

"My arm and leg- they are just sleeping"
Perspectives of younger people on their
experience of having a stroke

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Declaration

I hereby declare that this thesis has been composed by myself and that the research on which it reports is my own work.

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Abstract

Having a stroke at a younger age has been described as a complex experience that raises specific issues and related service needs, mainly to do with child care, employment and social life. However, there has been little research into how younger people define what a stroke means for them personally and socially and how they live with it in the long term. This study aims to capture the experience of having had a stroke in people under fifty-five during the first year after their stroke. The purpose is to develop an understanding of the experience and to make this knowledge useful - for other people with this illness, for health care in general - and nursing in particular.

An approach within the interpretivist tradition informed by Gadamer's philosophical hermeneutics was adopted to explore and interpret participants' experience. Data was obtained from semi-structured interviews with eleven participants at three-, six- and twelve-month periods after the stroke.

The study findings suggest that a stroke can be seen as a disruption of two main areas: time and being normal.

The life-times of these younger people are separated into pre- and post-stroke lives by the stroke. People who suffer it appraise pre-stroke values and beliefs and attempt to translate new insights into their post-stroke life; the stroke can thus be described as a turning point. It leads people to become conscious of the unpredictability of life and of their vulnerability and mortality. Along with this, stroke also leads to a disruption of the feeling of ontological security. There is also a tendency for shifts in time perspectives over this post-stroke year, from an orientation towards the pre-stroke life and towards regaining the pre-stroke status (three months afterwards), to a focus on current problems and also on the relevance of new insights (six months afterwards) and further on to an emphasis on 'closing the chapter' and looking into the future (one year afterwards).

Having a stroke at a younger age means taking an enforced break from the normality of life. On an individual level this means being given time to rethink priorities and to compare abilities before and after the stroke. Socially it means suffering from an old person's disease at an unusually young age. Norms of being young and healthy which are violated as a result can lead to feelings of stigma. Other people's reactions are appraised in the light of this feeling of abnormality.

The work environment provides a place of particular importance for those who are able to return to employment to appraise the post-stroke self and abilities and to compare these with their previous equivalents. However, coping with the tension created by stress at work, the fear of getting another stroke and the desire to be seen as normal and not as someone after stroke can be a difficult and lonely task.

The disruption of the feeling of security demands explanations as to why the stroke happened and how to prevent another one. The disruption of normality demands explanations that can legitimise this abnormal illness and the changes it brings to the outside world. The extent to which people manage this disruption and arrive at an acceptance of themselves as people post-stroke is highly individual. As simple as it sounds, accounts suggest that it is most helpful for participants if they are treated as normal and as the younger people they see themselves to be and not as people who have had a stroke. This thesis describes the disruptive nature of having a stroke at a younger age; but also the unique response of each individual to this experience. The findings provide an evidence base for sensitive and individualised assessment of needs and the planning of services to best assist these people in coming to terms with their illness.

Introduction

Young people are increasingly becoming the focus of advertising campaigns on health. Magazines feature advice on preventing skin cancer, comedians promote awareness of prostate cancer, television adverts target the stigma of mental health problems and buses carry advice on healthy eating. Information about stroke is also widely available - newspapers, leaflets, posters and radio and television broadcasts inform the public about risk factors, symptoms, treatment options and care issues. Newspaper articles on aphasia are also becoming more common: "I can think, but I can't bloody say it" (The Times, 27 August 2003) or "When it's hard to speak your mind" (The Observer, 9 February 2003) are just two examples from this year. Increasingly, younger people are the focus of attention in such articles. However, the idea that stroke is an older person's illness continues to dominate. This is accurate to an extent - in 2000/2001, 77% of people admitted to hospital in Scotland following a stroke were aged sixty-five or over (Banks et al., 2002), but that still leaves a group of over 20% who were *under* sixty-five. This 'old person's illness' also affects younger people.

Percentages of younger people with stroke differ greatly. One study found that 4.8% of all people admitted to hospital with ischaemic stroke were under the age of forty-five (Leys et al., 2002). Another gives the percentage of younger people in rehabilitation who were under fifty years of age as 15% (Teasell et al., 2000). Younger people have better chances of survival than older people which causes an increase in the percentage present in rehabilitation centres (Anderson, 1992). In the university hospital in Germany where contact with participants for this study was established, the percentage of people under fifty-five years during the time of data collection was high, accounting for 21.06% of the total number of people with ischaemic stroke. One explanation for this high figure is the fact that older people are more likely to be treated in local hospitals whilst younger people are treated in specialised stroke units, such as the university hospital.

Numbers do not convey anything about what it is like for these younger people to suffer from what is thought of as an old person's disease. It has been acknowledged that younger people's issues after a stroke may differ from older people's. Child care

issues and role changes might be more dramatic for a person in the working process than for older people (Tully Farzan, 1991). Although younger people usually regain more (measurable) functional abilities than older people, they might perceive the decline of mobility as more drastic and give up more of their social activities (Anderson, 1992). Interesting as these statements are, they are all *about* younger people's experiences, not *from* the younger people themselves.

In recent years younger people after stroke have slowly started to appear in the public sphere and have their voices heard. This has resulted in the development of the organisation '*different Strokes*', a charity set up by younger people after stroke in the UK, which is very active in pointing to the specific and undervalued needs of younger people after stroke:

Recovery and rehabilitation from stroke present particular challenges for the younger survivor. One day fit and well, the next moment disabled. The stroke survivor must come to terms with physical and emotional changes as well as significant lifestyle adjustments- mobility, job, income, dependence, relationships - everything changes. With 90% of strokes affecting those aged over fifty-five, current provision inevitably focuses attention on the older stroke survivor. The specific and complex needs of the younger and the more active stroke survivor have not received the full attention that they deserve. (*different Strokes*, 2002)

In Germany the "Deutsche Schlaganfall-Hilfe" (German equivalent to The Chest, Heart and Stroke Association) is acknowledging younger people and has started a campaign called "Young People and Stroke" with an emphasis on children after stroke.

An area where younger people do describe their experience of the stroke is autobiography. These stories are a signal to people "in the dark universe of ill health

that says 'you are not alone'" and to people who are well to tell them what happens when illness disrupts "lives we take for granted" (McCrum, 1998, cover notes). These autobiographies give witness to the journey after having had a stroke at a younger age.

Becoming a witness assumes a responsibility for telling what happened. The witness offers testimony to a truth that is generally unrecognized or suppressed. People who tell stories of illness are witnesses, turning illness into a moral responsibility. (Frank, 1995, p.137)

It is relatively easy to find media coverage of younger people who are willing to talk about their experience of a stroke. However, a far more thorough search is needed to find their stories in health care research and there are no investigations asking younger people openly what it is like for them to have had a stroke. Studies, if there are any, mostly focus on specific aspects such as work or service needs. Many are surveys, not narrative approaches and thus filter the experience by focusing on specific questions.

In nursing this is even more striking since studies about the experience of this client group are absent. Nursing care is based on available studies about older people's experience of having had a stroke. It focuses on physical aspects of care such as how to prevent spasticity and increase awareness of the affected side of the body (Booth, 1994), how to "relearn how to sit and transfer, walk, improve the sense of balance as well as improving the activities of daily living" (Kyriazis 1994, p.32) or addresses problems caused by immobility, bladder and bowel incontinence, dysphagia, perceptual impairments and sensory deficits (Tully Farzan 1991). However, Doolittle (1990, 1994) states that care for people after a stroke has to go beyond the restoration of lost function.

Therapy strategies which deal with the meaning of the stroke for the person, and which treat preferred activities and

personal concerns as paramount, best assist the person to experience progress post-stroke. (Doolittle 1990, p.106).

In order to achieve this goal, it is vital that people after a stroke have the chance to talk about their feelings and personal concerns. What is crucial are *their* goals for recovery and how *they* define their progress. Studies are needed to investigate this from the point of view of the person who suffers the stroke and to develop specific nursing interventions.

As someone who had a stroke at the age of thirty the topic of the study is of personal concern to me. As a nurse it struck me that I did not know of younger people having strokes and most of all, I had no idea how someone with a stroke felt, no matter what how old she or he was. The nursing literature about the experience of a stroke and of care after did not cover the issue from the perspective of younger people and I found it utterly irrelevant to my own experience. The discussion was entirely concerned with the effects of physical impairment in older people. Writings on stroke in younger people from other disciplines mostly described the stroke as highly problematic; medical writings were only on physiological processes and autobiographies written by younger people themselves were often success stories describing a difficult journey with a happy ending.

If nursing is to provide care that meets younger people's needs, then it must be concerned with what a stroke, ischaemic or haemorrhagic, means for these people in all aspects of human life and being. This implies that care has to move away from focusing on functional problems after stroke. Most likely it will have to include stories about the personal experience of health, illness and of health care, about structural aspects of service provision, as well as covering social issues as to how it is to live as a person with any kind of impairment. Since there is no knowledge base in nursing for this, an open approach is needed to allow people to express their experience in all the personally relevant aspects.

This research therefore aims specifically to develop an understanding of the experience of having an ischaemic stroke from the perspective of eleven people who

are under fifty-five years of age. The concentration on this age group reflects the desire to capture the experience of people who are likely to have been working, may be aiming to return to employment instead of taking early retirement and who may have dependent families. The focus on ischaemic strokes is because of the different aetiology, treatment and prognosis in ischaemic and haemorrhagic strokes, and thus the potentially different experience.

In order to capture the acute phase as well as different rehabilitation phases this study looks at the experience at three points within the first year post-stroke.

On terminology

Nursing literature on strokes talks about 'patients', 'survivors' or 'victims'. In psychological and sociological literature about strokes, the terms 'client' and 'patient' are commonly used. However, any specific term labels people as belonging to a group consisting of 'abnormal' members of society. This is because "language provides both the foundation of a shared cultural identity and the means for the reproduction of social difference" (De Bernardi, 1994, p.861). Furthermore, it "does not reflect 'reality', it *creates* it." (Annandale, 1998, p.46) From this point of view using specific terms when talking about people who had a stroke is not only discriminating but also stabilises or creates categorisations of normality and abnormality. To emphasise the importance of the language used, some terms commonly used to describe people who had a stroke (or any illness) will be defined briefly and the use of terminology in this respect throughout this thesis will be stated.

The term 'patient' "describes a person receiving or registered to receive medical treatment" (The Concise Oxford Dictionary 1995) and implies that he or she socially has the 'sick role' (Thompson et al., 1988). However, since this is only one of many roles of a person and might not be the most important, Conrad (1990) suggests speaking of "*sufferers* or 'people with...' rather than patients" (p.1260). For similar reasons, Frank (2000) suggests speaking of an 'ill' person.

A 'victim' is someone who is injured or killed, harmed or destroyed (The Concise Oxford Dictionary 1995). It indicates a passive and helpless position as opposed to an active and forward-looking outlook.

The stronger-sounding 'survivor' is often used as an alternative. It indicates someone who is still alive after going through an event. An argument against using this term in the context of stroke is that it focuses on the aspect of pure survival, whereas the goal of recovery for people who have had a stroke is to come to terms with the experience and possibly integrate it into their lives.

The term 'client' stands for a person who uses the services of a professional person, who is a customer. A client is also described as a 'dependant or hanger-on' (The Concise Oxford Dictionary 1995). The advantage of viewing a person who is ill as a customer or a consumer is that it raises the economic profile of this group and emphasises their importance for the health care market. However, at the same time it points to their dependency on this market, on health care workers and, at least in Germany, on health and care insurance policy.

Throughout this thesis I will talk about 'participants', 'people after a stroke' or a 'person' who has had a stroke. Whilst this sometimes sounds awkward, it includes three important aspects. Firstly, it allows someone who has had a stroke to be seen in the entirety of his or her personality and individuality. Secondly, it does not attribute a particular role in life, defined by illness, to this person. And finally it does not label the participants as 'abnormal'.

Although this study investigates the experience of having an ischaemic stroke and excludes people with haemorrhagic stroke, for the benefit of readability I will talk about younger people after stroke, not specifically after *ischaemic* stroke throughout this work.

On the use of Gadamer's work

This study is greatly influenced by Gadamer's philosophical thinking. As a native German speaker, I worked with the original writings and not with the translated versions. In the body of the thesis' text therefore I will refer to the original sources of Gadamer's work. However, to make these sources comprehensible to non-German-speaking readers I will give reference to the translated version whenever available in footnotes. This is the best way to remain true to Gadamer's thoughts on translation emphasised by the translators of "Wahrheit und Methode" (Truth and Method):

Gadamer teaches us that the idea of a perfect translation that could stand for all time is entirely illusory. Even apart from the inevitable mistakes that reflect limits of erudition or understanding, a translation must transpose a work from one time and cultural situation to another. (Gadamer, 1989, p.xi)

Bearing this in mind, I have used Gadamer's work for the specific situation and time of the study. If differences between my understanding and the translated version occurred, they will be commented on in connection with the reference in the footnote.

The structure of the thesis

After this introduction to the problem and the reflections on terminology and translation, Chapter I outlines and discusses the literature regarding issues about younger people after stroke. This experience is assumed to be influenced by many factors. Thus a biomedical perspective on stroke provides background to the differing and sometimes contradictory knowledge about causes, diagnosis, prognosis and treatment for this particular group of people. A discussion of care issues highlights the quality of services for younger people after stroke and the available knowledge – or rather, the lack of available knowledge – about nursing care for this group. The psychological perspective emphasises stroke as a crisis and is interesting in terms of coping with this. Then vocational issues are examined. The only specific writings on this topic are from the USA, all published in one issue of a journal that focused on this topic. Lastly, younger people's accounts as published in the media will outline concerns as seen from their perspective.

In Chapter II the conceptual framework of a theory of crisis and coping provided by Lazarus (1991, 1992, 1993, 2000) and of selected models of chronic illness are examined and provide an understanding of chronic illness on different levels. These psychological, sociological and anthropological writings provide grounds for a critical examination of whether having a stroke at a younger age precipitates a crisis

and whether it can be classified as chronic illness. A stroke is an unusual illness for younger people and thus it is assumed to raise issues of stigma. The issue of stigma and social exclusion and mechanisms related to this are explored. Whether illness is experienced within dualistic constructions of self and body or whether it extends beyond these categories is a matter of debate. In the last part of this chapter an alternative to this dualism, the *Leib*, is introduced.

Chapter III discusses the epistemological and ontological underpinnings of researching experience, in particular illness experience. It addresses methods employed and maps out the process of the investigation. Since this study is in keeping with Gadamer's framework of philosophical hermeneutics, core concepts from this school of thought relevant for this study are explained.

Chapters IV, V and VI present the findings of this study. Each of these chapters is structured according to the times of the conversations: they start by giving an account of specific aspects of the experience at three months after the stroke, moving on to issues described at six and then at twelve months after stroke.

In accordance with the data they focus on the impact of the stroke on the self: the self as an individual, in interaction with others and self and work.

Chapter IV captures effects of the experience for the individual. It explores how participants describe their confrontation with this life-threatening and potentially disabling illness. An account is given of how for many of them this led to a shift in priorities of their pre- as well as the post-stroke selves.

Since the self does not exist in a vacuum, but is in constant interaction with the environment, Chapter V gives an account of the experience in the light of this interaction, thereby focusing more on social and cultural aspects. Feelings of normality and abnormality are described at all points of investigation and are the main focus of the chapter.

Employment emerged as a central issue for younger people's feelings about themselves as well as their public identities. Therefore this issue is granted specific attention in Chapter VI. Employment issues took on increasing significance throughout the year. Thus accounts given explore issues connected with

employment, mainly to do with cultural meanings of participation or exclusion in a productive society of 'normal' younger people and the personal meaning of this. It is suggested that people have great difficulty dealing with issues of stigma and stress in the workplace.

The final chapter presents a discussion of the findings using relevant theoretical perspectives. Implications of the findings for younger people after stroke, for nursing care, education, politics and research are discussed. It explores the stroke as a disruption of participants' life-time, emphasising the temporal nature as well as the individuality of the experience. From this individual perspective emphasis is shifted towards social aspects of the stroke, exploring it as a disruption of the feeling of being normal in a society in which productiveness is highly valued. Mechanisms of social exclusion based on the work of Crawford (1984) and on stigma provide grounds for explaining participants' struggles with this issue. Furthermore the vicious circle of dealing with stress, trying to avoid another stroke and attempts to appear the same as before the stroke is described. The next part of the chapter emphasises the multidimensional nature of the experience of having a stroke and suggests that this illness affects people in their very being, in the dimensions of the *Leib*. The last part of this chapter reflects on the attempt to translate these insights into nursing and health care for these people, with an emphasis on practical implications. However, these implications can only be put into practice if nursing can receive the necessary resources and a supportive environment. Therefore concrete political concerns, areas for further research as well as implications for teaching are raised. The chapter ends by advocating a view of nursing according to the perspective of the *Leib*.

Chapter I:

Younger people and stroke

There have been a number of media reports recently concerning the increase in the number of people having a stroke at a young age. These reports take scant regard of the current medical views on this complex area. Experts in the field of stroke may well point out that the *awareness* of the incidence of stroke among younger people has greatly increased; they could also mention the improvements in diagnostic options, particularly CT scans that show even the smallest defects. But to report a sudden increase in the actual number of strokes suffered by young people is to misrepresent the situation.

This review investigates the body of literature about younger people after stroke from different perspectives. The search was done manually for journal articles and electronically searching databases CINAHL, Medline, BIDS, Science Direct and the library catalogue for English and German journals.

Looking at literature about stroke, the experience of having a stroke can be seen as being influenced by the following main aspects: biomedical knowledge; service provision and care; psychological aspects; and vocational circumstances. To reflect this, the literature review is structured into five main categories: articles which investigate biomedical knowledge about ischaemic stroke in younger people; studies that describe the quality and appropriateness of services and care; literature on a stroke from a psychological perspective; studies about return to work behaviour; and narrative descriptions written by people who have had a stroke.

1.1. A biomedical perspective

Since this study focuses on younger people with ischaemic stroke, the biomedical perspective will be limited to people with this type of stroke and this particular age. Although Warlow et al. (2001) state that "There is nothing very different about the young compared with the elderly ischaemic stroke or transient ischaemic attack patient" (p. 328), other authors suggest that incidence (Jacobs et al., 2002), aetiology (Camerlingo et al., 2000), causes (Munts et al., 1998, Kristensen et al., 1997),

outcome (Leys et al., 2002) and prognosis (Camerlingo et al., 2000) are different in younger people. Furthermore, it has been argued that this group is of particular interest for clinical research and policy because of the length of time they might live with their disability, as well as their proneness to medical complications. Jacobs et al. (2002) examine a further aspect: the potential costs for society following the loss of productivity among this group. In this thesis, biomedical aspects of stroke at a younger age will provide background knowledge about definition and symptoms, aetiology, causes, recurrence, outcome and management of stroke for this particular group of people. These are stated in turn.

1.1.1. Definition and symptoms of ischaemic stroke and TIA¹

Whilst the definition of stroke and TIA is not age-related, it is important to underpin this study by giving the biomedical definition of this cerebral illness. An ischaemic stroke is a "Focal cerebral ischaemia, caused by acute occlusion of a cerebral blood vessel or sometimes just by low blood flow" (Warlow et al., 2001, p.442). As a result of this, two processes occur: vascular, haematological or cardiac events cause a reduction in blood flow; then changes in cellular chemistry, caused by ischaemia, lead to necrosis of brain cells. The occlusion is usually caused by a thrombus or embolus. Approximately six hours after the occurrence brain cells are irreversibly damaged (Warlow et al., 2001).

If the same process occurs but lasts for less than twenty-four hours, they are usually called 'transient ischaemic attacks' or TIAs. According to Warlow et al. (2001), most TIAs are characterised by symptoms that last for minutes, rather than hours. Functional modalities affected by the ischaemic stroke or TIA² can be related to consciousness; to higher cerebral function regarding attention, concentration, memory, speech and language; to motor function; to disturbances of sensation, for example feelings of pins and needles; of visual function and hearing; of balance and co-ordination (Warlow et al., 2001) and finally to neuropsychiatric problems (Robinson, 1998). This author describes several mood disorders such as anosgnosia

¹ Transient ischaemic attack

² Warlow et al. (2001) suggest that there might be value in using the term "brain attack" for both forms of cerebral infarction (p.34)

(the absence of recognition), catastrophic reaction (frustration, depression, embarrassment), indifferent reaction (towards failure, lack of interest in family and friends, inappropriate jokes), pathological laughter and crying, emotional withdrawal or hallucinations as all related to brain injury. However, there has been little understanding of how these disorders occur, historically as well as in recent studies. There is also disagreement as to whether they are caused by the injury and brain damage or by the strain that the illness puts on people.

Three subtypes of ischaemic stroke and their mechanisms have been identified: the atherosclerotic ischaemic stroke due to atherosclerotic plaque which occludes the lumen of cerebral arteries; lacunar strokes caused by a thrombosis of small arteries; and cardiogenic embolic strokes caused by cardiogenic emboli (Habel, 1997).

Having defined an ischaemic stroke or TIA in a younger person and located the brain defect caused by the ischaemia, the clinical interest now is to define the cause of the ischaemia. This issue is of major biomedical interest, reflected in the number of studies investigating potential causes of ischaemic stroke in younger people.

1.1.2. Risk factors and causes

Conditions that are seen as risk factors for stroke, such as age, sex, blood pressure, smoking, blood lipids, alcohol, race, social deprivation, stress and others (Warlow et al., 2001) are often studied as aetiological factors for stroke in younger people. However, whether the relationship between a particular risk factor, for example, stress, is causal and if so, what stroke mechanism leads to this, is hotly debated. Whilst ischaemic stroke among elderly persons are mostly attributed to arteriosclerosis or embolism, conditions that contribute to the occurrence of a stroke in the younger age group are much more diverse (Munts et al., 1998). Various probable causes for ischaemic stroke in young people have been described, such as cardiogenic embolism (Martin et al., 1997) and arteriosclerosis (Albert, 1995); contraceptives (Albert, 1995, Heinemann et al., 1997, Warlow et al., 2001) or coagulation disorders (Munts et al., 1998); migraine (Albert, 1995, Warlow et al., 2001, Lamy et al., 2002); pregnancy and the puerperium (Warlow et al., 2001) or high blood pressure in combination with psychosocial factors such as deprivation and stress (Everson et al., 2001). However, in terms of the causes of stroke, researchers

can agree on little more than the fact that these could all be causes for stroke in younger people.

The patent foramen ovale as a source for cardiac embolism has been of interest in Germany as a major cause for stroke in young people (see for example Albert, 1995). It has been studied intensely internationally, both as a risk factor and as a possible cause for 'cryptogenic strokes' (strokes without any other aetiological cause). As this issue receives a great deal of attention throughout the biomedical literature, particularly with regard to young people with strokes, it will be explored briefly here.

A patent foramen ovale (PFO) is defined as an "opening between the left and right atria (upper chambers) of the heart" that does not close directly after birth. In one estimate, it remains open in 20% of the normal population (Medline Plus Medical Encyclopedia, 2002). Since the prevalence of a PFO is higher in people with a cryptogenic stroke than in strokes with a definite cause, many authors agree that a PFO could be a cause for stroke in young people in the absence of other causes (Meier and Lock, 2003, Bogousslavsky et al., 1997, Lamy et al., 2002, Steiner et al., 1998) or in combination with other risk factors (Isayev et al., 2002; Lamy et al., 2002). However, they disagree over treatment of PFO. Whilst Bogousslavsky et al. (1997) recommend surgical closure of PFO in these young people, Homma et al. (1997) found that closure did not prevent future strokes. The controversy over PFO as a cause for the stroke seems also to be culturally determined - more studies outside the UK are concerned with this problem than those conducted in the UK. For example Warlow et al. (2001) regard PFO as one of many risk factors for stroke, but of no particular importance.

Considering the uncertainty regarding probable causes it is not surprising that the proportion of unexplained aetiology of strokes is high, ranging from 40% (Sacco et al., 1989) to 21% (Kristensen et al., 1997) or 17% (Albert, 1995). The exact figures depend on whether people with a TIA are included, on the diagnostic procedures and on the conditions that were defined as causes.

All these studies indicate that explanations of the aetiology of ischaemic stroke in younger people are complex and diverse, that many strokes remain unexplained and

that a single cause is very rarely identified. For individuals this means that they live in great uncertainty not only in terms of how to explain their strokes but also in terms of appropriate treatment and the prevention of future strokes.

