

			Content
N1	3-7	Going to church	Regular church goer, stopped for 4 years
N2	13-14	Getting help	help from church, chaplains
N3	15-17	Leaving home	Deprived of children, mother role
N4	19	Staying with cousin	Exiled from home - stairs
N5	20-21	Gradual change	Homecoming time with children
N6	22-24	Attempting suicide	Despair helplessness useless
N7	26-28	Walking again, helping children	being useful again
N8	29	Back to church	Having somewhere to go
N9	30-31	The vow	Covenant for survival
N10	32-36	The help line	Useless faith into useful action
N11	40-42 helping	The book shop	Organising skills resources for others
N12	48-51	Giving testimony	Efficacy working for God
N13	53-55	Family life	More peace and understanding
N14	58-59	Youth work	New avenue – mobility obstacle
N15	62-63 `	Spoken testimony – before and after	Living proof, role model

2 Reflective/ evaluative sections (non-narrative)

R1	8-12	Expecting healing	Spiritual and emotional healing needed
R2	23-25	Despair, no answers to prayer	helplessness no hope or future
R3	29	Faith & church	action (return) increases faith
R4	37-39	Encouragement	Agency – what to do and say
R5	41	Bookshop reflection- being worthy	Makes me feel useful and valuable
R6	43	Faith questions	faith shaky – asking questions
R7	44-46	Using experience	Able to counsel much better
R8	50-52	Reflecting on testimony	Going through same thing Is God real? Nothing was happening 52
R9	56-57	The future	Difficulty of diet issue, mobility
R10	60-61	Healing	The church believe it will happen

3 Narrative analysis

3.1 Narrative structure

Orientation complication/crisis evaluation transition resolution

Orientation	N1, N2
Crisis	N3, N4, N6
Evaluation	R1-R6

Transition N5, N7, N9, N10, R8
Resolution N11, N12, N13, N14, R7, R9

3.2 Evaluation

Evaluation of life and faith story/

R1 EXPECTING HEALING

8 Because I felt uncomfortable, expecting a quick answer to my prayer. A lot of people were praying for me

9 Yes I was expecting to be a lot better emotionally and physically and so on

10 I was expecting healing. That's what I meant, even spiritually and emotionally. I was very down at the beginning.

The answer to prayer was expected to be physical emotional and spiritual, to combat the low spirits

R2 DESPAIR - NO ANSWERS

23 Oh yeah I was that low. I felt like I as was another child in the house. I just couldn't do anything. I was just in despair. I just felt like a body like a child

Q24 What was it - the helplessness?

24 Yes I felt like a body, another child

25 Well at that time I just felt it seemed that - well it seemed like the world was so bad, He wasn't answering anyone, including myself or anybody's prayer for me. It was not going anywhere.

'Another child just a body' is a powerful image of helplessness and dependency – a role reversal that was especially difficult for a nurturing mother. J5's story includes both exile and estrangement – exile from home and estrangement from the spiritual life of the church in which she was no longer 'emotionally involved'

R3 FAITH & CHURCH

Q28 What's important for this is how your idea about God changed, because you felt that before he wasn't answering your prayers?

28 Oh it was an interest and improvement in myself.

The transforming moment here is not a faith breakthrough but physical change – faith and prayer had to result in physical improvement

29 'I got back to church after I started to get a lot better physically. Even then when I was going to church I was not really emotionally involved. I was just going. It was just getting out for a couple of hours instead of being stuck. Just an opportunity of having another place to get to instead of being stuck in on my own. The spiritual way was not really spiritual. But the more I was going, the more happier I felt of being in there. The more happier I felt there, then I decided to have more faith, because I see that my life was different from what it was, so it looked like a time of answered prayer.'

The return to church is described in a mundane, honest way as an escape from being stuck at home. Physical improvement offers the opportunity to take control to change the way one responds to difficult events: it offers a way out, after the long waiting with nothing happening. The decision to have more faith is a saving event [Root 1.5] To begin with faithful action rather than relying solely on prayer or waiting for a miracle is the chosen solution

R5 BOOKSHOP REFLECTION – BEING WORTHY

41 I was able to run it. I was able to read my books, more spiritual books or magazines…. You can read books, so that when you counsel people and you don't know what to say to them and how to counsel them, emotional things. Even for my own personal [growth], it keeps my mind active ,it makes me feel useful and valuable, maybe worthy. Before I was just there, but now it's like my time is occupied. I am doing things I enjoy, it makes me a better person.

The experience of being fulfilled and useful person in a new area outside of home offers J5 salvation.

R6 FAITH QUESTIONS

43 It's gone back to before the illness. Before the illness I was really faithful and I was very strong in my spiritual life. After it became shaky and I was thinking, is certain things true, is certain things real - then you ask questions. But then I think I begin to ask questions, and then I think I began to pick up again, it brings me now to where I was thinking better, and to have even more faith in God.

Questioning is seen as negative religious coping in research (Pargament 2000) and is not encouraged in Pentecostal tradition: God always remains sovereign. Brueggemann's arguing and assertive complaint (1995) is not found here. But the vow (30) is here close to covenant address. It makes the partnership more equal. Instead of passive waiting for prayer to be answered, the partners become co-creators.

R8 REFLECTING ON TESTIMONY - REDESCRIPTION

52 I tell them my stories. I tell them where I have been. I even tell them I once tried to commit suicide. And I tell them if I had committed suicide then, I would not be enjoying what I am enjoying now. And they are not to give up too soon, they must have hope. You know, be patient. You know, some times I think I was saying, is God real, I was saying, is this really a merciful God? All this kind of people shouting and praying and praising. Nothing was happening. Then gradually I said to myself I saw things happening, that I was able to do more

Faith is augmented here through a different perspective – the miracle is not a supernatural event, it is the miracle of starting to do normal things again. Receiving divine healing requires no skills or will or agency, but here the faith work J5 does allows her to become a free agent again.

R10 HEALING

Q60 Is it a problem for you that you haven't been healed completely?

