

This is the post-print version of the final paper published in *Social Science and Medicine*, 71(9), 1576-1583, 2010. The published article is available at <http://www.sciencedirect.com/science/article/pii/S027795361000643X>. Changes resulting from the publishing process, such as peer review, editing, corrections, structural formatting, and other quality control mechanisms may not be reflected in this document. Changes may have been made to this work since it was submitted for publication. Copyright © 2010 Elsevier B.V.

Article Title: "I feel like half my body is clogged up": Lay models of stroke in Central Aceh, Indonesia

Names and institutional affiliations of all authors, in the order they are intended to appear in the final publication:

Meriel Norris, Brunel University, UK

Pascale Allotey, Monash University, Sunway Campus, Malaysia

Geraldine Barrett, Brunel University, UK

Corresponding author, institutional affiliation, and contact details:

Meriel Norris, Brunel University, UK – meriel.norris@brunel.ac.uk

Keywords: Indonesia; Stroke; Lay concepts

Acknowledgements: The authors would like to acknowledge the valuable input from the reviewers in preparation of this paper. We would also like to thank all who were involved in this project, particularly those in Central Aceh.

Abstract

Stroke in low and middle income countries is an increasing cause of death and disability, with rates and the estimated burden considerably higher than that of high income countries. Lay explanatory models are believed to be one of the major influences on health seeking behaviour and essential to understand for appropriate education strategies. Despite stroke being a considerable health concern in Indonesia and particularly in Aceh, no studies to date have explored lay stroke models in that context. This paper presents the findings of a qualitative study informed by both hermeneutic phenomenology and ethnography. Based in rural communities in Bener Meriah and Aceh Tengah in Central Aceh, Indonesia, data were gathered through interviews, photographs and observations with 11 persons with stroke (aged 32 to 69 years) and 18 of their carers. Fieldwork was conducted over nine months between 2007 and 2008. The study examined lay concepts of stroke, described as a condition resulting from a local blockage in blood from multiple causes, many of which are not recognised within the biomedical frame. The blockage is understood to be reversible and therefore the condition curable. This understanding is embedded and sustained in the specific political, cultural, religious and social context. The results illustrate similarities and differences with other cross-cultural studies and suggest areas of future research and points of consideration for stroke education strategies.

Introduction

Burden of disease studies estimate that stroke will become the leading cause of death and disability not only in high income countries, but also in those of lower and middle income, overtaking communicable diseases by 2025 (Feigin 2007). Countries like Indonesia become a powerful illustration of this concern. Indonesia has a number of

risk factors for stroke, including a rapidly aging society (SEARO 2008), an increase in obesity (Kisjanto, Bonneux, Prihartono & Grobee 2005), high rates of smoking (Ng, Stenlund, Bonita, Halimi, Wall & Weinehall 2006) and stroke is reported as the highest cause of death in those over 5 years (Kusuma, Venketasubramanian, Kiemas, Misbach 2009). Although Indonesia has yet to publish a specific strategy for stroke, government papers on non-communicable diseases emphasise community education as key to tackling the health transition from a predominance of communicable to non-communicable diseases (Ministry of Health 1999). Despite this background, very little is currently known about how stroke is understood and experienced in Indonesia, particularly in rural areas. This is important as research indicates that held beliefs and behaviours are critical to understand for effective health education (Frankel, Davison, Smith 1991)

Research exploring the stroke experience in other low and middle income countries, mainly in Africa, has predominantly focussed on explanatory models and health seeking behaviour (Alloh, Nandjui, Manou, Bombo, Datie & Zouzou et al 2007, Al-Oraibi 2002, Bham and Ross 2005, Hundt, Stuttaford & Ngoma 2004, Mshana, Hampshire, Panter-Brick & Walker 2008, Mshana 2008). Explanatory models are conceived as the notion about a sickness episode and its attempts at remediation which includes explanations of aetiology, onset, pathophysiology, course and treatment (Kleinman 1980). Indeed there are strong indications that aetiological knowledge is one of the major influences on health seeking behaviour (Good 1994, Kleinman 1988, Laderman 1991, Murray, Manktelow & Clifford 2000, Pugh 2003). Significantly, although held by individuals, Kleinman (*ibid*) contends that explanatory models are embedded within the culture and social structure of a particular place and

time. As a result they emphasize the dynamic inter-relationship between bodily experience, action and the context in which they occur.

In broad terms the Africa based studies illustrate that stroke-like symptoms are perceived as an indication of both a physical illness and social disequilibrium.

Assigned causes range from problems with blood flow and hypertension to: over-exertion, spirit possession, a test from God, the result of a curse, breaking socially ascribed sexual taboos, a hard life, and depression. The ascribed causes affect the action taken to remediate the symptoms in addition to prevention of further events. As such, the lay understandings have a critical impact on the resulting behaviour. Indeed, some studies indicate that causation theories may influence health seeking more than factors such as cost and accessibility (Mshana et al. 2008, Mshana 2008).

Furthermore, these studies highlight the numerous contextual influences on how these concepts are formed and operate including: religion, interaction with healers and treatment, and family amongst others.