1.1.3. Recurrence

Recurrence of stroke can be defined as "a sudden appearance of neurologic signs, lasting longer than twenty four hours, indicating different vascular territories or worsening of the neurological status after a period of stabilization or improvement." (Camerlingo et al., 2000, p.88) Whilst the overall figure for recurrence of an ischaemic stroke is 12% in the first year (Warlow et al., 2001, p.659), the probability of a second or third stroke for younger people is low, ranging from 1.4% during the first year to between 1.0% (Leys et al., 2002) or 2.26% (Camerlingo et al., 2000) in the following years. The causes of recurrent stroke are again fiercely debated. Whilst Leys et al. (2002) state that recurrence is not related to age, hypertension, diabetes or cardiac diseases in people aged between sixteen and forty-five, Warlow et al. (2001) and Ebrahim and Harwood (1999)³ state that age, diabetes mellitus, hypertension and various cardiac diseases are predictors of recurrent strokes. This difference may be explained by the fact that in younger people secondary problems due to these illnesses, such as damaged blood vessels, may be less severe. Despite this, the literature offers no clear line on the causes of recurrent stroke in younger people.

1.1.4. Prognosis: Survival and recovery

Studies which look at survival rates state that of those who die as a result of stroke, most people (4.5%) die within the first year after the stroke (Leys et al., 2002). On a more long-term scale, in Petty et al.'s study (2000) eight years, the mortality rate was found to be 2.2%. The authors of these age-related studies suggest that age, subtype of stroke, causes and time after the stroke are all indicators for survival. In the non-age related report of the Department of Health (1994), variations in geography, social class and country of birth have been identified as predictors for prognosis after stroke in the United Kingdom. Thus mortality rates were higher in the north of Britain, for

people from lower social classes and for people living in the Caribbean and African Commonwealth.

A further study points to the fact that the suicide rate amongst people under fifty following a stroke was three times that of the normal population of this age group (Teasdale and Engberg, 2001). In this study a group of people who were discharged after stroke between 1979 and 1993 were screened for causes of death. In the older age group suicide rates did not differ greatly amongst people who had had a stroke and those who had not. Apart from age as a determining factor, the authors state that the length of hospital stay and length of time after stroke both influence the suicide rate. Thus younger people with a short length of stay are of greatest risk of committing suicide in the first few years after the stroke. This study raises two important aspects: firstly, it emphasises the long-term impact of stroke on younger people, which is of particular importance as most studies restrict the time of investigation to the acute phase. Secondly, it demonstrates that social and psychological factors clearly need to be taken into account when investigating survival after stroke.

Outcome after stroke in younger people is measured with various foci. To give some examples, there are studies that measure the functional status according to stroke subtype (Naess et al., 2002); return to work (Wozniak et al., 1999, Camerlingo et al., 2000); focus on independence and residual symptoms (Leys et al., 2002); the ability to walk (Jackson et al., 2000) or speech impairment (Laska et al., 2001).

Whilst all these measures provide varying information about functional status, they all raise at least two important ethical and sociological questions. Firstly they come from an ideal that places functioning, including returning to work, at the centre of recovery. Thus one could argue that they reflect a modern ideal of recovery as a healthy productive individual (Crawford, 1984). Secondly all these studies describe goals as seen from the outside, leaving open whether or not these match the younger person's goals. The question is: are goals which influence assessment and planning of treatment defined by the people with a stroke or are they determined by others' interests?

³ These are non age-specific studies.

1.1.5. Assessment and treatment

"Whenever two or more doctors are asked to assess the same patient it is unlikely that they will agree completely on their clinical findings" (Ebrahim and Harwood, 1999, p. 81). This could also hold true for the assessment of a person with a stroke. Apart from non age-related information such as demographics, history of onset, risk factors, co-existing diseases, medication, social details, pre-stroke function, general examination and neurological examination (Warlow et al., 2001), only a few authors with biomedical backgrounds argue that young people with a stroke have specific age-related psychosocial problems. However, a quantitative Canadian study by Teasell et al. (2000) investigated social factors such as the primary caregiver, the presence or absence of children, separation from spouse, institutionalisation and return to work as well as psychological difficulties recorded by staff, in people under fifty with any type of stroke, using patients' records (n=563). They found social factors such as relationships with partners, but also anxieties about returning to work, child care issues and loss of independence all to be important factors for the assessment. Thus the authors emphasise the importance of addressing potential problems, "in particular marital relationships, return to work, and anxiety on the part of the patient and caregiver" (p.208). Although this study does give clear hints to relevant issues it does not investigate or state any relation between variables, for example whether the return to work was related to psychological difficulties. However, since clinical studies that focus on social issues of younger people after stroke are very rare, this study makes an important contribution.

Treatment of younger people with a stroke clearly focuses on the biomedical model of cause and effect, studying aetiology, prognosis and treatment. Since causes of stroke in younger people are complex and often remain unknown, it is not surprising that according to Warlow et al. (2001) treatment varies greatly between different countries and indeed within a country. The use of heparin is an example of this. The authors state that there is not sufficient evidence to justify either the use of heparin, or of anticoagulants or the use of thrombolysis. A further problem indicated in this literature review is whether or not PFO is defined as the cause for the stroke. This

has important consequences for the individual: it means heart surgery or life-long therapy with anticoagulants if it is seen as a cause and no treatment at all if it is not. This demonstrates Bury's (1997) view that whilst modern medical knowledge of a condition can help to reduce uncertainty, it can also highlight what is *not* known about a condition, thus increasing uncertainty. How do younger people deal with the lack of certainty about the cause for their stroke and by extension about the best way to prevent a relapse? How do they feel about taking medication or undergoing heart surgery if they are advised to do so? Are they confronted with different opinions regarding treatment and if so how do they perceive these? The debate on conflicting biomedical aspects reveals that subjective aspects are still neglected in the treatment of younger people after stroke.

Stroke in the young has received little attention from the scientific community, perhaps because the high incidence of stroke in the elderly overshadows the problem of early-onset stroke and because of the difficulty of conducting research in this population. (Kittner, 2002, p.6)

Kittner, as well as Teasell et al. (2000), argues that it is crucial to include issues psychosocial aspects such as child care, work and marital problems into the assessment of younger people after stroke.

If these are of concern for younger people after stroke the investigation of care provision for this particular group is believed to provide insight into services and gaps in service provision.

1.2. A care perspective

This literature review highlights the extent to which care after stroke is often concerned with older people and with the wider issue of service provision and appropriateness of services as seen from the participants' perspectives. The situation of younger people receives little attention by comparison. This contradicts Pound et al.'s (1998) criticisms that stroke is commonly represented by younger people in the

media and in literature as a devastating illness and that older people are underrepresented in sociological analysis and chronic illness. From the data gathered through interviewing the authors state that their older participants (40-87 years old) describe their stroke as "not that bad" (pp.495, 503). The authors point to the fact that a stroke can be an expected illness for older people, just another of many crisis situations that happen throughout the course of people's lives. By doing so they emphasise the importance of treating age not just as a 'confounding variable' but as an important factor for analysis of individual experience. Whilst it is true that there is a growing number of younger people's stories about their experiences of a stroke in English as well as German media and literature, this is not reflected in research into stroke care. Only a few studies with a focus on quality and on appropriateness of services for younger people can be described here.

1.2.1. Quality of services

Bendz (2000) questions whose rules of relevance determine the rehabilitation process. Data from interviews with ten participants (all under sixty five) in Sweden during the first three months after their strokes and from medical records, analysed by discourse analysis, reveals that the agenda is set by health care professionals, mainly doctors. The author criticises the fact that people after stroke are:

portrayed as fragmented male or female bodies of a certain age with certain impairments and dysfunction in medical records (p.713).

According to her, both participants and health care professionals focus on the ill body and its recovery. However, whilst participants define recovery as having fully regained their previous position as individuals, health care professionals focus on impairments and deficits in function. The author states that biomedical discourse and the role of the people after stroke does not provide space for anything other than biomedical needs. Thus the author points to the dominance of medical power over the individuals who have had a stroke. This important finding suggests that young

people are left to deal with concerns regarding the regaining of their pre-stroke abilities by themselves, with very little support coming from medical doctors.

It is often assumed that nursing fills this gap since it has been argued that stroke units provided 'advanced' nursing care (O'Connor, 1996). However, this assumption is questioned by Pound and Ebrahim's sociological study (2000). Although this study is not age-related, its findings are interesting here in terms of service provision for younger people. The authors report data from observations about the care provided for people after stroke in a stroke unit, a general medical ward and elderly care unit. Although the focus of this study is on *nurses* in stroke units, the findings are in accord with Benz' study in that the health care professionals focus on functional aspects of care and neglect interaction with individuals. On a more positive note, this care is more carer-focused, less institutional and provides more activities for people who have had strokes. The authors conclude critically that:

...it might be that the better physical outcomes on stroke units are being achieved at the expense of patient's emotional well-being and that patients on stroke units have better outcomes *despite* rather than *because* of the nursing they receive there.
(p.1445, italics in original)

Better care in terms of rehabilitation nursing, interdisciplinary teamwork and focus on the individual is provided in the elderly care unit. These findings indicate that people with stroke are best cared for in such units. However, as Banks et al., (2002) have shown, younger people often experience psychological stress as a result of being treated alongside elderly people. If this is warranted then it counters the fact that better care for younger people is available in elderly care units. From a nursing perspective, this is striking. Since data was obtained through observations in Pound et al.'s study, it does not deal with the issue of how participants would describe the care they received. It must be of utmost importance to investigate further what nursing was and was not helpful from participants' point of view and to develop appropriate services.

1.2.2. Needs and appropriateness of services for younger people after stroke

Stroke has been said to cause strong emotional and physical constraints on the person and his or her family (Banks et al., 2002, Brereton and Nolan, 2000, Anderson, 1992). However, since most services are geared towards the large number of elderly people, there needs to be more investigation into the experiences of younger people, their families and their needs for services (Banks et al., 2002).

In a national UK survey, Kersten et al. (2002) investigate long-term needs of more than 300 people younger than sixty five with ischaemic strokes (response rate 49%). Findings suggest that the need for increased therapy, particularly for respondents with poor mobility and no employment, has not been met. Gaps in service provision in terms of intellectual fulfilment, help with family issues and the need for a holiday are reported mainly by younger respondents (younger than 45 years). Moreover, 65% of people who worked before the stroke have had to give up work and another 14% have changed either their job or the hours they worked as a result of the stroke. Difficulties with their sex lives are reported by 64%. However, Korpelainen et al. (1999) describe post-stroke sexual dysfunction as a non age-specific issue.

Kersten et al.'s (2002) study clearly points to the constraints of stroke on younger people particularly with regard to employment and to partnerships and it suggests that needs are not being met, particularly those of younger people and of people with mobility and employment problems. The high number of people who have had to give up or change work due to the stroke points to the need for studies regarding vocational issues. This survey was limited to people who were living in community housing in the UK and thus findings might not be generalisable.

An older survey parallels some of these findings (Hartke and Brashler, 1994). This study, carried out by the Rehabilitation Institute stroke team in Chicago reports the needs of 100 people aged between 21-57 years and compares them with medical doctors' perspectives. Participants were asked to rank their needs and to comment on them. In addition, some took part in a focus group meeting. Of all participants, only 27% were employed (including people attending university/college). Ratings of needs varied according to physical functioning. All participants rated the need for exercise or fitness programs highest, followed by educational programs, counselling,

stress and social programs. People with high physical functioning (approximately 70%) rated vocational training higher but others with lower function voted for more family counselling. In contrast to this, medical doctors valued educational programs and counselling as well as sexual adjustment, parenting and interpersonal relationships more highly. The last three had no priority for the young people with stroke at all. The authors do point to the potential divergence in service priorities as estimated by professionals compared with the perspective of younger people after stroke. For example child-care and parenting issues were given lowest priority by the younger people. This study makes it clear that younger people's needs must be investigated individually and not stereotyped to any one particular group. This is an important finding, although there are some limitations to the study. Firstly data was not adjusted for time although the length of time since participants' strokes varied greatly and was between one and twenty-one years. Needs are likely to change over time and thus might not be comparable. A second limitation is that the needs suggested in the survey might be different from the needs participants would have reported in a more open approach. No information is given as to whether this manipulative effect was acknowledged or compensated for in the focus group meeting.

Younger people who participate in stroke groups have been the focus of investigation in Oehring and Oakley's study (1994, p.34). Using questionnaires which were followed up by telephone and face to face interviews, findings unsurprisingly suggest that the group participants found it important to meet with their peers. They gained support by talking about vocational concerns, issues about child care and family issues. Although most of these issues might not differ too much from those relevant for older people the difference as described by a participant is "We have the same set of problems but a different set of circumstances" (p.34).

These studies all have their potentials and their limitations. The most important fact in terms of limitations is that most are surveys and with a response rate of between 30% and 47% they are likely to capture people with the greatest needs and problems. This might explain the low number of people who were employed. Secondly, by asking participants who have been members of a stroke group for one to ten years

about the value of such groups, Oehring and Oakley (1994) are likely to get results that point to the importance of such groups. Despite these limitations, these studies do still investigate needs as seen from individual perspectives and point to the need to provide intellectual or educational programs and offer help with family issues and with vocation for younger people after stroke. Furthermore, the needs as seen from younger people's perspectives must be investigated in order to be able to provide appropriate services for them. The studies indicate that there is a gap between younger people's needs and service provision.

This gap is reflected in a study carried out by the Strathclyde Centre for Disability Research at the University of Glasgow in which needs and service provision in Scotland for people aged between 18-49 and their carers or relatives are investigated (Banks et al., 2002). As it is particularly relevant for the purpose of this thesis it will be described in some detail here. The data consists of qualitative as well as quantitative material, collected over a period of nine months. The sources of qualitative data are two interviews (with fifty people for the first and twenty-nine for the second interview) plus data from diaries, covering the time from three months pre-stroke (data collected in retrospect) to a year post-discharge. The health status of participants and carers or relatives was investigated using the SF 36. As Bouchet et al. (2000) explain, this self-administered instrument measures quality of life in eight dimensions of health, including a general health evaluation, physical functioning, social functioning related to physical capability, role activities and vitality. Bugge et al. (2001) found this test useful in measuring quality of life after stroke, however the authors suggest that qualitative data is needed to specify the perception of health status that is measured with this test, a requirement met by Banks et al.'s (2002) study.

This work unequivocally demonstrates that younger people not only deal with their physical rehabilitation but also with specific social issues such as child-care, relationships and employment. However, service provision does not address the participants' needs. Problems identified in this study are manifold and occur on every level: acute, rehabilitation and community. They are as follows: physiotherapy and occupational therapy are provided for too short a period of time; returning to

employment is more difficult the longer participants are unemployed; being treated alongside older patients has a psychological impact for participants; there is a lack of information, particularly immediately after the stroke; the hospital/ community interface appears to be difficult and there is little advice about lifestyle changes in the community, particularly with regard to diet and smoking cessation. The researchers state that access to appropriate services depended on whether participants lived in rural or urban areas, but not on their socio-economic status or on gender. These findings imply inequality in service provision related to mobility and to geographical aspects.

Recommendations made by the authors are far-reaching. They suggest developing clear pathways and a special support package for people experiencing a stroke, with particular regard to younger people and their needs in terms of returning to employment. Information relevant for this particular group of people including welfare benefits, lifestyle changes, diet, smoking cessation, voluntary organisations working in their area and suitable exercise classes must be made available. The authors point to the importance of acknowledging the input of relatives or other supporters and the particular needs of family members with multiple responsibilities, for example young children and employment. They make a case for a defined and standardised role of a stroke nurse to provide all the information needed in hospitals and communities. In addition they call for multidisciplinary teamwork on the rehabilitation of younger people post-stroke.

This study is clearly very important in that it sheds light on the situation of the studied section of the population and indicates that the social and psychological impact of having a stroke at a younger age reaches far beyond issues of body function. It has political implications and points to the need for more service provision in the community, for specialised nurses as advocates and advisors for these younger people and for the need to provide welfare benefits particularly when return to employment is difficult.

Pound and Ebrahim's (2000) sociological study calls for nursing studies to investigate whether the lack of nursing care in stroke units and on general medical wards for older people after stroke which they identified is described by people who

had a stroke and particularly how younger people after stroke feel about this. However, a literature review on nursing literature about the experience of a stroke reveals that studies have neglected younger people's perspectives (Immenschuh, 2000). This is surprising since from a nursing view Tully Farzan (1991) states that "Family role and age are significant variables in considering the impact of stroke" (p.1038). The author continues that younger people who have strokes are more likely to be the family breadwinner, and either responsible for the care of a parent, or parents of young children themselves. She concludes that issues for a younger person might focus on child care, financial issues and home maintenance.

Clearly, unless these conclusions are thoroughly investigated, it is impossible to say whether they do indeed reflect reality and whether they can be addressed by nursing. One study with a focus on nursing does include people under sixty-six but this is by accident rather than design (Backe et al., 1996). In this phenomenographic study, six people are interviewed in their first week after stroke. This small sample size as well as the focus on the first week after the stroke clearly limits the generalisation of the findings and does not provide insight into later phases of the experience of having a stroke at a younger age, for example the hospital rehabilitation or the rehabilitation-home interface. Findings suggest a homogeneous picture of these six people; they describe losses due to loss of physical functioning, denial of the severity of the illness and an altered self-image. A stroke is described as a "crisis" and a "personal catastrophe" (p.292) for these younger people. The authors argue that nurses should be knowledgeable of the theory of crisis. They emphasise the importance of good communication in contributing towards recovery of the person after stroke. They also state the importance of integrating the next-of-kin into care and of developing care management plans for the early phase after stroke based on crisis intervention.

Issues raised by other studies concerning employment, family and financial issues are not addressed and might not have been relevant at this point. However, this study clearly indicates the need for further research. Longitudinal studies which allow investigations to be carried out at multiple points in time are needed to capture the experience on a scale that includes times when care interfaces as well as the return to work are likely to happen. The rather generally stated implications indicate that investigations are needed to provide grounds for the development of guidelines for

care that take into account specific strains. In addition, they need to utilise programmes known for other chronic illnesses and evaluate them for appropriateness for care for this specific group of people.

1.3. A psychological perspective

Clinical psychology is concerned with the psychological processes that occur as a response to illness. VanderZee et al. (1995) state that these subjective evaluations:

are even better predictors of mortality than objective health status. The implications for professional caregivers may be that much more attention should be paid to psychological processes and sources of social information which influence the patients' well-being. (VanderZee et al., 1995, p.63)

The authors make a case for more studies to investigate the effects of subjective evaluations as well as of inter- and intrapersonal factors on health perception. Many psychologists describe a stroke as a crisis and highlight the impact of psychological problems on rehabilitation outcome and life satisfaction (Hager and Ziegler, 1998, Herrmann et al., 1995).

1.3.1. A stroke is a crisis

Whilst the common assumption that stroke causes a crisis for everyone who experiences one may be unwarranted, the literature review does suggest that the stress of the event can precipitate a crisis. Although hardly any studies look at the psychological impact of having had a stroke at a younger age, they do often include relatively young people between twenty and seventy years of age. These are the studies that will be referred to here.

The process of coping with a crisis is described in phases similar to those in bereavement. Drawing on relevant psychological literature, coping with a stroke in younger people can also be said to follow roughly the same pattern of phases (Kallert, 1993, Frank et al., 1985). A comparison of different models for coping with

a stroke but also with bereavement (displayed in the following table) suggests that having a stroke is associated with changed bodily function and with a threat to the self. The process of adaptation is described as a standardised pattern regarding issues of coping.

Selected models for coping with a stroke and with bereavement:

| | Parkes 1971 (bereavement) | Frank et al. 1985 (coping after stroke) | Kallert 1993 (coping after stroke) |
|-----------------------------|--|--|---|
| Model or Theory | Process of grieving | Uses others' models for orientation in psychotherapy | Calls it 'intrapsychic reaction patterns' |
| Phases | <p>Four stages</p> <p>1. Numbness phase of shock, confusion and disorganisation. Needs time and protection</p> <p>2. Pining The urge to search for a lost object, alarm, tension, restlessness, loss of interest in personal appearance</p> <p>3. Depression Is abnormal if it doesn't happen, not pathological per se but depends on the individual how it is expressed and how strong it is</p> <p>4. Recovery There is no one point of recovery but several turning points. 'Abandonment of old modes of thinking and living' (p.176), developing new interests</p> | <p>Four phases</p> <p>1. Shock Fear, depression</p> <p>2. Defence Denial, suppression, rationalising</p> <p>3. Pre-adaptive phase Grief, aggression, feelings of guilt, helplessness, emotional ambivalence</p> <p>4. Restitution Re-establishing a new self-image, acceptance of body changes</p> | <p>Five phases</p> <p>1. Resignation, depression, despair, suicidal thoughts, feelings of guilt, blaming oneself</p> <p>2. Depression but also task- and problem oriented work, mobilising of own resources, rationalising the illness and the consequences of it.</p> <p>3. Changing feelings of fear and hope and active work on concrete plans. Grieving about losses and thinking about new options occur interchangeably. Increase of inner stability.</p> <p>4. Increase of self assurance and trust in own abilities. Establishing daily routines to achieve own goals. Still insecure about the future.</p> <p>5. Further increase of consciousness about consequences of the illness and disability. Trying out, how much effort is needed to maintain health.</p> |
| Main characteristics | <ul style="list-style-type: none"> • Process is highly individual in duration and in the characteristics of the stages. • Only after depression can recovery occur. • Developed for bereaved people but these should be treated as sick people in terms of taking time off from work and other privileges of being sick | <ul style="list-style-type: none"> • Process does not always follow this order, sometimes there is stagnation. • For assessment they postulate professional observation, not only self observation of the client. | <ul style="list-style-type: none"> • States factors that influence recovery such as brain damage, perception of the illness, age, sex, education, and the way someone views the world and its predictability. Social integration, ego-strength, psychic health are further aspects to consider. |

These three authors point out that phases do not have to appear in a linear way or as static; they can also occur repeatedly. Other authors, for example Herrmann et al.

(1995) doubt whether this categorisation is helpful at all. In their investigation of the impact of aphasia on the way people who had a stroke cope, the authors emphasise the individual aspect of coping. Fifty people in two control groups with and without aphasia aged 21-75 years and their families are included. Data is obtained one, six and twelve months after the stroke using five different German questionnaires investigating coping strategies, changes in occupation and social relations, cognitive and emotional changes, psychological adjustment and activities of daily life. Findings from statistical analysis suggest that neither physical functioning nor aphasia have a significant impact on how successfully people cope with stroke, despite the fact that people with aphasia face more social and occupational difficulties. These authors state that personal explanations of the stroke as well as psychological states change over time in both groups of people. Overall there are no significant differences in ways of coping between people with and without aphasia. Thus this study suggests that problems in motor function and speech are two of many aspects that have an impact after a stroke. The authors point out that they did not find evidence of coping patterns according to phases in the studied population.

A more open approach, as described for example by Kallert (1993), allows room for individuality and therefore seems to be more appropriate for understanding the experience of having a stroke at a younger age. From his work as a psychologist with people after stroke in neurologic rehabilitation, Kallert provides specific knowledge about variables that influence the process of coping with a stroke. Although this is not a scientific investigation but a reflection on his practice, and he does not refer to a particular age, he mentions several issues that are important for the purpose of this study. Firstly he states that the brain-damaging nature of a stroke may play a role for the individual, not only manifested as neurologic or neuropsychiatric problems but also in terms of cultural attitudes and beliefs about brain-damaged people. Secondly, the extent to which an individual copes with stroke is influenced by their personality, which incorporates age, gender, education, world views, life concepts, psychological health, relationships as well as spiritual beliefs. Thirdly, previous experiences with crisis can either help or hinder the process. Fourthly, a stable social network may be a valuable resource for a person in this situation, with family support and financial

situations both playing a role in the process of dealing with the stroke. Fifthly, the prognosis given and also the individual perception of the severity of the illness are stated to be considerable influences. Lastly, the process can also be influenced by problems with concentration, memory problems and speech.

On grounds of Herrmann (1995) and Kallert's (1993) work the view that there are specific phases in the process of coping with the crisis of having a stroke can be challenged for several reasons. Firstly, such models suggest that a stroke always results in functional problems that the person who suffers them perceives as problematic - a questionable assumption for younger people who have better chances of a quick recovery than older people. Secondly, they suggest a coping pattern more or less applicable to all people who experience a crisis situation, despite all other factors that influence emotions, appraisal and coping (see Lazarus 2000, explored in the next chapter). Thirdly, having a stroke at a younger age can manifest itself in a wide variety of forms, ranging from a complete lack of symptoms to total dependency on others. The assumption that all younger people go through a process as suggested by these models is problematic. Fourthly, the phases models treat coping with the potential crisis of having had a stroke as an individual problem and neglect cultural social influences, which can vary from attitudes towards people with brain injury to insurance problems.

Kallert (1993) emphasises the need for age-specific psychotherapeutic interventions for people after stroke, based on thorough assessment.