60 Well not really.. I have come to accept and you know I believe I will be healed one day completely. That's my belief , and because of where I'm coming from and where I am now, I have that belief - it gives me that confidence, that I am on the road.

The hope of healing has not been given up even though salvation has come another way. In order to remain in the main stream, a role model within the church, the accepted belief in future healing remains an anchor and source of hope

Evaluation of faith situation – faith development

3.2 Transition

Key turning points N5, N6 N7

Reflecting on turning points R2 R3 R5

3.3 Resolution

Family Life and church – hopes for future N12 N13 N14
Role as testimony giver – faith witness, faith model
Role as counsellor – weather beaten witness, confronting harsh reality

4 Summary and discussion: Interview J5 analysis

Key themes in J5's narrative were previous faithful observance, exile from home – estrangement from family role, despair helplessness dependency, return to church as escape from captivity, covenant renewal – making a vow, testimony as meaning making – setting story within wider story of salvation.

This interview is rich in narrative data – a long struggle, various crises, a suicide attempt, the journey back to self esteem and a useful role in family and church.

The main outline of the story details how J5 previously had been an active and involved church-goer. She then becomes ill and stops going to church for about four years because she was uncomfortable with her illness. This discomfort arose from the fact that she and other church members were praying for her healing, but nothing happened. The emotional consequences of this was withdrawal and severe loss of self esteem. This was enhanced by her inability to perform mothering role in the family which was vital for her.
The turn-around came when she decided that she could act to improve her situation – losing weight improving mobility etc. She started going back to church to get out of the house, but gradually returned to faith as a result of the improvements that were happening which she saw as answered prayer.
This story then is an example of empowerment within the illness rather than escape from it. A key point in the story was when J5 decided she would make a bargain (the vow) to God to serve him if he would help her with the illness. This resulted in her offering to assist in manning the 24 hour helpline in her church, at which she became proficient. This led in turn to her being given responsibility for church bookstall, and becoming a respected counsellor of those in trouble

The faith narrative running alongside this story has two aspects. The interviewer challenges J5 about whether her faith has changed through this experience. She insists it has not, it has just become even stronger. Challenged further as to whether her experience had not in fact made her better able to counsel people in trouble she accepts that it has.

At a particular point in the story there is a moment of despair when suicide is contemplated, but not carried through. There is no sudden epiphany or revelation of love, as happened with D13. The breakthrough comes through willpower, the resolve to take action to improve her situation. The particular and unusual feature of this story is that from this point on J5 harnesses her prayer and faith resources into improving her life. Before her and her church colleagues had prayed for years for miraculous healing (i.e. escape from illness) without result. Improving life within illness requires a prior acceptance that illness may be within God's plan, and He may work in and through it. This is an example of Roots augmented narrative theory [1989] where the alien event or threat which cannot be removed is then included in the story-plot, and thereby controlled and dealt with.

Does this account provide evidence of spiritual disruption? Not according to the narrator who insists her faith remained rock solid. But she describes in some detail how her faith was for four years ineffective (9-11), and of no practical use

9 Yes I was expecting to be a lot better emotionally and physically and so on
10 Oh yes definitely. I was expecting healing. That's what I meant, even spiritually and emotionally. I was very down at the beginning
11 I was a bit moody, I wasn't as friendly, I didn't really want to talk I just want to withdraw and I didn't want to read my bible either
12 I stopped reading the bible. The only thing I did was pray, though not as much as I used to

J5 then describes the turning point when she decides to do some things 'by herself'. Instead of an all powerful God who acts upon the believer, the story changes to a partner God who helps the believer to change things

20 One or two things I started to do by myself. My faith started to grow I read my bible I prayed more
Q21 Can you think of a particular moment when it changed?
21 It was a gradual change. What made that better was when I was able to spend more time with my family, then there was an improvement as a result. I was able o go into the house, I was able to spend more time around my children. So that I was able to turn my emotions around.

The faith disruption experienced by J5 is clearly evidenced in the text. It comes in the form of despair, because her prayers have not been answered – there is no healing. This despair comes alongside a profound loss of self esteem (23)

23 Oh yeah I was that low. I felt like I was another child in the house. I just couldn't do anything. I was just in despair. I just felt like a body, like a child

In the model in Ch 4 faith disruption is followed by faith evaluation (taking stock), faith transition (revising or adding to faith story), resolution (restored or reconstructed faith). J5 story perfectly illustrates these stages as follows:

Faith disruption	No healing – faith is ineffective: despair
Faith evaluation	Can I pray for practical help instead of healing?
Faith transition	Include practical steps, walking again, in new faith story (narrative repair)
Faith resolution	God has helped each step of the way: faith is confirmed and strengthened

Spiritual disruption is here evidenced by the need to disrupt the authorised faith story, which says that the only correct response to illness is to pray for divine healing, and instead to pray for empowerment and the recovery of moral agency (Frank), the ability to take effective action within the strict limitations of the illness.

5 Summary and conclusions – J5 interview

J5 interview offers substantial evidence of spiritual disruption. The authorised faith story about healing leads nowhere and undermines self esteem and faith observance to the point of despair. The turning point is the determination to apply faith to achieve betterment, small improvements in mobility and weight loss and restoring effective family relationships.
This story of overcoming profound difficulties later becomes a testimony about faith overcoming obstacles. In the testimony there is no faith disruption, only final victory. J5 is therefore torn between loyalty to faith tradition and truthfulness to the lived experience.