Illness research in Indonesia indicates that numerous factors may influence health seeking behaviour. These include: the impact of the illness on functional ability (van Eeuwijk 2003); age and gender (Adlakha & Rudolph 1994, Schroder-Butterfill 2002); type of medication on offer and reputation (Sciortino 1992); cost and availability (Broch 2001). However, there is also evidence suggesting that lay understandings are also critical (Kurihara et al 2006). To date, there have been no studies exploring the lay concepts of stroke in Indonesia.

In an attempt to begin to address the gap the aim of this research was to explore the lay understanding of stroke in Central Aceh, Indonesia. Specific objectives included: to explore the understanding and perception of stroke in rural Central Aceh; and to identify the mediating factors in that understanding.

This research was part of a broader doctoral study exploring the experience and health seeking behaviour post stroke. Central Aceh was selected in part because of its rural location and because of access to potential participants afforded by MN's association with an international disability organisation based in the region. Subsequent to this fieldwork, data have been published indicating that Aceh has the highest rate of stroke in the country making this choice of location particularly pertinent (Kusuma et al. 2009).

Methods

The study necessitated an understanding of depth and complexity in people's accounts, rather than surface comparability between large numbers of people (Lopez and Willis 2004, Moran 2000). Qualitative methodology is best suited for such an endeavour as it both attempts "to make sense of, or interpret phenomena in terms of the meanings people bring to them" (Denzin and Lincoln 2003:4) and stresses the importance of the context in which those meanings are formed (Gibbs 2002). This combination places this research mid-way between realist and constructionist approaches (Maso 2007). This research was influenced by both hermeneutic phenomenology and ethnography. Phenomenology assumes that the meanings people ascribe to experiences can be uncovered through the words of the individual's narrative (Maggs-Rapport 2000). Ethnography on the other hand explores the webs of

significance (Geertz 1973) which precede and extend beyond the individual. Both approaches are complementary and accept the interpretive nature of the research encounter and analysis (Geanellos 2000, Geertz 1973). This combination has previously been used to effectively explore the stroke experience (Doolittle 1994).

Multiple methods of data collection were used to explore the individual's narrative and context including: in-depth interviews, photographic facilitated interviews and participant observation. All interviews were conducted in the location of participant choice, which was always their home. The photographic interviews, which nine of the stroke survivors completed, utilised self-selected images that the participants themselves had taken as representations of their current life experience. They acted as an additional mechanism of discovery and discussion in an attempt to emphasise the participants' priorities and explore more personal and emotionally charged concerns (Clark-Ibanez 2004, Collier 1967, Samuels 2004). Participants, many of whom had never used a camera, received written and verbal explanations of the purpose of the photographs, completed an additional consent form, which included potential publication of photographs, and were given training on how to use the camera and guidance topics. The study was approved by the ethics committee of Brunel University, UK and all participants consented to each stage of the study and have been given a pseudonym to maintain confidentiality.

Recruitment and samples achieved

The study was based in Central Aceh in the two districts of Aceh Tengah and Bener Meriah, Indonesia. The fieldwork took place in 2007 (seven months), with a further two months follow-up period in 2008. The research explored the lived experience, lay

models and health seeking behaviour held by those with stroke (n=11) and their carers (n=18). Those with stroke were purposively selected through a sampling frame developed from data of an international disability organisation working in the region. Strict inclusion and exclusion criteria were followed including a confirmed diagnosis of stroke and the absence of cognitive and language disorders. A mix of gender, ages, and length of time since stroke was purposively selected. Details are given in table 1. The carers were identified by the individuals with stroke. All the participants were of low socioeconomic status with a history of working as farmers, mobile labourers or in domestic roles.

Insert table 1

Data collection and analysis

Data included narratives from interviews, written information and photographs taken by MN or by the participants themselves. Interviews were undertaken in either Bahasa Indonesia or one of two other local languages by MN and a research assistant with appropriate language skills. They were audio recorded and later transcribed and professionally translated. Translated scripts were read alongside original recordings to confirm accuracy. Field notes, observations and daily reflections were written up in full. All written material and the photographs were imported into the *Atlas.ti* data management package. It was analysed using a thematic analysis approach as described by Braun and Clark (2006). This involved open coding at sentence level, followed by the identification of family codes. Broader themes were then developed and the inter-relationship between them expanded diagrammatically. The total process

involved continuous movement between quotes, codes, themes and the data as a whole.

Prior to the presentation of the stroke specific findings, an overview of the context of Central Aceh is essential particularly focussing on the history of the conflict, the family unit and general concepts of health and illness. This information is drawn from both the literature and empirical data.

Context

Central Aceh is a predominantly rural and mountainous region with one of the lowest development figures in Indonesia (World Bank 2008). It is estimated that 57% of the total population of the region are reliant on agriculture as their main source of income (Bupati 2007). This farming activity usually occurs on small family holdings (*kebun*) and the family is the unit of both production and consumption (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*).

The people of this region are devout Moslems, with an estimated 97% of Aceh declaring Islam as their faith (Ananto 2007). *Syriah* law was formally established in 2005 and Islam is evident in the dress and numerous mosques in the region. However, Islam in Indonesia is complex and contested and while there is move towards modernist approaches to Islam, there remains a strong link with Sufism and its concomitant tolerance of religious pluralism and a belief in spirits (Ricklefs 2001).

