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"It burdens me": The impact of stroke in central Aceh, Indonesia

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Abstract

The complex primary and secondary consequences of stroke have often been equated with the concept of biographical disruption, although a number of mediating factors have been identified. However, the research to date is almost exclusively based in western contexts, despite the fact that stroke is increasing most rapidly in low and middles income countries. This research explores the experience of stroke in the rural community of central Aceh, Indonesia. Participants included 11 stroke survivors and 18 carers, with data collected through in-depth interviews, photographic facilitated interviews, supported with participant observation over a nine month period. Participants discussed and illustrated the disruptive result of their stroke, but for most, their ability to maintain religious duties and contribute to their family resulted in a form of biographical continuity. The mechanisms and challenges to this are discussed alongside the implications for care in this context.

Introduction

Stroke, as the primary cause of acquired adult disability, is of global health concern (Lopez and Mathers 2006). It not only results in the neurological impairments described biomedically, but also the functional, personal and social consequences of that altered state. In western based literature stroke is presented as a disruptive event which challenges the known self through the multiple losses of physical capacity, role and identity (Alaszewski et al 2004, Kaufman 1988, Becker 1997, Dowswell et al 2000, Ellis-Hill et al 2000, Faircloth et al 2004, Wiles et al 2004). Indeed, the extent of that loss is such that stroke survivors and their carers have equated it to death, “stroke, like death, represents a catastrophic loss” (Dreslin 2008:16). This loss has most commonly been equated with Bury’s (1982) concept of biographical disruption including that of: the taken for granted aspects of life; the held explanatory systems; and the mobilisation of resources.

Further research has challenged the appropriateness of this concept in the case of stroke. Pound et al (1998), for example, indicate that age, the stage in life-course and familiarity with the symptoms and sequelae affects the interpretation of stroke, with some of their informants suggesting it was no real disruption at all. Faircloth et al’s (2004) work with veterans furthers this critique by suggesting that stroke is configured more appropriately as part of the chronic illness narrative. Dowswell (2000) in the UK highlights the importance of previous abilities, activities and roles within the context of the time pre-dating the stroke and the people significant in the individual’s life as shaping the post stroke experience. Williams (2000) cites some of this research to re-emphasise the need to consider timing and context in relation to biographical disruption.

More extensive critiques have come from the field of disability studies in which it is argued that a focus on the individual self, even within context, fails to account for the disabling capacity of social structures (Oliver 1996, Thomas 1999). Thomas (1999, 2002) however, also argues against ignoring the impairment effects of experience, but alongside writers such as Williams (1996) calls for the influence of broader socio-cultural structures on experience to be at the heart of studies on ill-health and disability. McKevitt et al’s (2003) study in post

Soviet Latvia illustrates the importance of this balance. They discuss how the historical and socio-political context of post soviet Latvia had a determining impact on people's experience of physical and social deficits following stroke. They described how the suffering at societal level, due to economic deprivation and political disharmony, exacerbated the individual's difficulty with managing their own experience post-stroke. The result was a concern less with the physiological function of the body, but the individual's ability to function as a social being.

As a result of these findings the universalistic nature of disruption should not be assumed and the need to examine the experience in relation to concerns beyond the individual is highlighted. This paper develops this idea through examining the experience of stroke survivors within the specific context of central Aceh, Indonesia.

The need to focus on countries such as Indonesia is clear. The World Health Organisation estimates that stroke rates will increase most substantially in low and middle income countries (WHO 2003). In 2001 stroke was identified as being within the top ten causes of Disability Adjusted Life Years (DALYs), with developing countries having almost seven times the burden of developed countries (Feigin 2007). In Indonesia stroke is already reported as the primary cause of death in those over five years (Kusuma et al 2009). Such figures are supported by reports of high rates of risk factors such as increasing obesity (Kisjanto et al 2005), a high prevalence of smoking (Ng et al 2006) and critically a society that is rapidly ageing (SEARO 2008). Despite this background very little is currently known about the experience of stroke and the impact that it has on stroke survivors and their family.

Prior to a description of the methods and presentation of the results a brief overview of the context of central Aceh is appropriate.

Central Aceh, Indonesia.