APPENDIX C3 J5 Life line showing theoretical coding against disruption events

Diagram C3.1 Interview Analyses J5 Life line with three Stage coding – scatter pattern

Stage 1 Coding: N & R

N	Narrative Episode
R	Reflection & Evaluation

Stage 2 Coding: five part CI model

GH	Life in good health
SD	Spiritual disruption
EE	Expression & evaluation
FR	Faith recovery- Faith Work
RN	Resolution: new faith story

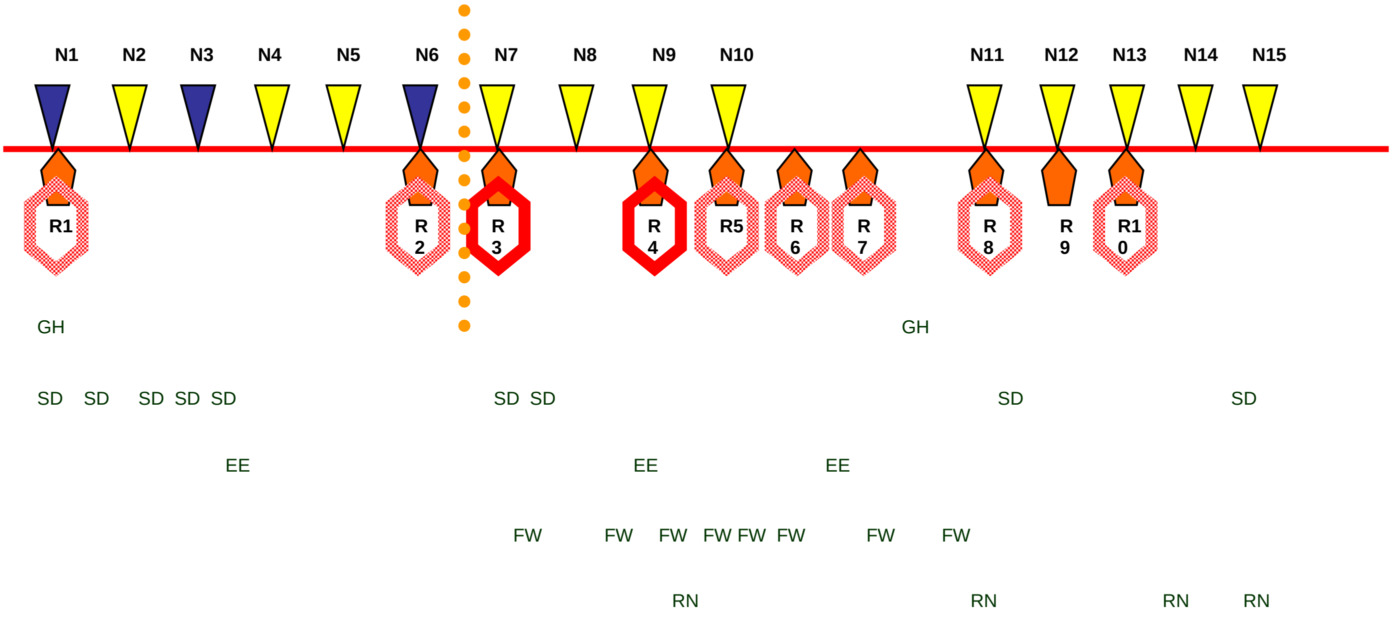
Stage 3 Coding: D

Disruption Response

F	Faith Response
NF	Non faith respon

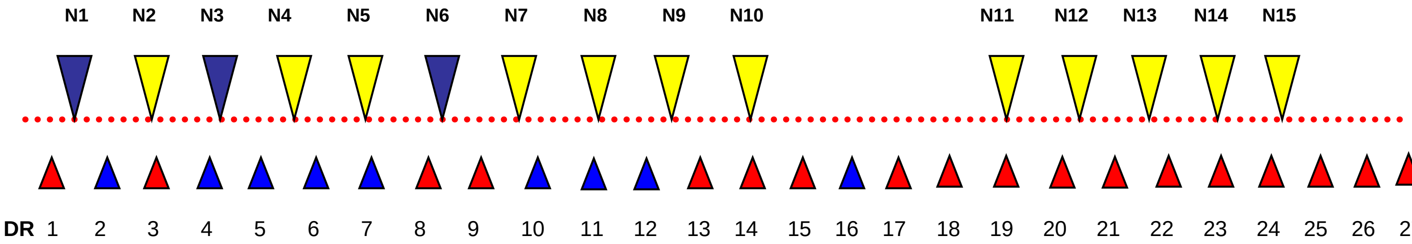
Stage 1 Coding: N & R

Reflection episodes occur throughout and may be grouped. A turning point occurs after N6. Reflections R2-R7 are linked to series of FW faith work codings (Stage2)



Stage 2 Coding: Five part CI stages

The scatter of theoretical chronic illness stage codings [GH SD EE FW RN] indicates a continuous pattern of processing through disruption cycles. The process continues and does not back-track when next cycle occurs. J5 has higher no of resolution codings than others



Stage 3 Coding: DR

Disruption responses occur throughout narrative episodes, sometimes in groups. The pattern of faith and non faith responses in J5's narrative clearly show stabilisation of faith responses – evidence for empirical learning

KEY **Narrative episode** ▽ **Adverse narr, episode** ▼ **Reflection/evaluation** ⬡

Faith Response ▲ **Non Faith response** ▲

APPENDIX D
Narrative analysis diagrams & chronic illness models

Diagrams were an important tool in the study for analysing data, observing processes in the field and then representing these processes in visual form. The diagrams were not necessarily definitive – they evolved developed and changed – but they led o to developing concepts processes and theories. They are grouped in Appendix D under thematic headings.