1.3.2. Therapeutic interventions

One issue for psychotherapeutic interventions raised by Frank et al. (1985) is how to assist people with depression or denial after stroke. According to the authors depression can be part of the normal process of grieving for someone or something that has been lost. Only when people stagnate in this stage or when the depression becomes severe do they need psychotherapeutic help. The same holds true for denial which can be a useful strategy to avoid stress in the initial shock phase after the event, but which may need to be treated with psychotherapeutic interventions at a later stage. Kallert (1993) states that these interventions must be based on a good

relationship between therapist and stroke patient and they must be changed according to the individual's recovery state. He as well as Frank et al. (1985) suggest starting with individual behaviourist therapy sessions. Kallert (1993) states that the potential stresses of group therapy may mean it would only be appropriate in a later phase of rehabilitation. However, Bucher et al. (1984) found that group therapy was a good option for younger people after stroke in rehabilitation. The basis for comparison of three different groups run by the authors is formed by results from informal evaluation at the end of a series of group therapy sessions as well as a questionnaire three months later. According to the description of the study, the groups were run differently due to different therapists and circumstances, which limits the plausibility of results. However, group members stated a number of beneficial aspects of the groups, such as sharing of ideas, gaining information about participants' conditions, dealing with the fear of future strokes, and also the possibility to express their feelings. These might be relevant issues and point to the benefit of such groups for younger people after stroke.

This psychological perspective on what a stroke means for a younger person raises some important questions. One wonders whether younger people would describe their stroke as a crisis comparable to bereavement. Another issue concerns the stigma which is still attached to people who undergo psychotherapeutic treatment in Germany. Therefore, despite the usefulness of psychotherapeutic interventions, the question is whether people after a stroke would accept such treatment. Furthermore this literature is not always based on systematic research and no longitudinal information is available, for example about the influence of work on recovery. Therefore a few studies dealing with this issue will be stated now.

1.4. Across disciplines: vocational rehabilitation

Since this thesis deliberately includes people who are likely to be working, return to work is an important issue. However, it is poorly understood at present and is often studied as related to functional abilities:

Currently the medical and rehabilitation perspective would treat severity of injury, measured by the degree of impairment, as a biological barrier preventing return to work. However, the individual's perception of the impact of their impairment upon ability and function to work differs. As such, the determination of work disability cannot rest with biological determinants alone. (Shaw et al. 2002, p.193)

This qualitative study employs in-depth interviews with eleven younger people (aged 24-48) who suffer from various impairing diseases. The authors report unique individual viewpoints of the impact and meaning of the impairment, and of the individually defined importance of work as an influence on participants' behaviours in relation to return to work. These individual viewpoints include personal as well as societal attitudes to illness and work disability, perceptions of whether societal roles are related to work or not and family and activity issues. This indicates that "return to work is a complex issue necessitating a broad understanding." (p.194)

A similar conclusion is reached in Black-Schaffer and Memieux's (1994) literature review about vocational outcome after stroke. They state that the comparison of studies about return to work is difficult in itself, due to varying definitions about work (whether one includes students or volunteers), different age groups, sample sizes and time of investigation, or even interests of payers to get positive results out of a study. Most importantly they state that return to work is a complex issue involving many layers of abilities: physical, cognitive, communicative, and visual-perceptive, that may all influence each other. Furthermore a successful return to work is influenced by socio-economic factors, since people

...with higher educational levels and white collar positions are more likely to return to work after a stroke than those with little education and blue collar positions..., (maybe because) ...those with better education tend to have more interesting, better paid and less physically demanding jobs,...have more flexibility in terms of hours and duties. (p.84)

The authors make the case for close collaboration between occupational therapists and employers in order to achieve the best possible conditions for the person with a stroke and for better training of professionals to best assist these people.

In a three-year study started in 1999, the charity organisation '*different Strokes*' tried to enhance understanding of issues related to the return to work. The first step of the study, a survey among members of the organisation and employers, revealed that almost half of the respondents had not returned to work because they did not feel "fit enough". Apart from policy implications as described by Black-Schaffer and Mimieux (1994) '*different Strokes*' calls for more awareness of specific problems stroke causes in young people, as well as easier access to services and better conditions at workplaces - such as more flexible sick leave, financial and practical support for adjustments and work-focused case management. It is hoped that additional results in the next step of the study will follow interviews with younger people and with employers (*different Strokes*, 2000). Although results from this study are clearly important in understanding the return to work behaviours in younger people after stroke, it has to be borne in mind that participants are recruited from a self-help organisation and thus might be more vocal about their problems than others who do not belong to such organisations. However, the numbers of people who have returned to work are almost double the numbers mentioned earlier in this review (in Kersten et al., 2002, Hartke and Brashler, 1994).

Whilst all these studies seek to understand and explain return to work behaviour, Kempers (1994) has developed an outpatient programme and evaluated it with twenty-five younger people after stroke. The author argues that employing this programme results in better return to work outcomes across different occupations and different levels of impairment, compared to return to work rates from the literature. The programme includes a thorough assessment of memory, strength, balance and work skills. One strength to this approach is that it is geared towards reaching the goals set mainly by the person who had the stroke. Evaluation includes work-related demands, such as punctuality, appearance, tolerating pressure and managing frustration, to mention a few. The author's support for further development of the programme in terms of follow-up evaluation and stronger integration of client

feedback is another step into a more person-centred approach to issues of stroke in younger people.

These studies indicate the complexity of vocational rehabilitation. Their emphasis on the variety of aspects that influence return to work behaviour is important for the purpose of this study. Thus not only functional criteria but also personal, social and socio-economic factors as well as the meaning of the impairment and of going back to work need to be borne in mind. However, these studies do not question structural issues such as appropriateness of workplaces for people with a stroke or cultural issues such as potential attitudes towards younger people who have had a brain-damaging illness. They also do not question that the return to work agenda can be driven by economic interests of getting people off insurance benefits (Herzlich and Pierret, 1987). Furthermore they imply a norm whereby everyone wants to return to work, thus following the ideal that younger people's identities are tied to work, to being productive and healthy. They do not ask what it means for younger people after stroke to return to work. Do they want to return as quickly as possible or not? What does their decision depend upon? Is there any financial or social pressure to return to work or is it a major goal of the people themselves? Are these issues coming from studies done in the USA comparable to different countries in Europe despite different insurance systems and cultural values? Do vocational needs depend on the degree of the impairment as is suggested by various authors (see for example Kersten, 2002)?

The different perspectives outlined here more or less all include how younger people themselves describe their situation. However, there is a growing number of publications in which younger people describe their experience of having had a stroke. The last section of this literature review will be devoted to a small selection of these, published mainly in mass media and books, but some also in nursing (Coubrough, 1992, Christine P., 1993).

1.5. Younger people's perspective

Publications from people between thirty and sixty years of age are sought to give insight into their feelings, perceptions of the illness, role changes, future plans and hopes or the absence of these.

Act III, Scene ii

Someone has altered the script
My lines have been changed.
The other actors are shifting roles.
They don't come on when they're expected to,
and they don't say the lines I've written
and I'm being upstaged.
I thought I was writing this play
with a rather nice role for myself,
small, but juicy
and some excellent lines.
But nobody gives my cues
and the scenery has been replaced.
I don't recognize the new sets.
This isn't the script I was writing.
I don't understand this plot at all.

To grow up
is to find
the small part you are playing
in this extraordinary drama
written by
somebody else.

Barbara Vance (1998) refers to this poem written by Madeleine L'Engle¹ when she describes her experience of a stroke eight years earlier. She is back at work full-time

¹ L'Engle, M. (1978). Act III, Scene ii. In *The Weather of the Heart*. Wheaton, IL: Harold Shaw

as a professor and her "disabilities are silent, invisible ones" (p.155) However, as the poem indicates, the experience of the stroke suddenly altered her life. She describes changes in terms of health – she has developed a sensitivity to noise, and post-traumatic stress disorder, which causes great fear at times. At the same time she has started to realise how important other people were to her, to appreciate the beauty of nature. She has also slowed down and learned to take work less importantly. She has learned to accept that there are things she cannot control, to be more patient with the setbacks in her recovery and to live in the moment. Most importantly she describes spiritual changes, the main one being her belief that all people are inextricably connected to each other.

Most personal accounts follow this pattern of a sudden, difficult and life-changing experience. Fiona Coubrough (1992) describes how she changed from an active thirty-one year old woman working as a neuro-specialist nurse, to a dependent recipient of care. She had to give up not only her independence but also her previous roles in life.

For some it takes years to grasp the illness and to accept it (Christine P., 1993, McCrum, 1998). This acceptance does not come about by itself but after a long and painful process of dealing with the question of the stroke's cause and meaning, both for themselves and for their lives, typically expressed in questions such as "Why me?" (Fritschi, 1988) or "What had I done to deserve this?" (Kelly, 1994, p.88).

A stroke can also be disfiguring and cause feelings of shame, depression and isolation. Iris Norton (1993) was horrified and embarrassed by her changed appearance. Together with her difficulties coping with everyday activities such as eating, dressing and washing, this caused periods of deep depression. Since her facial paralysis has become worse she has communication problems which "threatens to isolate even more than lack of mobility" (p.64).

Not only devastation but also contradictory feelings can occur after stroke. Jean Dominique Bauby (1997) describes this in the context of a situation when he saw the reflection of a face in a window.

Reflected in the glass I saw the head of a man who seemed to have emerged from a vat of formaldehyde. His mouth was twisted, his nose damaged, his hair roused, his gaze full of fear. One eye was sewn shut, the other goggled like the doomed eye of Cain. For a moment I stared at that delated pupil before I realised it was only mine. Whereupon a strange euphoria came over me. Not only was I exiled, paralysed, mute, half deaf, deprived of all pleasures and reduced to a jelly-fish existence, but I was also horrible to behold. There comes a time when the heaping-up of calamities brings on uncontrollable nervous laughter- when, after a final blow from fate, we decide to treat it all as a joke (p.32/33).

Suffering from 'locked in syndrome' caused by a stroke the only means of communication was with his eyelashes. However, no staff member used it except his speech therapist and a psychologist. Thus in these accounts people do also express their needs, for example, like here, the need for communication respective of the impairment. Furthermore, being recognised as the person they were before the stroke is mentioned as central by many. This involves things like listening to their own music, eating food they like, getting their hair done, having undisturbed sleep (Norton, 1993) or wearing their own clothes and make-up (Coubrough, 1992). Getting out of the hospital environment and back into the 'normal world' is described as a relief (Coubrough, 1992, Bauby, 1997). From a medical background, Nicholas Mikula Jr. (1998) argues for full utilisation of all possible therapies for people who have had a stroke. In his poem "The One-Armed Paperhanger" (p.204) he expresses the feeling that he lost one side of himself at the age of thirty-five. However, his visible impairment of a hemiplegia is "only in physical appearance". The conviction that "love will always come out on top" is stronger (p.204). Thus he expresses the view that his physical problems do not impair on his emotional well-being or positive outlook on life. In Barbara Vance's (1998) example the same fact is described, only vice versa: although she does not have any physical problems she suffers from the

emotional problem of great fear. Thus both of them treat physical impairment and emotional well-being as totally separate issues.

All these accounts describe the stroke as a life-changing event. However, Paul T. Kelly (1994) informs us that this might not be the case.

My life after the stroke is not that different than before it. I had always heard that people are supposed to look at life differently after surviving something like a stroke, but I honestly have to say that I don't (p.89).

This is a small selection of the ever-growing number of published material about younger people's experience of having a stroke. It indicates several important points: a stroke affects the whole person including their physical, social, psychological, emotional and spiritual being. Long-term physical aspects of this illness as described here affect mobility, speech and writing. There are social implications involved with role changes, for example from a professional to a recipient of care (Coubrough, 1992) or from a husband to a divorced man (Mikula Jr., 1998). However, weakening relationships and feelings of isolation as well as stronger relationships are described in these personal accounts. Psychological changes are portrayed as mood changes, post-traumatic stress disorder and depression. Shame can occur because of the disfiguring effects of the stroke. The question as to why people have the stroke leads both to searches for medical causes as well as for meaning. This and the confrontation with death is described by some as leading to a discovery of spiritual meaning in the stroke. The need for as much therapy as possible and for a recognition of their individuality is expressed. However, whilst most accounts relate a stroke in similar terms to the descriptions from the psychological perspective, indicating that it was a crisis, a few others highlight positive aspects of it, in one case even saying that his life did not differ much after the stroke.

Accounts also raise questions. For example, why do some people describe a stroke as terrible, whilst others do not? These accounts are published in mass media and could be accused not only of being filtered to get enough publicity but also of representing

the voices of a specific group of people who are able and willing to use these media, not of the 'ordinary' young person after stroke. The question then is how 'ordinary' younger people describe their experience. Do issues described here apply to other people with a stroke?

1.6. Summary

The aim of this chapter was to outline how a stroke at a younger age is described from different perspectives.

A stroke at a younger age is a medical problem provoking controversial discussions about causes, treatment and prevention of future strokes. It remains unclear how younger people deal with the potential uncertainty related to this.

The literature suggested that younger people's concerns extend to functional issues. However, services for people after stroke are driven by a biomedical perspective focusing on symptoms and their treatment and geared mainly towards the needs of elderly people. This review revealed that there is a gap in meeting younger people's needs in terms of age-specific issues, mostly family issues, employment, information about welfare benefits and role changes.

There is a general assumption that a stroke is a crisis for an individual and that psychotherapeutic interventions are helpful. However, this raises questions as to whether this is a fair generalisation, in particular with regard to personal accounts of younger people's experience of a stroke. By contrast, this review suggests that some people describe a stroke as a crisis, but others do not. Literature from the field of clinical psychology suggests including cultural influences as well as personal and social variables into the assessment of what a stroke is for a younger person.

Depending on the impairment, vocational issues emerge as of importance for younger people after stroke. Specific assessments that include not only functional aspects but also motivational and social ones could lead to programmes that assist people to return to work. However, as studies indicate, return to work behaviour is not well understood and there is need for further investigation into cultural or personal influences on motivation.

In summary it must be said that younger people after stroke receive little attention and whether or not they have specific needs is often a matter of debate. The gap in knowledge is most striking in the context of nursing, since nurses' roles in the rehabilitation of people after stroke has been emphasised in terms of the time they spend with people (Hafensteinsdóttir and Grypdonck, 1997), as specialised stroke nurses (Banks et al., 2002), their role as a co-ordinator of care (Tully Farzan, 1991) and as a counsellor (Jones, 1995). Yet the nurse's role has not been clearly defined and is underestimated by nurses (Kirkevold, 1999). Moreover it is difficult to quantify the effect of the care given (Jones, 1995). In the Greenwich Stroke Study the sociologist Anderson (1992) investigated the impact a stroke had on the quality of life of the person after a stroke and of his or her family and the contribution "health and social services made to the process of change following a stroke" (p.29). The study started in 1983 and 173 people (older than sixty years) and their carers were interviewed at one, nine and eighteen months post-stroke. Regarding the role of nurses he states that:

Nurses appear to be the key figures influencing the quality of the patient's stay in hospital. It is likely that more comforting, counselling and communication are provided to stroke patients by nursing staff than by any other group in the hospital; they spend more time with patients than any other group, and may be most knowledgeable about problems associated with bowels and bladder, emotions...and diet. ...Altogether, nurses appear to be the most critical element in the patient's experience of daily life in hospital. The balance between their expressions of interest and indifference may have a profound effect on patient's attitudes to the stroke and to themselves. (p.62/63)

These role descriptions indicate that nurses are in a position to understand, accompany and coach people through the process of coping with having had a stroke. However, the absence of studies from a nursing perspective examining younger people's experiences on a long-term basis, how they deal with care interfaces and

what implications for nursing care could be drawn from this, points to a need for studies to enhance the knowledge not only for nursing.

The meaning of having a stroke at a younger age, particularly its long-term effects, must be seen in the wider framework of how illness impacts on individuals, the families and how this can be influenced by their social and cultural environment. Thus the next chapter will outline some of the writings on chronic illness and discuss their relevance for the topic under study.

Chapter II

Theoretical perspectives

This chapter looks at social and psychological implications of chronic illness and of stroke in younger people. Stroke is commonly described under the rubric of chronic illness (Burton, 2000, Charmaz, 1991, Kirkevold, 2002). It is therefore first explored whether a stroke at a younger age can be seen as a chronic illness or as an acute illness that could or could not lead to living with impairment and disability. Then stroke as a crisis and related psychological implications are examined. Since a stroke has been described as a disruption of self (Ellis-Hill et al., 2000) models of chronic illness as a disruption are explored for the purpose of the study. Having a stroke at a younger age is abnormal and can therefore be considered to carry a stigma, thus the issue of stigma is described and discussed. A more holistic view on chronic illness is then believed to be useful in widening the perspective on what a stroke could mean for a younger person, if this can extend the thinking from *having* an impaired body with implications for an individual's life to *being* a person who is affected by illness. The purpose of this chapter is to place the experience of having a stroke into a framework that allows thought to transcend dualism and to allow an exploration on many levels of experience: personal, social, cultural and metaphysical.

2.1. A stroke as a chronic illness

A stroke is referred to as a chronic illness. Indeed, when looking at features that classify chronic illness, many of them do indeed apply to stroke: it is long-lasting and even though the symptoms might not always be dominant, the person is nevertheless aware of them. The literature review has revealed that a stroke at a younger age often cannot be cured as its causes are often unknown. It is life-threatening. The likelihood of contracting it grows with age and is also higher amongst poorer populations (Everson et al., 2001). These are all features of chronic illness as described from a perspective of social psychology by Radley (1994), and referred to by other writers from the wider field of sociology (Bury, 1991, Rolland, 1988). Defining chronic illness in this way represents a medical view which emphasises it as a combination of

medical diagnosis according to aetiology, symptoms and treatment (defined as disease in Radley, 1994, p.2ff), the individual experience of the disease (defined as illness, p.2ff) as well as a social attribute of people which is influenced by societal factors (defined as sickness, p.2ff).

However, is it accurate to attribute the label of chronic illness to all people who have had a stroke? For example would the 57% of people who survived their stroke at a younger age and were without any symptoms or impairments three years later (Leys et al., 2002) consider themselves to be chronically ill? Amongst these might be people who did not return to employment despite not having symptoms - how could they be classified?

On the other hand a younger person with a stroke who has a hemiparalysis, incontinence problems and is unable to speak presents a completely different picture of what a stroke is at a younger age. This person might more readily be classified as chronically ill. The classification used does have an impact, both for individuals in terms of the treatment they receive, the benefits for which they are considered eligible and the attitudes other people have towards them. On an institutional level it is a question of consumer orientation and providing appropriate services. In social policy it has implications for the assessment of needs and for adjusting policy regulations to changing needs and to disabling structures.

That people cannot be classified using neat dichotomies such as disabled/not disabled, chronically ill/acutely ill, impaired/not impaired has been acknowledged by the World Health Organisation (WHO) and led to a shift away from the 'International Classification of Impairment, Disability and Handicap (ICIDH) to a new classification, 'The International Classification of Functioning, Disability and Health'. This new framework for health and disability is "the conceptual basis for the definition, measurement and policy formulations of health and disability" (World Health Organization, 2002, p.2). This comprehensive tool is designed to assess personal factors as well as environmental and structural factors that lead to disability. Emphasising the importance of combining the medical with the social model of disability, a new model is presented, called the 'biopsychosocial model'. According to this model, having a stroke at a younger age would be assessed according to the diagnosis, the impairment, the restrictions of activity and

participation, including environmental as well as personal factors. The assessment has to include views of health care professionals as well as the user's view. With this model the WHO moves away from the view that disability begins where health ends and acknowledges that:

every human being can experience decrement in health and thereby experience some disability. (2002, p.3)

Having a stroke at a younger age can result in impairment. This impairment can consist of chronic conditions such as memory problems that need continuous treatment, weakness in a limb that requires constant training and numerous others. On grounds of such impairments younger people can be disadvantaged and thus a stroke at a younger age can result in disability. While it is true that all these categories may apply to people after stroke, nevertheless this raises the question why stroke at a younger age should be classified in any of these categories at all? Would a more open approach not be more beneficial for the understanding of this illness? In order to answer these questions some selected theoretical frameworks of crisis and coping and of chronic illness will be presented: as a crisis, a disruption, as stigma and as a phenomenon that challenges lifeworlds previously taken for granted.

2.2. A stroke as a crisis situation

The literature suggests that having a stroke at a younger age results in a crisis situation that people are then required to cope with. The word 'crisis' originates from the greek word *krisis*, or *krinein* - 'to decide' (The Concise Oxford Dictionary, 1995). Writing within the field of crisis intervention psychology, Golan (1978) suggests that an event is a crisis when it interrupts a stable situation, exists for a certain (undefined) period of time and extends the person's ability to deal with the situation. It is a stressful situation characterised by an imbalance between demand and resources (Schumacher and Reschke, 1994) and which forces us to make changes in life or to enter a 'transition process' (Brammer, 1991).

The literature on coping with crisis situations is vast. For the purpose of this thesis, coping will be defined based on Lazarus' (1991, 1993, 2000) 'motivational-cognitive-

relational theory of emotion' which provides a theoretical background for understanding a stroke as a crisis.

Lazarus (2000) associates with the epistemology of "a modified subjectivism" (p.198) and thus emphasises the highly subjective nature of emotion, appraisal and coping. Coping is thus a process, reflecting a person's appraisal of the situation, including his or her goals and individual resources. Lazarus (1993) defines the process of coping as:

ongoing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. (p.237)

'Lazarus' cognitive-motivational-relational theory of emotion' (Lazarus, 1991, 1993, 2000) has developed over the last forty years. He distances himself from the view that coping is a process occurring after emotions arise, seeing it instead as "an integral part of the emotion-generating process" (2000, p.213). The central features of his theory are appraisal, emotions and coping.

The appraisal of a situation, for example of having a stroke at a younger age, determines whether a person takes action to change the 'troubled person-environment relationship' and if they do, what kind of action. This process can be deliberate and conscious or it can be intuitive and unconscious. In either case:

it must be based on a full exploration of what is going on in the mind of a particular individual and the context in which the person-environment transaction occurs. (2000, p.206)

Emotions, which are part of this process, again have several underlying features. Firstly they are motivational, in other words dependant on a person's goals and their meaning for the self. Lazarus emphasises that the meaning of an encounter is personally constructed depending on the personal goals and thus he seems to neglect

the cultural meanings that influence the appraisal; for example the cultural norm to live healthily and to prevent illness could make someone feel guilty for becoming ill, thus violating this norm.

Lazarus states that a situation is individually appraised as harm, loss, challenge and/or threat. In earlier work he differentiated between threat, insult or benefit as results of appraisal that caused emotions to be dealt with: 'namely, anxiety, anger and pride respectively' (Lazarus, 1991). Thus emotions force us to 'appraise' and the appraisal in turn influences our emotions.

However, emotions are not irrational. This is contrary to what many authors who divide emotion and reason state. Heim's (1998) definition of coping, although using Lazarus' theory, reflects this divide when he says that coping is an attempt to try to digest *emotionally and/or rationally* existing or expected strains, or to set goals and act according to them. In contrast, Lazarus (2000) points out that occurring emotions follow a logic with the variables being individual, depending on the appraisal of the individual in a certain situation. Emotion and reason influence each other inseparably, as do 'positive and negative emotions'. Emotions can always be appraised as positive or negative, sometimes even both. For example, happiness might also incorporate a fear that the happy situation will end, which would then require some form of coping. Although he distinguishes between problem-focused coping (people acting to solve their problem) and emotion-focused coping (people trying to regulate emotions tied to the stress-situation) he points out that there is no clear distinction between the two and they often occur together.

He further states that coping strategies are not universally effective or ineffective. For example, denial, once thought to signify pathology, can be beneficial or harmful depending on the circumstances. A person in a crisis situation may not be able to change the situation and be unable to face the truth. In such a situation, Lazarus (2000) says that this person might be best to use 'ego defences', such as denial, in order to preserve the morale. Such strategies are only harmful if they prevent this person from taking necessary life-saving or health protecting actions. It is important to point out that 'denial' is value free. Whether it is harmful or not depends on the

individually appraised situation. As described in the previous chapter, it has been stated that denial is a helpful coping strategy for younger people after stroke in the early stages of their illness (Frank et al., 1985).

Lazarus' theory does not deal only with coping. Rather, he demonstrates the inter-relatedness of emotion, appraisal and coping. The whole theory is based on the assumption that psychological reaction to stress (or crisis) is constructed by the individual as an expression of a complex process:

Emotions are complex, organised subsystems consisting of thoughts, beliefs, motives, meanings, subjective experiences, and physiological states. They depend on appraisals, which arise from and facilitate our struggles to survive and flourish in the world (2000, p.219).

Many authors refer to Lazarus' theory or describe similar issues in their definition of the process of dealing with stressful situations in general or with the crisis of a life-threatening disease (see for example Heim, 1998). The great strength of his theory as applied to coping with having a stroke at a younger age is that he emphasises the individuality of the appraisal of the illness situation, as well as emotions related to this and coping. The influence of age on other variables could be an important aspect in the subsystem of emotion and has to be taken into account. His theory does not lead to a dichotomous categorisation of people as chronically ill or not but urges us to acknowledge the individual within his or her context.

