Curing the blood and balancing life: Understanding, impact and health seeking behaviour following stroke in Central Aceh, Indonesia.

A thesis submitted for the degree of Doctor of Philosophy

by

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Abstract

Previous studies have highlighted the importance of understanding the subjective illness experience. Stroke, as the second highest cause of death and highest cause of adult morbidity internationally, is no exception. However, the research to date has significant gaps. Lay understandings of stroke in low and middle income countries remain poorly understood, and very few studies have explored the links between experience and the context in which they occur. These gaps in knowledge have resulted in insufficient attention being paid to the relevance of local contexts in the implementation of international and regional recommendations for stroke.

The study presented in this thesis explores the experience of stroke in Central Aceh, Indonesia. It drew on phenomenology and ethnography and used a range of qualitative methods. People with stroke and their carers were involved in the examination of stroke understandings, its causation and mechanism, the impact of stroke on their lives, and actions taken to remediate the symptoms. This information was complemented with an in-depth study of healers, within the context of the health systems through which they operate. Further information on current social, religious and cultural practices was gathered through participant observation.

The study revealed that lay understandings occurred within a range of explanatory models. Also highlighted was the complex relationship between the understanding of the condition, the impact on the family, and the health seeking behaviour. All were influenced by the specific context and an attempt to regain a homeostatic balance in life; within the person, with others, and with the supernatural.

The results of this study demand critical interrogation of the international guidelines both for stroke and for policies to promote access to health personnel at the primary care level.

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Completing this thesis has been a job and a half. The job was mine, but the half has been supported by many other people. Without them, I either would not have finished or would have completed in a much poorer state. To all I offer my heartfelt thanks.

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Chapter 1

Introduction

1.0 Aceh 2005

In early 2005, following the Indian Ocean tsunami I accepted a post as a rehabilitation specialist in Aceh Besar, the Northernmost tip of Indonesia that had been most severely affected by the tsunami of December 2004. As a physiotherapist with considerable clinical rehabilitation experience both in the UK and Asian countries, my role within Handicap International, the agency that recruited me, was to develop an outreach rehabilitation programme for people with disabilities. The programme included people who acquired their disability as a result of the tsunami, but also those with pre-existing disabilities. Prior to this posting I had been working as the stroke clinical specialist physiotherapist in a large central London teaching hospital. I had no expectation that my stroke specific skills would be called upon in the new role, but this assumption proved to be wrong. In the five month period in Aceh, the majority of cases identified and with whom I worked had a clinical diagnosis of stroke, a pattern that continues in the project to date. Stroke appeared to be both common and previously under-diagnosed and under-treated in the region. These two factors sparked my interest. As a biomedically trained physiotherapist I was intrigued about the frequency of the presentation, the rehabilitation services people with stroke may have accessed at the time of their event, and the goals of recovery they still wished to achieve. As a medical anthropologist, I was interested in the ways they talked about their illness and the variety of paths they had taken to maximise their recovery, many of which were at odds with my biomedical understanding.

As a result of these interactions I sought out and met a number of people responsible for the treatment of stroke. This included staff in the hospital, in the local health centres and traditional healers who were based in the communities. All had been significantly disrupted by the tsunami, but continued to practice and work with people with stroke, as well as many other conditions. I began to form a picture of stroke in this corner of Indonesia. It was an image of diversity in understandings and

inclusion of multiple methods towards recovery. In both the government funded health service and the work of Handicap International, stroke was understood and treated within the parameters of biomedicine. The people affected, however, had their own stories to tell and their own explanations. I heard people, for example, describe their stroke as a result of grief, eating white buffalo meat, or stress caused by the years of conflict in the region. They had been to the hospital, their local health centres, private doctors, nurses and therapists, and a myriad of traditional healers who used herbs, prayer or acted as spirit mediums to heal. Since the tsunami, many had been to see the scientologists and other faith healers who were practising in the city. The lay explanations of stroke were as broad as the choices for seeking help. Both incorporated aspects that were difficult to integrate with a biomedical perspective. My role was in rehabilitation, yet it became increasingly clear that in order to achieve this aim I had to both understand and interact with these lay models of stroke. It became apparent that lay understandings of illness and the context in which they are formed, moulded and perpetuated, were the fundamental business of both my professional career and the provision of quality health services. This thesis is a continuation of that journey to understand stroke in one part of Indonesia.

1.1 Introduction to thesis

The summary of my experience in Aceh highlights many of the key features addressed in this thesis; lay and professional concepts of stroke, who is sought to aid recovery and why, and the potential challenges when different concepts combine. Stroke, as will be illustrated shortly, is a key health concern internationally. Much is already known about the condition and its treatment, yet much is still under-researched. This is particularly the case in middle and low income countries where the number of people with stroke is estimated to rise most significantly and where lay understandings of stroke have been shown to have a strong influence on the health seeking behaviour. The research presented in this thesis adds to the knowledge base on stroke, adding important insights into the influence of context on the understanding of the condition and the subsequent health seeking behaviour.

In this introductory chapter I include background information relevant to this study. This includes a brief overview of stroke and its biomedical understanding. Through

this summary the importance of stroke as a research priority and the particular need to focus on lay understandings and experiential aspects are emphasised. Following this, a review of stroke in Indonesia is presented. The incidence of stroke and current available literature are reviewed, highlighting the necessity for further research. The selection of Central Aceh as the field site of the research is also introduced. The last part of this chapter briefly presents the thesis. It includes an outline of the study design which has influenced the selection of chapter order, and concludes with a summary of the following chapters and their contents.

1.2 Stroke

1.2.1 Biomedical perspective

My experience in Aceh highlighted that the biomedical model in which I had been trained and through which I understood stroke was not universally held. It is however, the perspective that both informs international recommendations and is promoted by national governments as the medical model of choice. As a result, it is not only seen as the 'gold standard' by which services are judged, but also informs the training of medical doctors and the allied health professionals throughout the world.

Stroke is the biomedical term given to "a focal (or at times global) neurological impairment of sudden onset, lasting more than 24 hours (or leading to death) and of presumed vascular origin" (World Health Organisation 2006b). More simply, the Stroke Association describes it as "a brain injury caused by a sudden interruption in blood flow" (The Stroke Association 2006:4). This is linked to the two main mechanisms by which blood flow can be interrupted – blockage (ischaemic) or bleed (haemorrhagic), resulting in brain cell death. Over 300 risk factors have been associated with stroke. Five modifiable factors have been highlighted as most significant in high income countries. These are; smoking, cardiovascular disease and related hypertension, high cholesterol, diabetes, and obesity (Intercollegiate Stroke Working Party 2008, Rosamond *et al.* 2008). Similar trends are seen in middle and low income countries (Connor et al. 2007, Garbasinski *et al.* 2005, Mendis *et al.* 2005, Ng *et al.* 2006, Poungvarin 1998, Singh *et al.* 2000, Tesfaye *et al.* 2007, Walker *et al.* 2000). Key non-modifiable factors include genetics and age, with the

latter being the most powerful and independent of other risk factor status (Abbott *et al.* 2003).

Stroke can lead to numerous problems depending on the site and extent of the damage to the brain tissue. Common presentations include problems with mobility, speech and language, and cognitive function amongst others (Baxter 1997, Hachinski & Norris 1985, Sutin 1986). In high income countries, it is estimated that approximately one third of those affected will die, with 50% of those surviving having an incomplete recovery (Bonita *et al.* 1997, Sandercock *et al.* 2001). Currently, morbidity data from middle and low income countries is lacking, although it is noted that the death rate following stroke is higher than that of high income countries (Strong *et al.* 2007).

Stroke treatment is individualised and involves a combination of complex and coordinated interventions. However, there are a number of fundamental principles which are considered the ideal care pathway that should be implemented. These include: stroke is a medical emergency and treatment should be initiated as soon as possible preferably in a hospital environment; treatment should be given in a discrete stroke unit; the unit should include a multi-disciplinary team of specialist professionals; and rehabilitation should be intensive. This proposed pathway theoretically leads the person with stroke through a number of distinct phases. The first is a period of super-acute intervention, which increasingly includes treatments such as thrombolysis, or 'clot busting' medication (Schwam *et al.* 2005). Following this is a period of rehabilitation which focuses on treatment of impairments, adaptations to assist in the recovery of functional capacity and then adjustment, functionally, socially and psychologically, to the residual sequelae (Baer & Durwood 2004, Chandra *et al.* 2006, Lennon 2004, Wade & de Jong 2000).

Guidelines, papers, and consensus reports based on these recommendations have been published internationally (Puerto *et al* (2008) identify well over 100 such documents). These include guidelines from the UK (Department of Health 2007b, Intercollegiate Stroke Working Party 2008, National Audit Office 2005), United States of America (Schwam *et al.* 2005), Europe (Aboderin & Venables 1996, Hacke *et al* 2003), the Asia Pacific region (Donnan et al 1998, Singapore Ministry of Health

2003), Indonesia (Indonesian Society of Neurologists. 2000) and developing countries more generally (Brainin *et al.* 2007, Chandra *et al.* 2006). These recommendations on stroke care to some extent reflect the origin of authorship, however all agree on the principles presented previously. The universal relevance of these recommendations is an issue discussed shortly.

1.2.2 Need for study

Stroke is currently the second most common cause of death and the primary cause of adult acquired disability (Lopez & Mathers 2006, World Health Organisation 2006b). It is stated that 87% of those deaths occur in low or middle income countries (Strong *et al.* 2007). In 2001 stroke was identified as being within the top ten causes of Disability Adjusted Life Years (DALYs) (*ibid*), with developing countries having almost seven times the burden of developed countries (Feigin 2007). It is estimated that by 2025, alongside other cardiovascular diseases, stroke will be the highest cause of DALYs worldwide (World Bank 2003). As such, stroke is of global health concern. Yet this concern is not universally recognised. In high income countries, where chronic and non-communicable diseases dominate the pattern of ill-health presentation, the interest and investment in stroke research has grown significantly in recent decades (although it is still far behind the investment in other common conditions such as chronic heart disease). In the UK for example, stroke has a yearly economic burden of £2.8 billion (Saka *et al.* 2005), with a combined government and charitable research expenditure of £12 million annually over recent years (National Audit Office 2005). In middle and low income countries, which find themselves at varying stages of the health transition and battling both communicable and non-communicable diseases, the picture is very different. Little investment has occurred either in research or in the development of appropriate stroke services, despite growing evidence that stroke is an increasing medical and social problem (Brainin *et al.* 2007). This lack of investment results in a paucity of accurate data on the incidence of stroke in many middle and low income countries and an underestimation of the burden that stroke creates (Poungvarin 1998).

The imbalance in engagement with stroke between high and low income countries also leads to inequity in representation of appropriate models of care. As a consequence, international recommendations, as described in the previous section,

are based almost exclusively on models appropriate within a high income country context. Such countries are dominated by both biomedicine and western concepts of social identity and structure. There are therefore a number of potential limitations to the appropriateness of the recommendations for middle and low income countries which have a different cultural and social history. Brainin *et al* (2007), in a recent overview of stroke management in developing countries, acknowledge that a number of factors need to be considered when the stroke-management strategies devised for a developed context are extrapolated to developing countries. These include; availability of resources, social beliefs, and cultural practices. Other authors acknowledge that implementation may be difficult and in some cases suggest that cultural resources, such as local healers, could be utilised in lieu of rehabilitation professionals (Donnan *et al* 1998, Poungvarin 1998,). However, to date studies on factors such as social and cultural practices and local resources, and how they interplay with the international recommendations are lacking.

1.2.3 The importance of lay understandings and experience

The deficiency in awareness of local models of stroke is unfortunate as there are strong indications that knowledge of what people experience, and how they understand and act during a period of illness is essential in the delivery of good health care. As will be discussed in the following chapter, evidence suggests that how people understand and interpret their condition affects their interaction with health services and potential for recovery (Good 1994, Kleinman 1988, Laderman 1991, Laderman 1992, Murray *et al.* 2000, Pugh 2003). Furthermore, influences such as economic capacity, age, family dynamics, cost and accessibility of resources amongst others, have been shown to impact on what help is selected, when and why (Jones & Williams 2004, Schroder-Butterfill 2002, Sepehri *et al.* 2008, Liefooghe *et al.* 1995). In the case of stroke however, the experience of those affected and the meaning they make of their altered status remains relatively unknown. Available research, both in high and low income countries, consistently highlights that differences in concepts of stroke, life goals, and expectations of behaviour exist between the client and medical personnel (Alaszewski *et al.* 2004, Al-oraibi 2002, Dixon *et al.* 2007, Townend *et al.* 2006). This is particularly apparent when different cultural understandings and expectations combine (Mold *et al.* 2003). This is evident in high income countries, but is even more so when biomedicine is adopted in areas

with a history of non-western cultural understandings. Some research also illustrates the additional complexity created by medical pluralism; the co-existence of multiple healers with different interpretations of health and illness (Alloh *et al.* 2007, Bham & Ross 2005, Hundt *et al.* 2004, Mshana *et al.* 2007). In such scenarios, multiple healers are sought and the reasons for selection are both complex and deeply embedded in the local context. The research is, however, limited and much more needs to be known if stroke care is to adequately consider and incorporate local meanings and context. This lack of information alongside the global burden of stroke highlights an urgent need for ethnographies of stroke.

1.3 Stroke in Indonesia

1.3.1 Incidence of stroke

Indonesia was selected for this study for a number of specific reasons. In-keeping with the anecdotal evidence I found in Aceh, the region is at very high risk of stroke. Indonesia does not yet have centrally held figures on stroke numbers and no national estimates were available from the Ministry of Health. Yastroki (2006), the Indonesian Stroke Association, suggest that 500,000 new strokes occur in Indonesia every year, in a population of approximately 225 million (World Bank 2007). However, Yastroki do not state their source of data, although members of the association have suggested that it is an extrapolation from figures from the USA and therefore may not be an accurate reflection of the number of people with stroke in Indonesia.

Although accurate incidence data are not known, there is evidence that Indonesians have a number of both modifiable and unmodifiable risk factors for stroke. It is a society in the midst of a dramatic demographic transition. It was estimated that the size of the population above age 60 would nearly quadruple between 1980 and 2025 (United Nations. 1985), a trajectory that is substantiated midway (SEARO 2008). Details on all of the modifiable risk factors are not known; however, cardiovascular disease is the leading cause of death in Indonesia (Ng *et al.* 2006) and 53.9% of men are estimated to smoke, a known risk factor (*ibid*). In a further study, Ng *et al* (2007) found that physicians rarely asked patients about their smoking habits and 80% of the physicians questioned believed that light smoking (up to 10 cigarettes per day) was

not detrimental to health, a scenario that would suggest that behaviour changes to certain risk factors is unlikely in the near future. Kisjanto *et al* (2005:21) state that Asian populations are "vulnerable to the consequences of an opulent lifestyle, in terms of obesity, diabetes and its correlates…therefore increase stroke risk". Indeed, a study by Tesfeye *et al* (2007) indicates that obesity is already a significant problem, particularly amongst women, although the possible reasons for this gender bias were not explored.

The combination of all of these factors indicate that stroke is already a significant issue in Indonesian health and disability concerns and will become increasingly so as socio-economic and ageing trends continue (Ng *et al.* 2006, Misbach & Ali 2000, Tan *et al.* 2006, Wong 1999). The result is a warning from Ng *et al* (2006) on behalf of the World Health Organisation (WHO) of an anticipated epidemic in non-communicable diseases. Cardio-vascular disease and stroke, as a corollary of this, are the prime concerns. Such predictions have led to an increased focus on stroke in the regional medical communities with a call from the 2006 Asia Pacific Stroke Workshop that "stroke research must occupy a prominent area in Asian neurology" (Tan *et al.* 2006).

1.3.2 Available literature

This call for research has only been partially met in Indonesia. In 2000 the first hospital based study of stroke was published (Misbach & Ali 2000). This study highlighted a range of interesting issues. These included a very high percentage of people with risk factors such as hypertension that were untreated prior to their stroke (33.5% of 2065), the short length of stay in hospital (mean 10.9 days), and the issues that delayed admission such as unawareness of having had a stroke and undergoing other, traditional treatment. These results raise a number of questions. These include the awareness in the community of both stroke and the associated risk factors, issues of preventative care, access to services within the hospital and on discharge, explanatory models of stroke, and traditional treatments. However, none of these issues were discussed in the paper and no follow-up studies have been identified. Other studies (Immanuel *et al.* 2006, Kisjanto *et al.* 2005, Mendis *et al.* 2005, Widiana *et al.* 1997) cover general epidemiological data and specific risk profiles

and indicate that recommended medical treatment of stroke is not rigorously carried out.

Research published in the national language of Bahasa Indonesian is also available[1]. All of these studies are hospital based and almost exclusively consider risk factors of stroke. One discusses depression post stroke (Arman & Samino 2005) and another the benefits of stroke unit care (Kurniawan *et al.* 2005), but none explore the experience of stroke in any domain. There is very also little qualitative research to provide explanations through which the reasons behind some of the findings can be developed.

Limited information was also available through gray literature, in the form of masters theses held in the library of the University of Indonesia. A number of these studies have considered more experiential components of stroke; including aspects of hope post-stroke (Sumampouw 2006), anxiety (Banowati 1989), the influence of family on physical rehabilitation (Minarti. 2006), and perception of quality of life following stroke (Rachmawati 2006). These also predominantly utilised quantitative methods, but indicated some interesting findings for consideration. For example, Sumampouw (2006) suggests that hope post-stroke is closely related to physical recovery and the desire to return to meaningful activity. Minarti (2006) found that the progress of the client's independence following stroke was significantly related to the family input on treatment. However, while relationships between recovery and social factors were found, these MSc theses do not discuss the reasons for the establishment or sustenance of these relationships. It should be noted that all of these papers were based on data in large cities and therefore not only is information lacking but it is disproportionately absent for the rural populations.

Given the high risk, it is further surprising that stroke is not reflected in health policy documents from the Government of Indonesia, or relevant regional policy makers. In the Strategic Plan for Health Development in the Province of Nanggroe Aceh

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[1] See Arman & Samino 2005, Kurniawan *et al.* 2005, Kusuma *et al.* 2005, Khosama *et al.* 2005, Ampil *et al.* 2005, Condrad *et al.* 2005, Hanif *et al.* 2008, Uganda *et al.* 2008, Wahyulati *et al.* 2005 for example

Darussalam 2006-2010 (Provincial Health Office 2006), which covers the region of Central Aceh, ten community health priorities were identified. None consider stroke or indeed any of its risk factors and related conditions. The Health Departments' wide ranging document to promote a healthy Indonesia by 2010, does acknowledge the increasing risk of cardiovascular and other non-communicable diseases and suggests a programme of awareness of risk factors, many of which are relevant to stroke. However, stroke itself is not explicitly mentioned in this programme with the focus remaining on maternal and child health, and infectious diseases (Ministry of Health 1999).

Beside the Government, Indonesia has two associations which focus on stroke, *Yastroki* and *Himpunan Peduli Stroke*. They aim to increase awareness of stroke, its risk factors and impact, in order to improve the health of people who are at risk, and the quality of life for those who have had a stroke (Yastroki. 2006). They also encourage research, but currently are not involved in any research programmes (*ibid*). At present they are only active in Java Island.

This brief overview illustrates that stroke is almost certainly a significant health (and social) problem in Indonesia, and one that is likely to increase. However, data on numbers is insufficient and research is predominantly limited to biomedical studies in urban hospitals. The emphasis on biomedicine alone is inadequate. As will be explored more fully in chapter 3, Indonesia has a complex pluralistic medical system in which non-biomedical approaches are frequently utilised, often in preference to biomedical services. Furthermore, anthropological research indicates that the Indonesian concept of health and illness differs in many key respects from that of biomedicine. Equally, the therapeutic services that are based in biomedical understandings are considerably underdeveloped in the country and as a result are often inaccessible, particularly in rural settings. As a result, Indonesia encompasses all the aspects that demand an urgent ethnography in stroke; high risk/ incidence with different cultural models of health and illness coexisting, the consequence of which has been not been researched to date. A need to study the experiential components of stroke and the context of their development, specifically in a rural environment, is evident.

1.4 Central Aceh

The site of this fieldwork was the region of Central Aceh, on the Island of Sumatra, Indonesia. It was chosen for a number of reasons. Primarily, it was a current area of activity of Handicap International (HI)[2]. HI had identified that stroke was of considerable concern in the region, accounting for 10% of the population of persons with disabilities in the area, making it the largest single diagnostic group. The activity of HI also included therapy for people with stroke. This allowed access to potential participants. The region also offered a combination of therapeutic options, from nationally provided governmental services to local traditional therapies, thereby offering a plural medical environment. Furthermore, it is a rural location and an understudied area of Indonesia. Much has been written about Aceh, specifically its political and religious history and there have been a number of detailed cultural and medical anthropological studies in other regions on Indonesia, specifically Java and Bali. However, other than the work of anthropologist John Bowen (Bowen 1989, 1991, 1993a,b,c, 1998), and geographical studies, no contemporary work available in the English language in the region of Central Aceh has been identified. As a result it is a region where there is a considerable gap in the body of knowledge on traditional medicine and health systems.

1.5 Thesis overview

This thesis begins to fill this gap with an in-depth analysis of the stroke experience in Central Aceh. Central to the analysis are the individuals with stroke and their carers. They are studied within the context in which they live, the multiple health system and health providers to which they have access, and the national and global health policy environment.

1.5.1 Aim

The aim of this research was to explore the subjective experience of stroke and subsequent health seeking behaviour in Central Aceh.

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[2] A summary of Handicap Internationals activities in Aceh is given in appendix 13.

1.5.2 Objectives

In order to achieve this aim, a number of objectives can be identified.

1. To explore the understanding and perception of stroke in rural Central Aceh.
2. To develop an explanatory model of lay stroke causation.
3. To describe the impact of stroke on the lives of those affected.
4. To investigate the available 'therapies' in the field area and their theoretical and social basis of practice.
5. To describe the health seeking behaviour of those affected by stroke.
6. To identify the mediating factors in the understandings of stroke and its recovery pathway.
7. To consider the findings of the research in the light of the international literature pertaining to stroke care and make recommendations applicable in an international context.

The purpose of this research is to contribute to an improved understanding of lay concepts of stroke and recovery and the contextual factors which influence that understanding. Such insight can assist in the customisation of rehabilitation and public health strategies for stroke in Indonesia. It can also offer alternatives to the Western dominated biomedical and social concepts of clinical diagnoses such as stroke and recovery.

1.5.3 A note on study design and thesis order

This research was based on a combination of approaches, predominantly ethnographic and phenomenological. This research examined both the meanings and actions related to stroke, and the context of Central Aceh. The specific methods chosen in this research, which are detailed in chapter 4, reflect the desire to examine both aspects. Yet, in-keeping with much qualitative research, the process was iterative. The methods used were influenced by the context, as much as they facilitated the context to be understood. In writing this thesis I have had to make a decision as to which would come first, context or method. Finally I have decided to place a review of the context of Indonesia and Central Aceh prior to a description of the methods used, referring the reader to the appropriate chapter as necessary. This may be unconventional, but I deemed it to be the most effective way to shape the

thesis, while maintaining the centrality of the understanding, experience of, and response to stroke from a lay perspective, which is at the heart of this work.

1.5.4 Thesis chapters

In **chapter 2** I review the literature pertaining to the topic as a background to the study. This chapter covers an examination of the understandings and experiential aspects of illness, alongside the health seeking behaviour. After an overview of the general literature, that relevant to stroke is explored. The need to understand experience in terms of perception, living with, and response to a specific condition is highlighted. Throughout this chapter the importance of the context in which experience evolves is highlighted.

Chapter 3 details the specific context of Central Aceh. The information in this chapter comes predominantly from information gathered in the field, although reference is made to literature when available. The chapter starts with a brief overview of the region of Central Aceh. It is followed by descriptions of general health and illness understandings, and the general health services available in the area.

Chapter 4 is devoted to the methodology. The chapter starts with an overview of the relevance of ethnography and phenomenology. Following this, I provide a detailed description and justification of the specific methods chosen to conduct this research. Issues such as participant recruitment, ethics and confidentiality, the collaboration with Handicap International and the implementation of the methods are detailed. This is followed by a description of the process of analysis undertaken. I conclude the chapter with a reflection on the subjectivity of ethnographic research which highlights important influences on the gathering and interpretation of the data.

The findings of the research and discussion are offered in the following three chapters. In **chapter 5** I present the stroke stories, exploring the narratives of the participants with stroke and their families. Their explanatory models and experience of living with stroke are described. In **chapter 6** the specific healers available for the treatment of stroke are reviewed and health seeking behaviour post stroke is presented. **Chapter 7** deals with these findings within context and introduces an

overriding theme of homeostasis. This homeostasis includes a drive to reach a state of equilibrium within the body, the family, and the supernatural. The narratives of the people with stroke, their family, and the healers, alongside the behaviour pattern of health seeking are drawn together to demonstrate that the desire for homeostasis, in the reality of the current context, results in a dialectic of loss and hope.

In **chapter 8** I discuss the relevance of the findings to a wider international policy context and conclude the thesis. I raise the potential difficulties that emerge when local understandings interplay with international recommendations and suggest dangers of implementation without detailed knowledge and inclusion of the former. I also consider international drives to use 'local resources' in light of the findings. The chapter ends with a summary of specific contributions and recommendations that arise from this research.

The appendices provide further details of the documents related to the research process and Handicap International. A glossary of local terms and abbreviations is also provided. A shortened glossary of the most commonly used terms in this thesis is additionally provided on the bookmark, for ease of reference for the reader.

Chapter 2

Literature Review: The subjective experience of illness and stroke

2.0 Introduction

In this chapter I review the literature on the subjective experience of illness and stroke. Section one explores the 'subjective illness experience'. It starts with an exploration of why the subjective experience is important and includes examples from both stroke and other illnesses. This leads to an examination of explanatory models as a framework for understanding illness. Section two presents experiential literature on stroke in which three aspects will be considered; perception of, experience of, and response to stroke.

I will argue that an understanding of the subjective experience is essential for effective health-care. Furthermore, understandings must evolve from an awareness of personal, social and cultural factors. These should be placed within the context of time and place and the specific bodily experience of an illness.

2.1 Subjective experience and meaning of illness

> "The humane practice of medicine, if it is to help people in their experience of illness, must acknowledge the uniqueness of the individual as subject and try to respond, rather than refusing to engage with any claims that cannot be supported by findings from a probalistic sample…we need to know how people understand their situations, not just how we fix the pathology" (Rapport *et al.* 2005).

The study of illness as a subjective phenomenon has a long and varied history, in both academic and clinical fields. From ancient texts, to modern policies, fields of anthropology and biomedicine, evidence of the importance of the person in illness, at least in part, is noted (Carmichael & Ratzan 1991, Manson 2005). It has been argued that the rise of biomedicine (also variously termed as Western, modern, allopathic or biological medicine) saw a decline in the emphasis given to subjective experience

(Helman 2006). Foucault (1973) suggests that much of this distancing from the patients discourse was a result of the development of the 'medical gaze'. Indeed some authors assert that the basis of biomedicine disavowed the influence of subjectivity, instead focussing firmly on the biological facts underlying the conditions of health and ill-health (Goldenberg 2006, Kleinman 1980). In recent decades, such an objective position has been consistently challenged, with a resultant re-emergence, if not yet total acceptance, of the centrality of subjective experience. Evidence of this shift is seen in the UK's National Stroke Strategy (Department of Health 2007:21) which states that "people who have had a stroke and their carers are meaningfully involved in the planning, development, delivery and monitoring of services".

2.1.1 The need to consider the subjective experience

The need to consider the experience of illness outside of biomedical parameters is driven by a number of significant concerns. One is the observation that the promotion of biomedical approaches alone do not necessarily result in improved health condition. This has been illustrated in the case of infectious, chronic diseases, and preventative public health drives. For example, increasing access to health resources does not necessarily result in either increased utilisation of the service or improved outcome (Liefooghe *et al.* 1995, Preez *et al.* 2009). Likewise, targeted health education does not automatically equate to a decrease in incidence or a change in health seeking behaviour (Baker & Murdoch 2008, Esse *et al.* 2008, Michell & Amos 1997). As a result, health reforms, awareness campaigns, prevention and intervention drives, may not have the impact expected (Baker & Murdoch 2008, Preez *et al.* 2009).

A further concern is the evidence of disparities in disease frequency, outcome and health systems utilisation for which biological explanations are insufficient. Numerous examples can be cited to support this position across different disease categories and countries. Stroke is no exception. For example, the National Centre for Chronic Disease Prevention and Health Promotion (2000) in the United States reports that deaths associated with stroke show inequity in their racial/ethnic distribution. Bourke *et al* (2006) demonstrate that recommended tests for risk factors such as high cholesterol, and medication given post-stroke are related to ethnic

background of patients rather than clinical needs alone. Ottenbacher *et al* (2008) illustrate racial and ethnic disparities in post acute care outcomes in stroke. Other influencing factors include socioeconomic status, age, and gender, which have all been related to discrepancies in access to care, treatment and outcome (Arrich *et al.* 2005, Arrich *et al.* 2008, Kaufman 1988, Putman *et al.* 2007, Wolfe *et al.* 2007). In a review of the literature pertaining to inequalities in the provision of stroke care, McKevitt *et al* (2005) conclude that inequalities do still exist. However, they raise the issue that the patterns of these inequalities are not clear and strongly suggest that more needs to be known about the decision making process of both clinicians and those affected by stroke in order to disentangle the reasons for this imbalance.

McKevitt *et al's* (*ibid*) call for a deeper understanding of the decision making process acknowledges that the subjective experience lies at the heart of health care. Pathological conditions do not exist in a vacuum, but are lived, interpreted and experienced by people who exist in a particular time and place. Kleinman (1980) suggests that to consider health and illness outside this context is to risk seriously distorting social reality. Such an approach prevents the implementation of optimum care for the very people in need. As a result, the need to consider the 'construction' of illness and health seeking and the factors that influence that process are emphasised (Helman 1994, Kleinman 1980, Radley 1993). Kleinman (1980) argues that such an approach develops an understanding of the local health care system in which all health-related components of society are examined. This may include patterns of causation beliefs, the processes by which treatments are chosen and evaluated, and the health services available. But also involves an understanding of social status and roles, power relationships and the interaction between individuals engaged in the health seeking process, amongst other social and cultural influences.

Research has demonstrated many types of influence that can impact on these concepts of health, illness and subsequent health related behaviour. One significant factor is the understanding of how the body is constructed. Anthropologists have illustrated that cultures have different conceptions of how the body works and what may affect its functioning. For example, concepts of the body which involve humoral theory, such as Ayurvedic and Unnani-Tibb or Islamic medicine, emphasise health as a balance of different substances. These can be affected by injury, food intake, mood,

spirits, weather, proximity to other people, leading to a state of health or ill-health (Good 1994, Laderman 1991, Laderman 1992, Pugh 2003, Wujastyk 2003). Such an approach is distinctly different from the biological processes of western medicine, in which cells, organs and functional systems in the body form the basis of understanding (Foucault 1973, Helman 1994). These ways of understanding health and illness however, are themselves embedded in particular historical and cultural environments. As a result, the way they are interpreted and the influence they have on the experience of the body are constantly shifting. Helman (1994) and others illustrate this in western societies by exploring how broader technological changes are reflected in lay descriptions of the body. Hence the metaphor of the body as a plumbing system was overlaid by the mechanistic body, the computerised body and more recently the cyborg (Haraway 1991, Lupton 2003).

These concepts have an impact on the subjective experience of illness as they have a bearing on how problems are communicated, what is communicated and ultimately what is labelled as illness (Leatherman 1992). They also direct knowledge in what is curable, what is not, and the potential paths for treatment through the development of causation theories (Kleinman 1988, Murray *et al.* 2000, Murray 2004). However, although broad conceptual frameworks may direct health and illness knowledge, they may also be challenged by a number of other factors. For example, at the level of the individual, previous experience of illness, reaction to specific interventions, and the bodily experience of symptoms can all change or reinforce previously held ideas (Hare 1993, Hyden 1997). Equally, while the prevailing medical system undoubtedly directs the communication of illness, it is not the only active influence. Wider social and cultural patterns also affect the dynamics of communicating illness. There is compelling evidence to suggest that methods of communication, both verbal and non-verbal have a significant impact on illness encounters. Social status, class, education, language use and dress have all been implicated (Helman 1994, Kleinman 1980, Zola 1973). These can affect what is said, in what way, what information is heard and ultimately what treatment regimes are negotiated (*ibid*). Furthermore, gender, position in the family, or perceived importance to household income can dictate who can request assistance, how they do so, what assistance they can request and when (Jones & Williams 2004, Liefooghe *et al.* 1995, Schroder-Butterfill 2002). Situational factors, such as the number of sick people in a household at any one time

have also been shown to be relevant (Sepehri *et al.* 2008)). The impact that the illness has on an individual's ability to function in the socially desired manner is also important. This may be influenced again by gender, the labelling of young and old, able and disabled, useful or useless, for example. Rather than being *a priori* categories, research has consistently indicated that these are socially defined concepts (Allotey *et al.* 2003, Reidpath *et al*. 2005, Strauss 1997).

These observations suggest that although frameworks of health and illness may exist, they are shaped by the specific and current environment. Such specificity does not negate the influence of either the broader health frameworks or macro considerations. Infrastructure of health services and physical access, and individual or family level economic capacity for treatment are still important. It does, however, illustrate the complex, dynamic and interwoven manner in which individual, social, cultural, and environmental factors, amongst others, influence the construction of health and illness and subsequent behaviour. Kleinman (1980) contends that an appropriate way to conceptualise these complex understandings of health and illness is through the development of explanatory models. He summarises these as "the notion about an episode of sickness and its treatment that are employed by all those engaged in the clinical process" and continues, they "are embedded in larger cognitive systems, which in turn are anchored in particular cultural and social structural arrangements" (*ibid*:105). As a result they emphasise the dynamic inter-relationship between bodily experience, action and the context in which they occur. Kleinman (*ibid*) further suggests that the influence of each factor is in part mediated by the specific illness in question. Therefore it is relevant to consider what is currently known about the experience of stroke.

2.2 Experience of stroke

The literature pertaining specifically to the experience of stroke is limited (Mold *et al.* 2003) and as was demonstrated in chapter 1, is essentially absent in Indonesia. As a result, the following review will include research that explores stroke in a variety of international settings. This section is split into three parts; the perception of stroke, the experience of living with stroke, and the personal response to stroke. Within the perception of stroke, available literature on clinical knowledge and explanatory

models will be considered. The experience of living with stroke will include a review of both the individual and the social unit. For the individual, models of 'disruption' and 'trajectory' will be explored. The concept of reciprocity will be examined in the discussion of the social unit. The final section, response to stroke, examines the help sought by the person with stroke and the interaction between those seeking and giving help.

2.2.1 Perception of stroke

The lay understanding of stroke as a condition has been studied in two contrasting ways: clinical awareness and explanatory models. The following review will demonstrate the limitations of assessing clinical knowledge alone. The factors which have been identified in the literature as influencing the construction of stroke understandings will also be presented.

2.2.1.i Clinical knowledge of stroke

Assessments of clinical awareness of stroke are the most frequently seen in the literature (see for example Evci *et al.* 2007, Ferris *et al.* 2005, Greenlund *et al*. 2003, Koenig *et al.* 2007, Muller-Nordhorn *et al.* 2006, Pandian *et al*. 2005, Schneider *et al.* 2003, Sullivan *et al.* 2006, Yoon *et al.* 2001). Tools such as the Stroke Knowledge Test (SKT) have been developed for this purpose (Sullivan & Waugh 2007). This test and other questionnaires used are based on a biomedical understanding of stroke as presented in the introductory chapter. This understanding of stroke, as an acute event, precipitated by a combination of risk factors, leading to brain damage and frequently long term disability through weakness, speech and other problems are the main 'facts' which are assessed through knowledge test procedures. The stated aim of most of these studies is to assess the need for educational approaches, seen to be key to more effective and timely treatment seeking. Indeed, Schwam *et al* (2005:693) state that "improving the patient's knowledge of the risk factors, signs and symptoms of stroke is critical to improving the quality of stroke care". These knowledge based studies have been carried out in numerous countries and with various groups of people; general community (Evci *et al* 2007, Greenlund *et al* 2003, Muller-Norden *et al* 2006, Pandian *et al* 2005, Schneider *et al* 2003, Yoon *et al* 2001), 'at risk' individuals and people who have had a stroke (Sullivan *et al.* 2006, Weltermann *et al*. 2000), in Europe (Muller-Nordhorn *et al*. 2006), America

(Ferris *et al.* 2005, Schneider *et al.* 2003), Australia (Sullivan *et al* 2006, Yoon *et al* 2001) and India (Pandian *et al* 2005) for example. These studies generally indicate that biomedical knowledge is lacking, but few explore what other understandings are held and why. For example, a study of public awareness in India found that while some warning signs and risk factors were known, 45% of the subjects did not relate the brain to stroke. However, which organ(s) and processes were ascribed were not highlighted (Pandian *et al* 2005). A similar study in Turkey utilised open-ended questions which theoretically gave space for alternative explanations. However, they only presented those deemed 'correct' within a biomedical frame (Evci *et al* 2007).

Simply measuring what people know against ascribed 'facts' is insufficient to understand lay perceptions of stroke. Even within the narrow frame of identifying educational needs, such an approach has been noted as being inadequate for its purpose. Sullivan *et al* (2006:1340) state of the SKT, " a more comprehensive assessment of the quality of stroke knowledge, including possible misconceptions about stroke, would represent a significant advance in developing educational approaches for individuals and the general public". These authors remain within the biomedical paradigm, suggesting the need to search for misconceptions rather than alternative conceptions, but the desire and need for more comprehensive understandings and quality of knowledge is unambiguous.

2.2.1.ii Explanatory models of stroke

The development of explanatory models of stroke may fulfil this need for comprehensive understanding. This, however, is difficult to assess as there is a dearth of literature on explanatory models in stroke. In total only six studies specifically focussing on lay understandings of stroke were identified, with incidental references to lay beliefs suggested in a number of others. It is interesting that despite the vast majority of stroke research being based in Western countries, five of the six papers were focussed on non-Western countries. The findings of these six papers will be reviewed below.

In Agincourt, South Africa, Hundt *et al* (2004) found that stroke-like symptoms were understood within local ways of viewing health and disease. As a result symptoms such as one sided body weakness (hemiplegia) and numbness were seen as both

natural and social. The former resulted from problems in blood flow, the latter as a consequence of jealousy and hatred. Social disequilibrium resulted in animosity between community members and it was asserted that those dissatisfied set out to create the catastrophe that stroke inflicted on both the affected individual and household. This resulted in different labelling of the 'illness' itself, calling into question the appropriateness of the term stroke within communities where biomedicine is not the only or predominant paradigm.

In Islamic communities, beliefs around causation have been noted as being influenced by religious concerns. This is concomitant with the understanding that Islamic Law influences and guides every aspect of a Muslim person's life. The belief that Allah alone "is the Agent and He alone is the Cause" (Eaton 1994:67) has been demonstrated as being relevant in stroke in the Middle East (Al-oraibi 2002) and in Muslim communities in South Africa (Bham & Ross 2005). The result is that illness is seen not as a punishment, but as a test. Bham and Ross (2005) also describe other less frequently cited causative factors. These included biomedical explanations such as high blood pressure and non-biomedical reasons such as flu and over-exertion.

Mshana *et al* (2007) in Tanzania found evidence of both biomedical understandings, such as hypertension and fatty foods and traditional beliefs such as possession by demons, witchcraft and God's will as ascribed causes of stroke. Some of these were adapted to local Islamic interpretations. This study explores some of the factors that influence these beliefs, including locality and access and familiarity with biomedical services, as well as the experience with healers themselves, which resulted in adjustment of individual's explanatory models of stroke.

In the Ivory Coast, the Tchaman people predominantly believed that their stroke was a result of a curse, which was generally referred to as a malicious attempt by another to cause harm through the practice of black magic. Hemiplegia, the most significant sign of stroke, was also attributed to a divine punishment as a result of breaking sexual taboos. Acquired and hereditary factors were also found to be relevant, but further details were not given (Alloh *et al*. 2007).

Closer to the western base of biomedicine, similar discrepancies to the official biomedical pathways arise. In a study based in Scotland on beliefs about preventing recurrent strokes, many participants reported "idiosyncratic beliefs or fatalistic ideas about strokes" such as overdoing it, having a hard life or a depressing experience (Townend *et al* 2006:747). Such beliefs have been demonstrated in other western based studies (Bendz 2000, Pound *et al*. 1998, Runions & Arnaert 2006, Treulsen *et al*. 2002).

These studies had broader aims than the knowledge test, linking beliefs and understandings to the subsequent health behaviours. Further results relating to health seeking behaviour will be discussed in subsequent sections.

The reviewed literature thus far, although limited, indicates the necessity of developing deeper understandings of lay perceptions of stroke than is possible within the constrained clinical knowledge frame. It further illustrates that cultural influences may have an important impact on perception and therefore highlights the need to situate understandings in the local context.

2.2.2 Experience of stroke

The literature on stroke experience has increased substantially in recent years, although this is almost exclusively in Western countries. While it has been cautioned that "because of pre and post injury individual differences, stroke survivors will experience a unique configuration of changes in their identity and in related personal processes" (Mukherjee 2006:30), a number of common scenarios have been proposed. These are presented within two broad frameworks; disruption, and trajectory, and both will be explored. In addition, Kleinman (1988) notes that the illness experience involves not just the individual affected, but also the social unit. As a consequence, the literature pertaining to both will be reviewed.

2.2.2.i Individual

The individual experience of stroke has been presented in the literature in two distinct ways; the disruptive impact of the stroke itself, and a trajectory of the stroke experience over time. The most described and explored experience is that of a disrupted world created by the serious and sudden loss of the known self. A

theoretical point is made by Strauss (1997), which may partly explain why stroke is perceived as being such a disruptive event. He argues that the particular physical losses precipitated by stroke; language, hand dexterity and bipedal gait for example, challenge the very concept of what it is to be human. More broadly, testimonies from people with stroke suggest that the loss of self is precipitated by the multiple losses of: physical capacity, role, sense of self, identity, for example, which have been described in many contexts following stroke (Alaszewski *et al.* 2004, Kaufman 1988, Becker 1997, Ch'ng *et al.* 2008, Dowswell *et al.* 2000, Eaves 2006, Eaves 2000, Ellis-Hill *et al.* 2000, Faircloth *et al.* 2004, Glass & Maddox 1996, Haggstrom 1994, Hjelmblink & Holmstrom 2006, Murray & Harrison 2004, Wiles *et al.* 2004). Evidently, stroke not only results in the neurological impairment described biomedically, but also the functional, personal and social consequences of that altered state. This has been most commonly equated with Bury's (1982) concept of biographical disruption. Indeed, the extent of that loss is such that people with stroke and their carers have equated it to death, "stroke, like death, represents a catastrophic loss" (Dreslin 2008:16). The concept of biographical disruption is briefly reviewed next.

2.2.2.i a Disruption

Biographical disruption as a concept was developed following the exploration of the experience of people with Rheumatoid Arthritis. It refers to a situation where the normal rules and assumptions of life are disrupted by an illness. It results in a rethinking of how the individual conceptualises themselves, a challenge to previously held concepts of self (Bury 1982). Kaufman (1988) later translated this to signify an 'existential transformation' a result of what Scheper-Hughes and Lock (1987:29) describe as the capacity of illness "to deconstruct the world of the patient".

While found to be relevant in a number of chronic conditions, research has found that there are a number of mediators to the level of disruption. Factors such as age (Lawton 2003, Williams 2000), awareness of condition (Williams 2000), gender roles (Bendelow 1993), cultural understandings of the ideal body (Estroff 1991, Lock 1993, Tighe 2001), historical and socio-economic context (d'Houtaud & Field 1984), religion (Williams 1984) and previous experience of chronic illness (Williams 2000) have all been found to be significant. These factors may indeed result in biographical

reinforcement (Carricaburu & Pierret 2003), agitation or flow (Ferzacca 2001) rather than disruption. A number of these mediators have also been found to be relevant in stroke.

Pound *et al* (1998), for example, indicate that age and the stage in the life-course that a stroke occurs affects its interpretations, with some of their informants suggesting that 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 a chronic illness narrative, due to the long history of pre-morbid problems with which his informants presented. Such a history familiarises them with altered bodies, and as a result stroke is merely part of their biographical flow. In a similar vein, and a point noted by Faircloth *et al* (*ibid*), Pound *et al* (1998) added that peoples' knowledge of the condition and familiarity with the symptoms and sequelae had an impact on their interpretation.

McKevitt *et al* (2003), in a paper based in post soviet Latvia, illustrated how the historical and socio-political context had a determining impact on people's experience of physical and social deficits following stroke. They describe 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. They also highlighted the altered expectations on service provision, which may equally have had an indirect impact on experience.

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. As McKevitt *et al* (2003:2107) summarise "understanding the role of the skilled cultural and habitual body is central to understanding the experience of stroke".

A further note of caution regarding the concept of disruption is noted by Kirkevold (2002). Her study, which is unusual as it employed a prospective and longitudinal approach (rather than the retrospective approach employed in most other studies),

found that "stroke is not necessarily experienced as an abrupt psychosocial crisis by the stroke patient" (ibid:887). She found that biographical issues, both experiencing a disruption and the adjustments that follow this understanding, occur gradually and over a prolonged period of time. Kirkevold (*ibid*) argues that disruption, therefore, is potentially a framework created by retrospective analysis of the situation which is emphasised by the methods commonly chosen for investigation. It is possible that other methodological differences may account for the lack of sudden disruption in this study. For example, Kirkevold (*ibid*) notes that her participants had only mild or moderate disabilities as calculated by the Barthel score (this is a commonly used measure of disability based on the completion of Activities of Daily Living). However, it is impossible to compare this with most of the other studies cited, as they either give no information on the disability level of their participants or use other measures such as Rankin or the Rivermead scales which are not directly comparable with Barthel.

2.2.2.i.b Trajectory

In contrast to a focus purely on impact, some literature considers how the experience of stroke evolves over time; its trajectory. The concept of illness trajectory was first proposed by Glaser and Strauss (1968) following their study of people with cancer. Garro (1988) argues that a strength of the trajectory concept lies in its ability to link the individual response to social and cultural influences. Evidence of this appears through the shifting of trajectories as a result of information, power, experience of therapy, religious beliefs and perception of risk (Becker 1997, Bendelow 1993, Faircloth *et al*. 2004, Hare 1993, Kaufman 1988, Murray *et al*. 2000). In the case of stroke, Kirkevold (2002) presents a trajectory which encompasses four distinct, but overlapping phases: trajectory onset, initial rehabilitation, continued rehabilitation and a semi-stable phase. Each phase is linked with personal physical, emotional, and psychological processes. These are: surprise and suspense, hard physical work, focus on psychological and practical adjustment, and going on with life, respectively. The fact that phases have been explicitly linked with rehabilitation is important and a point that will be discussed further in the section on response to stroke.

Other research, some of which pre-dates Kirkevold's (*ibid*) study, lends some strength to her interpretation. Holbrook (1984) for example, discusses the phases of

stroke in line with a bereavement model; crises and shock, treatment and denial, realisation, and adjustment. A similar process is described by Strauss (1997), Buschershot (1998) and Cott (2007). Other studies equally describe the processes of intensive physical recovery work followed by a need of biographical or narrative re-establishment (Dowswell *et al.* 2000, Hilton 2002, Jones *et al.* 2008, Remer-Osborn 1998). Common to all of these studies is a presentation that the individual experience of stroke should and/or does finally result in adjustment and acceptance of the altered personal and social state.

However, in line with Yoshida's (1993) study on Spinal Cord Injury, other literature indicates that this is not always a linear process. It has been illustrated that individuals may move between concepts of their current condition and ideas of previous normality, indicating an apparent difficulty/ reluctance to move towards acceptance of their changed condition (Ch'ng *et al.* 2008, Dowswell *et al.* 2000, Jones *et al.* 2008). Indeed alternative trajectories, such as recovery, rather than adaptation, are often adopted (Hafsteinsdottir & Grypdonk 1997). There may be many reasons for this, including the fact that some people do make a full recovery post stroke and most regain some of their lost functions in the early stages (Remer-Osborn 1998). It has further been suggested that the process of rehabilitation itself may encourage a belief in recovery, a point discussed later in this chapter.

2.2.2.ii Social unit
Like other illnesses, there is an understanding that stroke not only affects the individual but their family as well (Anderson 1992, Draper & Brocklehurst 2007, Hunt & Smith 2004, Low *et al.* 1999, Smith *et al.* 2004). Indeed Remer-Osborn (1998:51) states boldly "no matter the age of the patient, prior medical history, stage of life, or economic circumstances, a stroke is devastating to family members". While such an assertion is difficult to uphold in all circumstances (see Pound *et al* 1998 for a discussion on stroke as biographical flow for example), the acknowledgement of the impact beyond individual is clear.

There are various ways in which stroke has influence beyond the individual. For example, direct impacts of the stroke on the individual may challenge long established patterns of behaviour within the family unit. Physical needs result in

previous carers now become those who are cared for (Hunt & Smith 2004, Cox *et al*. 1998). Personality changes following stroke, communication, and cognitive problems (Cox 1998), and changes in sexual ability and needs (Hunt and Smith 2004) may strain familial relationships. Furthermore, decision making responsibilities regarding care options may be transferred (Eaves 2006). And Clark (1999) notes that the resources of the family, including financial, can be severely strained by the disabling consequences of stroke which can negatively affect the functioning of the family unit.

Such concerns have led to calls for a family-focused approach to stroke care (Anderson 1992, Brashler 2006). In this paradigm a balance is sought between capacity and demands, where the interests and well-being of the family are considered alongside those of the individual. Much of the literature considering the family focuses on the type and degree of burden that is placed on the carer and potential interventions, such as information and training, which may limit that strain (Bugge *et al*. 1999, Draper & Brocklehurst 2007, Scholle op Reimer *et al*. 1998, Smith *et al*. 2004, Wallengren *et al*. 2008). However, although some of the literature acknowledges that carers may continue to live their life normally, in effect usurping their assumed caring responsibilities (Wallengren *et al*. 2008), very little discusses the mechanisms through which the decision to become a carer is made, sustained or changed. Indeed, Draper and Brocklehurst (2007), suggest that carers are effectively not given a choice about whether to care or not. Eaves' (2006) paper exploring caregiving in rural African American families post-stroke is an exception. Through an examination of the individual and their family's narratives, Eaves (*ibid*) explores the process of care decision making. She concludes that a balance between the individual with stroke and their carers is struck through the concept of reciprocity. This predominantly involved a sense of indebtedness on behalf of the carers, a way of giving back for previous care they had received. However, present pressures can also result in that balance shifting, such that the decision to care is revoked. This presentation has a marked similarity to concepts of reciprocal exchange and a brief overview of that concept is warranted.

2.2.2.ii.a Reciprocity

Reciprocal exchange is a term initially coined by Trivers (1971) and has been associated with coping with misfortune such as ill-health, in many societies (Fehr *et al*. 2002, Gurven 2006, Hill 2002, Nowak & Sigmund 1998, Winterhalder 1986). Reciprocal exchange in this context is seen as the giving and receiving of assistance in its multiple forms. This assistance is most commonly seen through kinship or community and friendship ties. While reciprocity is based on past behaviour, the future potential of an individual to continue exchanging is key to stability of the current exchange and implementation (Gurven 2006). Those with a perceived poor ability to return to activities within an exchange process are less valued as potential exchangers than those with a perceived positive prognosis. This may result in either active or inactive deliverance of the needs required by the ill individual, which can be seen as part of the history and projected future of reciprocal exchange. This idea of potential exchange capacity has been linked with wider concepts of social value and inclusion (Reidpath *et al*. 2005). It has further been illustrated that in long term disability the context and physical infrastructure impacts on the ability to participate, exchange and thereby be a valued member of a social group (Allotey & Reidpath 2007). These influencing factors are not static. Changes in the individuals' condition, understandings of the illness, family economics and other resources for example can all result in an altered balance (Eaves 2006).

Trivers (1971) further notes the importance of communication within the exchange process. He adds that knowledge of behaviour is linked to reputation and emotions such as guilt and gratitude and argues that these are central to the workings of reciprocal exchange particularly in more complex societies. There is also a moral dimension of both coping and reciprocal exchange. This moral dimension is embedded in the local culture. Indeed, there is considerable evidence that cultural and religious expectations have an impact on how and where care is given and by whom (Ahmed & Jones 2008, Eaves 2006, Ismail *et al*. 2005, Jones & Williams 2004, Lewis *et al.* 1995).

Within the limited stroke literature, there has been insufficient exploration of the processes of reciprocity to examine the specific mechanisms involved. For example, in Eaves' (2006) study, the decision to give care was presented as being based purely

on past giving. The decision to relinquish care was based on present pressures. There was however, no discussion as to what the family or individual expected in future in terms of care. Furthermore, how the concepts of stroke and the experience of the trajectory to date influenced these decisions was not explored. There is a need for further examination of the complex interaction between individual and their social unit in the case of stroke.

2.2.3 Response to stroke

The response to stroke is the third part of the subjective experience that will be discussed. Two main aspects will be considered in the following review; what help if any is sought following stroke, and how the interaction between those seeking and giving help can influence the stroke experience. Through this it will be illustrated that the understanding of stroke, its impact and expected trajectory are dynamically related with the choice of and interaction with the healer.

2.2.3.i Help sought following stroke

The exploration of health seeking patterns is limited in western based studies. This is partly due to the formalisation of health care provision. For example, in the UK it has been estimated that 80% of all people with stroke are admitted to hospital (Burton 2000). This percentage is likely to be an underestimate as there has been increasing acceptance of the emergency nature of stroke and as a result fewer are being treated in the community at the initial stages. However, more up to date figures were not found. Once in hospital, while an individual has a right to refuse care, or request specific services, care generally follows the recommendations outlined in chapter 1. As a result, once the medical intervention has been initiated, the specific health seeking choices of an individual are framed within those of the institutional boundaries of the National Health Service provision. There is evidence that people with stroke in western countries do seek care outside of the biomedical/government system. For example, Shah *et al* (2008) found that 46 % of stroke survivors used the services of complementary and alternative medicine in the United States. However, this study lacked temporal specificity with no indication if the alternative medicine had been used before or after the onset of stroke. As a result the pattern of use post-stroke and its effect on health seeking behaviour was unavailable.

In countries where pluralistic health systems and individual choice are more prominent, the literature is more revealing. Hundt *et al's* (2004) study in South Africa, illustrated how different understandings of stroke resulted in a variety of health seeking behaviours or 'double treatment'. This was supported by the multiplicity of healers available, the understandings of their healing processes and social expectations. Through this behaviour physical, mental, and social well-being were addressed. Interestingly, the authors note that when treatments were ineffective, faith in the treatment type was not challenged. Rather the specific healer was accused of 'playing' with the client, the latter responding by seeking an alternative healer. The authors remark on the tenacity of individuals to seek treatment, despite economic, physical and social barriers, but unfortunately do not expand on the reasons why they do so.

In the South African Muslim community studied by Bham and Ross (2005) biomedical doctors, therapists and traditional healers were all sought, alongside self treatment at home. These different healers were often consulted concurrently in an attempt to find the most effective care and improvement in symptoms and quality of life. Cost, alignment with local culture, and religious beliefs were cited as some of the reasons why specific healers were sought. Similarly, Mshana *et al* (2007) in Tanzania illustrate the complex but important interaction between beliefs and treatment choices and comment "beliefs in stroke causation are central to the ways in which people respond to the condition and seek treatment" (*ibid*:49). However, their work hints at other motivators, such as "a future with hope, rather than dread" (*ibid*:49), indicating that causation beliefs are not the only factors which influence stroke response. Indeed, they comment that a deep desire for recovery inspires people to seek any treatment possible in the hope that one will be effective in resulting in cure. Unfortunately, they do not expand their discussion to consider why the need for cure is such a strong driving force. They further suggest that understanding and considering these factors is essential to effective policy development and implementation.

Alloh *et al* (2007) describe how the Tchaman people in the Ivory Coast also seek help from multiple healers following stroke. In their sample, 68% looked to both modern medicine and traditional practitioners for treatment, although diagnosis was

almost exclusively sought within the hospital environment. The authors discuss the availability of transport which assists in the physical access to the hospital, but also comment that the longer term costs of treatment are a strong drive to seek cheaper traditional therapies. Although they present explanatory understandings of the healers and those affected by stroke, they do not examine how these influenced the health seeking behaviour.

In East Asian countries such as China and Hong Kong, stroke research has gained some momentum. The majority is based within a quantitative biomedical frame. However, some literature indicating cultural influences relevant to health seeking is emerging. For example there is evidence that alongside biomedical treatments, Traditional Chinese Medicine (TCM) and specifically acupuncture have been used (Kwok *et al.* 2006, Lui *et al.* 2007). However, the reasons why are they are sought are not discussed.