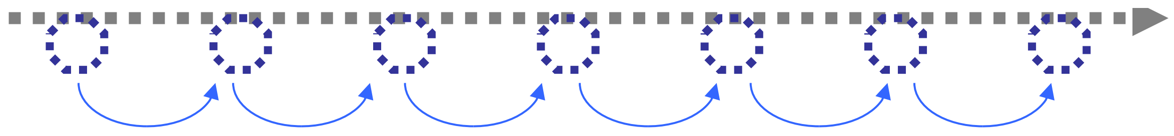
D1 Four Narrative Models of Chronic illness

D1.1 Model i: Five part progressive narrative quest

Model (i)	**Good Health**	**Illness & Disruption**	**Expression/Evaluation**	**Life Recovery**	**Resolution**

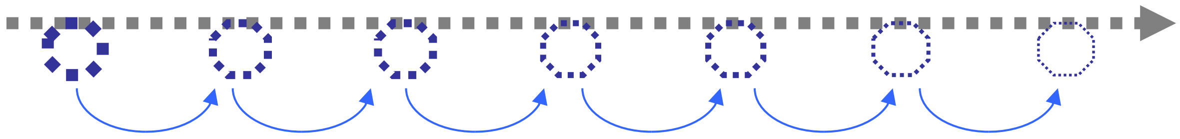
D1.2 Model ii: Disruption response cycles, illness work and progression (Level 1 – Level 3)

Disruption response cycles: disruption events are broadly similar, and are repeated in each cycle. No illness No learning and illness work occurs so disruption remains constant.



em ev rec gr fw ev fw fw gr rec id em gr gr fw fw gr ev em rec fw fw gr em id fw id id ev fw gr fw ev res id

Disruption response cycles: disruption responses are broadly similar, and are repeated in each cycle. But learning occurs, so responses and illness work are more effective, and disruption is reduced



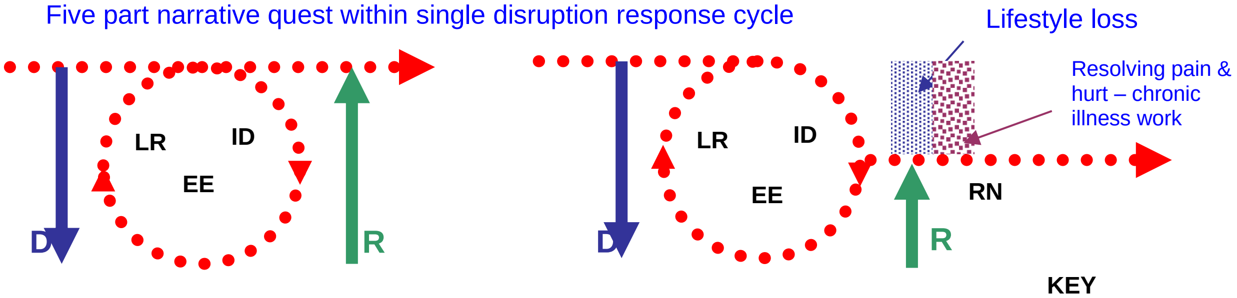
em ev rec gr fw ev fw fw gr rec id em gr gr fw fw gr ev em rec fw fw gr em id fw id id ev fw gr fw ev res id

Level 1 Disruption response ····› **Level 2 disruption response** ····› **Level 3 disruption response**

Illness work coding & Levels 1-3 Disruption response, showing learning and progression

D1.3 Detail of single disruption-response cycle

Five part narrative quest within single disruption response cycle



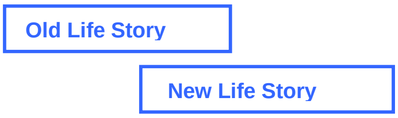
Full recovery D=R

Partial recovery D>R

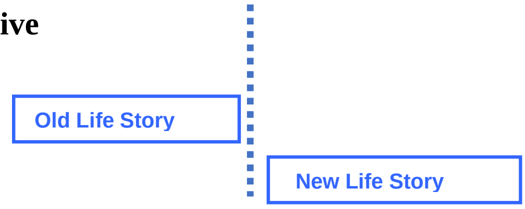
KEY	
GH	Good health
ID	Illness disruption
EE	Expression & Evaluation
LR	Life recovery
RN	Resolution

C1.4 Model iii

D1.4 Model iii Augmented/ new narrative



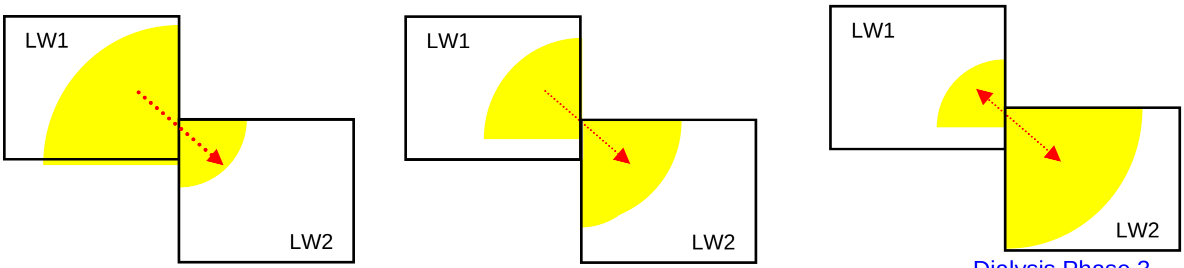
Augmented narrative - overlap



New narrative – complete break

D1.5 Model iv Living in two life worlds

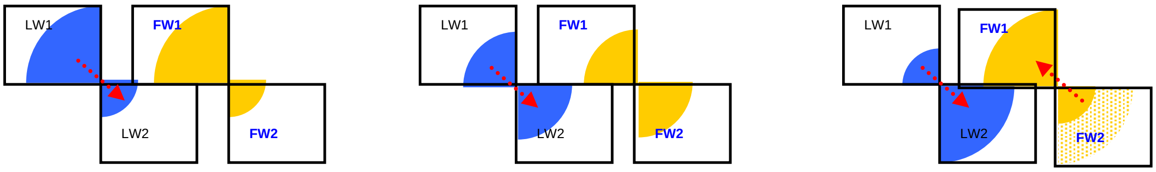
Diagram C Moving between LW1: good health and LW2 Chronic Illness