However, this individualistic perspective is also a limitation of this theory. Whilst Lazarus does emphasise the importance of the individual within his or her environment, as was indicated in the example of the cultural value of prevention, he has rightly been accused of neglecting cultural and social structures (Bury, 1997). In addition, and this is acknowledged by Lazarus (2000), the neuropsychiatric effect of a stroke has to be borne in mind. According to the author, people with neuropsychiatric problems can misjudge a situation and react inappropriately (p.216).

This is not to deny the value of the cognitive-motivational-relational theory of emotion for understanding the situation of younger people after stroke. However, in addition models that focus specifically on the impact of illness on a person including the social and cultural environment are believed to be beneficial to enhance the understanding of illness.

2.3. A stroke as a disruption

Chronic illness has been described as a threat to a person's biography and self (Corbin and Strauss, 1987), as an interruption of self in time (Charmaz, 1991) or else as a biographical disruption (Bury, 1982, 1991, 1997). In all these models chronic illness is seen as a life-changing event that leads people who suffer it to question who they were and who they are now, how the illness impacts on their lives and how they cope with the resulting changes. In the following, Bury's model of chronic illness as biographical disruption will be outlined briefly and complemented by other theoretical approaches, with a particular emphasis on their potential to enhance understanding of the experience of having a stroke at a younger age.

As a medical sociologist, Bury has explored the issue of chronic illness and its impact on the self within the wider social and cultural context. His understanding of chronic illness as a disruption of people's lives stems from his studies with people with rheumatoid arthritis in the seventies in England (Bury, 1982) and has been employed as a theoretical framework to explain the experience of having had a stroke (Ellis-Hill et al., 2000, Pound et al., 1998). Bury argues that the disruption includes the disruption of assumptions and behaviours; a re-thinking of a person's biography and self-concept and a mobilisation of resources. In his later work (1991) he specifies these aspects as 'disrupted biographies', 'explanation and legitimation' and 'the impact of treatment regimens'. In further later work (1997) he again reworks these definitions. Although the content of his approach does not differ much, here I will refer to his most recent work.

Bury draws on Corbin and Strauss' approach (1987) who describe the threat of chronic illness to a person's biographical time, body and continuity of self (referred

to as the BBC chain). These authors focus on the impact of chronic illness on the individual and argue that bodily failure is a threat to the continuity of the chain, necessitating biographical work with the "central task...of putting the BBC chain, metaphorically speaking, back together" (p.264). Bury goes beyond the meaning of chronic illness for the individual, emphasising:

the symbolic significance disease, disability and illness have within segments of modern cultures, the metaphorical roles they play in everyday discourse and the attendant expectations people have of them. (p.124/125)

In other words, cultural and social norms and beliefs influence the significance that a chronic illness can have for an individual.

These cultural influences that impact on the chronic illness experience of an individual include treatment and health care. According to Bury, medical knowledge and treatment options can offer subjective relief in that they suggest control over the illness. At the same time, frequent limitations of treatment, side-effects, possible restrictions and the intrusiveness of treatment can all be difficult for the person. This point is particularly relevant for younger people after stroke. As indicated in the literature review, stroke in younger people often remains unexplained and treatment options lack evidence. For example, the question of whether to operate on a patent foramen ovale is complex, firstly because of the controversy surrounding such operations in terms of necessity and success, and secondly because of the range of options available: no treatment at all; no operation but lifelong treatment with Warfarin; minimal invasive operation or open heart surgery, as well as the decision about which of the many available patches to implant. Thus Bury makes an important point for health care workers to bear in mind when working with a person who is in the potentially difficult situation of having had a stroke in helping them to make treatment decisions.

Another point Bury emphasises is that health care workers can help people to explain the illness and legitimise it to him- or herself and to others. By offering medical explanations, they can also help to answer the question 'why me?'. However, as a

diagnosis can be important to legitimise the illness, he also points out that it is often not sufficient to explain the illness on an individual basis. Explanation goes beyond describing medically defined causes and effects. As Williams (1984) describes, the genesis of the illness is reconstructed in order to make sense of it and to allocate it a place in a person's biography. According to Bury (1997) this is to sustain " 'cultural competence' and personal authority in the face of threat" (p.126). In the context of this research, this is of particular importance since a stroke is commonly seen as an unusual illness for younger people and the restoration of competence in other people's eyes might be crucial.

To complete the description of Bury's model his three approaches to adapt to chronic illness must be mentioned. These are: coping, strategy and style. Whilst he acknowledges Lazarus' contribution (see above) to coping, he criticises the use of the term for its normative character (good versus bad coping, successful versus unsuccessful). He prefers to use the term 'strategy' because it "brings the rules and resources of social hierarchies more clearly into focus than the term 'coping'" (p.131).

The third approach in Bury's concept is different styles used to adapt to chronic illness as described by other authors. Bury quotes other authors, for example Radley (1994), who describes how chronically ill people engage in performance to suggest they are actively involved in social life. The 'style' is how people manage their social life in illness, or how they manage their illness within their social environment. For this study this could be the question of how they deal with remaining symptoms, for example fatigue or weakness of limbs as they might interfere with demands of work.

The strength of Bury's model is that it underlines cultural and social influences on a person's experience of illness. However, since this study aims to investigate the experience of having a stroke at an age in which many people are raising children, the impact of illness on the family system also needs to be looked at. Here Rolland (1988), a medical psychiatrist, offers a systems-oriented approach which examines the impact of chronic illness on the family system. According to him, a family's values and beliefs are important aspects that need to be assessed when looking at the impact of chronic illness on a person. Here the assessment of the 'life cycle' in which

a family is hit by an illness is of particular importance. Rolland explains that if a family is in a phase of closeness (centripetal), for instance if they are raising young children, the illness will affect them differently than if they are disengaging (centrifugal), for example when they have adolescent children who are leaving the house. He argues that chronic illness normally has a centripetal effect, meaning that it forces the family to maintain closeness rather than to disengage. The life cycle is also characterised by "life-structure-building/maintaining periods" and "transition periods" (p.59). In the former, the family is trying to preserve its structures, whereas the latter describes processes of change in which the normal state is questioned and revised. In the case of chronic or life-threatening illness these different periods and the life cycles can clash, throwing a family out of equilibrium. Age (as well as ethnicity) is said to have a profound impact on the effect of an illness on the family because chronic illness or death are expected to occur in late adulthood, but not for young people, who are often raising children (Herz Brown, 1989). The author argues that at this time the occurrence of serious illness or death can be most disruptive.

As has been described in the literature review the experience and needs of younger people after stroke differ from those of elderly people because of the family situation. Rolland's systems-oriented approach specifies this rather common-sense assumption and might help us to understand why a stroke at a younger age could be more disruptive if it was in stark contrast to the normal life cycle of a person and his or her family.

2.3.1. Stroke and time

A further aspect in understanding the experience of illness is time. Many authors therefore refer to changes in chronic illness by describing different phases. Of all the possible examples, two will be briefly described to contrast them with a more open approach to the impact of time. Rolland (1988) calls the first phase the crisis phase, in which a person recognises symptoms, seeks treatment and makes first adjustments. This is followed by the chronic phase, in which the person and his or her family attempts to lead a normal life. The third, terminal phase is characterised by loss and bereavement.

Radley (1994) talks of stages and related tasks: The seeking of help for the emerging symptoms, then the stage of diagnosis, characterised by uncertainty but also relief that the illness has been named. This is the stage at which disruption of who the person was and of the roles associated with this occurs. The problems which follow with learning to live with the chronic illness are manifold: restrictions due to functional changes, social isolation as a result of this, discrimination and feelings of burdening others.

Authors who describe chronic illness in phases acknowledge that these phases are not static and do not occur in a linear pattern. However, in comparing these two explorations it becomes clear that it is difficult to tie the complexity of how to cope with chronic illness into a neat bundle. Firstly, such an approach suggests that any younger person who has a stroke goes through the same phases, in spite of the huge variety of forms that this illness can have. Rolland (1988) does suggest that the type of illness plays a role in the experience of illness, thus indicating that people with the same illness can be categorised. Secondly, these models differ on important points, for example in describing when a crisis occurs. According to Rolland (and in crisis models described in the previous chapter) a crisis is expected to occur early on, whereas in Radley's model the stage of disruption, and arguably the crisis, is the third stage, coming after seeking help, uncertainty and relief. Relating this to Lazarus et al's theory (2000), a crisis is not related to a particular event such as illness, but to the individual's appraisal of a situation. This theory suggests that a more open approach is needed to capture the individual experience of illness.

Charmaz' (1991) investigation on chronic illness offers just such a more open approach, describing several aspects related to the self and time. Charmaz presents results and knowledge from in-depth interviews done over more than twenty-five years with people with various types of chronic illness at different stages in the illness trajectories from a sociological point of view. She describes how time perspectives shift for these people: living one day at a time instead of planning ahead; merely existing day by day to manage uncertainties and strains. These are both examples of how the impact of illness and the treatment can affect a person's time perspective. Time becomes "marked" (p.198 ff), for example as times of illness

and non-illness, of recovery and crisis, but also by calendar time - one year after the occurrence of the illness can mark an important point in time. She also describes turning points that can occur. These can be positive events, such as new insights, or negative events, for example situations that cause feelings of shame or humiliation. When she speaks about the self in time she explicates how people try to relocate themselves in the past, present and future. Here the picture Charmaz draws of someone who became chronically ill is that of a person who finds themselves in an "irretrievable past, an unsettling present, and an irrevocably changed future [that] alter an individual's view of self" (p.229). According to her, people who become ill often relate to a positive and sometimes idealised past. The present can be filled with many activities, or intense with more depth than before. The future can be dreaded by people who fear dependency and dying. It can also be perceived as an improved future if people are hoping for more fulfilment. A further option is that it can be taken for granted. In this scenario, the future remains unquestioned and there is the concept of the "everlasting future" (p.255) in which people examine the possibilities of death and life after death.

Charmaz offers important aspects that highlight time as relative to individual experience and to personal construction. It allows questions to be raised such as: has a younger individual's experience of his or her lifetime been affected by the experience of the stroke? Were there important points in the illness trajectory that marked shifts in perspective and priorities? How does this person describe him- or herself in the past and present? What do they expect in the future? However, this openness offered by Charmaz is constricted slightly by her statement that people describe themselves in an idealised past, an enriched but unsettling present and uncertain future. This draws a picture of chronic illness as being devastating and difficult per se - a statement that might not be true for many chronically ill people. This view limits what is otherwise an approach that probes individually shaped questions.

Some common characteristics of descriptions of a chronic illness or stroke as a disruption can now be summarised:

Illness is an event that disrupts assumptions, time structures and self-definitions. The loss of control over the body, health and life is widely used to explain why this disruption occurs specifically in illness (Charmaz, 1991, Bury, 1997, Giddens, 1991). The individual who suffers the illness interacts with the environment which influences the perception of the illness and its impact on life. A certain amount of work is needed to cope with the disruption, to integrate the illness into one's biography and to regain a sense of security. Descriptions of this process of coping mostly focus on an individual level, sometimes pointing out social and cultural influences. One is left with the assumption that a long-lasting illness such as stroke is mostly a devastating experience that needs work and entails losses but can lead to transcendence through different processes (Charmaz, 1991). However, these models talk too little about the social and cultural implications of having a stroke at a younger age. Since this illness is thought of as a disease for older people, younger people who suffer it are different from what is socially and culturally expected of them. As a result, these people can be labelled as abnormal, in other words stigmatised.

2.4. A stroke as stigma

In a modern world in which being healthy "means to be a good, respectable, and responsible person" (Crawford, 1984, p.1348) having a stroke at a younger age threatens this ideal. Crawford's exploration of the development of cultural norms in the study of AIDS provides grounds to understand why younger people with a stroke could feel and become stigmatised in modern societies - not only if they suffer from AIDS. According to Crawford, the idea of maintainable health arose in tandem with the ability to research, describe and measure the body. This "medicalized body" (p.1351), together with the results of economic growth called for "useful bodies" (p.1351), meaning healthy bodies that can be controlled and that function not only on an individual level but as part of an economically productive society. The idea that health could be maintained and 'made' placed 'diseased' people who failed to achieve this outside society and the collective (p.1355). Crawford explains this exclusion by the fact that unhealthy people remind the healthy of their own vulnerability. The fear of loss of control creates a need for self-protection, which leads to projection of the

other as being out of control, resulting in these others being blamed for their illness. Crawford points out that this projection and stigmatisation of the 'unhealthy other' is not only a protection of the individual but also of the collective social self.

According to this explanation the norm of being healthy and productive, which is naturally applied more to younger people, can label young people who have had a stroke as abnormal and can lead to more stigmatising attributions (Goffman, 1968). Goffman sees stigma as deriving from a societal conceptualisation of what constitutes difference or deviance. Resulting rules and sanctions are applied to people labelled with stigma. He argues that there are two forms of stigma: the 'discredited' person who assumes that other people know about the stigma and the 'discreditable' person who assumes that the difference is not known by others. Using this definition, younger people with a stroke could be both discredited and discreditable. However, the view that people with an illness or impairment are automatically stigmatised by others has been called an 'orthodox viewpoint' and was thrown into doubt by Scambler and Hopkins (1986). The authors interviewed people with epilepsy, investigating their perceptions of their illness, with particular regard to the issue of stigma and the impact it had on their personal and social lives. The study's findings led to a new concept of felt versus enacted stigma. Enacted stigma is defined as discrimination solely on grounds of difference; felt stigma refers to the shame associated with having epilepsy and the fear of enacted stigma. The evidence suggests that felt stigma is much more common than enacted stigma. Three propositions outline the model invented by these authors. Firstly people with epilepsy "learn to perceive their status as 'epileptics' as socially undesirable" (p.38). According to a 'special view of the world' they define epilepsy as stigma and are afraid of enacted stigma. Secondly, this fear leads them to conceal their condition and to try to pass as normal. Thirdly, this concealment reduces the rate of enacted stigma, particularly in the context of relationships and at work. Hence, what is disruptive in these people's lives is felt stigma and the fear of enacted stigma, not the enacted stigma.

The visibility of the stigmatising condition clearly plays an important role. Young people who are discredited by others knowing that they have had a stroke or by exhibiting signs such as hemiplegia have to manage the tension of being stigmatised

(Goffman, 1968). On the other hand 'discreditable' people who do not have visible signs of a stroke have to manage the information about their condition, namely when to disclose this information, as well as to whom and how. This information management is necessary in order to pass in the eyes of others. Goffman (1968) describes different strategies of passing, including the concealment of problems, distancing oneself from others, attributing oneself to a less stigmatised group of people (for example, calling oneself a daydreamer instead of revealing a hearing problem) or dividing others into one large group who does not know anything of the individual condition and a small group who does.

Disclosure is risky, particularly for younger people (Charmaz, 1991). It means revealing feelings, vulnerabilities and potentially discrediting information.

Perhaps most fundamentally, young and middle-aged adults risk losing acceptance by telling... Not only must they handle their feelings about telling, but also they must handle their feelings about another's response to being told. Lovers, spouses, friends and jobs may vanish from their lives. (p.109)

Although there are negative effects involved, disclosure can be beneficial. In Charmaz' terms it can mean gaining control and power and it can protect a person from others' demands. In Kelly's (1992) terms disclosing can elicit sympathy and praise and it can give manipulative power (p.87/88). According to Charmaz (1991) avoiding disclosure serves the purpose of minimising attention given to the health status, of distancing the illness from the self, supporting preferred self-images and of avoiding stigma. Thus concealment can help to maintain a creditable public self.

When do people disclose? Kelly (1992) describes that there are situations when disclosure is unnecessary, others in which it is unavoidable (for example with insurance companies) and situations in which it is optional. Charmaz (1991) adds that disclosure can happen spontaneously or it can also be planned. In this latter case a person decides what information to disclose, as well as when and to whom. Whether or not to disclose is described by Charmaz as a decision that has to be made mainly by people whose condition is invisible to others and influenced by these other

people's responses. People who experience negative responses to their disclosure can attempt to avoid disclosure in the future. This can lead to a vicious circle, as has recently been stated as a result of a sociological study about the experience of courtesy stigma in families of children with disabilities (Green, 2003). The author writes that interaction with others which is perceived to be negative can cause fear of stigma. This can in turn increase the perceived stigma, which again increases negatively felt interactions and so on. Positive responses on the other hand can have a supportive effect and help the person and family to deal with the disability.

This emphasises that disclosing personal information is intertwined with other people's responses. As Charmaz (1991) points out taking others' reactions into consideration helps to protect self and others from shock, anger and fear about the illness.

As described earlier more than half of the younger people after stroke have been found to be without any signs or symptoms of a stroke three years on. These individuals have to manage the information of having had a stroke as well as others who suffer from invisible impairments such as memory problems, mood disorders or weaknesses of limbs. The literature review revealed that to date no study has examined the issue of stigma in younger people after stroke although many of the issues related to stigma may apply to this group of people. How do they "make themselves acceptable to the healthy in the world of 'normality'" (Radley 1994, p.161)? Radley describes the supposedly thin line they seek to manage:

If sufferers ignore symptoms and press on as normal, they risk being perceived as 'reckless'. If they take great care of themselves, they run the risk of being seen as 'invalids' or as 'malingers'... this dilemma does not exist in a vacuum; it arises out of the demands that the world of health makes upon the sick. (p.157)

Stigma thus can be summarised as a socially and culturally constructed condition in which both the 'normal' and the stigmatised person play a role. Hyman's (1971)

suggestion to dissuade people who had a stroke from their belief that they were stigmatised is inappropriate bearing in mind the complexity of the issue. It seems more appropriate to support what some authors (Jacoby, 1994, Joachim and Acorn, 2000) suggest, namely to admit that there is simply not enough understanding of the reasons why some chronically ill people feel stigmatised and others do not, when they disclose or not and the relation of the (in)visibility of their condition to this. This is an issue that particularly needs further investigation in the experience of younger people after stroke.

Having explored the experience of having a stroke at a younger age as a crisis, as a disruption of self and as a stigma, a phenomenological focus will expand the view and highlight aspects of the very act of being to the understanding of illness.

2.5. A phenomenological perspective on stroke

In the field of medical anthropology Good's (1994) work has been chosen for this study to provide a phenomenological view on chronic illness experience. In accordance with phenomenological ideas, Good does not speak of subjective illness experience but of illness as an "object of understanding and striving" (p.170). Illness experience is seen as embodied, entailing "intersubjective meaning, narratives that reflect and rework illness experience, and the social practices that mediate illness behaviour" (p.118). He uses the example of cancer to illustrate the complexity of chronic illness. For example a tumour is a histologically defined material:

But it is more than this as well. It is a part of the sensuous, lived body, a dramatic rupture of a life history, an object of intense diagnostic and therapeutic activity, and a politicised object of social attention. (p.170)

Good develops his thoughts by drawing on phenomenologists such as Husserl and Schutz, combining philosophy with examples from his studies with people with chronic pain and epileptic seizures. In Good's view, the rhythm of life is disrupted in case of illness and the body and the self become two different entities:

Sickness and pain submit experience to the body's vital rhythms, infusing everyday experience with its distorting presence, focusing our awareness on the body as object, alien to the experiencing self, the object of cultural practices. The normal personal and social rhythms of experience are often subverted, shaped to the body's demands. (p.131)

This view is reflected in the literature review: having a stroke at a younger age has mainly been described as an illness of the body. Functional problems are described as the source for various other problems, for instance social exclusion, dependency or depression. Bodily function is made the centre of experience. Questions such as how disabling the environment is for younger people after stroke or how people who recovered from functional problems experienced the stroke have not been addressed at all. According to Good (1994) this view of the body and the self as separate entities reflects the medical view of localisation of the source for pain (or illness) in the body, which forms an object that can be made visible and treated. The author finds this body-mind dualism reflected in illness narratives. However, he points out that far from occurring in the body, illness occurs in life, meaning in time, place, history and context of lived experience - in the body in its world.

It is hoped that an exploration of an integrated approach that enables a move away from the body-self dualism will open the space and allow understanding of the experience of having a stroke at a younger age beyond dualism.

2.5.1. Dualism and Leib

It has been said that "Human experience is incarnated" (Leder, 1990, p.1). However, the body as a source for experience is absent in daily life. Leder states that only through discomfort or disfunction the body *dys-appears* (p.69 ff). This absence and dys-appearance provides grounds to view the body as problematic and separate from the mind. However, as Leder explores his phenomenological viewpoint, he argues that the incarnation of experience does not allow Cartesian dualism of body and mind or body and self. Instead, he calls for an integrated view of the 'lived body', the English word for '*Leib*'. The German word *Leib* and the English word 'life' have the

same roots, namely 'lip' or 'lif' and refer to life, person and body as one and the same entity (Uexküll, 1991). The Cartesian worldview breaks down particularly in case of illness. This is explored by Barbara Duden (1987) as she investigates the relationship between women and their physician in a small German town in the 18th century. Her historical study reveals how the worldview of those times was manifested in explanations of illness. Not the mere *Körper* (body) was ill, it was the *Leib*, the

lived object of *Klage* (complaint, lamentation), *Sorge* (trouble, worry), fear and *Selbstgefühl* (feeling about oneself); (p.207).

This description indicates that the *Leib* is not a materialised object. It includes physical existence, emotions, values, interaction with the environment and the very being - it is the whole person.

Both a historical and a feminist point of view explain why a perspective of the *Leib* was overridden by Cartesian thought.

Several authors from various fields of expertise explain how the rise of new productivity and technology in the 19th century changed society. Mechanical images of the body led to the desire to describe, research and standardise the body (Leder, 1990, Duden, 1987, Uexküll, 1991). In this climate:

the doctrine that no other than physical and chemical forces are acceptable in an organism, became the dogma of modern medicine and along with it, the exorcism of the soul out of the body was scientifically sanctioned...Along with the exorcism of the soul out of the body came the exorcism of philosophy out of the art of healing. (Uexküll, 1991, p.484)

More recently the philosopher Böhme (2002) speaks of the same development when he argues that medical methods of dissecting, analysing and combining have parallels with what were called scientific methods. He emphasises that this

worldview simply has no place for the *lebendige Leib* (living *Leib*) with its vagueness, variety and heterogeneity.

Gadamer (1996) describes how this changed worldview became incorporated in language: in the measurable *Körper*, and the *Leib* which is intertwined with life and extending scientific methods⁵. This separation is reflected in semantic expressions, for example in speaking of "the physical body (and) the lived body" (Good, 1994, p.176) or of the 'incarnate' and the 'corporal' body (Monks and Frankenberg, 1995). Monks and Frankenberg explore people's experience of having MS. They refer to the *Leib* as the 'incarnate body', the "historical and actively experienced and experiencing body...of being in the world". The 'corporal body', the *Körper*, is referred to as "the physical structure"(p.108).

Stopczyk (1998) describes the decline of the *Leib* as the oppression of feminine wisdom (Sophia⁶) by masculine rationality⁷. From her viewpoint as a feminist philosopher she argues that this wisdom has been oppressed since Christianity. However, philosophers such as Paracelsus, Nietzsche and Adorno have all described varying '*Leib*-philosophies'. She calls for a development towards the end of oppression of the female body and a new awareness of the holism integral to existence itself.

Feminists go on to argue that the distinction between body and mind as well as between emotion and reason is gendered (James, 2000). The mind and its capacity to reason is associated with masculinity and the body together with emotional sensibilities is associated with the feminine. The author describes that the terms "masculine" and "feminine" are not used neutrally, but that the feminine terms are marginalized in comparison with masculinity. Davis' (1997) exploration of this oppression described as a "masculine fear of femininity and a desire to keep the female body and all the unruliness which it represented at bay" (p.5) is in line with

⁵ see Gadamer, (1996a) In most parts of the book *Leib* is translated as *body*, an incorrect translation as body is the translation of *Körper* (for example p.98 equivalent to 1996, p.128).

⁶ According to Gadamer (1990) Sophia is human wisdom that cannot be passed on from "one person to another like water over a thread of wool. It is the awareness of not knowing..." (p.33). This knowledge means a "Wendung zur Idee" - "a turning to the idea"- that is, a turning to that which lies behind all the mere postings of supposedly knowledgeable persons." (p.33)

⁷ Leder (1990) calls the oppression of women one of the social effects of Cartesian thought leading to hierarchical dualism (p.4)

Stopczyk's (1998) statement of the heterogeneity of the *Leib* and the oppression of the female body.

Indeed, every exploration of the body as something that we need to be able to control in order to sustain our sense of self and to be trusted by others (Giddens, 1991), or of the body as 'other' that belongs to a lower order as opposed to the spirit and the mind (Kidel, 1988) indicates the loss of integrity that was inherent in the concept of the *Leib*.