In a study based in Jordan, Al-oraibi (2002) highlights the influence of religion (Islam) in all aspects of stroke. This includes causation theories, as mentioned previously, but also guidelines as to how the individual and family should respond to the illness. The view that stroke is a 'test' from Allah and that children have a responsibility to care for their parents, are demonstrated as key concerns to a Muslim. The author also introduces the Islamic rule that "for each illness Allah has provided a remedy so long as the remedy does not conflict with Islamic regulation" (*ibid*:66). He links this with the health seeking behaviour within the pluralistic services available in the country, alongside other considerations such as cost and general accessibility. Unfortunately, Al-oraibi's (*ibid*) concern is focussed on how these 'other' services interfere with the 'appropriate' therapy. As a result he presents only the negative consequences of their availability, without exploring their potential positive impact on the individual/ social unit or indeed a detailed description of the participants' reasons for healer selection.

The studies cited on the previous pages, illustrate the effect understandings and impacts of stroke have on the choice of help sought. They also indicate the influence of culture and religion, for example, on that process. However, these studies do not explore how understandings, impact and culture may shape the interaction within the

healing encounter itself, and how these in turn have a bearing on the response to stroke. To explore this, it is necessary to return to the western based literature.

2.2.3.ii Interaction between those giving and seeking help

In chapter 1, the biomedical understanding that stroke rehabilitation involves both the initial medical and therapeutic processes of stabilisation and remediation, and the later stages of adaptation to a disabled state was introduced. This movement from a focus on recovery to that of acceptance bears considerable similarities to the experience presented in Kirkevold's (2002) trajectory discussed earlier in this chapter. However, the apparent congruence between the professional and lay expectations belies a number of differences. These can result in a complex dynamic between therapist and patient which directly influences behaviour. The evidence of this complex interaction is explored next.

As mentioned previously, many people post stroke do not focus on adaption but rather consistently articulate their desire to return to previous levels of activity, i.e. their 'normality' (Alaszewski *et al.* 2004, Becker & Kaufman 1995, Bendz 2000, Dowswell *et al*. 2000, Hafsteinsdottir & Grypdonk 1997, Jones *et al.* 2008, Kaufman 1988, Mckevitt & Wolfe 2001, Wiles *et al.* 2002). Indeed, Dixon *et al* (2007) suggest that the active nature of rehabilitation itself may contribute to a belief in complete recovery. But within the therapeutic encounter, this goal of normality is a double edged sword. On one hand, the literature indicates that the hope for recovery is a strong driver in seeking and participating in treatment (Clarke 2003, Kaufman 1988, Lobeck *et al.* 2005, Samsa & Matchar 2004, Wiles *et al*. 2004,). Such a focus is believed to maintain patients' motivation, which is seen as key to recovery and effective participation in rehabilitation (Becker & Kaufman 1995, Kaufman 1988, Kaufman & Becker 1986, Maclean *et al.* 2000, Pound & Ebrahim 1997). Its importance is such that it is cited as being fundamental criterion for access to services, such as further rehabilitation (Mold *et al.* 2003). On the other hand, a continued focus on recovery when the therapist believes goals should move into the realm of adaptation, can result in the patient being labelled as 'stuck' (Alaszewski *et al.* 2004, Dixon *et al.* 2007). Evidently the patient is not following the 'appropriate' recovery pathway and these different perspectives and aims can result in negative judgements, which may lead to certain therapeutic options being closed (Hammell

2004). Furthermore, the realisation and articulation of these differences can result in hope becoming hopelessness, which can result in a negative change in engagement and response to therapy (Becker & Kaufman 1995, Kaufman 1988, Kaufman & Becker 1986, Wiles *et al.* 2004,).

As a response to some of these issues, Jones (2007:515) has suggested that "if therapists adjusted their treatment planning to accommodate each individual's perception of their recovery, as well as the personal goals that they value then individuals would be more motivated and more likely to perceive their recovery as successful". While this may be true, such a statement does not adequately confront the issue of potentially unrealistic goals which may be held and the ethical consequences that therapists would have to accept if they were to support ends that they professionally believed could not be achieved.

It is evident therefore, that while there is an apparent route in rehabilitation, this is neither completely shared nor understood by all the parties involved. Indeed, Jones *et al* (2007:508) state that "more research is required to explore the stability and nature of beliefs about future recovery and whether personal beliefs are unduly influenced by negative or positive interactions with professionals".

A number of authors have commented that the investigation of the influence of culture on both personal beliefs and the interaction between client and professional, is notably absent from the western based literature to date (Ellis-Hill 1998, McKevitt, Redfern *et al.* 2004). This is despite the fact that Becker (1997) notes that therapy is more effective when goals between patient and therapist are aligned, goals that are influenced by shared cultural understandings. Mold *et al* (2003:409), pursue this point further by suggesting that people with stroke from ethnic minority groups may have barriers to accessing and interacting with services as a result of "differences in health knowledge…cultural assumptions about the cause and recovery process of stroke illness and differences in patient relationships with service providers in terms of shared language, class and educational background". Considerably more research is required, however, to dissect the mechanisms of these influences on the response to stroke.

2.3 Summary

The literature presented in this chapter highlights a number of key concerns. I have argued that a detailed understanding of the subjective experience of a specific illness is required to assist in the delivery of effective and equitable health care. Through the literature, I have also illustrated the need to consider that experience within the wider context in which it evolves, develops and is reinforced. A summary of the multiple contextual influences which may impact on that experience were presented.

The review of the available stroke literature further illustrates the need to consider the subjective experience and begins to identify some of the potent influences. This review has shown that the concept of stroke, the experience of living with stroke, and the health seeking behaviour following stroke are not identically presented. In contrast, the impact of religion, social status, politics, age, sex and culture amongst others, have been identified. However, it is equally evident that the literature to date is considerably lacking. There is insufficient knowledge to understand the range of factors that affect the experience of stroke as well as the relationship between those factors, experience and outcome. This scenario identifies an urgent need for further studies exploring this interrelationship, and studies which are contextually embedded.

As a result of this review, a need to understand the broader context in which stroke understandings, experience and behaviour exist is highlighted. The following chapter introduces the context of the research presented in this thesis.

Chapter 3

Context

3.0 Introduction

In this chapter I will introduce the context of Indonesia and specifically Central Aceh where this research took place. Over the last four years I have periodically worked with Handicap International in Indonesia. As a result of both general exposure and the application of anthropological approaches to observation and interaction, my knowledge and understanding of the context and the people has improved. That knowledge was developed and formalised through the process of this research.

The information in this chapter is presented in three sections. Firstly, a brief introduction to the geography, people, religion, and recent political history is given. The second section describes the general concepts of health and illness in Indonesia and Central Aceh on which the understandings of stroke are formed. This includes the influences of body porosity, flow, temperature, food and drink, spirits, thoughts and religion within a framework of balance. This is followed by an introduction to the plural health system which exists in Indonesia and available information on health seeking behaviour.

The literature on the region is limited and as a consequence will be presented alongside ethnographic and general health related information gathered through this research. Much of this information was elicited through observation and opportunistic conversations with community members, government officials, colleagues and others. The method of participant observation, used to gather this data, is described in chapter 4.

3.1 General background

3.1.1 Geography

The archipelago of Indonesia is the fourth most populous country in the world with an estimated population of 228,864,000 in 2006 (UNDP 2006). A summary of the age and gender structure of this population as derived from 2005 census figures is given in table 1.

Table 1 showing the age and gender structure of the Indonesian population

Age group (years)	Male (x1,000)	Female (x 1,000)	Total male and female (x 1,000)
0-4	10188.7	9832.7	20021.4
5-9	11157.3	10788.9	21946.2
10-14	10824.1	10413.9	21238.0
15-19	10652.3	10611.7	21264.0
20-24	9759.0	10333.2	20092.2
25-29	9135.4	9596.1	18731.5
30-34	8455.4	8507.0	16962.4
35-39	7537.0	7454.4	14991.4
40-44	6495.3	6143.6	12638.9
45-49	5170.3	4689.9	9860.2
50-54	3880.6	3625.7	7506.3
55-59	2995.3	2941.5	5936.8
60-64	2481.5	2592.1	5073.6
65-69	1810.6	2012.2	3822.8
70-74	1267.6	1392.3	2659.9
75+	1369.2	1728.2	3097.4
Total	103179.9	102663.4	205843.3

From Badan Pusat Statistik (BPS 2005 http://www.bps.go.id/)

In 2006 the life expectancy at birth was 66 years for males and 69 years for females. Only 2.2 percent of the GDP was spent on health at that time (WHO 2006c).

Of the 17,000 islands that make up this archipelago, Sumatra is tha largest. It lies at the North West end of Indonesia.

Map 1 Indonesia

The province of Nanggroe Aceh Darussalam (NAD), commonly referred to as Aceh, lies on the Northern tip of Sumatra.

The area of Central Aceh is in the highlands formed by the Bukit Barison mountain range which creates a steep and dramatic border between neighbouring coastal districts. The highland region was previously known as Aceh Tengah. In 2004, this district was split to form the two districts of Aceh Tengah and a new district to the North, Bener Meriah.

Map 2 The area of Central Aceh

Adapted from http://www.indonesiamatters.com/1248/girl-caned/

Map 3 Bener Meriah and Aceh Tengah

Adapted from the Health Information Centre (HIC), United Nations in Banda Aceh
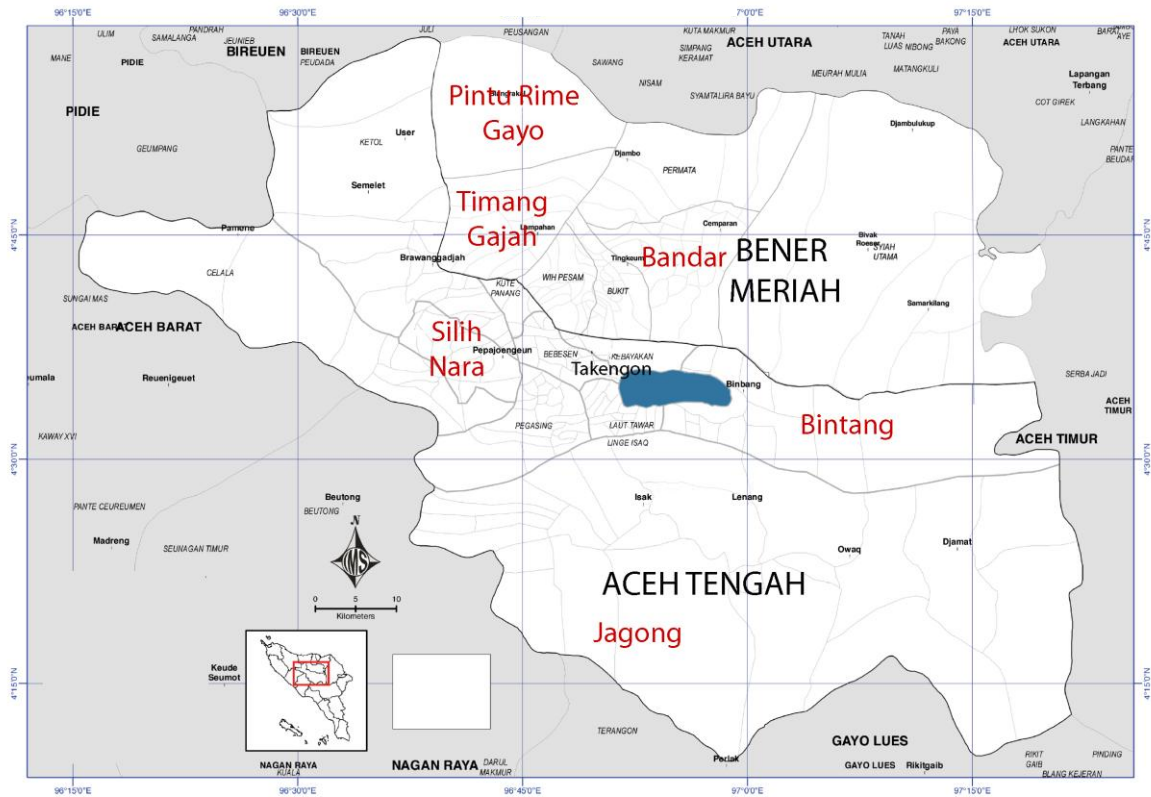
Bener Meriah and Aceh Tengah are the two districts that formed the site of this study. Within each district, there are a number of sub-districts. Six, three in Aceh Tengah (Silih Nara, Bintang and Jagong) and three in Bener Meriah (Timang Gajah, Pintu Rime Gayo and Bandar), were involved in this study (they are highlighted in red on the map). This choice corresponded to the work areas of Handicap International. There is one main town in the region, Takengon, which lies on the shores of Lake Tawar.

Table 2 Populations of sub-districts covered in this research

District	Subdistrict	Population
Aceh Tengah	Bintang	7832
	Jagong	8440
	Silih Nara	24623
Bener Meriah	Bandar	24910
	Timang Gajah	23421
	Pintu Rime Gayo	8353

Quick Count Population Census 2005:Badan Pusat Statistik (BPS/ Bureau of Statistics)

Central Aceh, at 4,000 feet, is a large producer of coffee and with other fruits and vegetables, the majority of the population is involved to some extent in agriculture. For example, it is estimated that 51% of the total population are reliant on agriculture as their main source of income, although the number involved for personal use or as a secondary income is likely to be much higher (Bupati. 2007). In addition, people who live around Lake Tawar can make a living through fishing and many inhabitants in rural areas far from the lake have fishing ponds for both personal and commercial consumption. Trade is mainly centred on the town of Takengon, but weekly markets and small daily trade stalls flourish in the surrounding villages. It is thought that approximately 35% of the population has their income based on tertiary services of which trade, food and basic items such as clothes and small café's play a large part (*ibid*).

3.1.2 The people

The province of NAD is mainly inhabited by the Acehnese ethnic group. However, Aceh Tengah and Bener Meriah are two areas of the cultural homeland of the Gayo people. The Gayo are culturally distinct from the Acehnese, but their origin is the subject of conflicting histories (Bowen 1991). Living alongside the Gayo, are a large number of Acehnese who base themselves mainly in the town of Takengon. A number of Javanese settled in the area following central government promoted transmigration programmes in the early 1980's and previous immigration during the Dutch colonial period in the 19th century (*ibid*). Some rural areas, such as Jagong are dominated by Javanese communities. There is also a small community of Indonesians of Chinese descent, who form a tight business orientated community in Takengon town. This mix of inhabitants, of which the Gayo are the overall majority, appear to live relatively harmoniously together. However, they have been caught within a protracted political and armed conflict resulting in community tensions. This is relevant to this research on stroke as the conflict had an impact on the development of the region, including the health structures, the mobility of community members and therefore access to health services, and their psychological state.

3.1.2.i Community

Some inhabitants of Central Aceh live in very remote locations within the forests, but the vast majority have homes within established villages. These villages vary in size

and infrastructure and while many are connected by tarmac roads, a number are not and therefore are at risk of being cut-off during heavy rains which are common in the area.

Photograph 1 showing a village in sub-district Silih Nara

The village community is of central importance to the people of Central Aceh, of all ethnic backgrounds. A number of community leaders exist with various roles to ensure the smooth running of community activities and that all members behave appropriately to maintain social harmony. These include cultural, religious, agricultural, youth, security, and women and children's leaders. Alongside these official guardians of community harmony is the social expectation of inclusion in all major celebrations. Functions such as the *akikah*, celebrated on the seventh day after the birth of a child, marriages and funerals, as well as independence day and *puasa*, when the fast is broken during Ramadan, involve community members, usually to share food.

3.1.2.ii The family

The family is also a key social group in Central Aceh. It is the unit of production and consumption which is illustrated in both the practices of farming and financial control (Bowen 1998). As Bowen states, "kinship provides an underpinning for an

egalitarian ideology over and against official hierarchies" (1991:23). Most people live with or within easy travelling distance of their immediate family. Practical considerations often dictate this proximity, including the distance to the family *kebun* (plantation), or the practicalities of child care. Equally, many people discussed the emotional bond within the immediate family and as a result choose to remain close.

Marriage between two members of the same village is prohibited in Gayonese culture, but spousal choices do not generally occur far beyond the familial base. A number of reasons were given for this; shared culture and religion, the desire of the parents to have their child nearby, and the difficulty of long distance travel. However, marriage outside the local community is not forbidden and both marriage and work can result in people leaving the area. Travel and outside marriage is more common in the Acehnese and Javanese communities because of their familial connections with other regions. It is not unusual to find three generations of a family living within one housing compound, but it is rare to find more than one married child living in the familial home. Nuclear families are encouraged, but often remain within proximity of the wider family, unless work requires a move further away. The choice of whether a newly wed couple live independently or with parents is somewhat dependent on the finances of the family. It is common for young couples to remain living with their parents for a period of time, often stated as a couple of years, while they save for their own property. It was observed that new couples usually stayed with the man's family, although residing within the woman's was both acknowledged and socially sanctioned.

Family members rely on each other in very practical terms. Although there are gender dominated occupations, there is equally evidence of overlapping responsibilities. Men may help with the shopping or cooking, and women often work in the field or sell vegetables and are active income generators in the family. The region has been noted for its tendency towards egalitarianism and women can inherit both land and houses and often manage the finances (Bowen 1998). There is also family based activity across generations and retirement is an undeveloped concept here. For example, elderly members of the family work in agricultural activities for as long as possible, or transfer to other duties such as caring for grandchildren, so other members can complete required tasks. While this arrangement is dependent on

the individual economic capacity of the family, all families met through this research required the active input of elderly members. People commented further that continuing to work in the field was also often their choice. They took enjoyment from this activity and soon fell 'sick' if this work was taken from them. Those in government employment who officially retire, usually use their time to focus on family business concerns. As a result, there was little reference to 'older people' based on age, but on functional capacity. Those unable to work in the fields or participate in other family activities because of age related infirmity were considered elderly, others continued their roles as they had previously done. This pattern of elderly Indonesians sustaining physically productive roles is noted in other parts of Indonesia and has been related to the high levels of successful aging in unskilled workers (Lamb & Myers 1999).

Education is highly valued in this community and all children, where possible are encouraged to study. Indeed, Bowen (1991) notes that education is one of the four debts that parents owe to their children in Gayonese society. This includes religious study and both formal and informal classes are available to boys and girls. This focus on education reflects a complementary aspect of the family unit, that of personal independence as children are encouraged to develop skills to ensure they can provide a service of some kind in order to earn an income. The overall impression is that people within the Central Aceh region, Gayonese and others alike, work within a frame of desired independence alongside practical interdependency with their family. Thus an individual is encouraged to develop skills, develop his or her own household and live independently when possible, yet at the same time retaining close practical and emotional ties with the family.

Communication within the family unit appears generally open and there are few gender or generational restrictions. However, people in Central Aceh are governed by a sense of *sumbang*. This term refers to things that should generally be avoided. There are four facets of *sumbang*; talking, behaviour, seeing and hearing. As a result, communication on intimate topics such as sexual activity is prohibited. Despite this, discussions of a personal nature were frequently encountered. Indeed, gossip was declared the favourite past-time by a number of informants.

3.1.2.iii Homes

The size and quality of the main home is dependent on income, but most houses are constructed from a combination of cement and wood and include an entrance room, where guests would be entertained, a living area, often next to the kitchen which may also double as a sleeping area, bedrooms, a kitchen and a bath/ washroom that is often separated and at the back of the property. Most homes in the larger villages have running water and electricity. The infrastructure surrounding the house varies widely in quality. Many houses are based on the main roads, maintained by the government. But for those who live off these permanent roads, access is usually via hilly terrain on paths made of mud and stone. These paths can be difficult to negotiate during heavy rainfall. Cars are not commonly owned, but most families have access to a motorbike which can be driven by men, women, young and old alike. It is not unusual to see children as young as 12 riding small engine motorbikes.

3.1.3 Religion

Indonesia has a complex religious history. Buddhism, Hinduism, Animism, Christianity and Islam have all been adopted in certain areas and times. Currently, Islam is the predominant religion. Like their coastal neighbours, the Gayo people are devoutly Muslim. An estimated 97% of the population of Nanggroe Aceh Darussalam (NAD) are Muslim (Ananto 2007). The date of their conversion is unknown, as the histories of the region have been predominantly oral with several contradictory versions. However, Islam has dominated since at least the seventeenth century and Islam is central to their identity (Bowen 1993). As part of the province of NAD, the people are subject to *Syariah* law, which was established formally in 2005, although aspects had been implemented previously (Ananto 2007, Milallos 2007). *Syariah* relates to laws specifically interpreted from the major Islamic text and oral histories (*Qur'an* and *Sunnah*) and cover aspects of everyday activities, both public and private including sexuality, hygiene, and social issues. However, unlike other areas of Aceh, the laws are not strongly enforced and *Syariah* police were not visible. For example, Muslim women are expected to cover their hair with a *jilbab* or *selendang* (different types of head scarf) and dress in a manner that ensures their flesh is covered, but in the fields and informal gatherings inside the home this was seldom done. To date there have been no reports of sanctions against people in this region for non-compliance, unlike neighbouring districts of Aceh where reports of

caning and other punishments for breaking *Syariah* Law have been intermittently reported in national, international newspapers and websites[3]. Likewise, while there is evidence of a rapid expansion on the number and size of mosques in the area, not all men attend the obligatory Friday prayers and sermon. Equally, several people were able to give directions to restaurants where alcohol could be purchased. Despite these apparent external deviations from the 'correct path' stipulated by *Syariah*, people declared themselves to be of strong faith, and religious teachings in general were an important aspect of everyday life. Much of the practices of *Syariah* are in-keeping with a more modernist approach to Islam, but it is important to understand a little about the history of Islam and the complexity of its expression in Indonesia.

There are a number of different forms of Islam and Islamic expression and these are important to understand briefly as they relate to active debates and influences in Central Aceh. There is evidence that historically the predominant Islamic influence on Indonesia was through Sufic teaching (mystical form of Islam) rather than orthodox schools of Islam (Ricklefs 2001). By the early twentieth century, however, modernist Islam became increasingly influential and a struggle between the orthodox and modern interpretations of Islam became heated (Eliraz 2004, Ricklefs 2001). In Bowen's (1989, 1991, 1993b) publications on Central Aceh, he notes the dominance of modernist thought with an apparent exclusion of many older and cultural practices. This shifting from local practice, to one more fixed on universal and scriptural Islam has been labelled as 'greening' (Howell 2001). Howell (*ibid*) argues that the Islamic revival has been represented within the frames of the outer (*lahir*) aspects of Islam, particularly the practice of rituals such as prayer, fasting and the wearing of *jilbabs*. But Howell (*ibid*) demonstrates that such a focus obscures a thriving parallel revival of Islam's inner (*batin*) spiritual expression, which is evident both in its traditional village base but also in cities. This more mystical side of Islam, which is most influenced by Sufic practices, emphasises a felt connection with God and is tolerant of religious pluralism. Its development and revival has acted to bring the modernist and traditionalist proponents closer in outlook. Its practice is noted in

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[3] See http://www.militantislammonitor.org/article/id/720, http://www.timesonline.co.uk/tol/news/world/article756104.ece for example.

Aceh by Siapno (2002) and Bowen (1989, 1991, 1993b). Although different forms of Islam are practised, the continuity of religion has acted as a unifying force in Aceh. However, political differences have resulted in considerable social disruption and this is explored next.

3.1.4 Recent political history

The province of NAD had been engaged in a 30 year civil unrest. This conflict was resolved with the signing of a peace accord (Memorandum of Understanding MoU), which included partial autonomy for the province, in 2005 (Barron *et al*. 2005, Le Billon & Waizenegger 2007). In-depth details of the conflict will not be discussed here, but a summary is appropriate as it was a significant aspect of life in the very recent history of many informants.

The Acehnese had a history of resistance, with the colonising Dutch, and the Jakarta led politicians since Indonesia's independence. From 1976, the Free Aceh Movement (GAM *Gerakan Aceh Merdeka*) has been in an armed struggle with the central government of Indonesia with the goal to increase Aceh's independence from central control. This conflict has flared and waned over the years, with violations of humanitarian law and arbitrary attacks on civilians and their property undertaken by both sides (Human Rights Watch 2001). A Cessation of Hostilities Agreement was signed in 2002, but soon broke-down resulting in a surge of violence and the implementation of martial law. The increase in military activity reduced the capacity of GAM and the political will from both sides shifted towards a peace settlement. The 2004 tsunami and 2005 Nias earthquake, which devastated large areas of coastal Aceh acted as a trigger to push the MoU forward. The disasters led to a huge number of international organisations entering NAD. However, until the signing of the peace agreement none had been active in the Central Aceh area. Violence continued from the period after the tsunami until the signing of the MoU and so although the tsunami had facilitated the peace process by increasing the international profile of Aceh, it is also apparent that significant political shifts had also occurred that made a peace agreement possible (Barron *et al.* 2005).

Throughout the period of unrest the Gayo heartland had been isolated from its regional neighbours. The tense Eastern coastal area of Bireuen, which has the main

trade link with Takengon and the rest of Central Aceh, was a key area of conflict. It was, and remains, alongside Pidie and Aceh Utara, the cornerstone of the GAM's stronghold. As a result, trade and personal movement in the Central Aceh highlands had been restricted for a prolonged period and thus development had been stalled. Indeed, Aceh, despite its natural wealth with oil and other commodities, has remained one of the lowest developed areas of Indonesia, with the central highland area being particularly neglected in terms of support (Barron *et al.* 2005).

The highland area, with the exception of Pintu Rime Gayo and Timang Gajah, has been categorised mainly as low conflict, but the activities of both GAM and the TNI (*Tentara Nasional Indonesia/* Indonesian army) were felt by many of the inhabitants[4]. Stories of house burning, forced temporary migration, villagers used as human shields for both parties, decapitated bodies left in fields, and death of family members and friends were common in general conversation. This is reflected in research done by Harvard and the International Organization for Migration (IOM) which explored the mental health of people in Aceh as a result of stressful conflict related events (IOM 2007). They report that in the central highlands 62% witnessed combat, with 85% suffering from a lack of food as a result of the conflict. This was the highest in all the regions they surveyed. 79% reported stress as a result of being unable to provide for their family. Those who had the financial means, moved from their rural villages to the town of Takengon or other regions of Sumatra such as Medan, during the conflict for their own safety. For all who moved and those who remained in the villages, crops were left unattended, harvests often not collected, through fear of injury or death. As a result income was poor and deprivation common. In 2004, prior to the tsunami, the poverty levels in Aceh were recorded at 28.4%, substantially higher than Indonesia as a whole at 16.7%. This figure was 32.6% in rural areas including Central Aceh (World Bank 2008). At the point of this study, there had been limited hostilities for two years and regular activities of daily life had returned.

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[4] This categorisation is quoted as part of an unpublished World Bank document which was utilised by the International Non-Governmental Organisation's working in Aceh.

This section has illustrated that the Central Aceh region is predominantly a rural community that is governed by a strong sense of community, family and religion. Religious values are generally followed, but are mixed with non-Islamic practices. The region is under-developed and recovering from 30 years of conflict which has challenged the community's coherence. It is from this geographical, political and social background that concepts of the world, and within that health and illness, are based.

3.2 Concepts of health and illness

There have been a number of ethnographic and other studies exploring health concepts in Indonesia (Bernstein 1997, Hobbart 2003, Muninjaya 1982, Sarwono 1996, Sciortino 1992, Slamet-Velsink 1996 for example). However, given the cultural diversity across the archipelago it would be imprudent to use these studies as the only source of reference for this study as most were based outside Aceh. In the section presented below, a summary of these previous studies acts to complement information gathered in the field from various sources. Key informants, the participants of this research and general conversations with community members have all been included to give this overview of health and illness.

The Indonesian paradigm of health is a complex amalgamation of the major medical traditions (biomedicine, Buddhist, Hindu, Chinese and Islamic systems), on a bedrock of Animism. Research in the archipelago indicates that vast differences appear between Islands, districts and even within the same community group (see Bowen 1993, Bernstein 1997, Hobbart 2003, Muninjaya 1982, Sarwono 1996, Sciortino 1992, Slamet-Velsink 1996). There is, however, one underlying principle that appears consistently, in both the literature and the field discussions, that of balance.

3.2.1 Balance

It has been noted that Indonesians have a general desire for equilibrium and order in all things, resulting in anthropologists concluding that Indonesians deplore chaos (Geertz 1960). Heider (1991:66), in a study of emotions in Indonesia concludes that "Indonesian concern for order and the concomitant fear of disorder appears strongly.

Probably every culture has some concern with order and resists manifestations of disorder, but in Indonesia the focus on this dichotomy is especially strong…it pervades Indonesian life". And within life it is relevant in health and ill-health, as disruption in equilibrium and order 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).

Health in Central Aceh was talked about in many different spheres and circumstances. Comments on food, illness episodes and recovery, the ageing process, the importance of the outdoors, work, the conflict, sleep, family dynamics and my body were a few of the topics discussed which resulted in 'health talk'. Through these interactions, a broad understanding of the concept of health emerged. These are presented in the following section under the sub-headings of body porosity, flow, temperature, food and drink, and non-physical influences such as spirits, thoughts and emotions, and religion.

3.2.1.i Body porosity

Central to an understanding of health and illness in Central Aceh is the concept that the human body is porous. For example, air, either cold or dirty, can enter the body causing internal problems. Some describe this air as coming through the skin, but others discuss the intake of certain foods, such as cassava and jackfruit, or already being bloated with gas facilitating its entry. This porosity is not uniform throughout the body and periods of vulnerability also vary. The individual's mental state, level of fatigue, the ambient temperature, other environmental features such as weather and pollution and the food consumed were all reported as having a relation to susceptibility to air entry. The permeability of the body facilitates a close relation between an individuals' physical and mental state and their surroundings and is a feature reiterated in many discussions on health and illness (Ferzacca 2001, Hobbart 2003, Muningjaya 1992, Sciortino 1992, Slamet-Velsink 1996). Once in the body, the air can interfere with another key feature of health; that of flow.

3.2.1.ii Flow

Flow of many things related to the body has been highlighted both from the participants in this study and the literature. Ferzacca (2001), in his ethnography of diabetes in Java discusses the idea that a flowing body is like an "organisable integration that when operating smoothly signifies good health" (p118). This is not simply the effective functioning of internal structures, as may be understood from a biomedical systems approach to health. It is rather a body that is nimble, pleasing to the eye, free of tensions both individually and in the social body and is appropriate for "a particular individual at a particular time in life, residing in a particular social space" (*ibid*:127). However, while some aspects of these were discussed by participants, it was largely in the context of a disruption to one fundamental flow; that of blood. Indeed, blood flow was consistently referred to as the most significant sustainer of health. Participants did not discuss the details of how blood completed its role, but were absolute with their conviction that maintaining its flow was essential. Any sluggishness or blockage resulted in a disruption to the normal balance of the bodily functions and therefore numerous symptoms including: stiffness, pain, blocked sinuses and fatigue. If this was not remedied, the condition could evolve to have more serious manifestations. If the blood is totally disturbed paralysis and death can result.

Blood flow could be altered through a variety of mechanisms. Amongst them, alignment of body parts, muscle tension and injury were frequently described, most consistently through the action of falls. Other causes such as hard physical work were also noted. These created a physical disruption to blood flow and resultant bruising, pain and difficulty moving. In discussing problems such as these, participants consistently referred to local massage as an appropriate remedy. The massage, which is deep and often very painful attempts to re-align everything, loosen and smooth the muscles thus promoting blood flow and re-establishing the internal equilibrium. Massage was also related to the prevention of further complications. Both masseuses and their clients noted that allowing this blockage to remain could potentially result in longer term difficulties with weakness, stiffness and tightness in the muscle and tendons leading to limitations in movement.

3.2.1.iii Temperature

Temperature and the weather were mentioned in a number of contexts as being relevant to health. Participants explained the significance of sitting in the heat of the sunrise as a mechanism of warming the body to improve blood flow. In contrast, exposure to excessive rain and becoming cold were noted as a reason for the onset of illness. This was often described through its direct impact on making the blood 'too thick' and therefore difficult to move around the body. Laderman (1991), Muningjaya (1992) and Sciortino (1992) discuss details of illnesses created by imbalances in hot and cold elements of the body. Laderman (1991) particularly relates this to humoral theories. The balance of temperatures can be achieved in a number of ways. Direct contact with heat is the most obvious to balance the cold. Medication, much of which is included in the *Jamu* system (Indonesia's herbal and root based medicine), was also used to heat or cool the body. The flow of blood and other bodily elements including temperature can also be maintained by regular massage (Mitchell 1982).

3.2.1.iv Food and drink

Concerns with temperature extended to food intake as many foods and drinks were considered to be either cooling or heating. For example goat curry was believed to heat the blood and consequently had to be served with cucumber juice which balanced the heat with its cooling properties. These concepts were often held in conjunction with more scientific explanations, such as influencing cholesterol levels or blood pressure. For example, seafood such as prawns, was cited as a potential cause of illness because of its extreme heating quality and resultant effect on increasing blood pressure. Participants explained that hot blood was in a state of agitation and consequently the pressure would increase giving rise to symptoms such as skin rashes, headaches, confused thoughts and collapse in extreme circumstances. Coffee, a very commonly drunk beverage in central Aceh, was likewise deemed to potentially heat the blood and was avoided by most people who had signs they related to increased blood pressure. Its effect was through increasing the work of the heart and many spoke of their experience of their heart beat increasing after drinking coffee as evidence of this. The consumption of fat, particularly of goat was relatively common in central Aceh, either in curry or *satay* (a local dish of skewered marinated meat, barbequed and served with a soya or peanut based sauce). While people would

often choose these dishes over other equivalents, such as chicken, they acknowledged that it was not good for health. The fat and the meat were described as being both heating and a cause of increasing cholesterol[5]. One informant described that goat meat was full of spirits and that was the reason for its heating quality.

Generally, people in Central Aceh had an overall understanding of whether the foods they consumed were heating, cooling or neutral. They did not always agree in their categorisation, but a number of extreme examples in each category were consistently labelled. These are summarised in table 3 below.

Table 3 Food and heat

Food	Heating	Neutral	Cooling
Durian	X		
Seafood	X		
Goat	X		
Chicken	X	X	
Beef	X	X	
Coffee	X		
Tea		X	X
Cucumber			X
Potato		X	
Mustard greens (*sawi*)	X		
General vegetables		X	
Bread		X	
Rice	X		
Coconut			X
Mangosteen	X	X	
Rambutan		X	
Pineapple		X	
Watermelon		X	X
Mango		X	X

Three non-physical attributes were also described as important to understanding health: the effect of spirits, the effects of thought and emotion, and religion.

3.2.1.v Spirits

Spirits had an interesting and often contentious influence on health. Spirits were noted not only as a potential cause of ill-health, but also of other mis-fortunes such as

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[5] The term cholesterol is used here as it was the term that was stated by the informants. However, it is not clear that the term used is directly comparable with the western understanding of the term, as it was not a central point of investigation in this study.

bad luck in work and relationships. Some discussed the random entry of spirits as a cause of both minor and major ailments. Spirits could be accidently kicked or disturbed, sent by someone else or simply randomly fly into you. While some informants suggested that spirits were related to people now deceased, more frequently they were connected to *djinn*; spirits that have always existed throughout the world. *Djinn* are frequently referred to in the *Qur'an* and are stated as a creation of Allah, alongside that of man (see Qur'an 55.11). Other informants suggested that the spirits only affected people who had not maintained their religious obligations. There were yet other participants who totally denied their existence. The discussions with participants regarding *djinn* and spirits were complex and fraught with political complications. Aspects of both traditional lay beliefs and those steeped in Islamic thought were expressed, which often did not make for a happy partnership. Bowen (1993) and Siapno (2002), discuss this issue in relation to modernist and traditionalist Islamic thought in the region. During data collection for this study, animated and heartfelt discussions were often held in reaction to explanations people had offered in relation to the action of spirits. While many of the more educated community members I spoke with tried to distance themselves from lay beliefs that did not fit with modernist Islamic thought, they had neither considered alternative explanations, nor were they immune to utilising these traditional ideas personally when the perceived need arose. Siapno (2002) discusses how the people in the province of Nanggroe Aceh Darrussalam (NAD), believed themselves to be at risk of mass hauntings as a result of the conflict and lack of appropriate burial for those killed. This suggests that the action of spirits could be particularly powerful at present. However, participants did not agree, insisting instead that spirits were present at all times and in all places and made no connection between the conflict and their presence.

An alternative view of spirits was presented by a traditional healer. She introduced the idea that we all have associated spirits that will protect us from harm, including ill-health. She described these as helpers and often utilised them to assist her in the removal of harmful spirits. Healers have also been noted to embody spirits to facilitate their ability to act as a medium between worlds (Hobbart 2003, Stephen, Suryani 2000). Aceh has healers who used the somewhat arbitrary presence of spirits to diagnose and suggest treatments. In one instance this resulted in a long delay in

'treatment' as none of the known helping spirits were in the vicinity and therefore could not be called upon.

The spirit's action on the body was possible because of its porous nature. Once they had entered they could do many things. Data from participants describe effects such as dirtying and blocking the blood flow, disturbing the mind and sleep, causing pain or an inability to toilet. Their entry was also facilitated by the mental state of the individual.

3.2.1.vi Thoughts and emotions

Thoughts and emotions, in this community, were not conceived as distinct from the body. They were an integral part of the person, inseparable from the physical being. Part of this relationship was noted in the associations made between organs and mental functions, as different organs had different 'mental' roles. For example, the brain was the seat of intelligence and knowing right from wrong, a process of reasoning the informants referred to as *akal*. The heart was seen as containing the soul and was associated with fear and anxiety and the liver with love and care.

As a consequence of the close relationship between organs, these mental and emotional activities had a close association with health. Thoughts were frequently discussed in relation to maintaining good health. A healthy mind was intricately associated with a healthy body and vice versa. For example, too much thinking was reported to cause headaches and it was also a prime aggravator of hypertension (*hypertensi/darah tinggi*) due to sluggish or excessive blood in the head. Equally poor blood flow could result in illogical and disturbed thinking with a heavy mind. Informants discussed how thinking that you had a problem, such as cancer or possession by a spirit was sufficient to result in it occurring. Thinking could be affected by a number of different influences. For example, a good environment, which generally referred to one which was clean and had space, trees, appropriate temperature, and had people to interact with, resulted in a lighter mind. Isolation and an indoor existence conversely stimulated heavy thoughts and ill-health. In a similar vein, community harmony, or the lack of it in this post conflict region, was related to too much thinking and resultant ill-health as will be demonstrated through the stroke stories. Indeed, friends and colleagues were often concerned that I would fall sick as

a result of the 'heavy thinking' I appeared to be doing as a consequence of this research. A state of heavy or negative thinking, anxiety or fear left one more vulnerable to the entry of unwanted agents. *Djinn*, dirty and cold winds were all identified as being more able to enter and influence an individual, if their mental or emotional health was disturbed. A similar pattern was identified by Hobbart (2003) who linked anger with the onset of illness and therefore the need for its avoidance to maintain health.

3.2.1.vii Religion

A final point to note was the influence of Allah in health and illness. Several participants stated that all things came from Allah and as a result He was finally responsible for whether someone was ill or healthy. In this vein it was suggested that a lack of piety could result in an increased likelihood of illness. Illness was also posited as a test for the individual. The converse was also stated; if one maintained a pure being in the eyes of Allah, then His blessing would result in good health, or alternatively, He would give you the strength to endure periods of ill-health and provide the means whereby health can be restored. In this conception, the individual was not purely a recipient of Allah's dictates, but was given the agency to meet the demands of the test and adjust his or her own behaviour in very practical terms to promote health. Many discussions were had about how the *Qur'an* supported this outlook on the individual's agency in health. Instructions on washing, eating and abstaining from alcohol quoted from the *Qur'an* and *Hadith* were all given as examples of how Allah, through the prophet Mohammad, promoted that agency (see for instance Qur'an 2:168, which states "You People! Eat of what is lawful and wholesome on the earth" and Qur'an 2:219, "They ask you about drinking and gambling. Say: there is great harm in both, although they have some benefits for the people; but their harm is far greater than their benefit"). Similar features are mentioned in much of the literature on Islam in health (Al-Oraibi 2002, Bowen 1993, Yamey and Greenwood 2004)

In general discussions on health, all of the features highlighted on the previous pages were raised by community members of Central Aceh. Blood flow and 'thoughts' were the most salient. However, participants who were ill at the time of discussion, or who had a disability, focussed more on the practical implications of the features.

Alignment and smoothness of muscle for example were presented within an ability to be mobile in a guaranteed manner, to be able to complete a task without having to question your physical capacity to do so. This physical ability, alongside a lightness of mind, were required to complete the tasks that informants stressed were the foundations of a healthy life. These included the ability to pray appropriately, to be able to work sufficiently for what the individual and their family may need, and be independent in life. So while informants were able to identify factors that influenced health, the signs that health had been achieved were very practical in nature. One informant summarized this most succinctly by stating, "as normal people, first we pray, second we do work, third we apply it in normal action, free to go anywhere. That is being healthy."

In summary, health in Central Aceh can be conceived as an interaction between the individual and external forces, of which the environment, temperature and weather, food, social harmony and spiritual domain are all pertinent. Through this, a combination of lightness and flow should be maintained to ensure adequate health that was expressed through freedom of movement and the ability to complete the religious obligations of prayer. It was on this understanding of health that stroke in this research study was interpreted.

3.3 Indonesian health system

This last section introduces the health system of Indonesia. Health systems include all providers of health care, both formal and informal (World Health Organisation 2009). In Indonesia, this includes both the government run National Health Service and an array of practitioners who work outside the government system. Medical pluralism is the norm in Indonesia and it is consistently noted that in the event of ill-health, people in Indonesia utilise both the formal and informal sector (Ferzacca 2001, Sciortino 1992, Slamet-Velsink 1996). The section ends with a brief review of the literature on health seeking patterns in Indonesia. Some of this information was directly available through government and other published documents, but much was availed from discussions with members of the local Departments of Health (*Dinas Kesehatan*), Social Departments (*Dinas Sosial*), from the hospital (Director of Hospital and Head of Physiotherapy Department), staff at the Primary Health Care

Centres (*Puskesmas)*, representatives from the national therapeutic bodies and specific healers.

3.3.1 Government supported general medical and therapeutic services

3.3.1.i Structure

The Indonesian government has a very structured health system which provides care from community to specialist hospital level, within a broad biomedical framework. The complex structure is illustrated in diagram 1.

Diagram 1 Ministry of Health from Central to District levels
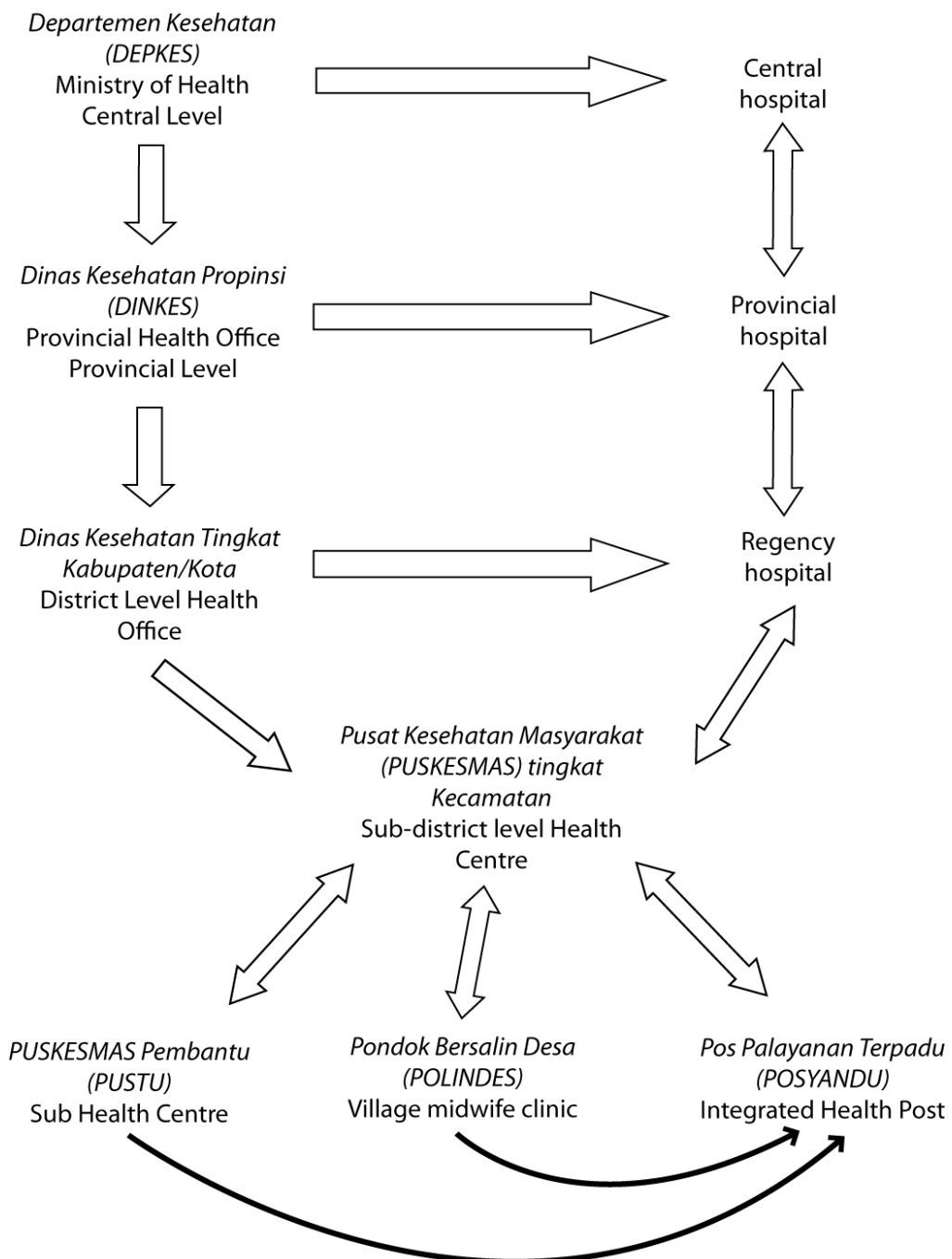
This hierarchy of care is inspired by a Primary Health Care (PHC) model of health which was adopted by Indonesia following the declaration at Alma-Ata as an approach to achieve Health for All (World Health Organisation 1978). It should be noted however that the development of the Primary Health Care Centres (*Puskesmas*) was initiated prior to this declaration, having been introduced in 1968 (Kristiansen & Santoso 2006). The principle was to bring basic health services as close to the community as possible and in doing so utilise the locally available skills that already existed. This included the use of traditional services if required. Shields and Hartati (2006), comment that the strength of PHC lies in its capacity to empower the community and specifically the family unit through education as the main decision makers in health care. Whether Indonesia has achieved that in the case of stroke in Central Aceh will be explored in later sections of this thesis.

The adoption of the PHC model coincided with an increased investment in healthcare generally in the 1970's. This investment resulted in an expansion in the number of Primary Health Centres in the community. To date, each sub-district has access to at least one health centre (SEARO 2008). That investment, however, decreased over the following decades and the combination of the economic crisis of the 1990's and a policy of decentralisation and promotion of privatisation has resulted in a fracturing of the health system from its earlier promise (Kristiansen & Santoso 2006, Gani 1996). One consequence of this is the number of issues regarding the quality of care provided at the primary level. Not only have concerns been raised about the skill level of the practitioners (Wahyuni *et al.* 2007), but a discrepancy has been noted between areas, with those living outside Java and Bali receiving poorer quality care than those on those two Islands (Barber *et al.* 2007). The variation in the quality of care is also dependent on the socioeconomic status of the client despite apparently equal accessibility (Kristiansen & Santoso 2006).

Even with these concerns, Indonesia has made gains in many indicators of primary care, particularly those that focus on child and maternity care and communicable diseases through this model (SEARO 2008). However, there is little evidence that the PHC model in Indonesia has made any attempt to prepare for the consequences of the changing demographic trends in the country and the concomitant increase in

chronic disease burden (World Health Organisation 2008). Indeed Barber *et al* (2007), note that such a transition is considered prohibitively expensive.

3.3.1.ii Structure in Central Aceh

A number of government run health services were available to people with stroke in the Central Aceh region. A large provincial hospital was based in Banda Aceh, some 8-10 hours from Takengon by public transport. This hospital provided a number of specialities not available in the smaller regency hospitals including neurology and neurosurgery, scanning equipment, prosthetic and orthotic services. The hospital services could be accessed directly through emergency admission or via referral from the regency hospital. A regency hospital based in Takengon, *Rumah Sakit Datu Beru*, served both districts of Aceh Tengah and Bener Meriah. This hospital had general in and out-patient facilities and offered a few specialities, although neurology was not one of these. It also had a pharmacy and a physiotherapy department which provided services to in and outpatients referred to the service.

At community level each sub-district involved in this research had a *Puskesmas*, which was usually headed by a medical doctor.

Photograph 2 Pukesmas in sub-district Silih Nara

The *Puskesmas* is designed to be a local health facility. However, the geography of the region is such that often the nearest *Puskesmas* was several kilometres away from individuals' homes on rough and invariably muddy roads. Public transportation was almost non-existent in these areas and so transportation to the *Puskesmas* involved using the main form of transport, the motorbike, or in the case of severe impairment or sickness (as is the case with stroke), hiring a car at considerable cost to the family. Some of the issues relating to this are discussed in chapter 6. More locally there were smaller health centres, *Puskesmas Pembantu* (*Pustu*) and *Posyandu* (SEARO 2008). There is in addition a *Polindes*, or village midwife clinic.

In addition to these government services, Handicap International (HI) also provided rehabilitation to people following a stroke. This was through attendance at the *Puskesmas*, where HI staff supported the government activities and through home visits for those unable to attend the *Puskesmas*.

3.3.1.iii Personnel

The government services provide access to a range of biomedically trained professionals. The hospital had a range of personnel, including doctors, nurses and physiotherapists amongst others. They offer both in an in-patient and out-patient service. The staff at the *Puskesmas* included doctors, nurses (*mantri* or *perawatan*), midwives (*bidan*) and occasionally dentists and physiotherapists. They are responsible for minor ailments and the general health in the community, including prevention. At the time of this study rehabilitation at community level was not provided by the government in most of the sub-districts studied. Even when physiotherapists were available, they did not always work in that capacity, often being involved in administrative tasks.

At the smaller health sites services were often offered by a lone nurse (*Mantri* or *Perawatan*) or midwife (*Bidan*), who may have a role far more diverse then mother and child care. The village midwife (*Bidan Desa*) is the only government employee to be based at village level. They are often the main link between isolated rural communities and health care and as a result may serve the needs of all people in need to health care who are unable to travel to the larger health centres. As a result, *bidan*

needed to be considered in this research as they were often called upon to assist the people with stroke.

Medical doctors are present both in hospitals and in the *Puskesmas*. The services of doctors, theoretically, should be of international standard. They are trained within universities at an internationally recognised level and technically have to attend post-graduate courses in order to maintain their registration with the Indonesian Medical Council (IMC). However, several informants noted that they were not supported by their managers to attend these courses and the IMC did not enforce their registration requirements. Furthermore, the courses rarely covered specific pathologies and indeed none of the doctors in Central Aceh had attended training specifically on stroke.

Although medics are employed in government run institutions, the extent of their availability is contentious. In 2006, it was estimated that there were only 13 doctors per 100,000 people (UNDP. 2006). In addition, Sciortino (1992), in her extensive review of practice within a *Puskesmas* and community, highlights that the doctors' role as health centre managers often results in them being unavailable for clinical practice. While this study is over 15 years old, a similar issue was observed in the *Puskesmas* during field work.

Stroke care, as introduced in chapter 1, requires the services of a number of health professionals, who with the medics make up the multidisciplinary team (MDT). Information on these therapies and allied health professionals in Indonesia illustrates considerable concerns in the availability and quality. For example, nursing education is not regulated fully and therefore standards of knowledge and practice are not adequately controlled (Puckett 2007, Shields & Hartati 2003). Issues with poor nursing standards of practice have been demonstrated through studies exploring understandings of mechanisms of disease and appropriate methods of testing for common diseases (Wahyuni *et al.* 2007, Barber *et al.* 2007).

A survey in 2003 by the Directorate of Medical Services in Indonesia, notes that stroke is one of the most common conditions managed by Physiotherapists (PT), Occupational Therapists (OT) and Speech Therapists (ST) (Sueuer 2007). Once

again, however, there are concerns regarding the quality of that care. The Indonesian Association of Physiotherapy (*Ikatan Fisioterapi Indonesia*, IFI) is a member of both the Asian Confederation of Physiotherapy (ACPT) and the World Confederation of Physical Therapy (WCPT). However, their training is neither internationally recognised nor uniform over the country. Curriculums have been set and all institutions have an obligation to follow this, but IFI admit that this is not enforced. There have been strong moves in recent years to improve the quality of training and continued professional development, but as yet the central government has not acted to confirm any specific actions.

The quality of OT is more easily monitored as only 2 schools operate in the country. The Indonesian Occupational Therapy Association (IOTA) plays some role in ensuring that that the two courses are of similar level, and indeed one (in Solo, Java Island) has been formally recognised as diploma level by the World Federation of Occupational Therapy, suggesting a level of internationally recognised quality. However, once again there is no national regulation and registration is not centrally compulsory. A similar scenario exists for Speech Therapists and the Speech Therapy Association (*Ikatan Terapi Wicara Indonesia,* IKATWI).

Although medical and nursing care may in principle be available through the government services, this is not the case for the therapies. Physiotherapists are employed in government hospitals, but are not routinely provided at *Puskesmas* level. *Puskesmas* are run at District Health Authority level and therefore employment of staff is locally decided, with validation at Provincial and Central Level. As a result there is sporadic employment of physiotherapists outside of hospitals. In total only 24 physiotherapists (0.22% of total health staff) are employed in Nanggroe Aceh Darussalam (NAD) (Provincial Health Office 2006). In the six sub-districts involved in this research, only two had government employed physiotherapists. Numbers of OT and ST are negligible and this in part reflects the limited number trained. There are only 650 OTs registered in the whole of Indonesia, 200 STs (Sueuer 2007). Indeed, there were no OTs or STs employed at provincial level in NAD (Provincial Health Office 2006).

3.3.2 Non-governmental services

3.3.2.i Background

In addition to the Western style therapists, 'therapy' in the community, is available from traditional healers many of which are known as *dukun*. This is a generic term given to someone who has mastered the traditional knowledge and skills of curing or treating illness (Boedhihartono 1982, Nitibaskara 1993). The Indonesian government believes that the use of traditional healers will decrease once biomedical services are more available (Chernichovsky & Meesok 1986). However, evidence would indicate that since the economic crisis of 1998, their practice has flourished (Ferzacca 2001, Mahoney 2002). According to the *Susenas* report (as quoted in PHO 2006), 47% of people use traditional health services, although a figure of 70% in rural areas has also been noted (Ritiasa 2000).

These traditional healers have their roots in the region prior to Buddhist, Hindu, Chinese or Islamic influence, but have adapted their practice in relation to these significant cultural systems, most significantly Islam and its concomitant Unani-Tibb system and more recently by Western explanatory processes (Bernstein 1997, Boedhihartono 1982, Ferzacca 2001, Mahoney 2002, Muninjaya 1982, Slamet-Velsink 1996). Such an amalgamation in practice is typical of a nation known for its syncretic and pluralistic nature.

Like many other countries which have adopted the PHC model, registration of traditional healers is incomplete in Indonesia (World Health Organisation 2001). Four categories of traditional healer are officially recognised, including; herbalists; skilled practitioners, spiritualists and supernaturalists, but in reality many of the practitioners cross a number of these boundaries. Despite the inclusion of traditional medicine in Indonesian Law[6] as an integral part of curative care, there is little formal recognition of the skills of the *dukun. Dukun bayi* (traditional midwives) have been included in development programmes and limited research is ongoing as to the benefits of *Jamu* (traditional herbal medications), but the government has invested little else in their cultural healing resources (Ritiasa 2000, World Health Organisation 2001).

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[6] Article 1 of Indonesian Health Law Act 23-1992 as reported by WHO (2001).

The guiding principle of traditional therapies is the restoration/maintenance of balance. Shamanic influenced supernatural rituals, herbal pharmacopoeia often as part of the *Jamu* system, *pijat* (squeezing or pinching technique) and *urut* (general) massage, *moxi* (using fire on the skin), sucking, removal of foreign objects, drinking of *Qur'anic* texts or *rajah* (a spell often transmitted through a substance), have all been cited as part of the healing practices one may seek to restore balance (Bernstein 1997, Boedhihartono 1982, Bowen 1993a, Bowen 1993b, Broch 2001, Hobbart 2003, Laderman 1992, Mahoney 2002, Rahasimyah 2005, Stevenson 1999).

The dramatic rituals and herbal pharmacopoeia have been studied fairly extensively, albeit predominantly in Java and Bali Islands and not specifically in relation to stroke like symptoms. The more apparently mundane practices like massage, have a conspicuous absence from medical and anthropological literature in the English language (see Hobbart (2003) for example). This is unfortunate, as it has been noted by a number of authors that massage, for example, is used for almost all illness conditions (Bernstein 1997, Boedhihartono 1982, Hobbart 2003, Mitchell 1982). Furthermore, in the media massage has been associated with 'rehabilitation' programmes of significant figureheads, such as Abdurrahman Wahid following his strokes immediately prior to his presidency of the Republic of Indonesia (Loveard 1999).