Dialysis Phase 1 Dialysis Phase 2 Dialysis Phase 3

D1.6 Model iv Moving between life worlds and faith worlds

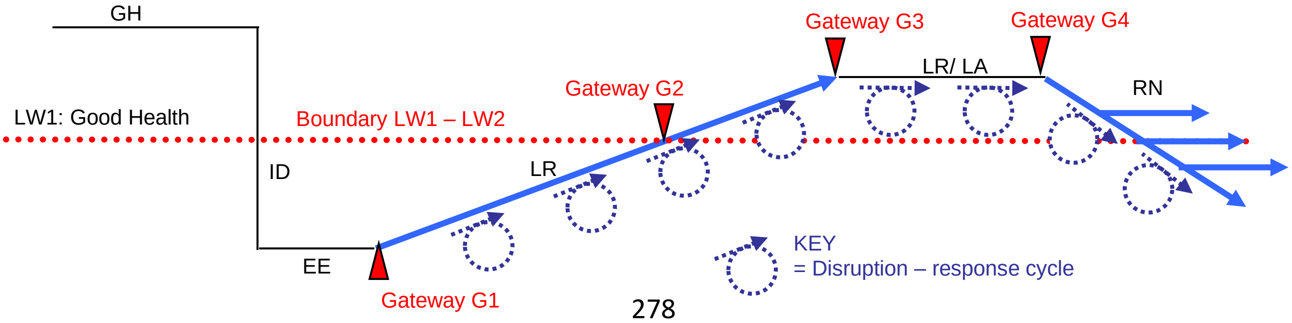
Diagram 6.11.2 Moving between FW1: faith in good health and FW2: faith in chronic illness



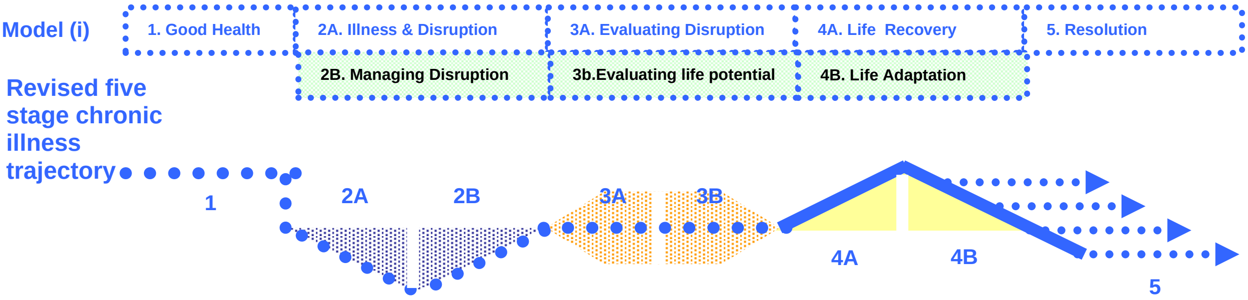
Dialysis Phase 1: active & mobile **Dialysis Phase 2: less active** **Dialysis Phase 3: semi-housebound**

D2.1 Development of primary study model: Combining models i and ii.

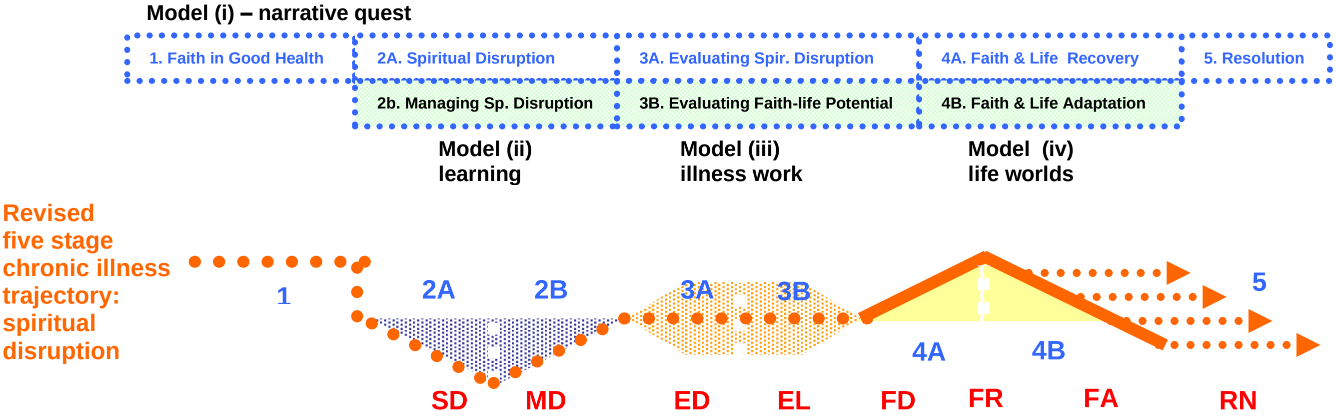
Integrating models (i) and (ii): narrative quest and disruption cycles



D2.2 The five part narrative quest: sub-stages added



D2.3 The five stage model revised: faith quest



Spiritual Disruption Stages

SD	Spiritual Disruption
MD	Managing Disruption
ED	Evaluate Disruption
EL	Evaluate faith-life potential

Spiritual Disruption Stages (cont'd)

FD	Faith deficit
FR	Faith-life Recovery
FA	Faith Adaptation
RN	Resolution – new faith story

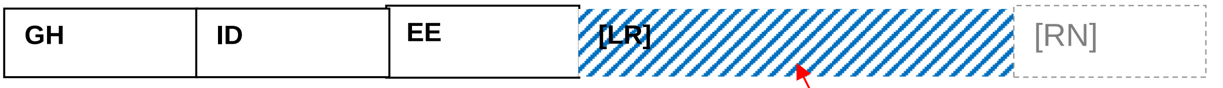
D3 The interrupted quest –suspended interrupted and resumed narrative quest