Aceh province was the centre of a 30 year civil conflict which was resolved in 2005 (Barron, Clark & Daud 2005). The conflict seriously disrupted life and trade resulting in significant personal tragedies and reduced development. The International Organisation for Migration (IOM 2007) estimate that in the central highland area 62% of the population witnessed combat with 85% suffering from a lack of food as a result of the conflict. 79% reported stress as a result of being unable to provide for their family. At the time of data collection for this study there had been limited hostility for two years and activities of daily life had resumed. Despite this, the experience of the conflict continued to play an important part of daily life as will be demonstrated.

A detailed description of the health services in Central Aceh is beyond the remit of this paper. However, it is relevant to note that the Government of Indonesia subsidises limited primary, secondary and tertiary health services. The Central Aceh area had one main hospital and several *Puskesmas* (Primary Health Care Centres) within each district, which employed medical doctors, nurses and midwives. Speciality services, such as physiotherapy were available in the hospital, but rehabilitation services were not provided by the Government in the *Puskesmas* or community and social services were practically non-existent. Although there is provision for subsidised health care for many in this community, all medical care incurs some direct costs. In addition to the biomedical personnel, numerous healers whose practice went beyond biomedical concepts were available in the region.

Also relevant to the context of this study is the underlying concept of the body, health and illness. The Indonesian paradigm of health is a complex amalgamation of the major medical traditions (biomedicine, Buddhist, Hindu, Chinese and Islamic

systems) intertwined with Animism. The notion of balance runs through all of these influences, the disruption of which is noted as being one of the causes of disease and illness. Indeed, health is posited as the restoration/maintenance of balance, “within the human body, between the individual and the environment and the environment within the community, the realm, the cosmos” (Slamet-Velsink 1996:73). It was on this understanding of health that stroke in this research study was interpreted.

Findings

This section presents the data on the understanding of stroke and its remediation. Central to this is the importance of blood and its flow in health and illness. Three themed sub-sections are presented: ‘being clogged up’, the slowing and agitation of blood, and curing the blood.

‘Being clogged up’

Stroke (*strok*) was a known term used interchangeably with the local phrase of *mati sebelah badan*. This literally translates as half dead body and signaled the recognition of stroke through the key symptom of weakness, paralysis, the inability to feel one side of the body, or the sensation of heaviness. Biomedically this equates to hemiplegia, and although other symptoms were mentioned, such as visual disturbance and dizziness, the altered function of one side of the body was consistent to all participants.

It means, it’s really stroke, is it not? Like that, with *mati badan sebelah*, someone cannot move, that’s what people said, (Arti)

I felt weak from above to the bottom...only half, the left side...paralysed
(Ramelan)

Thus, in line with Helman (2000), people predominantly perceived the condition from its primary symptom, albeit only one of the many biomedically recognized manifestations of stroke.

All participants reported that they believed stroke to be an alteration in blood flow. This was a plug or a block (*pembuluh darah*) and was located in the area of the body in which they had symptoms. They explained that weakness in an arm or leg was due to disturbed blood flow to the limb as a result of this plug. Four were able to pinpoint the area they believed the plug to be situated, most frequently pointing to their shoulder or lower back on the side affected. The extent of this blockage fluctuated, resulting in days when their limbs felt heavier or lighter or moved more or less.

“I feel that half of my body is clogged up. Yes, this part [points to left hip], this part is sick...sometimes if it relapses, if the blood does not circulate fluently...all is paralysed, I cannot feel anything.” (Pramana)

Interestingly, none of these cognitively intact participants related the alteration in blood flow to a problem in the brain. Indeed Arti specifically commented that her brain function remained intact stating, “I remembered all since the first time it took place...because there is no problem with my brain”.

The slowing and agitation of blood

Critical to the understanding of stroke were the reasons given for the disrupted blood flow. Numerous factors were considered which had two pathways of influence; one slowed the blood down, and through the other the blood could be agitated leading it to plug.

The slowing of blood flow was described by all but one participant. For two the over or under activity of muscles was responsible. Hard physical labour was said to cause tension in the muscles creating a physical block to flow. The extremes of fatigue and laziness could result in the blood becoming stagnant. Similar dynamics occurred through the influence of the weather. Cold weather reduced the fluency of blood flow and when combined with rain and sustained periods in that environment, the flow could stop altogether. Agus described,

“people said that it [stroke] is caused by the plug of the blood circulation. [indicates in his neck] ... I was caught in the rain before I got my stroke...maybe it was too long I was making a gate. It was raining really hard, which makes it cold in here [indicates neck]”.

The influence of the weather illustrates the porous nature of the body as understood in Central Aceh. This theme was central to the most commonly described cause for direct slowing or blockage of blood: spirits. Spirits (*djinn*), were identified by eight participants as having a direct and indirect effect on the blood. Once they had entered the body they could travel throughout, either contaminating the flow or altering thought processes.

“I think it is because we believe in djinn. When we think too much, remember something we can think negatively. Then maybe we disturb the djinn which makes it [the blood flow] worse.” (carer of Arti)

Spirits were most commonly encountered accidentally. Arti for example described how she must have kicked a spirit while visiting a friend in a nearby village. Despite

some research indicating an increase in destructive spirits in Aceh caused by the conflict (Siapno 2002), none of the participants reported this observation. Continuing the conversation, one of Arti's carers described;

“Of course, because it is called a djinn it will disturb all human beings. Everywhere, including England. Where there are human beings there are djinn...it is not a dead person.”