However, this concept was never completely lost. In several investigations about chronic illness experience, particularly studies about chronic pain (Jackson, 1994, Good, 1994, Bendelow and Williams, 1995) but also of chronic illness in general (Williams, 1996) this wider view on embodied experience of illness is employed. In line with this Bendelow and Williams (1995) plead for a more holistic view on pain:

Rather than merely reducing pain to a physiological 'symptom', it must be seen as culturally shaped by an individual's worldview, requiring an approach which sees pain as physical and emotional, biological and cultural, even spiritual and existential. (p.99)

This phenomenological viewpoint is also expressed by the sociologist Williams (1996) in his investigation into the issue of dualism and embodiment in chronic illness. Drawing on Leder's philosophy (1990) Williams argues that chronic illness leads to a shift from embodiment (initially taken for granted) to dys-embodiment and then to attempts of re-embodiment. The author suggests that chronic illness means a loss of body and thus of self. Treatment that focuses on the physical functioning of the body as well as medical procedures and language all contribute to the process of dys-embodiment. The body-self dualism is manifested in the experience of chronic illness. This necessitates biographical work in order to reintegrate body, self and society, finally resulting in a re-embodiment which will be different to the previous being.

Whether people actually dys-embodiment in chronic illness experience or not is a matter of debate. Jackson (1994), also writing from a phenomenological perspective, describes findings from her study in a chronic pain treatment centre. Although people with chronic pain indicate that they objectify the pain and thus separate it from the self, (which would be similar to dys-embodiment) at the same time they also identify with it. Pain is "both "me" and "not me"" (p.206). Jackson argues that the experience of pain extends beyond the language of dualism of body dominating the mind or vice versa. Pain is felt by a whole person, it becomes part of a new self that includes pain, "one *is* pain: one's selfhood and one's body combine with pain. And all the time pain is a major component of the new self, the new identity" (p.209, italics in original). This quote indicates the author's suggestion that language does not allow an adequate explanation of the experience of pain. It is limited to words which can only describe a relation between the body, self and pain, suggesting that these are different entities. This mirrors what Good (1994) calls the objectification of language, making it inadequate to describe subjective suffering (p.132/133). Jackson (1994) claims that people with chronic pain develop a "language of pain" (p.214), which is why they feel understood only by others who suffer it. What was described as dys-embodiment by Williams (1996) is referred to by Jackson (1994) as the lack of a language to express the phenomenological experience of pain.

If we look at these two seemingly different approaches from a *Leib*-philosophical perspective, the differences between them fall away. Since the concept of *Leib* gave way to dualism, not only the language but also the consciousness of this world-view has been lost. People who are confronted with the limitations of existence, for example through illness, might feel that illness affects them as whole human beings but also have incorporated the dualism in which they then not only describe their state of being but also feel it. Williams (1996) points out that embodiment and dys-embodiment should be seen as a continuum on which we all move. Narratives about chronic illness experience express in particular the struggles involved for people who seek to rebalance themselves on this continuum and one could argue that it is health care professionals' duty to best assist people in this struggle.

Several attempts have been made to look at the implications that a resurrection of the concept of the *Leib* would have for health care. Thure von Uexküll's (1991) psychosomatic view leads him to adapt a "theory of the living body" developed in the 20th century (by Jakob von Uexkül and Wesiak). In this theory, human beings are seen as individually created and functioning systems that are in constant exchange with their environment. It is not causality that is the leading question for a doctor, but the need to find an answer to the interaction between "different levels of integration of the body" (p.488) in interaction with the environment.

Gadamer (1996) calls for an orientation towards the *Leib*-philosophy for the understanding of health and illness. Health and illness would then not be seen as dualistic but reflect the:

rhythm of sleeping and waking, the rhythm of illness and recovery, and finally, at the end, the transition into the nothingness of the otherness, the expiring movement of life itself (p.105⁸).

According to Gadamer the doctor would recognise this rhythm and movement and acknowledge that the whole of the universe is reflected in human nature. The consequence of this would be the realisation that measuring and testing is only one way of looking at human existence in illness.

Uzarewicz (2002), a German nursing scientist, states that such an understanding also provides grounds for a change of paradigms in nursing. She points out that nursing care under this paradigm would expand limitations of medically driven measuring and testing of the ill body. This could lead to more autonomy and a humanistic view of nursing in Germany. Like Gadamer and von Uexküll, she points out that in this philosophical orientation person and environment are not seen as dualistic but as constantly influencing each other. Nursing does not distinguish between body and

⁸ see Gadamer (1996a), p.78; here the translation of "ins Nichts des Andersseins umschlagende, erlöschende Lebensbewegung" into "the transition into nothingness, the expiring movement of life itself" is not correct. Gadamer is talking about dying as transition not only into nothingness but into nothingness of the otherness.

mind or between physical and emotional care but attempts to do what needs to be done as coexisting human beings.

Dualism of body and mind or of body and self might be a phenomenon of particular importance in the experience of having a stroke. The lesion is in the head, associated with the mind. However, its effects are felt in the whole body, potentially but not always including symptoms of the brain. The literature has not revealed how younger people describe themselves - dichotomous, holistic or something else again. What does having a stroke at a younger age mean in this metaphysical sense?

2.6. Summary

By outlining theoretical frameworks about the impact of illness on people this chapter has sought to enhance understanding about what a stroke could mean for younger people.

It began by questioning whether having a stroke at a younger age should be classified as a chronic illness and argued that the old medical models of chronic illness and disability should be opened to a more individualised approach.

It then went on to explore Lazarus' (1991, 1993, 2000) 'cognitive-motivational-relational theory of emotion' to enhance understanding of a stroke as a crisis outlined in the previous chapter. This approach was seen as useful for two reasons: firstly as an alternative to the models of phases, described and criticised earlier, and secondly in that the appraisal of a situation, occurring emotions and coping strategies are seen as a complex individual process. The downside of this individualised approach to life events is that it neglects cultural and social aspects of the experience of suffering from a stroke at an unusual age.

Sociological writings on chronic illness suggest that potentially life-threatening illnesses such as stroke can cause a disruption: of assumptions and values, of one's own biography and continuity of self and of the self-concept (Corbin and Strauss, 1987, Bury, 1982, 1991, 1997). It can be a threat to a family system particularly for people at a younger age (Rolland, 1988, Herz Brown, 1989). This effect of illness on a person does not occur in a vacuum but is influenced by cultural factors, for example attitudes towards people with brain injury or treatment and health care

options. It was argued that this can be particularly difficult for younger people after stroke because of the limitations of treatment options and the controversy surrounding the success of these options. Coping with the disruption requires 'biographical work' with the ultimate goal to allocate the stroke a place in a person's biography. Time is an important aspect in the experience of illness. Again, models that describe this process in phases have been questioned and a more open approach provided by Charmaz (1991) has been advocated. The experience of having had a stroke at a younger age changes over time and thus the call for longitudinal research, with investigations at different points in time as stated in the previous chapter, has been underlined.

The final part to mention here is that a stroke at a younger age is likely to be stigmatising. Issues of enacted and felt stigma (Scambler and Hopkins, 1986) and of managing the potentially stigmatising information of having had a stroke (Kelly, 1992, Charmaz, 1991) might be existential issues for younger people after stroke.

In the last part the thesis moved on to explore metaphysical implications of illness. This phenomenological exploration led to a rejection of dualistic terms of body-self or body-mind. Instead different writings on the concept of '*Leib*' (Leder, 1990, Duden, 1987, Stopczyk, 1998, Gadamer, 1996) opened the gateway to explore what this paradigm shift would mean for health care and nursing: an approach that includes but extends methods of testing and measuring illness and acknowledges the constant exchange between a person and the environment, including metaphysical thinking.

This individualised focus that was advocated throughout the exploration and discussion of theoretical frameworks and in the previous chapter suggests the need to ask younger people who had a stroke about their experience and more importantly, to listen to them. This thesis now explores epistemological and ontological underpinnings of researching experience as a basis for the approach utilised in this research.

Chapter III

Researching illness experience

*Different ways of viewing
the world shape different
ways of researching the
world (Crotty, 1998, p.66)*

The approach of this study lies within the interpretative tradition. In keeping with subjectivist epistemology it is assumed that human experience in general and chronic illness in particular is subjectively created and interpreted in communication with the environment. As one strand of the interpretative tradition, this study is underpinned by Gadamer's philosophical hermeneutics. It seeks to understand people's experience of having had a stroke at a younger age as expressed in dialogues and to reflect on how nursing can respond to the needs thereby created. In Gadamer's sense I bring my understandings, prejudice and knowledge gained through history and tradition into the research. At the same time he emphasises the great openness I need to bring into any conversation, with a person or with a text in interpretation. How this demand has influenced the research is discussed in the account.

Before discussing the design of the study I give a brief overview of the epistemological, ontological and theoretical understanding that underlies this interpretative research and describe the particular principles of Gadamer's philosophical hermeneutics that inform and guide it.

3.1. Epistemological and ontological underpinnings of researching chronic illness experience

Since the interest of this study focuses on the unique and individual aspects of the experience of having an ischaemic stroke, an approach that lies within the interpretative tradition is particularly suitable to capture those experiences. Crotty (1998) explains that interpretative approaches lie within more subjective epistemologies, which can be traced back to the beginning of the last century. The work of the philosopher Wilhelm Dilthey and later of the German founder of modern

sociology, Max Weber, shaped this epistemology. Its concern is to understand and explain human and social reality. Research that follows this train of thought "looks for culturally derived and historically situated interpretations of the life-world" (Crotty, 1998, p.67). The founders of this approach distinguish between the interpretative tradition, which seeks understanding of individual phenomena, and more positivist approaches related to the natural sciences which seek to generate general laws to explain reality.

Crotty (1998) describes two different stances to subjectivist epistemology: the constructionist and the interpretivist. From a constructionist point of view there is something that can objectively be described, for example a tree is a tree. However, the meaning of a tree – or of an experience or event – is constructed by the individual. Although this meaning is subjective it consists of objectives that have been constructed before and are therefore already present. These objectives and how someone works with them in the world becomes the focus of investigation.

This approach differs markedly from the interpretivist view, in which experience is created by individuals interacting with their environment. Since this study lies within this tradition, I will focus on this view of the world and of social life. Again Crotty (1998) describes that in the interpretivist tradition it is not a question of what reality would be out there to be researched but rather what interpretation of experience is presented. Gadamer's approach to experience leads us to the assumption that there cannot be such thing as an 'accurate' account in researching experience. In Gadamer's (1997) view, a person's perception of an experience is shaped by his or her worldview. This worldview itself is shaped by the person's experiences and by the meaning that he or she derives from them. Every experience leads the individual to question his or her assumptions and as a result, their sense of self is either shaken by it or confirmed and manifested. It is this process by which people gain knowledge of the world through experience (Gadamer, 1997, Sokolowski, 1997).

This experience can then be accessed indirectly through stories.

We of course do not have direct access to the experience of others. We can inquire directly and explicitly, but we often

learn most about experience through stories people tell about things that have happened to them or around them. Narrative is a form in which experience is represented and recounted, in which events are presented as having a meaningful and coherent order, in which activities and events are described along with the experiences associated with them and the significance that lends them their sense for the persons involved. (Good, 1994, p.139)

This emphasises the highly individual aspect of the representation of experience through stories, presented in a created order and shaped by the personal meaning of an event.

This epistemological stance can also be applied to a specific form of experience, namely chronic illness experience. Kleinman (1988) argues that health and illness are culturally shaped conceptions, just as experience is dependent on culture, society and personal perception. He understands personal illness experience, such as having a stroke at a younger age, as an internalised way of perceiving and viewing an illness in a certain society and of replicating these patterns. Thus created norms and patterns create a reality in which there are 'appropriate' ways of being ill as well as 'inappropriate' ways. These are not static; furthermore they are not only culturally shaped but can be negotiated and formed through personal relationships; they are what Kleinman calls "distinctive" (p.5).

In short, research on chronic illness experience under the interpretivist paradigm needs to be able to capture the great complexity of individual experience. In order to achieve this, it needs to acknowledge that the representation of experience is a product of the relationship between a person who is ill and the researcher which is made and remade, negotiated and reconstructed.

According to Crotty (1998) there are three main strands to interpretivism: symbolic interactionism, phenomenology and hermeneutics⁹. However, Gadamer's philosophical hermeneutics in particular throw such a classification into doubt. In his supplement to 'Truth and Method' (1993) he explores what he calls "the universality of hermeneutics" (*Universalitätsanspruch der Hermeneutik*). He bases this on the claim that interpretation, translation or understanding, all associated with hermeneutics, are older than the idea of scientific exploration and explanation. He further says that interpretation and understanding - the basis for all inquiry - rely on language (*Sprache*), of course not restricted to verbal language. Whilst he acknowledges what value the use of methods has for reaching understanding, he emphasises that interpretation of questions of human being must go beyond the utilisation of methods. Thus from Gadamer's epistemological point of view, hermeneutics could be described as the overarching philosophical orientation of any form of interpretation, it is not theoretically focused but open. The advantages and disadvantages of this openness for this study are indicated throughout this thesis.

My decision to do a hermeneutic study related to Gadamer's philosophy was the result of an investigation into the strength and weaknesses of social interactionism, phenomenology and Gadamer's philosophical hermeneutics. Thus principles of social interactionism and of phenomenology are outlined briefly before describing Gadamer's philosophical hermeneutics that underpinned this research.

3.1.1. Social interactionism and phenomenology outlined

The social interactionist perspective puts personal experience into the wider framework of culture and society. According to Blumer (1969) the underlying assumption of this theoretical framework is that meanings of experience are created within the dialectic between an actor and the environment. It is this process, in which the individual interprets experience and how it is influenced by the presence of others, that forms the focus of studies within this school of thought. Or, for the study of health and illness:

⁹ These have also been described as the "three underlying theoretical paradigms...interactionism, phenomenology, and historical-biographical constructionism based on Max Weber's theory of social action" (Gerhard, 1990, p.1155)

These processes- the ways in which individuals give meaning to social events (such as childbirth, surgery, death); the ways in which they manage changed identities in ill health; and the 'negotiation' that takes place in formal and informal health-care settings- are the subject matter of interactionism (Annandale, 1998, p.21/22)

In other words the processes that take place to deal with a changed identity are the focus of investigation. A good example of research on the experience of having had a stroke within the interactionist perspective is Pound et al.'s study (1998), described earlier (p.25). In short the authors state that a stroke at an older age can almost be an expected event, one of many crises which occur throughout people's lifetimes. However, as they take into account the interaction between people and their environment – in this case, the London area - they state that participants' lives were characterised by poverty and hardship and their reaction could be described as an expression of stoicism in the face of such a life. They highlight the fact that the experience of a stroke depends on the context in which it occurs. In other words, if people are living in difficult housing or financial situations a stroke can appear to be 'not that bad'.

This study focuses on how people of a certain age and within socioeconomic circumstances interpret their experience of a stroke. The same study undertaken within phenomenology would not focus on the social processes of the creation of meanings but assume that meaning was there already and can be studied. However, Kelly (1992, 1992a) Kelly and Field (1996), Williams (1984) or Charmaz (1991) are examples of how these two stances can collapse in the study of health and illness.

Phenomenology has become the framework of choice to underpin research of experience in nursing (Draucker, 1999). It has two main characteristics:

...it has a note of objectivity about it. It is in search of objects of experience rather than being content with a description of

the experiencing subject. Second, it is an exercise in critique. It calls into question what we take for granted (Crotty, 1998, p.82/83).

Crotty goes on to explain that phenomenology as founded by Husserl tries to go back to 'the things themselves'. Inherent in this is the assumption that there are 'things themselves' that can be studied objectively. Furthermore, phenomenology assumes that due to their mere 'being in the world' (Dasein) humans experience the world immediately with all its meanings already formed and present. The emphasis thus falls on the phenomenon itself, not on the process of making meaning of an experience, nor on the interaction that takes place. Crotty (1998) points out that this focus on the phenomenon asks phenomenologists to 'bracket out' their presumptions and to take a fresh look at the phenomena under study. Common concepts as well as assumptions must be set aside. Kvigne et al. (2002) emphasise the importance of self-reflection, reflection with other researchers and openness to achieve this objectivity.

Doolittle's ethnographic study underpinned by phenomenology serves as an example of this theoretical basis as she investigates bodily recovery following lacunar stroke (Doolittle, 1990, 1994). Her study focuses on physical aspects, suggesting that bodily changes due to the stroke are the source of experience. However, the experience of a stroke, according to Doolittle, is more than malfunction of the body. It is an identity crisis, but one which is related to bodily and hence individual changes. As she focuses on the phenomenon the social or cultural environment does not play a substantial role in her investigation.

This study reveals a characteristic of much of the work within phenomenology, namely that it focuses on the individual experience, thereby often neglecting social and cultural processes of creating meaning.

The question as to what constitutes sound phenomenological research is a matter of some debate. Crotty (1998) and Draucker (1999) criticise phenomenological research for neglecting essential phenomenological principles. Crotty (1998) provides a critique of the current (mis)use of phenomenology in social science research. He states that although the vocabulary still remains, what is made, for instance of

'bracketing' or 'experience' is quite different from what Husserl intended (p.83/84). Instead of presenting a critical appraisal of objectively existent phenomena, Crotty argues that phenomenology has developed to a subjectivist approach and has become expressly uncritical. However, Crotty's view of phenomenology has been accused of being narrow, misguided and poorly informed (Darbyshire et al., 1999). These authors respond to Crotty's criticism and make a case for the use of Heidegger's phenomenology for interpretive research in nursing.

Two main reasons led to my decision to do a study within the framework of Gadamer's philosophical hermeneutics. Firstly I was not seeking to focus on meaning created between participants and their cultural and social environment but aiming to investigate the experience of having had a stroke from as wide a perspective as possible. Gadamer's philosophical hermeneutic advocates above all openness and prohibits any focus, be it on psychological or on social processes. Secondly, I would not claim to be objective or able to 'bracket out' my presuppositions, a main characteristic of phenomenology.

Thus the notion of prejudice appeared to me as a particular strength of Gadamer's thought. This and the notion of dialogue as part of Gadamer's philosophy of understanding, coupled with the idea of the *Spiel*¹⁰ are aspects that helped me to define my role in the research process and to guide my ethical and practical thoughts about this research. I will first relate Gadamer to the wider context of phenomenology before moving on to discuss the philosophical principles underlying this research.

3.2. Gadamer's philosophical hermeneutics

Gadamer (1990) defines hermeneutics as the "art of understanding texts" (p.169, 194)¹¹. He does not limit the interpretation of texts to historical or biblical texts but includes any text, conversation, a piece of art or a play in his definition of "text".

His work has been acknowledged as being useful for nursing research (MacLeod, 1990, Koch, 1998, Annells, 1996) but also serves a function in nursing practice,

¹⁰ See pages 81ff. for a further discussion of this term.

where it serves as a framework "to generate knowledge that is not split between subject and object, mind and body." (Pascoe, 1996, p.1311) However, studies have been accused of failing to address the obligations inherent in Gadamer's (and Heidegger's) work, particularly concerning the clarification of the authors' presuppositions and how this influenced the research process, including the interpretation (Geanellos, 1998). This means that conscientiousness in describing the framework for the methodology and its adoption to the research is essential for a hermeneutic study.

Drummond (1997) gives a thorough overview of the development of Gadamer's philosophical hermeneutics and how this is to be placed in relation to Husserl's and later Heidegger's phenomenology. As the founder of phenomenology, Husserl is described as incorporating a hermeneutic view in the sense that he talked about the fact that every form of awareness is already interpretation. Whilst Husserl's phenomenology aspired to be without presuppositions, Heidegger began to take into account the fact and the chance that lies in using our "understanding of being" (*Seinsverständnis*) (p.305). However, his account of discourse and language remains fundamentally in agreement with Husserl's doctrine of 'bracketing out' presuppositions. Although some would claim that his later work was hermeneutic in the sense of "the very practice of making interpretations" (p.306) he remained related to objective phenomenology.

As Drummond goes on to explain, Gadamer developed this philosophy further by adding several aspects. Firstly he emphasises the ethical aspect in dialogue, that is, the openness of one speaker to another. Thus he gives hermeneutics an "ethical twist" and phenomenology an "intersubjective twist" (p.306). Secondly, whilst Heidegger's interpretation can be done by anyone person alone, interpreters in Gadamer's tradition can never proceed alone. Each interpreter's understanding is guided by his or her own history and tradition.

In the following, key aspects of understanding in Gadamer's philosophy will be outlined.

¹¹ see Gadamer 1989, p. 164

3.2.1. Understanding

The focus of this research is to understand how younger people make sense of their experience of having had a stroke. Gadamer (1997) defines various elements of understanding.

The core element of his philosophical hermeneutic is the historicity of our understanding (e.g. p.27) - all understanding is shaped by history and tradition. Therefore what we understand can never be described out of the historical and personal context. It forms our "historically affected consciousness" which is "more being than consciousness"- (*mehr Sein als Bewußtsein*) (p.27). In other words we incorporate norms, attitudes and values. Although we are often unaware of them, they shape our view of the world. The specificity of Gadamer's philosophical hermeneutics is often reduced to and criticised for this historicity of understanding (see for example Crotty, 1998). However, this aspect is important with regard to the issue of objectivity and subjectivity in research. Grondin (1997) describes how Gadamer insists that "what 'we are' consists of the traditions that are alive within us." (p.166). Moreover, in his sense it is our understanding of the world that enables us to ask questions and receive answers – that is, to enter into a dialogue.

In this dialogue the questions we ask based on our previous understanding and given by the *Sache* (subject-matter) open us up to the *Spiel* (play or game) of language that takes place between question and answer. In describing it as a *Spiel* Gadamer tries to show that a dialogue reaches far beyond the consciously constructed conversation. Although we strive to reach understanding in a conversation it is something that can never be achieved, as understanding is infinite.

It is obviously correct that no understanding of one person by the other can ever achieve complete coverage of the thing being understood. (Gadamer, 1997, p.50).

This process is not done as an end in itself, rather it aims to enhance "practical knowledge" based on understanding, which is being generated through research in the praxis (Gadamer, 1997, p.31). "But both the practical wisdom and philosophical

hermeneutics arise out of praxis and are a waste of time without it." (p.57) and vice versa "knowledge is meant to lead [his] doing." (Gadamer, 1990, p.320)¹².

Understanding is understanding **of something** through some form of *Erfahrung* (experience)¹³. Understanding the experience of having had a stroke through this research can be like a *Spiel* in Gadamer's sense. In the following, this core element of Gadamer's philosophical hermeneutics, the *Spiel* is described as another underlying concept for this research.

3.2.2. *The game of understanding*

The word *Spiel* is used to describe anything from a game for one or more people to a play, drama or piece of music. For these multiple meanings of the word *Spiel* here I will use this German expression¹⁴. A *Spiel* (Gadamer, 1990, p.107-174) is characterised by the 'back and forth of a movement'. This movement is without a fixed destiny. Its goal is to be repeated over and over again. A *Spiel* is not serious - it is for relaxation, yet at the same time the players must take it seriously. Someone who does not take it seriously is a spoilsport.

It is not only played once, but continually. It is the repetition of the game that leads the individual to recognise it. Gadamer emphasises that recognition is not only a single act of recognition of something we know already, but a constantly evolving process in which we see more or different aspects every time. The *Spiel* itself contains meaning which is experienced by the players. Repeated recognition of this leads to cognition (*Erkennen*). This process extends all consciousness. Gadamer's aim is to make clear:

that the hermeneutic dimension goes beyond the sort of
thinking that is based on consciousness, that is, beyond what

¹² see Gadamer 1989, p.314

¹³ On different German meanings of the word "experience" see Gadamer 1989, p.xiii/xiv. In addition to meanings described here there is the verb and the noun "erleben". *Erleben*, the verb is translated as to suffer or to undergo (The Collins German Dictionary, 2001), and *das Erleben*, the noun, stands for the individually shaped perception and sense of something we do experience.

¹⁴ In the English translation "Spiel" is translated as "play" (Gadamer 1989, p. 101- 169). However for the reasons given, this is not entirely correct. (See page 119 where Gadamer is referring to the *Spiel* as a piece of music or a drama).

German philosophy calls "self-consciousness"-
"Selbstbewußtsein" (Gadamer, 1997, p.41).

Playing in a *Spiel* is effortless; without strain (*Angestrengtheit*). The players are taken up with it. The "*Spiel spielt sich ab*" (the game unfolds)¹⁵. Not every *Spiel* is the same. Each has its own spirit (*Geist*), which is expressed in the rules and orders which confine its movement to a particular 'playing field'. A *Spiel* is everything: the *Spiel* itself, the players and, if there are, the spectators. The *Spiel* is the subject; it is there independently of the musicians, actors or players yet at the same time it needs these participants. It is only through them that the *Spiel* can come to depiction.

The reproduction of a piece of music or a drama transforms it. Transformation (*Verwandlung*) does not illuminate the original, but the original is still there. In this transformation its sense should become clearer to the audience because it is translated into the present time. However, it is not open to any variations, the criteria is *die richtige Darstellung* - (the correct performance / representation)¹⁶. The interpretation is led by the original piece itself in its time and by tradition (all interpretations up to date). At the same time there is not one particular *richtige Darstellung*. Everything is open to interpretation. However, the "reproduction is obliging and free at the same time" (Gadamer, 1990, p.125)¹⁷.