D3.1 The complete five-part quest

Good health	Illness disruption	Expression & evaluation	Life recovery	Resolution

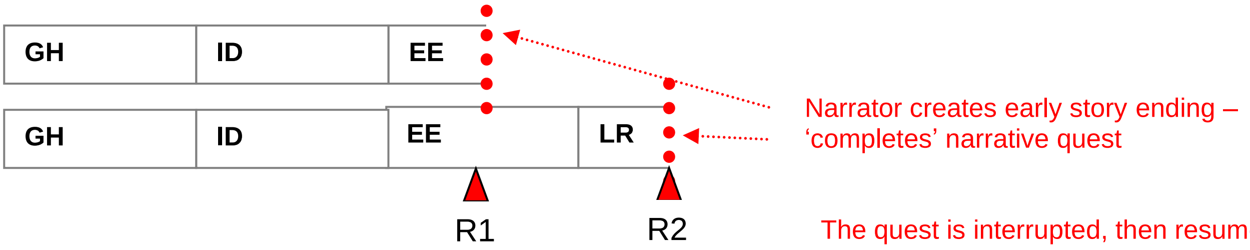
Transition points between five stages: illness work and learning is required before next stage can be reached

D3.2 The suspended quest – no resolution



Life recovery quest is never completed nor achieves its goal

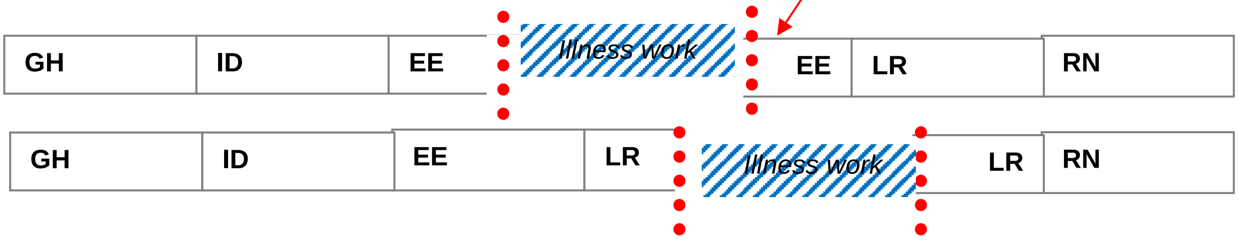
D3.3 The five part quest – interrupted quest



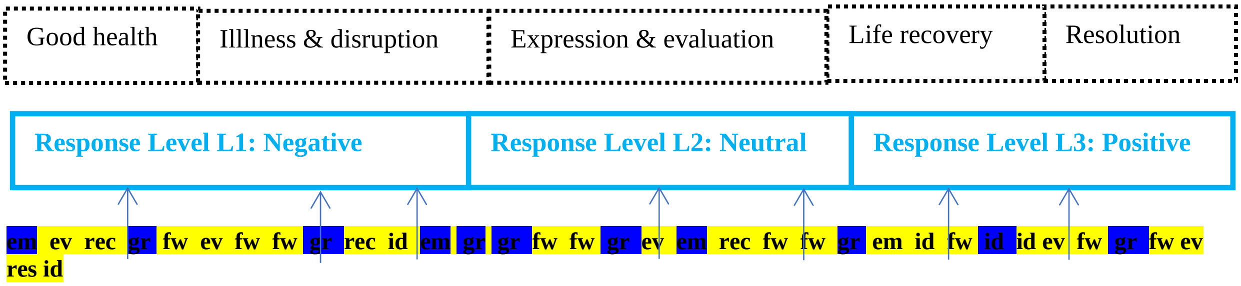
Narrator creates early story ending – ‘completes’ narrative quest

The quest is interrupted, then resumed when illness work has been done and learning has taken place

D3.4 The interrupted and resumed quest



D4.1 Five part narrative quest, Response Levels L1 to L3 and illness work

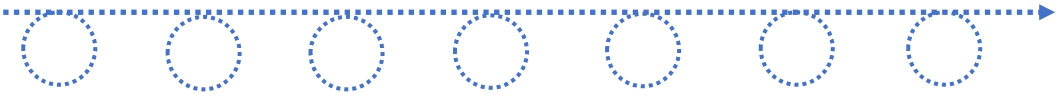


Illness work coding & severe disruption events (blue) – D4 coding (5.3)

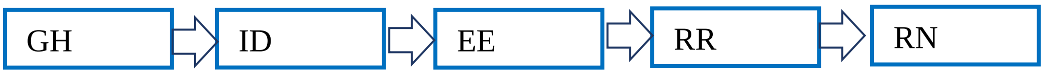
Here the five-part quest is superseded by successive response levels L1- L3. In response level 3, the subject responds consistently to disruption and engages in all types of illness work according to the needs of the situation. By contrast in L1 illness work would be occasional and ineffective, because subject had not yet learned full range of skills needed.

APPENDIX D: Diagram D5 – Evaluating LWP
LWP Theory development: Twin track story structure: disruption & recovery

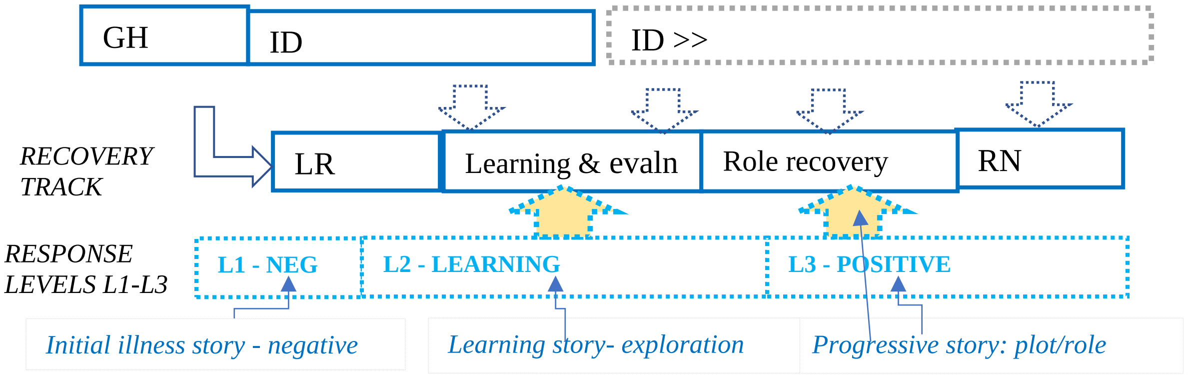
1. DISRUPTION TRACK– Disruption- response cycles 1.1 & 5.2