For one participant, the time of day of stroke onset was indicative of spirit involvement,

“at that time, we as villagers believed that because this had happened at 11.30, before midday that it was because of the devil, a bad spirit had entered” (husband of Sujatmi).

The involvement of human agents using spirit power in a curse was mentioned by one participant. However, this possibility was fraught with social implications and he soon retracted the theory.

Wife of Faisyal: Sometimes there is also occult force.

Faisyal: hmmm occult force...He [the traditional healer] said it was because of an occult force. I do not believe what he said. He said someone did this to me.

Interviewer: according to you, what is the cause?

Faisyal: in my opinion there are three causes, first because of food...second, because of thought...third is occult force.

Interviewer: so you also believe in occult force?

Faisyal: it is the common sense, but we do not believe it...I only believe the first two causes...he [the traditional healer] said it was an occult force, if we tell him for example that it is like this, then it will destroy that person, the sender and many others...to believe would make me suspicious of the others in the village.

Although spirits, the weather and muscles could directly affect blood flow, the clogging of blood was more frequently ascribed to an indirect process which involved an initial agitation in the blood. This agitation was closely associated with concepts of hypertension.

Hypertension (*hypertensi*) was a condition discussed by all but one of the participants as being in some way related to stroke. A carer of Arti stated,

“People said that stroke makes the body becomes heavy. Then I say that is stroke... I think it is from too much disturbance. Because the disturbance comes from thought then it causes hypertension which will become a stroke”.

Participants suggested that hypertension caused agitation in the blood and this could directly cause a plug to form resulting in stroke. As indicated in the following quotes, some of this information was drawn from interactions with biomedical staff

“I asked Pak mantri [male nurse]. He said your blood pressure is high so your blood circulation is clogged up. All is paralysed.” (Ramelan)

“He [the doctor] explained nothing. First he said hypertension, then finally stroke, he said because of the vein is clogged up, yes, it is clogged up.”

(Pramana)

In addition a number of the symptoms associated with stroke; loss of sensation, speech disturbance, dizziness, heaviness and physical fatigue were also related to hypertension.

“I had no feeling. It was hard to speak. I did not want to go out. In my heart I said this was hypertension”. (Indri)

Participants explained however, that stroke was a more serious disruption and the symptoms were more obvious and persisted longer. For example, stroke was the only condition that could cause *mati badan sebelah* for a prolonged period of time.

It should be noted that the concept of hypertension was not always clear. Although it was associated with a raised level in measurement, taken by biomedically trained personnel, reported levels ranged from 13 to 380 with no unit of measurement.

They [the doctor] said that it was only hypertension, hypertension. At that time her blood level was 15. (*husband of Filza*)

Every month, I check my blood pressure because I am a *posyandu kader* [village health volunteer]. My blood pressure is around 13-14. (*Lastri*)

He [the doctor] said that my blood was 380 (*Faisyal*)

The blood agitation related to hypertension was influenced by a number of factors. As Arti's carer intimated in the earlier quote, thinking was key. Indeed, the effect of stress and the quantity and quality of thought were the most frequently identified causes of blood agitation.

The quality of thoughts were intimately connected to the personal and socio-political environment of the participants. For five of the participants stress was related to their family and the economic pressures of everyday life as illustrated in the following two quotes.

Interviewer: What do you think caused your stroke?

Ramelan: Because of high blood pressure. At that time, one of my children experienced ...

Interviewer: What happen?

Ramelan: He had had an accident. He had a crash. That time was a feast day. I did not give him permission to, to ride a motorcycle. I was afraid that he would fall, if I gave him permission, he would die. That was in my mind at that time.

Interviewer: We were afraid that he was hurt.

Ramelan: I had a lot of thoughts... A lot of thoughts...

“Maybe her spirit was very low because of her husband. My father was getting married again. As a woman she was under pressure because my father never stayed here again after that. Maybe that lowered her spirit... Was it [the stroke] because of her weakened condition?” (Son of Indri)

For a further five, the civil conflict was noted as a negative influence. Arti, described how she believed the conflict related to her stroke.

“I was thinking too much. My husband died, I have 3 daughters, there were issues of daily life. This caused an increase in my blood pressure... Also it was conflict time... I had to move many times, I was afraid, this may have caused it... combatants asked villagers to move, the army came, but I couldn't move, I was afraid my house would be burnt. This happened before my stroke. The army were also shooting guns... so I was very afraid... fear, this may have caused my stroke because the heart is related with fear. If there is a gunshot or a car backfires I still feel very afraid because of what has happened.”

Three participants and their families had had to move several times, either at gunpoint or to avoid the *GAM* (Free Aceh Movement) or Indonesian army using them as human shields. Others had seen members of their family killed, decapitated bodies in their fields and lived in fear of their lives. All had struggled to maintain their economic stability as the danger posed by travelling to their plantations increased.

Ramelan: Before that [the stroke], I just saw a lot of people die

Wife: children, children...in the conflict

Ramelan: although they were in the hills.

Wife: We left all, our home, garden. The economic condition was bad. All that we had we left.

Food was also described to have multiple influences on flow and the onset of stroke.