Indonesia is an archipelago of over 17,000 islands and is the fourth most populous country in the world (UNDP 2006). The area of central Aceh is based in the northern tip of Sumatra Island and is made up of two districts, Aceh Tengah and Bener Meriah. Both districts are rural and mountainous with small scale agriculture a main source of income (Bupati 2007).

Aceh was the first province in Indonesia to declare *Syriah* law, with 97% of the population declared Moslems (Ananto 2007). This accompanies an apparent change in the expression of Islam in the region. The twentieth century saw an increasing dominance of modernist Islamic thought within Indonesia (Bowen 1989, 1991, Eliraz 2004, Ricklefs 2001). Howell (2001) argues that this scriptural Islam is represented within the frames of the outer (*lahir*) aspects of Islam, particularly the visual rituals of dress, fasting and mosque based prayer. Although a proliferation of mosque building was apparent and dress codes in formal public engagements were strictly adhered to, *Syriah* was not as strongly enforced in central Aceh as in other parts of the province.

Despite its rich natural resources, the area of central Aceh is underdeveloped compared with other areas of Indonesia (World Bank 2008). This in part is due to the prolonged civil conflict in Aceh province, which after 30 years was resolved in 2005 (Barron, Clark & Daud 2005). During this period central Aceh was separated from its trade routes, but was also the site of active conflict. The combination led to a critical lack of food for an estimated 85% of the population and 62% directly witnessed conflict (IOM 2007). By 2007, when this study started, farming and trading had resumed and development programmes by the Government of the Republic of Indonesia and overseas aid had been initiated.

The family is the key social group in central Aceh and family members rely on each other in very practical terms. It is the unit of production and consumption, illustrated in both the practices of farming and financial control (Bowen 1998). The region has also been noted for egalitarianism and women can inherit both land and houses and often manage the family finances (*ibid*). All of the participants in this study lived with, or in very close proximity, to a number of their children and shared some of their land and finances with that immediate group, although not with extended relations. Indeed, it has been suggested that the conflict created suspicion amongst more distant relations resulting in a closing of the family unit (IOM 2007). As will be demonstrated later, a key concern for parents is the education of their children, both academic and religious. This reflects a complementary aspect of the family unit, that of personal independence as children are encouraged to develop skills to ensure they can earn an income. The overall impression is that people in central Aceh live within a frame of individual development with practical interdependency. It is within this specific socio-environmental and historical context that the life after stroke was experienced, lived and discussed.

The aim of this study, which formed part of wider doctoral research, was to explore the subjective experience of stroke in central Aceh. Specific objectives included a description of the impact of stroke on the lives of those affected, to identify the mediating factors in that experience, and to consider the findings in light of the international literature pertaining to stroke experience.

Methods

The study involved an in-depth exploration of the meaning and impact of stroke for the stroke survivors and their carers. A qualitative approach informed by both ethnography and interpretative phenomenology was selected. Phenomenologists assume “a chain of connection between people’s talk and their thinking and emotional state” (Smith and Osborn 2008:54) As a result, the meanings people ascribe to experiences can be uncovered through the words of the individual’s narrative (Maggs-Rapport 2000). Critical to interpretive phenomenology is that those narratives, like the experiences that inform them are not lived within a vacuum, but are situated in the social, political and cultural contexts (Lopez and Willis 2004, Moran 2000). Ethnography explores the creation of local meanings and actions within the social and cultural life of the community under study and their environment more broadly (Gibbs 2002). This combination has previously been used in stroke research (Doolittle 1994).