Aside from their direct physical or spiritual intervention, healers are noted for offering a broader service to people who seek their assistance. Interestingly, some of these factors bear a striking resemblance to the 'unofficial' benefits of rehabilitation in the West. Slamet-Velsink (1996:75) notes that traditional healers are "more interested in the patient as a person and in his or her unique individual circumstances". Such concern often encompasses more than the individual themselves, but their family and social situation. The process of diagnosis and the negotiation of care has been described as providing meaning, to what may appear as a random and arbitrary event (Mitchell 1982). While Mitchell (*ibid*) was not discussing stroke like symptoms *per se*, the applicability of such a process could be argued to be highly relevant for stroke, with its sudden and often dramatic onset. Researchers further discuss the active dialogue between the healer, person and family, resulting in a discussion on the hope of recovery. This linguistically bears

relation to the narrative reconstruction proposed in a western stroke trajectory (Mahoney 2002, Slamet-Velsink 1996). Indeed, in discussing psychology and counselling, Hobbart (2003:59) states "it is mainly traditional healers who take over this role, enabling clients to reconstruct their worlds."

A further note regarding traditional medicine is extrapolated from research in Malaysia, a neighbouring country which shares many cultural characteristics with Indonesia. In research on depression following stroke Glamcevski and Pierson (2005) found a relationship between depression and the non-use of traditional medicine. While found to be a confounder rather than having a direct link with depression, its presence is intriguing, particularly as the attendance at formal rehabilitation had no impact on depression outcome. It further supports the idea that traditional services may offer some form of rehabilitation highly relevant to people post-stroke.

While the cultural familiarity of these healers is usually posited as an important factor in their healing success (Bernstein 1997, Mahoney 2002, Slamet-Velsink 1996), it should be acknowledged that their use of culturally relevant symbols and beliefs does not always present them in a positive light. Their healing ability is presented as a gift from Allah. This results in a code of ethical conduct which directs their practice, without which the gift would be withdrawn. However, it is evident that this is not always rigorously followed, for example services are rarely, if ever, free (Bernstein 1997, Mahoney 2002, Woodward 1985). Equally, the very capacity they have to heal, for instance through the removal of spirits held responsible for an illness, renders them open for accusations of sorcery (Woodward 1985). Such issues have resulted in many traditional healers being viewed with considerable suspicion and moral ambiguity. This suspicion is increased when religion is considered. Firstly, the study of traditional healing requires the acquisition of 'power' and this is held to be a distraction from the more significant quest of union with Allah. Secondly, the *Qur'an* itself is ambiguous about the use of such power. Finally, the basis of much of the healing potential associated with healing has its roots in Hinduism (Woodward 1985). This has proved to be a potent mix recently with a fatwa against the practice of Yoga being declared in Indonesia in January 2009 because of its links with Hinduism (Mackinnon 2009). With such a combination of factors to consider, it is

perhaps unsurprising that the placement of traditional healers within the health system of Indonesia is difficult to define and that that the government has not been proactive in incorporating their practice, as encouraged by bodies such as the World Health Organisation (Connor & Higginbotham 1986). Nevertheless, given their very active role in healing in the community, more effort needs to be made to understand their practice and usage.

Despite their lack of commitment to traditional therapies, the Indonesian government acknowledges their potential role, instigating a plan of action for the investigation and development of proven safe and effective traditional treatments. However, this plan is yet to see significant action (Ministry of Health 1999). Likewise, Donnan *et al* (1998), for the Asia Pacific Consensus Forum on Stroke Management, identified as a key goal that

> all stroke patients should have access to rehabilitation aimed at achieving optimal function, independence and quality of life through restorative care, including locally and culturally available resources…resources include not only current rehabilitation therapies, but also traditional and locally available therapies (ibid:1735)

However, there has to date been no investigation of what these traditional and locally available therapies may include. A lack of or unbalanced information on these services inhibits meaningful dialogue on the requirements of the increasing number of people following a stroke and appropriate delivery of these needs. As a result it was essential that non-biomedical healers were included in this research.

3.3.3 Health costs and other factors known to potentially affect access
3.3.3.i Costs
Health care and therapy, on the whole, are not free in Indonesia, even within the government run institutions. There is a cost for both for the use of facilities, such as hospital beds, and commodities, such as medication. At the time of the research there was a medical insurance process, ASKES and ASKESKIN[7] (which is now being reviewed nationally) which was aimed at assisting with the medical needs of those who were in government service and those who were judged to be very poor (PT.

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[7]Program Jamian Kesehatan Bagi Masyarakat Miskin (PJK-MM or ASKESKIN)

Askes. 2005). However, even with such coverage, costs of medicines were still incurred by the individual. It has been estimated that 66% of health care is paid for privately and 74% of that is out-of-pocket expenses (SEARO 2008). There were also anecdotal reports of a poorer service delivery when using the ASKESKIN system, such as doctors not visiting patients routinely and as a result people may choose not to utilise this facility even when eligible.

Generally the cost of traditional or non-biomedical healers is assumed to be less than formal care, but Boedhihartono (1982) argues that traditional healers are often more expensive than medical doctors. In the Central Aceh area, the cost to see a doctor privately was around 100,000 IDR (Indonesian Rupiah), although in the *Puskesmas* it was free. Physiotherapy in the hospital cost 20,000 IDR per session. This sum, which is the equivalent of just over £1 is a significant proportion of the daily wage of a labourer for example who is paid between 20,000- 50,000 IDR per day in the Central Aceh area. Many of the non-biomedical healers charged for their services. The amount varied dependent on what treatment was given or the length of time the person had stayed in the clinic. The exact cost was not stated by the healers themselves, although some of their clients had mentioned costs such as 70,000IDR (approximately £4) per treatment session. A number of traditional healers did not charge a set fee. However, some of their treatment process had significant expenses related to them. As a result the absolute costs of treatment remain unclear.

3.3.3.ii Health seeking patterns

Very little is known about patterns of health seeking in Indonesia. However, a few studies have been carried out and it is worth briefly reviewing them as a precursor to the stroke specific findings presented later in this thesis. A number of factors have been found to influence peoples' choice of practitioner. For example, Kurihara *et al* (2006), found that in schizophrenia, the causation beliefs had a determining effect on which healer was sought. In this case a belief in spirits and sorcery led to an increased tendency to seek traditional treatments and a decrease in biomedical practitioners. For van Eeuwijk (2003), however, the behaviour of elderly people to seek health in the event of illness was strongly influenced by the impact of the illness on their functional ability. As a result, if they were incapacitated they were more likely to seek help then if merely inconvenienced by the condition.

In contrast, an earlier study by Broch (2001:278) indicated that "patients and their relatives do not think in terms of what might be more or less efficient medical systems but in terms of available health care options". This availability may be in terms of financial costs and physical access, but there are a number of other factors which may influence 'availability'. Potentially most significant of these are the influences on access to resources and decision making. Age and gender are significant considerations in this regard. Schroder-Butterfill (2002), in an ethnography on ageing, remarks that the extent of health care provision and the type of provider is influenced by two main factors- gender and the persons relation to wealth flow within the family. As a result, men are more frequently seen by biomedical specialists, women by traditional healers. Those that are net providers access hospitals, whereas dependents more often utilised traditional services. This may be an indication of perceived value within the social unit and investment in a future exchange capacity. It has further been noted that elderly women generally receive lower remittances than elderly men and generally have access to fewer resources (Adlakha & Rudolph 1994, Rudkin 1993).

Sciortino (1992), in an extensive study based in Java, found a number of factors beyond 'availability' which influenced the choice of health assistance. The diagnosis itself, type of medication on offer, perceived knowledge of the care giver and reputation were cited as motivating factors in the choice of assistance. She, along with other ethnographers, discussed many of these influences within the concept of *cocok*. This word translates as fit and has been described within the concept of recovery to define an appropriate 'therapy'. As Ferzacca (2001:87) explains, there is a "constant search…for a medicine and therapy that fits their unique health problem that presents itself differently during its course from sickness to cure". This would indicate that the people themselves carry a concept of their issues and needs and seek the remedies, judging their success by the resolution of those issues they identified.

As a result, a mix of *cocok* and pragmatic considerations, of which cost is only one aspect, appear to influence the therapy choices of people in illness. It is yet unknown how these factors interact in the case of stroke. Unlike many illness and injuries, the trajectory of stroke is initially unknown and highly variable. With the potential for

improvement, the desire to seek remediation may be strong, but with the high risk of long term disability, the pattern of therapeutic requirements is complex.

3.4 Summary of chapter

In this chapter I explored the context of Indonesia and specifically Central Aceh. The purpose has been to give an overview of the region in which the study was conducted, one in which stroke has been identified as a significant cause of disability.

The description of local concepts of health and illness, alongside the overview of the social and cultural features of Central Aceh, identifies issues that may influence the understanding and experience of stroke and the utilisation of health services. These included the recent conflict, the centrality of the family unit, and the concept of a porous body in which physical, mental, environmental and spiritual aspects interact, and where health is presented as a state of unimpeded flow demonstrated through free physical action.

This chapter has also introduced the health system available in Indonesia, indicating the presence of both government supported biomedical personnel alongside non-governmental traditional healers. Issues were raised about the quality and availability of the biomedical healers and a significant lack of knowledge about the practice of traditional healers. Literature indicates that a number of issues may influence the choice of healer selected. These include cost, availability, *cocok*, gender and income potential. This particular place, with specific understandings of health and illness and a variety of healers, was the context in which the subjective experience of stroke was explored.

Chapter 4

Methodology

4.0 Introduction

In this chapter I consider all aspects related to the methodology used in this study: its design, specific methods selected, the participants, and process of analysis. The chapter concludes with a reflexive account of me as researcher. In order to justify the choice of methodology, it is first necessary to state the aim and the objectives of this study.

4.1 Aim

The aim of this research was to explore the subjective experience of stroke and subsequent health seeking behaviour in central Aceh.

4.2 Objectives

In order to achieve this aim, a number of objectives can be identified.

1. To explore the understanding and perception of stroke in rural Central Aceh.
2. To develop an explanatory model of lay stroke causation.
3. To describe the impact of stroke on the lives of those affected.
4. To investigate the available 'therapies' in the field area and their theoretical and social basis of practice.
5. To describe the health seeking behaviour of those affected by stroke.
6. To identify the mediating factors in the understandings of stroke and its recovery pathway.
7. To consider the findings of the research in the light of the international literature pertaining to stroke care and make recommendations applicable in an international context.

4.3 Study design

To answer the aim and objectives stated on the previous page required a study design that would be able to explore two interrelated phenomena; the experience of stroke and the context in which that experience evolves. The study necessitated an understanding of depth and complexity in people's accounts and experiences, rather than surface comparability between large numbers of people. Qualitative methodology is best suited for such an endeavour as it both attempts "to make sense of, or to interpret, phenomena in terms of the meanings people bring to them" (Denzin and Lincoln 2003:4) and stresses the creation of experience within social and situational constraints (*ibid*).

Epistemologically, I believe that people have the greatest access to their own experience, but that time, culture, and situation, for example, will influence both that experience and its expression. Experience is therefore only partially knowable and is a co-construction between the individual's consciousness and its surrounding context (Maso 2007). The exploration of the individual meaning of the experience of stroke, and the context in which that meaning both evolved and was enacted, places this research mid-way between realist and constructionist approaches (Braun & Clarke 2006, Maso 2007). Such a stance acknowledges the links between individual experiences, and the influence of socio-cultural factors on the production and reproduction of those experiences.

There are numerous approaches to qualitative enquiry which have different purposes, strengths and weaknesses. This study draws on two complementary methodologies, ethnography and hermeneutic phenomenology. Such an approach has been effectively used to explore the stroke experience previously (Doolittle 1994). Both ethnography and hermeneutic phenomenology will be briefly described followed by a justification of the utilisation of both and the advantages of that approach specifically for this research.

4.3.1 Phenomenology: introduction

Phenomenology is a European philosophy widely attributed to the work of Edmund Husserl (Giorgi 1997). In phenomenological thought, the world is only knowable

through the experience individuals have of their world. The constitution of objective knowledge inextricably involves subjectivity. Consequently, the experience and meaning individuals make of their lived human world, becomes the necessary focus of study (Bryman 2005, Starks & Trinidad 2007). 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). In Husserlian phenomenology, a key component in this explication of meaning is the ability to refrain from interfering with the data; a process referred to as 'bracketing', leading to the researcher being without presupposition. Husserl suggests that it is only in this state, that life as it is lived, can be captured (Lopez & Willis 2004, Moran 2000).

Phenomenology, however, has undergone many transitions and a significant deviation from Husserl's conception relates to the researchers ability to 'bracket''. Hermeneutic, or interpretive phenomenology was initially developed by Heidegger (1962), a student of Husserl's. Others, such as Gadamer (1989), Merleau-Ponty (1962), van Manen (1997) and Smith (2008) have been involved in further extending the understanding and use of hermeneutic phenomenology. Unlike the descriptive phenomenology of Husserl, hermeneutic phenomenology suggests that the 'bracketing' of all presuppositions is impossible to achieve. Indeed, some authors suggest that such held knowledge is both useful and necessary (Geanellos 2000, Koch 1995). As a result, and in line with many anthropologists (Geertz 1973), interpretation becomes a core feature. Smith and Osborn (2008) describe the presence of a double hermeneutic; participants attempting to make sense of their world, while at the same time the researcher is trying to make sense of the participants interpretation.

Another specific feature of hermeneutic phenomenology is the importance given to context. Like Husserlian phenomenology, hermeneutic phenomenology posits that individuals are free to make choices, and therefore individual experiences and actions are essential to understand. However, that freedom is situated as individuals cannot detach themselves from the world in which they live (Moran 2000, Leonard

1994, Leonard & Masatu 2005). As a result "subjective experiences are inextricably linked with social, cultural, and political contexts" (Lopez and Willis 2004:729).

The focus of individual experience and meaning, in conjunction with the need to understand context, and the interpretive role of the researcher, leads to the use of ethnography as a complementary approach in this study.

4.3.2 Ethnography: introduction

Ethnography is a methodological approach which has diverse definitions. Some authors take the term to refer exclusively to the study of culture (Chambers 2003). Others equate it to participant observation, suggesting that it is a method rather than a methodological approach to research (Bryman & Teeran 2005). In this study, ethnography is understood to explore 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).

For ethnographers, individuals exist within a world where meaning and actions are in some way ascribed with a significance which precedes and extends beyond the individual. Geertz (1973) refers to these influences as webs of significance and it is the exploration of those webs, the mechanism of their existence and sustenance which lies at the heart of ethnography.

The ethnographic process uses two parallel capacities; the participant's awareness and ability to articulate the context in which they live, and the experience of the researcher. In ethnography participants are viewed as experts of their own context. In line with phenomenology, this aspect of ethnography is committed to the participant (*emic*) perspective. The specific methods of inquiry used are designed to draw out local explanations and lay concepts by focussing on the insider's interpretation of reality (Nyanzi *et al.* 2007). To elicit this perspective, ethnography typically utilises a number of strategically chosen methods of inquiry, which may include in-depth interviews, life-histories, focus groups, and vignettes for example (Bernard 2006).

The use of the researcher's experience is based on the assumption that many of the webs may be so deeply imbedded that they may be unidentifiable by the participants.

As a result, the ethnographer uses themselves as a tool through the processes of enculturation and detailed observation of everyday life. The method of participant observation, frequently used in ethnography, exploits the researcher's ability to objectively review their subjective experiences and observations to highlight potential areas of contextual significance.

The combination of both approaches creates depth in the findings, which Geertz (1973) refers to as 'thick description'. Others relate the use of multiple methods as a form of triangulation through which the researcher can get a "better fix on the subject matter in hand" (Denzin and Lincoln 1998:3). The quality of this 'fix' is essential, as ethnography in all its forms is inductive and hence theories are formed from the research, rather than the research testing pre-conceived theoretical ideas (Brazanger & Dodier 2004). Consequently, researchers are challenged to illustrate the confirmability and credibility of the theories they develop. Denzin and Lincoln (1998), suggest that triangulation is key to these alternatives to validation.

Despite a focus on the participant's perspective, and the objectivity inferred in participant observation, it is generally accepted that ethnography does not present the 'native's view' as suggested by early anthropologists such as Malinowski (1922). As with hermeneutic phenomenology, the particular researcher's influence on the collection of data and the analytic process results in an interpretive account of particular understandings, experiences or activities and their creation (Geertz 1973). Indeed, all qualitative research is fundamentally influenced by the subjectivity of the researcher (Hammersley 1992, Schweizer 1998). A strength of ethnographic research is that in centralising the role of the researcher in its methods and analysis, it accepts this subjectivity and attempts to highlight its influence through an honest presentation of its construction and bias (Scheper-Hughes 1992). Continuous checking of the influence of presuppositions through the use of reflexivity in the collection, analysis and presentation of data is part of this process.

4.3.3 Drawing on phenomenological and ethnography: methodology of choice

From the previous descriptions it appears that hermeneutic phenomenology and ethnography are compatible approaches. Furthermore, drawing on both approaches has specific relevance for achieving the aim and objectives of this study.

The literature review in chapter 2 highlighted the need to examine illness experiences in light of the specific cultural and social context in which they occur. Many qualitative approaches may explore the *emic* perspective of experience, but few of these methodologies also inquire into the conditions that mould that experience (Bourdieu 1990). The use of phenomenological and ethnographic approaches achieves both. The phenomenological interest in the individual is matched with the ethnographic study of context through which the complexity and inter-relationship between experience and context can be captured (Barry 2006, Gibbs 2002, Henderson 2005, Maggs-Rapport 2000, Mckevitt & Wolfe 2001).

Equally specific to this study was the geographic area of Central Aceh. One of the challenges of this research was to examine the experience of stroke within an area where very little related research had been undertaken and disseminated. Ethnography and phenomenology have been noted as being particularly suited to exploring such unknown environments, as they assist in identifying what information is perceived locally as important (Henderson 2005). They achieve this by emphasising the use of open and naturalistic approaches. One such is participant observation. This flexible and iterative approach to research has the potential to "reveal the unanticipated loose ends and discontinuities of everyday (which) are critical to a deeper understanding of social complexity" (Seymour 2007:1189). The depth and focus of phenomenologically informed interviews also centralises the subjective experience, giving space for the aspects the individual deems relevant (Moran 2000).

The focus on the contextualised *emic* perspective was particularly important in this research as the study considers aspects of life which have been pre-defined elsewhere. In this case, stroke and its care are well documented in a Western framework. A methodological approach that would decrease the influence of these *etic* conceptions and give space for alternative, local explanations was required. However, this focus on local explanations within context has led to criticisms that ethnographers have been satisfied with particularities, not examining the generalisability of their findings (Nichter 1992). I personally believe that such specificity is to some extent unavoidable. Both phenomenology and ethnography are

idiographic. However, it also describes how the particular is shared in more general patterns. As a consequence, larger cross-cultural regularities and differences can potentially be identified as different ethnographic accounts are compared (Knapp 1999).

A final justification for the utilisation of a phenomenological and ethnographic informed approach is their combined capacity to explore meanings and actions. Many research approaches, qualitative and quantitative, rely on verbal or written accounts alone. However, there is evidence that what people say and do are often different (Kristiansen & Santoso 2006). The combination of narrative accounts and observation can assist with the development of a more developed and multidimensional representation of events.

In summary, this study has methodologically drawn on both phenomenology and ethnography because of their specific ability not only to explore the subjective experience and subsequent behaviour, but to do so in a manner in which the influence of context and the dynamic interaction between that context, experience, meaning, and action could be examined.

As mentioned previously, multiple methods of data collection can be used in the approach adopted. In this study, participant observation of life in Central Aceh, semi-structured interviews with people with stroke, their carers, and healers were conducted. Photographic-facilitated interviews, focus groups, observation of healing encounters and vignettes were also used. Each was selected for its specific ability to gather data relevant to the objectives of this study. A detailed examination of each method, their justification and implementation will be given following an overview of the fieldwork period and an introduction to the participants of this research.

4.4 Fieldwork

The fieldwork for this study took 14 months over three years and consisted of three different phases. The first, as introduced in the chapter one, was opportunistic time spent in Aceh and other parts of Indonesia as a result of employment with Handicap International (see appendix 13 for further details on HI's work). This included two

discrete periods of time totalling seven months (five months of which occurred pre PhD registration). During this phase general information on aspects such as the Indonesian health structure, community organisation, role of religion in daily life and language and cultural skills were developed. Much of this knowledge facilitated phase two which was the main data collection period for this study. This occurred in 2007 over a six month period in which I was based exclusively in Central Aceh. During this phase I was employed by Handicap International as their part-time Central Aceh site manager, based in Takengon. I was employed to work for approximately 10 hours in a week, although these hours were highly flexible. This role was predominantly managerial, ensuring the smooth running of the office and local employees. Handicap International was both aware and supportive of this research agenda and my responsibilities with them reflected my data collection requirements. As a result, I was able to use office facilities, including vehicles to facilitate my fieldwork, and meetings, for example, were timetabled around my planned interview and observational arrangements.

In 2008 I returned to Takengon for a further six week period. This third and final phase, occurred after the data had been fully transcribed, translated and initial analysis undertaken. During this time I was able to follow-up a number of the participants and clarify aspects which were unclear from the interview, photographic and observational data. During this period I was not employed by HI, but continued to use their facilities with permission.

4.5 Participants

In this section the process of locating and recruiting the participants of this research will be discussed. After a note on the use of the term 'participants' and a general introduction to identification and recruitment, the section is split to consider the groups of participants separately. People with stroke are presented first; the process of identification and recruitment is given, inclusion and exclusion criteria, and the implications of those criteria on whom was selected. Confidentiality and consent issues are also discussed. This is followed by brief consideration of the carers. The healers are presented next. As different processes were used for biomedical and non-

biomedical healers, they are reviewed separately. The section ends with a presentation of the samples achieved.

4.5.1 A note on terminology

A number of different terms have been utilised when referring to people involved in research; participant, informant and co-researcher for example. Each may infer a particular power relation to the researcher, and involvement in the process or manner in which data was collected. However, no formal definitions are offered that are universally agreed and as a result the choice of terminology is largely left to the discretion of the individual researcher. In this study, data was generated through multiple means and therefore different people were involved in various ways. Some people were sought as experts in their field and the relationship was limited to that of the research, others became friends and information was shared through informal conversations and observations of everyday life. Many crossed into a number of categories being both experts and friends with the form of interaction changing as the research progressed. In writing this thesis, I have had to make a choice as to the terms of reference. The term participant was selected to refer to all people involved in data collection as it acknowledges the involvement of the individual in the creation of the information. However, the extent and manner of that involvement varied. Where names of participants have been used, they have been changed to maintain confidentiality.

4.5.2 Locating and recruiting participants

Two different approaches were taken to locating participants; specific selection applying inclusion criteria to a sampling frame, and opportunistic recruitment. For data on the stroke experience and the healers sought, purposive and snowball sampling was used. In the following sub-sections, the details of this process and the samples achieved will be given. The broader ethnographic data, most of which was presented in the previous chapter, involved observation and a significant amount of opportunistic data collection. In-keeping with ethnographic work, all social interactions were seen as a potential opportunity to explore particular phenomena. An indication of who was involved in that process was given in chapter 3.

All the participants lived in the two districts that border the town of Takengon, Aceh Tengah and Bener Meriah and interviews were conducted in those districts. All the data was collected by myself, assisted by a translator. Issues related to this are discussed shortly. The following description will focus on each participant group in turn.

4.5.3 People with stroke

Stroke can result in problems that would make involvement in research of this kind difficult. As a result some inclusion and exclusion criteria were set prior to identification and recruitment of participants. In the following section the identification process will be described followed by the recruitment of participants.

4.5.3.i Identification

Given the fact that people who had experience of stroke were the target of this research, it was necessary to use purposive sampling. As there was no database available at either the hospital or the *Puskesmas*, information from Handicap International (HI) was used to develop a sampling frame. HI maintained a list of identified people with disabilities in the region along with selective information such as the diagnosis. All those with a history of stroke were highlighted and a database created which recorded relevant information like age, sex, Barthel score, and ability to communicate. In total 139 people with a diagnosis of stroke were included and became the sampling frame used for the identification and recruitment of potential participants.

Potential participants were identified either by myself or by Handicap International's community workers who were fully briefed on the research methods and criteria. At the initial stages of the research, contact with potential participants was made as a result of other activities related to HI, whereas at the later stages of data collection, younger people were specifically targeted. The purpose of this was to try to capture the experiences from a range of perspectives. Research in the West has indicated that people with stroke at younger ages identify different difficulties and needs (Intercollegiate Stroke Working Party 2008) and therefore I deemed some representation of these voices pertinent.

4.5.3.ii Recruitment of participants

Prior to recruitment being initiated clear inclusion and exclusion criteria were developed.

4.5.3.ii.a Inclusion criteria

In all cases participants needed a diagnosis of stroke by a physician in order to be included in the study. However, participants had no formal documentation of their diagnosis. Therefore in addition to the verbal report of stroke, I made a brief assessment to ensure that participants had symptoms and a history that would be in-keeping with the WHO STEPS Stroke Surveillance criteria (2006a and b, summary in appendix 1).

4.5.3.ii.b Exclusion criteria

Those with serious language and cognitive problems were excluded from the study, due to issues with consent and the communication requirements necessary for the methods chosen. Because of a lack of access to screening tools or appropriately qualified professionals, a pragmatic approach to the judgement of language and cognition was taken; if the person was able to consent, following the consent guidelines, and was able to participate in conversations and express his or her ideas, they were included. As a qualified health professional with over 15 years of experience, and particularly working with stroke, I was able to undertake this assessment. The restriction of language and cognitive screening may have resulted in people with mild language and cognitive problems being included. This may have led to some problems when personal or more abstract/ complex thoughts were being discussed. Equally, I acknowledge that it is possible that mild language and cognitive problems may have gone undetected, which may have had an impact on the data collected.

4.5.3.ii.c Implications for type of stroke

The use of exclusion and inclusion criteria necessarily means that some people are not represented in the study and it is worth reflecting on the implications of this for stroke types and severity. The first, as noted above, is that people with significant cognitive and language disorders were not included. Equally, those who had very minor physical symptoms without hemiplegia were also not represented, as well as

those with signs more indicative of posterior circulation stroke[8]. This suggests that people with the extremes of symptoms following stroke, both mild and severe are missing voices in the data that follows. This is unfortunate as the exclusion of sub-groups in stroke research, particularly those more severely affected with cognitive and communication difficulties has been noted in the literature (Gillen 2005, Murray & Harrison 2004,). However, in the context of Central Aceh, such exclusion is extremely difficult to avoid even if resources and specialist communication professionals are available. The reason for this is simple; people who suffer severe strokes with sequelae that may result in medical complications, such as swallowing and severe cognitive problems, and require very high levels of care, rarely survive the sub-acute period. Like other stroke data, mortality data is not available in the region, however observation of the people with stroke identified through HI, indicate a lack of people generally with very severe levels of disability. At the other extreme, those with very mild, or resolved symptoms were equally not identified. The reason for this may in part be as a result of the database developed. HI's data is community based and identifies those with residual disabilities; those with no functional difficulties would not be included in this data. Equally, those with resolved symptoms may never have received the diagnosis of stroke.

Once potential participants had been identified the recruitment was initiated. In all cases I conducted the recruitment process, which included an assessment of the criteria stated above. Nine people were excluded for a number of factors, such as recent diagnosis of cancer with considerable emotional trauma, combined untreated severe mental health problems that did not allow for conversation, and a non-professional diagnosis of stroke which could not be verified by STEPS criteria.

4.5.3.iii Confidentiality and consent

All those identified as suitable for inclusion were given a research information sheet which had been translated into Bahasa Indonesian (appendix 2). This study was reviewed by the ethics committee at Brunel University and in line with ethical requirements, the information sheet includes details of the research, its voluntary

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[8] Stroke involving the posterior circulation often result in a wide variety of symptoms such as visual, balance and coordination problems often without a distinct hemiplegia. They are estimated to include around 24% of all infarcts, which make up 80% of all stroke types (Bamford *et al* 1988, 1991)

nature and specifics on confidentiality. In some cases participants were unable to read this sheet and in these instances it was read to them by a carer. All were given the opportunity to ask me any additional questions. Following this a consent form was signed (appendix 6) in the presence of a witness and carers. On two occasions the participant themselves were unable to sign the form. In those circumstances they gave verbal permission for the carer to sign on their behalf, which was witnessed. A further consent form for photographs was also signed.

This process led to the recruitment of 11 people with stroke. A summary is shown in diagram 2.

Diagram 2 Recruitment of people with stroke
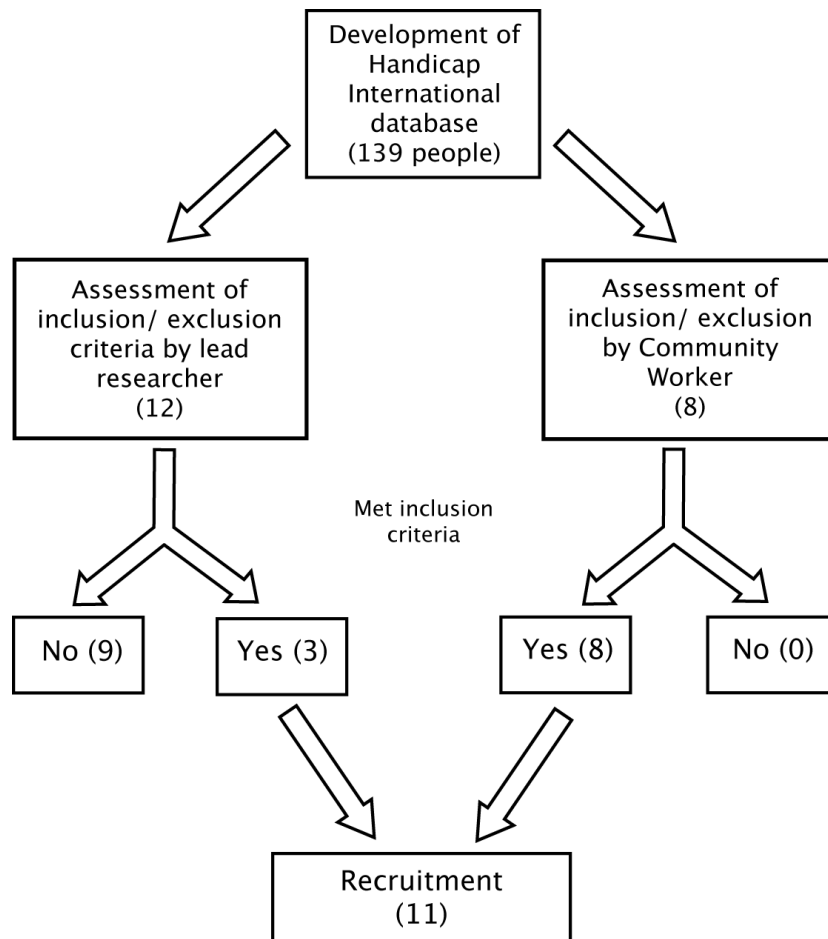
Recruitment outside of the process described was attempted through other organisations as well as snowballing. However, these methods were unsuccessful as those identified were either already known or did not meet the inclusion criteria.

4.5.4 Carers

The inclusion of the carers was more straightforward. In this study a carer referred to a person who ensured activities of daily living and the personal needs of the person with stroke were met. They were identified by the person with stroke.

4.5.5 Healers

An important aspect of this research was to capture the various views and activities of all people who are involved in the remediation of symptoms of stroke. From previous experience in the region, I was clear that it would involve a number of different categories: doctors, nurses, therapists and traditional healers (*dukun)*. These are collectively described as healers.

The healers for this study were identified by a mix of purposive and snowball sampling. Such sampling was necessary to ensure that the healers had active experience of working with people who have had a stroke. The different types of healer were identified through various means and will therefore be considered separately

4.5.5.i Biomedical

The variety of biomedical healers included was based on those identified by people with stroke as being active in their care post-stroke. As a result, doctors were recruited from the primary health care centres (*Puskesmas*) and the hospital and *bidan* (midwives) and nurses, both clinic and village based were included as they were often referred to by families and people who had had a stroke. It is important to note that in Indonesian health care, the *bidan*, particularly the *bidan desa* (village midwife) have an extended role to that experienced in the West. *Bidan desa* specifically are the only government provided village based health professionals and are therefore sought for almost any medical problem. Physiotherapists were recruited from hospital, *Puskesmas* and Handicap International (HI).

These biomedical healers were mostly identified through purposive sampling. I directly contacted every physiotherapist known to work in the Central Aceh area. This was relatively straightforward as there were very few and the physiotherapists of Handicap International were aware of all of their professional colleagues in the region. Other biomedical staff, who worked in the sub-districts included in this study,

were directly approached to participate. The head of each *Puskesmas* in the sub-districts covered was approached. Once general permission was given individual practitioners were identified, often with the recommendation of the head of the *Puskesmas*. Snowball sampling was used in the case of the hospital doctor as he had been specifically mentioned by a number of the people with stroke. Prior to contacting him, permission was gained from the director of the hospital.

All potential participants were initially given the participant information sheet (appendix 3) and the opportunity to ask questions. In each case this was done in person by myself. Having had informal agreement, the formal process of consent was completed. In total 15 biomedical healers were involved in this research. Details are given in the section on samples achieved.

4.5.5.ii Traditional and alternative

As traditional and alternative healers work outside mainstream health providers they were more difficult to identify independently. As a result snowball sampling was used. This mainly occurred through information from people who had had a stroke. Two were identified through other contacts in the community. Once identified it was necessary to clarify that they did indeed work with people who had strokes, so further purposive selection could occur.

The manner of approaching these healers for the purposes of the study differed. Some were directly contacted by the person who had had a stroke, others by the community workers and some by myself. The approach most suitable for each case was adopted. Once approached, they were all verbally given the outline of the research and a copy of the participant information leaflet for healers (appendix 3). On initial agreement, an appointment was made for me to come to a site of their choice and the formal consent process was completed. In total, five traditional and three alternative healers were involved in the research process.

In the following chapters, traditional and alternative healers are often collectively referred to as *dukun*, as this was the term often used by the people with stroke. This is done in full knowledge of the huge variations within the group. Where the generic name creates confusion, clarification of the specific type of healer if known is given.

4.5.6 Samples achieved

In total 51 people were involved in the specific data collection process in this research. This included 11 people with stroke, 18 carers and 22 healers. A summary of the people with stroke and their carers is shown in table 4. The healers are shown in table 5 on the following page[9].

Table 4 People with stroke and their carers

Participant		Age (years)	Date of 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

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[9] The Barthel Index is a measure of function in Activities of Daily Living covering 10 activities. A higher number indicates better levels of function with a maximum of 20 (Mahoney & Barthel 1965, Wade 1992)

Table 5 Healers

	Participant	Practice category	Practice name	Years of practice	Sex
1	Yesi	Biomedical	Community Physiotherapist	3	F
2	Diah	Biomedical	Community Physiotherapist	1	F
3	Fitri	Biomedical	Community Physiotherapist	7	F
4	Hasnah	Biomedical	Hospital Physiotherapist	2	F
5	Adi	Biomedical	Hospital Physiotherapist	5	M
6	Yanti	Biomedical	Hospital Physiotherapist	2	F
7	Zara	Biomedical	Hospital Physiotherapist	3	F
8	Heri	Biomedical	Hospital Physiotherapist	3	M
9	Zaiful	Biomedical	Hospital Physiotherapist	6	M
10	Tika	Biomedical	Midwife (*bidan*)	15	F
11	Wijaya	Biomedical	Nurse	19	M
12	Putri	Biomedical	Village midwife (*bidan desa*)	10	F
13	Dr. Maya	Biomedical	*Puskesmas* doctor	1	F
14	Dr. Guntur	Biomedical	Hospital doctor	15	M
15	Karina	Traditional	Village teacher	3	F
16	Budi	Traditional	Village *dukun*	36	M
17	Armisar	Traditional	Village *dukun*	40	M
18	Wenny	Traditional	*Mamak* (mother)	12	F
19	Farah	Traditional	*Mamak urut* (masseur)	5	F
20	Ismail	Alternative	Alternative	7	M
21	Abdul	Alternative	Traditional or alternative	20	M
22	Paujan	Alternative	Alternative	1	M

A few details about this sample are important to note. Firstly, there was some indication that four of the participants might have had mild communication difficulties. In three of the four, other family members frequently spoke on their behalf, potentially masking their own communication difficulties, although it is possible that they were simply being spoken over. The fourth was very often slow to respond, and when he did, sentences were often short and broken. However, in all cases, the fluency of conversations within the interview fluctuated and in most cases during the second interview, the person illustrated a more fluent ability to converse and less interruption by his or her family. As a result, it was felt that none presented signs significant and consistent enough to warrant the exclusion of their data.

In relation to carers it is important to recognise that the UK model of social care does not apply in the Indonesian context. The government is not responsible for any care outside the health system. Carers were in all cases family members. However, it was apparent that this was rarely a role allocated to one person. While the spouse was

often the carer, frequently, it was a shared responsibility amongst the whole family. This is in-keeping with the findings of a previous study of elderly in Indonesia (Schroder-Butterfill 2002). As a result 'carer' may refer to more than one person.

A point of interest was an apparent lack of sex bias in the role of carer (shown in table 4). Wives were always the main carer when present. In the case of a woman having a stroke, the husband, if present, was also the main carer in all but one situation. But in the absence of a spouse, children of both sexes were equally involved. Indeed, it was clear that even in intimate care, like bathing and toileting, caring was not isolated to same sex.

4.6 Methods of data collection

The challenge of this study was to explore the understandings and behaviour of the participants following stroke, alongside the broader influences on their lives. Hence, it was important to give space for personal explanations and experiences and equally imperative to develop a picture of how those evolved and interacted in reality. As described at the start of this chapter, phenomenological ethnography facilitates the study of both through the use of a number of inter-related methods. By using numerous tools to facilitate access to the experience of the people studied, it was hoped that the subject matter in hand could be seen from different angles, developing a richer tapestry of disclosure (Denzin & Lincoln 1998, Hammersley & Atkinson 2007).

In this section the specific methods used in this research are described in detail. It starts with a consideration of translation, which permeated all aspects of the research and a description of participant observation which was a method employed throughout the research. This is followed by an overview of the participant's research journey and then specific details of the other methods selected. These include: depth interviews with people with stroke and healers, photographic facilitated interviews with people with stroke, focus groups for the physiotherapists, vignettes for the healers, and observation of specific healing episodes.

4.6.1 Translation

Prior to undertaking the fieldwork, I studied Bahasa Indonesia, the national language of Indonesia. While not fluent at the point of arrival, my command of the language was sufficient to understand the majority of what was said to me within context and to ask and answer basic questions. However, I felt that this might not be sufficient for the type of research I wanted to conduct. As a result, all interviews were done in the presence of an interpreter. Three were used over the period of field work as a result of turnover. They were all from Aceh, fluent in Bahasa Indonesia, English and another local language, either Gayonese or Acehnese. All were fully briefed on the research, the approach of encouraging the participant to tell their story and the process of consent and confidentiality.

The turnover of translators was recognised as not ideal, as the relationship between translator and researcher takes time to build and may potentially lead to an inconsistency in the interview process. All attempts to ameliorate the disruption were made. For example, previous interviews were discussed to highlight the flow and potential challenges in translation, systems of signalling were developed prior to going into the field in case of difficulties with speed or content, and considerable social time was spent with each to facilitate understanding of personal mannerisms.

The change in translators had some advantages. All had their strengths and weaknesses and the change resulted in potentially less consistent bias on the study. Significant to this was that they were a mix of male and female and ethnic backgrounds. This facilitated my observations in general social interactions and had a direct impact on some of the interviews. In one case an informal observational visit with a female participant and female translator led to discussions about difficulties toileting and dressing. These were topics that had not been raised in previous interviews with a male translator. Further issues relating to language and how data were managed is described later in this chapter

4.6.2 Participant observation

Participant observation is the preferred method most associated with ethnography, to the extent that some authors equate the two (Bryman & Teeran 2005). It describes a process of data collection in which the researcher immerse him or herself in the daily

lives of the people under study, but equally removes themselves in order to intellectualize the experience (Bernard 2006). It is generally accepted that it is most effective when the researcher remains within the community for a prolonged period of time and is familiar with the local language. Through this, the researcher attempts to observe and record information that evolves in its natural setting. The purpose is to "stalk culture in the wild" (*ibid*:344) and in doing so develop a rich and broad understanding of the world in which the people under study both live and create.

However, there is little agreement of what specifically constitutes participant observation and recently researchers have been challenged to reflect on the extent of their participation and observation (Dewalt *et al.* 1998, Dewalt & Dewalt 2002). In this research, I engaged in 'active participation'. I lived in a basic house, shopped regularly in the local market, and enthusiastically joined in with community activities. I ate in the street stalls, went fishing in the lake and smaller ponds and joked with the farmers planting the *padi* (rice) as I walked around the neighbourhood. I was also subject to the vagaries of the local environment. I regularly got drenched, my electricity was as erratic as my neighbour's, and fled my house or office as quickly as any other when earthquakes occurred which they did regularly. Through all of that participation, I observed and experienced life. However, despite this I am under no illusions that my participation was complete. My status was privileged. I had access to a vehicle, a mobile phone and an extensive support and security network. My accommodation was basic, even by local standards, but I lived alone in a home built for a family. I also lived in the town rather then the villages where most of participants in this research were based. I have no doubt that for many people in the community I was accepted as their neighbour and friend, but I was always somebody different, and all knew that at some point I would leave.

In addition to my interaction within the general community, I also used participant observation in my work environment and through the more formal aspects of the research which are described shortly. Within the interviews themselves I observed how people responded to questions, who attended to which answer and body posturing for example. More generally I observed the family interactions during the interview period, for example who gave the request for coffee, who made it, who was

served first. The environment in which the interview occurred was also examined, where we sat in the house, who sat with us and who did not, what furniture was there and what was on the walls.

Beside the interview informal interactions with the people with stroke, their families, healers and government officials were common. I attended the weddings of their children, walked around their *kebun*, ate meals with them, played with their grandchildren and kittens, or just popped in to share coffee when I was passing. These interactions were invaluable in the research process. As friendships grew, so the ease of discussions increased. Reactivity to me as researcher was reduced. Furthermore, information raised in the formal interviews was clarified and more personal details added to the depth of data.

These observations and interactions were documented through extensive field notes and audio recording when possible and appropriate. I frequently checked details with my translator to improve the accuracy of recall. Notes included records of what was done in the day including places and people met, what was observed, informal conversations that were held or overheard, and my response to the situations encountered.

4.6.2.i Participant observation and ethics

Ethics is an important consideration for all research but the use of participant observation poses some unique dilemmas for the researcher. Formal interviews and other anticipated interactions can use consent forms relatively effectively to ensure that the participant both knows what is being requested of him or her and consents voluntarily. The use of these is discussed later in this chapter. However, participant observation is necessarily less formal and predictable and encompasses different levels of trust and disclosure over time (Parker 2007). Indeed, Bernard (2006:369) suggests that it inherently involves deception and "impression management", which are replaced by the euphemism of 'gaining rapport'. Researchers conducting participant observation want those around them to forget they are being researched in order that they share the richest data possible. Confronting this is both essential and difficult.

Standard practice of providing anonymity is one approach to protect participants, however it does not adequately ensure consent in the research process. In this research two approaches were taken. For all participants who were formally recruited, the participant information sheet (appendix 2 and 3) explicitly stated that observation would be an integral part of the research. This included healing episodes, but also referred to everyday life activities. The second approach was more general and involved the overt advertisement that what was being undertaken was research, as suggested by Dewalt & Dewalt (2002). On introducing myself to my neighbours, work colleagues, community leaders, and others I explicitly highlighted my role as researcher and my desire to understand more about their lives. I did not repeat this information on a regular basis, but occasionally pulled out my note book during conversations, sometimes referring to previous information I had noted as a way to stress that ongoing role. This process is not without limitations and there is no guarantee that participants were fully informed that the information they gave during informal encounters would be included as research data. However, I believe the process used was the best compromise between the informed consent of universal ethical standards and the practical application of the method of participant observation.

4.6.3 Participants' research journey

4.6.3.i People with stroke and their carers

Each person with stroke and their respective carers were involved in a number of stages in this research. They were invited to participate in in-depth interviews, photographic facilitated interviews and observations of both treatments and general life. As a result of these multiple stages, participants were visited on a number of occasions, varying between 2 to 6 visits. In addition, some participants were met informally through weddings, *puasa,* or other social events. A summary of the formal aspects of their research journey is given in diagram 3 overleaf, although general observations were undertaken at all stages.
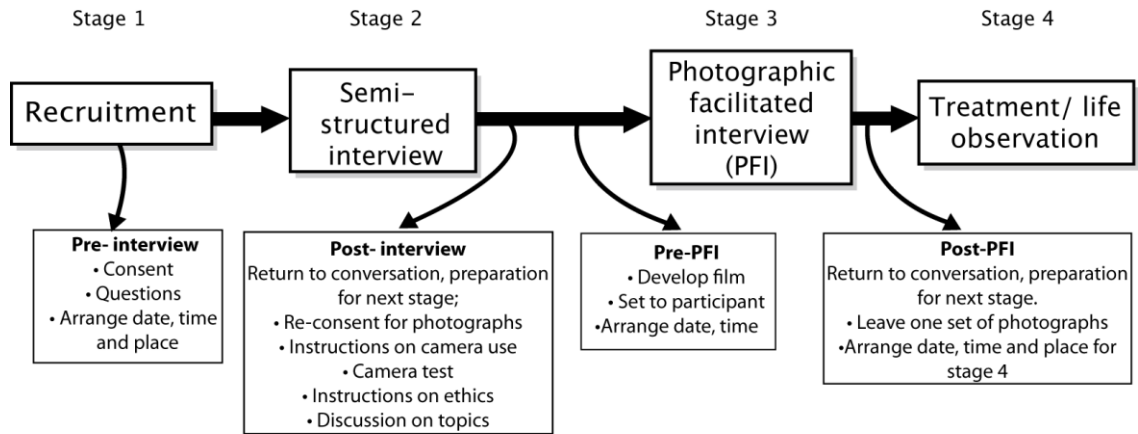
Diagram 3 Research journey of people with stroke

4.6.3.ii Healers

The healers were equally invited to participate in a number of research activities. These included semi-structured interviews, focus group discussions, paper vignettes on stroke cases and observed treatment sessions. A summary of the healers research journey is given in diagram 4.
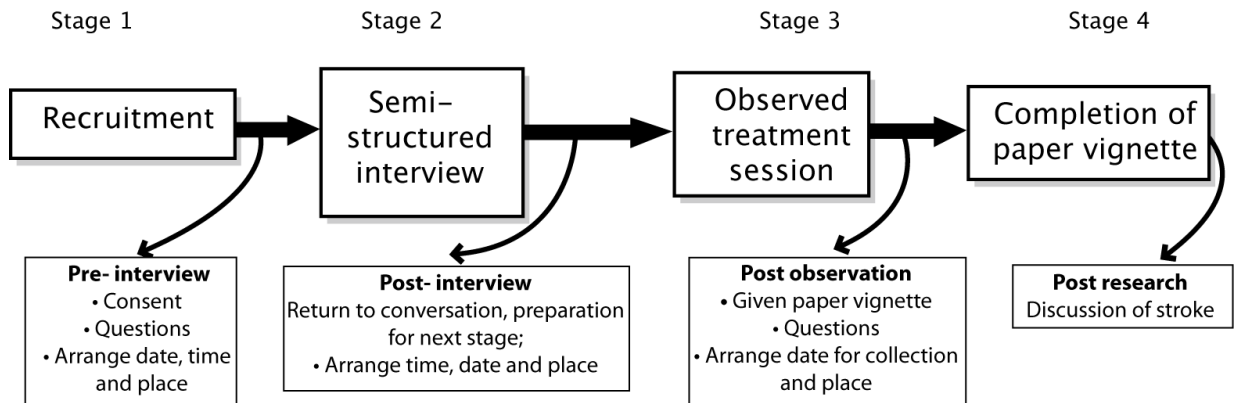
Diagram 4 Research journey of healers

4.6.4 Depth interviews

In order to elucidate the experience of stroke, a method that can capture both depth and the complexities of people's accounts is required. Evidence suggests that predetermined categories can limit the range of response (Patton 1999). It may also be constrained in group interviews where sensitive and personal information may not

be shared. Therefore in-depth semi-structured interviews with people who have had a stroke, their carers and healers were the primary tool of research.

Miller and Crabtree (1999:107) note that "good depth interview research preserves the multivocality and complexity of lived experience". Through the interviews an attempt is being made to document the individual's reality in his or her terms. There must, however, be some evidence of the 'good' and the 'depth' in the interview. Acknowledging this, there are two broad areas that were considered: the interview structure, and the context of the interview.

4.6.4.i The interview structure

Each interview had its own internal structure, dependent on the wishes of the participant, but there was a general format which all followed. This involved a pre-interview phase, the interview itself, and a post-interview phase.

4.6.4.i.a Pre-interview phase

The pre-interview phase had many variations. For example, in one, the interview could not begin until we had all had coffee and snacks, a sign of their hospitality. In another, certain members of the family were gathered before initiating questions. However, certain aspects in this stage were consistent to all. Firstly the purpose of the research was re-explained. Prior to the consent form being signed (see appendix 6), questions were asked and answered. This allowed the participants an opportunity to clarify points. Without exception participants had read, or had had the information sheet read to them (appendices 2 and 3) and had a number of queries. Most of this was regarding the potential cost of the photographs, or their confidentiality, but others also questioned the value of their input. Conversations were had amongst the family and time was given for this prior to the consent form being signed.

This part of the interviewing process, the pre-interview discussion, is rarely highlighted in the literature. However, in this study it was an essential part of the process to ensure the quality of what followed. Without assurances of the value of their stories, their ability to remain anonymous and with no cost implications for them, what followed would have been potentially very different. It was also an opportunity for me to discuss my role as the researcher and my links with HI. The

time that lapsed during this process also allowed everyone involved to shift positions, both physically and within the room and to settle into the rather strange rhythm of talking with translators.

Far from remaining a theoretically neutral researcher, I allowed myself to become involved in personal questions. Did I like the area? Don't I find Takengon cold? Where was my husband? And the such like. My experience of Asia indicates that questions of this kind are routine introductory probes. I was careful not to say anything contentious, but being open to such questions and answering honestly and often with humour was both culturally appropriate and further facilitated a more relaxed atmosphere. The issues relating to the researcher in the interview and me as a researcher are developed later.

The consent form was signed once all questions had been answered and once I was satisfied that there were no reasons for exclusion. The formality of the form was occasionally rather difficult and my way of dealing with it varied. Initially, I had given it to the participants to read, answering further questions when they arose. As I understood more about the issues they identified, I gave clearer explanations prior to giving the form. This resulted in less disruption to the conversational type atmosphere that had developed. Once that was completed, the audio recorder was switched on and placed clearly in view. Having believed that being recorded might be a point of reticence, I was surprised and relieved to find that the participants were not apparently concerned by its presence and no-one refused its use.

4.6.4.i.b The interview
Stage two was the interview itself and involved a series of conversational questions based on the interview guideline shown in appendix 4 (people with stroke and their carers) and appendix 5 (for healers). The guidelines were developed considering the areas that I believed were significant in the experience of stroke. Some of these themes had been identified in the literature on stroke as described in chapter 2. For example, the understanding of the cause of stroke itself, the meaning of the word, and concepts of recovery. The order changed dependending on the flow of the conversations. Other avenues, opened by the participant were also followed. This included discussions on the social expectations following divorce, the importance of

education, and family structure. However, for all, the basic themes in the interview guidelines were covered.

4.6.4.i.c Post-interview phase

The post interview phase occurred once all questions had been completed. All the participants were thanked, not only for their participation, but for their hospitality as well. More general questions directed to me invariably followed, about the research, stroke in general or me personally and time was taken to answer these. More coffee was drunk, invitations to stay, to marry their sons, and visit frequently were given. This focus on me as the guest acted as a return to a more normal balanced conversation and often served to stabilise any awkwardness the interview had created for the participant. Follow-up activities, if required, were arranged and explained prior to departure. At this stage, the healers particularly asked me questions about my experience with stroke. Often they wanted me to explain how I would approach treatment of people with stroke, what medications we used in the UK and whether I could provide them with machines to help them with their work. In these interviews is was apparent that I was a peer, a professional colleague and an opportunity for them to extend some of their understandings as I had mine. I reciprocated in answering their questions as honestly as I could, but took care to do so after the research process had been completed. In many cases this resulted in me visiting healers specifically to have a conversation in which I was key informant.

4.6.4.ii The context of interviews

Outside the structure of the interview itself, thought was given to the environmental context of the each interview and how that might influence the quality of the interaction. Firstly, the interviews were done in the location of the participant's choice. For all people with stroke this was in their home. The healers were interviewed at their place of work, although for the traditional and alternative healers this was also their home. Such an approach allowed an ethnographic component as the verbal responses were complimented with observation. This contextualised the information received, but equally influenced the very questions which were asked (Knapp 1999, Spradley 1979). For example, mobility aids and medication which the person with stroke had been given, purchased or made, were often visible in the room, prompting questions about their use. Watching how people responded to

questions, who attended to which answer, body posturing for example, were all noted and became part of the data for analysis. Further observation of the family interaction: who gave the order for coffee, who made it, where we sat in the house for example were all noted. Such observations were documented during the interview and developed immediately after the interview and within the transcription of the verbal data.

Secondly, the interviewee was in control of who was present during the interview. In all but one case this involved the main carer(s) being present. More frequently, several members of the family were present, with neighbours and children moving in and out. These additional participants naturally had an impact on the story being told and who was doing the telling, a point demonstrated in later chapters. But they equally had a 'normalising' effect on what is a rather strange encounter. Interviews, with their forms, note taking, and tape recorders are not normal events in any household. Yet, by having a selection of other people present, other, more usual interactions often occurred simultaneously. Coffee was ordered, children were fed, jokes were made in and around the interview. The informality that was created facilitated the conversations at one level. They did, however, also pose some difficulties with flow. Pauses in the questioning were inevitable as neighbours arrived and a joke was made about me, the *buleh* (foreigner)*,* sitting on the floor. Having had considerable experience working in Asia prior to this research however, such interruptions were managed reasonably easily, gently guiding the conversation back to the topic at an appropriate juncture.

Despite my statement that the interviewee was in control of who was present, it is important to raise a question regarding control and agency. Research has indicated that people with disabilities are both often disempowered as decision makers and often have others representing them (Coleridge 1993, Sneeuw *et al.* 2002). Equally, gender roles in Asia have been shown to have an impact on representation (Siapno 2002). It is therefore perhaps presumptuous to suggest that the person with stroke was in control of who was present. Without doubt, the person with stroke did in some circumstances argue with someone else present, but did not ask them to leave. This could be interpreted as an indication of their disempowerment or simply an indifference to that's person's presence. Equally the sense of hospitality in Indonesia

is very strong. None of the relatives/neighbours who wandered in were requested to leave. In fact conversely, they were invited to sit and the interview was disrupted as coffee was made. As a result it is difficult to know exactly what 'choice' means in this context. Two points are clear though, I as the researcher never requested the presence or removal of any particular individuals, therefore the decision, as much as there was one, was that of the participant, and on the one occasion when the interviewee did not want someone present, she clearly requested them to leave.

Part of the contextualisation of the interviews was the presence of myself as the interviewer. The reflexive process of considering the influence of this is considered separately later in this chapter. It is also possible the questions that I chose ask in the interviews and the observations I made, would equally be influenced more generally by my presuppositions, my agenda, my cultural and social influences. While the measures discussed previously were aimed to limit this, a further tool - a photographic facilitated interview, was used to try to counteract this influence.

4.6.5 Photographic facilitated interviews

The photographic facilitated interviews were a second round of interviews which all people with stroke were invited to complete. All but two participants agreed to complete this stage. The use of photographs within the interviews was chosen primarily to increase the participation of the people being interviewed and to potentially explore different information (Rapport *et al.* 2005).

The literature on photographs within interviews is varied and coins terms such as photovoice (Baker & Wang 2006, Wang & Burris 1997, Wang & Redwood-Jones 2001), Photo-Elicitation Interview (PEI) (Clark-Ibanez 2004) and autodriven photo elicitation (Samuels 2004). It covers photographs or images previously produced (e.g. media), taken by the photographer or by the participants themselves. For this study, as I was particularly interested in the persons' experience of stroke, photographs taken by the person with a stroke or their carer were chosen as the most appropriate method.

Cameras are not universally available in rural Indonesia and as a devoutly Islamic region it was anticipated that there may be some cultural inhibitions with taking or

being in photographs. This proved not to be the case and indeed photography was generally seen as a source of interest and excitement.

4.6.5.i Instructions and procedure

After a specific consent form was signed (appendix 6), a disposable camera was given to each participant. In each case this occurred at the conclusion of the initial interview. Instructions on how to use the camera and a demonstration was given to both the person who had had a stroke and at least one of their carers. A discussion about the ethical considerations of taking photographs of other people and the need for their consent was also conducted. This included the need to ask permission of individuals prior to taking their photograph, explaining the purpose of the photographs, and avoiding sensitive sites such as official buildings.