Food in Central Aceh was generally described as heating, cooling or neutral in character and although agreement was not always reached on the categorisations, a

number of extreme examples were consistently identified. Fatty foods such as goat meat could cause an increase in the hypertension resulting in blockage and was avoided by most of the stroke survivors. Likewise, durian, a local fruit, was considered heating and therefore caused an increase in blood pressure. Coffee however, was the most consistently mentioned blood agitator and despite being the most ubiquitous drink in Central Aceh, was avoided by all following stroke. Interestingly, despite a high prevalence, smoking was not mentioned.

Two patterns are important to note in the development of causation theories. The first is that the initial ascribed causation was influenced by past experience. As a result the four participants who were aware prior to their stroke that they had hypertension initially ascribed this as the cause. The other seven showed a greater variety of explanatory processes. For example as previously illustrated, Sujatmi and her husband were influenced by the time of day the event occurred.

The second is that no participant mentioned only one cause, rather over time and different influences a combination were identified. As a consequence there was fluidity with causation theories which had a constantly revising nature. These influences included interaction with health providers, both biomedical and non-biomedical, stories from community members including accepted social narratives and the influence/ impact of intervention based on particular theories. For example Lastri, a community health visitor, originally believed her stroke to be caused by hypertension. Medical treatment in the hospital which reduced her blood pressure did not result in a change in symptoms so this causal explanation became unconvincing. A local healer suggested it could be due to a *djinn* and as she began to improve with

prayer, she believed this could be the case. However as severe symptoms persisted she sought another explanation. Lastri was Javanese and she discussed at length her vulnerability during the civil conflict and resultant mental tension. Community members suggested that it was this fear and negative thinking that had caused her stroke and this was her currently held theory.

Curing the blood

For the participants in this study recovery/ cure was both expected and sought.

Lastri's son for example discusses the initial action of the family.

“When she had her stroke, we immediately gathered here. We did nothing for almost 10 days. Going nowhere and doing nothing. We gathered, the family, to find the solution to cure her.”

Recovery was discussed primarily as a return to health, to the individual's normality. Underlying this concept was a sense of flow; the physical body, the blood and thoughts all needed to flow for the person to complete the tasks that were the foundation of a healthy life. Indri summarized this most succinctly by stating, “as normal people, first we pray, second we do work, third we do normal action, free to go anywhere. That is being healthy.” In line with this general concept of health, stroke recovery was in part framed within the capacity to move freely.

Arti selected the photograph entitled ‘Arti standing’ (figure 1) and commented on its significance.

Interviewer: Why did you select this picture? What does it mean to you?

Arti: I am very happy to stand. Makes me think I can walk independently, even though I know I can't...gives me hope that I will be able to do it eventually. I am happy when I stand. I ask myself when will I be able to walk?

Insert figure 1 here

Also highlighted was the desire to return to work, illustrated by the following two quotes.

I want to be recovered like normal...I think I will feel comfortable when I can hold something in my left hand. If I can hold something, then I can go to the garden holding a hoe. Like when I was healthy...and get some money for the family (Agus)

Interviewer: what is the meaning for you to be recovered?

Faisyal: recovered?... I can work ... yes work. Go to the garden yes, in the farm. I have a garden, but I am not working anymore ...because I am sick.

With God's help – inshalah, but if I am healthy, I will work again

Even a number of years after the stroke event and multiple therapeutic interventions, some of which included education on the biomedical understandings, participants discussed their efforts and desire to find a cure and achieve recovery as demonstrated below.

Five years after his stroke Pramana explained:

Pramana: I have a big hope to be healthy...back to normal so I can do things like usual

Interviewer: What do you need to do to make yourself healthy?

Pramana: Of course, find the medicine, control the blood.

“I look for treatment to be healthy...treatment in order to be healthy again, to recover. I could do anything in the past...I could do a job, and earn money but I cannot now ...I am just wondering how I can be healthy, what is the medicine. That's all...what is the medicine in order to be healthy soon? What is the medicine?” (Melati)

These last two quotes indicate the connection between recovery and resolving the altered blood flow. Participants described how symptoms created by the block in blood flow, could be reversed and resolved once the blood flow was restored. While Melati and Pramana focused on medicines to restore and control the blood flow, Filza's husband described treatment using *bekam* (cupping with heat or sucking) through which the dirty blood, caused by spirits, is sucked out of the body.

Husband: you do bekam in the dirty place

Interviewer: and this sucks out the dirty blood?

Husband: yes, it enters into the cup

Interviewer: what is the relationship between dirty blood and stroke?

Husband: ahh stroke...the relation between stroke and dirty blood...for example...if he could not walk, automatically if it is done, the treatment would go inside this place and then the blocked blood can flow...

A host of treatments were accessed in order to achieve this goal, both biomedical and non-biomedical. In addition to those described above, massage and acupuncture were used to physically clear the blockage and facilitate flow.

“For example, umm...the blood is not clear, so massage makes it run very smoothly.” (Ramelan)

Massage was also used in combination with other interventions. For one massage was done alongside a conversation with the spirit and offerings of chicken and rice to gently entice the spirit out the body, a process referred to as the redemption. There was also description of internal massage where a powerful energy force is applied without physical contact called *totok*.