Data were collected via multiple methods in-keeping with the philosophical tenets underpinning the methodological approach and research aims. Predominantly these involved in-depth interviews, which were followed by photographic facilitated interviews by all but 2 of the stroke survivors. These second interviews involved participants taking photographs of aspects of life that were of importance to them and then using the images as the focus of discussion during the second interview. Training on camera use and guidance topics were given and the photographs were produced at no cost to the participant. This method was selected as previous research indicates that it assists in prioritising the participant’s agenda, facilitates the discussion of more personal experiences and is effective in cross cultural contexts (Clark-Ibanez 2004, Collier 1967, Samuels 2004). These personal narratives were complemented by participant observation over a 7 month period (2007), with a two month follow-up period (2008). This was completed by MN who lived in Aceh Tengah while working part-time with a disability organisation. Everyday life in the local community, as well as the familial interactions of the participants and other persons with disabilities and their carers, were the main focus of observation and informal enquiry. A reflective diary was maintained throughout the data collection and analysis process in which aspects such as the researcher's gender, age, nationality, profession and physical characteristics were considered. For example gaining access to participants and the intricacies of their stories was influenced, generally positively, by gender (female). However, limited discussions on the male participants' personal hygiene concerns as well as limitations to access their religious space were clear disadvantages. At a deeper level, consideration had to be given to personal reactions to gendered based actions, such as husbands talking on behalf of their wives, or indeed apparent financial abuse within the relationship. Likewise, being a western trained health professional had implications for perceived power and knowledge within the formal and informal interactions, the responses given by participants and the paradigm in which responses were interpreted.

Informed consent was obtained at each stage of the study which was approved by the ethics committee of Brunel University, UK. Further details of the study are published elsewhere (Norris et al 2010, 2011).

Recruitment and samples achieved

Stroke survivors were purposively selected through a sampling frame of people with disabilities in the two districts of Aceh Tengah and Bener Meriah, Indonesia. Inclusion criteria included a confirmed diagnosis of stroke and an absence of cognitive and language disorders. Those with multiple pathologies or insufficient language skills to participate in in-depth interviews were excluded. Variety in time since stroke, age and gender were purposively selected. Stroke survivors (n=11, age 32-69 years, 4 male, 7 female) identified their main carers (n=18). These included wives, husbands, sons and daughters and in most cases more than one person was identified. In-keeping with the post conflict context, all participants were of low socioeconomic status and none were in professional or government employment. All but one were involved in maintaining the family *kebun* pre-stroke (a kebun is a small plantation in which crops are produced for sale as well as personal consumption). Three participants prior to their stroke also had additional societal roles such as religious teacher and community health volunteer.

Data collection and analysis

Interviews, which were conducted in Bahasa Indonesia or local languages by MN and a local research assistant, were audio-recorded and transcribed verbatim. The use of a local research assistant enhanced the research as they were able to add contextual detail and manage the multiple languages spoken in the area. However, translation impacts on the both the fluency and the accuracy of the verbal interactions. For most interviews the translation could be monitored as Bahasa Indonesian was understood by all parties. For those undertaken in Gayo or Javanese meanings were discussed and clarified during the interview itself. The informal and conversational nature of the interviews and familiarity with participants and interview team facilitated this process. Regular reviews and discussions were held between MN and the research assistant to develop a fluent and productive working relationship. All transcribed data were then professionally translated and cross-checked alongside the original recordings. Occasional difficulties arose with terms whose meaning alters within context. These were agreed between MN and the research assistant and minor changes made. Additional notes from interviews and field observations were written up in full. All data were analysed thematically following the approach described by Braun and Clark (2006). An Atlas.ti data management package was used to facilitate this process.

Results

Stroke was described as impacting on the lives and the individual in a number of ways. The onset of physical limitations was immediately identified by the participants as being beyond the realm of normal. The presenting physical weakness was not a usual illness, one to be slept through or managed with home remedies. It was something unusual and severe and as a result outside assistance was required. But it was not only the impairments and health seeking that were raised by the participants, but the effect they had on the persons' ability to participate in the life they led. Evidence of the consequences of stroke was illustrated in many ways, through the dialogues, photographs and in observation, through which two broad themes emerged. The first was the burden of a disrupted life, in which the direct personal impact of impairments was particularly related to familial and emotional consequences. The second was the rebalancing of life over time. Both illustrate the interconnectedness of the individual to their immediate familial and spiritual context.

The burden of a disrupted life

The onset of physical weakness and continuing sequelae of stroke limited the individual's ability to function, resulting in the disruption of many day to day activities. Difficulties with activities of daily living such as washing, dressing, toileting, cooking and eating were identified by all participants as Filza's (F, 55 years) daughter describes.

> "There were many things [she couldn't do], shopping, cannot do gardening, cooking, she was just able to sleep. Even to eat was difficult. We have to help her eat…We

> have to do everything, she can't lift her arm…she has to ask for help to even eat" (Filza's daughter)

Arti (F, 46 years) similarly described her inability to complete tasks independently.