Photographs with instant cameras are not technically difficult to take and research with children and people unfamiliar with cameras have utilised this technique effectively (Clark-Ibanez 2004, Jurkowski & Paul-Ward 2007, Samuels 2004). However, while it was possible for the person to take pictures one handed if outside, if a picture was desired inside then it required two hands to activate the flash. For all participants, this required the carer to take the picture, due to their own physical limitations as a result of the stroke. This was discussed and it was reiterated that the choice of the picture should be that of the person who had had a stroke.

The participants were not given a list of things to photograph, but were given some guidelines on topics; including what made them happy, sad and what they would like to be able to do (the list of guidance topics is given in appendix 7). These were chosen as topics which could facilitate further insight as to the impact of stroke induced disability and where and from whom they have sought assistance. But it was hoped that such guidelines would also give them enough flexibility to choose their own priorities of image.

Once the camera film was complete (27 pictures), cameras were returned and the pictures were processed with two copies being made. There was no financial cost to the participant. One set was returned to the participants and they were asked to choose the photographs that were most significant for them. They were further asked

to label these photographs with an appropriate title. These chosen photographs formed the basis of the second interview, where the content and meaning was explored.

In this second interview the participant was asked to select each chosen photograph in turrn. They were then requested to explain what was shown in the photograph, its meaning and why they had selected that specific image. This process led to personalised descriptions of aspects of life which had significance and allowed the participant to direct the interview, not being constrained by my agenda. In some instances particular features in photographs were not spontaneously discussed. In these cases I asked the participant about the relevance of the feature. For example, in one the participant was sat in a wheelchair, but the wheelchair itself was not raised in his description. Such probing facilitated further discussions and clarification of the most salient aspects for the participants themselves.

These interviews were audio-recorded and the verbal descriptions were used as the basis for further textual analysis, alongside the data from the first interviews. The process of this analysis is described later in this chapter.

There was naturally a time delay between the photographs being taken and the following interview. This time delay had two potential consequences. On one side, the space between taking the photographs, receiving them and returning for discussion allows time for the participants to reflect. By using a tool that they have to use and then later return to, time is given for the participants to select their narrative choices. This has the advantage of hearing their main considered points, not just what they remembered at the time of the interview (McKevitt 2000, Rapport *et al.* 2005). However, priorities change as situations change and often the narrative choice at one moment is not the same in another (Castleden *et al.* 2008). This is particularly the case if there is a long gap between stages of research, or if the participants have conditions which are either fluctuating or create difficulties with memory. In this research every attempt was made to complete the photographic facilitated interview as quickly as possible once the photographs were processed. In all but one case this occurred within two weeks.

4.6.5.ii Gains and dilemmas from photographic use

There are a number of potentially significant advantages of photographic facilitated interviews, which theoretically at least made it a method of choice. Firstly, they can increase the volume of the participants' voice (Baker & Wang 2006, Castleden *et al.* 2008, Clark-Ibanez 2004, Collier 1967, Jurkowski & Paul-Ward 2007, Lopez *et al.* 2005, Rapport *et al.* 2005). For example, by using their images to direct later interviews, the issues that the participants themselves felt are relevant can become the focus of the interview. In doing so, they set both the question and the answer. This was essential to try to counteract the commonly placed criticism of *etic* control over interviews and interpretative meanings which are dictated by the interviewer rather than the interviewee. As Wang and Burris (1997:382) state "such an approach avoids the distortion of fitting data in to a predetermined paradigm: it enables us to hear and understand how people make meaning themselves or construct what really matters to them". Samuels (2004) further adds that such an emphasis on the participants' world assists in the bridging between different cultural realities and the breaking of the researchers frame of reference.

Such 'breaking of frames' was evident in the use of the photographs in this research. The choice of images was varied between participants and covered aspects not previously alluded to in the earlier interview. Both in the images taken and in the choices that followed, the priorities of the participant were evident. A number of common themes emerged which are discussed in later chapters, but these themes were not directed by myself. For example, many took pictures in the coffee plantations, yet at no time had we suggested that they might like to take pictures of their work place. Equally, it was clear on discussion that the reason for taking those images varied between participants.

Many users of photographic facilitated interviews comment on their capacity to access areas of the participants lives that a researcher would never see. As a result previously invisible aspects of their lived experience become a point of discussion (Baker & Wang 2006, Clark-Ibanez 2004, Collier 1967, Gold 2004, Samuels 2004, Wang & Burris 1997). This was certainly the case in many of the interviews. Relationships of the body and health with heat, body image and the impact of using aids; the importance of having a role, were all aspects of their life with a stroke that

became much more clearly illustrated with the use of the photographs than with the first interview alone.

Photographs in interviews have also been shown to have a positive impact on the flow of discussion. By having an object of concern within an interview, the emphasis is taken off the participant's themselves and placed onto the object (the photograph). This has been shown to facilitate discussion of potentially sensitive subjects and also allow development of more emotional charged responses (Clark-Ibanez 2004, Collier 1967, Samuels 2004).

4.6.6 Focus groups

Focus groups have a variety of forms, but are recognised as having a few key features. These include a focus of subject matter, the involvement of a group in the interview, and set questions which direct the discussion alongside flexibility to probe answers when appropriate (Stewart *et al.* 2006). In this research focus groups were used in conjunction with individual interviews for the physiotherapists and were selected for two specific reasons. The first was because of the capacity of focus groups to explore the ideas that a particular group may hold as well as the variations that exist within that group (Dawson *et al.* 1993, Morgan 1997). This was particularly pertinent for the therapists as they had varied training experiences and different settings of their work. The second was to facilitate the inclusion of data from the hospital physiotherapists who were reluctant to have individual interviews. This was as a consequence of their lack of confidence in the subject of stroke, but they consented happily to having a group discussion which included many of their colleagues. Two focus groups were run as part of this research, covering two different groups of physiotherapists, those that worked in the community and those that worked in the hospital.

4.6.6.i Selection of focus group participants

Six to ten people have been recommended in the literature as an appropriate number to include in focus groups (Brown 1999, Bryman & Teeran 2005, Greenbaum 2000, Morgan 1997), however, in both of the groups held the numbers were a little lower. Five were involved in the group of hospital physiotherapists, but only three in the community group. In total, there were five qualified physiotherapists known to work

in the community in the region covered by the research. All five had agreed to join the focus group, but two did not arrive at the designated date and time. It was decided to continue, although it was accepted that the number was very low and as a consequence the discussion may not have resulted in the same level of interactive discussion facilitated by larger focus groups.

There is much discussion about who should make up such groups and the advantages and disadvantages of certain mixes (Brown 1999, Morgan 1997, Tynan & Drayton 1986). For the purposes of this study and practicalities of the area, natural groups were utilised. This may have resulted in some issues of pre-existing interaction styles and possibly some status issues, although the hierarchy of the paramedical professions in Indonesia is not as complex as that in the UK.

Each focus group was held in the meeting room of the Handicap International office and ran to a similar structure. They were conducted in Bahasa Indonesian in the presence of a translator. After a general introduction as to the purpose of the research and the focus group within that, each participant was given a participant information sheet (appendix 3), a consent form (appendix 6) and a basic biodata form to complete (appendix 9). Any questions arising from these forms were answered. The biodata form was designed to give an overview of not only their work setting but also their experience of working with stroke, courses attended and confidence. This allowed any responses to be put in some context retrospectively. At the end of completion, each participant was asked to write down their definition of stroke. These were then shared as the opening activity of the group. The group discussion was then facilitated by themed topics. The themes selected for discussion were similar to those indicated in the semi-structured interviews for healers (appendix 8). There were some variations, dependent on the group response, aiding the development of some of their answers. Both ran smoothly with all participants offering their point of view.
Both focus groups were audio-recorded and fully transcribed. Notes were also taken by myself. The result of both of these activities, and the small number of participants meant that the response by individual participants could be noted.

4.6.7 Observation of healing episodes

In addition to the participant observation described earlier, specific observation of healing episodes was undertaken. These observations added another layer to the narratives of healing described in the interviews by the people with stroke and healers. They also furthered the understanding of the healers' activities and roles. While interviews allowed the healers to discuss their understanding and procedures theoretically, the addition of observed treatments gave room for the performative and interactive aspects of healing which are limited through descriptions or case-studies.

In total 22 healing episodes were observed. All involved the participant healers in this research, eight also included participants with stroke (the others included other people with stroke who were not participants in this research). Twelve with biomedical healers, five with traditional healers and five with alternative practitioners were completed. It was not possible to observe all healers for a variety of reasons. The traditional healers for example, do not run set clinic times. They are called upon when someone is ill and therefore can rarely predict when or where they may be called. As a result I sometimes witnessed illustrative treatments rather than actual clinical encounters. Equally, it was not possible to observe all participants with stroke as at the point of this research not all were undergoing active treatment. For example Sujatmi was pregnant and her family had decided to suspend all treatment until the baby was born. Pramana had achieved all the goals set by his therapist and so had been discharged.

Each session observed had a different format dependent on the healer and participant's wishes. However, all involved agreed that I could ask questions during the session. As a result I was able to watch the treatment unfold, listen to the conversations between practitioner and client, make notes, and ask questions regarding both the activities that were occurring and how the person with stroke felt during those activities. I tried not to disturb the flow of the interventions through either my presence or questions. At times this resulted in me clarifying what was said or the meaning of actions made after the session was completed.

4.6.8 Vignettes

One of the difficulties of examining a range of very different healers is the additional complication of a client group who can vary enormously in symptoms. Vignettes were selected as an appropriate technique to facilitate some sort of comparison of approaches to the treatment of stroke. Vignettes, or paper case studies, have been utilised for assessments of competence, professional decision making and also comparative approaches to care (Hughes & Huby 2002, Leonard & Masatu 2005, Taylor 2006). They have the advantage of presenting the same data to different people and therefore responses can be compared more easily then in the natural setting (Hughes & Huby 2002). They have also been found to reduce the influence of socially desirable and unreflected responses as participants are able to complete them in their own time (Bryman & Teeran 2005).

Vignettes are however not without criticism. It has been noted that they reflect what people say they would do rather than what they actually do in practice (Bryman & Teeran 2005, Leonard & Masatu 2005). In this research the paper vignettes were given in addition to the interviews and observed treatments and therefore such a limitation was less relevant as they were not the sole form of data.

An important consideration with vignettes is that they are based on appropriate and realistic examples. As a result, the vignettes were only developed after a period of observation and initial data collection. Each vignette had four themes that were manipulated: age, work responsibilities, symptoms/severity and personal situation. These themes are illustrated in table 6. The purpose of these variations was to try to assess what impact, if any, they had on the treatment approach of the healers. Given the almost total lack of reference to posterior circulation symptoms, these were covered in the second vignette.

Table 6 Themes of vignettes

	Vignette 1	**Vignette 2**	**Vignette 3**
Age	Old	Middle aged	Young
Work	Not specified	professional	Farmer
Symptoms/severity	Severe	Balance/coordination	Mild
Personal situation	Dependent on children	Not specified	Responsible for wife and children

In developing the vignettes care was taken to avoid technical terminology that would not be relevant across the different types of healer. A pilot of the vignette was trialled on one of the HI physiotherapists, resulting in minor changes in language and spacing of the text. The final vignettes are shown in appendix 10.

Each healer was given the vignettes after completing the other stages of the research. They were requested to complete them in their own time and the papers were collected at a later date. All the healers could write. In total nine vignettes were completed. This represented a total of 17 healers as the therapy groups and *Puskesmas* staff chose to complete them communally rather than individually.

4.7 Analysis of data

Information from participant observation, the different interviews, focus groups, observations, and vignettes all produced extensive data. Through the course of the data collection a first level of analysis occurred. Notes from interviews, observations and field notes were read, re-read and had an influence on how the research itself continued. However, on leaving the field site a more formal process of data management and analysis was completed.

This later more formal process of analysis followed that described by Braun and Clarke (2006) as thematic analysis. This method was selected because of its flexibility and therefore ability to be used within different theoretical frameworks. Braun and Clarke (*ibid*) state that it can effectively be used in research which is contextualised, situating itself between realist and constructionist paradigms. Thematic analysis acknowledges both "the ways individuals make meaning of their experience, and, in turn, the ways the broader social context impinges on those meanings" (Braun & Clarke 2006:81). Such inclusivity was ideal for this research which used two complementary methodologies. Other analytical methods, such as Grounded Theory (Glaser & Strauss 1967) are theoretically bound and were therefore unsuitable. The following section describes in detail the preparation of data and the process of thematic analysis that followed.

4.7.1 Preparation of data

Firstly, the data needed to be prepared for analysis. This involved transcription, translation and back-checking of all interview, focus group and vignette texts. This stage was somewhat complicated as three languages had been used through the research. Although most interviews had been conducted in Bahasa Indonesian, some had included Gayonese and Javanese, languages I did not know. This mix of languages and use of interpreters posed some unique challenges for me as the researcher. It not only added other voices to the story-telling, but also a further layer of interpretation. In an age of increasing emphasis on validity of techniques, it was essential that I tried to limit the level of interference that such variety introduces.

Initially all interview recordings were transcribed verbatim by people fluent in the local languages. In the case of Javanese and Gayonese, these were translated to Bahasa Indonesian following transcription. All transcripts were then translated by a professional translator fluent in both English and Bahasa Indonesian. Following the written translation, I listened to all of the original recordings alongside the translations and my written notes from the interview itself, checking again the accuracy and interpreted meaning. I deemed this process of translators, alongside detailed notes within the interview themselves, transcription, professional translation and then further back checking of the translation, to be the most appropriate way to deal with the multiple language issues.

Bahasa Indonesia is a modern language with a relatively straightforward grammar structure and no tenses. The result, however, is that tense is often implied and a number of words have multiple meanings. This resulted in occasional alterations being made from the formal translation to the contextual translation on my checking. For example, a frequently used word was *pusing*, often interchanged with *pening*. Both can be translated as dizzy, upset, puzzled or worried. It is clear that such differences can have significantly different meanings in context. Where variations like this arose, I have chosen the translation that most accurately portrays the meaning I interpreted within context.

Following the transcription and translation process, the texts were then read alongside the field notes and additional observations of relevance were included.

Field notes not directly related to interviews were typed separately for analysis. All texts and photographs relating to the research, both participant taken and my own, were prepared in appropriate format and inputted into an Atlas.ti hermeneutic unit (www.atlasti.com version 5.5). These constituted the data for analysis. All data were treated in this manner and were analysed and interpreted together. There was no differentiation on the basis of how data were collected nor was one method of data collection prioritised above another. A computer data management package was selected because of the quantity and variety of data to be analysed. Atlas.ti was chosen in preference to other packages as it has advanced facilities for linking images to text.

4.7.2 Thematic analysis

Once input was completed, all texts were read and re-read. Initial thoughts on themes were noted in the memo section of atlas.ti. In-keeping with an inductive process first stage coding of data was completed through identifying codes that appeared within the texts itself, open coding (Gibbs 2002, Kelle 1997). This involved codes predominantly at sentence level. Broader themes, as they appeared, continued at this stage to be documented in the memo section. A reflective diary was also included in the memo section where general thoughts and ideas were noted. Through this initial coding process, the data from the participants with stroke and healers were separated.

Following open coding, the content of each code was re-read within context. This process had two purposes, the first to re-check the appropriateness of the code selected, and the second to consider the broader theme that the code may relate to. At this stage, and with reference to the notes previously made in the memo section, thematic/family codes were developed. An example of family coding is given overleaf in diagram 5.

Diagram 5 Example of family coding
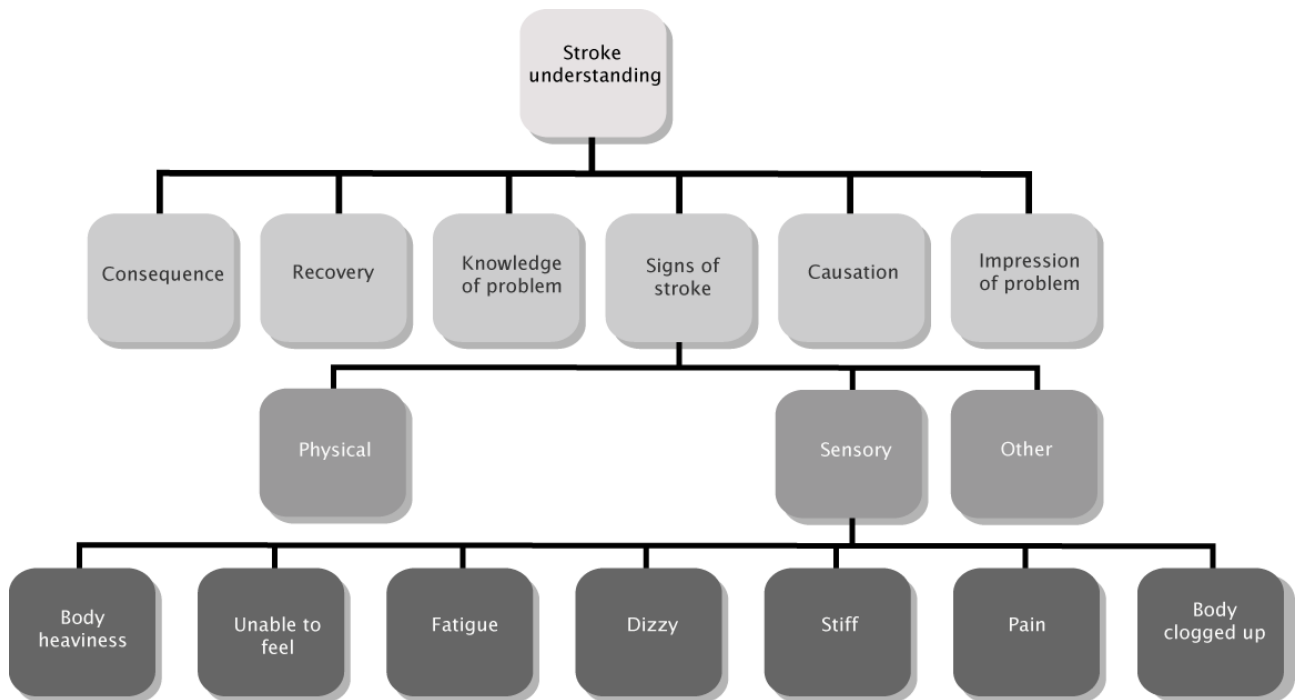
The texts were then re-read and photos re-viewed with specific reference to the themes devised and the relationships between the themes within the larger narrative were considered.

Once the specific quotations pertaining to codes and themes were confirmed, they were outputted from Atlas.ti and the nature of the inter-relationships between them explored diagrammatically. This resulted in the development of theoretical relationships between different themes. Once again, before confirming schematic diagrams, the quotes were re-checked in *situ* to ensure their appropriateness.

The final process involved re-reading the texts alongside the schematic diagrams and checking for evidence of cases which did not follow the theory developed. Through this process, a few exceptions were found which will be discussed in the relevant sections later. The total process involved continuous movement between quotes, codes, themes and the data as a whole. It also included periods of reflection and a certain degree of trial and error, particularly when considering the relationships

between themes. Such a dynamic relationship with the text, and crystallisation through immersion have been described in the literature (Denzin & Lincoln 1998).

4.8 The researcher in the research

As mentioned at the start of this chapter, the perspective of the particular researcher is central to how a study is conducted and the results interpreted and presented (Hammersley & Atkinson 2007). Despite efforts to limit reactivity, break cultural frames and increase the voice of the participants through the choice of particular methods of data collection, I cannot avoid the fact that I am in this research at many levels. If I cannot be avoided then I should be understood. In the following section I describe my attempts at reflexivity and the aspects of myself which I believed to be most pertinent in this research. Although this is presented in rather a fixed form here, an attempt was made to consider these aspects throughout the data collection, analysis and writing phases.

A reflexive account on your own participation is difficult to do. However, a field diary is generally accepted as the most appropriate way to document your thoughts, initial responses and feelings toward each encounter and one was used throughout this research (Denzin & Lincoln 1998, Mason 1996). There is little guidance on how to write an effective field diary, but I followed a number of principles identified in the literature (Bryman & Teevan 2005). Firstly, reflections were written as soon after the event as possible. This usually occurred later the same day, but occasionally occurred immediately after the event or in some circumstances, the following day. For each entry I tried to follow a model of reflection which included a retelling of the event and my action. I then further documented a reflection on my action. This process indicated that occasionally my personal response to specific interview situations had a direct impact on the way the interview proceeded.

> "Saw Dewi in an attempt to do the second interview, but this was very hard. She is still very sick – in clear heart failure with a probable DVT...She's basically given up and wants to die – yet doesn't want to leave her husband. No research is worth invading that place so I didn't really try. I don't think she will be here that long. In the car afterwards I felt incredibly sad and

lonely... The whole thing was very strange and was my first experience where my therapist self knowingly and completely over-ruled my research self. Nothing is worth making her personal suffering worse"

<div align="right">31st July – post 2nd interview with Dewi</div>

This quote clearly illustrates the complex relationship between the researcher and participant, where personal suffering is transferred into an emotional response by the researcher. However, it also highlights other aspects of myself which potentially influenced the research process. Five different aspects showed themselves to be particularly relevant through this research and are therefore require highlighting. These include: professional training, role within HI, gender, age, and physicality.

4.8.1 Professional training

Both my training and practice as a physiotherapist have potential to impact many levels of this research. As part of the para-medical professions, physiotherapy is in many ways aligned to biomedicine and its desire for objectivity. It also has a distinct way of understanding the human body and individual function, its paradigm, which is influenced both by biomedicine and the western based culture from which it was developed. Awareness of this potential internal influence was essential throughout this research, from understanding ontological and epistemological beliefs, methods chosen and undertaken, and within the interpretation of the data. The strength of this influence is potentially somewhat diluted by my training as a medical anthropologist. That training highlighted the very existence of this paradigm, and indeed resulted in me exploring the cultural development of physiotherapy (see Norris & Allotey 2008). I am still a physiotherapist, but I hope one who is at least aware of its specific lens and potential influence.

It was not only my awareness which is important to consider. All participants knew from the outset that I was a physiotherapist. I was concerned that this knowledge would encourage them to focus more exclusively on the physical. I hoped that by directing them to tell their story, *their* priorities would be explored.

For all participants, my experience as a therapist was a point of interest. Following interviews many asked me directly about whether I had seen people cured from

stroke, and what medications or treatments existed in the West that may facilitate their recovery for example. These discussions were occasionally professionally awkward, both as a researcher and as an employee of HI, as I was increasingly aware of the curative beliefs they held and the options for assistance that existed in the region. In all cases I tried to remain as honest as possible, sharing my experience, as they had shared theirs. However, it is fair to state that there was some 'economy' with that honesty as I avoided explicitly discussing treatments that involved facilities unavailable to them. I also made efforts to present this exchange as 'my experience', rather than an expert opinion, although I am not clear at all that it was perceived in that vein. These exchanges also had elements that added insight to their understanding of the condition and wishes for the future, which were treated as background and reference data for analysis.

My position as researcher and therapist has other dimensions, which were alluded to in the first quote in this section. Being a therapist with long experience in stroke gave me access to information and knowledge which challenged my position as a researcher. With Dewi, for example, I was certain that her medical condition was extremely poor. Indeed she died two months after the second interview following further cardiovascular complications. That awareness had a direct impact on my response to the interview situation. My inability to act on that knowledge was furthermore frustrating for me individually. I discussed her medical follow-up with her and her husband, but by this stage she was refusing medical intervention. In this example, it could be viewed that my therapist self, interfered with my research self, in effect altering the research process. I was aware that this influence was occurring at the time, but made the decision that it was the most appropriate course for the participant and myself.

4.8.2 HI staff member

One aspect that has to be considered in detail is the impact of my dual role on the participants. There was no escaping my association with HI in the field. I had rather foolishly believed that in the field I could keep my two worlds separate. I had forgotten that all HI vehicles have very visible stickers on every available surface and that being only one of three expatriates in the town, most people knew my association before I arrived. Having believed I could present myself to the

participants as a researcher from Brunel University, I quickly amended my approach. I decided to be honest at the outset, setting out my role with HI and my research role and clearly stating that I was there for the latter.

I have no doubt that the participants' knowledge of my HI position had an impact on their responses, but my reflection on that response is not the same as my initial assumptions. Initially, I had been at pains when designing the fieldwork to keep the roles separate. I wanted to avoid, as much as is ever possible, any feeling of coercion on the participants. Equally I wanted them to be honest and it seemed that my neutrality as a researcher would facilitate that. I had the feeling that their knowledge that I worked for HI would somehow contaminate their response and make them feel obliged to participate. In reality, the influence showed itself to be something slightly different. People were at ease in refusing certain parts of the research (evidenced in two refusing the photographs) and were occasionally brutally honest about how they saw HI's intervention. As a result of these experiences, I feel more confident that the association with HI was not sufficiently disruptive as to invalidate the results, although attendant awareness of that relationship is appropriate in interpreting the results.

4.8.3 Gender: Female

There is a fair amount written about the role of gender in fieldwork and interviews. Bernard (2006: 373) for example highlights two potential consequences; "it limits your access to certain information" and "it influences how you perceive others". Gender presented itself as an issue to be considered very early in the research process. At the point of initiating my research plan, I was told by a respected Indonesian researcher that "there are also the added difficulties of working in an area recently at war and noted for its fervent Islam, both of which complicate matters for a female researcher." I was a little at a loss as to what to do with this comment. It was true, Aceh is known for the strength of its Islamic faith, further developed by the implementation of *Syariah* law in 2005. The area had been at war for around 30 years, with the peace agreement only signed in 2005. And yes, I was a woman. Ethnographic work in the region (Siegel 2000) further indicated that women were generally seen as less logical and more prone to emotional rather than considered

responses. It was possible that these factors could complicate matters for me as a female researcher sufficiently to make the research unviable.

My personal experience in the region gave a different perspective of both this comment and in part to Bernard's (2006) concerns. In my previous work in Aceh, I had freely moved in and out of people's houses, talking and working with both men and women. While there were minimal restrictions on my dress, I had found the Acehnese to be extremely open to me as a Western woman, as long as I respected their rules. I had participated in and led meetings with high ranking government officials, being openly respected for my opinions and organisational skills. In the end I politely disregarded the quoted concerns, choosing instead to trust my own recent experience. Once in the field, my decision was justified. My movement was not restricted in anyway because I was a woman[10]. In fact, being a woman helped in many of the personal discussions around bathing and other personal activities with my female participants. Religious and cultural norms may have prevented such discussions with a male researcher. Rather than limiting my access to certain information, it was potentially increasing it, although it is possible that male participants shared less of their intimate experiences as a result of my gender.

One aspect of being female was a concern participants had with my lack of family. Many of my participants commented that I was spending too much time on my career and should be concentrating more on having children. Engaging in this topic informally led to conversations and insight into the cultural importance of family and the balance of life and helped build a rapport between myself and the participants.

With some of the healers, the gender situation had a slightly different influence. While all male healers were happy to be interviewed and observed by me, one female healer was only allowed to talk to me because I was a woman. Her husband had disallowed her from working with any men. However, one male healer did respond to my gender, including sexual innuendos in his explanations. While I politely ignored such references and continued with the line of questioning, his response did require me to have a lengthy debrief with my translator (female), who was distressed

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[10] The general security rules that I had to follow were the same for both sexes

both by his attitude and the disrespect he had shown towards me. This scenario was interesting at many levels. Firstly, his attitude was the only negative one towards women I personally experienced. Secondly, while it was not necessarily pleasant, it had little deleterious effect on the interview content. Indeed, he shared many aspects of his treatment techniques with me in direct response to his belief that as a woman I would not know. Thirdly, it prompted a conversation with my translator and other members of staff about attitudes between the gender groups. And finally it reminded me again of the complications of working through translators and the need to understand their personal response to the research process.

4.8.4 Age

In addition to gender, Manderson *et al* (2006) note that age affects the interviewer interviewee interaction. My age, 35 years, did show itself to have an influence on the research process. Indonesian society respects the wisdom developed through life, yet it is also a country respectful of education. When the issue of my youth was raised, my years of experience working in disability, combined with the level of my education appeared sufficient to offset any concerns. Indeed, my youth in some cases encouraged elder participants to explain details fully, in effect teaching me. Equally, unlike the work by Bowen (1993), many of my participants were my contemporaries in age: healers, carers and people who had had strokes all within their thirties. Arguably, that made me more accessible and approachable as a researcher.

4.8.5 Physicality

One aspect the literature in research rarely highlights is the effect on a researchers' physicality on the process. As a rare exception, Seymour (2007) discusses the effect her physical disability may have had on the research she has conducted. She concludes that "fieldwork is pre-eminently body work. Ethnography involved visible bodies: bodies bearing messages and messages bearing bodies" (*ibid*:1195). Throughout this research, I could not fail to notice the impact of my height and size as it was a key topic of conversation or comment in almost every interaction. My very presence resulted in discussions on health and strength, many of which were about me. It did however serve to highlight the physical features valued by participants in general. It further assisted in building rapport as jokes were shared and requests for me to work in their *kebun* were made.

Photograph 3 Illustrating my physical size relative to participant Melati (to my right) and her family

There were potentially many other influences. I am white, middle classed, English and not Muslim. These features amongst others undoubtedly had an impact on my participation in this research. Throughout the research I have tried to keep an awareness of these factors in mind.

4.9 Summary of chapter

This chapter has described in detail the methodology and specific methods used to address the aim and objectives of this research. It has presented the framework of ethnography and the application of interviews, observation, vignettes, photographs, and focus groups with the participants. It has also examined how participants were selected, and ethical and confidentiality issues. An overview of how data was managed and the process of analysis was given. Throughout the chapter reference has been made to the centrality of the researcher. In the final section an introduction to important personal features I deemed influential on the research was given. These are as relevant in the methodology as the results and discussions which are presented in the following chapters.

Chapter 5

The stroke stories

5.0 Introduction

In this chapter I focus on the experiences of the stroke event from the perspective of the people who had stroke and their families. I provide a description of the onset of stroke, the recognition of the problem, and both the concept of stroke and its causation. The need for action is introduced alongside the reasons why help was sought. This leads to an examination of the impact of stroke in which personal independence in Activities of Daily Living (ADL's), religious obligations of prayer, and family responsibilities such as income generation and domestic and family support are discussed.

This chapter includes a number of extended illustrative quotes. The cases presented were chosen because they epitomise the general experiences that will be described. Accounts were individual, but concepts are drawn together to develop an understanding of the meaning of stroke within the context of Central Aceh.

5.1 The onset of stroke

Pramana's story

Pramana is 66 years old. He lives with his wife and five of his 14 children in a mainly concrete house on a hill in the outskirts of a village in Pinte Rime Gayo. They are a religious family and many pictures of Mecca and Arabic text are hung in the reception room where we talk. Prior to his stroke, Pramana worked full time on the family *kebun*. This plantation, some two kilometres from the house, was almost entirely dedicated to coffee, although some vegetables were also cultivated predominantly for personal use. Three of his elder sons also worked with him on the *kebun*. His wife was always present during his interviews and occasionally children would walk in and out on their way to or from the *kebun* or school. However, Pramana was the narrator of his story and unlike other participants, his family, while listening, rarely joined in. He had his stroke five years prior to the interview and yet can describe the details of that day with remarkable clarity.

On Saturday, yes Saturday, I planted tomatoes in the backyard. I only know the month, the month is the first month. The year is two two (2002). Ehm, after spraying the tomatoes, around ten, I went to a food stall, it was Saturday, weekend. There, I had a drink, then went home after finishing eating, bringing the plough and manure. I arrived around half past two. After drinking and changing my cloth, I took the manure, I put it in the bucket, I bailed out twice, I moved it left to right, walked to the backyard, to pour it on the tomatoes, ... in brief, I poured out continuously, then it was nearly finished, I still had one more bucket. When it was almost half full, I could not lift it, I could not remove it, how could I? I should finish it, that was in my mind, then I took it in my right hand, I continued to pour, after that I could not lift my legs. I dropped the bucket, then I intentionally dropped to the ground, I was scared, I called my children, nobody came, ... I, I was scared, then I tried to walk, crawled to the edge of the plantation, I called my children once again, then they came, my wife was not at home, she was at the food stall, then the neighbour brought me home, nearly adzan (call to prayer). That is the story.

<div align="right">Pramana</div>

Like Pramana, all but one of the participants were very active prior to their stroke and had had no previous serious illnesses. Women and men, older and younger alike all participated in both domestic and income generation activities[11]. Each was involved in working on the family *kebun*, but others had also been market and mobile food sellers.

At the time of stroke onset, nine of the eleven were engaged in an activity. Of the nine, three had been farming, one praying in the mosque, one climbing a tree and another two going to the bathroom. These participants described how their body changed as they attempted to continue their activity. Weakness or heaviness in one limb spread to include one full side of their body, eventually forcing them to stop

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[11] The exception, Dewi, had had a series of illnesses prior to her stroke and as a result had already ceased both income generating and domestic duties.

their activity. For two of these, their immediate reaction to the onset of leg weakness was to pray, which they did seated, but as their arm also became weak, they also ceased this. Two fell as a consequence of the developing paralysis, but did not believe that caused any further injury. Other problems also developed, including difficulties with speaking, facial weakness and a blurring of vision. Two other participants were in static positions at the time of onset, one lying to watch TV and the other sitting watching the local children go to school. They noticed problems after an unknown period of time, as it coincided with a reaction from a family member (both daughters). For these two, facial weakness was the initial problem identified, resulting in half of the face sloping downwards and the tongue hanging out. It was the sight of this facial change that alarmed the daughters to comment. Once the alarm from the children had been raised and the individual tried to react, other limitations in movement were noticed, indicated through an inability to get up from their position. The final two participants had woken with the problem. One explained how he had been having an afternoon nap after making a fence in the rain for several hours previously. The other was arising in the morning. Both were unable to get out of the bed, struggling with a heavy and unresponsive body. The gentleman who had been making the fence soon collapsed in an unconscious state to be found by his wife.

As the participants shared their stories, it became clear that not all could understand what had happened to them. The sudden change in their physical status, often mid-way through a physical task left them bemused. Expressions of fear, panic, surprise and confusion were common. All called for assistance in some way. For a few, like Pramana, that involved both a time delay and repeated efforts to attract the attention they required. For others, family members were at their side at the point of the incident, or were the first to notice a problem and therefore assistance was at hand. Other than the gentleman who was praying at the mosque, all requested and received assistance from family members. Daughters, sons, husbands, wives and nephews were all convenient initial points of contact. Rarely did these assistants try to manage the situation independently. Other immediate family members were called if they were in the vicinity, or neighbours dispatched to recall workers from the *kebun* or market. The assistance they initially offered was practical in nature. Those who were outside at the time of onset wanted to return home and were either carried or

transported in borrowed vehicles to the family home. Those already within the home, if not already in a supported position, were lifted and made comfortable. There was at this point a delay in action as the close family gathered and the preceding events were recalled. For all participants, this meeting of family members was essential prior to further action being taken.

Unlike Pramana, not all participants completed the description of the stroke onset independently. Family members were enrolled to elicit details of dates or reiterate the problems as they occurred. As the story proceeded to explicitly involve the family, the narration became more shared. Family members who had been present at the time of the illness explained their initial reaction to the state of the individual, highlighting their own sense of panic and bewilderment at what was presented before them. In some cases, where they sat slightly distant to the discussing group, they moved closer; children in their care were passed to other people nearby; their attention more fixed on describing the events in which they had played a key role. In all but one case, the individual affected appeared to welcome this narrative support and the clarity that was gained from sharing the tale. They often looked at other members to confirm the accuracy, directly requested support or were prompted to add another detail they had initially missed. In one interview however, the story of onset was not a shared tale. Discrepancy in details emerged between co-narrators and while consensus was never achieved, some clarity was mediated by younger family members who presented a united story that incorporated aspects from both of their apparently warring parents.

5.2 Recognition of problem

The next phase of the stories crudely followed a similar path. Participants described discussions held between the person affected and the family about what the signs could mean and a suitable course of action. However, the significance of the signs and the actions taken varied. Six of the eleven participants and their family members explained their total bewilderment as to what the problem could be. The other five, being familiar to some extent, through observations or learning, surmised that their relative could have had a stroke or severe hypertension. This sharing of their understandings and experience involved both male and female members of the

family, young and old. Familiarity with other community members with similar conditions, formal education, and events in their life that had preceded this event were brought to bear in their explanations as is illustrated in the excerpt given below.

Lastri's story

Lastri: *I felt nothing. I was not dizzy or saw the stars. I just watched TV in a sleeping position, but I felt nothing. My daughter, Farida, asked me, what happened to you, Mom? When she saw me, she screamed and called her big brother. I couldn't speak on my own*

Son: *Her mouth and half of her body were weak*

Lastri: *I asked myself why I became like this? Yes, I also asked my children.*

Interviewer: *What did you think had happened at that time?*

Lastri: *I just thought why this happened to me.*

Son: *It happened suddenly. We were all surprised because we were not here.*

Daughter: *They were called home.*

Son: *We only knew that she was sick, then we lifted her up. Above all, we were surprised.*

Lastri: *Farida (daughter), who saw me for the first time, after she knew that I could not speak felt shocked. She screamed and called her father and brother. Father, what happened to mother? She only thought what has happened to me.*

Daughter: *First, I thought she was just kidding. I was shocked when she had a stroke.*

Interviewer: *Farida, why did you think your mother had had a stroke at that time?*

Daughter: *Before that, I knew about it. I had heard stories, what people said about it. OK, we heard that, we knew what we had heard, but we did not think about that. Before we experienced it by ourselves, I had heard about it from a friend and I had seen people who had had a stroke in hospital who had become half paralysed. Only that. I did not think about it deeply, and I was really surprised.*

Son: *When she had her stroke, we immediately gathered here. We gathered, the family, to find the solution to cure her.*

At the time of the illness onset, some symptoms were described as being more indicative of stroke than others. As demonstrated in the example above, a weakness on one side of the body (*mati badan sebelah*/ hemiplegia) was named as being related to stroke. For all the participants who believed they may have had a stroke at the time, this feature was consistent. Also frequently mentioned was difficulty speaking.

As described previously, some participants at the time of stroke were unaware of a diagnostic category and therefore did not associate their presentation with stroke. That situation had changed at the point of the interview, and all participants were aware that they had had a stroke. With that additional personal perspective, the participants were asked what signs indicated stroke and how they would now recognize it. Once again, features related to physical weakness and paralysis were the most common. Participants described their inability to get up, walk or their legs giving way when they attempted to do so. Speech was also highlighted alongside visual problems such as blurring. Other sensory problems were identified, most frequently an inability to feel part of the body, bodily heaviness and dizziness. A summary of all the features identified, those previously held now amalgamated with their own personal experience, are illustrated in diagram 6, where the size of the circle indicates the frequency of response.

Diagram 6 Recognised symptoms of stroke

Sensation (21)
- Body heaviness
- Unable to feel
- Fatigue
- Dizzy
- Stiff
- Pain
- Body clogged up

Other (13)
- Speech
- Vision
- Increased BP

Physical (55)
- Paralysis
- Unable to move
- Weakness
- Hemiplegia
- Facial droop
- Unable to walk
- Fall down
- Leg giving way
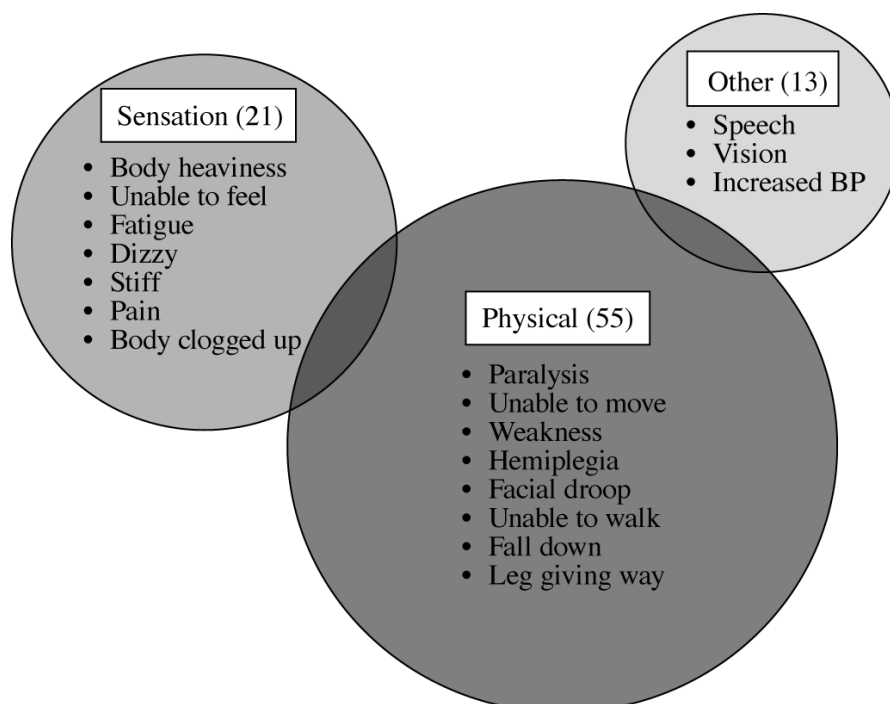
As the narratives evolved, there were indications that a number of these symptoms were perceived to be related with alternative problems and therefore were not associated with stroke alone. For example, dizziness, fatigue, visual disturbance, falling and heaviness were raised in discussions on hypertension, stress and *masuk angin* (a local condition resulting from dirty air entering the body). As a consequence, the participants were asked directly what they now understood by stroke; what the term meant to them. The answers revolved around two interrelated concepts: an interruption to blood flow, and its corresponding symptoms.

5.3 Concept of stroke

With the hindsight of their own experience, participants discussed that they believed stroke to be an alteration in blood flow. This was usually a plug or a block and was located in the area of the body in which they had symptoms. As a result they explained that their arm and leg weakness was due to a lack of blood to the limbs as a result of this plug. A number of them 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. Altered blood flow was also attributed to the symptoms of hypertension, which many of them introduced in their narratives. They explained however, that stroke was a more serious disruption and as a result the symptoms were more obvious and persisted longer. For example, stroke was the only condition that could cause *mati badan sebelah* (half dead body/ hemiplegia) for a prolonged period of time. Indeed, the association of this symptom with stroke was such that it was an interchangeable term often given as the local translation of stroke.

5.4 Causation of stroke

The participants' descriptions of stroke causation were complex. Understanding them included an amalgamation of the perceived mechanisms of altered blood flow, and how these interplayed with the individual's history and social environment. The detailed descriptions given below are combined diagrammatically at the end of the section.

In the view of the participants, the interruption in blood had many potential origins. These are summarized in table 7 below.

Table 7 Causes of blood flow disruption

Cause of disruption	Example
Lifestyle	Hard work, decreased exercise, lack of sleep
Environment	Very cold, wet
Mental	Stress, thinking too much, fear
Food	Fatty food, chemicals in food, durian, coffee
Spirit	*Djinn*, evil wind, curse

Many of these bear a resemblance to the concepts of health and illness described in chapter 3. The lifestyle examples related to a physical disruption to flow primarily as a result of muscle over or under activity. Hard physical labour was said to cause tension in the muscles creating a physical block to flow. Participants illustrated this through an understanding that tension in the shoulders had caused a problem in blood flow down into the arm. The extremes of fatigue and laziness could result in the blood becoming stagnant. This was sometimes mentioned alongside 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. The effect of stress and the quantity and quality of thought was the most frequently identified cause of interrupted blood flow. For many this stress was about the responsibility of providing for the family and the economic pressures of everyday life. For others, most specifically, although not exclusively of Javanese origin, the conflict was noted as a negatively influencing factor. The person with stroke, rather than their family members usually recounted the effect the conflict had had on his or her life. A number had had to move several times, either at gunpoint or to avoid GAM or TNI using them as human shields. Others had seen members of their family killed, decapitated bodies in their fields or lived in fear of their lives. All had struggled to maintain their economic stability as the danger posed by travelling to the *kebun* increased. These experiences and memories not only resulted in too much thinking, but also negative thinking which was also seen to affect the blood. In these cases the blood was seen to do one of two things, either become sluggish or agitated.

The latter resulted in hypertension which then could cause a plug if it was sustained for too long. While some of the healers talked about the blood vessels potentially bursting with high blood pressure, the people with stroke themselves remained consistent with the concept of plugging.

Like the concepts of general health and illness described in chapter 3, in their explanations, food had multiple influences on flow and the onset of stroke. Fatty foods could directly cause the blood to block or indirectly cause an increase in the blood pressure. The action of chemicals was unknown, but respondents discussed their understanding that they were harmful and could have a direct effect on slowing the blood. Durian was heating and therefore caused an increase in blood pressure that could result in a plug. But of all foods coffee was the most consistently mentioned. Many participants explained that coffee contained a substance that increased the blood pressure. Some called this substance nicotine. In their understanding, coffee consumption was a prime cause of blood agitation, evidenced through the quickening of their heart rate after they had consumed it. Almost all had ceased its consumption following their stroke. Interestingly, despite the reference to nicotine, the very common habit of smoking was not mentioned in any lay context.

The final category, spirits, were believed to have a direct effect on the blood. They could move around the body and cause a disruption in flow. Allah was discussed by some participants as being involved in the onset of stroke. However, His involvement was not discussed as a direct cause of stroke, but rather that the stroke must have been sanctioned by Him. This is discussed further in the chapter 7.

Participants rarely mentioned only one of these causes, but posited that a number of them in combination may be responsible. They justified their theories based on those that had personal significance or ones which had been supported in their interaction with others. Ideas that were deemed irrelevant to their life were mentioned then later discarded. In one case, a respondent suggested the possibility that spirits may be responsible, sent by a jealous village member. He later retracted this possibility explaining that he both had cordial relations in the village and did not want to focus on such theories as it would result in community disharmony. Another participant laughed loudly creating a cascade of humor through her family as she considered the

possibility that she thought too much. That idea was thrown out as she explained that she was well known for not thinking about anything. This pattern of causation theory development is illustrated in diagram7

Diagram 7 Causation theory development
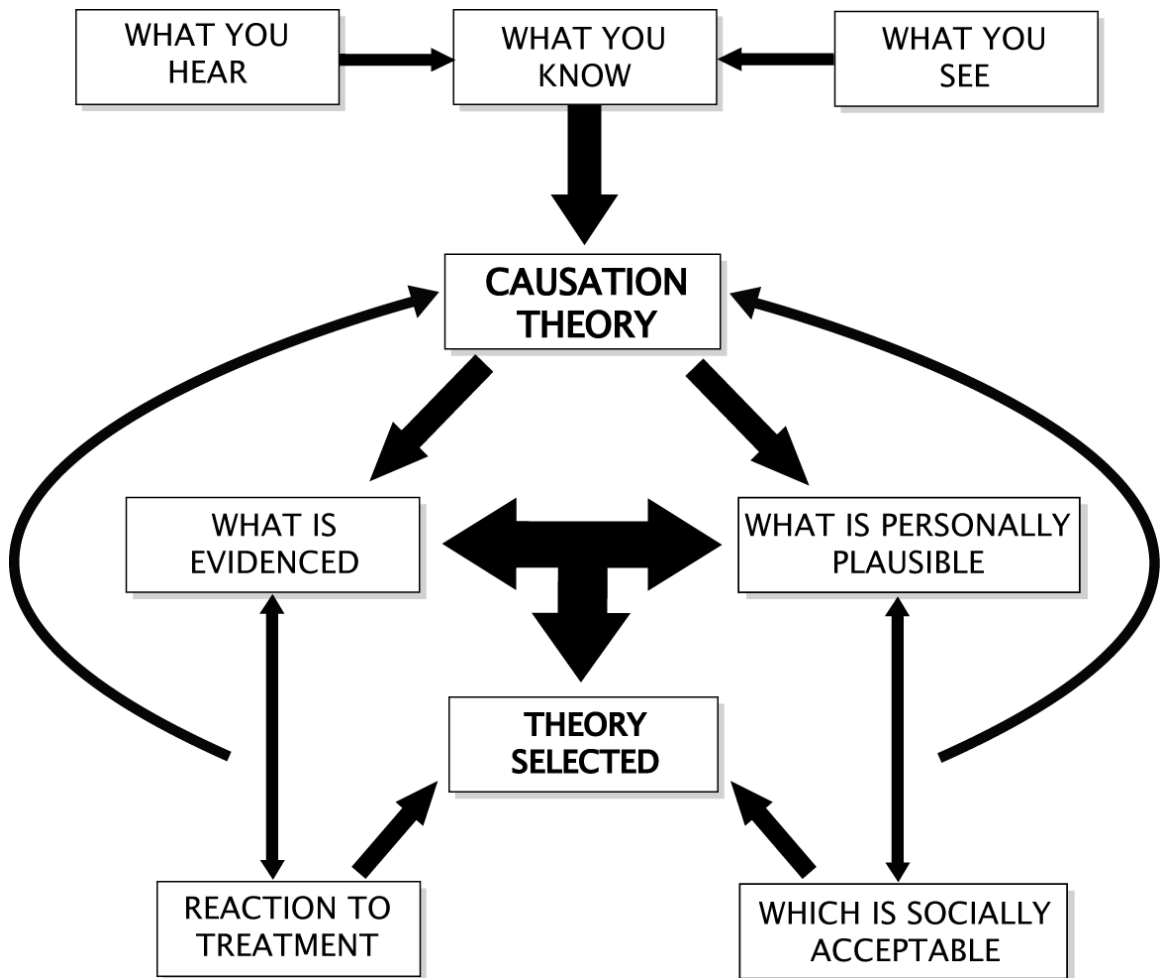
A number of these explanations were developed, modified, accepted or discarded through the period that followed the stroke. They both influenced and were themselves altered by the interactions and effects of the actions that were taken. For example, Lastri described her initial belief that the problems were caused by high blood pressure alone. However, after treatment in the hospital and a decrease in her blood pressure, the lack of improvement in her condition made her question this connection. Traditional healers suggested the weakness was related to the presence of an occult force. Treatment through prayer was linked with a partial improvement in her condition and therefore this explanation was given some importance. It was

her last explanation however, that of too much thinking, which was finally stated as the main cause. She and her family are Javanese and she discussed at length how vulnerable they had been during the conflict. Furthermore there had been a landslide in the vicinity of her son's house which had increased her anxiety. Although she suspected that an occult force was at play, it was the direct effect of excessive thinking and fear which was ascribed as the cause of her stroke.

5.5 Action taken

Arti's partial tale

Arti is a 46 year old widow. Her husband died nine months prior to her stroke leaving the family in a difficult financial position. She lives with one of her daughters. Her eldest two daughters are married and live very nearby. They and their husbands spend a lot of time in the family home, cooking and eating together. Arti has been unable to walk since her stroke and so requires substantial support to toilet and move around the house. All her children and their husbands are actively involved in this care. The family's income is through a coffee plantation that they own in which her children and sons-in-law now work. Arti had a stroke 18 months before the interview. In the quote below, she and her daughters recall some of the actions taken.

Arti: *…then there was a midwife here, she was brought here, my blood pressure was checked, I had 240.*

Daughter: *The blood tension was high and she could not move her leg. The midwife said that she could not take charge of her, I took her into the Puskesmas Lampahan first. They also couldn't take charge of my mother due to her blood being high, "into her head," she said., "into my head," she told. The blood was high, we couldn't do anything, "take her directly to Takengon" they said. In the hospital they said nothing, they gave her medicine, had infusion, said nothing, they didn't say that she had got stroke. After taking medicine, then, we saw that there was no impact after five days, it was better to be outpatient, we said, then we came out from the hospital, we were five days in the hospital, no?*

Arti:	*around five days.*
Daughter:	*she got injected, also medicine. No change though, no change*
Arti:	*only the blood tension was decreasing, it was decreasing, they gave medicine. Decreasing to 120.*
Daughter:	*after she had already come back from the hospital, there were some, like dukun; they were brought here, we went to the dukun's house, also what is it called?, therapy, therapy, therapy, took her there (physiotherapy dept).*
Arti:	*therapy, to the general hospital to get therapy, three times a week, am I correct? A week?*
Daughter:	*three times, it was not helpful for her,*
Arti:	*nothing, they used a light! They put it on my back [she indicates around the hip],*
Daughter:	*that's all, there was no change… O, with the dukun, when she got stroke, she was treated for one or two months by the dukun, at the first time she got stroke, then it was not continued anymore,*
Interviewer:	*what did they do?*
Daughter:	*many things. He put something into her skin, the traditional medicines, we do not know all..,*
Arti:	*he put it three times, something like powder, he said,*
Daughter:	*"a sour fruit" he said, jeruk purut*
Arti:	*….that (medicine), there is still some now,*
Daughter:	*I put it (onto the skin), as he asked for one month, to make her hand stronger until her leg, from her body until the leg,*
Arti:	*in order to strengthen the muscles, he said that the muscles, the muscles, because of the blood supply, the muscles are not functioning. They had become tight, to soften, he said.*

As Arti's testimonial illustrates, action was taken. Following the discussions that were held after the family gathered, all participants and their family reacted in some way to the events that occurred. Through the interviews, the individual affected and their family recalled who they had seen and, when questioned, explained why. On initial hearing these accounts sounded complex with little consistency of influence. Family members, neighbours, or random people met in the hospital for example,

were all quoted as offering suggestions which were subsequently followed. Biomedical approaches were followed by alternative or traditional and vice versa. It was only following closer analysis of the data that some patterns of influence began to emerge. These patterns are described in the following chapter and cover who was sought to help and why, who was the decision maker, where healers were sought, and finally why their intervention was continued or ceased. A multitude of influences are seen to be at work and those such as understanding of the disorder, financial constraints and the effectiveness of the healer cut across a number of the sections. Prior to the presentation of these trends however, it is important to understand why help was sought at all.

5.6 Need for action: The impact of stroke

As was illustrated in Pramana's and Lastri's stories, the onset of stroke precipitated several changes in the body of the people affected. These changes were immediately identified by the participants and their family as being beyond the realm of normal. When asked why help was called, a number replied that they did not like to be in the situation they found themselves. The condition of 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. Others, faced with a partner or parent who was unconscious or unable to speak and move were clear about their state of panic. They had no idea what to do and so called whatever help they could think of that may be able to resolve the situation or give them an adequate explanation about what had happened.

But it was not these changes alone that prompted the search for help both initially and subsequently over time, but the effect they had on the persons' ability to participate in the life they had led. From the very outset of my contact with these participants it was clear that things were not functionally how the individual wished them to be. Traditionally in this part of Indonesia, greeting amongst adults should be done standing and is accompanied by a gentle touch of right hands followed by placing of your hand over your heart. Those unable to stand could not comply with this tradition and those with a right sided weakness required their left arm to support the right. Each apologized for their alternative approach on first meeting. Evidence

of the consequences of stroke was illustrated in many ways, through the dialogues, photographs and in observation. Two main areas were repeatedly highlighted; personal independence in activities of daily living (ADL) including religious obligations, and roles and responsibilities. These areas were identified by several participants, but in some the men and women had slightly different emphases, which are important to explore.

5.6.1 Personal independence in religious obligations and ADL's
5.6.1.i Religious obligations
All participants commented on their frustration at their inability to move independently and the resultant tasks that they could not complete. An activity that was related by all, male and female alike, and captured in a number of photographs, was that of prayer. Within Islam there are obligations, the five pillars of Islam, the completion of which are central to being a good Muslim. Prayer is one such pillar. It is a complex activity that requires specified ablutions prior to prayer (*wudhu*), the prayer procedures themselves (*shalat*) which have a set physical regime, and the need to attend the mosque on Fridays (for men). All have considerable physical demands for the individual, which had been disrupted by their stroke. The participants spoke of their inability to walk to the bathroom and to complete *wudhu* which required both hands. They also commented on their difficulty to put on the specific clothes for prayer or to walk the distance to the mosque or *menasah* (small local prayer house).

Photograph 4 Illustrating the adapted position of prayer adopted post stroke.

The participant, Melati, used this photo to discuss the assistance she still required with *wudhu* and dressing for prayer.

Photograph 5 Ramelan praying at home. Ramelan added the following comment

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.

The adaptations that participants made in order to complete prayer are sanctioned in
Islam. But while they were used, all discussed their frustration at having to do so and
indicated strongly their desire to complete the responsibilities in a normal fashion.

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 as participants appeared
to have little concern with them post stroke. However, for those whose pre-stroke life
had involved activities such as religious teaching, or *adzan* (call to prayer), these
responsibilities were also raised. For example, one gentleman who had been
responsible for the call to prayer found that his inability to do so post stroke resulted

in an increase in his social isolation. In discussion, he noted his sadness at being unable to complete this important social duty, and his wife repeatedly noted that former religious colleagues had stopped coming to see him as a result.

5.6.1.ii Activities of Daily Living (ADL's)

The difficulties faced with completing Activities of Daily Living were mentioned with different frequency by men and women and covered different topics. For the women, the disruption with cleanliness was of particular concern. They gave examples of how they were unable to walk to the toilet or wash area independently or at all, and how the inability to use one arm led to problems with cleaning themselves appropriately. A few explained how at the initial point of their illness they had required members of the family to carry them to the bathroom and had then toileted on their back. Others discussed (and one took a photograph) of the assistance they required to maintain the squatting position for toileting[12]. For one, the situation was such that she had to toilet in the bed that had been placed in front of the house, waiting for a family member to come to clean her.