In summary these results suggest that stroke in this part of Indonesia was understood to be a block in blood flow with various causes. Causation was initially ascribed through past experience but was fluid and influenced by interaction with others and response to interventions. Two pathways were described, factors which directly caused a reduction in blood flow and others which aggravated hypertension which resulted in blockage. Some factors, such as spirits, were common to both pathways. These causation theories were embedded in the specific historical, socio-political, cultural, religious and physical environment. The blockage was reversible and as flow returned there was an expectation that the symptoms would resolve with a return to functional normality. These features are conceptually illustrated in figure 2.

Insert figure 2 here

Discussion

This study in Central Aceh illustrates a number of interesting points when compared with other studies of lay explanatory processes for stroke. Such cross-cultural comparisons can lead to useful insights in directing future research and stroke education strategies. The first is the inter-connectedness of explanations. In Central Aceh stroke was described as a physical condition, in contrast to the distinct conditions described by Hundt et al. in South Africa (2004). There were, however a number of causation pathways which included both physical and social/spiritual factors. These were interrelated and variable such that social problems affected the physical status and ascribed causes were frequently altered with experience. Such a finding is in line with Mshana et al. (2008) and indicates a need for underlying the inter-relationship between influencing factors. It also highlights the importance of engaging with all perceived causation factors within health education approaches.

Notable in this study was the lack of social judgment within the ascribed causes, i.e. attribution of curses or occult forces. This was a common explanation in a number of the other studies in both Muslim and non-Muslim participants (Bham & Ross 2005, Hundt et al. 2004, Mshana 2008). There are two potential reasons for this difference apparent in the narratives. The first is the complex social consequence for the belief in spirits themselves as a result of the current debates on Islamic interpretation in Indonesia. To believe in spirits at all risks negative judgment as uneducated and significantly a 'bad' Muslim (Bowen 1993). Second was the need for social harmony within this post conflict situation, which led to reluctance to judge individuals, as illustrated by Faisyal. It was apparent that the wider social narrative of the conflict and general hardships was a preferred explanatory pathway. Linked with this was the observation that participants in Central Aceh did not look to Allah as a cause of their

condition. This is in stark contrast to research in other Muslim areas (Al-Oraibi 2002, Bham & Ross 2005, Mshana et al. 2008). Such differences should encourage researchers and policy makers to consider 'situated religion' rather than religious meta-narratives.

There were however a number of areas where similarities existed between studies. One example of this is what Mshana (2008) has described as the lay biomedical explanatory discourse. The familiarity with stroke as an interruption in blood flow and hypertension are examples. These may act as useful starting points for stroke education campaigns. But there are issues with the lay interpretation of these which have not been discussed in other literature. The quoted hypertension figures themselves illustrate some of this confusion as does the site of the blood blockage. Although it is evident that some of this information was gained from interaction with biomedically trained personnel, further research on how this information is gathered, interpreted and acted on is required. It was further apparent that other biomedical risk factors such as smoking have not infiltrated the lay explanation to date, in-keeping with other research in Indonesia (Ng, Stenlund, Bonita, Halimi, Wall & Weinehall 2006). Understanding why smoking is so resilient to negative health implications would be a fruitful area of future research.

Another area of interest was the focus on stress. In the biopsychosocial model of health, stress has been linked with the timing and severity of stroke, although the mechanism of its influence is still unknown (Harmsen, Lappas & Rosengren 2006, Harmsen, Rosengren & Tsipogiani 1990, Macko, Ameriso & Barndt 1996). Stress has also been identified as an important causation concern in a western based study of lay

concepts (Townend, Tinson, Kwan & Sharpel 2006). As demonstrated in this study too much, and specifically negative, thinking were clearly linked with stroke onset in Central Aceh. Of particular interest in this study was the focus on the conflict as a direct and indirect influence of stroke onset. Whether through the direct trauma or the indirect material hardship as a result of the conflict, the ascribed relationship was apparent. Figures that suggest that stroke incidence is higher in Aceh than anywhere else in the archipelago (Kusuma et al. 2009) add to calls to further investigate the potential links between mental trauma/stress and stroke.

Finally it is important to note the commitment of the participants to their recovery. Hundt et al. (2004:442) comment that the “sustained and focused efforts to do this...is remarkable”. Such efforts were also evident in Central Aceh, with participants not only trying multiple routes to remediation but also altering their explanatory theories based on their success or not. Interestingly, despite multiple differences in context, similarities between Central Aceh and the western experience can be drawn. For example a focus on a recovery model, rather than adaption has been demonstrated not only in the African studies but also in the UK (Alaszewski, Alaszewski & Potter 2004, Dixon, Thornton & Young 2007). The recurrence of this theme internationally suggests that further research is required to ascertain why the recovery model has potency, what factors create and sustain it, and its potential role.

In summary this study has indicated that the lay understanding of stroke in Central Aceh is influenced in part by a number of factors specific to the location. This suggests a need to understand the local context when planning health strategies. However, others are shared across continents and may indicate areas where future

international research would be fruitful. Furthermore, other factors, such as Islam show patterns that are distinct from other Islamic areas. Consequently necessary caution is required in making generalisations about particular groups of people based solely on one attribute.

Conclusion

This study has explored the local explanatory model of stroke in Central Aceh, indicating the importance of blood flow and the multiple factors of influence. It has highlighted key areas where these lay models parallel and differ from similar studies in different contexts. The results indicate a need to understand how lay models are embedded in the local context but also directed by wider influences such as biomedicine. Such information can influence the approach to local and international health strategies as well as future research agendas.