2. RECOVERY TRACK – Five stage progressive quest 2.3 (revised 6.3)



3. COMBINED MODEL – DISRUPTION & RECOVERY



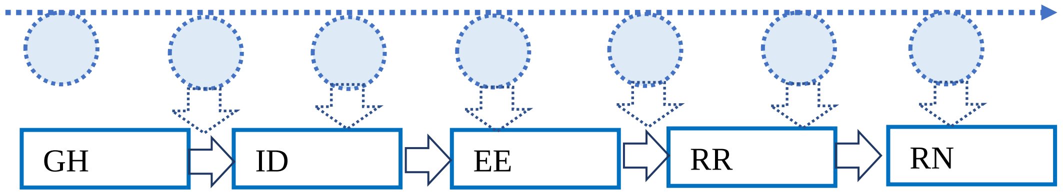
LR = Life recovery: begins during ID stage, but may fail
LE = Learning and Evaluation (was expression & evaluation EE)
RR = New stage: Role recovery – developed story plot & role
ID >> = Disruption story – ongoing

Disruption track is a counter narrative (containing suffering) and continues for all subjects (L1-L3)

Recovery track begins with life recovery attempts which may fails, then learning & evaluation stage, then role responsibility RR and Resolution stage RN

REVISED STORY STRUCTURE

Story 1: Disruption & response cycles: counternarrative of suffering, disruption & loss (L1-3)



Story 2: Five stage progressive (modified) narrative quest: developed illness story (L3)
Story 1 & Story 2 continue in parallel: one or other may be interrupted, then resumed

APPENDIX E
Patient Information Sheet and Consent Form

E1 Patient Information Sheet

The Lifestyle Project

Living Well Programme

Research study - biographical and spiritual disruption in renal dialysis patients

Patient Information Sheet Version 2: 13 4 09

PART 1

1 Description of Study

1.1 Heading: The Lifestyle Project: Living Well Programme

1.2 Title: Research study: Narrative and spirituality: biographical and spiritual disruption in renal dialysis patients

1.3 Invitation paragraph

We would like to invite you to take part in this research study. Before you decide you need to understand why the research is being done, and what it would involve for you. Please take time to read the following invitation carefully. Talk to others about the study if you wish

1.4 Purpose of study

The Living Well Programme (LWP) is about living well with kidney disease. Its aims are to promote holistic care of kidney patients. In pilot phase in 2007-8, 20 patients agreed to prepare Living Well Plans which addressed physical mental social and spiritual aspects of a healthy lifestyle. In Development Phase 2, 2008-9, additional resources were developed to help kidney patients with lifestyle issues. These included specific spiritual care resources including ‘My Faith Story’ and My Living Well Journey’. These employed patient narratives in order to understand better some of the spiritual issues involved in chronic kidney disease (CKD)

A key aim of LWP is to empower patients to take an active role in pursuing the best possible quality of life they can achieve within the limitations imposed by kidney disease. The research side of LWP therefore also embraces the principle of participatory research – that patients should be partners in the research process, and have a say in research methods and contribute to the research discussion and findings.

1.5 Why have I been invited?

You are being invited because you have participated in LWP, and have expressed an interest in exploring spiritual growth as part of your LWP.

1.6 Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet, which we will then give to you. We will then ask you to sign a consent form to show you have agreed to take part. You are free to withdraw at any time, without giving a reason. This would not affect the standard of spiritual and medical care you receive. Spiritual care in NHS is available to all patients under NHS charter on demand but is optional.

1.7 What will happen to me if I take part?

- How long will I be involved in the research?

Experience on Living well programme has indicated that 6-12 months is the optimum period of involvement, during a period of time when the patient is getting accustomed to living with their treatment regime (eg haemodialysis or transplant). Some patients have already been involved for up to 2 years.

- How long will I need to attend?

All the coaching and interview time for dialysis patients can be done during dialysis shifts – so no 'extra' patient time is needed. For transplant patients arrangements can be made to see them at outpatient clinics during normal attendance for routine check-ups.

- What exactly will happen?

Participants will normally already have completed living well plans (LWP's) and have discussed lifestyle issues with an LW team coach. If you participate in the research study you will be asked to have an initial one hour semi-structured narrative interview with the chief investigator (CI) on the subject of your faith response to your illness (CKD). Material from your LWP may also be discussed. There may be a shorter half hour follow up meeting to check narrative and agree transcribed text.

1.8 Expenses and payments

Interviews and meetings will take place during normal visits to hospital – so no extra expense is envisaged

1.9 What will I have to do?

The PI will arrange to conduct interview or meeting during dialysis shift/outpatient clinic timed so that it will not interfere with your treatment regime. The interview may be interrupted at anytime if medical staff need to do checks or procedures.

1.10 What is the procedure that is being tested?

The study is a qualitative study of patient experience using first-hand narrative accounts, and focuses on spiritual disruption and faith development during CKD. It is known that spiritual belief is a valued coping resource for patients with chronic illness: but little work has been done on how this works – is faith unaffected, or does it develop in response to the challenges of illness?

1.11 What are the alternatives?

You may choose to continue your participation in LWP but not take part in the research programme. Some patients do not require any spiritual care during their treatment. Some LWP patients focus on physical aspects of LWP – diet fitness mobility – but not on spiritual growth. This research is for those that wish to help explore and expand specific spiritual care resources which are targeted specially at the needs of chronically ill kidney patients.

Disadvantages and risks

Chaplains and LW team members involved in spiritual care are trained to address difficult issues – pain, mortality, spiritual distress and loss of hope. Some kidney patients eventually withdraw from treatment, finding the treatment burden too onerous and demanding. A key aim of LWP is to identify long before this time the things that make life 'worth living' for a particular patient, so they can be supported in prioritising quality of life alongside treatment compliance.