The assistance was given mainly by husbands and female carers, but in some cases younger male carers were involved. Most of the people with stroke had recovered sufficiently that at the point of interview such assistance was obsolete or limited, but they still recalled the burden that such needs had placed on their family. The women also mentioned difficulties with managing their hair and dressing, but infrequently and with little emotional association.

Male respondents did not approach the subject of toileting, but did explain how they had needed help in dressing and fetching food to eat. Again both spouses and children were involved in providing the support they required. As they expanded on these difficulties, they partnered their inabilities with gratefulness that their family was on hand to give them the care and love they required.

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[12] In line with much of Asia, squat toilets are the norm in Indonesia households, although western style sitting toilets are becoming more common in the major cities.

5.6.2 Roles and responsibilities

A further impact of stroke that was focused on by the respondents was that of roles and responsibilities. Like the activities of daily living, difficulties with ascribed roles were related to their physical limitations. This included not only the weaknesses, but also the inability to guarantee that their body would function as they required. Participants expressed their frustration that their body was always apparent, having to be considered prior to action.

5.6.2.i Income generator

The most passionately discussed role was that of income generator. The ability to work and contribute to the family's income was key to all but one participant[13] and its loss post stroke was seen as a threat to the family. For the respondents, the threat was posed not only through financial insecurity, but also because other family roles, such as children's education had to be sacrificed in order to maintain stability.

The concern with income generation was related as often by the women as by the male participants. A division of labour is evident in the Central Aceh community, such that the women were more responsible for domestic care. However, it is also common for both men and women to work alongside each other, whether that is in the fields or in the shop or office based business (Bowen 1991). That was clear in the cases reviewed here as all but one woman had been actively involved in agricultural labour prior to stroke. In some families, the females' income generation and control over expenditures was reported as being secondary to that of her husbands. But for others it was evident that prior to the stroke, the women had been the most significant bread winner and had controlled the household finances. Through these discussions participants gave the strongest indication of the emotional sequelae of stroke. Participants expressed their distress at their inability to go to the *kebun*, tend their crops, sell the vegetables in the market or complete any of the income generating activities that had been part of their life pre-stroke; an inability created by the physical demands of these activities and the weakness they suffered from their stroke. Expressions of sadness, frustration and burden were common, but equally

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[13] This participant (Dewi) had a number of other illnesses which had reduced her capacity to work many years prior to her having a stroke.

conversations faltered somewhat, pausing while tears were cleared and in one case abandoned totally as the participant became too emotional to speak. This inability to work was marked even for the participants who had made a 'good' recovery and were able to complete all ADL's independently. For these participants the difficulty lay with the complexity of the physical demands in the *kebun* and the isolation, which made them fear the consequences if their now unstable body had a relapse.

In addition to the aspect of income generation, working on the *kebun* was associated with considerable pleasure, one that was now lost. Participants took several photographs of them with their crops and used these images, not only to talk about the importance of work, but also the pleasure they gained from being outdoors and fresh.

5.6.2.ii Domestic and familial support

A second responsibility that was frequently commented on was that of domestic and familial support. In addition to financial support, the participants discussed several other tasks which had been key to their role within the family unit. Once again, while some were shared between the sexes, different roles were highlighted by the male and female respondents.

One common to all and linked to the previously discussed ability to be an income generator was the capacity to be a provider of education. The need to earn sufficient income to support the children's education was reiterated in many interviews. Those who had young children discussed it as a pressure that loomed. Those with older children counted their blessings that the stroke had occurred after the obligation was completed. But for many it was a current pressure that had emotional consequences for the individual.

> *I think about my children, three of them, because they have to go to school.*
> *Can I ehm…because…why other people can send their children to school, but*
> *I can't and I must fulfill the needs of my children…It burdens me because my*
> *children need a lot of money to pay for their studies.*

> Faisyal

It was not the finances alone that participants discussed. Many had supported their children's and grandchildren's education in very practical ways, directly supervising their studies. This was a task they had also found unable to do initially after their stroke and commented on their resultant frustration.

It is perhaps unsurprising however that the majority of domestic tasks were recalled by the female respondents. Difficulties with cooking and cleaning were mentioned, but in some families this was accompanied with the consequence that the men of the household had to take on more of these tasks, which created some amusement from all parties. However, two more overarching duties, that of child bearer and wife, were also raised. These were not universal, but because of the salience to the individuals affected they are important to report. One young respondent, Sujatmi age 32 years, 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 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. The potential consequence of not completing this 'task' was not directly stated, but through quoting the heresay of neighbours, her husband suggested that he could take another wife. Two women with stroke, who were known but excluded from this study, were left by their husbands following their stroke and therefore such concerns cannot be considered a benign risk.

For some of the women, it appears that the impact of stroke was a direct threat to their position in the family. But for many of the others and the men, when they talked about the domestic tasks, in similar vein to that of income generation and ADL's, it was not the task itself which was of critical importance, but the impact that its incompletion had on other family members. For example, Lastri recollected her inability to collect clothes from the line when it rained, sweep the yard, or stack the firewood. As a result, her children who should have been either working in the *kebun* or at school, remained at home. She lamented that her inability to be independent resulted in her children's inability to be independent, expressing her relief that her recovery was now sufficient to allow her to participate in the family activities.

Photograph 6 Lastri collecting firewood. Lastri stressed her desire for her own and children's independence in every photograph that was taken.

Equally, in the discussions on toileting and washing, participants emphasised the physical burden they had or still posed to their relatives, discussing these issues far more frequently than any concerns with their appearance or lack of privacy. Indeed, the lady who toileted on the bed in front of the house mentioned on several occasions the difficulty her family had with lifting and carrying her, yet never commented on any compromise of self she made in order to toilet in a public area.

Participants discussed many problems, mostly functional, that resulted from their stroke. They also expressed their sadness, frustration or the burden that these inabilities placed on them. Throughout their narratives a concern with the consequences for the other family members was highly evident. A summary of all these factors and how they interact is shown in diagram 8.

Emotional consequences

Familial consequences

Personal impact

Event

Regret

Surrender

Want to die

Sad

Isolation

Lonely

Concerned

Frustrated

Children unable to do their role

Spouse and children take on role

Stop treatment

Poor economic situation

Housebound

Need help walking

Need help with ADL

Loss of social role

Unable to walk

Unable to do activities

Unable to fulfil role

Unable to work

Paralysis

Speech problems

Altered sensation

Stroke

Diagram 8 Summary of the impact of stroke

But like Lastri, when talking about these limitations, participants did not simply express their inability to complete them, but their driving motivation to be able to achieve them independently. As Arti stated,

> *My biggest motivation is to be able to walk and pray, do shalat (prayer).*
> *Walking is very important…it is the most important so I can go and pray.*

Whether it was to contribute to the family income, complete required domestic tasks, religious obligations, or not be a physical burden on the other family members, participants reiterated their desire to return to a state of independence. This aspiration was their most articulated reason for seeking help and as will be evidenced later, also the way in which they judged the success of intervention.

5.7 Summary

This chapter has introduced some of the key features that were highlighted through the stroke stories and their subsequent analysis. Central to these narratives was the description of physical incapacity as a result of an interruption to the blood flow from a multitude of causes. These incapacities had a significant impact on the ability to complete their own personal tasks, but also contribute to the family unit in which they lived. As a result, a chain of health seeking was put in place. The health seeking patterns are described in the following chapter.

Chapter 6

The road to health

6.0 Introduction

In this chapter I consider the health seeking behaviour of the people with stroke. I examine which healers were sought for help and the reasons for selection. Issues of cost, gender, age and diagnosis are raised within the narratives. The location of the healers is explored followed by a discussion on who made the health seeking decisions and what prompted change in treatment.

Prior to this discussion it is imperative that an overview of who is available for stroke treatment is presented. This chapter starts with an introduction to the three types of healers that were active in treating stroke in Central Aceh: biomedical, traditional and alternative.

6.1 The stroke healers

6.1.1 Government and other biomedical stroke services in central Aceh

As described in chapter 4, a range of Government personnel were interviewed and observed to obtain the following information. Government employed doctors from the hospital and *Puskesmas*, nurses, *bidan*, *bidan desa* and physiotherapists were all included. In addition, the two physiotherapists who were employed by Handicap International were also involved.

6.1.1.i Local biomedical concept of stroke

A summary of the biomedical concept of stroke and treatment processes is given in table 8. Specific differences and similarities will be further discussed below.

Table 8 Biomedical healers and their concept of stroke

Practice name	Knowledge gained	Diagnostic method	Causation theory	Treatment techniques
Community Physiotherapist	Study – college. Practice from 1-7 years	Examination – hemiplegia, decreased sensation, speech problems, test muscle strength	Block or bleed in brain – dead brain cells, hypertension, lifestyle, food, coffee, cholesterol, stress – mind, diabetes	Positioning, passive movement, active movement, strengthening, aids, balance, ADL, speech therapy
Hospital Physiotherapist	Study – college. Practice from 2-6 years.	Observation – paralysis, motor and sensory test, motor problems – weak, movement order incorrect	Blood plugged or bleed in brain, smoking, hypertension, living behaviour, stressful thoughts, poor nutrition, DM	Strengthening exercises, active/passive exercises, normal activity, breathing exercises, speech therapy, infra-red
Bidan	Study – college. Practising 15 years.	Examination, BP increased, Hemiplegia/ full paralysis, fall	Hypertension, DM, cholesterol, heart, alcohol, birth control medication, spinal column defect – back pain, smoking, coffee, durian, decrease or increase in blood to brain	Oxygen, medicine, infusion
Nurse	Study – college. Practising 19 years.	Observation – consciousness, breathing, blood pressure, paralysis – hemiplegia or complete	Hypertension, cholesterol, tiredness/tension, coffee, inherited, blood supply broken in brain	Medicine, infusion, positioning, exercise, rest, food restriction
Bidan desa	Study – college. Practising 10 years.	BP check, hemiplegia – heavy, dizzy	Increased BP, lifestyle – hard work, thought burden, fatty food	Infusion, injection, food advice – decrease salt, advice on BP

Practice name	Knowledge gained	Diagnostic method	Causation theory	Treatment techniques
Dr *Puskesmas*	Study – college. Practising for 1 year.	Examination, decreased movement, reflexes, BP, dysarthria, altered walking, trembling hands	Hypertension, smoking, fatty food, cholesterol, blockage in nerves, alcohol, narcotic abuse	Medicine, infusion, exercise and eating advice
Dr hospital	Study – college. Practising 15 years.	Examine – haemorrhage or infarct – meningeal signs, BP, cholesterol, other lab tests, hemiplegia	Smoking, cholesterol, increased BP, hyperleukemia, hyperuricaemia, NSAIDS, durian	Medicine, Oxygen, education

All the biomedical personnel interviewed had key concepts of stroke in common. But there were also a number of differences that are interesting to highlight.

6.1.1.i.a Diagnosis

All stated that diagnosis followed a clinical assessment which should be carried out by a medical doctor. That assessment included laboratory tests, particularly to highlight risk factors, and observation and clinical assessment for differential diagnosis of stroke and its sub-type. For all, the sign of a hemiplegia was indicative of stroke. Other problems, such as decreased sensation and speech problems were also named, but in the absence of hemiplegia, the diagnosis of stroke would not have been given. This emphasis and exclusivity helps to explain why strokes without a hemiplegia (for example posterior circulation/ cerebellar strokes) were not seen in the field area. It is likely they would have been given an alternative diagnosis. The signs and symptoms given are recognised in the international guidelines. However, others such as trembling hands are not. Interestingly, the doctors stated that although they would make the diagnosis they would generally avoid giving bad news. As a result they rarely discussed the diagnosis or details of stroke itself with the client or their family unless it was specifically requested.

6.1.1.i.b Stroke mechanism and its causes

On the whole, the understanding of the mechanism of stroke was aligned with biomedical understandings. This included damage to the brain from either infarct or haemorrhage. However, the identification of risk factors which could result in this interruption to blood flow showed more variety. A number, such as hypertension, high cholesterol and diabetes were named by most participants. But other key risk factors, such as smoking were inconsistently mentioned. Furthermore, a number of lay explanations such as eating durian, drinking coffee, thought burden and spinal column defects were given. Such influences were apparent through all professions and level of practice.

6.1.1.i.c Treatment

The explanations regarding treatment showed a large degree of professional differences as would be expected. The doctors and nursing staff focussed on medication to stabilise the patient. Much of this was in line with international recommendations; decreasing blood pressure and cholesterol, stabilising vital signs such as heart rate and insuring adequate nutrition and hydration when self feeding was not possible. They also discussed advice they would give regarding food restrictions, limiting fatty foods and coffee, and exercise both through general advice and referral to physiotherapy. Some also mentioned massage to increase the recovery. Indeed one nurse positively encouraged the family to seek out traditional masseurs as not only did they make the patient feel more comfortable, but they assisted in recovery through improving blood circulation.

There are three aspects of the drug regimes, however that are worth highlighting. The first is that one doctor stated that he used aggressive antithrombotic drugs to break up the infarct in non-haemorrhagic stroke. This bears some resemblance to thrombolysis, but not within the context of a clinical trial or with the necessary precautions of time limitations and diagnostic scans, making it potentially very dangerous[14].

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[14] The details of the regime he would use was discussed with a stroke consultant in the UK.

The second point is that both doctors stressed the need to control blood pressure carefully, stating clearly that certain drugs like Nifidipine should not be used in the acute stage because they lower the blood pressure too quickly. Both in the hospital and the community, acute and sub-acute, the main anti-hypertensive drug that was regularly used by people (as witnessed through drug charts or people with stroke showing their medications) was Nifidipine. There is some indication here that knowledge and practise are not aligned and that concepts from Western trials have filtered through but been reinterpreted to local context.

The third relates to the continuation of the drug regime on discharge. Blood pressure, for example was controlled via oral medication. The doctors and nurses discussed how the patient would be given a three day supply. The expectation was that the patient would return every three days to get another course of medication. However, all noted that patients rarely did so and complained that they were too lazy to care for their own health.

Therapeutic treatment was given in a number of different settings: the hospital as both an in-patient and out-patient, the *Puskesmas,* and through home visits. Some approaches towards rehabilitation were shared, but significant differences were noted between the hospital and community based therapists. Both groups had regular contact with people with stroke. In the hospital, stroke accounted for 26% of all treatments given in the physiotherapy department[15]. The community based therapists also worked with people with stroke more regularly than any other diagnostic group.

All the physiotherapists conducted an assessment prior to treatment. They completed this through a process of physically testing the strength of specific muscles, minimal observation of completing basic activities such as rolling and sitting, and crude sensory tests on the skin (photograph 7). Problems identified were then used, to an extent, as the basis of treatment planning. However, there were some significant differences in approach to treatment between the hospital and community based therapists.

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[15] Figures from the department statistics for the year 2006.

Photograph 7 Showing Zaiful with client

For both groups, treatment was reportedly based on the individual presentation of the person. However, there was evidence both within the focus group discussion and in the observations that treatments within the hospital were more formulaic and utilised for purposes other than therapeutic efficacy. For example, the therapists discussed the routine of passive and active exercises[16], but did not relate them to specifically weak or functionally important muscles. In observation, all major muscle groups were exercised in the same order and manner for each patient. Finally all outpatients had a course of infra-red therapy to start their treatment. Justification of this was given as warm-up. As Zaiful commented,

> I use it because the community is motivated when I use it. It makes a difference between physiotherapy and dukun, so it is a very important piece of equipment.
>
> <div align="right">Zaiful, head physiotherapist at the hospital</div>

Three aspects are important to highlight from this quote. The first is the symbolic importance of the machine that defines the physiotherapists as something other, and potentially more advanced given the choice of electrotherapy, than a *dukun*. The second is the concept of heating as an important requirement for people post stroke, and finally, an introduction to the concept of motivation. Like their western colleagues motivation was seen to be important, but it was not a well developed concept. On the whole, they reported that patients were often too lazy to do exercises, got bored quickly and were therefore unmotivated to participate in

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[16] Passive exercises are completed by the therapist on the client with the latter not attempting activation of the muscles.

physiotherapy. However, other than the use of infra-red, they gave little insight into their role to increase motivation and in fact showed some evidence of their own lack of motivation in treating this client group.

Zara: I like giving passive exercises because it is not tiring

Adi: Maybe the problem is uncleanliness, the bowels, which produces a disgusting odour.

For the community based therapists, treatment was more clearly focussed on the individual needs of the person, although some evidence of routine practice was also apparent. The therapists spent a considerable part of the treatment time doing mobilisations to several small joints in the hand and foot. In post treatment interviews they could not justify the specific reasons why they had done this for the particular person, but discussed it in terms of a pre-treatment warm-up, in a similar vein to the use of infra-red by their hospital based colleagues.

Treatment plans were not simply based on assessment findings but also on the priorities identified by the individual person with stroke. This often took the physiotherapist beyond pure exercises, to functional activities, speech development and a considerable amount of energy on communication with the family. While exercises were completed, as is shown in photograph 8, one of the most commonly discussed problems post stroke was self-confidence and a lack of belief in recovery and motivation. The therapists referred to this as a 'lack of spirit' and an understanding and management of it was seen as being central to their role as physiotherapists.

Photograph 8 Yesi with client

Yesi: Mostly, ehm, mostly we start from their feeling. Yes, their feeling. When we observe people with stroke, the severe ones, usually they have no spirit at all. We start from their feeling, then we observe their internal characteristics and their thoughts about their physical condition.

Interviewer: From your previous explanations it seems that, ehm, as a physio, the focus is on the paralysis and related to the spirit of the patient himself. What technique does the physio use for those two problems?

Diah: ehm, we think, we think, firstly is the return of their spirit, by doing approachment, personal approach to the patient. If it is successful, returning the spirit, then we do the other, ehm, other treatment.

The community based therapists described how they initiated discussions with their client, asking them about what they wanted to achieve. When the person with stroke was unable or unwilling to identify a particular activity, the therapists would suggest goals, such as going to the toilet independently, or being able to walk to their neighbours' house. They followed this with an indication of how it could be achieved. This drew on evidence of progress they had already made or the specific exercises they would work on. The justification of this approach was two-fold. Firstly, without believing that they could do something, the therapists found their clients to be passive and unmotivated in treatment. As a result, treatment would be unsuccessful. This belief related to the family as well, so the approach of 'lifting the spirit' of the individual was extended to that of their carers. Belief in recovery was essential for all. This latter point relates to the second important justification. The therapists were well aware that their treatments were short and insignificant if their client did not practice regularly in their absence. To achieve this, they understood that the person and their carers had to believe that the specific exercises were important and would be effective if practiced regularly. 'Lifting the spirit' therefore was a process of motivation and belief in the goals and techniques of therapy. The similarities of this to the western literature are unmistakable.

Equally distinctive was the frustration felt by the therapists when this motivation was lacking and joy when it was active.

Yesi: I like working with patients who are enthusiastic to get better.

Fitri: The patient says yes when we are there, after we leave, he does nothing. When we check, he says 'I do it', but actually he does not…we cannot help them if they are basically lazy. Moreover their family also ignores them, how can they make a change if they are disorganised? I find several families place them in the corner, not in an open place. That makes us really, really frustrated, how dare they ignore them.

6.1.1.i.d Concepts of recovery

Improvement for this group of practitioners came with time and to a variety of levels. The *bidan* believed that total recovery was possible if the appropriate medications were taken. The nurse and doctors had more complex answers suggesting that incomplete recovery was possible and was maximised through lifestyle changes, effort and physiotherapy. None, however, were able to explain the mechanisms by which recovery occurred.

All therapists believed that the patients could recover to some extent. 'Being normal again' was seen as an impossible goal, and so independence in daily activities and adaptation to their limitations was presented as the aim of rehabilitation. However, in discussions post treatments, the therapists occasionally referred to very high levels of recovery, even using phrases such as 'get back to work as usual', suggesting that a full recovery paradigm may also be held. Furthermore, while they discussed initial goals with their clients, explicit commentaries on projected prognosis were not witnessed in any observed sessions. The hospital therapists in particular commented that they rarely witnessed this recovery as the patients did not return for regular treatment, instead choosing to see the *dukun*. They believed this to be a consequence of the patient's economic condition, lack of understanding of recovery and belief in magic. None questioned the relevance and effectiveness of their own treatment as a potential factor.

6.1.2 Non-biomedical healers in Central Aceh

Two main categories of non-biomedical healers were identified as being active in the treatment of stroke in the Central Aceh region. These include practitioners who

described themselves as being traditional healers or *dukun* and others who chose the title 'alternative'. Both will be described.

6.1.2.i Traditional healers and their concept of stroke

The traditional healers interviewed were predominantly based in villages outside of Takengon. They did not have an organised practice and all had other jobs; such as farming or selling food in a small shop. Their practice was known by word of mouth and they either had clients call on them or they would be called to see clients in their homes if they were too sick to travel. Two were men and three were women. None charged a set fee for treatment, but would accept gifts if they were offered by the client. There was a subtle difference in relation to the gifts amongst the traditional healers. The older healers specifically commented that they did not expect payment and indeed payment would belittle the fact that they had been given the gifts of healing by God and therefore must practice in His service.

Wife of Budi: he does not use money when he gives a treatment
Budi: I do not need oiling. I directly cure them.

> My late father used his ability as a charity. While I also do the same, if they give me with sincerity, I will accept it. I never ask payment. I consider it as a charity although I am not a masseur. Their healthiness is the gift from The Almighty. I am only the media. I never ask payment.
>
> Wenny

The younger healers, while not having a fee, did expect to be given something in return for their treatment. The amount, or indeed what, that was to be given was left to the client to decide[17].

The traditional healers illustrated a number of different practices and justified their techniques through various explanatory processes. They were neither specialised in healing one particular group of problems, nor were they always fixed in their approach, although it was clear that the older healers had fewer applications at their

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[17] Indeed one requested that I pay an amount of my choosing following the interview.

disposal. This differs somewhat to the categorisation of *dukun* found in Java (see Nitibaskara 1993 for example)[18]. A summary for stroke is given in table 9.

Table 9 Traditional healers and their concept of stroke

Practice name	Knowledge gained	Diagnostic method	Causation theory	Treatment techniques
Village teacher	Through prayer- from God. Practising 3 years.	Through egg, message from God, see paralysis	Blood circulation plugged, too much thought, occult force	Medicine (made), massage with medicine, bath with leaves of flowers
Village *dukun*	Gift from God, fasting. Practising 36 years.	Observation – tight tendons, glass sticking	Genie/devil, increased BP, evil wind – closes heart	Bekam – burn it, God's permission, prayer – rajah, flower bathing
Village *dukun*	Secret. Practising 40 years.	Where glass sticks – sign of dirty blood, physical signs – unable to walk	Blood flow plugged, decreased blood to heart	Corn/butter leaf, bekam – removes dirty blood, purut fruit
Mamak (mother)	Inherited. Practising 12 years.	Body heavy, decreased movement	Hypertension, flying genie, too much thinking, fear	Traditional medicine, massage, forbidden foods, conversation with spirit, chicken and rice donation – redeemer, syukuran
Mamak urut	Inherited/ course. Practising 5 years.	Feel muscle – hard, paralysis	Fall, cold air, something on mind, muscles tight	Soft massage

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[18] In Java, *dukun* have been subdivided in a number of categories dependent on their field of activity.

The traditional healers in Central Aceh obtained their skills through a number of methods. Some inherited their skills, often from a grandparent.

> When he (my grandfather) was dying he shook my hand, then that ability entered in me so that I can heal. I can heal a patient if I do it with love. Suddenly all of my body is moving.
>
> <div align="right">Wenny</div>

Others obtained the skills directly from Allah through prayer and pious behaviour.

Interviewer: Where did you get this knowledge?

Budi: This? This...this...I got it directly in a fasting month. By fasting. The inspiration is not demanded. A gift from God...

Interviewer: Sir, you said that you had got the inspiration in fasting month. How did you know that it was the inspiration to cure people?

Budi: It's like this...before that, I was not a dukun. At that time, my wife and my children were ill...aaaa

Interviewer: All were sick in one time?

Budi: aaa...It came in my dream, He said that if I use al fatihah, kulhu, kul auju alfatihah and then tomorrow they will be better..aaaa.

Interviewer: So in that dream, that man said something to cure your family who were sick. You read those verses. And since that time, you have used them to cure people.

Budi: aaaa...yes...others.

For all but one of the traditional healers there was no way to study the skills they had; one must have the gift of healing. The *tukang urut*, in contrast, had studied aspects related to delivery of babies, but this was not related to all of her practice as a healer. Her massage skills had been inherited from her grandmother, although it is possible that she also studied informally by observing her grandmother as a child.

6.1.2.i.a Diagnosis

A core part of the healing gift was the ability to diagnose what the problem was and equally *where* the problem was. Diagnosis was often performed using diagnostic tools. These tools took the shape of an egg or a piece of glass that was run across the

skin. In addition, the healers also utilised observation of the client and touch as part of their 'assessment'.

Photograph 9 Diagnostic glass and other tools of Armisar

In the case of the egg, the healer described how the illness would show in the egg; a light would appear as she held the egg, calling the clients name, and with that light the condition could be seen. The condition showed itself through a code, one that was only known to her and her husband. As a result, the healer could directly see if the problem was in the stomach or shoulder for example. While the diagnosis would appear in the egg, the glass had a more physical approach, by sticking to the body part where the problem was based.

Budi:	The illness will be detected by this glass...if there is an illness, then it will not go anywhere. (he demonstrates moving the glass down his arm, imitating when it got stuck)
Interviewer:	Oo. So the glass will not move.
Budi:	Yes, it stays stable if there is an illness...
Interviewer:	You said that if it does not move then there is an illness, do you know what the illness is?
Budi:	If the illness is here (neck), if it gets stuck here, it is means the location is in the head.
Interviewer:	So it depends on the location.
Budi:	If it is here, then he usually has a headache.
Interviewer:	If in …
Budi:	if it is in the chest, then he will cough.
Interviewer:	If the patient has a stroke, where does this glass stop?
Budi:	this glass?
Interviewer:	Yes, the glass with stroke...
Budi:	All the body is connected. If it is the most affected half, then it will stop there.

In the case of people with stroke, the glass always stopped somewhere on the hemiplegic part of the body, but often in multiple places. Other methods discussed by the healers included a second magnifying glass that could see the purity of the underlying blood, contact with the body to feel the sections of blockage and a very direct conversation with spirits inside the body to ask them what they were doing there.

These processes may at first glance appear very different, but they have a number of things in common. Firstly all were based on the assumption that some 'thing' was causing a blockage in the flow of the body. This was invariably referred to as the flow of blood, although other references to the flow of the muscles were also added. This 'thing' had a number of potential origins: genies, dirty/cold winds, occult forces, and a number of variations on thinking (fear, heavy thought, thinking too much). Often these were directly related to high blood pressure, which itself caused a problem in the blood flow. This designation of origin was the most contentious aspect of the healers' practice, as the belief that a blockage could be caused by a *djinn*, spirit or genie was hotly debated in the community generally. Indeed, in one interview, the wife of the healer consistently asked us not to use the word genie, despite the fact that her husband had been using that term in his explanation. For many, to suggest that spirits even existed was to speak against the teachings of Allah. For others, their existence is evident in the *Qur'an*, *Hadith* and sufic practices, but they can only cause ill-health when the person has acted in a way that is against a Muslim path[19]. As a result, to suggest spirits as a cause of ill health is to indirectly suggest that the person afflicted was not a good Muslim. For the healers interviewed, however, religious connections were absent. The environment and bad luck, as well as evil intentions of another and fear, were enough to bring the misfortune of these spirits upon you.

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[19] There are several references to *djinn* in the *Qur'an*, explicitly inferring that not only do they exist but that they were created by Allah. See Qur'an 55:15 "He created man from potter's clay and the jinn from smokeless fire" for example. However the status of *djinn* is complex with several references to both their evil nature (e.g. Qur'an 114:6, 6:128), the negativity of worshipping them (34:41), powers that they have that are sanctioned by Allah (55:33), and their understanding that God is the all powerful (72:1-30). Hence their status is somewhat ambiguous.

> We should not be surrounded by the devil spirit because the devil is dirty and his food is the garbage. We should avoid the rubbish... If you are doubtful, you can try it. If you pour hot water, then you will feel sick directly because the rubbish contains a genie. Try it.
>
> Budi

The second commonality was that the location of that 'thing' had to be known for it to be removed. Such diagnostic processes worked alongside and reinforced concepts of flow and blockage as understood by the client. But they also required a certain level of belief. While physical discomfort may be felt with blockages diagnosed with manual contact, the glass and egg processes require trust in the healer as it was only through their interaction with the tool that diagnosis was made. All these methods have the effect of making the unseen seen, whether that is visually through the tools, or somatically through feeling the contact with the healer. While there was a symbolic quality to this diagnostic process, it was relatively mechanical and was not accompanied by dancing, chanting, music or the consumption of special substances as has been noted elsewhere (Stephen & Suryani 2000). *Dukun* who worked as mediums were observed in Aceh. They sometimes, but not always, utilised tools such as chanting and specific outfits to assist them in their healing trance. However, these healers were not sought in the case of stroke by the participants in this research and therefore are not included in this review.

6.1.2.i.b Stroke mechanisms and its causes

The term stroke was used by all the traditional healers, but in a descriptive context and without much importance. Healers noted stroke because the appearance of a one sided weakness.

> There is a part of the body which is not proper! The face is lame,--sloping, vary. Then it is called stroke.
>
> Karina

This weakness did not however, have to encompass all of one side of the body or even one limb which led to some references to stroke which could have been alternative conditions. Indeed, one described a previous client with stroke, on the basis that the shoulder was dropped and the arm was not functioning well after a fall.

The description had more in common with a dislocated shoulder than stroke, but as the signs fit the generic terms of stroke, it was utilised. For them, however, the term gave no assistance to understanding the cause of the problem and little guidance of the location for treatment.

An interruption in blood flow was consistently cited as the main mechanism of stroke, itself being influenced by both internal and external factors. Biomedical concepts, such as hypertension, were combined with more local concepts. These were expressed as disturbances from too much thought, cold weather, muscle tension, flying genies and evil wind. Two factors were particularly emphasised. External 'things' which enter and disrupt the body, such as spirits, genies and winds were part of the explanation given by all traditional healers. Related to this, the conflict and subsequent fear was also consistently mentioned as factors which increased peoples' susceptibility to 'attack'.

> Most of them have happened after they experience something scary, like seeing decapitated head. Both the old people and the young one will be scared.
>
> Wenny

6.1.2.i.d Treatment

Treatment, as mentioned previously, involved removing both the blockage and if possible, the cause. All felt confident to treat stroke and would not routinely refer people they believed to have stroke to other services. The only exception to this was the healer who specialised in massage. She noted that massage following stroke could cause death, although she was not clear how (it was based on experience of colleagues of hers). As a result, while she would work on clients who had had a stroke, she did so with care and was somewhat unenthusiastic at the prospect of treating this client group.

Healers utilised different methods, but all had both physical and symbolic qualities. General massage was the most commonly used as a means to physically move the blockage and facilitate flow once more. This, it was suggested, would result in a resolution of the symptoms. For the *tukang urut*, this was the only treatment

technique she used. For the others, it was utilised as a supplement to their other practices. For example massage was also used in the case of genies and spirits, a way to gently entice the spirit to leave the body and therefore let it flow. In this case the massage was done alongside a gentle conversation with the spirit, with the offerings of chicken and rice in place.

Wenny: For example, me. I say "whoever you are, please go from here. This is the redemption. We already redeem you, so you must go". While he says like that, he will massage slowly on the sick part.

Interviewer: After saying like that, you massage him slowly.

Wenny: yes, all over the body, but it must be very gently and slowly….

Interviewer: so you ask the spirit to go and you physically encourage it to go through the massage?

Wenny: yes

An alternative physical technique was that of *bekam*. This technique uses either cupped heat or direct sucking by the healer. It targets specific parts of the body where the blockage is most severe and aims to remove the offending cause, whether that is a malevolent spirit or dirty wind. Some forms of *bekam* seen in this region bear similarities to the Chinese concept of *moxibustion (moxa)*, which is a treatment process for wind stroke (a type of stroke in Traditional Chinese Medicine concepts), although the justification for its use is very different (Maciocia 1994).

Photograph 10 Fire bekam by Budi

Interviewer: After you know where the illness is, what will you do?

Budi: I take that disease.

Interviewer: You take the disease.

Budi: Then I grasp it. Grasp it with special aid. Until it dies. Using bekam, using the fire (he leaves to find some of the equipment)

Interviewer: Using a candle?

Budi: No, we take the illness by burning it. We borrow it. This can be demonstrated. By Allahs permission, the illness disappears after five minutes.

Photograph 11 Sucking bekam by Armisar

Armisar: yes, you do bekam in the dirty place

Interviewer: how long we have to do the bekam?

Armisar: ooo not too long

Interviewer: how many minutes

Armisar: three minutes

Interviewer: and this sucks out the dirty blood?

Armisar: yes, it enters into the cup

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

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

Traditional medicines from herbs and leaves were also used in a number of ways. For example the butter leaf was used to assist with the removal of spirits through *bekam*, and a form of nightshade to assist the cleansing of the body. The 'tradition' of these medicines was however questionable. While some healers had learnt the medicinal combinations from their ancestors, others had created their own mixes with little justification for their use other than a comment that they didn't cause any side effects. None had a compendium of medicinal plants and nor did they use the term *Jamu* (the traditional herbal compendium of Indonesia) in their explanations of their mixes.

In addition to, and to support the physical removal processes, other symbolic acts were pursued. Some used prayer, either directly before or during the procedures to ensure Allah's blessing on the acts. Those prayers could be said aloud or internally by the healer. They may be quotes directly from the *Qur'an* or *Hadith*, or specific prayers that had been revealed to the healer in their sleep. Others had offerings of rice and chickens prepared to 'bribe' the spirits to come out, a process they described as the redemption of spirits.

> Yes, it functions as a redeemer, to let the disease go. We tell the spirit the chicken and rice is for you, now please go. The chicken and rice encourages the spirit to leave the person.

<div align="right">Wenny</div>

Alternatively, a *mangkur* fruit (*jerok purut*) was on hand to capture the removed spirit, which then had to be thrown in the river or lake. According to lay descriptions *jerok purut* are used in many ways by *dukun*. It was stated that *dukun* believed the fruit to represent the world and therefore had the potential to contain everything within it. In some instances reports were given that after specific incantations to the fruit, it was thrown on the floor and broken open. This allowed the internal problem to be seen, as it was mirrored in the fruit. Such a process is noted by Bowen (1993). This, however, was not witnessed in the cases of stroke discussed with the *dukun* in this research. The capture was not always immediate and in some instances the client had to sleep with the fruit for a number of days and then wash in some of the juice prior to discarding it.

Photograph 12 Jerok Purut fruit used by Armisar.

Finally, a number had events to signal the end of the process, which also acted to protect the client from future harm. These took the form of baths with a mix of

flowers or a *kenduri/ syukuran*, a community meal to give thanks for the healing process[20].

Interviewer: What happens next with the hen and the rice

Wenny: usually it is given to an orphan or it is slaughtered, then he calls the orphans, then feeds them. It can either be just a lunch, but if they have enough money there will be ceremony.

Interviewer: What is it called?

Wenny: Syukuran. It is held after the holder is getting well.

It is interesting to note that although this healer referred to *syukuran* as an event to be held at the point of recovery, a number of participants with stroke had completed several of these meals/ ceremonies in an attempt to recover.

An important point regarding these additional processes is that they are neither free nor cheap. While the services of the healer may not incur significant financial outlay, many of the instructions, particularly the offerings and *kenduri/ syukuran* come at high cost to the client. Issues related to this will be expanded upon later in this chapter.

6.1.2.i.d Concepts of recovery

The expectation for all of these healers was that the removal of the blockage and cause would result in a resolution of the symptoms. They all reported that a total cure was possible and the expected outcome. When this did not occur immediately, it was perceived as an indication of the strength of the spirit or other causative agent and the complexity of the body parts affected. This often acted as an indication for more treatment. Alternatively other explanations were given, such as the client having eaten inappropriate food immediately after the event, or a delay in seeking their assistance, both of which resulted in a difficulty in their curative powers.

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[20] *Kenduri/sykuran* was the local terms for *Slamatan* which is common across Indonesia and has been written about extensively by Geertz (1960) and Beatty (1999).

Wenny:　　　　It should not be like this. There are 4 things that you should not eat with this illness. This is traditional medicine, onion, garlic and two others, I forget. But she had already had them before I came....

Interviewer:　　You suggested to this woman to not take the 4 things, garlic etc so that she did not get stroke.Why did you ask her to do that?

Wenny:　　　　In the traditional point of view people should not take these things because they are closely related to the flying ghost. If they take them then the ghost will enter more. Otherwise, I can heal them. Like this woman, she was already bad when she was brought here, so it was difficult to make her recover.

6.1.2.ii Alternative healers and their concept of stroke

Alternative is a term derived from the field and describes a group of practitioners who have neither had formal biomedical training, or relied solely on inherited or Allah given gifts. This group presents itself as a hybrid, utilising concepts and practices from all sectors of health understandings: biomedicine, traditional, religious and overseas paradigms, specifically Chinese. This is represented in diagram 9 where the dark grey inner circle represents the practices of the alternative healers. In all aspects of their activities: understanding of health and illness, diagnosis and treatment, these practitioners illustrated these mixed influences to one extent or another.
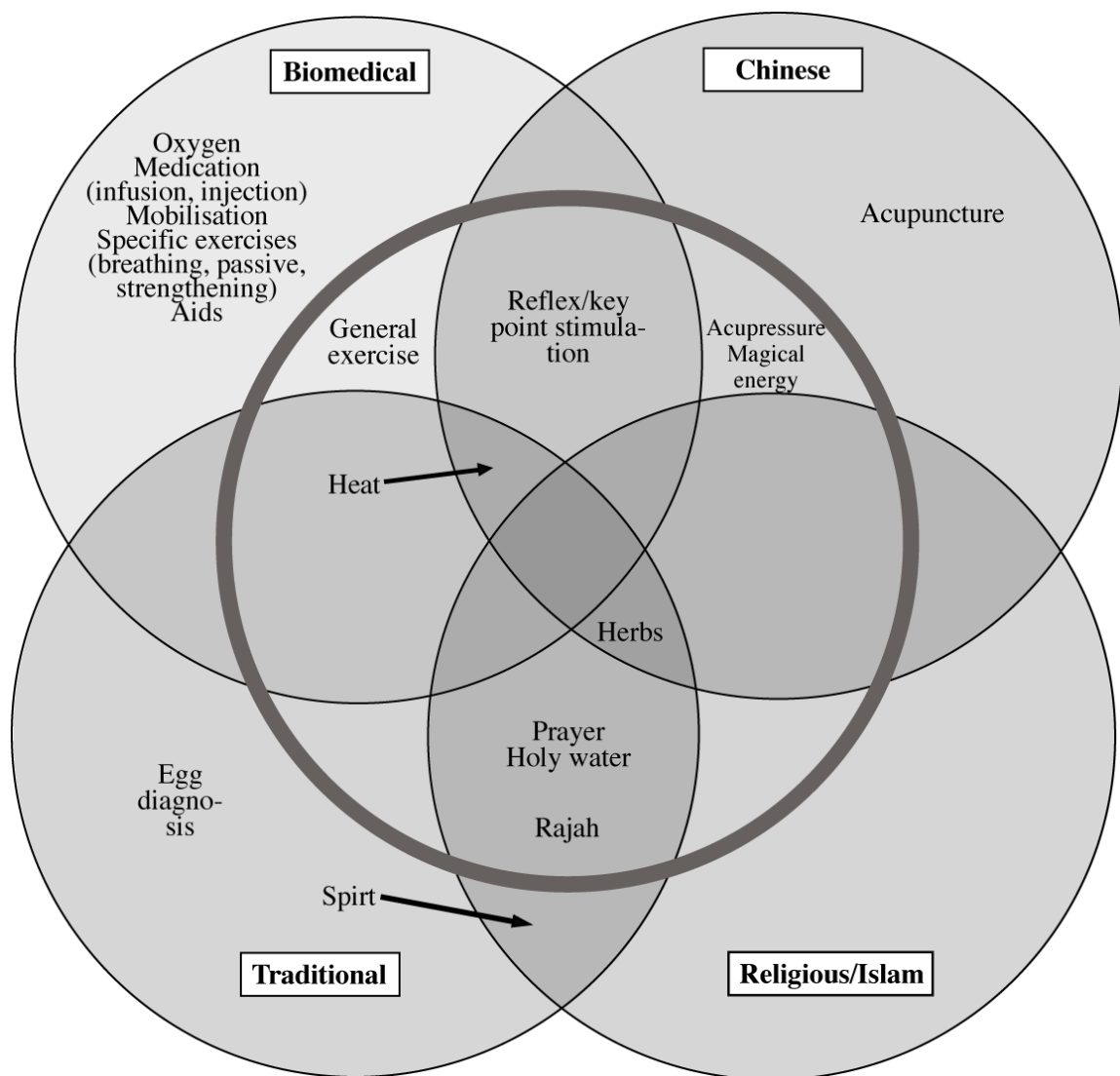
Diagram 9 Treatments used by alternative practitioners

The three alternative practitioners interviewed and observed were younger than the traditional healers and were all male. While one, who had only just started practising, worked from house to house, the others ran very successful and busy clinics from their homes in Takengon town. These clinics ran like mini-hospitals with people both attending as outpatients and also staying for a number of days if the severity of the disorder required. While they did not record numbers of attendances, it appeared as if they were extremely popular, one quoting that he saw 80 people a day. On all visits, both planned and unplanned, the main treatment room was full of people and both healers commented that they no longer had time to do home visits.

A summary of their understanding and approach to stroke is shown in table 10.

Table 10 Alternative practitioners and their concept of stroke

Practice name	Knowledge gained	Diagnostic method	Causation theory	Treatment techniques
Alternative	Inherited/ study course. Practising 7 years.	BP, heart beat, looking at walk, balance, movement check- arm, totok, speak with spirit	Hypertension, anaemia, cholesterol, diabetes, ghost in body, plug in blood – blood excessive in brain, blood too hot, blood imbalance, blood frozen, kidney smaller	Rajah, exercises, herbal medicine, ask God's help, magic power, totok, massage, reflex stimulation, rid the ghost, food avoidance advice, ritual shower, heat, muscle stimulator
Traditional or alternative	Study course. Practicing 20 years.	Way they walk and move – deviation, massage – feel, should alignment, BP, secret	Hypertension, heart shock or trauma	God's help, medicine (bought and made), reflex massage, slamatan, holy water, movement facilitation, prayer, motivation
Alternative	Study course. Practising 1 year.	Pulse, massage – feel for protusion	Weak heart, decreased blood to kidney, increased BP – fall – stroke	Massage, acupuncture (pressure), cupping

Skills were obtained from a combination of study and inherent gift, with the former the most emphasised. All were at pains to highlight the legitimacy of their interventions evidenced by their completion of courses in Medan[21]. Even for the healer who had also inherited gifts, he emphasised the 'research' that had been done within his family that further validated his practice. This mix of inheritance and study poses some difficulty in where to place such a group. In some ways they resemble the alternative healing scene in the West, where professionalization and limited integration to mainstream biomedical healthcare has occurred (Helman 1994). Yet the courses they have attended are not accredited and, as will be shown, their understandings and techniques are infused with influences from multiple sources and a degree of mysticism.

6.1.2.ii.a Diagnosis

Assessment and diagnosis of a problem such as stroke involved both biomedical and non-biomedicial measures. Biomedical 'tests' such as blood pressure monitoring, observation of body alignment, muscle function and ability to complete tasks, such as walking were commonly used. However, these were not always completed in the manner and for the purposes that they are usually understood. For example, blood pressure monitoring was done to check for the presence of hypertension, but also multiple other organ functions.

Interviewer:	e… when this lady came for the first time. What did you do to this lady?
Abdul:	hah, tension
Interviewer:	e…use tension yes sir?
Abdul:	using tension machine
Interviewer:	is there one here?
Abdul:	a… there is, a…. there (he gets and shows a blood pressure monitor)
Interviewer:	why do you do that? What is that for?
Abdul:	to know the blood, nerves, kidney, heart, haemoglobin

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[21] Medan, in North Sumatra, is the largest city in Sumatra Island. It is about 11 hours bus ride from Takengon and all had completed courses their of varying length and content

And relevant biomedical factors were assessed through atypical processes. For example, one healer explained that he assessed high cholesterol through the observation of walking, the rhythm of the heart beat and speaking with the spirit of the patient.

As the examples above demonstrate, biomedical concepts were mixed with approaches from other healing traditions. These most commonly took the form of measuring internal energy and its flow. One healer, Ismail, described the process as being a connection between his internal energy and that of his client. What he felt, vibration, harmony of movement or independent movement of her energy in relation to his, formed the basis of his diagnosis. It further acted as treatment as will be discussed later. In the case of stroke, a lack of vibration, indicative of poor blood circulation, was a diagnostic sign.

Another, Paujan, also focused on flow, but that of the blood. This however, was not through the circulatory system as understood in Western concepts. He monitored the blood flow through two methods, taking the pulse and feeling the muscles for tension and protrusions that would indicate a problem with flow. He was particularly concerned with the flow to organs such as the heart, kidney and spleen and used a variation on reflexology to identify the problem areas.

Both the use of internal energy and the focus on organs such as the kidney bear a resemblance to Chinese concepts of *Qi* and the prioritisation of internal organ function. Indeed one healer had a book entirely in Chinese which he proudly produced as validation of his knowledge. This is perhaps unsurprising given the long history of exchange between the countries. Furthermore, the Indonesian understanding of the centrality of flow to health and belief in agents of illness that cannot be seen, results in a receptive condition for Chinese concepts. However, the specific influence of Chinese medicine in Indonesian alternative practice requires significantly more detailed study.

In addition to biomedical and Chinese diagnostic processes, more traditional and religious paradigms, such as secrecy and messages direct from Allah, were also apparent. As a result, the diagnostic processes of these healers were truly eclectic,

using the known concepts of flow, but wrapped in a slightly mystical package of religious authority and secrecy combined with the equally mystical 'sciences' of the West and East.

6.1.2.ii.b Stroke mechanism and its causes

Like the traditional healers, stroke was a known category and was closely related to hemiplegia or half dead body (*mati badan sebelah*). But unlike the traditional healers, the alternative group had a more expanded and nuanced understanding of stroke. These, however, appeared to be individual in nature and were different between the three alternative practitioners.

Interviewer:	Back to stroke, what do you know about stroke? According to you, what is stroke? Can you describe it?
Ismail:	Stroke according to my observation, from my ancestors, stroke is divided into three categories. One of the categories, which is the same as doctors is hypertension. Hot pressure causes the blood to be excessive in the brain, then it causes a plug. In the language of alternative medicine is...the blood is hot then goes out from the heart to the brain. The heart beats then become unstable, than it makes a plug.
Interviewer:	Anything else?
Ismail:	It also can be caused by anaemia, the white blood cells are not balanced. Then, the blood is frozen. It is harder to be cured than stroke caused by hypertension because we should pay attention to the HB.
Interviewer:	What else?
Ismail:	There is stroke which caused by diabetes. He is totally unable to move. He has collapsed, completely weak.

An interesting point to note in this excerpt is the reference to the brain. The alternative practitioners, unlike their traditional colleagues appeared to make a link between stroke and the brain. However, despite the connection being made, damage to the brain was not explicitly noted and in descriptions of treatment and recovery, the brain was totally absent.

A further aspect was the reference to the heat of the blood. Concepts of hot and cold when relating to flow were common in the descriptions given. Both were cited as being potential causes of plugs. Hot blood was generally more related to hypertension and cold due to physical limitations in flow, such as muscle tension. The origins of these categories are difficult to unravel. The ethnographic work done in Malaysia cited in chapter 2 (Laderman 1991, Laderman 1992) discusses in detail the origin of hot and cold concepts from both Islamic concepts of health and pre-Islamic concepts. They have many similarities, but are the reverse of each other. Given that both hot and cold are assigned as causative agents here, it is difficult to suggest whether this is an Islamic or pre-Islamic influence. However, the ascribed cause was important in the treatment decisions.

These mechanisms of how blood flow affected the bodily systems were also expanded in terms of the internal organs. In these descriptions the importance of the kidney was once again highlighted. This emphasis is unique to this category of healers and is once again an indication of a possible Chinese influence on understanding. The description given by this practitioner was compared with the Chinese concepts of wind-stroke (Maciocia 1994) and later confirmed with qualified practitioners of Traditional Chinese Medicine (TCM) in the UK. The centrality of kidney-yin in the causation of wind-stroke is clear and it would appear as if he is working within an understanding closely aligned to Chinese concepts. However, discrepancies arise in the treatment protocols.

While the concept of stroke as a condition may be nuanced, the causation pathway continued on very similar lines to the people with stroke. All were related to blood flow in some manner or other and factors such as thinking too much, shock, physical tension and falls, blood pressure, eating incorrect foods, as well as ghosts in the body were all cited.

6.1.2.ii.c Treatment

Treatments similarly illustrated a combination of concepts, as diagram 9 revealed. Many of these had been uniquely interpreted by the practitioners.

From the biomedical perspective, exercise and movement facilitation was commonly used. In fact this was presented as a main differentiating factor between traditional and alternative practice.

Interviewer: Is there any difference between your treatment and the treatment from the dukun?

Ismail: yes, there is.

Interviewer: What is that?

Ismail: We give less magic sign (rajah), but more exercise, the therapy is more.

Describing how these methods were used though is complicated. While the practitioners advised on positioning of limbs, facilitated movement, stimulated muscle activity and practiced functional movements, they did so in ways often very different to those practised by physiotherapists and with different justifications. Once again it becomes apparent that terminology alone is inadequate for comprehensive understanding. For example, a subluxed shoulder, secondary to weakness from stroke, was treated with strapping and support (which is used by physiotherapists in the UK and is recommended in the National Clinical Guidelines), but only after selected pressure points had been stimulated and a powder of fruit and leaf essence had been applied. In this case the pressure points did not align concretely with Chinese points but a mix of Chinese and points used in *pijet*[22].

Photograph 13 Ismail indicating pressure points stimulated prior to strapping subluxed shoulder in patient with right sided hemiplegia.

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[22] The points that the practitioner had used were compared with the points recommended in two texts (Rahasimyah 2005) and Maciocia (1994) and in discussion with qualified practitioners of TCM.

Facilitation for active movement was given in what the healer described as key points. It is interesting to note that the term key points is common in Western stroke rehabilitation terminology, to denote areas where movement can most easily be influenced. While it appeared that he was stimulating the abdominal muscles to assist with sitting (a technique also used by physiotherapists), on questioning he did not discuss the muscle as such, but rather that there was a specific point which when stimulated with pressure would switch on the movement, like a car is switched on with a key.

The example given above had a striking physical similarity to western techniques. However, other stimulatory techniques were used that were more aligned to traditional and eastern massage techniques. All three utilised what they termed as reflex pressure/massage. This consisted of deep stimulation to specific points or muscles which were believed to aliven the dead limb again.

Photograph 14 Illustrating pressure points emphasised during massage by Paujan.

Note that the lower point on the foot relates to Chinese meridian point Yongquan KID-I which is recommended for lower limb paralysis secondary to wind stroke (Maciocia 1994). The healer identified these points on a diagrammatic representation of the body given to him during his training in Medan.

Two of the practitioners discussed the clear importance of active exercise and the dilemmas of volition on behalf of the client. They highlighted that exercise was up to the client to do and the only tool they as healers had was to show them and motivate them. This they achieved through discussion, making the activity relevant to the life and future wishes of the client and by strong positive encouragement during the activity practise. These are all techniques that physiotherapists across the world would recognise.

Biomedical medications were also used by these healers. Most medicines are available in pharmacies and do not require formal prescription forms. As a result, anyone is able to buy any available medicine. All admitted to prescribing medications for conditions such as pain and blood pressure, but would not expand on how they knew what medication to prescribe or the name of the medicines themselves.

There were many treatment techniques however, that are not part of the Western compendium. In common with the reflex stimulation, the Chinese influence was very evident with the use of cupping on acupressure points. This was utilised to stimulate blood flow, but also as an indication of whether there was still dirty blood in the patients' body.

Photograph 15 Cupping by Paujan on points to 'unlock' (improve the blocked blood circulation) on the left (hemiplegic) shoulder. The shoulder is seen as a result of the problem in the left hip and leg and therefore treatment should have an effect on the leg. Because of the interconnectedness of the body, points on the right side are also selected.

Photograph 16 After cupping the skin is assessed for evidence of discolouration.

This black spot is caused by oil contents. If the oil in the blood is clean then it is back to normal.

Paujan

The theme of improving blood flow continues through a technique with an unknown heritage, *totok*. The word *totok* is used in many different contexts in Indonesia. On one hand it is a slang term for Indonesians of Chinese origin. It is also a strike in *silat*[23]. It has also been used to describe a number of treatment processes; facial massage and hard finger pressure over specific points with intent to alter flow beneath the finger[24]. In Takengon, it was found to resemble the last definition, with a distinctive difference, no pressure was required to elicit the change in flow. The healer describes his use of *totok* as a powerful energy force which requires no contact. *Totok* was briefly referred to in the diagnosis section as a way in which the healer 'felt' the internal energy of the client. In treatment it is presented as a means to improve blood flow.

Ismail: If the patient has hypertension I will totok him first, in the part which is plugged.

Interviewer: wait a minute, is totok the same as a massage?

Ismail: The effect is almost the same, but totok uses internal power. It makes the blood run well.

Such a description bears significant relation to descriptions of the use of *Qi Gong* in Chinese healing (Hsu 1999) and Bowens (1993) description of the use of *maripet*. However, it is clear that with so many different descriptions of the same term, a complete understanding of *totok* is elusive.

Blood flow was also affected by a myriad of herbal concoctions. These were used for problems related to hypertension of hot and cold origin and high cholesterol. While some leaves were mentioned, the list was incomplete as the mixtures were both too numerous and there was some reluctance to share the secrets of their medicines. As a result it is unclear if these medicines are related to either *Jamu* medicines or those blended by the traditional healers.

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[23] *Silat* is the traditional martial art of Indonesia and Malaysia.

[24] This description was given by traditional masseurs in Yogyakarta, Java.

Finally there was ample evidence of religious principles within treatment. Indeed the unseen power of *totok* was placed within the sphere of religious control.

> I know that my body, my super power can be used to cure people.
> With Allah's permission, I can cure many illnesses.

<div align="right">Ismail</div>

Like the traditional healers, treatments were usually initiated or accompanied with a plea to Allah for his blessing. These had a stronger performative quality than the traditional healers, as the prayers were said aloud and with a distinct physical posturing.

Photograph 17 Abdul praying prior to treatment

Nah, like this, for example, astagfirulahal azim lailahaillallah, we ask your grant to cure this illness, ya Allah

Photograph 18 Abdul praying as part of treatment to Pramana

6.1.2.ii.d Concept of recovery

The three alternative healers agreed that full recovery from stroke was possible. Two gave examples of people they had 'cured'. Three months was the length of treatment generally required for full recovery. However, they stated that if the individual was in good physical condition prior to their stroke then it could take less time. A delay in seeking treatment could result in complications which would take more time to resolve. These estimates were based on their experience. They added that success was not just dependent on restoring the blood flow and the commitment to exercise, but also on Allah's desire for them to recover. Cure, finally, was not in their hands.

6.1.3 Summary

These three healing categories understood and approached the treatment of stroke in very different ways. Yet they also had a number of points in common. A comparative summary of all of the healers identified is given in diagram 10.