> "All [activities] is with help, all. If I want to go to the toilet, with help…I went to the plantation…now it's gone…I can't, walking…I feel bad, my heart is broken." (Arti)

Because of the personal nature of the activity, the inability to toilet independently was particularly important. This was especially so for the women. However, it was not just the loss of privacy that was of concern, but the burden it put on others to assist with this essential task. Immediately after her stroke Lastri (F, 56 years) had to be carried to the bathroom to toilet, she described "I was put on the back like a child". In the photographic interview she addressed this issue again.

> "This [the photograph] is when I got up from squatting…I was in the bathroom. This is the most important for family life. For a woman, using the bathroom is important. It is easier if we can do it independently…If we can do it alone, we do not have to ask some else to carry us just to urinate or any other bathroom activities." (Lastri)

Filza, Arti and Lastri, like the other participants, relied on close relations to assist with their daily care. They were fortunate to have older children or spouses who were able to assist in these tasks, although as Lastri indicates this was not a burden they wished others to bear. This assistance was often very difficult and physical in nature. While Lastri was successfully carried to their indoor and relatively spacious bathroom by her sons, Arti's daughters had a more challenging task. Their toilet was away from the home, very small, along an uneven path and Arti herself was larger than her daughters and physically very dependent. As a result they often had to compromise and use improvised commodes at the bedside. This was very distressing to Arti and created some tension between the family members, nevertheless the necessity for this was understood. In other observed families, this assistance was not available or offered. As a result individuals were left bed-bound and soiled for prolonged periods of the day.

For the stroke survivors themselves there was one activity the limitation of which had particular salience: work.

> Interviewer: From all these pictures which is the most important?
>
> Pramana (male, 66 years): This one. I am unable to work. I want to be able to work but I am unable to work freely and independently… it has a big influence. At that time, I could break the tree branches, but I cannot do that now. I used to take avocadoes. I used to be able to go from one coffee tree to another, now I can't, I have to take a stick with me. It has a big influence to my condition now. I used to go to the garden in five minutes, but now I reach there in two or three hours… This [picture] shows when my children were working together, tending the garden. I could not walk to the garden, so then they took me by motorcycle and I was there with them. I only sat down and took care of my grandchildren, while my children were working together… I, of course, cannot work.

The ability to work was key to all but one participant. Its loss post stroke was not just a personal loss, but was predominantly seen as a threat to the family. For the participants, the threat was posed not only through current financial insecurity, but also because other family duties, such as children's education, had to be sacrificed. The following three contextualised quotes illustrate these concerns.

Agus, a married father of two children below the age of four years, had been a cart vendor prior to his stroke as well as tending to crops, jobs he could no longer do. He struggled to discuss the implications of these loses for his family. In the first interview he raised his concern about the economic condition of the family.

> Agus: It [my health] is really, really important… If I was healthy I would get some money for the family… I have to be able to walk [to work]…Now, I am more emotional, quick to get angry…I am getting angry easily, the economic condition is my concern.
> [Long pause]
> Interviewer: can you tell me more?
> [Long pause]
> Agus sits for a long time with his head down breathing deeply. His wife, cradling the youngest child asks how he is feeling. He does not respond. The interview is stopped.

Agus' wife was his main carer and with young children was fully occupied in the caring role. She was supportive of Agus and together they pursued multiple health seeking options in the hope that his condition would improve. But as the months passed and no functionally significant improvement was made, this energy, time commitment and financial investment was reduced, being redirected to the well-being of the children and the family as a whole.

Faisyal (male 58 years) had his stroke in 2006. He lived with his wife and three of his seven children. Prior to his stroke he had been a religious teacher but his income primarily came from selling coffee and vegetables grown on the family plantation. In the following extract he alludes to both the familial and emotional consequence of his lost income generating ability.

> Faisyal: I think about my children, three of them, because they have to go to school…why other people can send their children to school and I can't, and I must fulfil the needs of my children.
>
> Interviewer: What is the biggest problem you face?
>
> Faisyal: That I cannot work again, yes it burdens me because my children need a lot of money to pay for their study…It is hard. It may cause them some trouble. Of course there is a problem. They all have to help me.