Gadamer's explication of the ontology of a *Spiel* (or a piece of art) inspires and reflects my own view of this research. I am playing the game of research which is 'obliging and free'. For this study I dedicated myself to researching younger people's experience of having a stroke. I did not start from nothing; rather I built on former research relevant to the experience of having a stroke and the tradition of qualitative research (Gadamer's notion of "tradition"). This constitutes the *Spiel* with its rules and with its playing field. The participants are the players in the piece. They play it within their own personal and historical traditions. This game would be performed

¹⁵ see Gadamer 1989, p. 107, translated as "something is happening"

¹⁶ see Gadamer 1989, p. 119. Here the translators rightly point out that it is not correctness in the sense of simple imitation of a model that is striven for.

¹⁷ see Gadamer 1989, p. 119

regardless of my presence, yet at the same time, it is only my presence and the existence of this research that brings it to depiction.

I am a viewer of their performance. I do not see who participants are every minute of their lives. In a performance actors show in a new light that which is there but would otherwise be hidden. The *Komödie und Tragödie des Lebens*, "the comedy and tragedy of life" is what is acted out. (Gadamer, 1990, p.118)¹⁸. The participants repeat aspects of their experience of having had a stroke and as they repeat, they leave out some aspects and emphasise others. The reproduction is never identical with the original. It is translated in order to make it comprehensible to others (Gadamer, 1993, p.350).

The search for understanding the experience of having a stroke at a younger age is a constant *Spiel*, a back and forth of a movement between a serious performance and being at ease, rules and free space, parts and the whole. It requires interest, total engagement and at the same time distance to the performance. The understanding of this *Spiel* does not have a beginning nor an end; it is a circular movement with the awareness that "parts are determined by the whole, yet they determine the whole", which Gadamer refers to as the 'hermeneutic circle' (Gadamer, 1990, p.296)¹⁹.

Along with the parallels between Gadamer's *Spiel* and this research there are also limitations. One of these is that participants in this research did not choose to take part in any *Spiel*. Indeed, if we define a *Spiel* as a game that we do for fun, describing their experience of having had a stroke as a *Spiel* could rightly be argued to be unethical. Therefore it is important to point out that this analogy does not seek to play down the seriousness of the illness experience. Gadamer uses the term *Spiel* in a neutral way – its only value is the one we give it. Thus this analogy underlines the great openness we need to bring to the research, whilst at the same time acknowledging that we also bring our understandings and presuppositions into it.

Another limitation of Gadamer's philosophical hermeneutics concerns the 'fusion of horizons'. This has widely been described as something that happens when

¹⁸ see Gadamer 1989, p. 112

seemingly different world views are shared (Koch, 1998) or when a nurse really starts to understand a patient's world and acts accordingly (Pascoe, 1996). However, these descriptions appear too simple when applied to Gadamer's philosophy. He refers to the fusion of horizons as something that involves a resurrection of some historical past (Gadamer, 1990, p.380). Later, in his supplement (1993), he extends this, by saying that if two different viewpoints and standpoints melt together it is a fusion of horizons (p.351). I would claim that a fusion of my horizon and of the participants' experience can never happen, not in Gadamer's sense. Whilst I do strive to get as close to their experience as I can, I would consider it a success if our horizons touched each other or overlapped. I do not think there can ever be a complete fusion.

In summary the following principles of Gadamer's philosophical hermeneutics are particularly relevant for this research. Firstly our understanding of another human being and of the world is determined or at least influenced by the knowledge we gained through experiences shaped by our culture and tradition. The values, presuppositions and prejudices created in this way generally help us to understand. Secondly in order to understand something or someone we need to enter into a dialogue. A dialogue is more than a consciously constructed conversation; it is characterised by the *Spiel* of question and answer. Thirdly this *Spiel* is the infinite action of interpretation with the goal of reaching understanding. Constant movement between the parts and the whole results in repetition, recognition and thus enhancement of cognition. The fourth principle comes into play in this process: the transformation of the original. This transformation is obliging in that it needs to follow rules and is bound to the original yet at the same time it is a free and creative act.

In this obliging and yet creative process of gaining access to the experience of younger people who had a stroke and to interpret it, the rigorous application of research methods is a prerequisite.

¹⁹ see Gadamer 1989, p. 291. Here the translators speak of detail instead of parts (original "Teile")

3.3. Rigour

The term rigour is used to describe criteria to evaluate the quality of a study, traditionally understood to be reliability and validity. Writers who subscribe to this term not only seek to overcome the positivist language and to vote for the use of different language to describe what makes interpretative research 'trustworthy'. More importantly they emphasise the fact that rules for good quality research applied to research under the positivist paradigm do not apply to subjectivist approaches, particularly to feminist or hermeneutic studies (Koch and Harrington, 1998, Harrison et al., 2001, Sandelowski, 1993). Instead of claiming that multiple realities of the social world should be reproducible by different researchers at different times in different settings (as reliability is defined for example in Powers, 1995) it is acknowledged that:

Even when confronted with the same qualitative task, no two researchers will produce the same result; there will inevitably be differences in their philosophical and theoretical commitments and styles. (Sandelowski, 1993, p.3)

The mere aim to reproduce results would violate the perceived assumption that phenomena under study are subjectively created in interaction with an environment. However, any effort to study systematically the social world would be reduced to absurdum if there were nothing stable to be studied. The debate is concerned with how to make qualitative research trustworthy, in other words believable to the reader. If this is to be achieved it is of little help to emphasise qualitative research as art and reject rigorous application of rules (Sandelowski, 1993) or to emphasise the reciprocity of the relationship between researcher and participant (Harrison et al., 2001).

Although these are important aspects of qualitative research, any research needs to follow rules and to "describe to the readers 'what is going on' while researching." (Koch and Harrington, 1998, p.889). This is achieved through a process of reflexivity in which the researcher has to reflect on the entire research process. According to

Koch (1992, 1996, 1998) the methodology (the theory behind the methods) "describes the process by which insights about the world and the human condition are generated, interpreted and communicated" (1996, p.174). She introduces key philosophical constructs of Gadamer's philosophical hermeneutics to demonstrate how the hermeneutic circle, dialogue, the fusion of horizons and prejudice shape her understanding and interpretation. To ensure representation (the question of whose voice is being heard) she demonstrates how her understanding from literature as well as from her personal background participated in making the data. Legitimation (rigour) in her research is demonstrated by a thorough description of her decisions, thoughts and underpinnings as well as by a process of self-reflection and the use of a field diary to ensure the research was kept in context. In addition to this she draws on Guba & Lincoln's concept of 'transferability' (Koch 1992, 1996, 1998). Thus she demonstrates what she means by determining criteria for her own research in relation to her philosophical and theoretical background. In addition to this she gives an account of her analysis and how she transferred the philosophical background into the research so that the reader is able to decide on the quality of the research.

Fleming et al. (2003) also use Gadamer's philosophical hermeneutics and identify five steps that are to guide nurse researchers. Basically these steps describe how to move between the whole of a research account to its parts and back again. Bearing in mind the philosophical principles in Gadamer's work outlined above, these authors' attempts are questionable at the least for their benefit for rigorous research, if not for their appropriateness. For instance, the authors advocate multiple interviewing following Gadamer's emphasis that our understanding is bound to a historic situation. Looking at Gadamer's interpretations this assumption is questionable since he mostly interprets existing texts such as poems or Mozart's *Magic Flute* and thereby demonstrates how the various historic situations of these interpretations are taken into account (Gadamer, 1967).

Apart from applying philosophical and theoretical principles to the research, the use of methods to ensuring rigour are also to be considered. Conrad (1990) describes that in research on chronic illness these are decisions concerning sampling, generalisability and interviewing technique.

The criteria used to select people for a study clearly has a profound effect on the research. (Morse, 1991, Thorne et al., 2002). Regarding stroke most researchers recruit the participants from a hospital setting, thus excluding people who were not admitted to hospital. As a result, findings can only represent certain people's experience and may not be representative of others.²⁰ A good sample should allow a general statement to be made about a whole group of people. Thus the issue of sampling has to do with the generalisability of findings (Silverman, 2000). Although some authors would claim that generalisability is not sought in qualitative research (Parahoo, 1997, Janesick, 1994), others (for example Silverman, 2000) suggest that generalisable results are produced through applications of adequate sampling procedures, for example in choosing a purposeful sample which is likely to include the subject under study. Conrad (1990) on the other hand stresses that research on chronic illness experience should seek to produce generalisable results in terms of concepts, not of single cases or of data.

Not only the participants in research but also the method used to collect data influences the quality of the research. The key method in investigating the experience of having a stroke in nursing research is interviewing. This is employed in all studies, sometimes amplified by observations, questionnaires and measurements such as the Barthel Index or ADL scores (Ellis-Hill et al., 2000, Ellis-Hill, 2000, Lui and Mackenzie, 1999). The use of interviews in all studies implies that people who suffer from severe aphasia or who are not articulate for cognitive reasons are excluded from investigations in nursing. This is not to say that there are no studies on the experience of people with aphasia (see for example Tacke, 1997). Furthermore measuring functional abilities when researching experience from the participants' perspective implies that subjective functional well-being needs to be complemented by 'objective' measures and cannot stand on its own.

²⁰ The issue of sampling becomes ethical when considering that there are popular and unpopular diseases and groups of people who are studied frequently in chronic illness research: competent, articulate, white middle-class women with rheumatic, cardiovascular or endocrine diseases. Illnesses that influence verbal communication (such as stroke) are unpopular (Thorne et al., 2002)

Chronic illness research seeks to capture the process and changes of the illness trajectory, therefore Conrad (1990) questions the suitability of one-off interviews and suggests multiple interviewing with a six to twelve month gap between sessions.

However important these thoughts about methods are, they are purely rhetorical if the story produced by the research is not plausible. Even more so, they are unnecessary to determine if, as Melia (1997) points out, the link between the description of the actual approach and the philosophical position described to justify methods is clear. By reflecting on her research with student nurses in the late 1970s and on the development of grounded theory, she points out that the use of methods should be pragmatic rather than overly concerned with epistemological backups and description of methods. The overall goal is "translating data from the field...into an explanation of the topic in hand which can be conveyed to others and understood by others" and she goes on to state "If we can collect data with which to tell a plausible story, perhaps we should settle for that" (p.35).

Part of making research plausible involves demonstrating the process of how an interpreter has made participants' experiences understandable to a wider audience (Gadamer, 1993, for example pp.345, 350). This process as it evolved in this research is described following the four principles of Gadamer's philosophical hermeneutics that were outlined earlier. Thus from providing background information and ethical underpinnings (due to the historicity of understanding and prejudice) it turns to issues about data collection and dialogue. Then Gadamer's philosophy of understanding and of textual transformation provides the framework to describe the procedure of interpretation of this research. Wolcott's work regarding transforming qualitative data and on writing (Wolcott, 1994, 2001, 2002) is woven into this structure.

3.4. Background of the researcher

Following the first of the principles outlined above it is important to describe the background I bring into my interpretation and understanding of this research.

Firstly and most importantly is the fact that I myself had a stroke at the age of thirty. This event inspired this research and has been my main motivating factor. Although my speech and the hemiplegia of the right side of my body recovered quickly, I was shocked by the diagnosis of having had an ischaemic stroke at this age and by my feelings after the stroke²¹. What struck me most was how little care I got from nurses. Since I was independent in my daily activities nurses did not provide any care for me. From this background, I bring into this research my experience that younger people who had a stroke are not well cared for and my conviction to investigate whether this was only my personal experience or similar for others.

For me the stroke was a hard experience which threw me off balance for at least a year. However, now I have integrated it into my life and its meaning has changed from being a threat to being a chance in life. During my research I was particularly careful to keep my feelings, including this last insight, separate from the participants' experiences and struggles. Of great help for this was my reflection on the experience of my stroke in a long process of counselling which lasted through most of the research period.

From this background I am part of the group I am studying - I am an insider. This means that I can never be objective, although "objectivity should be the common aim of all social science" (Silverman, 2000). Objectivity in the sense referred to here is not meant to be judgement free but as Hammersley (1995) argues the researcher's values must be made explicit. My role is that of an observer and an interpreter who is part of the *Spiel*.

I am sitting in the audience. As a member of the audience, so Gadamer (1990) says, I am part of the play. My duty is to be there, to 'pay attention'. Gadamer calls this 'to give oneself up' (*sich hingeben*). It is different from someone who is seeing a play just out of curiosity, who remains detached. To be a member of the audience in Gadamer's sense means to engage in the subject-matter (*Sache*) for the duration (his orientation to the "*Sache*" in interpretation). *Sich hingeben* is to be 'out of oneself'²²

²¹ For a more detailed description of my experience please see the manuscript of the radio broadcast in the appendix.

²² see Gadamer 1989, p. 126. Also referred to as self-forgetfulness.

(*Außersichsein*). "In truth, being out of yourself is a positive possibility of being completely present at something" (Gadamer, 1990, p.131)²³.

This means it is important to distance my own self and thus my own experience of having had a stroke from the participants' experiences, and at the same time to 'give myself' (*sich hingeben*) as the person I am. In Gadamer's terms it is the "truth of his own world, the religious and moral world in which he lives, which reveals itself to him and in which he recognises himself" (Gadamer, 1990, p.133)²⁴ that I bring into my observation and interpretation. Someone who denies the prejudices that come from this will find him- or herself ruled by them (1990, p.366)²⁵.

Gadamer shows how background influences understanding; it has certainly influenced my view of participants and of the dialogue and the way I ask questions. It is this second principle of Gadamer's philosophical hermeneutics that this chapter now turns to.

3.5. Dialogue and ethical implications

As mentioned earlier Gadamer adds an ethical dimension to phenomenology by emphasising that the other (in persona as well as in a text) has to be seen in his or her uniqueness and otherness²⁶ (*Andersartigkeit*). The ability to "truly accept something" from the other person requires an openness and curiosity that assumes that the other person (or the text) has something to tell me (Gadamer, 1990, p.367/368)²⁷. Following Gadamer's ethics raises questions regarding the hierarchy in a conversation or of power of an individual over another as raised in much research literature - feminist (Bergum, 1991) or other (Hammersley, 1995).

To me the participants in this research are partners in a dialogue; there is no hierarchy of power. To emphasise the back and forth in the dialogue, throughout the thesis I do not speak of 'interviews' but of 'conversations' or 'talks'. That there is no hierarchy in the talks is not contradicted by the critique that the researcher who sets

²³ see Gadamer 1989, p. 126. "In fact, being outside oneself is the positive possibility of being wholly with something else."

²⁴ see Gadamer 1989, p. 128

²⁵ see Gadamer 1989, p. 360

²⁶ This word is used by Gadamer himself (Gadamer, 1997)

the agenda, asks the questions and interprets the results implicitly holds the power (Hammersley, 1995). On the basis of Gadamer's philosophical hermeneutics I would argue that power in this sense relates to having control over the process. The question is whether I use this power to obtain a good outcome or whether I misuse it as to oppress others.

As a researcher it is my duty to be in control of the research process, to keep it focused and to be responsible for it. Within this framework I need a continuous openness and curiosity towards the other person; I must also acknowledge my own ignorance.

In order to be able to ask one must have the desire to know,
this means however: knowing that one does not know.
(Gadamer, 1990, p.369)²⁸.

I need to be aware of the other person's otherness (*Andersartigkeit*). Any question that lacks this is a *Scheinfrage*, or fake question²⁹. Every question has to be open and at the same time focused on something, a limitation to the answer.

These principles of absolute respect for participants' otherness and open questions have increasingly led my research. Through constant reflection on occasions and my own feelings I grew into this openness.

The openness to the other and the reflection on one's own prejudices is to me the most ethical implication of Gadamer's philosophical hermeneutics for research. It requires a dedication to the subject-matter, self-awareness and reflection in every part of the research process. These reflections must be written down in a diary to keep as much of the process as possible (an account of this is given in Chapter V, p.201)

This background knowledge provides the basis for the following description of the research process, starting with access issues.

²⁷ see Gadamer 1989, p. 361/362

²⁸ see Gadamer 1989, p. 363

²⁹ see Gadamer 1989, p. 363, translated as "apparent question"

3.6. Ethical dilemma of access

Access to participants in this study was obtained through a stroke unit of a University hospital in south-west Germany. Although most younger people in the area who had a stroke would be admitted to this stroke unit I am aware of the fact that younger people who were not are excluded from the study.

There was no ethical approval to be obtained for this study and access to participants was very easy. However, the lack of any ethical guidelines contradicts my values and beliefs and was difficult for me. It can only be explained by the fact that in Germany nursing research is still in its infancy and gatekeepers are not yet used to this kind of research.

The procedure needed to obtain access was as easy as a fifteen minute talk between the nurse manager, one of the head doctors of the neurological clinic, the ward doctor, a nurse from the stroke unit and myself. It was agreed that I would call the ward physician once a week to ask for people who met the inclusion criteria. He would then ask permission from the person to see me. If that permission was given I would visit that person to introduce myself and the study.

I provided written information about the purpose and design of the study as well as the information sheet and the consent form for participants. However, no one was interested in seeing them.

In the following months the ward doctors constantly changed. Although none of the new doctors knew about my research they were willing to give me all the information I needed over the phone: whether there were any people who had a stroke and were younger than fifty-five, what other illnesses these people had, and to allow access to these people.

There was no protection of the 'patients' at all. None of the participants was asked permission for me to see them although I asked physicians to do so. Access was easy: not one of the (constantly changing) staff on the stroke unit (which is an ICU) asked me who I was. At a meeting where I introduced my research to the nurses of the ward I raised this issue but to my knowledge this had no effect at all.

I was aware that it was my duty to ensure as much protection for participants as possible. I did this following several principles. Since people who had a stroke can be in shock during the first meeting, (Scheidt and Schwind, 1992) the initial visit was kept short. I approached them in an empathetic and non-threatening manner and asked their permission to stay and introduce myself and the study. If they agreed I then did so. As my own experience of having had a stroke has been the motivation behind this research I decided to tell them that I had a stroke myself. However, I made sure that the attention was not on my but on their experience. At this initial meeting they were given an information sheet and consent form as well as a stamped envelope. Most of the people decided to participate at this stage and signed the consent form right away. In these cases I assured them that anonymity would be strictly ensured and I pointed out that they could withdraw at any point without giving any reason. (Weaver Moore and Miller, 1999, Silverman, 2000)

With this procedure I felt confident regarding the ethics of access although the lack of confidentiality and of patient protection was striking. When I later asked permission to obtain information from participants' medical records, similarly no one took note of the written consent given by participants. Access to this data would have been no problem even without participants' permission.

The positive side to this is that I had to reflect on ethical considerations in research. I have become aware of the many ethical implications that are inherent in research, of the lack of any ethical guidelines in German nursing research and of the work that needs to be done to change this.

3.7. Dialogue and data collection

The data collection started in June 2000 and ended in March 2002. During this time three conversations were held with each of the participants. These conversations followed a semi-structured, in-depth arrangement, according to a topic guide that was developed from the results obtained in a focus group meeting.

This meeting, in which seven people aged between thirty-four and forty-eight took part, was held in April 2000. Access to addresses was provided by one of the leading

doctors of the University hospital. Inclusion criteria were: aged under fifty-five, first ever stroke, no other chronic or acute illnesses and able to communicate. Since I was seeking to investigate the experience during the first year after the stroke, members of the focus group had had a stroke at least one year ago. The aim of this focus group was to capture the variety of people's experience of having had a stroke and to identify common themes that could form a topic guide for the individual conversations. In focus groups it is believed that the group dynamic helps to bring attitudes and beliefs to the fore that would otherwise be hidden (Kean, 2000). I was primarily interested in the content of the discussion, not in the group dynamics. Since group dynamic is of primary concern in this method (Kitzinger, 1994, Kean, 2000) it might be more accurate to speak of a group discussion instead of focus groups in the context of this research.

The meeting was held in a neutral setting and I provided snacks. After the issue of confidentiality was addressed and members had introduced themselves, the discussion between the members evolved, requiring a minimum of involvement from my side. The discussion was recorded using a mini-disc player.

For analysis I listened to the tape several times and extracted quotes. A verbatim transcript was not regarded as important since the goal was to identify overall issues, not provide detailed information. Issues were grouped using the cognitive mapping technique. This method has been described to be useful for research in that it:

generates a picture of the constructs and ideas of individuals and of groups in an 'intersubjective' way that combines the researcher's view with those of the respondents. (Northcott, 1996, p.458)

In this study themes emerged concerning physical function, psychological problems, spirituality/ identity, experiences with care, causes for the stroke and fears about the future. For the topic guide these issues were grouped under the headings 'health issues and stroke', 'image of self', 'stroke and care' and 'thoughts about the future'. These broader headings allowed me a more open approach during the conversations.

This group discussion also led to revision of the inclusion criteria in that I decided to exclude younger people with haemorrhagic stroke. This was because the one woman in this group with a haemorrhagic stroke did not share many of the other people's concerns; the cause for the bleeding was clear and operated on and thus unlike the others she did not worry about causes and the uncertainty of future strokes. On the other hand she had more problems with motor function than the others. My impression that the type of stroke could influence the experience was confirmed by Hafensteinsdóttir and Grypdonck (1997) as they state that it is "...not unlikely that different types of strokes, with differences in onset, symptoms and sequelae, lead to differences in experience" (p.582). My interest was on younger people's experience of ischaemic stroke; firstly from my own experience and secondly because this is commonly thought of as affecting older people.

Although this group meeting was set up as a one-off event, at the end of this meeting the participants enquired about the possibility of further meetings on a regular basis as a form of self-help group. Thus as an unintended by-product of this research, the first official self-help group for younger people associated with the "Deutsche Schlaganfall-Hilfe" (equivalent of the Chest, Heart and Stroke Association) has formed. It has twenty members and meets on a monthly basis.

As indicated earlier, participants of this study were approached in the hospital setting for initial contact and in order to introduce myself and the study. Three people (all women) decided not to participate in the study; however, no one dropped out during the process.

The intervals for the conversations were three, six and twelve months after the stroke. This parallels intervals described in other studies (see for example Dowswell, 2000). The timespan of studies on the experience of having had a stroke differs widely between the first three weeks after the stroke (Backe et al., 1996), twelve months post stroke (Lawler et al., 1999, Kirkevold, 2002) and up to three years after the stroke (Boynton De Sepulveda and Chang, 1994).

As described in the previous chapter, multiple conversations are obligatory in order to capture the process and longitudinal impact of the stroke or any other chronic illness on participants. As Conrad (1990) states:

Since most qualitative research on chronic illness focuses on process or change, it is probably most useful to conduct multiple rather than single interviews. While this may necessitate a smaller sample, 2 or 3 interviews of the same respondents 6 months or a year apart can more accurately capture and highlight change (p.1258).

As described in Chapter I recovery after stroke is expected to be rapid in the first six months and to slow down afterwards. Therefore a shorter timespan between the first and second conversation and then six months time to the third was chosen to be appropriate for capturing the change process.

In order to give participants time through the first phase of the grieving process (Scheidt and Schwind, 1992) I decided not to do the first in-depth conversation in the first three months after the stroke. Whilst this was a sound decision at the time, in retrospect I would say that a first conversation at six weeks after could have been beneficial for capturing feelings about nursing and health care nearer to the experience and would still have taken account of the grieving process. However, it had been unforeseeable that recovery would be this rapid and that participants would hardly need any nursing care after the first few weeks.

According to participants' preference, most conversations were held in their own homes. Three participants chose to meet in a pub or in a cafe. Although all these settings were sometimes subject to disturbance, participants seemed to feel comfortable in their chosen settings. This also allowed me to be 'in the field' and to make observations in the natural setting of participants' lives. For example Thomas chose to meet me in a pub where he met his friends after we had finished our conversation. Sofie met me in her own pub and thus provided an insight into her social environment. Robert and Matthias chose to have their wives participate in the conversations, thus revealing something about their marital relationships. Two of the first conversations took place in the rehabilitation clinic, both with people who had undergone heart surgery; this influenced the conversation in that most of it was around this topic.

In the different environmental conditions recording with a minidisc player was of great help because of the excellent recording qualities.

The topic guide, initially developed from the group discussion, remained standard through all the conversations, but was altered slightly to allow individually raised issues. It consisted of overall topics that were covered according to the flux of the conversation, not in a pre-set order (Mishler, 1986). The multiple conversations allowed me to pick up on issues and to raise them in later conversations. Sometimes I used data to probe and generate more data (see for example Chapter V, p.177). I usually started the conversation by asking what had been most important or significant in the time between the conversations.

All conversations went well and had a friendly atmosphere. They lasted between 35 and 75 minutes. Although all participants knew that I had a stroke this issue was rarely brought up by anyone. On their request two participants received the transcripts.