Diagram 10 illustrating a comparison of biomedical, traditional and alternative healers
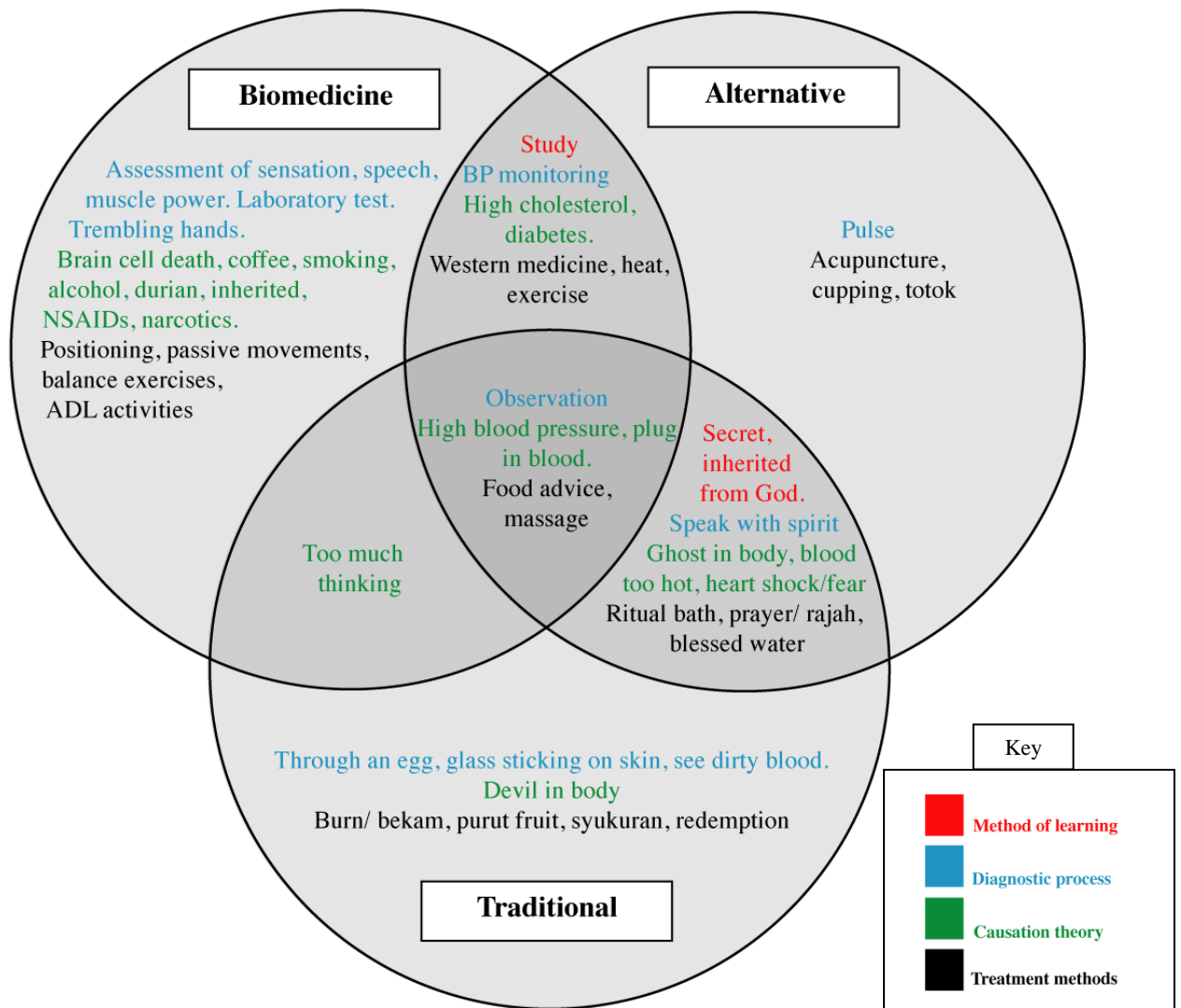
6.2 Who was sought and why

With such an array of health care options, a decision had to be made as to which healer would be sought for help. Through the narratives of the people with stroke and their carers, a pattern of multiple health seeking emerged. Hundt *et al* (2004) described this as double healing. However, in the context of Central Aceh, it would be more accurate to suggest it was at minimum triple healing. While each individual was at a different stage of their post stroke life, and therefore comparisons of numbers are of limited appropriateness, it is worth highlighting that the average number of healers sought was seven with a range of 3-14. Even those who had recently had their stroke (4 months) had seen a minimum of four healers. Almost all participants sought help from all three categories of healer. Within some of those

categories, they equally sought multiple healers. Some had seen so many traditional healers, for example, that retrospectively they could not remember the total number, except that it was well over 10. Although this study was based in a rural area, anecdotal evidence from people with stroke in big cities such as Jakarta suggests similar patterns of serial use of multiple healers. A member of *Yastroki* explained how he had seen over 100 *dukun* in his post stroke journey to health.

In total 37 different treatment periods occurred with biomedical healers, a minimum of 30 with traditional healers (given that some participants had forgotten the exact number) and nine with alternative healers. Looking at the total numbers alone would indicate that, in line with government predictions, biomedical services were being sought at the same or higher rate than other services. However, overall numbers alone give little insight as to why people make their decisions, the order in which they do so and what instigates change. A closer examination of the narrative detail is more appropriate for illuminating that understanding.

Participants relayed the stories of their help seeking in rough chronological order and that time based sequence highlighted some interesting differences. In the initial consultation, between the participants, almost all types of healers were sought. But a pattern emerged relating to the family's previous knowledge of a medical problem and therefore the 'habit' of who they consulted. As a result, those who had previously known medical conditions, of which high blood pressure was the constant, sought out a local biomedical healer initially, either a *bidan desa* or nurse (*mantri* and *perawatan*). They spoke of this choice as being their 'habit' and a need to know their blood pressure before any other decision was made. Those who had no previous knowledge of medical problems and therefore had no set patterns of behaviour took a different source of action. One was to call a *dukun*, the second was to seek a doctor, either directly at the hospital or through a private home visit. These two differing pathways had a clear separation based on gender. With the exception of one, women saw the *dukun*, while the men took the biomedical option. In conjunction with a gender separation also came one based on an understanding of the disorder. Those who sought the *dukun* expressed their belief that the presenting problems were indications of occult forces or the devil. One reason given for this was the fact that the event had occurred before mid-day, a locally understood sign of

spirit possession. As a result, the appropriate action was to seek traditional help. This pattern is illustrated in diagram 11 and indicates decision making similar to that found by Schroder-Butterfill (2002) in the ill older person in Java. However, while this pattern was seen in the initial decision making, a more heterogeneous arrangement was evident with subsequent choices, with a multitude of factors affecting the decisions made.

Diagram 11 showing initial health seeking choices
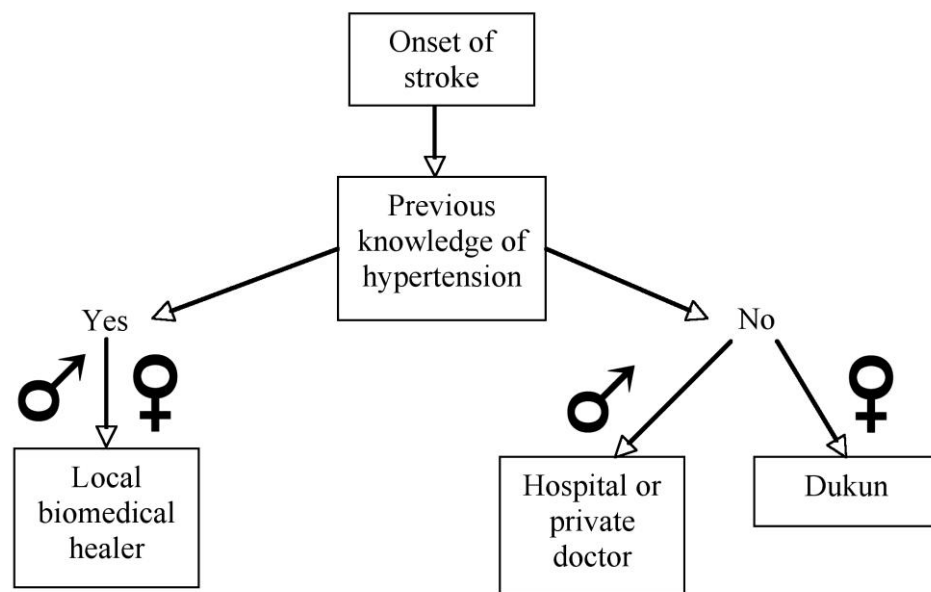
For those who sought local biomedical healers, a flow through other biomedical services, up through the hierarchy of local, *Puskesmas* and hospital, was evident. Of the four participants who initially sought local biomedical assistance, three continued to see further help at the *Puskesmas* and/or hospital. The inference here could be that they had been referred by the local biomedical professionals to services more able to manage their condition. Such referral is part of the normal pathway of healthcare as described by the medical doctors and specifically what all the biomedically trained personnel identified as their usual course of action on encountering a person with stroke. The only exception to this was when the *Puksesmas* doctor believed that the condition of the patient was terminal, in which case they would not refer the patient to the hospital but would advise the family on palliative care.

However, this formal reasoning was not consistent with the participants' explanations. One of the three who had onward biomedical treatment described a

process of referral, but the other two had other explanations for seeking further help. One did not believe the measurement of the *bidan desa* and therefore wanted to confirm the reading himself in another place, the *Puskesmas*. The other family indicated that it was the family itself that made the decision to go to hospital and at no point suggested that the *mantri* had been involved in the decision. So while the pattern may suggest that the majority who sought biomedical treatment had an 'appropriate' onward referral, in biomedical terms, this does not appear to have come about as a result of the established biomedical referral system.

There is an interesting point to note about the one who sought biomedical treatment initially but then did not follow it up with further biomedical intervention. The nurse that they initially called was a family member, a niece of the person with stroke. As a result, while she was a biomedical professional, it is possible that she was called more as part of the lay sector and therefore a progressive link with the professional sector was not made by this family. Evidence of similar relationships was observed with people with stroke not included in this research. Where family members were biomedically trained, they dispensed medicines and checked blood pressures without recourse to further referrals or check-ups with other biomedical specialists.

A series of events which follows from the people who went to hospital is also interesting to note. In total eight of the eleven participants attended hospital at some point in the course of their illness, three initially and five later. Of the three primary attendees, none saw a physiotherapist in the hospital. The also all followed up the hospital visit immediately with assistance from a *dukun*. All inferred that although the decision had been made by the family, the recommendation of who to seek had come from other members of the community who were also in the hospital at the same time. It is evident therefore, that the hospital itself was not seen as a place for rehabilitation for these people, but was used as a potential community and informal resource for ideas of further assistance.

Diagram 12 showing treatment pathways
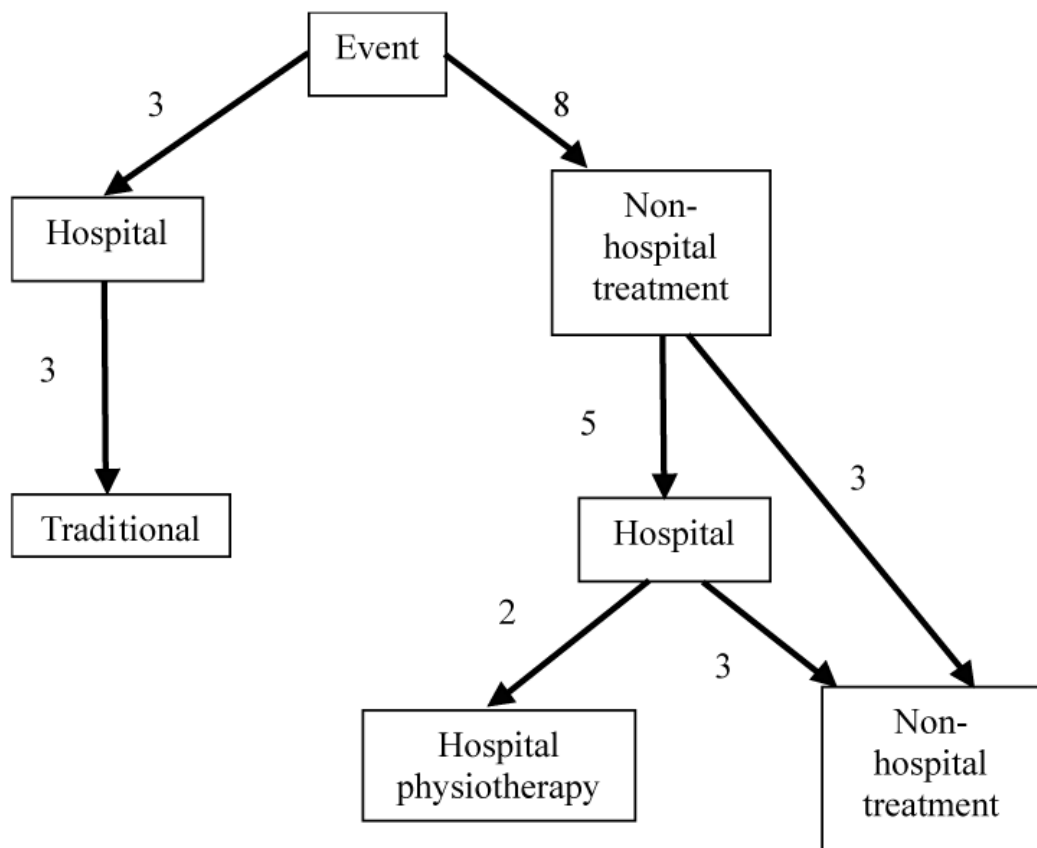
Of the five who attended the hospital later in their illness episode, only two were referred to the hospital therapists. Participants discussed a number of reasons for this. Some described the hospital as an uncomfortable place to be and therefore discharged themselves. Others highlighted the cost aspect, not only of being in the hospital itself, its associated medicines required, and the physiotherapy, but also the cost of family travel and loss of income as a result of visiting and informal care. In hospitals in Indonesia it is normal that food would be provided by the family. Additionally, support to toilet and wash, if required, is expected to be covered by family members. However, participants retrospectively also suggested their lack of physiotherapy was due to a lack of referral, questioning in interview why the doctor had not informed them of this option. Thus a difference between what the doctors said they would do and what the people with stroke and their families understood them to have recommended emerges.

6.2.1 Cost

Like the hospital costs mentioned above, participants discussed their issues with the financial burden of treatment generally. This covered the healer's direct fee, but also included medicines that had to be purchased, transportation, living costs when the treatment was residential, and the high price of supplementary procedures, such as the rituals of *kenduri/ sykuran*. While all family members discussed these issues, it was more common for the person with stroke themselves to highlight the indirect costs to the entire family. When perceived costs of treatment were mapped over time, these narrative concerns were demonstrated in practical action with an increased tendency to seek those perceived as being less expensive. This is illustrated in diagram 13.

Diagram 13 Showing the total visits over time in relation to perceived cost of healer.
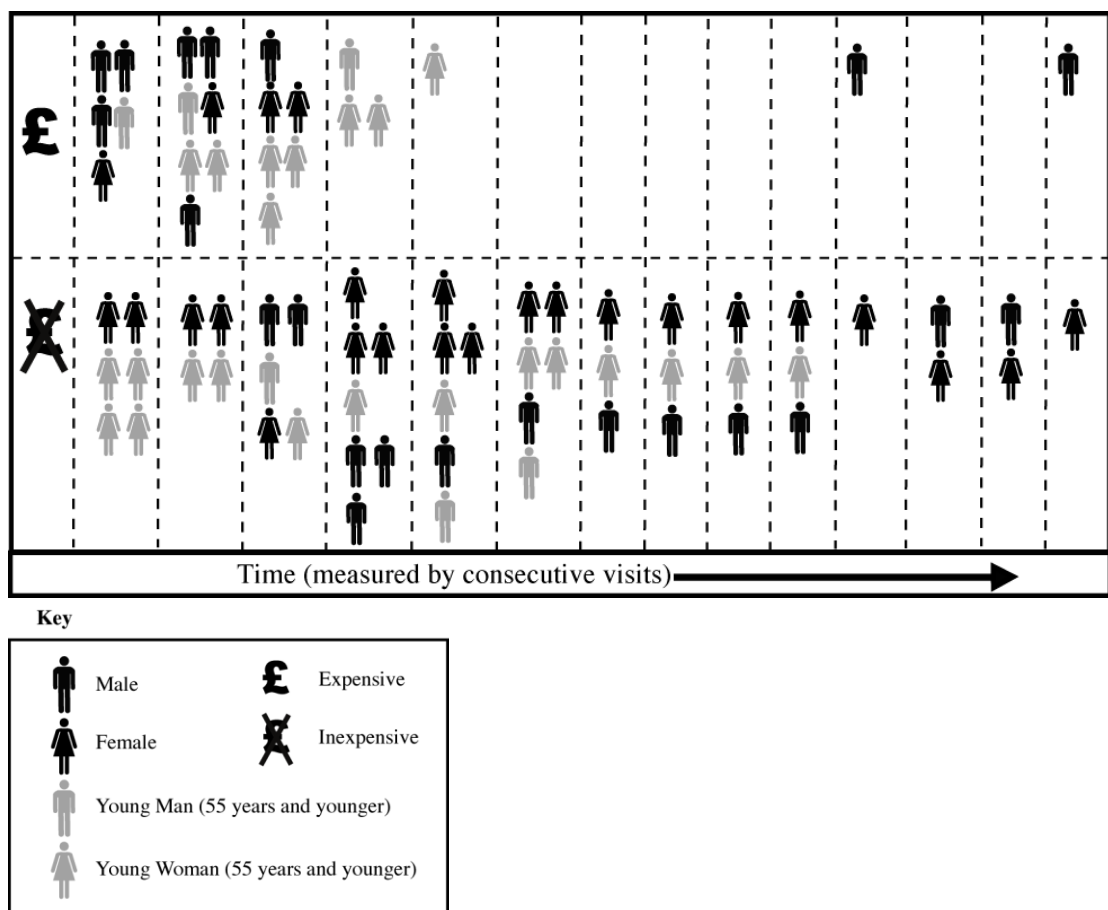
It was suggested in chapter 3 that the assumption that biomedical treatments were necessarily more expensive than traditional treatments should be taken with care. This was subjectively supported when the trend for seeking biomedical or non-biomedical help was mapped. There was some indication that non-biomedical

treatments became more popular over time, but there was blurring of this pattern as is indicated in diagram 14.

Diagram 14 Showing the total visits over time (as represented by subsequent visits) in relation to biomedically or non-biomedically based treatments.

Key

♂ Male

♀ Female

♂ Young Man (55 years and younger)

♀ Young Woman (55 years and younger)
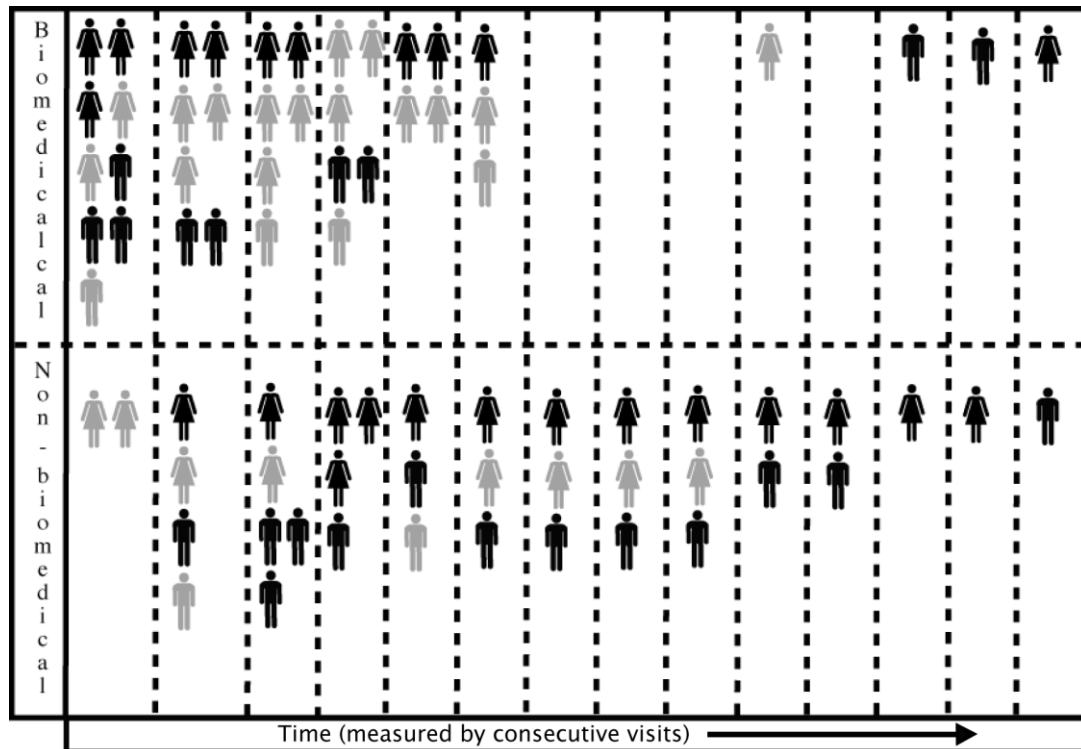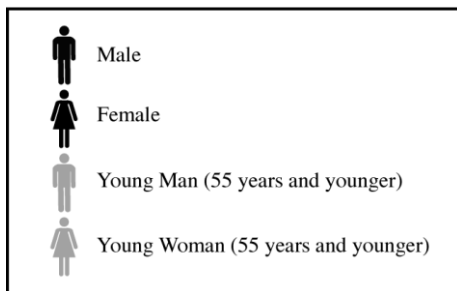
The narratives illustrated many reasons for this mixed picture. On one hand participants discussed their continuing desire for cure, an outcome with which the traditional healers often concurred. They also mentioned that many of the traditional healers would visit their home, unlike biomedical healers. They highlighted the advantage that this bestowed on them and their family. It not only reduced transportation costs, but also allowed the family members to continue with their daily lives. This latter point was also raised with the use of one biomedically based option, that of the Handicap International's therapists. These therapists did not hold an idea

of cure, as was illustrated earlier in this chapter, but did complete home visits free of charge. It is this service that in part resulted in a fluctuating increase of biomedical intervention over time.

One final aspect that was raised by the participants was the use of traditional healers in order to prevent further problems. This was particularly the case with healers who included massage as part of their treatment. Participants commented that after any injury or illness that caused problems with moving, a number of changes in the body could occur that would make recovery more difficult. This included issues such as muscles becoming tighter and out of alignment. Massage was believed to prevent and correct these problems and therefore was actively sought by many.

6.2.2 Gender

Previous research has indicated that gender has an impact on the type of treatment sought (Schroder-Butterfill 2002), specifically that men were more likely to see biomedical healers than women. This was seen in the choice of initial treatment, as previously discussed, but as a general trend it was not seen in the Central Aceh region. The type of treatment sought was in the main equally distributed for both genders. This is illustrated in diagram 15.

Diagram 15 Showing treatment choice by gender
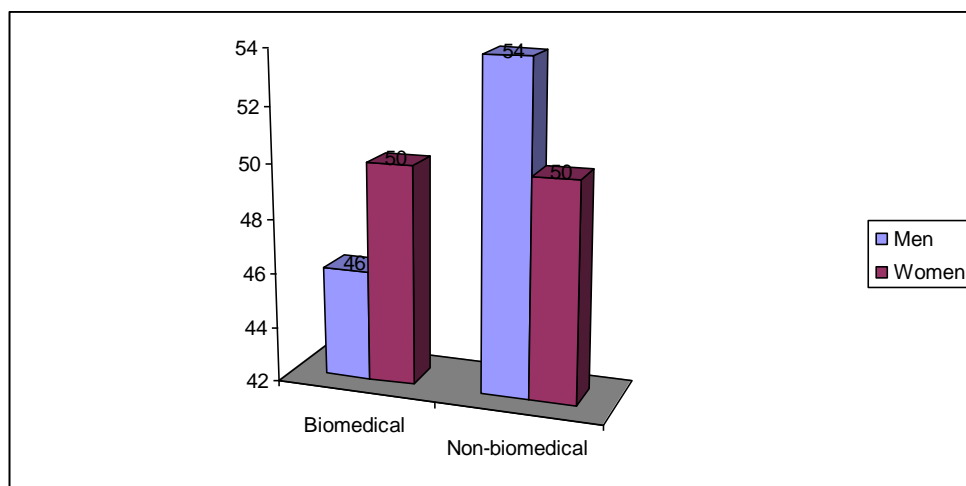
6.2.3 Age

While gender had little overall influence of type of treatment sought, the age of the person with stroke did. Generally, younger people (under 55 years) were more likely to see biomedical practitioners than older people, with 57% of all treatments types being biomedical in the younger group, comparative to 40% in the older. Interestingly, while the younger group may have seen more biomedically trained healers in total, they were less likely than the older group to see them first, as illustrated in diagram 14. No clear reasons for this could be ascertained from this analysis.

This difference in health seeking relating to age requires further investigation. Age has been noted as an influencing factor in access to rehabilitation in the UK, leading to accusations that stroke rehabilitation is ageist (Kilbride 2007). Schroder-Butterfill (2002) illustrates that in Java investment in health care is likely to be higher for those who remain economically active, which would suggest a potential increase in investment in healthcare for younger adult members of the household. However, the situation in Central Aceh is not clear cut. As was introduced in chapter 3, 'the elderly' is more a functional capacity concept rather than purely an age related one and seeking biomedical assistance in Central Aceh does not equate to either financially cheaper care, or perceived better care. A more detailed study on the concept of ageing and how it relates to family, finances and health seeking dynamics in the region would be of value.

6.2.4 Diagnosis

A note should be added about the role of diagnostics in health seeking. It has been mentioned that a number of the participants and their families both sought an answer to their confusion of what the problem could be and that their understanding of the disorder had some influence on who was sought initially. It has also been noted that over the period of their health seeking the diagnosis of stroke became known to all participants. What becomes apparent through the narratives, however, is that the diagnosis of stroke did not in itself influence who was sought and that the name came from multiple sources.

Participants discussed how they became aware of the word stroke and its relevance to the individual affected. The majority had the term suggested by family or community members familiar with the signs through their own personal experience. Only a few acquired the label through their interaction with the medical doctors. Indeed the medical staff at the *Puskesmas* (doctor, *bidan* and nurse), were consistently identified as having avoided labelling what had occurred to the individual. Within the hospital, according to the participants a vague approach was adopted, with an apparent circumvention of giving a definitive diagnosis. Relatives recalled how they were told that their family member *may* get a stroke, despite having had the symptoms for a number of days and continued to recollect how the hospital doctor had given no explanation of what stroke may be. In retrospect, this lack of information created frustration. Participants stated that they wished to be given more information on what had happened to them, but they and their family also admitted to not asking the medical staff for more information. The main reason they gave for this was that as poor people, the doctor spent very little time with them and they felt unable to ask for clarification when they were more concerned with the medications they had to buy and other instructions that were being given. They also noted that while they had been given information booklets by the HI therapists they had not read them all and had not asked information from that source either[25].

As a clear diagnostic moment did not appear to occur, it is perhaps unsurprising that the awareness of the term did not equate to a change in treatment bias. Whether the name was introduced through formal or informal mechanisms, the apparent diagnostic moment (in so much as one occurred at all), did not result in a focus towards biomedical treatment. Indeed the opposite seemed to occur as some respondents noted that following the name being given, the labeller proceeded to suggest healers that were effective in treatment, which spanned all three categories.

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[25] Interestingly, the majority asked me questions about the nature and cause of stroke in the informal conversations after the interviews were completed. During these conversations, they listened intently and often asked insightful questions about their own personal circumstance and lifestyle

6.3 Where healers were sought

Healers were sought from many different localities. The majority of those utilised by the participants were within the Central Aceh region. However, a few practiced in Bireuen, the coastal city to the East of the highlands, some three-four hours by public transport from Takengon. Generally speaking the traditional healers were more locally available than both alternative and biomedical, although this was not always the case. The location and type of those within Central Aceh in relation to the location of the participants is shown in diagram 16.

Diagram 16 Map of participant and healers location
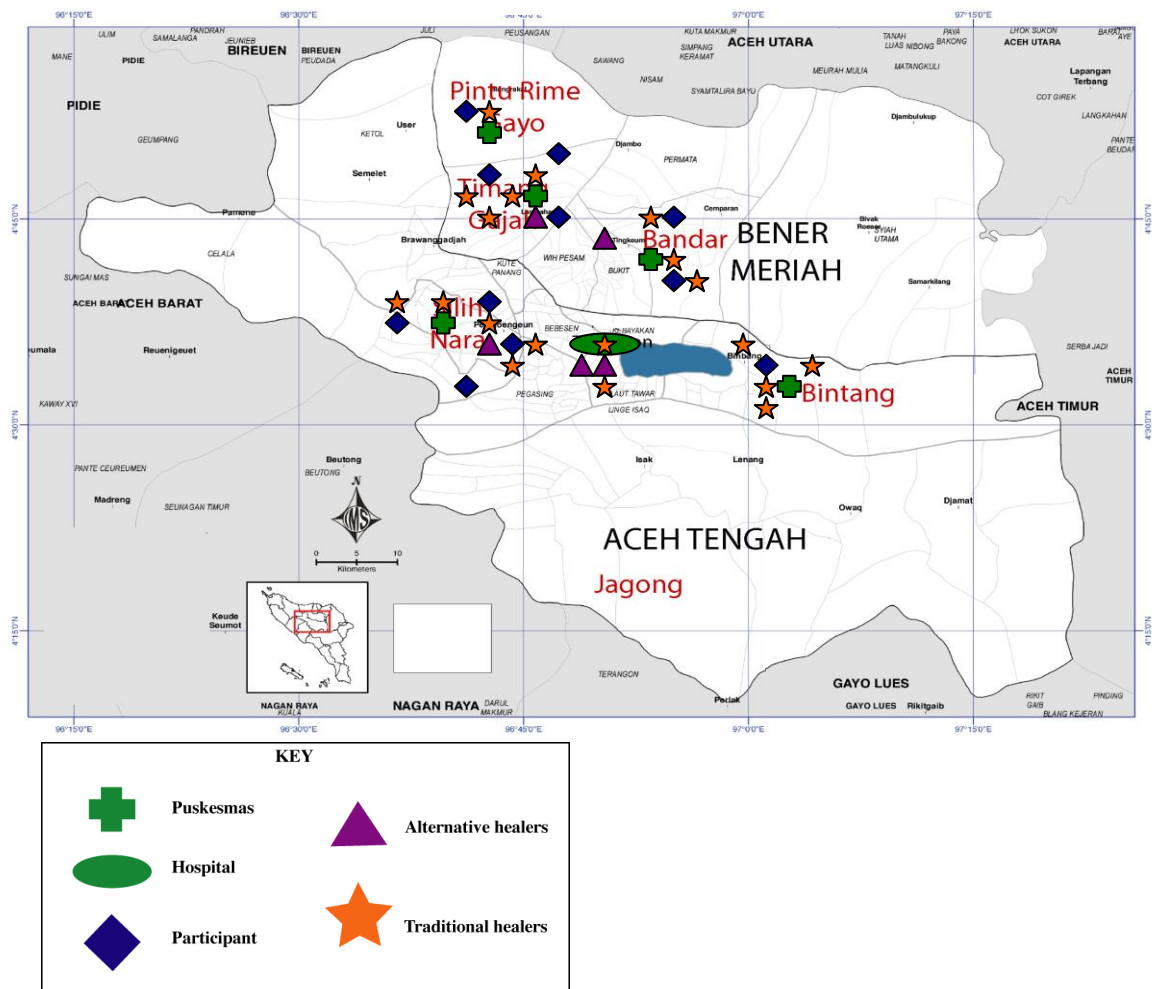
Diagram 16 illustrates that there were often clusters of healers near the locality of the participants. However, the people with stroke did not solely seek assistance locally. Healers were sought who could deliver treatment in the home, in the nearby community or further afield at district level. The majority of treatment changes

occurred between home and healers based locally in nearby communities. But participants also illustrated a considerable degree of mobility in their desire to seek help.

Participants discussed their willingness to travel significant distances to follow treatments that had been recommended in spite of the often unsustainable financial strain. When the treatments they had sought were plotted against time, as measured by the chronology of visits, it was apparent that the tendency was to find treatments closer to home. However, there is also an indication that treatments at a distance were still an option, even several months post stroke.

Within this overall trend, it was evident that men were more likely to travel further than women and the young more so than the old (diagram 17). However, the narratives gave little specific reasons as to why this may be the case.

Diagram 17 Showing the visits over time in relation to perceived distance of healer
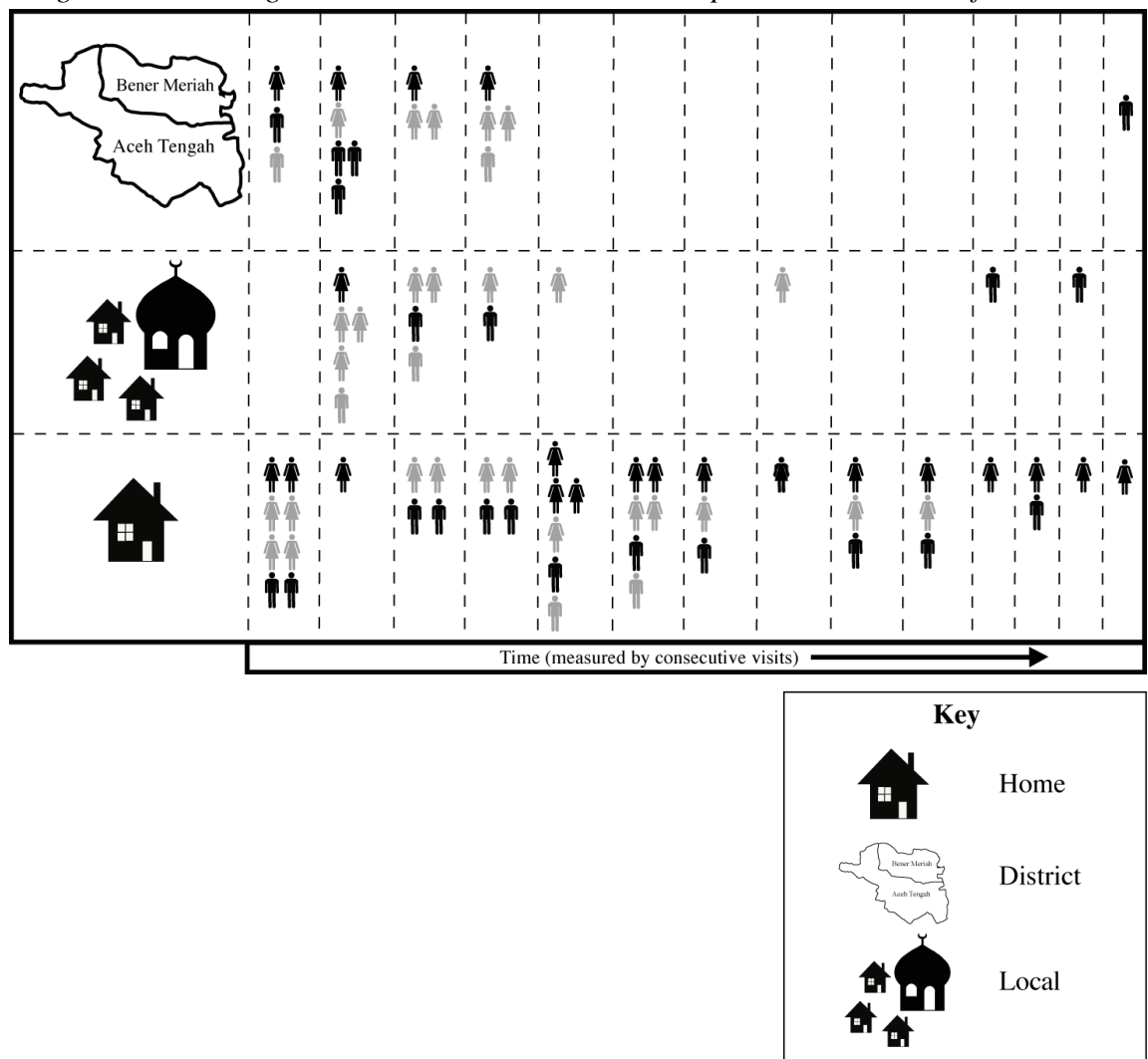
6.4 Who made the decision

Two overall trends were illustrated through the narratives. The first was that the initial decision was made within the immediate family. Who acted as decision maker in the family, however, was dependent on gender and the age of the family. The result was that women with husbands had the initial decision of health seeking made by their husbands. Husbands with wives and older children had the decision made by the whole family. But in those families with younger children, the wife took on the role as decision maker. For women who had no husband, the children made the decision. While there was a gender difference in the responsibility of who would make the decision, this did not extend to the children. Both sons and daughters were involved in decision making. A retrospective report cannot illustrate the intricacies of involvement, but it was apparent that daughters as well as sons were actively involved in not only agreeing that there was a serious problem and that help was required, but also in the identification of a suitable person to help.

Following the initial choice the narratives illustrated a multitude of people who influenced the decision to change treatment. These incuded: community members, immediate and extended family members and biomedical professionals. However, these groups did not have equal influence.

The immediate family remained an important source of information, with the older children of the family often named as being responsible for identifying suitable healers. However, as time went on, the extended family and community advice and know-how became more and more influential. As mentioned previously, despite the 'normal' referral process, very few decisions to change treatment were made on the recommendation of biomedical personnel. The final decision of where to go and how long to stay, however, was finally left in the hands of the family unit, including the person with stroke. Participants described how opportunities were taken if sufficient people in the unit supported the idea and the practicalities of attendance could be overcome. Exceptions to this occurred when healers, predominantly traditional but also occasionally the HI therapists, nominated themselves, turning up at the household in response to community reports of the individual's illness. In this case, the need to make a decision was in effect removed, as participants explained their

social need to try services that were directly offered. They clarified how refusal would both cause offence and leave them open to social criticism and therefore these services were always tried.

6.5 Why treatments were changed or discontinued

As previously mentioned, advice from others was a commonly cited resource and featured heavily in the reasons people gave for changing treatments. Suggestions that others had been cured of similar conditions by specific healers, for example, were common in prompting the change.

However, the most frequently cited reason for changing treatment was a lack of impact of their current therapy to change their health status. This is illustrated in diagram 18 in which the numbers represent the reasons given for each treatment change.

Diagram 18 Illustrating why treatments were changed
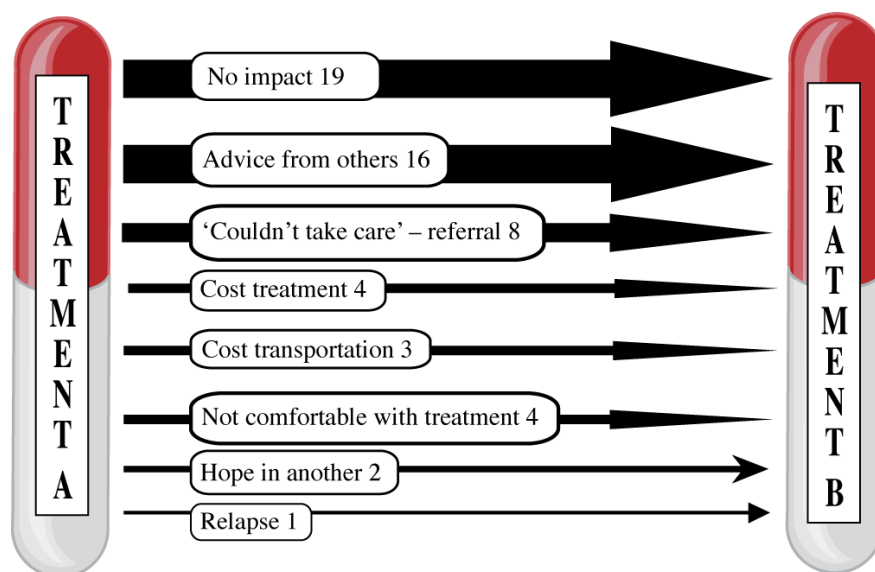
Impact was not simply any positive change in status. When asked how they understood improvement in their condition, participants focussed almost exclusively on the physical, at impairment, activity, and participation level. However, while with some participants any increase in movement, or reduction in the heaviness of the body was seen as improvement, in others that was not deemed 'special' enough. For these people, improvement was only valued if it impacted on the activity or participation level. As one respondent explained, the ability to move her arm, which

had occurred following treatment from an alternative practitioner, was insufficient to allow her to use a spoon to eat and cook. As a result the improvement was classified being 'normal' rather than 'special' and the treatment was discontinued. This understanding of the value of change has been indicated elsewhere. For example, Dixon (2007), discusses one participant who explains that walking with his wife and daughter was not really walking and therefore not valued.

There was little consistency in the narratives on how long the participants would persevere with a treatment while waiting for change. Some switched after one treatment, others after following a regime for up to six weeks. There was some indication however, that this decision was related in part to the participants understanding of the treatment offered. As such, traditional treatments involving spirit or dirty wind removal were quickly discarded if no immediate effect was noted. Similarly medications were not continued for prolonged periods of time. Alternative and therapeutic treatments, involving exercise and massage, were given the longest period of time to prove their efficacy. But even these were abandoned after a maximum of six weeks if sufficient improvement was not noted.

Much of the literature on health seeking has focussed on the financial aspects of decision making, but it is apparent that other reasons, principally the desire and evidence of improvement, were a stronger drive in this context. However, while the numbers were small, it is important to reflect on the decisions prompted by financial restraints, as it was particularly salient for certain participants. Six of the seven references to changes initiated as a response to financial pressure, whether through cost of treatment or transportation, were made by families who could be classed as being more financially vulnerable; these were the women without husbands and the young man with a young family. In both of these scenarios, the principal income generator is rendered unable to work, and there is a limited flexibility for back-up because of the particular family situation. The potential significance of this is discussed further in the following chapter.

The data presented in this chapter comes exclusively from the interviews and observations with the stroke survivors and their carers who met the inclusion criteria for this study. Through the work with Handicap International, which ran alongside

this research, a number of other people with stroke were met and observed and a few brief comments will help to place this chapter's findings in the broader context. As a general observation, participants with stroke had a certain level of basic functioning. All could swallow and all had a level of consciousness that allowed them to interact with their surroundings. A few required considerable physical support for all activities and others had language and/or cognitive problems that rendered communication difficult. However, none had both simultaneously. Reports were given by staff and community members of people who had severe strokes that resulted in unconsciousness or an inability to eat and communicate. These individuals did not survive for a prolonged period after their stroke.

Not all those encountered through the work with HI were cared for by their families in the manner described by some of the participants in this chapter. It was not uncommon for instance for individuals with stroke to be left alone for several hours a day in bed in a darkened room. Some of these were able to sit with minimal support and were able to follow commands, even when speech was limited. However, family members were frequently working or away from the house and therefore unavailable to fully support their relatives daily and therapeutic activities.

6.6 Summary

This chapter has introduced some of the key features of health seeking in Central Aceh following stroke. The healers available were described and the reasons why they were selected examined. The narratives of people with stroke indicated that the healer selected, the distance they were willing to travel and how long treatment could be sustained was influenced by the information available, financial flexibility, but most centrally an ability of the treatment to instigate change. When viewed alongside the information in the preceding chapter, these features illustrate a number of interconnected themes, which are explored in the following chapter.

Chapter 7

A life in balance: the search for homeostasis

7.0 Introduction

In the preceding chapters the understanding and effect of stroke on people in Central Aceh has been presented alongside a description of the action they took and the healers they accessed. This chapter brings these descriptions together and presents a theory of 'homeostasis' to explain the experience of stroke in Aceh. Homeostasis has many varied definitions. The Collins English Dictionary (Treffry 2000:740) states that it is "the maintenance of metabolic equilibrium within an animal by a tendency to compensate for disrupting changes", adding a further reference to "the maintenance of equilibrium within a social group or persons". In this context, it is applied beyond the more common biological understanding to encompass the attempt to achieve equilibrium that occurs both within the organism, in this case the person with stroke, and between the organism and others, both people and supernatural.

The argument that follows will present three tiers of homeostatic interaction, which inform and influence each other. The first is within the individual themselves. Secondly, the interaction between the individual and others will be introduced. Finally, the balance between the individual and other realms is explored.

Between and within these three levels, a tension appears involving two interacting ideas; loss and hope. These are evident through all the discussions, but are highlighted and drawn together at the end of the chapter. It will be argued that the balance between loss and hope has to be found, even when practical limitations force the other homeostatic equations to a state of disequilibrium. This meta-homeostatic need results in a further fluidity within the tiers, with different emphasis and importance resulting from the current situation. However, it will also be posited that the relation with Allah is subject to less negotiation than the other relationships and therefore acts as a constant throughout the process.

7.1 Homeostasis within the person

Flow in the individual was conceived both as the unimpeded movement *of* the body and *within* the body. These two aspects were closely related such that interruption in one would have an effect on the other.

7.1.1 Internal flow

The flow of blood was subject to an internal homeostatic equilibrium that has to be forged between itself as a representation of the physical, the mind through the action of thoughts, and the spiritual domain. This relationship was of critical importance to participants and associations were repeatedly made between them. Each had the potential to disrupt the other. For example, physical injuries or muscular tension with resultant blockages in flow led to headaches and a lack of clear thought, too much or heavy thinking was seen to agitate the blood causing it to plug, and spirits were more able to enter the body in the presence of negative thinking and once in could directly disrupt the blood flow. In stroke, this internal homeostasis had been interrupted, often in a multitude of ways as was described by the participants in chapter 5.

Interestingly, the participants in this research, other than those biomedically trained, made no direct reference to the brain as being affected by the interruption of blood, although through symptoms such as headaches and dizziness some felt that blood flow was locally disturbed through the head. Indeed, some made a point of excluding the brain as a site of damage on the basis that their memory had remained intact throughout the illness[26].

> *I remembered all since the first time it took place until we came back here*
> *[house] because no problem with my brain*

Arti

It is worth recalling here that in the local conception of the body, the brain is not a privileged organ. While the brain and head were associated with intelligence and were therefore important, they were not synonymous with the source of all thoughts.

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[26] It is interesting to note that historically Islamic medicine, using Aristotelian concepts, also suggested that the brain may not be the seat of stroke (or apoplexy as it was known), rather focusing on the heart and vessels (Karenberg & Hort 1998). However, given the complex and rather blurred understanding of the movement of Islam to the Indonesian archipelago, it is unknown if such concepts would have been influential in any substantial way.

The heart and the liver were more related to emotions, such as fear and anxiety, emotions that were closely associated with heavy thoughts and blood flow problems.

> *Combatants asked villagers to move, 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 - combatants had told us not to tell the army that they had asked us to move so I was very afraid… fear and this may have caused my stroke because the heart is related with fear.*
>
> Arti

It was not only damage to the brain that was unarticulated, but any permanent damage at all. Muscles which did not function were not seen to be damaged, but were simply not receiving the blood they required in order to activate. This difference between an inability to work and damage is subtle but crucial, for the former is a temporary condition which is perceived to be wholly reversible. In discussing their understanding of the condition and their wishes for the future, participants repeatedly articulated their belief that they could return to normal functioning, a belief fuelled by the reversibility of the plug in the blood; the potential that homeostasis could be achieved once more. Once the plug was removed, the symptoms would ease and function would return. Throughout their descriptions of health seeking this desire for and belief in cure is reiterated (see Lastri's son's final comment in chapter 5 for example). Their personal experience however, illustrated that this was a goal they had not yet achieved. A number of explanations were given for this, including their inability to find the right medication, the cost of treatments that were too high for them to sustain, and other medical problems which complicated their recovery. Nevertheless the belief that total recovery was at least theoretically possible was maintained. Stories of others with presumed stroke that had made a complete recovery were cited in many contexts and gave validity to this understanding. Their own recovery to date also gave indications that a reverse in the problem was possible. As a result participants, as demonstrated in the two quotes below, presented themselves as being on a journey to normality, an incomplete journey at the time of interview, but one with a clear, hoped for destination.

Melati: *My leg feels quite light…my shoulder is less heavy now…I have been*
             walking around outside often

Husband: *It is good that she is getting better*

Melati: *but sometimes, I still have to do more treatment and practice…I look*
             for treatment to be healthy…treatment… in order to be healthy again,
             to recover. I am just wondering how I can be healthy, what is the
             medicine. That's all...

Photograph 19 Arti standing. Photograph was accompanied with the following comment;

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

Arti: *I am very happy to stand - makes me think that 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?*

This concept of a reversible condition is consistent with both the explanations of causation and much of the health seeking behaviour, which is considered shortly. Causation concepts, as described in chapter 5, were invariably related to factors that participants knew to affect blood flow. This knowledge, whether through education, hearsay, experience, cultural understandings or machines such as blood pressure monitors, was brought to bear on their own explanatory process. As many factors were known to affect blood flow, it is unsurprising that causation theories included many possible protagonists. And with each potential protagonist, a healer was sought

to resolve that particular obstruction to allow the blood to flow once more. This process is graphically illustrated in diagram 19.

Diagram 19 Showing the connection of blood flow with causation and treatment

Altered blood flow – hypertension/ plug

Ill-health

Cause of disruption
• Lifestyle - Hard work, cigarette, economic stress, decrease exercise, lack of sleep
• Mental - Stress/thinking
• Food - Fatty food, Chemicals, Coffee, Durian,
• Spirit – Djinn, evil wind

Cause of improvement
• Medication – herbal, biomedical
• Physical treatment - Massage, acupressure, exercise, positioning
• Spirit – *totok*, redemption, *bekam*

Health

Normal fluent blood flow

The belief in cure is also encouraged and sustained by two different sources, that of the healers and religion. Whereas the former group has the potential to both reinforce and challenge the concept of cure, it will be argued later that for various reasons the challenge was rarely pursued. The religious dimension is developed in the third section of this chapter.

7.1.2 Flow of the individual

The lack of homeostatic balance *within* the body resulted in symptoms of paralysis, amongst others, which disrupted the homeostasis *of* the body. As described in the literature and by participants, the ability of the body to move independently and in a guaranteed manner is part of the conception of health. In its absence, the body loses its flow and/or becomes unpredictable in its capacity to complete the activities desired. A balance between will and physical capacity, and between one side of the body and the other is lost. Through the stories told, it was evident that the nature of this loss was most acutely felt in relation to personal activities as well as familial roles. As a result, the individual forgoes their independence and their ability to

partake in family life as they had previously. Equally, even when movement had returned, participants believed or had experienced that a relapse was possible and as a result the continuity of their physical functioning had been lost. Flow of the body had to allow for an uninterrupted capacity to complete the required and desired tasks, for it to be considered in balance. Many of these ideas are in-keeping with the work of Ferzacca (2001) on diabetes in Java.

As the cause of this disequilibrium was conceived as being reversible, so the flow *of* the body was also believed to be restorable. Participants were aware and acknowledged that many factors had complicated the balancing of this homeostatic equation. A prolonged period since the event, the consumption of inappropriate foods, falls, old injuries were cited as reasons why muscles now may be tighter then appropriate for example. Part of their health seeking strategy was to seek assistance to ameliorate these issues. However, despite these complications, it was considered that movement had the potential to return, once and/or if the balance *within* the body had returned.

7.1.3 Loss, hope and biographical agitation

The dialectic created by the interrupted flow and the belief in its reversibility acts as an appropriate introduction to loss and hope and through them a critical review of the appropriateness of the concept of biographical disruption in this context. For the participants, the consequence of the plugged blood was an inability to live the life they knew. As described in chapter 5, their physical incapacities led to a loss of independence and completion of their previous roles. There were also feelings of loneliness and isolation as a further corollary of their inability to function as previously. These emotional responses were most commonly related to losses that directly affected the family, a point which is developed in the next section. On initial analysis, the pattern of sudden losses and emotional response could indicate the relevance of biographical disruption. However, with deeper consideration, while the losses identified evidently did interfere with personal functioning, it does not necessarily follow that they resulted in a disruption of the individual's biography, and "challenge the whole of the individual's being" (Ellis-Hill *et al* 2000:731).

From the literature reviewed in chapter 2, two aspects are identified as key to disruption; the contrast of the known 'silent' body to that of the new, rebellious and objectified body, and the resultant disturbance of the expectations and plans for the future created by the sudden onset of disability. Neither of these points was clearly expressed by the participants in Central Aceh. The body, while not functioning as 'normal' and having 'reappeared', was not objectified by the participants themselves. The physical loss they experienced was expressed as a change in *his or her* body, with little evidence of the objectification of malfunctioning body parts described elsewhere (Bendz 2000, Burton 2000, Ellis-Hill *et al.* 2000). Despite the terminology of *mati badan sebelah* (half dead body), there was no reference to 'it'. The dead body was *his or her* dead body, the inability to complete an activity was because *his or her* hand was unable to grasp the spoon. This ownership of the wayward body was common to all participants. In terms of the disrupted future, the belief and hope in cure insured that this disruption was firmly placed within the context of the present. Tomorrow, in the stories told, held the promise of a return to normality. With Allah's help and access to the correct resources, participants would return to farming their land, to work, to doing everything independently again. As a result of these features, which were interpreted directly from the participants' narratives, the permanence of change was not apparent. Consequently it is difficult to suggest that the individual's biography was permanently disrupted.

The description given by the participants equally does not lend itself to the concept of biographical flow as described by Faircloth *et al* (2004) and inferred by Pound *et al* (1998). In this model, the disruptions experienced are part of a narrative which already encompasses multiple disruptions because of previous chronic illness or old age. With the exception of one participant, all in this study were previously well and active and none considered the onset of stroke as simply another part of their life story. The participants described an unusual event, something worthy of note which disrupted their internal and external equilibrium with life, in sometimes very dramatic fashion, but a disruption which is nevertheless not conceived of as permanent.

The most suitable terminology, if one is required at all, would appear to be that of biographical agitation (Ferzacca 2001). The illness episode disturbs the 'taken for

granted' aspects of present life, but does not result in them being discarded in favour of new ones. Rather, over time and experience subtle adjustments are made as the agitation resolves, a new equilibrium is sought, but these adjustments are always temporary in nature and the vision of previously held desires are never far from view. The agitation creates a homeostatic imbalance *within* and *of* the body, which can be redressed and return to its previous state of harmony with the appropriate measures.

An important feature in the development of short and long term homeostasis is the interaction between the individual and their family and the influence of the healers, which will now be considered.

7.2 Homeostasis between people

7.2.1 The family and reciprocal exchange

Throughout the stories told, the importance of the family was highlighted. The strength of the connection of the individual within the family unit was evident in every encounter. What was said, who was involved in the telling, the stories of assistance, expressions of love and gratefulness for care, the explanations of responsibilities and the desire to return to independence all had the family at its core. The stories presented are of people who have survived their stroke and the role of their family in that survival was substantial both practically and emotionally. However, it is also evident that the family had a complex influence on the experience of stroke. On one hand, it was a critical support, but on the other it also had the potential to increase the burden on the affected individual. A closer examination of this dual influence is required if the desire to reach equilibrium within the family is to be understood.

In response to the stroke the family was presented as a source of support. They were there to assist the person with stroke and initiated the calls for further help. The family made the decisions of health seeking, but also took on other decision making roles within the family. They gave physical assistance to the individual, in order to complete necessary daily tasks, or attend treatment sessions. They also gave emotional support and maintained the economic stability of the family by working, often in lieu of their own personal ambitions. These positive roles were not

implemented without a cost, often literally. For example, time spent caring for the individual or taking them to treatment often resulted in lost income. Carers also spoke of arranging caring schedules to limit the impact on the family as a whole.

Despite the assistance, it was also apparent that a number of families also had a potentially negative impact on the individual both pre and post stroke. Participants discussed the burden they felt in relation to family responsibilities. Caring for them in the conflict period and the general need to have sufficient income for life and education were posited as factors which had precipitated the stroke. Equally, feelings of 'low spirit' as a result of husbands leaving or the responsibility to bear children were cited as possible factors which had led to the onset of stroke. Similar concerns were expressed post stroke, sustaining a sense that the individual was encumbered by their family responsibilities. Much of the desire for recovery was cloaked in the need to be a provider again and to release the family from the financial insecurity that resulted from their illness. When unable to resolve the burden due to insufficient recovery, sadness and frustration were expressed that others had to carry their load.

Not all of the factors highlighted above were relevant for every participant. The age of their children and the educational expectations varied, with those with younger children having the highest burden as both the basic education was incomplete and their potential for subsidiary income generation was poor. For these participants, the children could neither support the family financially, nor was the removal of their education socially acceptable. Interestingly, the sex of the children of all ages seemed to make little difference, as sons were as active as carers as daughters. The sex of the participant did however indicate some differences. Female participants often received care from their husbands, but the role of the wife could also increase their vulnerability. In this small group one woman had been left by her husband and another feared this outcome, but these were not isolated cases. Several other women, not included in this study, were known to have been left by their husbands following stroke or other significant illness. Women's vulnerability post disability has been documented elsewhere (Murray & Harrison 2004, Shakespeare 1996).

The size of the family and their availability in the nearby locality was also relevant. Larger families whose members lived nearby discussed the advantages of family

more frequently than the burdens. This aspect of access to informal care is noted in the literature, where numbers and proximity were features of successful family coping (Eaves 2006, Cox *et al.* 1998, Bakas & Burgener 2002). It should be noted however, that in this research extended family was rarely discussed. Cousins, uncles and other relatives were often based in the vicinity and were socially engaged in the family and may be sought for advice. However, it was only the immediate family that was involved in care or for whom the individual with stroke felt responsible.

Despite individual differences, generally it is evident that the family had both potentially positive and negative influences on the stroke experience and the ability to cope. Yet the individuals and families interviewed appeared to be coping and a number had been for several years. A balance of some kind had been struck. This is probably not always the case. As Schroder-Butterfill's (2002) ethnography of ageing in Java indicates, illness in older age often leaves those vulnerable in a fatal position, even when family members may be available. Observations of people with stroke not included in this study also indicated cases where care was substantially lacking, usually for very practical reasons. Coping then, is possibly not a guaranteed or stable state, but one which has a number of interrelated factors which influence its success, factors which must be balanced but also re-evaluated and re-balanced over time and changing realities. It is this shifting and re-establishment of homeostatic equilibrium which was evidenced by the participants of this research.