The relationship between lost income and the responsibility for children's education was reiterated by four stroke survivors. Melati (female, 46 years) had two children still at school-going age, but the income lost now she was unable to take the produce from the family plantation to the local market had resulted in the children being temporarily removed from school.

> Melati: I cannot work, no, I cannot, I cannot even cook anymore.
>
> Husband of Melati: cries, she very often cries
>
> Melati: just watching the tasks without being able to do them. I cannot help with the children's education, just watching them, and I could not work moreover….they can forget to go there, to school because my economic condition cannot make it

> possible…it is a responsibility, the heaviest one. There are many …but especially about the children's school, about the expense.

In addition to this common concern with the financial stability of the family, was a duty very specific to women, that of child bearer. This was not universal, but because of the salience to the individual affected it is important to report. Sujatmi (female, 32 years with one young son), was pregnant at the time of her stroke, some 4 months prior to the interview. This pregnancy had followed several miscarriages and both she and her husband believed that the stress of being unable to have a healthy second child may have been partly responsible for her stroke. However, the priority now was to carry this child to full term, something that the stroke threatened. Indeed, all treatment for Sujatmi herself had been suspended until after the birth. As her husband stated,

> "We think it [treatment] is enough for today. We will find another medicine, but we wait until she has given birth to her baby. It is our main consideration. We cannot think about the other [Sujatmi's health] today. After she gives birth, then we will follow every suggestion given by our relatives."

These relatives were not local and as her husband also worked away from the area Sujatmi was responsible for both full child care and managing the *kebun*. The potential consequence of not completing this 'task' was not directly stated, but through quoting the hearsay of neighbours, her husband suggested that he could take another wife. Two women with stroke, who were known but not formally interviewed in this study, were left by their husbands following their stroke and therefore such concerns cannot be considered a benign risk.

Sadly Sujatmi and the baby died during childbirth.

Rebalancing of life over time

Although the participants noted numerous ways in which the stroke had impacted negatively on their lives, all but two (Sujatmi and Agus) also discussed ways in which the resultant disruption had been remediated over time. Some of the rebalancing of their lives had occurred through recovery of function. Indeed, stroke was seen as a curable disorder and as a result recovery was both pursued and expected (Norris et al 2010). But this physical recovery, which was incomplete at the time of this research, was also supported by a reconfiguration of roles within the family unit.

Melati had previously been responsible for selling the produce from the *kebun* in the local market. While she was unable to return to this role, she had a number of children who had over time taken on the task. This allowed her to spend more time on other household jobs which she was able to manage and also for her husband to join her in a collaborative capacity such as cooking.

This rebalancing and shifting of roles was apparent in other cases. Prior to her stroke Lastri, a married woman with three children had worked as a village health worker as well as on the family plantation. She used all of her seven selected photographs to discuss her relief that her capacity to be independent in some familial roles now facilitated her children's independence.

> Lastri: This [picture] also impresses me.
>
> Interviewer: Why does this photo impress you?

> Lastri: Because I can help my children by finding firewood. It means I can already make an effort. It means I need no more help from my children.
>
> Interviewer: Why is it important that you have no need to ask the other's help?
>
> Lastri: I ... because I want to be independent. My children also do not need to help me anymore as they have had to do it until now. All [the photographs] are the same. Picking the clothes from the clothes-lines is also important. Especially, in rainy season because my children have to go to college and nobody is home. Here I can help my children to sweep and to pick the firewood
>
> Interviewer: Before you got your stroke, did you often do all these activities like cleaning the yard ...?
>
> Lastri: I cleaned everything ... planting koro fruit and vegetables. Then I just wait to harvest the fruits. Until I got sick...Now of course, I am happy. I can help by working again...I hope my children do not need to help me again.

Interestingly, although Lastri's husband was active and devoted, he had maintained his roles in the *kebun*, while the children (all over 16 years) had taken on the caring roles. Lastri herself often commented that their care was reciprocation of the love she had given them throughout their lives. Nevertheless, her relief that she was no longer the recipient in those relationships is evident.