Multiple contacts were very important in this study. They allowed me to reflect on issues and to explore some of them in more depth. During the four contacts a trust was established between the participants and myself that allowed more sensitive issues to be discussed.

However, I learned from my research experience that there is a downside to the openness advocated earlier in accordance with Gadamer's ethical implications. This downside had to do with my own limitations. It was when Andreas, who was the same age as myself, talked openly about problems in his partnership. Innocently I asked him at some point how the stroke made him feel as a man. In response he told me about his fear of becoming impotent (in connection with the dialogue reported on p.183/184). In this situation I felt very uncomfortable for several reasons. Firstly and most importantly I sensed that he liked me and might have been interested in me as a woman. In response I tried to keep the conversation friendly but distanced. Hearing about his fears regarding his sexuality was more than I wanted to know, bearing in mind his possible interest in me. I learned from this that my openness is limited and

that the intention to establish a relationship of openness and trust can confront me with my own limitations. I also realised how important it is to keep within my own limitations and not to provoke a situation that I know I cannot or do not want to deal with. As a consequence of this I never asked this question again, although I appreciate that important issues such as the one raised by Andreas might have thus remained undiscussed.

As was described earlier the participants (players in the *Spiel*) bring their background into the game. This means taking not only my own past and present being into consideration but also the history and circumstances of the participants, as well as the social and cultural context in which the whole research takes place. To provide grounds for this in the interpretation the background of the participants is now described.

3.8. Background of the participants

Albeit unintentionally, all eleven people (five women and six men) in this study share several aspects of their social and cultural background. All are German, all living in mostly rural areas of the south-west and speak the strong local dialect. All of them can be described as skilled workers and everyone was employed at the time of their stroke.

The inclusion criteria were being under fifty-five years old, having had a first ischaemic stroke and being able to communicate.³⁰ The age limit of fifty-five was not arbitrary but reflects the regulations in Germany concerning occupational rehabilitation. Although German law (SGB IX, §§33-38) does not set an age limit on this, a member of staff at a major retirement insurance company told me that long term rehabilitation (for example two years training in order to qualify somebody for another job) was more easily obtained for people under the age of fifty-five (phone conversation, January 2000). I wanted people for whom occupational rehabilitation was an issue and who could be considered to be ‘younger’ people after stroke.

³⁰ For details about age, gender and marital status please see table in the appendix.

All of the participants recovered from their visible symptoms quickly after the stroke. However, many shared invisible problems of fine motor movement, memory, concentration, fatigue and intolerance of stress and noise.

The participants' cultural background is influenced strongly by the Christian tradition and by the farming tradition of the area. The unemployment rate, although low compared to other parts of Germany, is approximately 8%, making it an issue for people in this area.

3.9. Understanding and transforming data

Since understanding and truth reach far beyond what can be researched by applying methods, (Gadamer, 1990, for example XXVII/XXVIII, Gadamer, 1997) using scientific methods to find truth would mean restriction and limitation. Gadamer does not offer a method for the interpretation of texts. According to him we interpret using our "common sense" (Gadamer, 1990, p.27ff)³¹ or our "feelings" (p.194)³². Although I do agree with him it does not help a novice researcher as myself to know that "Hermeneutics is art and not a technical procedure" (Gadamer, 1990, p.194).

At first I hoped to find a prescribed way of interpreting data in Gadamer's texts - there is none. Sometimes the hermeneutic circle is described as procedure of interpretation. This contradicts at least Gadamer's philosophical hermeneutics which calls it "the circle of understanding" and says that it "is never a methodological circle but it describes an ontological part of the process of understanding" (Gadamer, 1990, p.298/299)³³.

I found Wolcott (1994, 2001) offered a practical and useful approach to transforming qualitative data. It was method enough to help me working with the data but it was not too much of a method to restrict interpretation in Gadamer's tradition. Wolcott emphasises the second step of the process in which qualitative data which is already at hand is "transformed into intelligible accounts" (Wolcott, 1994, p.1) He uses the word transformation in the general sense, describing how data undergoes "a marked change in nature, form, or appearance" (Compact Oxford English Dictionary). In

³¹ see Gadamer 1989, p. 22 ff

³² see Gadamer 1989, p. 191

³³ see Gadamer 1989, p.293

short he suggests three steps for 'transformation' of data. First he advises the researcher to make descriptions about 'what is going on', including excerpts from the conversation as well as observations made by the researcher. This is followed by the second step, analysis, which involves identification of essential features and interrelationships, guided by the question what 'is there' and grouped under codes. Since this is the more technical approach, possibly involving the use of computers, he suggests that we speak of data *processing* rather than analysis. The last step may spring from the first or come after the second: interpretation. This is guided by the question as to what is to be made of it all. Here Wolcott (1994, 2001) offers some general thoughts rather than offering a method of interpretation. He warns novice researchers of the danger of inaccurate interpretations and reminds them that the goal is to reach out for understanding and to organise thoughts (for example 1994, p.10, 37). Wolcott emphasises the fact that each of these steps is already interpretation in that certain aspects are highlighted at the expense of others and of the context.

Immediately after each conversation I noted my observations and feelings during the time I spent with the participant, which helped me to retain the subtleties of the conversation. When I got home I transcribed the conversations verbatim on a personal computer. This immediate transcription allowed me to reflect on how the conversation had gone, how participants responded to my questions, if and where I asked leading questions or missed something important that I wanted to pick up on in the next conversation. According to Wolcott's steps this was followed by a description of the conversation, thus identifying broadly the issues raised. At first I did this in my own words, but as I continued I used almost exclusively excerpts from the conversation and let the data "speak" (Wolcott, 1994, p.10). Thus I got a first idea of 'what was going on'. I planned the conversations so that it was possible to keep this process together in a short period of time, usually two to three days.

After this I moved to the second step, the analysis using the ATLAS/TI version 4.1 computer package for working with qualitative data³⁴. As suggested by Wolcott

³⁴ Coffey and Atkinson (1996) argue against coding of narrative descriptions of experience because of the risk of losing the content. Lofland and Lofland (1995) argue that computerised filing of coded data allows more data to be handled than when done manually. However, they suggest the use of software

(1994) I read through the texts and coded them, meaning that I identified patterns, compared them with others and evaluated them. As I contextualised them within an analytical framework, codes such as ‘biographical disruption’, ‘interpersonal relationships’, ‘management strategies’ and ‘view of self’ emerged. These codes indicate how much my analysis was driven by theoretical frameworks at this point, instead of being led by the data.

To display the findings (Wolcott, 1994, p.31) I either produced a mind map linking short quotes to codes or produced a ‘network’ using ATLAS/TI. This display helped me to avoid focusing on specific codes and helped me to see the whole (albeit already reduced) picture. Furthermore, it allowed me to keep the data in the context of the individual. Additionally it forced me to read the transcripts several times, bringing me closer to the data. However, after all three conversations were completed with a participant I felt that I had lost the sense of each individual’s illness trajectory and had lost the feeling as to what themes had emerged when and how they had changed over the year. I had to find a way of getting more of a feeling of ‘what was going on’ during the whole of the year, so I decided to go back to the first step and produce descriptions of all three conversations with each individual.

For this purpose I abandoned the coded transcripts and returned to the original transcripts. As I reread the transcripts I made a cognitive map on A3 paper of issues brought up by each participant. Through this procedure I realised that the codes used initially did not capture the issues that emerged when looking at the whole picture of each participant. The codes were thus changed to ‘stroke experience’, ‘from cause to meaning’ and ‘back to normal’.

During this process I learned to stay closer to the data. As suggested by Wolcott, I moved from the first step of description straight to the interpretation. My intention was to write up the data according to the themes identified. However, I learned what it means that:

*No research has been done, in any sense that counts, until
writing has been done; and those who speak of ‘writing up’*

only to store qualitative data, not to *analyse* them because the software programmes are too limited.

rather than writing betray a total ignorance of what they are at
(Watson, 1987, p.40; italics in original).

The pitfalls I was facing when I started to write were threefold. Firstly I was trying to compensate for my lack of confidence in what I was stating about the data by drawing constantly on theory. Secondly my codes allowed me to focus on the personal aspects of the experience but neglected the influence of social relationships and of work. Thirdly my writing did no justice to the changes that happened throughout the year, one of the main themes that came up from the data. It took two drafts of first chapters before I realised that I had to go back to the original data again and see 'what was going on' but had been missed so far.

In the infinite movement back and forth as described in the *Spiel*, participants spoke about how their lives had changed, about their different outlooks on life and their negotiation or reconstruction of their selves over the year after the stroke; the selves as individuals but also in relation to others and to work. Again I read through all the transcripts, for example of the first conversations, and wrote quotes that related to self onto a big sheet of paper. Through reading, writing down, displaying and thinking I arrived at a deeper understanding what participants were telling me. Before I was too much in the *Spiel*. Now I was doing what Gadamer (1993) calls the function of the interpreter: I had to disappear in order to achieve the aim of reaching understanding (p.350). In other words I had to be 'out of myself' in the *Spiel* in order to be 'totally engaged in it'. In MacLeod's (1990) words: through constant writing and re-writing interpretation and deeper understanding emerged.

An important issue in transformation of the data is the issue of translation. Gadamer (1993) says that "Every translation, even the so to speak word for word repetition, is some form of interpretation" (p.342).

I had to do two translations: first when I transcribed the talks from the strong spoken local dialect into written high German and then the second translation of high German into English. Apart from doing the linguistic translation, there is also a need for cultural translation.

Cultural translation must accommodate itself to a different language not only in the sense of English as opposed to Dinka, or English as opposed to Kabbashi Arabic, but also in the sense of a British, middle class, academic game as opposed to the modes of life of the 'tribal' Sudan. (Talal, 1986, p.159).

In translation I have often had to decide which of many possible words to use. For example what does the participant who talks about a "Kumpel" mean? Is he talking about a friend, a lad, a guy, a colleague or a mate? To ensure I kept the danger of over-interpretation to a minimum I made sure that the process was as consistent as possible: I collected the data in the cultural background I come from and the dialect I speak myself, I conducted the conversations, the transcription and I translated most of the passages of the text that I quoted from. A Scottish woman who lives in Germany got my texts written in English with the quotes in English and in German. She checked and corrected my translation and we discussed any remaining questions. Although this worked very well I noticed that my ability to express aspects of German culture in the English language was limited. The woman who corrected my translations mentioned difficulties to do with dialect expressions, for example references to "Carneval" or with German's typical long sentences. She also was very conscious of the fact that the spoken word conveyed more than what she saw on paper, yet realised she should not read too much into the meaning.

The experience of having had a stroke can be seen as what Gadamer would see as a *Spiel*, the constant movement between the questioned selves in the social environment and cultural factors, mainly employment issues. It is the interpretation of these experiences that this thesis now turns to.

Chapter IV

Self

Identity formation and self-definition are issues that have led to a vast number of psychological and sociological publications. For the purpose of this study it is useful to give a few definitions from selected writers in this field and thus to define briefly what is meant by self and identity. Kelly (1992), in his sociological work with people who suffer from colitis, constantly describes the implications of this illness experience for the self and for identity. He gives a brief and straightforward definition:

At its simplest the term 'self' refers to the inner and private view an individual has of him- or herself, while identity is the public view which others have of that person. (p.50)

Of course the private self and the public identity are not two separate entities. We are always both self and identity. Furthermore, these parts are in constant motion. The psychologist Craib (1998) speaks of the self as the inner space. For him it is from this that we appraise the outside world. He gives an example of the relation between self and identity: according to his social identity as a man he could join a men's group to develop his "'real' masculine self" (p.170). Thus he would open up his inner space (self) by becoming conscious of the chauvinist elements and develop a new self. This example only gives an idea of the complexity behind reorganisation of the self.

I can talk about myself as a complex object, as containing (in interactionist terms) several or many 'mes' or (in psychoanalytic terms) a number of levels and objects. I am constantly trying to reorganize these contents in conscious and unconscious narratives, in which I both control and am controlled by different elements. (p.171)

In participants' accounts about their experience of the stroke there was a strong element of a private self, a self that dealt with the illness in a way that they did not show to others. This recalls what Leder (1990) refers to from his phenomenological viewpoint when he says that certain situations, such as illness or pain bring out "the body-for-me" (p.93), the body as an explicit and private object. This is what this first of the three chapters on participants' accounts will describe.

This was of course not the only dimension. Another dimension was the way in which they seemed to define and re-define themselves in relation to others and the third how they described themselves at work. Since the self is constantly created and re-created, mostly in relation to others, these three dimensions are clearly closely linked. The chapter division here - the self (Chapter IV), the self and others (Chapter V) and the self and work (Chapter VI) is for presentational purposes and is beneficial for two reasons. Firstly it does justice to this inner space, the 'body-for-me' that appeared as a strong element in the accounts. Secondly it highlights the three main dimensions described by participants: the individual, including metaphysical; the social; and work as a social space of particular importance. The separation is not to suggest that these would be separable. They are inextricably linked.

As has been said in the last chapter, openness and thinking across boundaries is the key principle in Gadamer's approach to understanding. Whilst this has been highly beneficial in that it prohibited focusing on certain aspects in early stages of the interpretation, later the downside of this openness became apparent: Gadamer's philosophy provides little clues regarding social structures; critical thoughts about cultural influences on the modern world, for example on health and illness, are almost absent. Here writings within medical sociology or anthropology, and thus mainly within social interactionism and phenomenology provided structure and focus for this thesis. The structure of the chapters into self, self and others and self and work are a result mainly of the influence of social interactionism on this work.

4.1. The first three months

This period can be characterised by attempts to recover from the stroke. Two participants (Thomas and Michael) were still in rehabilitation after undergoing heart surgery. Most participants seemed to still be concerned with finding out whether

anything had changed for themselves after the stroke, and if so, what. One could also say that the impact of the stroke seemed to be appraised in terms of the past or present, with little thoughts into the future, which remained uncertain.

4.1.1. A stroke is a disruption

None of these younger participants had ever thought that they could suffer a stroke. In Andreas' words "*I would never have thought that I could get a stroke at my young age*". Sofie, for instance, had been sure that "*I'm young, nothing could ever happen to me*". It was "*absolutely unexpected*" and "*came out of the blue*" (Robert) for all of them. All of the participants led a life that could be described as normal for younger people in a modern society, and their self-image was in keeping with this. As Matthias described, for example:

I felt, probably not like a young God, I wouldn't claim that but as if nothing could ever happen to me, as if everything was in order.

In such a situation the stroke was "*the end of the world*" (Andreas) for some of the participants.

I think, well it changes everything...I mean I realise that now, that it's changed a lot of things and I am not able to live as I did before and my main worry now is whether I can ever be the same as I was, that's really the question.

Thus Andreas indicated that the stroke was about changes: in his way of living and of being. According to himself, Andreas lost a lot due to the stroke. In this first talk he said that before the stroke he was a 36-year-old man who was earning a good salary working as a lorry driver, and living with his girlfriend. Apart from work, his main interest was playing darts with his friends, at which he had been very successful, winning many tournament trophies. Now he was still off sick, had problems in his

relationship and was not able to throw darts with his right hand. He tried to explain why he was different referring to changed bodily function:

I mean I realise that it's no longer like it was the way I think, the brain and that, I wanted to say more or take a risk or whatever, but it's not on anymore... I think about it, but I can't get it out...and I now really have problems walking or if I write a lot, it's just not like it was before, and when everything is okay again, then I think I will be the same as before.

Thus, according to Andreas the stroke led to a difference in the way he did things. The data suggests that this was an important issue for many of the participants. They appeared to struggle to various degrees with their symptoms, i.e. with memory and concentration problems, problems tolerating stress and noise or with fatigue³⁵. However, they were all still able to do everything, just differently than before. Judith described how fatigue impacted on her daily life:

Whenever I do something I have to sit down and rest, then I carry on for another half an hour and depending on what I'm doing, you know, totally normal things, I'm absolutely shattered.

Judith constantly compared her (in)ability to do things with her abilities before the stroke. The measure of her abilities was therefore working in an interior decorating shop for twelve to fourteen hours a day, plus doing additional sewing of curtains for people at home plus managing her household. Working and earning money had been very important to her. She was divorced, in a new relationship and living in the same house as her grown-up son.

³⁵ Please find an overview of impairment impacts in the appendix

Participants talked about their changed bodily function. However, their image of self revealed a much more complex picture than a collection of different impairments. Andreas described himself as *"a heap of misery"*. Judith spoke of her self as:

You know, like half a person, this person is missing half [gesture down the body vertically]... cut me here down the middle - one half is still functioning and you can put the other half [gesture to the right] away in a corner because it's no use anyway.

A stroke is experienced in the body. Self-images of being a heap of misery or half a person emerged as one way of expressing how the stroke altered participants' self-image. It is important to note that none of the participants had any long-term symptoms of the stroke that would have been visible to others. Thus Judith's feeling like half a person was not due to hemiplegia, but could rather be described as an expression of the embodied self-image. Being like this appeared to be unbearable, or as she described it: *"It's a huge problem for me – it makes me mad, it really pisses me off."* She felt like *"the biggest idiot, ...like a fool, ...not quite all there."*

Karin added another dimension to the experience of a stroke when she described how she felt:

I also had the feeling to begin with, gradually, I'm still fighting it, but I also had the feeling that something was wrong with my brain. After all my brain is damaged, yes, I'd say it is [with tears in her eyes].

Here Karin referred to the brain-damaging nature of the stroke. She had gone back to work as a nurse on a medical ward three weeks after the stroke. She said sometimes she had difficulties pushing beds and was tired but other than that she felt fine physically. She had problems not with motor function, but with her self-image of an *"old woman"*. However, her resistance to this was indicated when she said:

I'm actually always struggling with myself because in the evening when I feel tired and have a seat I think, "no you're not tired, you can't be, only old women get tired".

Her pre-stroke self-image of the vigorous 40-year-old woman who knew *"If I want something then I manage to get it somehow. Even if it was difficult but I've always managed"* appeared to be in danger. However, the only alternative she saw seemed to be to identify with old women who were brain-damaged: an unacceptable alternative for her.

All these people expressed their desire to be the same person they were before the stroke. Judith seemed to fight constantly against her exhaustion because all she needed was to be *"absolutely fit again, ...and then everything would be just as it used to be before this whole thing happened"*. Here she indicated that participants described differences on the basis of changes to their health status. However, the data also suggests that it was more than health that had changed, it was their sense of self.

4.1.2. A stroke is not a disruption

At this point of the illness trajectories some participants reported that they did not feel different after the stroke, for example Stefanie who had her stroke at the age of eighteen. At the time she was living at home with her parents and two siblings and was nearing the end of a two-year training course as a pharmaceutical assistant. As this job was not what she wanted to do, she had been planning to go to the USA as an au pair after she finished her training. Playing sports was important for her and she loved being with her friends. I asked her how she spent the three months following the stroke. She replied:

Totally normal. I still haven't fully realised what happened because I don't actually have any problems any more. Well yes, I did tell a lot of people about it, they'd come up to me and say "Huh? You? This early, so young?" Then you know I

told them everything and so on but I can't really put myself in my position.

Here she related the impact of her stroke on herself to the severity of the stroke and to the extent of problems which remained afterwards. Thus she appeared to talk about two related aspects: first she indicated that the stroke did not have any impact on her self; then she appeared to stand apart from the 'Stefanie' who had a stroke when she said later *"I really can't, somehow can't put myself into the situation"*. She explained this alienation in terms of a lack of problems. By explaining it in such a way she seemed to suggest that if she had problems the stroke would have had more of an impact on her. Interestingly Stefanie did not talk about having no *symptoms* after the stroke but about having no *problems*. Pursuing this train of thought an aspect emerges that appeared true for all participants: the effect of the stroke on the self must be seen in relation to subjectively defined problems, not to objectively definable symptoms. In other words: symptoms must not cause problems and problems can not necessarily be explained by symptoms. This assumption is best explored by looking at participants with more severe symptoms.

Sofie and Georg were the two participants with what could be considered as having had the most severe symptoms of all participants. Both suffered semi-paralysis, a limited field of vision, speech impairment and were dependent on care for the first few days after their strokes. Both of them appeared quite happy when I saw them in hospital. Sofie then said to me she felt really good that day and that had she not been paralysed, she would have felt up to anything.

Three months later she reflected on her way of recovery:

Sofie: I was in bed, couldn't even get up or sit up, and then when I started to walk again, that was like "Everything's all right again" well and then if someone asked "Well? "Super, no problem!" whereas now, it's only in retrospect I notice, notice the difference.

U.I.: What does the stroke mean to you now?

Sofie: I couldn't tell you. I couldn't tell you because, I talked to my mother-in-law about it and she said "What's wrong? Do you have any idea what happened to you?" Then I said: "Hey, I'm feeling fine and" in the end I don't, well I don't think about it too much. I'd rather keep my mind off it.

This account suggests two things. First the severity of the symptoms appeared not at all as an objectively defined figure but instead as one which depended on the perspective and on the context. Sofie's progress from being dependent on help to being able to walk might have made her feel as though everything were alright again. Her remaining problems with walking, a limited field of vision and weakness of her arm appeared to be minor. Secondly, and in connection with this, Sofie's determination to "*keep her mind off it*" seemed to be a coping strategy helping her to protect her self and contributing towards her feeling that things were alright. Her self was the 24-year-old woman who had left Slovakia at the age of thirteen and come to Germany on her own. At eighteen she started her own business, a restaurant. When she had the stroke she owned a pub, was married and living with her husband and five-year-old daughter. She used to work fourteen to sixteen hours a day. Not thinking about "*it*" too much seemed to help her to maintain her self-identity despite suffering some after effects of the stroke such as health problems and various other problems with her business and with her partner. She said talking to the guests in the pub helped her to suppress problems. Thus she might have protected her self to the extent that she did not experience changes and her symptoms as problematic. Concerning the stroke, Georg commented that he "*didn't really register it at all*" although he had been incontinent and dependent on care. His experience, as well as Sofie's, suggest that whether participants experienced the stroke as disruptive or not was not determined by the severity of their symptoms but defined individually within a personal context of history and management strategies.

How participants described their stroke did not only depend on the problems they defined for themselves. The point in time when a stroke occurred and the absence of pain also impact, as Michael informed us when he said:

It was nothing bad for me, because it occurred at night... I was only tired and and later I noticed that I have difficulties with my speech sometimes, like I didn't know certain words or so... But other than that, I didn't have pain, I didn't have anything. I myself wouldn't have realised it. I would have gone to work the next day.

It was his partner who took him to hospital. The absence of pain has been discussed as a common phenomenon in people who have had a stroke (Doolittle, 1990). Doolittle talks about the absence of pain as a lack of "a major legitimization and language for suffering" (p.76); in this study only Michael mentioned pain and then only as a potential indicator that could have made him realise he had suffered a stroke. Furthermore Michael said that he was not conscious of having had a stroke because it occurred while he was sleeping. This was paralleled by Matthias and Georg who also had their strokes in their sleep. Not realising the severity of the situation, they also wanted to go to work the next day and did not comprehend why they were taken to hospital.

Helene, a 51-year-old woman, found that a stroke can even be a release. She had gone through a horrible year before the stroke. She was working as a playschool teacher and finding it increasingly hard to cope with the strain of the job. At the same time she was living in an unsatisfactory relationship.

In her account of her experience of stroke, description and explanation are indistinguishable from one another. She said:

You go through hell...I couldn't control myself, I did what others wanted me to do and, or somehow you slipped into it...could never forget about everything, you take it all in and then somehow you built a protective wall...and then

later on there was the stroke [she uses the word 'Schlag' = bang]

According to Helene, her hell was not being able to distance herself from all sorts of problems, not being able to relax any more. She described an almost causal relationship: for her the pressure from her difficult situation caused a blood clot. This clot made it impossible to think clearly or to concentrate and she felt as if there was a lack of oxygen in her brain. Thus the stroke appeared to be the embodied experience of the state she found herself in. The infusion she received in hospital dissolved the clot, and she described the situation as follows:

and then during the first night in hospital...with infusions, already then I simply had the feeling all of a sudden I was able to, I don't know, I felt so loosened up, so relaxed, so free.

At this time of the illness trajectory she said that life had improved compared to how it had been before the stroke. She was freed from all the unbearable tasks that seemed to have been ruling her life and had been granted a task-free space - at least for a while.

This was the only point where some participants described the stroke as something they did not think about too much or as a release. This contrasted with other participants' experience of a stroke as a disruption.

4.1.3. Why me? Explaining a stroke

In these first conversations, most participants raised the issue of why they had a stroke. Answers to this question fall into three streams: bio-medically defined causes and treatment; spiritual beliefs; and finally, no plausible explanation.

The answer to "why me?" also implies the answer to a second question, obligatory for everyone in the study and apparently inseparable from the first: how do I prevent another stroke? At this point in the illness trajectory most participants presented a

bio-medical causality: they appeared to define a cause, underwent related treatment and/or made lifestyle changes so as to prevent another stroke.