1.12 Side effects

Spiritual care may mean addressing and confronting some of the spiritual pain involved in losing key roles and valued activities because of illness. This process may be painful but will normally help the patient in longer to term to face losses in a positive way and seek adaptive strategies.

1.16 Possible benefits

Faith and spirituality may be termed an 'adaptive strategy' in terms of coping with pain and loss. Major religious faiths all deal with suffering and mortality and offer an interpretive framework together with crisis support from ministers and faith community.

The study seeks to identify the key elements of such support so that they can later be incorporated into a specific spiritual care programme.

1.17 What happens after the study stops?

The study period extends from 2009-2012, when it will be submitted for a Ph D at Kings College London. It will also be disseminated via one or more articles in academic medical journals, and will be presented at kidney patient interest groups. This will lead it is hoped to improvements in spiritual care practice as well as patient awareness.

1.18 What happens if there is a problem?

Any complaint about the way you have been dealt with during the study, or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

1.19 Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision

PART 2

2.1 What if new information becomes available?

The Living Well Programme includes a literature search of spiritual care interventions in CKD and chronic illness to date. Sometimes we get new information about the treatment being studied. If this happens your research doctor will tell you and discuss whether you should continue in the study.

If the study is stopped for any other reason we will tell you and arrange for your continuing care.

2.2 What will happen if I don’t want to carry on with the study?

If you wish to withdraw from this study then we will advise you about the data we already have. It is usually important for the study to retain any data already collected for example summary data about LWP’s. It should be possible to remove identifiable data such as individual interviews if you wish.

2.3 Complaints

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions (0207 188 1185). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital

2.4 Harm : NHS based research

In the event that something does go wrong and you feel that you have been harmed by the research and that this is due to someone’s negligence, then you may have grounds for legal action or compensation against Guys and St Thomas Foundation Trust, but you may have to pay your legal costs. The normal NHS complaints mechanisms will be available to you (if appropriate).

2.5 Confidentiality

Data collection and storage

The procedures for handling processing storage and destruction of data will be in accordance with Caldicott principles and/or the Data Protection Act 1998.

How will my data be collected and stored?

LWP data: Some participants who have already done LWP’s – data is stored under password in CI’s word processing area. Each patient is given a number unique to the study

Interview data

Interviews will be recorded. Tapes will be stored in lockable cabinet within spiritual care offices which are kept locked (door code access). Transcriptions of tapes will be kept on hospital computer systems protected by password.

Use of data

Your data will be analysed for the study. Interviews will be coded by topics and results aggregated and tabulated. LWP's will also be summarised and represented by charts which will show types of targets chosen and compare physical mental social and spiritual dimensions and scores.

It is unlikely that any of the interview transcripts will be published in the study – though there may be short excerpts. Transcripts will be approved by participants and edited as necessary to protect confidentiality.

Access to data will be restricted to members of the LW team, and authorised persons responsible for regulating the research.

The data will be retained during the lifetime of the study. Once the thesis has been submitted, personal data (tapes and transcripts) will be destroyed. Any summary tables and excerpts that form part of the study or its supporting evidence will be retained for 7 years.

All information which is collected about you during the course of the research will be kept strictly confidential and any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised.

2.6 *Involvement of Hospital doctor or family doctor*:

The specialist responsible for your care will be notified of your participation, and be their consent sought using a standard letter plus copy of this patient information sheet

2.7 What will happen to results of study?

The study forms part of an academic thesis (Ph D). Normally the results of theses are publicised at conferences or in journals in abridged summary or article form. Participants may request and receive copies of any published material. They will not be identified in any report/publication unless they have given their consent.

2.8 Who is organising and funding the research?

The academic institution is Kings College London Centre for Biomedicine and Society. The study will be conducted within the rules of the academic faculty and supervised by an appointed academic supervisor (Professor Steven Wainwright). It is also hoped to appoint a patient representative to co-ordinate patient involvement within the research process

2.9 Who has reviewed the study?

The study has been reviewed and given a favourable opinion by Guys Research Ethics Committee. The approval no is….

2.10 Further information and contact details

a. General Information about Research. KCL CBAS have a website which list all current research projects: Google CBAS Home page or address http://www.kcl.ac.uk/schools/sspp/interdisciplinary/cbas/
b. Specific information about this research project: Contact Chief Investigator Rev John Watts Spiritual Health Care Team Tel 0207 188 1187
c. Advice as to whether to participate: The GSTT Kidney Patients Association (KPA) has participated in and given funding support to the Living Well Programme. Suggested contact - Trevor Cook (KPA committee member) tel.0208 695 5013. You can also discuss with your specialist or GP
d. Who to approach if unhappy with the study. For spiritual care aspects, contact Rev Mia Hilborn Head of Spiritual Health Care, St Thomas Hospital tel 0207 188 1187.

For patient care issues and complaints the PALS office at Guys (tel: 0207 188 1185) can help any patient with the NHS complaints procedure.

E2 Patient consent form

GSTT letterhead

The Lifestyle Project

Living Well Programme

Research Study: biographical and spiritual disruption in kidney dialysis patients

Ethics approval no

Research Participant Consent Form

I have read the Participant Information Sheet Version 2 ☐ (please tick)

I would like to participate in the research study ☐ (please tick)

I understand that my participation in the study is confidential, and that personal data will be protected as described in the PIS ☐ (please tick)

I understand that I can withdraw from the study at any time ☐ (please tick)

I give my consent to my interview data and LWP data (anonymised) being used as part of the research study ☐ (please tick)

Signed (Participant)

Signed (Chief Investigator)

<u>3 Copies:</u>
Copy 1 for participant
Copy 2 for CI
Copy 3 for file

If you have any queries about your rights as a patient participating in a research programme please contact PALS office at Guys tel. no 0207 188 1185