In addition to the adaptations made in roles were those made to facilitate prayer. Prayer was a key activity for all participants and one which was maintained despite their physical limitations. Five of the participants described alterations they had made with: their position for prayer choosing to sit rather than fully prostrate themselves from standing; their washing procedures prior to prayer doing *tayammum* which is a dry wash rather than the full ablutions (*wudhu*), or the dress they used. Ramelan (male, 60 years) used a photograph to explain how he adjusted to periods of sickness during which he could not attend the mosque.

> Interviewer: Where do you usually do shalat (prayer)?
>
> Ramelan: In the mosque…when I am healthy, I do it in the mosque…every Friday is a must.
>
> Interviewer: What about the other days?
>
> Friend of Ramelan: When he is ill, he does it here, inside the house.
>
> Ramelan: yes yes…I am still doing it although I am sick. I do it in a sleeping position if I cannot sit down. The most important is that I pray.

For the participants the importance of prayer had additional significance directly related to their stroke. Three participants discussed prayer as a form of surrender, a way to accept their mortality and put their life into the hands of Allah. Interestingly, this did not stop them from actively trying to change their situation but rather assisted in the resolution of negative feelings. As Pramana (male, 66 years) stated "firstly, I felt regret, but what for, so I surrender myself."

A further three participants also discussed the role of prayer in their own recovery, as Melati illustrates.

> "Praying is the most important for me. Insya Allah (by the grace of God) I'll be better, I pray to God that I will get better, that's why I feel happy. I hope that through prayer there is a change." (Melati)

The religious focus was discussed almost exclusively within personal activity. Personal prayer was important to all, but few regularly attended the mosque or had been involved in other religious activities prior to their stroke. Indeed these more social aspects of religion were conspicuous by their absence with only two participants, both male, concerned with them post stroke. Ramelan, for example had been well known in the community for his ability to call people to prayer (*adzan*). His stroke had initially rendered him too weak to continue this role, which had clear social consequences as he and his wife describes.

> Wife of Ramelan: Before when he was healthy he used to be a religious teacher and a *dukun* [healer], but now he does not do it.
>
> Ramelan: I was sad when I heard *adzan* because I couldn't do *adzan* again.
>
> Wife of Ramelan: People ignored him.
>
> Ramelan: These last three days I can do it again...I have to do it with deep feeling.
>
> Wife of Ramelan: everybody now comes here when he does *adzan*...

Faisyal, had previously run an informal group for religious education. With some recovery from his stroke he had chosen that re-starting this was a priority albeit on a smaller scale and with support of his wife.

> "It's very meaningful to me; it's a service that I could give to people. And it also is a communication between me and people around my life. For example, if one child doesn't understand the singing (Al-Qur'an), he, she will ask me… I ask them to sing the Al-Quran and if they find it difficult to know how to sing, then I'll teach them from my sitting position." (Faisyal)

The examples given illustrate how the disrupted life reformed its continuity in part, through both social (familial) support and adaptations to tasks, including that of prayer.

Discussion

This discussion will explore the experiences described in central Aceh in relation to Bury's (1982) three aspects of biographical disruption (the taken for granted aspects of life; the held explanatory systems; and the mobilisation of resources) and other stroke literature. Through this the importance of the specific personal and social context in mediating the experience will be highlighted.

Stroke, for the participants in this study, was a disruptive event. It was not usual, or an expected part of their normal pattern of hardship. Rather it drew attention to a suddenly very visible malfunctioning body and life as they knew it was interrupted. As such, the experience in central Aceh mirrors that described in many contexts post stroke (e.g. Alaszewski et al 2004, Wiles et al 2004), and would appear to fit Bury's (1982) first level of disruption, the taken for granted aspects of life. What is also apparent is that this disruption was exacerbated by the environmental constraints which are related to poverty at a familial and social level. Houses could not be adapted to facilitate independent activity, such as Arti's toiletting and accessibility to work areas as well as work alternatives were unsupported by both the underfunded state and limited family capacity in this post conflict rural context. The participants in this study had all been involved in physically demanding jobs and little opportunities existed to facilitate alternative employment.