Prior to giving examples of how this equilibrium was reached, it is useful to consider why a balance was desirable at all. Two perspectives need to be considered in this regard, that of the individual and of their family. For the individual affected by stroke, in the absence of social care provided by the government, care must be provided by the family. It is therefore imperative for survival that the family both believe that there is a need to give assistance and are motivated to do so. Leatherman (1992) discusses the need for the social unit to perceive that the health problem is sufficient to require a combined coping response. In this regard the severity of the stroke symptoms do not appear to have given much room for doubt. No respondent

was left without care in the belief that the symptoms would resolve independently[27]. The motivation for care is however more complex. Having a dependent member within the family, who was previously a net provider, shifts the family stability to the negative. Investment in their care, through time and money, potentially further increases the negative load on the unit. The question thus arises as to why the family make this investment. The testimonials from this research indicate a number of reasons as to why this imbalance is acceptable and even enhanced in the short term. Family members discussed how they felt obliged to return the care that had previously been received from the individual, but also expressed this in the more personal terms of love. For older children or spouses who felt well served by the individual, this duty to repay past kindnesses was strong. Equally, the individuals themselves gave thanks for the love that had been shown to them by their family through their troubles. This returning of care was never discussed in relation to an Islamic obligation to care for your parents which has been cited elsewhere (Al-oraibi 2002, Yamey, Greenwood 2004), but concretely as a return of care and love previously received. More substantially though, both the person affected and their family discussed the potential of their return to usefulness as being a reason to invest care. For all the participants, considerable energy and resources were focussed on achieving this aim, often for several years after the event. A return to functional productivity was a goal that was worth investment. The multiple efforts to seek health are testimony to this commitment as is the time and concern taken to complete tasks ascribed by the healer. Such a presentation suggests that the individual both wanted and was needed by the family to be useful in some way. The family invested resources of money and time in order that the 'recovered' individual can return to their role as an active member of the unit. This investment necessarily relies on the belief that recovery was possible and as a result acts to reinforce the prognostic beliefs described in the previous section. And indeed their requirement that a dependent member has the potential to be independent again encouraged the belief that the illness was reversible.

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[27] Indeed in cases seen outside of the research participants the opposite seems to have been true. For while family members understood the condition of stroke to be serious, it was so serious that intervention was perceived to be futile and therefore not implemented.

This scenario illustrates a form of reciprocal exchange at work within the family unit. On one hand giving by the family now was a way to balance the active giving that the individual had engaged in prior to their stroke. On the other it was also an investment that in future the individual could return to active productivity as a potential exchange partner. But in the cases of stroke presented in the narratives this was not a straightforward and stable equation. Resolution from the symptoms had not been fully substantiated at the time and expense in seeking the cure was often too great for the family to bear. Hence a virtual negotiation appeared to take place, where the potential benefit of investment to the unit and the moral obligation to care, were pitched against the cost (in general terms) of the investment itself. This negotiation was configured in many ways. The number of family members available for daily care was reduced over time, treatments were stopped if found not to be efficacious in effecting the changes desired, expensive treatments were stopped even when improvement had occurred and over time both cheaper and more accessible treatments were utilised. These amendments in the investment decreased the negative family outlay of care somewhat. However, they were still measured against the desired improvement and investment was increased again if recovery seemed to be forthcoming. This was very apparent with carers commitment to completing exercise regimes with their relatives if improvements in movement and function were noted, but also in the purchase of medications held to be responsible for increasing strength and capacity. As a result reciprocity was not acted on in a vacuum, a blank sheet where all required needs would be met. Rather it was a careful and often re-negotiated balancing act such that the homeostasis of the family unit could be maintained. In summary this homeostatic equilibrium appeared to rest on the position of three core variables; the perception of functional recovery (and therefore the individuals potential to become a net provider again), the financial means and flexibility of the family unit, and the moral conception of care. When all three were present in the positive, a state of active reciprocation was apparent with a concomitant commitment to seeking assistance in recovery. When they were negative, the reverse occurred. And over the period since stroke a number of subtle shifts occurred between these two extremes. These are illustrated in diagram 20.

Diagram 20 Showing the positive and negative balance of coping
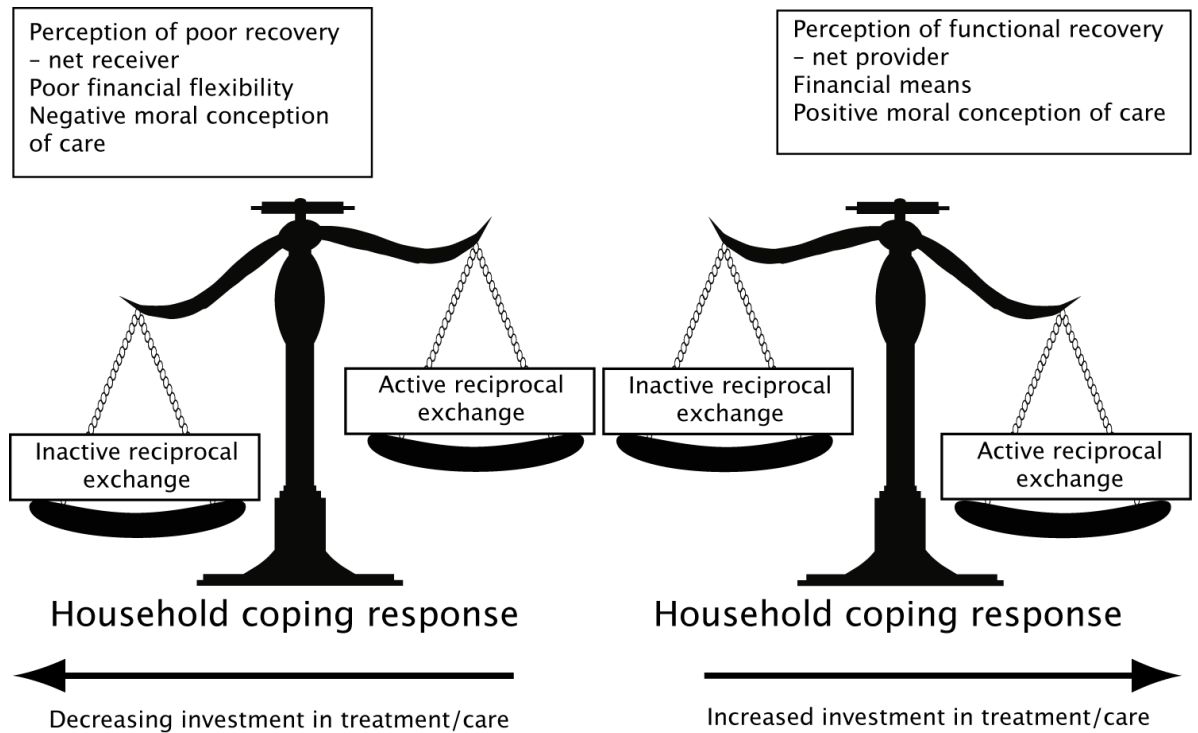
The family interactions presented, clearly illustrate both aspects of hope and loss. The loss of family roles and the potential loss of the needed care are partly offset by the hope that the family will both deliver the needed care and that recovery will be sufficient to facilitate a return to those roles. However, as the family coping response shifts in relation to the three main factors identified, so the loss may be presented as more permanent or the hope of recovery more actively pursued. That search for recovery leads to discussion regarding the homeostasis in interaction between the person affected by stroke and the healers. Prior to this, however, it is important to acknowledge the absence of reference to social roles and community homeostasis.

7.2.2 Society

Both in the experiential stroke literature and research in Indonesia, the importance of society and social roles is noted (Bowen 1991, Cox *et al.* 1998, Dowswell *et al.* 2007, Goodwin & Giles 2003, Lawler *et al*. 2000, Lyon 2002, Remer-Osborn 1998,). This research, however, yielded very little reference to social consequences outside selected religious roles, referred to in chapter 5 and the social disharmony created by the conflict as a potential cause of stroke. This contrast to both the experiences of others with stroke and a stated central tenet of Indonesian culture is worthy of

reflection. In this research three aspects were noted which could explain this discrepancy with other studies; the conflict itself, social responsibilities in sickness, and the priorities of roles. Firstly, the 30 years of conflict in the region has done much to erode social cohesion. It is noted that because of the different cultural groups within the central highlands and the upsurge of counter- insurgency groups locally, that an atmosphere of mis-trust has developed (World Bank 2006). As a result, dependency is acknowledged to have narrowed to the immediate family groups, often excluding extended family members whose political leanings were potentially unknown and often differed (IOM 2007). Secondly, although community harmony is an oft written and observed feature of Indonesian society, it has also been documented that in severe illness the responsibility of care falls to the family and therefore substantial community involvement is not expected, although even the support of the family is not guaranteed (Schroder-Butterfill 2002). Finally, unlike the narratives from people with stroke in the West, the focus here was firmly placed on roles that directly related to the family unit or Allah. Therefore when disrupted by stroke, it was the family unit and the individuals' role within that which was threatened as well as the individual's relationship with Allah. These factors may partially explain the lack of reference to social roles, although further investigation is warranted.

7.2.3 The healers

In chapter 6 a number of features of the healers sought by people with stroke were explored alongside how and why people chose them. This section brings together these different aspects through an examination of the concepts of stroke held by the healers and their healing practices, and the influence they have on the individual with stroke and their family. This impact will be shown to have both a positive and negative effect on hope and the demands on the family, which in turn affects the homeostatic equilibrium between people.

The healers had very different understandings of the stroke event, the main features of which were crudely split between the biomedically trained healers and the traditional/ alternative.

For traditional and alternative healers there was congruence of thought both in the reversibility of the condition and its longevity. All believed that cure was possible and was achievable in a relatively short period of time. Through the interviews and vignettes these healers expressed their expectation that cure would be realised either immediately following treatment or to a maximum of a few weeks after as result of resolving the blockage in blood flow. This belief in a timely resolution corresponded to that of the person affected by stroke. But significantly however, it was also consistent with their hope and that of the family. This shared belief in the outcome was potentially a strong determinant in the will to seek a multiplicity of healers in these categories, as the inability of any one healer to affect a cure was not seen as a reason to shake their confidence in the concept of cure, but as evidence that they had the wrong healer[28].

The situation with the biomedically based healers however was somewhat different, in theory at least. None of these healers believed that cure was possible. For them, permanent damage had occurred and while improvement was possible, total recovery was not. This potentially put them in a position of conflict with their client, as different explanatory models and expectations were held. However, this conflict did not seem to materialise. Unlike the western literature, there was little discussion by the biomedically trained healers as to false understandings and unrealistic goals. Indeed, while the differences in understanding were very apparent through the individual interviews, there was no evidence that the biomedically trained healers or their clients were aware that such differences existed. Equally in observed sessions, no discussions were had where these differences were raised. A conspiracy of silence, or assumption of agreement seemed to predominate. There are a number of potential reasons that could account for this, some of which were inferred by the participants of the research. One is the reluctance to give bad news. Doctors, nurses and therapists alike commented that they tended to avoid focussing on the negative aspects of illness, instead emphasising what could be done to assist. This included giving a diagnosis of stroke, which had been apparently avoided through a number of

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[28] A similar scenario is noted by Nitibaskara (1993) in relation to negative press coverage of specific *dukun* in Java. He notes that rather than damaging the "infrastructure of belief" (*ibid*: 129), it is the individual *dukun* alone that are discredited.

interactions with the biomedical healers. For the therapists, the reason was articulated in the frame of motivation and maintaining the spirit of the patient, an aspect which is developed shortly.

A second reason is an uncertainty of prognosis itself by the biomedical healers. It was clear that the biomedical healers did not believe cure was possible. However, none were able to articulate how recovery occurred and in the interviews and vignettes discrepancies arose as to how much recovery they believed to be possible. This lack of knowledge as well as the total lack of specialism in both stroke and neurology in the region could lead to a lack of professional confidence to assert their position. This was articulated by the hospital physiotherapists, but was not assessed in the other personnel. This would be reinforced by an undeveloped understanding and ability to assess conditions such as Transient Ischaemic Attacks (TIA's) which may lead to a lingering thought that cure may be possible. As introduced in chapter 2, the lack of certainty of prognosis has led to similar evasions of the topic in the West (Becker & Kaufman 1995).

Despite differences in concept therefore, it would appear that all healers explicitly or implicitly encouraged a sense of hope that the functional recovery that the individual and family so desired was possible. For the alternative healers and therapists this maintenance of hope was not simply a result of their understandings, real or implied, but formed a central tenant of their healing method. Both groups highlighted that motivation was key to success and was therefore a tool they used to encourage a commitment to their treatments by both the individual and their family. That motivation was theoretically presented as a commitment to the person's goals, which invariably revolved around personal independence in movement. It would follow that treatment would therefore focus on functional movement. In part this was demonstrated by the alternative healers whose general exercises in effect were the task at hand[29]. These healers were not specifically observed asking their clients what

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[29] From a therapeutic point of view it was particularly interesting to note this. The focus on activities in task has been increasingly emphasised in the last 10 years as research on motor learning has developed (Carr & Shepherd 2003). Its importance in terms of motivation for the client is also noted (*ibid*). It is inconceivable that the alternative healers are aware of this research. Equally this research showed little evidence that they had a developed formal understanding of movement analysis.

their goals were, but there was an informality in their communication which indicated that much had been shared between them and that the healer was aware of many aspects of the clients previous daily activities.

The situation with the physiotherapists was more varied. Those based in the community discussed their need to 'lift the spirit' of their client and that a focus on the activities the client and their family valued was a way to achieve this. In some cases this motivational tool was evident, with treatment interventions following a planned goal which had been negotiated by the parties involved. In others though, the habit of routine passive exercises and a lack of meaningful engagement with the client other than a list of instructions was also apparent. For the hospital based therapists the theoretical commitment to motivation through client led goals was particularly lacking. Routine exercise regimes, with a pattern of electrotherapy that was applied in the same way to all clients was both observed and reported. No specific and personal discussions were witnessed and through the testimonies of people with stroke, little explanation of the purpose of the treatments was understood, if given.

The differences in the physiotherapists approach could be explained from a number of perspectives. Therapists working in the community have no access to specialist equipment and therefore everyday activities are often the only way to effectively complete a treatment. Equally in the community the family were considerably more explicitly present and active, both in discussions and treatment. While present in the hospital environment, both on the ward and in out-patients, the families did not ask questions nor were they invited to participate in the therapy sessions. Indeed in the sessions observed, the only interaction between family and therapist came through the instructions of the next appointment. This involvement of the family in the community potentially shifted the balance of power such that discussions of the personal and family needs were encouraged. This seemed to be the case, in an informal manner at least, in the community. Coffee was always consumed before or after a treatment session and general conversations held. Through these, both the client and their relatives often raised specific functional difficulties or gains they had made as well as talking about their hopes; for example being able to walk without a stick before a daughters wedding. Another reason may be the direct influence of

international training. Prior to this research, an initial assessment of the community therapists by a French therapist employed by HI, identified a need to develop skills in client goal setting, motivation, communication and the centrality of functional therapy. As a result, trainings in these areas were conducted by both international and national specialists and their ability and commitment to incorporating these skills into their practice was noted over time.

It is apparent therefore that the concept of motivation is presented in a complex manner in Central Aceh. Its importance was recognised and relationship with client goals also noted, but the application in reality varied considerably. This complex relationship between the alternative healers, therapists and motivation displays many similarities to that introduced in chapter 2. It would appear that motivation is a concept that has cross cultural relevance and requires further study.

The emphasis on functional improvement from the perspective of people with stroke had a number of implications for health seeking. It resulted in a focus on goal achievement, where the means whereby they were achieved became subsidiary concerns. This, in effect, left the person with stroke more open to try any potential healer, creating the environment for the pluralistic seeking described earlier. It also generated part of the complex formation of causation theories as described in chapter 5. People did not necessarily seek healers purely based on whose explanatory process 'fit' with their own, as inferred by the work of Mshana *et al* (2007) and Hundt *et al* (2004) in Africa. Rather, if required, they changed their explanatory understanding if the healer they had seen had an impact on their condition. This evidence based theory development has a number of consequences with stroke, particularly in the very early stages, because of the part resolution of symptoms that often occurs spontaneously[30]. Consequently, treatments sought earlier may be seen to be more efficacious because their application coincided with this period of spontaneous recovery and as a result may have more influence on the explanatory models adopted. Finally, it also set up the criteria for judgement of healers. As illustrated in chapter 6, a lack of functional recovery was the most common reason that interventions were ceased.

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[30] In biomedical understanding, this early resolution is stimulated by a re-absorption and resolution of swelling around the infarct/ haemorrhagic site in the brain (Baxter 1997, Carr & Shepherd 2003).

From the discussions above, it is clear that the homeostasis between the individuals and healers/ family are closely connected. For the healers the combination of aligned approaches and conflicting ideas, which remained unarticulated, maintained the individuals hope of recovery. However, the lack of efficacy in achieving the hoped for gains, resulted in the drive to search for new hope. But this hope based on healing came at a price and was therefore mediated by the capacity of the family to sustain the search. This in itself was measured with the balance between potential gains and the family means and desire to pursue the goal.

7.3 Homeostasis between person and other realms

Through the stories of life and illness, people in Central Aceh highlight the interweaving of their existence with that of other realms. Spirits and Allah are not abstractions living in other worlds, but interact and influence their everyday lives. The discussions regarding both showed a desire for balance, but these manifested themselves in very different ways.

7.3.1 Spirits

Spirits, genies or *djinn*, featured mainly in causation theories of ill-health, although their potential protective nature was also referred to. This combination of capacity to harm and its reverse ran alongside an awareness that humans have always and should live alongside *djinn*. Spirits are part of the universe humans inhabit and a balanced relationship with them is as important as it is with the environment, community and within the person themselves. As a result, when seen as a cause of illness, the intent of treatment was not to destroy them, but to gently tempt them out of the individual, enticing them with food, massage, gently sucking them out of the body and spoken entreaties to leave. Even in the use of *bekam* using fire, the healer explained that it was the removal of the evil wind (genie) that is the aim, a removal that is achieved by restoring a balance. Paraphrasing Budi; the nature of evil wind is like fire, therefore the technique returns it to fire, its naturally balanced state[31].

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[31] The use of spirits to empower healers was not discussed or witnessed in the treatment of stroke, but was seen in other parts of Aceh on consultation of other disorders and social conditions. For example, spirits were invoked to assist with the confirmation of the whereabouts and status of missing people following the Tsunami.

Further evidence of the informants desire not to create an antagonistic relationship with the spirits is shown through the discussions of their existence. Throughout the narratives participants gave varied and shifting explanations of the influence of spirits. Their strength of belief in them and their action peaked and waned, was inverted and also reinforced. Public denials were paired with private belief, illustrated through their own use of *dukun* for spirit removal. Equally, compromises were found, where the spirits were cloaked within an Islamic frame, as was described in the neo-sufic revival in chapter 3. As a result, people accepted their existence, but placed them more firmly within the teachings from the *Qur'an*, their action no longer random, but a sign of inappropriate Muslim behaviour. Through these alternative explanations the homeostatic relationship between human and spirit was maintained but reinterpreted through concepts that also maintained a social equilibrium.

7.3.2 Allah

Until this point the attempts to regain homeostasis within and outside of the body have been shown to involve a fluctuating balance of different influences. The relationship with Allah, however, shows itself to be of different character, where compromise is resisted. The individual with stroke illustrated their interaction with Allah in a number of ways: through causation, duty, acceptance and the strength to continue to seek the cure they believe Allah may provide for them. Through all of these, experience of earthly realities were not conceived as something that can alter the individuals relationship with Allah, but rather were obstacles that needed to be overcome in order to maintain the sanctity of that relationship.

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, based on gratitude to Him, is one aspect of that test (Yamey and Greenwood 2004). The first of these has been referred to as fatalism and in the rehabilitation literature such beliefs are linked with issues of reduced motivation, dependency and a lack of agency (Al-oraibi 2002). The second has been associated with religious coping mechanisms and may assist with the appropriate adjustment to life post serious illness (Yamey and Greenwood 2004). This research in a devout Muslim community illustrated some aspects of this

commitment to Allah, but framed them in parallel with human accountability and action, such that a purely fatalistic approach to both the illness and its resolution was absent, while the sustenance of the relationship with Allah was prioritised.

When participants discussed the cause of their stroke, all focussed on the 'physiological' factors; conditions that resulted in the blood flow being disrupted. All of these factors were negotiated in importance and relevance over time. In addition, a few participants revealed that they also believed their illness had ultimately come from Allah. For them the decision of the illness, its timing and severity, was in His hands. This was not, however, presented as abject fatalism. The individual was neither helpless to prevent this occurrence nor to seek its remedy. Participants spoke clearly of their poor dietary habits, for example, that they should have controlled. Nevertheless, finally Allah had decided that the stroke should occur to them now. Knowledge of hypertension, cholesterol, spirit possession with the other possible risk factors were incorporated or discarded in line with its relevance and 'proven' appropriateness. Allah's role, when stated, did not decrease the relevance and importance of these factors, but acted to stem the questions of why me, why now?

A similar scenario presents itself in relation to health seeking and cure. As explored in chapter 6, all participants followed multiple roots. All the potential paths to health could be tried, judged and balanced with their effectiveness and accessibility. Such activity is promoted in Islam as all routes to cure are through Allah's grace and indeed Mohammad is noted as stating that Allah has created a cure for every illness except old-age (Al-oraibi 2002, Yamey and Greenwood 2004). In their stories, participants focussed on the practicalities of their health seeking, yet consistently gave thanks to Allah when improvement was noted. Once again, His grace was held in parallel with the human will to seek improvement.

The balanced relationship with Allah was not only apparent for those seeking cure, but also for some of those who were the means whereby recovery may occur; the healers. A commitment to Allah's power of healing was evident in all the alternative and traditional healers practice. Through prayers during and as part of treatment, or the acknowledgement that their power to heal had been ordained as a result of their specific dedication to Allah, these healers maintained a balance between their human

skills and the grace of the Almighty. There is, however, little space for such understanding in biomedicine. The specific interviews, observed treatment, focus group discussions and vignettes with the biomedically trained healers yielded no direct references to Allah or prayer (other than their clients desire to be able to achieve it). But they equally did not reveal any challenges to a religious explanation and by avoiding explanations at all, as was noted in chapter 5, the role of Allah was not denied.

Space for Allah was created even within the harsh terrain of western science. In the HI office, staff (both therapists and community workers), often discussed the beneficiaries' belief that Allah was responsible for ill-health and cure in a negative vein. In my presence, they presented these beliefs as unscientific and harmful to community health, although not as harmful as traditional (*adat*) beliefs. Yet when in the community, no such conversations or challenges were heard and in contrast, comments praising clients on their pious behaviour and their focus on prayer was encouraged. These comments arose during the informal conversations either prior or post the 'official' purpose of the visit. Such differences in behaviour suggest that a number of competing explanatory models may be held, which the staff highlight or hide depending on the particular circumstance. Perhaps even within the western understandings promoted by HI, the need for a constant relationship with Allah is understood by the local staff.

Earlier I suggested that the fatalistic side of Allah's influence on man was tempered with human agency. The commitment to maintain a relationship with Allah, however, had considerably less dilution. The dedication to prayer was noted in chapter 5. In both the concepts of health and the desire for recovery, the ability to complete the obligations of prayer was strong. As mentioned previously, it was also a desire to complete them fully and normally, even though adaptations are sanctioned. For a number of the participants in this research, the act of prayer was the biggest motivator for their physical recovery. They wanted to walk and have functional use of their arm, but this was stated in order for them to complete *wadhu* and *shalat*. It is possible to suggest that this primary focus on prayer is evidence that the sustenance of an appropriate relationship with Allah is paramount and above any compromise. However, such a statement belies a difference in the participants and the primacy of

religious duty over other functional tasks in all circumstances. The participants who focussed on prayer were the majority, had mixed physical capacities and many had been the primary income generator prior to their stroke. However, all had older children and the financial balance of the family unit was being sustained by others. In two narratives, discussion on the centrality of prayer, while present, was noticeably less emphasised. For these participants, prayer was important, but did not feature as the most pressing activity they had lost. Both were younger and had other responsibilities that appeared to take preference, that of child bearing and a return to work. As a result it would appear that the practical commitment to Allah was not prioritised in the event that survival of the family was being threatened. In these extreme circumstances, the sanctity of this most constant of relations was breached.

Despite these two exceptions, it is important to consider why the relationship with Allah should be prioritised. I suggest that it is because Allah is directly linked to hope. This returns us to the concept of Allah's omnipotence. In explanations and practical action towards health, I have argued that Allah's control over all things runs in parallel with an understanding and commitment to man's responsibility for his state. However, over the course of an illness, with an unknown trajectory, with remittance and relapse, rapid progress and plateaux in improvement, man's responsibility is both often unclear and subject to demands that require that it is forfeited for other needs. The negotiations that occur in order to maintain homeostatic balance between people, particularly lack of knowledge or accessibility to services, may result in individuals being unable to follow the path of their desired action. By maintaining their relationship with Allah, however, they invest in the other route to hope. The stability of Allah's grace acts as a constant to the fluctuations that are present in the man-made efforts for recovery.

The final aspect to discuss in relation to the equilibrium with Allah is closely related to the argument presented above. Many of the participants in this research had been living with their altered condition for a number of months or years. Necessary adjustments had been made to how they and their family conducted their daily life. Each discussed clearly their future hope for cure, but the present had to be managed and all were actively engaged in the process of negotiating how that management would be achieved. This led some to discuss how they emotionally handled the

discrepancy between their previous self and the person they believed they could and wanted to be, with their current capacity and ability to change. They did so through the concept of surrender. Surrender is a central tenet of Islam and indeed is the meaning of the word itself. It is a complex concept and while it may be stated simply as the following of the five pillars of Islam, as a philosophical and practical conception it has been debated and negotiated in a myriad of ways (Nygard 1996). In this research, the concept of surrender was specifically applied to the emotional and psychological adjustment to current realities. Participants commented that initially they had feelings of sadness and regret over the abilities they had lost. They added that they were often frustrated by their apparent inability to change their status sufficiently. However, in time they understood that these feelings were unhelpful and therefore they had moved beyond these through a process of surrender.

The process of surrender may appear to equate to a process of acceptance as introduced in chapter 2 which is conceived as a necessary step in the long term adjustment to disability. As such, it contradicts the arguments made previously that the participants in this research have invested in a recovery rather than an adaptation model. I suggest, however, that there is no such contradiction. The western model of acceptance infers an emotional response to a permanently altered body, an understanding of their current and future capacity. In contrast, surrender in this context acts to stabilise the present emotionally, it facilitates adjustment now, without negating the potential and probability that the future will result in further changes. In this model, surrender facilitates current acceptance without forgoing hope. As such, participants maintain the supremacy of Allah, without denying that they, through personal actions which Allah gives them the intelligence to follow, or Allah directly, can alter what is to come.

7.4 The homeostasis of hope and loss

Throughout this chapter, the shifting balance of loss and hope within the experience of stroke has been illustrated. Through the action of stroke *within* or *of* the body, the access to and action of healers, the support or burden of the family, or the influence of spirits; the fluctuation of hope and loss through the impermanence of the homeostatic equilibrium at each level is evident. It has also been argued that the

relationship with Allah is less prone to such fluctuations. Indeed, the only indication that it was threatened at all was in extreme circumstances of survival. The primacy of Allah's relationship has been presented as a stabiliser in the wider homeostatic changes that occur between the levels of interaction. Parallel forms of management are seen to exist in this community following stroke. One revolves around one's agency and ability to alter his/her condition. The other is through Allah's omnipotent control. The former finds itself caught within negotiations that occur between levels, where compromise is required. For example, the hope of returning the internal equilibrium of flow through an appropriate treatment was balanced with the potential loss to the family to do so. In this equation, if the loss to the family was perceived to be too great, then the hope of family care and stability would be prioritised over that of the individual's internal homeostasis. It is my contention that the latter, based on fundamental Islamic understandings of the relationship between man and Allah, is not subject to such inconsistency and as a result is presented as a resolute focus of hope. Amidst the turmoil of the unknown and the constant shifting of the homeostasis both within and external to the individual, a stable relationship with Allah acted as a guardian of hope.

Chapter 8

Relevance of understanding

8.0 Introduction

This study has provided a detailed account of concepts of stroke, experiences and health seeking in Central Aceh. It has also explored the factors that influence these understandings and behaviour and how they interact. In this final chapter I consider the findings of this research alongside the literature; juxtaposing the local with the international. Following this, I highlight the specific contributions of the research and suggest recommendations. Prior to this exploration of the relevance of the study, there are a number of limitations of this work that need to be recognised

8.1 Limitations of this research

The first, as discussed in the methodology chapter, is the specificity of this research. A necessary consequence of the detailed approach in both phenomenology and ethnography is that they focuses on a small number of people in a particular place. As a consequence the findings from this research should not be considered appropriate for generalisation. However, some of the principles discussed in this final chapter do highlight similarities and differences with other international ethnographies in stroke. Such cross-cultural comparisons can lead to useful development of more general theories.

A further issue with the approach selected, alongside other qualitative methodologies, is its subjectivity. I have attempted in this study to use methods that emphasise the participant's voice, but remain aware of my own influence on the collection, analysis and presentation of data. There are two practical limitations in this study which could have redressed this influence to a degree. The first was the length of time in the field. I spent 8 months in Central Aceh, with a further 5 months in Aceh Besar (a different district in Aceh) and 2 months on Java Island. Ideally a longer period in Central Aceh would have facilitated a more detailed understanding of life in general and closer interactions with the people involved in this research. Linked with this was my need to use translators. Although necessary there is always a risk that key conversations or comments are missed, questions are subtly

misinterpreted with further risk of extra levels of interpretation of data. In ideal circumstances I would have been fluent in Bahasa Indonesian, Gayonese, Javanese and Acehnese along with being able to transcribe and translate all of my own data. However, although I attained basic proficiency of Bahasa Indonesian, such a level of multiple language fluency was impossible given the time restraints posed by this study.

The participants knew that I was a physiotherapist and that I worked for Handicap International (HI). Some of the issues relating to this were discussed in chapter 4. It is not clear how much of an influence this had on the data collected, but potentially the study would have been quite different if these associations were not known or did not exist.

To cover the above, efforts were made to recruit participants from outside of Handicap International's (HI) dataset. However, this met with limited success and as a result it is possible that a bias towards HI or biomedical approaches in general could be evident. Ideally, recruitment would come from a general database that included all people with stroke, but this did not exist in the region.

As a result of the pragmatic approach taken in the assessment of language and cognitive disorders, some participants with mild disorders may have been included. This may have impacted on the quality of the data collected. More formal approaches could have been used, although I accept that the use of a formal language test, for example, may have resulted in an altered dynamic within the research. This could have been detrimental to the interaction between researcher and participant.

I further acknowledge that the broad definition of carers and consequently those present at interviews could have affected the data collected. Particularly it could have reduced the willingness to discuss private or intimate issues. This is a difficult issue to resolve in cultural settings where there are close family and social relationships. On the one hand privacy may enhance the freedom to discuss issues the participant does not want shared with other family members. On the other hand, interviews in which those present are decided by the researcher without consideration to the normal cultural interactive processes, can result in other restraints of discussion.

While I made the active decision to allow the participant to choose who was present, it is accepted that this may have influenced the data collected.

As a final remark, it is unfortunate that background data, such as incidence and mortality rates were not available in the region. Such information would have facilitated the selection of an appropriate cross-section of those affected by stroke and enriched the clinical, contextual information in the study.

Regardless of limitations, the findings of this study are an important contribution to medical anthropology and stroke rehabilitation in general. Specifically, there are important implications for:

1. Understanding local explanatory models within the application of international biomedical guidelines
2. The definition, recognition and development of human resources for stroke rehabilitation.
3. The development of an appropriate model for stroke care

These are discussed forthwith.

8.2 Relevance of explanatory models

In chapter 2, I note that health understandings and health seeking behaviour were important to study and understand because they had a direct relationship with the well-being of the individuals affected by ill-health. Through the presentation and analysis of the participants' narratives, the potential impact of their understanding and resultant behaviour has been illustrated. However, these concepts and actions do not occur in a vacuum. As Helman summarizes "beyond the disease is the person, but beyond the person are always the time and the place and particular circumstances in which they live and die" (2006:34). Some of those 'particular circumstances' were evident from the participants' reference to the conflict and the increasing Islamification of the region. It was equally apparent in the use, by the participants and the healers, of biomedical theories and tools, albeit in adapted form. This latter point is likely to continue and extend in the future as biomedicine is supported by the Indonesian government. Biomedical understandings are further perpetuated by the

influence of international organisations that work within a universal framework, whether in the field, through the influence of international therapists (and the result of their training to local staff), or mandates such as the WHO and global recommendations for approaches to stroke. Hence the universal meets the local and in so doing becomes part of the particular circumstance which is fundamental to the experience of and reaction to ill-health.

This study has illustrated the local, introduced the international and suggested some possible areas where the two have combined to create new forms of comprehension. However, the discussion has remained focussed on the experience of a few individuals in their journey. The insights that the analyses glean, however, has the potential for wider relevance. Local experience can act as a platform for re-considering the actions of the other 'players', such as the government employers. International recommendations and guidelines on stroke care consistently reiterate the importance of understanding the individual experience as a way to inform both best practice and the development of appropriate approaches to care (Intercollegiate Stroke Working Party 2008, Donnan *et al* 1998). The literature suggests that understanding and incorporating the experience of those who live with stroke is an integral and essential part of ensuring quality of care. The interplay, real or potential, of those experiences with the national and international 'players' is therefore an essential aspect to capture. This final chapter explores the relevance of this research to a number of the national and international stakeholders.

Mshana *et al* (2007), following their study of stroke in Tanzania, suggest a number of policy implications. These include the importance of engaging with the local explanations and interpretations, improving transparency with the limitations of medical and therapeutic intervention, and involving the multiple healing systems in the treatment of stroke. This chapter will consider similar themes, as they were both highlighted in the fieldwork and are prominent areas of concern in the international documentation. The arguments that follow will also discuss the dilemmas that are posed when such local and international perspectives are considered concurrently. These are presented as predominantly moral concerns and highlight the complexity of cross-cultural working when presuppositions are challenged.

8.3 Explanatory models: local and international

In Central Aceh, the human condition is conceived as an interactive state of balance and flow, in which the physical body is only one part of a perpetually unstable interaction between the mind, environment, spirit and cosmos. As a result, stroke in Central Aceh is understood as something different from the international biomedical understandings which were introduced in chapter 1.

Through an analysis of the narratives, I have illustrated that these two definitions of stroke both share a number of features, but have other diverging ideas. Notably, both accept that stroke is related to an alteration in blood flow. However, aspects of causation, the area of the body affected by that interruption in blood, and permanence of the damage differ. These are summarised in table 11.

Table 11 Summarising the international and local understandings of stroke

	International	**Local**
Definition	Interruption to blood flow through plug or bleed	Interruption to blood flow through plug
Area affected	Brain, symptoms related to area of brain affected	Local to area of blood interruption
Reversibility	Some brain cell death irreversible	Blood flow and therefore symptoms reversible
Causation	Multiple that affect blood flow	Multiple that cause imbalance in blood flow
Risk factors	Hypertension, hypercholesterol, smoking, diabetes, age etc	Hypertension, too much thinking, stressful thoughts, spirit/ dirty wind entry, heating foods, previous unresolved injury
Understanding of event	Abnormal, assistance should be requested	Abnormal, assistance should be requested
Treatment approach	Primary prevention, acute stabilisation, secondary prevention and rehabilitation. Prevention led with hyperacute symptom response.	Acute stabilisation and curative intervention. Symptom led.

These similarities and differences create the potential for both shared understandings and misunderstandings as stroke services are developed. Some of the complexity that this already creates was evident in the narratives.

Knowledge of these different explanatory models and how they currently interact with biomedical understandings could assist with the development of culturally-

compelling interventions (Mshana *et al* 2007). The local concept of flow and balance for example, bode well for the integration of certain aspects of biomedical stroke care. The understanding and importance given to blood flow could be used to expand on current concepts of blockages as a cause of stroke. It would appear that treatments such as thrombolysis would, conceptually at least, be acceptable with almost no alteration of theories required. The idea that medication can remove the blockage and therefore the problem, already exists, even if the brain is not understood to be involved in the equation at present. However, what disrupts the blood and the manner in which is does so varies quite widely between the local and international. The international focus is on problems that have been 'proven' to have a causal link with stroke within a western scientific understanding of bodily function. The local explanation incorporates what people experience and believe the cause to be within a broader understanding of how the body and world generally exist.

From a health seeking perspective the understanding that symptoms resembling stroke are abnormal and therefore require intervention resulted in prompt health seeking behaviour in Central Aceh. Such action is in-keeping with the international recommendation of acute care and the recently promoted concept of 'FAST' identification (National Audit Office 2005). However, prompt action itself is insufficient to ensure that international recommendations will be followed. For example, the help seeking may not be to a biomedical practitioner, or to the hospital environment as recommended. Indeed the facilities and resources recommended also may not be available. Furthermore, the action relied on a concept of help seeking which is symptom led and this understanding may create a dilemma when prevention, both primary and secondary, is emphasised.

Preventative measures, such as control of blood pressure, cholesterol level and a number of other risk factors could be built on the local concepts of balance and flow. However, a number of subtle but essential shifts would need to occur for this to be effective. As mentioned, health seeking behaviour is currently driven by symptoms; if they do not appear, neither does the behaviour. Prevention, both primary and secondary, requires intervention during periods of no symptoms and there was some evidence in the narratives that in those circumstances treatment was discontinued.

This pattern was potentially partly driven by the lack of symptoms themselves, but also the negotiation between severity and the costs of health seeking. Time and money are both required, particularly as the biomedical doctors insist that very short supplies of medications, around three days worth, should be given. As a result, in the absence of symptoms, there may be insufficient motivation for the expenditure required. These connections between underlying problem, symptom presentation, behaviour of the health personnel and the cost of treatment, need to be understood in detail if both primary and secondary prevention are to be effectively implemented.

It would appear therefore that some educational messages could be effectively integrated into the already held concepts of health and illness. This, however, may not extend to the brain as the principle organ affected by stroke, which has other potential consequences. It has already been demonstrated that in Central Aceh the brain is not considered to be primarily affected by stroke and the sequelae are deemed to be wholly reversible. In contrast, the permanence of the brain damage understood in biomedical terms results in a management focus on stroke as a long term acquired disability. It is apparent that a concept of a curable disorder is difficult to integrate into one that permanently damages the organ of bodily and mental control, coordination and communication. How it can be done is a point of further research and given some of the statistics of knowledge stated in chapter 2, is evidently something that is as relevant for the West as Indonesia.

The issue at stake here is not which understanding of stroke is 'the truth', but how people come to understand 'their truth'. Frank (2006) argues that health and illness behaviour are in part directed by the stories one hears, reads or experiences. But he adds that not all stories are accepted. Using the analogy of a journey on water, he explains how one chooses which stories will come on board while others are left to drift by, a process he refers to as health consciousness. Through this he infers that additional and new information regarding health and illness must find a place within the current broader understandings for it to be incorporated and potentially affect behaviour, a point supported by research in the field of public health (Jones, Williams 2004). This concept is of critical importance when exploring how local and international perspectives intermix. As introduced in chapter 2, education on risk factors is a key focus in stroke care. Indeed the government of Indonesia itself

highlights that education of the community and availability of adequate information on key health risks is central to developing the community capacity to become effective health decision makers (SEARO 2008). Yet the government papers, the international guidelines and the research papers reviewed in chapter 2, fail to consider that there is a knowledge base pre-existing that may have an impact on their strategy. The education plans aim to rid people of misconceptions by alerting them to 'the truth' without fully considering that 'the truth' as is internationally understood, will be evaluated by the local 'truths'. This research indicates that not only is a pre-existing explanatory model apparent, but that it has selective capacity to absorb and incorporate new information and is robust enough to both reject 'truths' it does not find palatable and re-interpret those which have some resonance of sense-making. If policy makers, promoters and funders of education strategies are serious in their desire to implement their programmes effectively, they would do well to acknowledge the existence of and engage with these alternative explanations.

8.3.1 The consequence of challenging explanatory models

The integration of biomedical and local approaches assumes that the adoption of biomedical concepts in a local environment is beneficial, without negative implications, and that biomedicine has a high value that is universally unassailable. I would argue that these assumptions need to be challenged. Attempting to change conceptual understandings has potential consequences. By highlighting these consequences, the apparently innocent venture of education will be challenged.

Through this research, one part of the local understanding of stroke in particular was shown to have an importance far beyond just an explanation of an illness; that of the reversibility of stroke. The slippage between the biomedical emphasis on stroke as a permanent disabling condition and the local understanding of its reversibility may highlight a need for an education strategy to address the apparent local 'misconception'. Indeed, Mshana *et al* (2007) suggest that not only should the likely prognosis of stroke been clearly communicated, but also biomedicines current limitations in addressing recovery. However, a shift in understanding from curable to long term disabling condition could have critical consequences in Central Aceh.

The belief in recovery is an integral aspect of the personal and family coping response as has been clearly demonstrated in this research. With this belief, an incentive to invest in that individual is inherent. Investment leading to recovery facilitates the return of a family member as an active reciprocator. This investment is essential given the almost total lack of support from services outside the family. Without a belief in recovery, the future potential of reciprocation is challenged. As a result, the fate of the individual rests almost entirely on the moral obligations of the family, their sense of duty and capacity to accept a negative shift in homeostatic equilibrium. Based on the findings of this research, care based almost exclusively on moral duty is of limited value in the long term. This is particularly the case in vulnerable family units or those with little financial flexibility. As a result, an educational approach that promotes the concept of stroke as a long term disabling condition may result in the withdrawal of the care required for recovery and possibly survival. Similar arguments have been raised based on research on other disabling conditions (see for example Reidpath *et al* 2005).

This does not imply that an understanding of a poor prognosis will result in neglect. I am, however, suggesting that an uncertainty in the prognosis, which remains a concern in the West, has even greater gravity in populations that do not have the protection of social security and government funded rehabilitation programmes. It is imperative that in places where the individual is firmly placed within the unit of family, as is the case in Central Aceh, the potential impact of all measures, including educational ones, are considered in relation to that social group. To summarise, if the persons with stroke need their families to believe they will improve in order to elicit support, great care should be taken in disrupting that belief. The consequence of not doing so could seriously undermine the individual's health and survival, with further impact on social relationships.

I make no attempt in this thesis to suggest which option is preferable, apparent 'ignorance' which may protect the individual, or 'education' which may support the family. The relationships are, of course, not linear and straightforward. They are equally bound within the frameworks of cultural acceptability and this is where the biggest challenge lies. The divide between local and international understandings of a condition such as stroke is not simply a difference in understanding of organs and

curability. Implied and carried with them are judgements on life itself: what constitutes life; when it should be prolonged; when it should not; whose life has value; and to what end. Questions like these constitute the ethics of 'medicine' and these questions, like the medical systems or practices themselves, are steeped in particular histories and ways of understanding (Nordenfelt 2007, Sheehan 2007). There is an obligation to consider these hidden cultural assumptions that highjack apparently simple medical 'facts' and to do so prior to action.

For example, for many in the West and for therapists in particular, the goal of intervention/life is to facilitate an individual to be autonomous and independent. This focus may not be shared internationally. In Central Aceh, this research indicates that the family unit is of critical concern and therefore needs a family based approach to care at all levels of intervention, including those that consider the explanatory models (Brashler 2006). Mackian *et al* (2004:141) state that,

> *When an individual makes a decision in relation to their health, they weigh up the potential risks or benefits of a particular behaviour. But they do so in a way that is mediated by their immediate practical environment, their social rootedness and their whole outlook on life more generally.*

It is essential that individuals and organisations responsible for improving health status understand and engage with these concepts of risk and context of all those involved in the decision making process.

8.3.1.i The authority of knowledge

There is a further aspect to consider with regard to explanatory models and education, that is who has the authority of knowledge. Despite growing awareness in the West of the importance of including peoples' experiences in the development of policy and recommendations, in practice the focus has been predominantly to influence how services are delivered and aspects of the more social side of care. The explanation of how a stroke occurs is, however, firmly within the remit of biomedical science. This scientific appropriation of explanatory processes creates a hierarchy that needs challenging. There is little argument that the scientific study of the body and disease has resulted in huge advances in one form of knowledge, particularly that of the physical body. But there is equally a growing appreciation, particularly in non-

communicable chronic diseases, that scientific explanations are only partial. In stroke, for example, factors such as stress are incompletely understood and researched, despite their reoccurring reference as a causative factor (Evci *et al.* 2007, Harmsen *et al.* 2006, Surtees *et al.* 2007).

In this research, the causative link between the mental and physical was particularly strong and resilient. The impact of heavy, too much and negative thinking was related directly to physical changes in the body, but also as a conduit for ethereal influences on the body. It furthermore linked the experience of living as a social being, with that of the internal functioning of the individual. Perhaps these reoccurring and particularly robust lay explanations should give the scientists, or those wishing to impose a scientific frame of illness, pause for thought. Perhaps they have something to learn from the explanatory processes of those whose life experiences include a wider frame of reference.

8.4 Multiple healing and the concept of the multi-disciplinary team (MDT)

In the few studies on stroke available in non-western countries, the issue of multiple healing has been highlighted. Research based policy recommendations suggest that healers outside the biomedical remit have an important role in stroke recovery and should be included in treatment planning and implementation post stroke (Mshana *et al* 2007, SAPSI project team 2004). Such an approach may find support in some of the international recommendations. For example, as introduced in chapter 3, the World Health Organisation, through the Alma-Ata declaration, suggests that locally available resources should be utilised to assist in developing health for all (World Health Organisation 1978). International recommendations for stroke also suggest that the local or traditional services may need to be incorporated into services, particularly in developing countries (Brainin *et al.* 2007, Donnan *et al* 1998). Within Indonesia itself, some documents refer to traditional services as being part of the 'health system' inferring their inclusion would be both acceptable and already implemented (World Health Organisation 2001). However, these statements of inclusion belie both the contradictory nature of the international community's tolerance of traditional healing practices, and the complexity of stroke rehabilitation.

For example, all the documents quoted above have additional caveats or comments which rework their previously positive stance towards non-biomedical healers. The Alma-Ata declaration for example, adds that the inclusion of traditional healers should occur when they are based on (Western) scientific concepts (World Health Organisation 1978: statement VII.7). More recently, the global policy of 'task shifting' promoted by the World Health Organisation (World Health Organisation 2007a, World Health Organisation 2007b), which is designed to tackle the serious shortfall of human healthcare resources, contains similarly contradictory statements. On one hand the documents state that all stakeholders and available human resources should be involved. Yet despite this recommendation, other than a brief reference to traditional birth attendants, non-biomedical healers are not mentioned in any part of the task-shifting guidelines. As a result, it is not known whether they are even considered a stakeholder or human resource and if so, in what capacity they should be engaged.

Within the international stroke recommendations, comments regarding the use of traditional therapies as dangerous and an impediment to good care are more common than the rhetoric of inclusion (Donnan *et al* 1998). And in Indonesia, other documents which list the section on Human Resources for Health include everything except traditional services and there is currently no official registration process of traditional or alternative practitioners that has any influence on their practice in real terms (SEARO 2008). As a result, calls for the inclusion of non-biomedical healers in the treatment of stroke appear to be some way off implementation.

This contradiction on the inclusion or exclusion of the non-biomedical healers appears when basic resource constraints result in 'pure' biomedical approaches being untenable. Affordable and available alternatives are required, but cannot be wholly endorsed when they do not fit the known frame of biomedicine and through that the international stroke recommendations. The indecisiveness also results in a lack of further questioning regarding these local resources. For example, almost nothing is known in stroke literature of which non-biomedical healers are sought and what they do. As a result, the recommendations are based on an assumption that treatment based on scientific knowledge is unquestionably superior to other alternatives. This is presented without any meaningful study into the nature and effectiveness of those

'other' treatments, or indeed the practice of biomedical interventions in a specific area. Such contradictions, matched with an apparent disinterest in seeking the information to challenge the assumptions in any meaningful way, result in simplistic suggestions for the transfer of western models, with the aside that they may not be practical, because of resource constraints. For example, Chandra *et al* (2006) and Donnan *et al* (2008) state that Stroke Care Units (SCU) should be a priority in low income countries. Yet Chandra *et al* (2006) add that they may not be practical in some low income countries. The reasons they give for this are a lack of hospital beds and specialist physicians, two relatively concrete resource issues that under-represent both the complexity of stroke unit care and reality of care seeking. Such recommendations are at best unhelpful, but may be potentially harmful if they preclude consideration of models of care more suited to the environment and capacities of the country or area concerned.

The remainder of this section will consider two of these issues in further detail. The first is that of human resources for health seeking and the second is their accessibility. The arguments presented highlight a need to develop a culturally appropriate approach to stroke and its rehabilitation, a summary of which concludes this chapter.

8.4.1 Human resources

This research has raised a number of issues with the concept of human resources in relation to post stroke health seeking in Central Aceh. Whether through the family or the myriad of healers available, resources have been shown to be complex, fluctuating and an important influence on the post stroke experience. This research questions the underlying concepts of what should be considered a resource and the authority on which that decision is based. It further develops the understanding of access to resources, going beyond an assumption that the existence of a resource is sufficient for quality care. This is a particularly pertinent subject as the short-fall of health-care professionals deemed able to implement the international recommendations has recently been highlighted (Donnan *et al* 2008).

8.4.1.i What constitutes a human resource and how is it judged?

From the narratives of the participants, it was evident that a resource was classed as someone who was able to help the individual achieve a positive change in physical status, by any means which did not involve a disruption to the familial or social equilibrium too great for a balance to be achieved. All healer types, as well as local community knowledge were utilised. Little hierarchy was evident and resource use was predominantly a pragmatic decision based on knowledge of, availability, accessibility and evidence of impact.

A question arises as to whether this description of a resource can run in parallel with the recommendations based in a biomedical paradigm. Is the collaboration and inclusion of all human resources, as recommended by Mshana *et al* (2007), a viable option in Central Aceh? To explore this, it is necessary to elucidate how the official providers of health care, that is the Indonesian Government with the support of the International Community, judge the resources available. The contradictory references to alternative healing practices discussed previously and the lack of research on biomedical practitioners in Indonesia (and professional regulation of the Allied Health Professionals (AHP's)), suggest that this is work yet to be done. However, inferences can be made from the international stroke recommendations which can indicate where possibilities and problems of amalgamation may arise.

8.4.1.i.a Traditional healers

For the healers that were categorised as traditional, the *dukun*, the situation seems somewhat hazardous. Focus on an explanatory process and treatment techniques, such as egg diagnostics, that have little resemblance to biomedical understandings, leaves them vulnerable to being labelled as unscientific. Without 'hard' evidence to 'prove' their effectiveness, the likelihood that any service which is based on a biomedical paradigm would find such practices acceptable is extremely unlikely. Furthermore, their process of learning, through inherited skill or direct from Allah, makes it difficult for biomedical concepts to be 'slotted in'. This potential scenario is unfortunate in many ways as these traditional healers are the very people that the Alma-Ata declaration and stroke recommendations envisaged as local resources: apparently cheap, locally situated and therefore accessible, and already known in their communities as sources of healing.

As a consequence, it would appear that the current pattern of biomedical dominance would find the inclusion of the traditional healers challenging. Such a forecast, however, omits a key consideration, that of the rehabilitation concept itself. As identified in chapter 2, rehabilitation as a concept is regularly renegotiated, both the goal of the process and the means whereby it occurs are still evolving. The identification of aspects such as hope (Becker 1997, Becker & Kaufman 1995, Jones *et al.* 2008) and therapeutic emplotment[32] (Mattingly 1998) as central to the success of rehabilitation, encourage professionals to consider factors that 'science' is unable to quantify. They should also give cause to re-look at the interaction with healers such as *dukun* in that light. Mattingly (1994, 1998), for example notes that similarities may exist between the process of therapeutic emplotment and the activity of traditional healers. Barry (2006) goes further, suggesting that non-biomedical healers may effect not just the individuals meaning of illness, but bodily experiences, identity and create a "transcendent, transformational and spiritual healing experience" (p2655), aspects fundamentally ignored and unmeasured in the current medical paradigm. Other research in Indonesia suggests that *dukun* (or *balian* as they are known in Bali) may have a similar role (Hobbart 2003, Kurihara *et al.* 2006, Slamet-Velsink 1996). Perhaps the *dukun* in Central Aceh have something to offer and potentially teach the West about these more inclusive aspects of rehabilitation.

It should not, however, be assumed that all traditional healers, deliver on these aspects of therapeutic effectiveness. Indeed, this research indicated little evidence that such activities occurred within the treatment of the traditional healers for stroke. The dramatic rituals, long conversations with the person affected and family members, and social labelling of the disorder described in other areas were not apparent. It was not clear that the services of a *dukun* were required before a label of illness was accepted and the only ritual of social significance, a meal, was apparently performed after cure. While in other circumstances these ritual meals may result in the reintegration of the individual back into the community (Geertz 1960), they seemed to serve no such purpose here, but rather increased the financial strain, with little output appreciated by the person or their family. In-keeping with this research,

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[32] Mattingly (1998) uses the term therapeutic emplotment to refer to the story-like structures that therapists and patients create as an integral part of the healing power of therapy practice.

Siapno (2002) also notes a remarkable lack of drama in the treatments of Acehnese *dukun* and Bowen (1991) comments that the understated manner of traditional treatment in the Gayo community is an inherent part of the social desire to maintain a calm and controlled presence. There was some evidence that the *dukun* most actively included causation concepts that had social potency, particularly those related to the conflict. This arguably could result in a greater level of sense making for the individual caught in social and personal disorder. However, their clients did not focus on this within their concept of healing and therefore my comments are merely unsubstantiated conjecture.

8.4.1.i.b Alternative practitioners

The situation for the alternative healers, those who crossed between the traditional and biomedical spheres, is somewhat different. Having already incorporated a number of biomedical ideas, and followed a training path more in line with that of the West, a potential collaboration would seen plausible. There may still be concerns, from a biomedical point of view, of their causation theory and the incorporation of religious ideas within both diagnostics and healing, but the dynamic nature in which they have amalgamated multiple philosophies and practices bodes well for future negotiations. For example, the alternative healers themselves vocalised their desire to learn more about physiotherapy to enhance their own treatment efficacy.

Importantly there is also much to learn from their practice. They are the healers who have most significantly crossed the cultural boundaries and through looking at the success of their practices, it appears they have done so in a socially acceptable fashion. By success I am not referring to the outcome of their intervention, which was not assessed in this study, but rather the use of their service witnessed by attending their clinics and also the number of times that participants continued their treatments, despite the high cost. Evidently they have understood something about the needs of their clients in illness. By adopting explanations and treatments from biomedicine, Chinese and traditional medicine they are able to draw their client into their world of explanation that creates many bridges. Flow and balance are mixed with blood and organs of significance. Foods and medications are suggested in treatment alongside exercise which addresses the desire from the individual and family to do something for their own benefit. Their chameleon like ability to portray

a world that makes sense to the client and yet also has a ring of higher knowledge (whether that is through education or other qualities) is a powerful skill. It places a value on both sides of the equation, the individual and their understandings, and that of various 'knowledge' bases. This combination is rare in biomedically based practice, despite a growing understanding of its importance in effective healthcare.

A significant part of alternative healer's practice, shared with traditional colleagues, is the involvement of religion. For the traditional healers, religion was something of a tricky ingredient given, a) the political nature of the traditionalist and modernist view of Islam in the region, and b) the appropriation of spirits in ill-health in those arguments. The alternative practitioners, however, circumvented the political religious arena by utilising religion in their capacity to heal and in the healing process itself, but largely avoiding the discussion of spirit as a causation category. Yet, they still maintained a powerful aspect of healing in this community. The narratives from the healers and the participants emphasised repeatedly the centrality of Islam to their life in a multitude of ways. This importance of religion in health and illness is substantially ignored in biomedicine. There is some evidence that religion has a role in health and in rehabilitation success (Chatters 2000, Fitchett *et al.* 1999, Idler & Kasl 1992, Johnstones *et al.* 2007, Levin 1996, Levin 1994, Levin & Vanderpool 1989), yet its explicit involvement in a partnership with biomedical practices is elusive. Research to date is particularly lacking both in the effect of religion in long term rehabilitation and specifically Islam (Yamey & Greenwood 2004). If religion and religious frameworks are meaningful to the client and their caregivers, it seems sensible that they are incorporated in some form in the journey to recovery. The alternative practitioners, in this brief introduction to their practice appeared to have done exactly that, and a closer inspection in further research of how, and the impact of that inclusion, would seem to be highly appropriate.

There are, however, a number of aspects of the alternative practice which strike notes of caution in a potential collaboration with biomedicine. The first is the rather informal way of acquiring their skills. While education is sought, there is to date no formal mechanism for monitoring what is taught, or that practitioners do not include other practices that could be harmful. Indeed there was evidence that the opposite was true. This is a complex issue, but one which would need careful consideration

and management, for quality control is an oft mentioned need in international health initiatives (World Health Organisation 2007b).

For example, the task shifting programme specifies that through either existing or new human quality assurance mechanisms, the process of delegation is accompanied by supervision, monitoring and continued educational support for all the health workers. This recommendation works on a basis that a 'gold standard' of care exists, which can be measured and monitored. In the case of rehabilitation post stroke, where the very purpose of rehabilitation is contested, such a position is untenable. It also assumes that the persons involved in delivery of care are based within a structure where such competency monitoring can be carried out and enforced. This research has highlighted that at present such monitoring does not effectively exist within the biomedical practitioners in Central Aceh. It is also apparent that the relationship between biomedical and non-biomedical healers is not hierarchical, but they co-exist. As a result there is no mechanism through which biomedically approved competencies could be enforced on others.