References

Adlakha, A. and Rudolph, D. (1994). Ageing Trends: Indonesia. *Journal of Cross-Cultural Gerontology*, **9**, pp. 99-108.

Alaszewski, A., Alaszewski, H., Potter, J. 2004. The bereavement model, stroke and rehabilitation: a critical analysis of the use of a psychological model in professional practice. *Disability and Rehabilitation* 26(18), 1067-1078.

Alloh, A., Nandjui, B., Manou, B., Bombo, J., Datie, A., Zouzou, A. and Beugre, D. (2007). An anthropological approach to how Tchaman people in the Cote-d'Ivoire view hemiplegia. *Annales de readaption et de medecine physique*, **50**, 225-230.

Al-Oraibi, S. (2002). *Stroke patients in the community in Jordan.*, University of Brighton.

Ananto, A., (2007). The Population and Conflicts. In: A. Ananto and L. Om, eds, *Aceh a New Dawn*. Singapore: Institute of South East Asian Studies, pp. 15-33.

Barron, P., Clark, S. and Daud, M., (2005). *Conflict and Recovery in Aceh*. Indonesia: World Bank.

Bham, Z. and Ross, E. (2005). Traditional and Western Medicine: Cultural Beliefs and Practices of South African Indian Muslims with Regard to Stroke. *Ethnicity and Disease*, **15**, 548-554.

Bowen, J., (1993). *Muslims through discourse: Religion and Ritual in Gayo Society*. New Jersey: Princetown University Press

Bowen, J., (1998). *Religions in Practice. An Approach to the anthropology of religion*. USA: Allyn and Bacon.

Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**, 77-101.

Broch, H.B., 2001. The villagers' reactions towards craziness: An Indonesian example. *Transcultural Psychiatry*, **38**(3), pp. 275-305.

Bupati., (2007). *Pendapatan Domestik Regional Bruto Kabupaten Aceh Tengah Tahun 2000-2006*. Aceh Tengah, Indonesia: Bupati.

Clark-Ibanez, M., (2004). Framing the Social World With Photo-Elicitation Interviews. *American Behavioral Scientist*, **47**(12), pp. 1507-1527.

Collier, J., (1967). *Visual Anthropology: Photography as a research method*. New York: Holt, Rinehart and Winston.

Denzin, N. and Lincoln, Y., 2003. Introduction: The discipline and practice of qualitative research. In: N. Denzin and Y. Lincoln, eds, *Collecting and Interpreting Qualitative Materials*. 2nd edn. California: Sage Publisher Limited, pp. 1-46.

Dixon, G., Thornton, E. and Young, C. (2007) Perceptions of self-efficacy and rehabilitation among neurologically disabled adults. *Clinical Rehabilitation* **21**, 230-240.

Doolittle, N., (1994). A Clinical Ethnography of Stroke Recovery. In: P. Benner, ed, *Interpretive Phenomenology: Embodiment, Caring and Ethics in Health and Illness*. California: Sage, pp. 211-224.

Feigin, V. (2007). Stroke in developing countries: can the epidemic be stopped and outcomes improved? *The Lancet Neurology*, **6**(2), 94-97.

Frankel, S., Davison, C., Smith, G. (1991). Lay epidemiology and the rationality of responses to health education. *British Journal of General Practice*. **41**, pp.428-430.

Geanellos, R., (2000). Exploring Ricoeur's hermeneutic theory of interpretation as a method of analysing research texts. *Nursing Inquiry*, **7**(2), pp. 112-119.

Geertz, C., (1960). *The Religion of Java*. Chicago: University of Chicago Press.

Gibbs, G. (2002). *Qualitative data analysis. Explorations with Nvivo*. Buckingham: Open University Press.

Good, B. (1994). *Medicine, Rationality and Experience: an anthropological perspective*. Cambridge and New York: Cambridge University Press.

Harmsen, P., Lappas, G., Rosengren, A. (2006). Risk factors for stroke in middle-aged men in Gotenborg, Sweden. *Stroke* **37**, 1663-1667

Harmsen, P., Rosengren, A., Tsipogiani, A. (1990). Long-term risk factors for stroke. *Stroke* **21**, 223-229

Helman, C. (2000). *Culture, Health and Illness*. 4th edn. Oxford: Butterworth Heinemann.

Hundt, G., Stuttaford, M. and Ngoma, B. (2004). The social diagnostics of stroke-like symptoms: Healers, doctors and prophets in Agincourt, Limpopo Province, South Africa. *Journal of Biosocial Science*, **36**, 433-443.

IOM, (2007). *A Psychological Needs Assessment of Communities in 14 conflict-affected districts in Aceh*. USA: IOM.

Kisjanto, J., Bonneux, L., Prihartono, J.R., T. and Grobbee, D. (2005). Risk factors for stroke among urbanised Indonesian women of reproductive age a hospital based case-control study. *Cerebrovascular disease*, **19**, 18-22.

Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing and the Human Condition*. New York: Basic Books, Inc.

Kleinman, A., (1980). *Patients and healers in the context of culture*. Berkeley: University of California Press.