Interestingly, unlike previous studies (Pound et al 1998) age did not appear to mediate the initial impact of the disruption. This perhaps reflects both the different concepts of ageing cross-culturally and the experiences that divide or are shared across generations. In Pound et al's (*ibid*) study for example, hardship was related to living through a war and its aftermath, which younger stroke survivors may not have experienced. In central Aceh, the challenges posed by the 30 year civil conflict were more recent and had been faced by young and old alike. Equally, ageing in Indonesia is seen less as an age or retirement related label, but more within the realms of functional capability. If you were able to work in the *kebun* effectively, you were not considered old. This pattern of elderly Indonesians sustaining physically productive roles is noted in other parts of Indonesia (Lamb and Myers 1999).

Despite this initial disruption to everyday life, the participants in this study, with the exception of Agus and Sujatmi, did not however illustrate a disruption to their explanatory systems (Bury 1982). Their stroke did not appear to "challenge the whole of the individual's being" (Ellis-Hill et al 2000:731). Three factors can be identified as key to mediating and supporting the re-establishment of their biographical continuity: the understanding of stroke itself and healing environment; the maintenance of religious continuity; and the dynamic reciprocity of the family unit.

The first of these is described in more depth elsewhere (Norris et al 2010, 2011). In summary, stroke was understood as both a temporary and curable disorder. As a result, it could be argued that stroke in this environment was not even considered a chronic condition. Furthermore, healers in central Aceh (both biomedical and non-biomedical) never presented the uncertainty of stroke trajectory to their clients. Bury (1982) considers that such uncertainty reinforces disruption, and this has been highlighted in the stroke literature

(Becker and Kaufman 1995, Wiles et al 2004). However, in central Aceh cures promising full functional recovery were frequently offered, and any concerns of limited recovery were left unstated (Norris et al 2011).

The second factor identified by the participants was the very specific role played by religion and more specifically prayer. Fundamental to the practice of Islam is the belief that Allah is the creator and decider of all things and that misfortune is presented as a test of faith, in which the maintenance of a relationship with Allah is one aspect of that test (Yamey and Greenwood 2004). This research in a devout Moslem community illustrated some aspects of this commitment and like previous research (*ibid*) suggests that it could be linked with an adjustment to life post serious illness. As illustrated the dedication to complete the obligations of prayer was strong and was presented as a potential source and motivator for recovery. It is our contention that this lived commitment acted as a point of stability, a constant in the many fluctuations that are present in life as a stroke-survivor. Indeed it was a critical factor in maintaining some biographical continuity, for while there may have been evidence of ruptures in the body, individual and social roles, continuity between the individual and sacred realms was maintained.

Linked with this was the very belief in Allah's capacity to heal 'if it is His will' and the concept of surrender which promoted an emotional stability. Such an approach to illness is demonstrated in other Moslem communities where Allah is presented as the locus of control in both health and illness episodes (Ypinazar & Margolis 2006). Similarly, Williams (1984: 192) discusses how belief in God can result in a "transcendence of causality and narrative reconstruction". In both of these examples devout believers may live with a meta-narrative derived from God/Allah with the consequence that changes in individual circumstance are minor deviations in a greater story. However, it is not the externalising of an individual's life story that predominated in this religious community, but rather that the continuity of a previously developed narrative which necessitated a regular connection with Allah, was facilitated though the adaption and continuation of prayer.

Interestingly, this continuity was limited to the private sphere of prayer. Although Faisyal was able to maintain his social religious duties and thus religion facilitated his social continuity, Ramelan's description illustrated the vulnerabilities of this position with fluctuating health and capabilities. This specificity is intriguing given the changing nature of Islam in Aceh. Shifts from an internal spiritual expression to the more modernist external presentation would potentially impact on an individual's ability to adequately maintain their lived connection with Allah. Ypinazar &Margolis (2006) caution against the homogenisation of Moslem populations and this research would support such a call both in terms of location and over time.

Consideration of the third factor, the dynamic reciprocity of the family unit, draws on the contextual influence on both the explanatory system and the third aspect of Bury's (1982) concept, the mobilisation of resources. It is in this regard that the biggest differences occurred between the participants and resultant level of disruption experienced.