The second is a potential issue of power within a collaboration with biomedicine. Programmes that have worked to combine the practices of biomedical medicine with traditional practices have been based on a significant power imbalance; on one side, biomedicine, being the side of 'truth' (and the money), and traditional healers being the ones with the social connectivity but little else that is brought into the programme (Pigg 1995). Such an arrangement would appear to be unviable for the alternative healers. The reason for this is simple; while they are interested to learn more, they have no need to be patronised by biomedical programmes. Indeed, their services were not only the busiest, but also the most expensive encountered in this research. Indeed, it is possible to posit that their development of 'effective' and socially acceptable services is driven by the private enterprise nature of their practice. The recommendations to incorporate culturally appropriate services in poorer countries work on the assumption that these services are more financially accessible and amendable to biomedical control. There is little evidence in this research that the alternative practitioners fall into either category. This should not result in the abandonment of the idea and principle of collaboration, but strongly highlights the need to understand what the needs are, the resources and the stakeholders. Once it is

clearly understood and accepted by programme planners and implementers that the central medical bodies, government or international organisations, are neither the only or indeed main concerns in the development of improved services, a significant move forward is possible.

8.4.1.i.c Biomedical healers

This research also highlights a number of topics for consideration with the biomedically trained healers. It was apparent that the presence of the medical and allied health personnel was insufficient to ensure that the resources were of a guaranteed quality. All the staff interviewed had qualified from professional institutions, yet with no regulation of the content of courses, other than for medicine, their knowledge on stroke and therefore ability to treat within international guidelines is questionable. Equally, the two doctors interviewed specifically stated that much of their knowledge of stroke was self-taught or accessed through texts with no other learning support. The issue of insufficient national capacity for continued professional development was something acknowledged widely by all health professionals met in the region. The result was some medical and therapeutic practices were of dubious efficacy and potential harm. For example, a focus on socially appropriated risk factors, such as coffee, seemed to obscure more established factors such as smoking, with the result that secondary prevention would be unlikely to follow internationally recommended best practice. Research by Ng *et al* (2007) on medical practitioners' attitudes to smoking indicates that this is a widespread problem in Indonesia, and Mendis *et al* (2005) note that primary and secondary prevention are sub-standard in Indonesia. Medication regimes, such as acute doses of Nifidipine with the purpose of rapidly reducing blood pressure, which are not recommended for stroke, were noted to be in use (Intercollegiate Stroke Working Party 2008). Likewise, the therapeutic tendency to use heat producing machines and complete passive movements as a significant part of their treatment have no evidence to support their therapeutic benefit and are not included in UK therapy guidelines post stroke (*ibid*). A more detailed study on the specificities of practice of biomedical staff and how they compare with recommended guidelines would be an appropriate piece of future research. It would appear that in line with the observations of Das *et al* (2008) that access to care is not a guarantee of access to care of sufficient quality.

In terms of the implementation of international recommendations, despite the evidence of current lapses in practice, there was some indication that 'education' in this group of biomedical healers would be effective. The differences noted in treatment approach between the hospital and community based therapists for example, suggests that training can affect the manner in which therapy is delivered, indicating the benefits of Continued Professional Development (Davis *et al.* 1995, Davis *et al*. 1999, Department of Health 1999, Goulet *et al*. 2007). This however was not the case with all communication between therapist and client, as the permanence of stroke sequelae and limitations of therapy were not discussed, even though they were known to the therapists. This raises questions about what national therapists are able to incorporate into their understanding and/or what they are willing to implement in practice. In-keeping with the previously expressed concerns regarding the consequences of shifting explanatory models, it is possible that an examination of what local staff choose to implement and equally choose to avoid despite apparent 'knowledge', may pinpoint areas of particular cultural significance in health understandings.

8.4.1.ii Access to human resources

There are other very practical considerations with regard to resources. Access is a very broad term that considers not just the geographical and physical access, but services available, attitudes held by the service providers and related costs. Some of these are cited as important considerations in the international recommendations. For example Donnan *et al* (1998:1734) summarise the commonly highlighted features by stating that in "rural areas of developing countries access to stroke services is specifically limited because of geography, lack of resources and cultural practices". These features were found to be partly relevant in Central Aceh. But other issues surrounding accessibility were also identified. Notably, a relationship between geography and the frequency of services required was noted, as were the 'cultural practices' of some of the biomedical personnel and finally the power of choice.

8.4.1.ii.a Geography and frequency of service needs

In the case of stroke, international recommendations would suggest that the acute period requires intensive and specific interventions which are ideally hospital based. This is usually over a short period of time until the individual is medically stabilised.

Theoretically, the pattern of behaviour and explanations given in this research would suggest that access to such services could be facilitated, if it was considered worthwhile in terms of impact. Rehabilitation, alongside primary and secondary prevention however, are more prolonged requirements, the latter being potentially life long. In view of the consequences of geography found in this research, common sense would suggest that these longer term resources are ones that are placed nearer the community. All types of longer term rehabilitation, whether from therapists, traditional or alternative healers were ceased when it involved regular travel. Much of this was related to a lack of perceived effectiveness of the intervention, but in some cases treatment was stopped despite evidence of improvement and in these cases the costs of travel was highlighted. This evidence would suggest that rehabilitation services should be developed at community level, which currently is not uniformly provided by the government.

The situation for primary and secondary stroke prevention however is a little different as, theoretically at least, this is provided locally at the *Puskesmas*. This research indicates that when services are appropriately placed the expectations of access need to be justified, clinically and socially, and communicated to improve effectiveness in implementation. Otherwise, unrealistic demands are placed on the individual and family, for reasons that are not understood and consequently alternatives are sought, as evidenced by the three day courses of blood pressure medication. Here, it was apparent that different cultural practices between client and service provider existed, in which each blamed the other for inappropriate behaviour resulting in accessibility difficulties and ultimately poorer primary and secondary prevention.

8.4.1.ii.b Choice
A wider aspect of access to resources that is inferred in all previous discussions is that of choice. Because of the nature of the health service provision in Indonesia, people have the choice of which style of treatment they wish to follow. This is markedly different from western nations where government services are fairly comprehensive, uniform and in many cases publically funded. Subsequently, models adopted from the West may underestimate the importance of the client's judgement

compared with scientific judgement. Treatments scientifically proven to be effective may have less power than those perceived as effective in such an environment.

The results of this research in Central Aceh do not make the process of resource identification, judgement of value, and accessibility more straightforward. In contrast, it not only highlights the difficulty of investigating resources where no formal registration and activity moderation is evident, but also questions ideas of what the resources are for and challenges an assumption that the biomedical frame is sufficient when evaluating the resource needs of people post stroke. It furthermore suggests that accessibility must not just consider the presence of services, but also their required regularity of use and the practices of both service user and provider which may facilitate or inhibit the ease of availability.

8.5 Cultural approach to stroke

The arguments presented in this chapter so far, point to the need for a culturally informed understanding of stroke and its rehabilitation, rather than one simply transplanted from a universal model.

How that is negotiated is unclear at present. This research indicates that it should involve a discussion of the clients' goals and how they are structured within the dynamic of their social unit, the family. It should further include a reckoning of the lay understanding of the condition and a sensitive negotiation of meanings in which a common and acceptable ground is found. Alongside this, the prognosis must be approached with caution, with an appreciation of what is known, what is not and the potential consequence of what is shared. A consideration of how rehabilitation is delivered and what constraints are faced by the individual and family unit must also be incorporated. A summary of these questions is shown in diagram 21.

Diagram 21 Cultural approach to stroke

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┌─────────────────┐        ┌─────────────────┐              ┌─────────────────┐   ┌─────────────────┐
│ What?           │        │ Whose definition?│             │ How much?       │   │ How?            │
│ • Causation     │        │ • Individual    │              │ • Total cure    │   │ • Effort        │
│ • Symptoms      │        │ • Social        │              │ • Adaptation    │   │ • Miracle       │
│ • Impact        │        │ • Professional  │              └─────────────────┘   └─────────────────┘
└─────────────────┘        │ • Religious     │
                           └─────────────────┘
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Understanding of disorder

Understanding of recovery

Cultural approach to stroke

Process of rehabilitation

Purpose of rehabilitation

How?
• Support factors
• Motivational factors
• Competence
• Availability
• Accessibility
• Attitude
• Resources definition
• Communication

Goals?
• Physical
• Functional
• Emotional
• Roles
• Sense of self
• Independence
• Interdependence

Whose definition?
• Individual
• Social
• Professional

Stroke is an international phenomena and as such is subject to both local and international influences. The international bodies that promote and often fund initiatives on conditions such as stroke are influenced by a 'universal' conceptualisation of stroke, which is governed by particular western ways of understanding the world, the body and health care. By understanding lay conceptualisations and experiences of the disorder, the particularity of this 'universal' approach is highlighted alongside its appropriateness or not in the local sphere. Examination of the points of congruence and divergence in lay and international conceptualisations, highlight potential areas where information may be shared and others where the consequence of doing so may have unforeseen negative influence. Understanding the dynamic of both international and local approaches

results in an appreciation that simple transfer from one to another is both undesirable and impossible, and brings to the fore the need for a more dynamic and culturally informed approach.

8.6 Specific contributions

This research builds on existing literature on the subjective experience of stroke. By examining this experience in an area previously unexplored and using an in-depth and contextualised methodology, specific additions to the current body of knowledge have been made. For example, this research reconfirms that a number of factors, many particular to the specific locality and culture, influence the experience of illness and subsequent health seeking behaviour. In doing so it highlights the need to localise health interventions. However, this research has further developed the relationships between influencing factors, linking the understanding of stroke to both the drive to seek help, and the social environment in which the help is facilitated. In doing so, significant concerns are raised about the implementation of educational strategies and the research strongly reflects a need to consider the relevant social unit in all aspects of stroke care. It further challenges designers and implementers of international health programmes to unmask the hidden assumptions on the moral values of life, such that local strategies can represent local moral concerns.

The experiential stroke literature to date has focussed predominantly on the individual consequence of the condition, without concurrently exploring how the lay concept of stroke itself and the needs of the caring unit impact on that experience. This research has taken a broader perspective and in doing so challenges the framework of biographical disruption as being appropriate for the experience of stroke in Central Aceh. This finding not only questions the universality of the concept, but also suggests that research exploring experience should broaden its horizons beyond the individual.

The review of the particular healers available in this region, along with the previous research on stroke in Africa, highlights the breadth of help which is sought. However, unlike these previous papers, this thesis does not directly support international policies of inclusion of all healers or task-shifting. Rather it raises the

complexity of such collaborative working and calls for a more radical approach to international intervention; one in which understanding is centralised and the location of power/knowledge is not assumed.

A significant theme that emerges in this research is the centrality of Islam particularly in the pursuit of recovery and within rehabilitation. Previous research on the effect of religion in illness has predominantly focussed on Judeo-Christian religions and the role of religion in rehabilitation has been understudied. This research adds to the body of literature by suggesting that religious beliefs and activities should be considered a potentially important influence on the rehabilitation process.

From a methodological point of view, the use of previously taken photographs has been used successfully to generate narrative engagement with people post stroke previously (Haggstrom 1994). However, this research is the first identified that has used the method of interviews facilitated with participant taken photographs with people with stroke. The implementation of this method proved to be both practical and insightful and should encourage researchers to include participant controlled activities within the methods tool box.

8.7 Recommendations

A number of recommendations follow from this work.

- There is an imperative to consider local lay experience and involve those concerned in the planning and implementation of programmes designed to improve their care at a local level.

- This study recommends that the exploration of the illness experience includes those who are directly involved. In the case of this research that involved the immediate family unit. However, it should not be assumed that such groups are universally defined and therefore a local understanding of the caring unit is essential.

- Following from this inclusive approach, it is recommended that educational programmes should consider those involved at a number of levels. It should be accepted that a concept is already held and new information will be judged in that light. Knowledge of those previously held understandings may assist in the effectiveness of programmes and may predict where difficulties may arise.

- Equally, information is not neutral and the potential impact of new information should be considered before it is shared.

- Furthermore education should be seen as a two-way exchange. The concept of stroke in Central Aceh is considerably more inclusive than that held by the biomedically influenced West. That breadth of understanding may have much to teach western models which have been shown not to be wholly satisfactory for those affected.

- A number of avenues of useful further study arise from the investigation, mentioned in the previous chapters. One is a need to gain a greater understanding of the role of Chinese Medicine in the practice of Indonesian alternative practitioners. This could usefully involve not only a historical perspective on the transfer of medical knowledge, but dissection of which aspects are included, which are not, how they are successfully transmitted and how they are re-interpreted in current practice.

- Another avenue is to investigate further why social roles were largely absent from the participants' narratives. Such an exploration may involve a further critique of the methodology selected, or its implementation, or alternatively the altered social dynamics in a post conflict scenario.

- A more detailed study on the concept of ageing and how it relates to family, financial spending and health seeking dynamics in the region would be of value. This is particularly relevant given the demographic transition that is currently occurring in Indonesia.

- This research indicates that further studies on the diagnostic processes of stroke are necessary. The centrality of hemiplegia and the absence of posterior circulation signs suggest that stroke, as biomedically defined, may be under-diagnosed.

- There is equally a strong indication that the concept of motivation was used by biomedical and alternative practitioners. Given the potency of the concept in accessing rehabilitation and resources in the West, further examination of the therapeutic use of motivation in cross cultural settings would be of value.

- This research was a broad ranging review of the experience of stroke in central Aceh. Such an approach naturally crosses many professional areas and requires information from multiple sources. The final recommendation therefore is that research on specific illness experiences and health seeking behaviour is complemented by parallel studies that explore other aspects that may influence the experience. This may include: community and religious dynamics, economic flow within the caring unit, age and gender patterns in relation to care, activities and responsibilities, central financing and structuring of health care and its quality of delivery for example. Illness, its impact and related behaviour is complex and as a result a comprehensive approach to its research should be applied.

Appendix 1
WHO STEPS criteria

The recommended standard World Health Organisation (2006b) stroke definition is as follows:

A focal (or at times global) neurological impairment of sudden onset, and lasting more than 24 hours (or leading to death), and of presumed vascular origin.

This clinical definition has four components:

- A neurological impairment or deficit of
- Sudden onset, and
- Lasting more than 24 hours (or leading to death), and
- Of presumed vascular origin.

Symptoms should be of a presumed vascular origin and should include one or more of the following definite focal or global disturbances of the cerebral function:

- Unilateral or bilateral motor impairment (including lack of coordination)
- Unilateral or bilateral sensory impairment
- Aphasia/dysphasia (non-fluent speech)
- Hemianopia (half-sided impairment of visual fields)
- Forced gaze (conjugate deviation)
- Apraxia of acute onset
- Ataxia of acute onset
- Perception deficit of acute onset.

Appendix 2

Participant information sheet: People with stroke and their carers

English version

The Experience of Stroke - a participatory study.
 (Information for people who have had a stroke)

What is the purpose of this study?
The purpose of this study is to improve our understanding of the experience of having a stroke. We also want to understand the impact it has on your daily life and from whom you have sought help.

Why have I been chosen?
The best way to know the experience of having a stroke is to ask those who have had a stroke. We would like you to participate because you have had a stroke and your experiences and choices are critical to this process.

What are the benefits of taking part?
Guiding others through the experiences you have had makes the impact of stroke clearer. Understanding how stroke has affected you and what you chose to do and why can help plan future service needs. There may, however, be no direct benefit to you if you participate.

What would my participation involve?
As a participant in this research you will be requested to participate in the following;
- Initial discussions to plan the interviews.
- Interviews on more than one occasion where the researcher will ask you to talk about your experience with stroke. Interviews can last from 1-2 hours. It is expected you will not be interviewed more than 4 times.
- The interviews may include the use of photographs which you will take or other participatory techniques, like keeping a diary or drawing pictures. All the equipment and processing will be provided. You will be able to keep a full set of the photographs you take. Any training required will be provided by the researcher.
- The researcher may also, with permission, observe therapy sessions and your daily activities.

This research process will have no impact on any current therapy you are presently undertaking.

You will be asked to sign a form which states your agreement to participation. You will have the opportunity to ask any questions regarding the research prior to signing this form.

The interviews will be done in Bahasa Indonesian by the main researcher Meriel Norris. A translator may also be present. The interviews will take place at the location of your choice. Notes will be taken during the interview and a tape recorder may be used, but only with your permission.

The study will run from April to September 2007. You may not be involved throughout this period.

Will my taking part in this study be confidential?
All records and information relating to this study will be kept confidential and you will remain confidential in any reports that arise from the research. You will not be identified by name or by any other personal data. Any photographs will be altered so all identifying features are removed.

Who is conducting the research?
Meriel Norris is currently undertaking research for a PhD at Brunel University, London, UK. She is also working part-time for Handicap International. She has 13 years experience of working with people who have had a stroke.

Do I have to take part?
Your participation is entirely voluntary. While your contribution is very important, there may be reasons why you do not want to participate. Should you decide not to be involved, be assured that this will not have any negative impact on any therapy you are currently receiving. The same assurance holds if you agree to participate, but change your mind later. If you wish to participate in some aspects of the study and not others, this may be possible. This can be discussed with the researcher at the initial meeting or at any point during the study.

Further information.
If you have any questions or concerns at any point during this research you should contact Meriel Norris on …..(mobile telephone number) or at ……. HI address.

Bahasa Indonesia version

Pengalaman Stroke - Sebuah studi partisipatif
(informasi bagi orang yang menderita stroke)

Apa tujuan studi ini?
Tujuan studi ini adalah untuk meningkatkan pemahaman kita tentang pengalaman
menderita stroke. Kami juga ingin memahami dampak yang ditimbulkan dalam
kehidupan Anda sehari-hari dan dari siapa Anda telah mencari pertolongan.

Kenapa saya yang dipilih?
Cara terbaik untuk mengetahui pengalaman menderita stroke adalah dengan
menanyakan pada orang-orang yang menderita stroke. Kami mau Anda berpartisifasi
karena Anda menderita stroke and pengalaman Anda dan pilihan-pilihan Anda
penting untuk proses ini.

Apa keuntungan –keuntungan dengan ikut serta?
Membimbing yang lain melalui pengalaman-pengalaman yang telah Anda miliki,
membuat dampak stroke lebih jelas. Memahami bagaimana stroke mempengaruhi
Anda dan Apa yang Anda pilih untuk dilakukan dan mengapa dapat membantu
rencana kebutuhan-kebutuhan pelayanan ke depan. Bagaimana pun, ada manfaat
tidak langsung bagi Anda jika Anda berpartisifasi.

Partisifasi-partisifasi apa yang dilibatkan dari saya?
Sebagai seorang partisifan dalam penelitian ini, Anda akan diminta untuk
berpartisifasi dalam hal berikut;
- Diskusi-diskusi awal untuk merencanakan wawancara-wawancara.
- Wawancara-wawancara lebih dari satu kesempatan yang mana peneliti akan
  menanyakan pada Anda untuk berbicara tentang pengalaman Anda tentang
  stroke. Wawancara-wawancara bisa berlangsung dari 1 sampai 2 jam. Hal ini
  diharapkan agar Anda tidak akan diwawancarai lebih dari empat kali.
- Wawancara-wawancara boleh menyertakan penggunaan foto-foto yang akan
  Anda diambil atau teknik-teknik partisifatip lainnya, seperti menerima diari
  atau menggambar gambar-gambar. Semua peralatan dan prosesnya akan
  disediakan. Anda dapat menjaga satu set penuh foro-foto Anda yang diambil.
  Berbagai pelatihan yang diperlukan akan disediakan oleh peneliti.
- Peneliti boleh juga, dengan izin, mengamati sesi-sesi terapi dan aktivitas-
  aktivitas Anda sehari-hari.

Proses penelitian ini tidak akan berpengaruh terhadap berbagai bentuk terafi yang
sedang Anda tangani sekarang.

Anda akan diminta untuk menandatangani sebuah lembar yang menyatakan persetujuan Anda untuk berpartisifasi. Anda akan memiliki kesempatan untuk menanyakan berbagai pertanyaan-pertanyaan menyangkut prioritas riset untuk menandatangani lembar ini.

Wawancara-wawancara ini akan dilakukan dalam bahasa Indonesia dengan peneliti utama, Meriel Norris. Seorang penerjemah juga boleh hadir. Wawancara-wawancara akan berlangsung di lokasi pilihan Anda. Catatan-catatan akan diambil selama wawancara dan sebuah tape perekam boleh digunakan tapi hanya dengan dengan seizin Anda.

Studi ini akan berjalan dari April sampai September 2007. Anda mungkin tidak dilibatkan sepanjang masa tersebut.

Akankah keterlibatan saya dalam studi ini dirahasiakan?
Semua rekaman-rekaman dan informasi yang berhubungan dengan studi ini akan dijaga kerahasiaannya dan Anda akan tetap dirahasiakan dalam berbagai laporan-laporan yang muncul dari penelitian. Anda tidak akan diidentifikasi dengan nama atau dengan berbagai bentuk data pribadi lainnya. Bentuk foto-foto akan dirubah sehingga seluruh bentuk-bentuk identifikasi dikeluarkan.

Siapakah yang mengadakan riset?
Meriel Norris sekarang ini sedang melakukan penelitian untuk PhD di Universitas Brunel, London, UK. Dia juga berkerja paruh waktu untuk Handicap International. Dia memiliki pengalaman selama 13 tahun berkerja dengan orang yang menderita stroke.

Apakah saya harus ambil bagian?
Partisifasi Anda adalah semata-mata sukarela. Sementara kontribusi Anda sangat penting, boleh jadi, ada alasan-alasan, mengapa Anda tidak ingin berpartisifasi. Haruskah Anda memutuskan untuk tidak dilibatkan, yakinlah bahwa ini tidak akan berdampak pada bentuk terafi yang sendang Anda terima. Jaminan yang sama diperoleh jika Anda setuju untuk berpartisifasi, tapi ubah pikiran Anda kemudian. Jika Anda berharap untuk berpartisifasi dalam beberapa aspek-aspek dari studi ini dan bukan yang lain-lain, ini memungkinkan. Hal ini dapat didiskusikan dengan peneliti pada pertemuan awal atau saat hal apa pun selama studi.

Informasi lebih lanjut
Jika Anda memiliki pertanyaan-pertanyaan atau mengenai hal apa saja selama penelitian ini, Anda harus menghubungi Meriel Norris di 081360243326 atau di Jalan Lintang Kampung Kemili, Takengon, Aceh Tengah – 24552.

Appendix 3

Participant information sheet: Healers

English version

The Experience of Stroke - a participatory study.
 (Information for therapists and healers)

What is the purpose of this study?
The purpose of this study is to improve our understanding of the experience of having a stroke. We also want to understand the options people have for remediation after having a stroke; the therapies that are used and their benefit.

Why have I been chosen?
The best way to understand which therapies are used for people after stroke and their benefits is to ask those who work with people who have had a stroke. We would like you to participate because you work with people who have had a stroke and your experiences and choices are critical to this process.

What are the benefits of taking part?
Guiding others through the experience and expertise you have makes the therapeutic options after stroke clearer. Understanding how your activity benefits people who have had a stroke and why can help plan future service needs. There may, however, be no direct benefit to you if you participate.

What would my participation involve?
As a participant in this research you will be requested to participate in the following;
- Initial discussions to plan the interviews and observation.
- Interviews on more than one occasion where the researcher will ask you to talk about your experience with working with people who have had a stroke. Interviews can last from 1-2 hours. It is expected you will not be interviewed more than 4 times. These will occur at a time and place convenient to you.
- The researcher may also, with permission, observe therapy sessions you give to people who have had a stroke.
- You may be asked to participate in a group discussion on stroke care. This would occur at a time and place convenient to you.

This research process will have no impact on any current therapy you are presently giving.

You will be asked to sign a form which states your agreement to participation. You will have the opportunity to ask any questions regarding the research prior to signing this form.

The interviews will be done in Bahasa Indonesian by the main researcher Meriel Norris. A translator may also be present. The interviews will take place at the location of your choice. Notes will be taken during the interview and a tape recorder may be used, but only with your permission.

The study will run from April to September 2007. You may not be involved throughout this period.

Will my taking part in this study be confidential?
All records and information relating to this study will be kept confidential and you will remain confidential in any reports that arise from the research. You will not be identified by name or by any other personal data.

Who is conducting the research?
Meriel Norris is currently undertaking research for a PhD at Brunel University, London, UK. She is also working part-time for Handicap International. She has 13 years experience of working with people who have had a stroke.

Do I have to take part?
Your participation is entirely voluntary. While your contribution is very important, there may be reasons why you do not want to participate. Should you decide not to be involved, be assured that this will not have any negative impact. The same assurance holds if you agree to participate, but change your mind later. If you wish to participate in some aspects of the study and not others, this may be possible. This can be discussed with the researcher at the initial meeting or at any point during the study.

Further information.
If you have any questions or concerns at any point during this research you should contact Meriel Norris on …..(mobile telephone number) or at ……. HI address.

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Pengalaman Stroke - Sebuah studi partisipatif.
(informasi for therapists dan healer)

Apakah tujuan studi ini?
Tujuan studi ini adalah untuk meningkatkan pemahaman kita tentang pengalaman
menderita stroke. Kita juga ingin memahami pilihan-pilihan yang dimiliki orang
untuk remediasi setelah menderita sebuah stroke; terapi yang digunakan dan
keuntungannya.

Kenapa saya yang dipilih?
Cara terbaik untuk memahami terafi mana yang digunakan untuk orang setelah
menderita stroke dan keuntungan-keuntungannya adalah dengan bertanya pada
orang-orang yang berkerja dengan orang-orang yang menderita stroke. Kami mau
Anda untuk berpartisifasi karena Anda berkerja dengan orang yang menderita stroke
dan pengalaman-pengalaman Anda dan pilihan-pilihan Anda penting terhadap proses
ini.

Apa keuntungan-keuntungan dengan ikut serta?
Membimbing yang lain melalui pengalaman dan keahlian yang Anda miliki,
membuat pilihan-pilihan terafis setelah stroke lebih jelas. Memahami bagaimana
aktivitas-aktivitas Anda menguntungkan orang yang menderita stroke dan mengapa
dapat membantu kebutuhan-kebutuhan perencanaan pelayanan mendatang.
Bagaimana pun, ada mamfaat tidak langsung bagi Anda berpartisifasi.

Partisifasi-partisifasi apa yang dilibatkan dari saya?
Sebagai seorang partisifan dalam penelitian ini, Anda akan diminta untuk
berpartisifasi dalam hal berikut;
- Diskusi-diskusi awal untuk merencakan wawancara-wawancara dan observasi.
- Wawancara-wawancara lebih dari satu kesempatan dimana peneliti akan
  meminta Anda untuk berbicara tentang pengalaman Anda dengan orang yang
  menderita stroke. Wawancara-wawancara dapat berlangsung dari 1 sampai 2 jam.
  Diharapkan Anda tidak akan diwawancarai lebih dari empat kali. Wawancara ini
  akan terjadi di waktu dan tempat yang menyenangkan Anda.
- Peneliti boleh juga, dengan izin, mengamati sesi-sesi terafi yang Anda berikan
  kepada orang yang mengalami stroke.
- Anda dapat diminta untuk berpartisifasi dalam sebuah diskusi kelompok tentang
  penangan stroke. Ini akan terjadi pada waktu dan tempat yang menyenangkan
  Anda.

Proses penelitian ini tidak akan memiliki dampak pada berbagai bentuk terafi yang sedang Anda berikan.

Anda akan diminta untuk menandatangani sebuah lembar yang menerangkan persetujuan Anda untuk berpartisifasi. Anda akan memiliki kesempatan untuk bertanya berbagai pertanyaan prihal prioritas penelitian untuk menandatangani lembar ini.

Wawancara-wawancara akan dilakukan dalam bahasa Indonesia dengan peneliti utama, Meriel Norris. Seorang penerjemah dapat juga hadir. Wawancara akan berlangsung di lokasi yang Anda pilih. Catatan-catatan akan diambil selama wawancara dan sebuah tape perekam boleh digunakan namun hanya dengan izin Anda.

Studi akan berjalan dari April sampai September 2007. Anda mungkin tidak dilibatkan sepanjang periode ini.

Akankah keterlibatan saya dalam studi ini dirahasiakan?

Semua catatan-catatan dan informasi yang berhubungan terhadap studi ini akan dijaga kerahasiaannya dan Anda akan tetap dirahasiakan dalam berbagai laporan-laporan yang muncul dari penelitian. Anda tidak akan diidentifikasi dengan nama atau bentuk data pribadi lainnya.

Siapakah yang mengadakan penelitian?
Meriel Norris sedang mengadakan penelitian untuk gelar Ph.D di Universitas Brusel, UK. Dia juga sedang berkerja paruh waktu untuk Handicap International. Dia memiliki pengalaman selama 13 tahun berkerja dengan orang yang menderita stroke.

Apakah saya harus ambil bagian?
Partisifasi Anda semata-mata sukarela. Sementara kontribusi Anda sangat penting, mungkin ada alasan-alasan mengapa Anda tidak ingin untuk berpartisifasi. Haruskah Anda memutuskan untuk tidak terlibat, yakinlah bahwa penelitian ini tidak akan memiliki berbagai dampak negatif. Jaminan yang sama dipegang jika Anda setuju untuk berpartisifasi namun rubah pikiran Anda kemudian. Jika Anda menginginkan untuk berpartisifasi dalam beberapa aspek-aspek studi dan yang lain, ini barangkali memungkinkan. Ini dapat didiskusikan dengan peneliti pada pertemuan awal atau dalam berbagai hal selama studi.

Informasi lebih lanjut.
Bila Anda memiliki berbagai pertanyaan-pertanyaan atau mengenai berbagai hal selama penelitian ini, Anda harus menghubungi Meriel Norris di 081360243326 atau di Jln Lintang, Kemili, Takengon, Telp: 0643-23969

Appendix 4

Interview guideline: People with stroke

Name:
Date of interview:
Place of interview:
Who present:

The initial experience of having a stroke
- What did you notice happening?

- What did you think was happening to you?

- How did this make you feel?

The impact on life
- What impact if any did it have on your life?

- How did it have this impact?

- What was the most difficult thing for you?

Remediation/help seeking
- What did you do?

- Who did you go and see?

- Why did you go and see them?

- How did you make this decision to go and see them?

- Who was involved in that decision and what was their involvement?

- What did they do?

- Did it help?

- What did it help with?

- How did it help?

- Did you go and see anyone else?

Recovery
- What issues face you now?

- How do they affect your life?

- Can you do what you want to do?

- What does it mean for you to be 'better'?

- How do you propose to achieve that?

Appendix 5

Interview guideline: Healers

Name of healer:
Date of interview:
Place of interview:

What do you call the practice you undertake?

What kind of activities do you do?

How did you learn these activities?

How do these activities help?

Can you explain a little about how you understand people and why they are healthy/unhealthy?

How long have you been practising?

How much do you charge?

What impact do you think that has on your clients?

What kind of problems might you work with?

Which are you most effective at treating – why?

How do people know about you/contact you?

Do you see people in their houses or in your place?

What dictates this decision?

Who is involved in your treatments?

What kind of questions would you ask someone before you treat them?

Why do you ask those questions?

Do you know the term stroke?

What does it mean to you?

What do you think causes it?

What problems can it lead to?

Do you have any other words that you would describe these problems like weakness on one side of the body, speech problems…?

Do you ever treat people with stroke?

Can you explain a little about what you may do and why?

What do you hope to achieve by this treatment?

How long would you expect for these effects to occur?

Appendix 6

Consent forms: People with stroke

Interview consent form – English

<u>Consent form for interviews and observation</u>

The following questions for participants will be tape recorded in the event of verbal consent being required.

Interview Number:
Date:

Please tick the appropriate box

	YES	NO
Have you read or have read to you the Research Participant Information Sheet?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Have you received satisfactory answers to all your questions?	☐	☐

Who have you spoken to? _____

	YES	NO
Do you understand that you will not be referred to by name in any report concerning the study?	☐	☐

Do you understand that you are free to withdraw from the study:

	YES	NO
- **at any time**	☐	☐
- **without having to give a reason for withdrawing?**	☐	☐
- **without affecting your future care?**	☐	☐
Do you agree to take part in this study?	☐	☐
Do you agree for interviews to be audio-recorded and quotes to be used in publications related to this study?	☐	☐

<u>Signature of Research Participant:</u>

Date:

Name in capitals:	
Witness statement: Researcher	
I am satisfied that the above-named has given informed verbal consent.	
Researchers signature:	
Independent witness statement	
I am satisfied that the above-named has given informed verbal consent	
Witnesses signature:	

Interview consent form – Bahasa Indonesia

Lembar Persetujuan Untuk Wawancara-Wawancara & Observasi

Pertanyaan-pertanyaan berikut untuk partisifan, akan direkam meski izin lisan sudah dipenuhi.

Nomor wawancara:
Tanggal:

Beri (√) pada kotak yang tepat

	YA	TIDAK
Apakah Anda telah membaca atau dibacakan untuk Anda Lembar Informasi Partisifan Penelitian?	☐	☐
Apakah Anda memiliki kesempatan untuk menanyakan pertanyaan-pertanyaan dan mendiskusikan studi ini?	☐	☐
Apakah Anda mendapatkan jawaban yang memuaskan dari semua pertanyaan Anda? **Kepada siapa Anda membicarakan masalah ini?** _____	☐	☐
Apakah Anda mengerti bahwa Anda tidak akan dirujuk dengan nama dalam berbagai laporan menyangkut studi?	☐	☐
Apakah Anda mengerti bahwa Anda bebas untuk mengundurkan diri dari studi:		
- **kapan saja**	☐	☐
- **tanpa memberikan alasan pengunduran diri?**	☐	☐
- **tanpa mempengaruhi kerja Anda pada masa mendatang?**	☐	☐
Apakah Anda setuju untuk turut serta dalam studi ini?	☐	☐
Apakah Anda setuju agar wawancara-wawancara direkam dan kutipan-kutipannya digunakan dalam publikasi-publikasi yang terkait dengan studi ini?	☐	☐

Tanda tangan partisifan penelitian:

Tanggal:

Nama dengan huruf balok:

Pernyataan saksi: Peneliti

Saya puas bahwa nama diatas telah memberikan pemberitahuan izin lisan.
Tanda tangan peneliti:
Pernyataan independen saksi
Saya puas bahwa nama di atas telah memberikan pemberitahuan izin lisan
Tanda tangan saksi:

Photographs consent form – English

Consent form for photographs

The following questions for participants will be tape recorded in the event of verbal consent being required.

Date:

Please tick the appropriate box

YES   NO

Have you had an opportunity to ask questions and discuss the purpose of photographs in this study? ☐ ☐

Have you received satisfactory answers to all your questions? ☐ ☐

Who have you spoken to?

_____

Do you understand that your photographs may be used in publications for educational purposes, but you will not be referred to by name in any report concerning the study and all identifying features will be removed? ☐ ☐

Do you understand that you are free to stop taking photographs:

    at any time ☐ ☐

    without having to give a reason? ☐ ☐

    without affecting your participation in the study? ☐ ☐

    And having taken them, you may refuse to submit them for use in the study or for publication? ☐ ☐

Do you agree to take photographs as part of this study? ☐ ☐

Signature of Research Participant:

Name in capitals:

Witness statement

I am satisfied that the above-named has given informed verbal consent.
Researchers signature:

Photographs consent form – Bahasa Indonesia

Lembar Persetujuan Untuk Foto-Foto

Pertanyaan – pertanyaan berikut untuk fartisipan-fartisipan akan direkam meski izin lisan telah dipenuhi.

Tanggal:

Beri (√) pada kotak yang tepat

	YA	**TIDAK**
Apakah Anda memiliki kesempatan untuk menanyakan pertayaan dan diskusi tentang tujuan dari foto-foto dalam studi ini?	☐	☐
Apakah Anda telah mendapatkan jawaban-jawaban yang memuaskan terhadap pertanyaan-pertanyaan Anda? Kepada siapa Anda memebericarakan masalah ini? _____	☐	☐
Apakah Anda mengerti bahwa foto-foto mungkin digunakan dalam publikasi untuk tujuan-tujuan pendidikan namun Anda tidak akan dirujuk terhadap nama dalam berbagai laporan menyangkut studi dan semua bentuk-bentuk identifikasi akan dihilangkan?	☐	☐
Apakah Anda mengerti bahwa Anda bebas untuk menghentikan pengambilan foto-foto:		
kapan saja	☐	☐
tanpa memberikan sebuah alasan?	☐	☐
tanpa mempengaruhi partisifasi Anda dalam studi?	☐	☐
dan setelah diambil, Anda boleh menolak untuk memberikannya untuk digunakan dalam studi ini atau untuk publikasi?	☐	☐
Apakah Anda setuju untuk mengambil foto-foto sebagai bagian dari studi ini?	☐	☐

Tanda tangan fartisipan penelitian:

Nama dengan huruf balok:

Pernyataan saksi

Saya puas bahwa nama diatas telah memberikan pemberitahuan izin lisan.

Tanda tangan peneliti:

Appendix 7

Information sheet: photographs

English version

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Information sheet for photographs

Why am I being asked to take photographs?
Photographs help us see how stroke affects your life. It is an opportunity for you to think about which aspect of your life you most want to show and capture it.

How will the photographs be used?
The photographs are for use within the interview. They are part of the interview and help the discussion about how stroke affects you life.

The photographs may be used for educational purposes, but only with permission. Your name will never appear with the photograph.

Who will pay for the equipment and processing?
All the equipment and processing will be provided and paid for by the researcher. You will be able to keep a copy of the photographs you take.

What if I don't know how to use a camera?
The camera you will be using is very simple to use. You will also be given some basic instructions.

What pictures should I take?
The pictures you take should be your choice – the parts of your life that most represent your experience with stroke. The researcher will discuss this with you when you are given the camera.

What if I decide I don't want to take pictures?
Taking and using the photographs is entirely voluntary. At any point you can decide that you don't want to take or use the photographs you have taken. This will not impact on the rest of your participation in the research.

Further information
If you want any further information about the photographs contact Meriel Norris on (mobile telephone number) or (HI address).

Bahasa Indonesia version

Brunel
UNIVERSITY
WEST LONDON

Lembar informasi untuk foto-foto

Mengapa saya diminta untuk mengambil foto-foto?
Foto-foto membantu kami melihat, bagaimana stroke mempengaruhi hidup Anda. Ini merupakan sebuah kesempatan bagi Anda untuk memikirkan tentang aspek mana dari hidup Anda yang ingin Anda tunjukkan dan mengabadikannya.

Bagaimana foto-foto akan digunakan?
Foto-foto digunakan dalam wawancara. Foto tadi merupakan bagian dari wawancara dan membantu diskusi tentang bagaimana stroke mempengaruhi hidup Anda.

Foto-foto boleh digunakan untuk tujuan pendidikan namun hanya dengan izin. Nama Anda tidak akan pernah muncul bersama foto.

Siapa yang akan membayar untuk perlengkapan dan prosesnya?
Seluruh perlengkapan dan prosesnya akan disediakan dan dibayar oleh peneliti. Anda akan menerima sebuah salinan foto-foto yang Anda bawa.

Bagaimana jika saya tidak mengetahui bagaimana menggunakan sebuah kamera?
Kamera yang akan Anda gunakan sangat mudah digunakan. Anda juga akan diberikan beberapa perintah-perintah dasar.

Gambar – gambar apa yang harus saya ambil?
Gambar-gambar yang Anda ambil merupakan pilihan Anda – bagian-bagian hidup Anda, yang paling menunjukkan pengalaman Anda menderita stroke. Peneliti akan berdiskusi dengan Anda saat Anda diberikan kamera.

Bagaimana jika saya memutuskan tidak ingin untuk mengambil gambar-gambar?
Mengambil dan menggunakan foto-foto adalah sepenuhnya sukarela. Dalam berbagai hal, Anda dapat memutuskan tidak ingin untuk mengambil atau menggunakan foto-foto yang telah Anda ambil. Ini tidak akan mempengaruhi sisa partisifasi Anda dalam penelitian ini.

Informasi lebih lanjut
Jika Anda ingin berbagai informasi lebih lanjut tentang foto-foto, hubungi Meriel Norris di 081360243326 atau di jalan Lintang, Kemili, Takengon, Telp: 0643-23969

Guidance for photographs

You are able to take 27 photographs with this camera. Please take images that are important to your life now. You can choose what you would like to photograph. Some examples may include;

- What makes you happy
- What makes you sad
- A good thing about your life
- A difficulty in your life
- An image of what stroke means to you
- Activities you do
- Activities you can't do, but would like to.
- Someone who is important to you
- A place that is important to you.

Appendix 8

Focus group guidelines

Please write down your definition of stroke?

Please share that definition with the group.

What other definitions are you aware of – local explanations?

What other words do people use to describe stroke – professional and lay?

What problems can stroke cause?

Which of these problems are physios involved in treating – directly or indirectly?

What methods do physios use to work on these problems?

How much can people with stroke recover?

How does recovery occur?

How long after a stroke is it best to treat? Why?

What do you like about treating people with a stroke?

What problems do you face as a therapist working with stroke?

Which other conditions is stroke related to?

What is the relationship?

Appendix 9

Biodata form: healers

Name   :

Age   :

Gender   :

Year of Graduation :

Working Area   :

Work Experience with Stroke:

Self confidence in working with stroke (please mark a line on the scale):

Very confident   Not confident

Trainings on stroke attended:

Definition of stroke (please write own definition here. This will be discussed in the focus group):

Appendix 10

Vignettes

Vignette 1

You have been asked to see a 65yr old widow who woke up 3 days ago unable to speak or get out of bed. Her children took her to the hospital where she given an injection and infusion, but she has not improved. She cannot move the right side of her body at all and her speech is very unclear. She is unable to sit without support from two of her children.

- What sorts of conditions do you see that present with these types of symptoms?

- What usually causes these types of symptoms and how do they cause these symptoms?

- What type of information would you normally ask her or her children to share with you?

- Why would you ask for that information? How does it help you as a healer?

- Would you try to help her?
- If yes, how? What would you do?

- How do you think these activities would help her?

- If no, what prevents you from helping her?

- Would you expect her to improve?
- If yes, how quickly and why?

Vignette 2

A 45 year old government office worker was taken ill in the office. He had a bad headache and his vision became blurred. When he stood up he found it difficult to balance and he kept falling over. His arms and legs are not weak, but he finds it difficult to coordinate his movements. He is unable to write and he knocks over the glass when he takes a drink.

- What sorts of conditions do you see that present with these types of symptoms?

- What usually causes these types of symptoms and how do they cause these symptoms?

- What type of information would you normally ask him or his family to share with you?

- Why would you ask for that information? How does it help you as a healer?

- Would you try to help him?
- If yes, how? What would you do?

- How do you think these activities would help him?

- If no, what prevents you from helping him?

- Would you expect him to improve?
- If yes, how quickly and why?

Vignette 3

A 32 year old farmer has come to see you. He collapsed in the plantation two weeks ago and since then he has some weakness in his left arm and leg. He is able to walk, but limps and is unable to work easily on the farm because his left arm is weak and heavy. He also feels tired quickly. He lives with his wife, 2 children and his mother.

- What sorts of conditions do you see that present with these types of symptoms?

- What usually causes these types of symptoms and how do they cause these symptoms?

- What type of information would you normally ask him or his family to share with you?

- Why would you ask for that information? How does it help you as a healer?

- Would you try to help him?
- If yes, how? What would you do?

- How do you think these activities would help him?

- If no, what prevents you from helping him?

- Would you expect him to improve?
- If yes, how quickly and why?

Appendix 11

Glossary of Indonesian terms

Adzan – call to prayer
Akal - reasoning
Angin duduk – sitting air
ASKES/ASKESKIN – medical insurance policy for government employees and the poor
Batak – ethnic group based mainly in north Sumatra
Bekam – cupping treatment, either with fire or sucking
Bidan - midwife
Bidan Desa – village midwife
Camat – government associated community leader
Darah Tinggi – high blood pressure
Das Wisma – women and children's welfare leader
Dinas Kesehatan – health department of government
Dinas Sosial – social department of government
Djinn - spirit
Dukun – person who has mastered the traditional art of healing
Gayo – ethnic group based mainly in central Aceh
Hati - liver
Hati yang paling dalam – bottom of my heart
Himpunan Peduli Stroke – organisation for stroke based in Jakarta
Hypertensi – hypertension/ high blood pressure
Ikatan Fisioterapi Indonesia – Indonesian Physiotherapy Association
Ikatan Terapi Wicara Indonesia – Indonesian Speech Therapy Association
Imam – Islamic religious leader
Jamu – traditional Indonesian herbal/root based medication
Jerok purut – sour fruit used in traditional spirit capture
Jilbab – head scarf worn by Muslim women, covers hair and neck
Karang taruna – youth leader
Karo – ethnic group based mainly in North Sumatra
Kebun - plantation
Kejurun – farming ritual leader
Kekasih hati - sweetheart
Kenduri – ritual meal
Linmas – community security leader
Mangkur – sour fruit used in traditional spirit capture
Mantri – male nurse
Maripet – use of powerful imagination used within traditional Gayonese healing
Masuk angin – the air has entered, a category of illness
Mati badan sebelah – half body weakness, hemiplegia
Menasah – small local prayer house
Moxi – healing technique using heat on the skin
Patah hati – broken heart
Pening – dizziness, tension or stress
Perawatan – nurse

Perhimpunan Dokter Spesialis Saraf – Association of Doctors Specialist in Neurology
Pijet – pinching or squeezing massage
Polindes – very small health centre exclusively for midwifery services
Posyandu – small health care centre
Puasa – meal to break fast in Ramadan
Pusing – dizziness, tension or stress
Puskesmas – Primary health care centre
Puskesmas Keliling – mobile health service
Puskesmas Pembantu – subsidiary health care centre
Pustu – small health post
Qi – Chinese concept for vital energy force
Qur'an – Koran, the holy book of Islam
Rajah - spells
Ruqah – Islamic healing tradition
Sarakopat – cultural leader
Satay – barbequed skewered and marinated meat
Selendang – head scarf worn by women, more informal than jilbab
Shalat - prayer
Silat – martial art of Indonesia/ Malaysia
Slamatan – ritual meal
Sunnah – manner or deeds of Mohammad, sometimes linked with the *Hadith*
Surah – a chapter of the *Qur'an*
Syariah – Sharia – Islamic religious law as extracted from the *Qur'an* and *Sunnah*
Syukuran – ritual meal
Tentara Nasional Indonesia – Indonesian army
Totok – powerful energy force with ability to diagnose and heal illness
Tukang urut - masseur
Urut – massage
Yastroki – Indonesian stroke association
Wudhu – ablutions prior to Muslim prayer

Appendix 12

Abbreviated terms

ADL -   Activities of Daily Living
BRR -   Badan Rehabilitasi dan Reconstuksi/ Bureau of Reconstruction and
             Rehabilitation
EBP -   Evidence Based Practice
GAM -   Gerakan Aceh Merdeka. Free Aceh Movement
HI -   Handicap International
IDR -   Indonesian Rupiah
IFI -   Ikatan Fisioterapi Indonesia/ Indonesian Physiotherapy Association
IKATWI -   Ikatan Terapi Wicara Indonesia/ Speech Therapy Association of
             Indonesia
IOTA -   Indonesian Occupational Therapy Association
MoU -   Memorandum of Understanding
NAD -   Nanggroe Aceh Darussalam
OT -   Occupational Therapy
PHC -   Primary Health Care
PHO -   Provincial Health Office
PT -   Physiotherapy
PwD -   Person with Disability
RCP -   Royal College of Physicians
ST -   Speech Therapy
TIA -   Transient Ischaemic Attack
TCM -   Traditional Chinese Medicine
TNI -   Tentara Nasional Indonesia/ Indonesian Army
WCPT -   World Confederation of Physical Therapy
WHO -   World Health Organisation

Appendix 13

Handicap International

Handicap International and their work

Handicap International (HI) is a non-governmental, non-religious, non-political and non-profit making organisation focusing on issues related to disability. HI initiated their work in Aceh in early 2005 as part of the post Indian Ocean tsunami response. With the signing of the Memorandum of Understanding that finally ended the 30 year Acehnese conflict, HI extended their work to the central highlands region and have been working there since 2006. At the time of the research Handicap International was one of five international organisations assisting in this re-development in the area of study coordinated by the BRR (*Badan Rehabilitasi dan Rekonstruksi*/ Bureau of Reconstruction and Rehabilitation). Of the others, only one, MDM Holland (Medicine du Monde, Nederland) was working in the field of health service delivery, but focussed on prevention of disease (mainly communicable) and other than one village, did not work in the same communities as Handicap International[33].

The work of HI in the region had a number of clear objectives. The first was to collect data regarding the number and types of disabilities in the area. This was achieved by trained community workers screening individuals identified as potentially having a disability through a number of local networks. This included the local *Puskesmas*, *Camat* (government associated community leader) and other community leaders such as the Imam (religious leader). Follow-up of information received by members of the communities was also conducted. The second objective was to provide appropriate physical rehabilitation to persons with disability in the region. This was achieved through the direct intervention of physiotherapy and delivery of mobility and other aids both within the *Puskesmas* and through home visits. When physiotherapists were already employed in the *Puskesmas*, HI staff worked alongside their government colleagues, giving professional support as

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[33] GTZ Germany was working on health systems management, IOM focussed on community reintegration, MDM had already closed the mental health screening programme they had initiated and ICRC had completed their needs assessment and had withdrawn from the area.

required. The physiotherapists employed at the Puskesmas had previously been acting in other capacities. For example, one had been maintaining the administration of ASKES and another supported the nurses in dispensing medication. As most had not been acting as a physiotherapist they were unconfident of their skills to work with persons with disabilities. A third aim was to increase the capacity of government employed staff to meet the needs of persons with disability. This was achieved by improving the infrastructure of rehabilitation in the *Puskesmas* and hospital and through training, both in screening and treatment of disabilities. This training was undertaken by national and international therapists. Other activities included community sensitisation to disability issues, livelihood support and specific accessibility needs. Some of these activities occurred in conjunction with local organisations. In 2007 two local non-governmental organisations were actively involved in working with disabilities, Yayasan Gemasih Karya Ni Cut and Yayasan Himpunang Penyendang Cacat, were classed as Disabled People's Organisations (DPO's). Run by local personnel and partially supported by the local government offices, their activities were exclusively in the realm of livelihood. Their aims were to teach specific skills to persons with disabilities as well as income generation as a means to sustain the organisational activities. Their primary interests were in tailoring and mechanical repair respectively. They provided no physical rehabilitation and none of their members had had a stroke.

Partnership with Handicap International (HI)

Prior to undertaking this specific research on stroke, I had worked with Handicap International in Indonesia on two previous occasions. In 2005, following the Tsunami I had managed an outreach programme targeting people with disabilities both directly and indirectly affected by the Tsunami. This work, which covered large areas of Aceh Besar and Aceh Barat, had involved significant interaction with persons with disabilities in the community. Indeed, it was this experience that had alerted me to the considerable number of people who had a stroke in the region and the complexities of therapeutic interventions in such a pluralistic and political health arena. The role also required a close interaction with the government bodies with whom we worked. Relationships and negotiations of activities were forged with provincial and district health officers, staff in the *Puskesmas*, hospital, local community leaders and healers. The following year, I returned to Indonesia

following the earthquake in central Java. This role included coordinating the rehabilitation response to people who had suffered traumatic amputations and spinal cord injuries and significantly, on behalf of HI, chairing the hospital and rehabilitation stream of the UN coordination meeting. These meetings which included the governmental and non-governmental sectors, national and international, facilitated insightful observations into the financial aspects of care and the challenges of accessibility to longer term rehabilitation. The context of Java also highlighted the similarities and differences to care and potential resources when compared with Aceh. These experiences have acted as both the drive to understand the experience of longer term disabling conditions in Indonesia and the grounding for a contextualised view. As such, although information from the previous visits is not expressly utilised in this research, the understandings I gained through those experiences is relevant to the research design and my interactions in the field and with the data.

The previous roles with Handicap International (HI) also allowed for the collaboration that occurred in this research. It was fortuitous that having decided to conduct my research in Indonesia, a post was available within HI that complemented my research agenda. As a result, the fieldwork and data gathering for this research occurred while I was employed as the site manager for HI Takengon. This collaboration had a number of advantages that are expanded upon shortly. The data collection upon which the details of this thesis are based, occurred in specifically over a 6 month period in 2007 with a follow-up visit for one month in 2008.

Advantages of the collaboration
Permission
There were a number of advantages of the collaboration with HI. Firstly HI already had permission to work in the region. Both from a Memorandum of Understanding (MOU) signed at a national level and local agreements with the Departments of Health (*Dinas Kesehatan*) and Social Departments (*Dinas Sosial*) in both Aceh Tengah and Bener Meriah. After discussions with the relevant authorities, it was agreed that this research came under the agreements previously signed and therefore new agreements or registration were not required. More locally, HI was well known in the district hospital, the Primary Health Care Centres (*Puskesmas*) and by sub-district and village leaders. It is culturally appropriate that permission to work in the

locality would be sought from all official and unofficial community leaders. Given my connection with HI, all did so willingly.

It is likely that permission would have been given for this activity without HI's involvement, but there is no doubt that my association with an organisation that was respected locally for their work with disability was a clear advantage and smoothed my path considerably. Personally it was also to my advantage that I had worked previously in Indonesia and specifically in Aceh. My knowledge of the history of the region and respect of their cultural rules, including who I needed to seek permission from, were noted favourably.

Not insignificant, my association with HI and more specifically their medical and security cover, assisted greatly with my ethical clearance from the university. While the peace agreement in Aceh was signed in 2005, it is still considered a post-conflict area. It is also in the heart of a very active earthquake zone and an area endemic for malaria and dengue. These are all things that make University insurers nervous. However, knowing that I was suitably covered by medication, security procedures, evacuation policies and insurance to cover any untoward circumstance eased their minds sufficiently to allow my research to proceed. These are factors that are rarely considered in the initial planning of research, but pose real dilemmas for the independent researcher.

Resources

Without doubt, having access to the human and other resources of HI's activities was invaluable. In a province that has no database on people who have had a stroke, having access to the data of the people with stroke that HI had already identified in the region was a distinct advantage. As a result, I was able to access information on 139 people with presumed stroke, including their ages and ability to talk, which immediately allowed me to initiate the recruitment process, which is explained in the following chapter. Also, within the team I managed were a number of human resources; including community workers, therapists and a logistician, all of whom could potentially act as information sources (diagram 22).
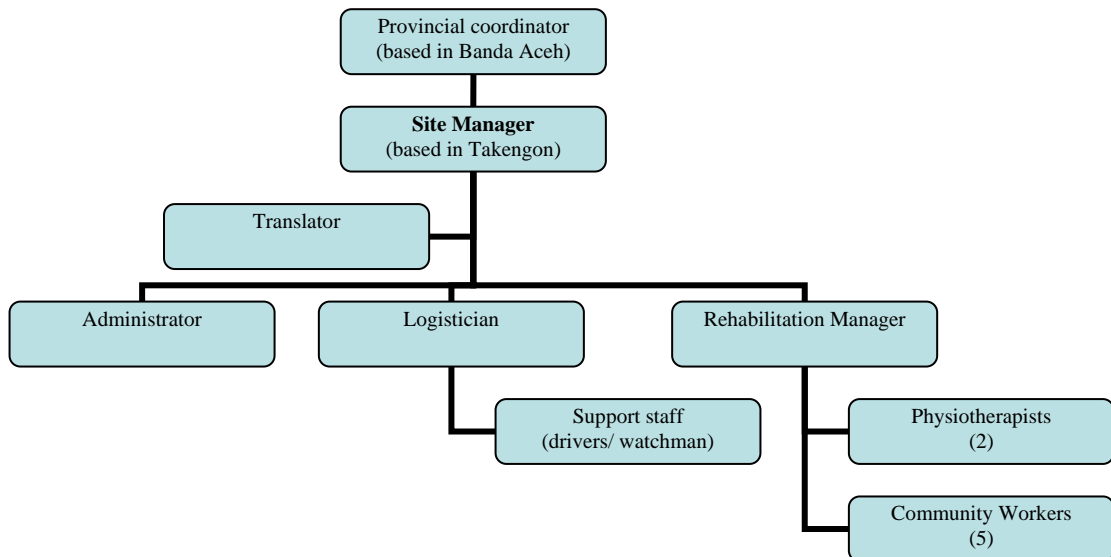
Diagram 22 Organisational chart of HI Takengon team.

While traditional healers had not been identified formally by the HI Community Workers, their knowledge of the communities and their contacts there, helped considerably in locating people mentioned by the participants with stroke in the snowballing process.

Access to broader scope of disability issues

My work with HI allowed close contact with many people with disabilities other than those with stroke and people who had had a stroke but did not meet the inclusion criteria of the study. That allowed a contextual view I may not have gained if solely focussed on my research. I also had reason to meet the other stakeholders in the disability field in the area, gaining better understanding of the governmental and local non-governmental organisations response to disability. The result, as I see it now is simply a *different* piece of research then that which would have resulted from a sole stroke focus.

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