Kurihara, T., Kato, M., Reverger, R. and Tirta, I. (2006). Beliefs About Causes of Schizophrenia Among Family Members: A Community-Based Survey in Bali. *Psychiatric Services*, **57**(12), pp. 1795-1799.

Kusuma, Y., Venketasubramanian, N., Kiemas, L., Misbach, J. (2009). Burden of Stroke in Indonesia. *International Journal of Stroke*, **4**, 379-380.

Laderman, C. (1991). *Taming the wind of desire: Psychology, medicine and aesthetics in Malay shamanistic performance*. USA: University of California Press.

Lopez, K. and Willis, D., (2004). Descriptive Versus Interpretive Phenomenology: Their Contributions to Nursing Knowledge. *Qualitative Health Research*, **14**, pp. 726-735.

Macko, R., Ameriso, S., Barndt, R. (1996). Precipitants of Brain infarction: Roles of Preceding Infection/ Inflammation and Recent Psychological Stress. *Stroke* **27**, 1999-2004

- Maggs-Rapport, F., (2000). Combining methodological approaches in research: ethnography and interpretive phenomenology. *Journal of Advanced Nursing*, **31**(1), pp. 219-225.
- Maso, I. (2007). Phenomenology and Ethnography. In: P. Atkinson, S. Delamont, M. Loustanaou, J. Lofland and L. Lofland, eds, *Handbook of Ethnography*. California: Sage, pp. 136-144.
- Ministry of Health, 1999. *Healthy Indonesia 2010*. Jakarta: Ministry of Health
- Moran, D., (2000). Introduction to Phenomenology. London: Routledge.
- Mshana, G., Hampshire, K., Panter-Brick, C. and Walker, R. (2008). Urban-Rural contrasts in explanatory models and treatment-seeking behaviours for stroke in Tanzania. *Journal of Biosocial Medicine*, **40**, 35-52.
- Mshana, G. (2008). *Stroke Discourses and Remedies in Urban Rural Tanzania*. Durham University.
- Murray, S., Manktelow, K. and Clifford, C. (2000). The interplay between social and cultural context and perceptions of cardiovascular disease. *Journal of Advanced Nursing*, **32**(5), 1224-1233.
- Ng, N., Stenlund, H., Bonita, R., Halimi, M., Wall, S. and Weinehall, L. (2006). Preventable risk factors for noncommunicable diseases in rural Indonesia: prevalence study using WHO STEPS approach. *Bulletin of the World Health Organisation*, **84**(4), 305-313.

Pugh, J. (2003). Concepts of arthritis in India's medical traditions: Ayurvedic and Unani perspectives. *Social Science and Medicine*, **56**(2), 415-424.

Ricklefs, M.C., (2001). A history of Modern Indonesia. 3rd edn. London, UK.: Palgrave.

Samuels, J., (2004). Breaking the Ethnographer's Frames. *American Behavioral Scientist*, **47**(12), pp. 1528-1550.

Schroder-Butterfill, E., 2002. *Ageing in Indonesia: A Socio- demographic Approach*. University of Oxford.

Sciortino, R., 1992. Care-takers of Cure: A study of health centre nurses in rural Central Java. Amsterdam, Holland.: Vrije Universiteit.

SEARO, last update, country health profile: Indonesia. Available: www.searo.who.int/LinkFiles/Indonesia_indonesia.pdf [08/19, 2008].

Slamet-Velsink, I., (1996). Some reflections on the sense of nonsense of traditional health care. In: P. Boomgard, P. Sciortino and I. Smyth, eds, *Health care in Java: past and present*. 1st edn. Leiden: KITLV Press.

Townend, E., Tinson, D., Kwan, J. and Sharpe, M. (2006). Fear of recurrence and beliefs about preventing recurrence in persons who have suffered a stroke. *Journal of Psychosomatic Research*, **61**(6), 747-755.

Van Eeuwijk, P. (2003). Urban elderly with chronic illness: Local understandings and emerging discrepancies in North Sulawesi, Indonesia. *Anthropology and Medicine*, **10**(3), 325-341

Wade, D. (1992). *Measurement in Neurological Rehabilitation*. Oxford: Oxford Medical Publications

World Bank, (2008). *Aceh Poverty Assessment 2008: The impact of the conflict, the tsunami and reconstruction on poverty in Aceh*. Jakarta: The World Bank.

Table 1: Participant details

Participant	Age (years)	Date stroke onset	Hemiplegia (side of weakness)	Barthel Score* /20	Sex	Carer	
1	Arti	46	2005	left	5	F	3 daughters
2	Pramana	66	2002	left	19	M	Wife
3	Devi	69	2007	left	9	F	Husband
4	Lastri	56	2006	left	15	F	2 sons and 1 daughter
5	Melati	46	2007	left	14	F	Husband
6	Filza	55	2007	right	8	F	2 daughters mainly with 1 son and husband
7	Ramelan	60	2005	left	17	M	Wife
8	Indri	50	2001	right	17	F	Son
9	Agus	35	2007	left	11	M	Wife
10	Sujatmi	32	2007	left	12	F	Husband
11	Faisyal	58	2006	right	15	M	Wife

* The Barthel Score is a commonly used measure of disability with a lower score indicating a higher level of functional dependence in activities of daily living such as personal care and mobility (Wade 1992).

Figure 1: 'Arti standing'



Figure 2: Lay concept of stroke