All the stroke survivors spoke clearly of the loss of both the role of income generator and also their personal independence. Their body, self and relationship with their immediate and wider society were initially altered. None had access to external and formalised social support of any kind, which resulted in very limited options. Nevertheless, many were able to renegotiate the significant roles in the family so they were able to actively participate in its success as a unit. The experience of Lastri and Melati for example demonstrates how they had adapted the nature of their contribution to the family, while maintaining a position of active contributor. Collecting firewood and cooking allowed others to go out to work. For Pramana, although his inability to work in the *kebun* was a personal loss, his capacity to care for the grandchildren allowed his children to complete the task. Previous research has indicated that the re-creation of roles can impact positively on adaptation post stroke and the establishment of narrative coherence (Kirkevold 2002, Remer-Osborne 1998). This study suggests however that it is not so much a creation of a new role and subsequently a new narrative, but more accurately an adjustment of an already established role, that of an active family contributor albeit in a new form. This finding has similarities with previous research in Indonesia (Schroder-Butterfill 2002).

It should be noted however that this was not the case for all participants and in particular was not evident in the experience of the two youngest stroke survivors Sujatmi and Agus. Critical to their experience was the centrality of their role in the family and the lack of resources. No-one but Sujatmi could mother a child, and given the young age of his children and their maternal care needs, no-one but Agus could be the primary income earner, yet the only job opportunity available to him necessitated physical capacities he no longer had. These notable exceptions are important as they highlight the specificity of circumstance in shaping the post-stroke experience and in the case of Agus illustrate the cross section of personal experience with the disabling environment, supporting the work of Oliver (1996), Thomas (1999) and Williams (1996). Without the potential of role exchange and with the external limitations on participation, the potential for a fundamental disruption increased. These examples, alongside the women deserted by their husbands following their stroke and others left soiled and isolated also demonstrate the fragility of the post stroke experience. Dependence in these cases cannot or are not accommodated and demonstrate the harsh realities of life post stroke when survival is in part virtually negotiated based on a capacity to participate. This theme supports the findings of Schroder-Butterfill (2002) who found that dependent elders on Java were often vulnerable to neglect and hence death. Williams (2000:50) suggests that “the biographically disruptive nature of illness is perhaps most keenly felt amongst the privileged…segments of society”. None of the participants of this study could be easily classified as privileged in any western sense of the term. However, in contrast to Williams (*ibid*) it is evident that those with the least resources and therefore least privileged were at most risk of critical disruption.

These results suggest that the biographical integrity of the individual is intimately connected with their support structure, in this case the family. Successful adaptation by the latter can support the re-establishment of meaningful activity of the individual even in the midst of disruptions resulting from stroke. However, when those disruptions in personal functioning cannot be exchanged because of familial constraints, choice or environmental/social limitations the biographical support is lost.

Such a finding has significance in how life post stroke should be explored and supported. In line with much of the literature, the disruptive nature of stroke appears to be a useful framework. However, it is essential that the wider social context is also examined in relation to the nature and degree of that disruption, how it is sustained or remediated. When the specific social context of the individual is considered with regards to both what potentially sustains their biographical continuity, but also what threatens it, including an inability/restriction to mobilising resources, key opportunities and threats to readjustment can be highlighted and addressed. In this case the influence of the immediate family and religious obligations were central to understand as mediators of the stroke experience, alongside the broader concepts of stroke understanding, social ageing, flexibility in gendered roles and the restrictive nature of the environment. Many of these factors are specific to the community under study and during a particular time period. However, the findings do have relevance for wider theories on the study of disability. What is indicated is a need to capture the breadth of influences, including the disabling capacity of social structures, but without losing sight of the specific context and biography of the individual involved. This study illustrates the complexity in how the different mediators of experience interact. A focus either on the individual or the society alone would fail to demonstrate that complexity sufficiently.

Conclusion

This paper has presented themes relating to the experience of stroke in a rural region of Indonesia. Key disruptions to life were noted such as activities of daily living and income generation. It has been argued however that these losses do not result in prolonged biographical disruption for all participants, as adjustment within the family and manner of prayer sustain the roles of active Moslem and family member thereby maintaining the narrative thread connecting life pre-stroke to post-stroke. This however is not the case for all participants. The results suggest a need to understand the experience of stroke more concretely within the specific social context of the stroke survivor and to broaden the understanding of biography to include aspects beyond the individual which are deemed key to biographical continuity.

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