This was the case for Michael, for whom the patent foramen ovale (PFO described in Chapter I) was regarded as the cause for the stroke. He was one of three participants who underwent heart surgery and was subsequently sure that *"the problem is solved, because of that it won't happen again"*. Similar sentiments were voiced by Robert, who said his high blood fat caused the stroke and was certain that he would prevent another stroke by keeping to a low fat diet, and also Andreas, who was sure that a narrowing of the throat artery caused the stroke and that an operation would help him ensure *"that everything will be the same as it was before"*.

In contrast to this, others explained their stroke in terms of their lifestyle. Instead of relating it to physical problems they placed the responsibility for having had the stroke on themselves. For example Thomas explained that *"...working and little sleep, a lot of alcohol, smoking, all that"* had led to the stroke. This explanation implied that strokes could be prevented by leading a healthy life and that they were thus avoidable. As a result those who had strokes would have themselves to blame, as Georg did when he said:

Firstly because I have had the history with the bad aortic valve and then my lifestyle, I am the one to blame, you can just put it that way... I don't blame it on anyone else, I only blame it on myself.

Georg explained that his lifestyle caused his *"bad valve"* which in turn caused the stroke. Thus he may have been expressing feelings of guilt for having violated a moral value, in this case the norm of having to care for one's own health.

The issue of self-blame and guilt brought up by Georg here also becomes relevant to other participants later, so it seems beneficial to explore this issue briefly here. From a psychological point of view guilt and shame have been contrasted (see Lazarus 2000, Giddens 1991, p.67). Lazarus (2000) describes shame as related to ego-ideals

such as self- or social esteem (p.212), in Giddens (1991) words to wrong-being from the point of view of self and others (p.67). Giddens contrasts this with guilt, which he says has to do with wrong-doing and thus does not bear on the sense of self in the same way. As will be described in the next chapter (p.161), using Karin's example, shame appeared to bear directly on feelings of personal insufficiency and self-esteem. However, as could be demonstrated by Georg's example here, guilt seemed not to have this kind of impact on his self-identity. He took the blame and bore the consequences such as having to undergo heart surgery, working less and sleeping more.

So far the data seemed to suggest that being able to explain the genesis of the stroke was important in order to gain control over the danger of suffering another stroke. Participants tried out different ways to explain their strokes, combining the medical professionals' perspectives and their own logic. However, the logic of cause and effect seemed to break down when the answer was not satisfactory and when participants wrestled for a deeper understanding of the eternal question "Why me?". This was expressed for example by Karin and Judith. After having tried out different explanations (low blood pressure because of pain medication, paradoxical embolism due to surgery or PFO) Karin stated:

And that question still remains, and I think why on earth, why me of all people? There are some who smoke, who take the pill and have so many other things that are regarded to be risk factors, I don't have any and I get it.

Judith also presented various bio-medically influenced thoughts to explain her stroke, wondering whether it was caused by high blood pressure and whether she was thus to blame for not going to the doctor and getting treatment sooner. On the other hand she had always led a healthy life, she did not smoke, not drink, and was not on the pill. Whilst these thoughts seemed to indicate the question whether she was to blame, later in the conversation she said:

Actually I think this was meant to happen to me. I'm religious and I think despite all this I had a huge guardian angel, OK, everyone only gets the load he can carry...then I think OK, I can carry it, that's why it's meant for me, now you have to make the best of it.

She appeared to have translated "Why me?" into a more essential question about the meaning of the stroke for her life. Her answer seemed to place the stroke within the context of her spiritual beliefs. However, she still hoped that a medical cause would be found, something that could be repaired, and she continuously struggled with the lost half of her self. Explanations of the genesis of a stroke all expressed a biomedical view of cause and effect. However, some participants appeared to be searching for meaning, an aspect that is explored further in the following chapters.

4.1.4. A stroke is a turning point

I will now use Robert's example to illustrate how he described changes in his outlook on life due to the stroke, whilst feeding other participants' descriptions into this example. He, like other participants described the stroke as a "*turning point*". He explained what he meant by this:

Simply the consciousness, that weakens as time goes by, that, that you take things as being important that weren't that important before and things that were important are not as important any more.

Here Robert expressed how the stroke had an effect on his self with regard to his outlook on life. Robert had bought a new house in a small village where he lived with his wife and two children aged eight and ten. Taking part in public life had been important for them all. He said after having had everything - his house and his family, a good job as a clerk in a car company - he felt that "*something is bound to happen healthwise*". In his eyes this was confirmed when he suffered a renal colic and "*now this*". Reflecting on his outlook on life before the stroke, he believed that

he should have been much more satisfied with what he had. He realised this now, and the stroke appeared to be a sign for him:

It showed you that all of a sudden, the aiming for wealth or for possessions that this can be over from one moment to the other.

The severity of the illness appeared to have made him realise the fragile nature of health and life. In one way or another this was mentioned by all participants. Helene for instance described her feeling after the stroke as "*Hurrah, I'm still alive*". Whilst Robert reflected on his pre-stroke values Helene indicated her appreciation for the mere fact of having survived. Many participants appeared to have become grateful for health and life, previously taken for granted. As Michael put it "*The gift of life has been given to me once again*". The confrontation with the possibility of impairment or death seemed to be entirely new for all these younger participants. It could be described as an encounter with the limitations of what is feasible in human lives in general, the end of the modern idea that everything was controllable, an idea younger people in particular often subscribe to. The stroke appeared to be a cut-off point in participants' lifetimes that made them reappraise the time before and the time ahead. This appeared to involve a re-thinking of values and of priorities in participants' lives and a questioning of their own belief systems.

Thinking about his way of living, Robert seemed to regret that he had lost God as the centre of his life. When I saw him in hospital and during the first conversation he mentioned that the stroke reminded him of this. He expressed a feeling of gratitude:

You learn to pray again when you lie there like this... I have the feeling that I owe an awful lot to Him up there.

It is interesting to view Robert's statement in connection with his earlier comment that as soon as he had everything something terrible would happen. He expresses his belief that if life was too happy, something negative was bound to happen. The stroke not only seemed to confirm this; in addition the life-threatening nature of the

illness appeared to have made him aware of his own limitations and helplessness and put him in the position of needing help. It could be more than gratitude that he expressed here; it could be read as the conviction that God was there for him when his fate was out of his hands. This spiritual experience could be what made the stroke a turning point in his life.

Robert's account serves as a representation of some participants' feelings of losses **and** gains in the illness experience. What they had lost seemed to be the feeling that their health was the most natural thing in the world, to be taken for granted, or, as Michael put it:

Health? Sure, you took that for granted, you're healthy and you don't think about it.

However, through the stroke they seemed to gain a different outlook on their lives, appearing more grateful for the little things in life, as Michael said: *"Things that you used to take for granted...you look at them with different eyes."* He referred to flowers in the park as well as other people's support and encouragement. The stroke seemed to take on meaning and to become defined. Robert defined it as a *"turning point"*, Georg as a *"warning shot"* and Michael as a *"kick in the shins"* or *"a kick in the pants for me to appreciate how [well] I am."* It might have been the potentially life-threatening and disabling nature of the illness that led participants to think about life in this way. Experience and identification of themselves as fragile and limited seemed to have made these participants feel grateful for having survived without having to live with major impairments.

Accounts of the selves three months after the stroke seemed to suggest that a stroke at a younger age could be perceived in ways ranging from highly disruptive to a release. The data indicated that the self was fragile in that some participants' coherent autobiographical story seemed to be seriously disrupted by the stroke. This can be inferred from these participants' use of expressions such as being half, a heap of misery, feeling brain damaged or questioning whether they could ever be the same

again. However, these as well as other participants also indicated a robust side to the self in that they did not give up the person they were before the stroke but instead tried hard to regain exactly the same status. Doing the same things as before the stroke and being able to do them in the same way seemed important to some of them. All explanations of the stroke appeared to be grounded in the bio-medical perspective of cause and effect. Having the physical cause for the difficulties "*repaired*" and making an effort to overcome the difference all appeared to be ways these participants thought of and explored in connection with reaching their goal, namely "*that everything'll be alright...that everything'll be the way it used to be*" (Thomas).

Some participants described how the confrontation with this potentially disabling and life-threatening illness marked a turning point in their lives. It appeared to split their time of life into a pre-stroke past and a post-stroke present and future. In this light they appeared to reappraise values and priorities of before and change their outlook on future life. The stroke apparently took on the meaning of a life-changing event for these participants.

4.2. Six months later

Disruption of life is a constant issue in human experience. As participants recovered and interacted more with the outside world, they appeared to include their environment more and more in the construction and maintenance of their selves. That the self is by and large socially constructed (Crossley, 2000, Jenkins, 1996) seemed to become clear in participants' accounts of their actions in relation to others and their reflection on these actions. However, telling the story of a body [self] which is ill has been described as a personal task (Frank, 1995). In Gadamer's (1993) sense human beings are constantly reflecting on themselves, be it in dialogue with themselves or in interaction with others. Thus they do maintain their selves not only in relation to others but also as an inner space (self). This inner space is something which participants can become more conscious of through experience and reflection on experience (Craib, 1998, see for example p.170).

Whilst three months previously some participants had described themselves as no different at that point of the illness trajectory, now only one participant did so. The idea of a stroke as no disruption at all was no longer relevant. More participants seemed to struggle with the disruption and no participant mentioned that they were not conscious of what had happened to them. Participants were looking ahead more than they had three months earlier. This is reflected by a shift from the need to understand why people had a stroke in the past to new attempts to explain the stroke, find meaning and cope with the uncertainty and fear of suffering another stroke in the future.

4.2.1. A stroke is a disruption

Andreas was the only participant who described himself as being happier than three months earlier. Others were still wrestling with the disruption and for some the situation seemed to have worsened. Whether this was because increased interaction made them aware of the effects of the stroke, or because they were not granted the protective space of being ill, because they felt tired of being ill, because they had become conscious of the limitations of what is controllable in life, or for what other reasons is difficult to say.

The situation seemed to have most severely changed for Helene, who from describing the stroke as a release three months earlier now defined the stroke as:

... a bloody awful illness. First people don't realise there's anything wrong with me and second, well, you're not the same any more. And and you try to find a way yourself and then at that moment nothing works any more.

She described how she tried to be more conscious of her own needs, and less of those of others, while at the same time realising that this made her feel lonely. She indicated that her self changed after the stroke but that all her efforts to cope with the situation had been in vain and nothing was going right any more. Moreover, the invisibility of her struggles appeared to add to her difficulties. The stroke seemed to have disrupted her life and self.

Whilst Helene referred to a general change of her being, most participants related their disrupted selves to changes in their health status or a changed view of self. Matthias for instance described problems memorising what was said or how things worked. He described several occasions when these problems led to difficulties in performing tasks, for example changing the car tyres:

Before I just went out, tyres flat OK, and that was that. And now? Catastrophe, catastrophe, it's a disaster.

Whilst Matthias would have changed the tyres easily before the stroke, it now took him one and a half hours and a lot of effort. He described himself as frustrated because he repeatedly had problems doing things correctly. He was measuring his abilities in terms of his old self, not his recovery. For example, the fact that his arm was better now compared to three months ago (his own statement) appeared of no importance to him. For him, the problems with memory dominated.

Apart from changed ways of doing things, a new issue was brought up by Judith and Sofie: the instability of their health condition. Judith put this into her own words:

Today I feel so awful and tomorrow I feel full of beans, then I'm OK again...well, so unstable...How should I put it, it's bloody awful, to put it bluntly, I think it's bloody awful.

Used to leading a busy life, planning activities and managing everything on her own she was also used to having total control over her life. Now her constantly changing condition and her fatigue put her into a position of being dependent - on her unpredictable health status. She was attempting to regain control by strengthening her own will to do things, expressed repeatedly in her words "*I can do it, I'll manage, well I have to manage*". However, the more effort she put into overcoming her problems the more frustrated she appeared to feel whenever she failed. At this point of the illness trajectory she kept stating how frustrated she was because of her own "*stupidity*" and how much effort she put into trying to manage tasks the way she

used to. She seemed to have lost faith in her own abilities, but still hoped that things would improve.

Sofie referred to the instability of her health, in that she sometimes felt "*feeble, tired and somehow, just heavy. And then...totally, yeah, wound up*". She not only struggled with this but indicated another dimension of disruption: her changed appearance. She said:

Well I look at myself in the mirror and then I feel ill or I look at myself, pale and then my arm is paralysed or not fit and then I have, OK, not much, but I've gained four kilos... you could say it's different, everything.

Sofie wore make up, dressed carefully and paid attention to her hair. She seemed to identify with the well-groomed 24-year-old woman she was. Her own image in the mirror confronted her with "the effect of the illness on her appearance" (Frank, 1995; p.44) and stood in contrast to her own self-image.

Apart from disruption to actions, appearance and health, Karin illustrated another form of disruption: her feeling of being a divided self. She described her self-image:

Well just recently I said I felt as if I were really big, if I was supposed to draw myself now, a big person, with my head way up high, but the rest of the body far below... A long neck and fairly far down in the bottom third the rest... Because my ideas and thoughts about my abilities are actually big, but my body keeps me back, always.

Here Karin appeared detached from her head, described as the active part, as well as from her body, described as the "*brake*". This idea was taken further when she described her head as "*me*" and her body as the "*other*":

I think it's not so much a medical problem, more a psychological problem, that I myself, that my body wants something different from what I want.

Engaging in this body-self dualism and splitting the dangerous part, her body, from her self could be seen as an attempt to minimise the disruption of her self. Karin presented a narrative in which she described her conflicting thoughts of what was the source of her problems and why it had arisen:

U.I.: And what is it about the stroke that's caused this?

Karin: I don't know. Alone that feeling of being old. I don't know what's changed in my head. I can't tell you. Somehow it wasn't just blood vessels being blocked, somehow there must have been some, nerves which. Don't know. But it's different.

U.I.: And you have the feeling that the reason is in your head.

Karin: The reason is, yes. Yes. What's holding me back is in my head. Although my head's still agile. But it's, the active part which was always active is still active. And then there's an area which is saying "Be careful, something once happened". And my body says "Better to slow down, something happened once before". Schizophrenic sometimes.

U.I.: Like split in two parts, schizophrenic?

Karin: Schizophrenic, like I really want to do something and then along comes this thought from somewhere "Slow down", or "You can't do it anyway" or whatever. But what that, but that's since the stroke, so there must be a connection somehow...

U.I.: Yes you said before that you think it's perhaps more of a psychological problem than a physical one.

Karin: I think so because there is a weakness, but what I say is if you break your leg then your leg is weaker for six weeks. But you exercise a bit more and then it's OK. But somehow, I don't want to say I'm accepting it but I have, it's somehow more or less the normal state of things. It's inside me, part of me. As if I'm saying "You'll have to get used to it, this is how things are now." One part of me says this, the lame part says "That's the way it is, forget it" although I do fight that. I feel schizophrenic sometimes.

As well as demonstrating her search for words to describe how she felt, her narrative gives an example of how reconstructions could change. Whilst at first she separated the bad part, the body, from the good and active part, her head, she appeared not to sustain this explanation as the conversation continued. Her attempt to rationalise the stroke using her physiological knowledge as a nurse seemed to force an awareness upon her that the stroke happened in the head. She thus relocated the problem to the head, which had previously been associated with the active part of her self, thus emphasising the schizophrenic aspect of this explanation. This in turn seemed to lead to a reconstruction and she started to make a different kind of distinction, not between body and self but between conflicting thoughts. She even incorporated the stroke, saying it had become "*inside me, part of me*". Thus she did not sustain the dualism. One could read her narrative as revealing her inner dilemma, the struggle between the old, pre-stroke self and the new, unclear and frightening side, the post-stroke self. In her words:

I've been hanging, I've been limping along after my old self, trying to catch up, for six months practically...

For her, it had always been out of question to ask anyone for help with the four children and the big house, neither her husband nor her GP, and she would never have considered consulting a psychologist. This appeared to be the old self asserting itself, the self she was holding on to. Although she realised her dilemma, she appeared unable to ease the disruption.

Accounts presented here indicated that the realisation of the disruption of selves was at the very least demanding, and for many participants frustrating. It appeared to impinge on participants, or as Judith said, it affected her self-worth:

I see how bad, yes, how badly off I am and that things aren't at all like they should be and this really takes it out of me and then I think "What are you actually worth?"

She did not exhibit any visible signs of her struggles. According to her what 'took it out of' her was that she could not do as much as quickly as she used to, which made her question her self-worth. Her losses appeared to be the embodied experience of functional and cognitive losses, thus of the whole person suffering. Her example seemed to illustrate clearly that the understanding of the 'embodied experience' of the stroke seemed to have an impact on all aspects of participants' selves.

Matthias described a loss of his self-image as an adult. He said:

To put it bluntly I don't feel like an adult any more but like a child...I see myself as a little child. Because you lose faith in yourself, when my memory is like this.

Repeated experiences of his cognitive problems, leading to misunderstandings in communication or to failures in doing things the way he used to do them, made Matthias lose trust in himself.

Karin talked about the same issue, but slightly differently:

I'm not as much prepared to take a risk as I used to. As I said in the past I never, I always thought about what could have happened afterwards or something negative, first I set about things and then I thought about it afterwards.

It appeared not to be a question of having major health problems, and to an outsider she seemed to have gone back to her pre-stroke life. However, for her the issue appeared to be the sudden and traumatic experience of having lost control over her body; it was this which disrupted faith in herself. Karin appeared to have lost the confident feeling she had of being a young competent woman able to take any kind of risk and described herself now as "*pessimistic*" and overcautious.

These accounts seemed to indicate that disruption of self took on a variety of forms and led to struggles and uncertainty about self for many participants.

4.2.2. Uncertainty and fear

Three months earlier some participants had asked why they had had a stroke and had offered various explanations. One could assume that these explanations offered a sense of security and control for participants, because now expressions of uncertainty regarding health and fear of suffering another stroke were mentioned by many participants - this had not been the case three months before. Having been hit by the minimal chance of having a stroke at a younger age, participants no longer seemed to feel in control of their health, or as Michael put it:

I did say "I'm 100% fit, so what?" And then there were the 5% that hit me.

This sense of loss of control appeared to be related not only to the past - the experience of having had a stroke - but also to the future, triggering a fear of a recurrence. As three months earlier, this issue was raised by all participants, although from a medical point of view it could be regarded unlikely for most of them, firstly because of the low statistical probability (see Chapter I, p.22) and secondly because they had undergone treatment or were taking medication. However, this

generalisation seemed not to apply on an individual level. Although knowing the cause of the stroke seemed to help some participants, as Michael indicated, overall they no longer felt entirely safe.

This was the case for Helene, who was taking Warfarin and had been assured by her GP that another stroke would not happen as long as she took her medication. However, it remained a fear for her:

Maybe I confuse myself a little bit, yes, the fear is there at the moment because I, like because I'm alone and then I think now and then, my God, if there is then a situation when I don't know where I am or when I don't manage to get to the phone any more, well, inside me, subconsciously there is a fear because before I had the same...

As noted earlier, Helene's feelings about the stroke had changed. Whereas three months earlier she had described it as a release, she now felt that she was not the same any more. After putting this into context the background rationale became clearer: Helene described how pressures in her life had caused a blood clot which led to the stroke. The stroke then released her from this former, unbearable life. The initial feeling of release she had felt after the infusions had now given way to a fear of returning to her pre-stroke life, of 'running away all the time' and of 'being tired'. She was afraid of "*falling under the same spell*", the logical conclusion to which was clear - another stroke.

These feelings of fear seemed to have two main causes: firstly the fact of their previous stroke and secondly situations that were reminiscent of the stroke. These combined to pose a threat to participants' feeling of security and caused uncertainty. In Sofie's descriptions this was the case whenever she experienced symptoms similar to those she had experienced at the time of her first stroke, for example a tingling sensation in her arm or shortness of breath. Whenever this happened, she described herself as panicking and that she then "*didn't know is this just my arm or what*". 'Or

what' could indicate that she immediately connected the appearance of symptoms with her fear of another stroke and of not being able to control this.

For Karin the mere memory of the stroke experience fuelled her fear of a recurrence, which she was certain would happen in any case. She said:

It is irrational what I think, because that's rare that the same shit happens twice, isn't it?? Really rarely. But I can't get it out of my head that it is that way... but I think I'll never get rid of that feeling when the stroke happened, often I'm lying in bed at night and rush head first through a tunnel, as I told you last time.

She still had nightmares about the stroke, when she felt that she was rushing head first through a tunnel and waiting to land on the ground and die. Afterwards she was unable to see or to imagine what her children looked like. This lasted several hours. She wanted to forget "this horror trip" or, as she said: "I just say to myself that's over and done with as far as I'm concerned". At the same time "it is as if my body indulges in it, in the feeling". She wanted to erase the horrifying memories, but said that tiredness or a weakness in her arm reminded her of them and she realised "I'm kidding myself, I do still notice it. Notice that the left side isn't as strong as the right". Like everyone else, she appeared to deal with the uncertainty by searching for reasons as to why she had her stroke: the foramen ovale, the extraction of ectopic thyroid tissue or her lifestyle. Similarly to three months earlier, she could provide no definite answer. These attempts to explain the stroke and her wish that the danger had passed can be seen as attempts to regain control over her disrupted self and to live a normal life.

4.2.3. A stroke is a turning point

As they had three months earlier, some participants spoke of the stroke as a disabling and potentially life-threatening illness. In Stefanie's words:

It really is something you can die from. Or if I was older then it might have ended differently, then I might have to start all over again from scratch.

Michael raised similar issues and described how this insight had led to a different outlook on life.

Michael: A little bit more serious, then you would probably not be here any more or someone who doesn't comprehend anything sitting in a wheel chair. I still do think about it.

U.I.: Does this have any consequences for you?

Michael: Well, consequences? You live more consciously. I don't put myself under pressure any more like "you have to do this and that and that and that" planning half a year ahead. I used to plan what will be in one or one and a half years or so. That's all passé.

In light of the possibility of sudden death, he had begun to reflect on life and define what was and what was not worth consideration. He used the following question to determine the relevance of things:

God, what's the point of it all when you could be gone tomorrow?

From this point of view only health appeared important to him. This view was shared by the other dialogue partners, for whom health was the top priority six months after the stroke. However, he seemed to go even further: his question revealed that, for him, the finite nature of life determined what he considered to be important and what was not - it became a spiritual question. Spiritual not in a religious sense but in the

question of ultimate meaning and purpose of life. One could say the understanding of morbidity and mortality led to a reflection of past and future values.

Stefanie touched on the same issue when she discussed the connection between getting her tongue pierced and the experience of having had a stroke. She had wanted to do this for a long time but out of consideration for her boss and parents, had never done so. She explained:

For me that was something, something where I said that's a sign for me that everything's alright and something I had always wanted to do and that's that's my thing and that, for me, shows that I'm still here...it simply means that I have, the illness, I'll just call it an illness, that I got over it and that I made it.

Having her tongue pierced was a sign that everything was alright, that she was still here and was coping with the difficult situation. This assertion implies that she considered the stroke potentially disabling, life-threatening and difficult to manage. Her piercing became a symbol of the stroke and for her gratitude that she "made it". She put her wish to have her tongue pierced before the need to consider others.

Other participants were also more consistent about putting themselves first and doing what they felt they needed to do. Andreas for example, said that he was "first now", reflected by the fact that he was more conscious of his appearance than he used to be:

Andreas: I used never make any bones about how I looked or anything like that. Then like, I simply went out the door, it didn't matter how I was dressed, I think like, that it's now, how should I put it extreme, that I pay attention to my appearance...And, I shave more often, and I also dress really well, like I do pay more attention to my appearance than I used to. That has changed perhaps, but

U.I.: How did that come about? Did that have anything to do with the stroke or do you think it would have just happened anyway?

Andreas: I don't know whether it would like I think in that respect the stroke really led to something positive. I'm not saying that I used to let myself go, but now it's simply become better...I simply take more care of myself now and what other people do is, like I am first on the list and then other people. Before it was like the other way around.

Visible changes such as Stefanie's piercing and Andreas' more groomed appearance were regarded by both as positive manifestations of the changes brought about by the stroke, although they described them slightly differently. Whilst Stefanie felt that the piercing "*shows that I'm still here*", that she had made it, Andreas interpreted his change in appearance as a sign that he was taking more care of himself now. Despite this slight difference, it is possible to infer a more general principle from both narratives: for them and others it had become important to put their own interests first.

Some participants' post-stroke lives were also marked by lifestyle changes. Mindful of their own individual risk factors, they described how they tried to live healthier. The actions they took to achieve this differed: Georg was "*doing sports now*", Robert had made "*changes in the diet... and then I've got like a personal trainer, with that I exercise for twenty minutes every day*". The smokers reported that they had either given up or cut down, and all of them were trying to lead a quieter life, avoiding stress and sleeping more. These participants reported new insights about health and lifestyle and appeared to put them into practice. These actions may have been a sign of the new awareness that "*you have to care*" (Stefanie) for health. They may also have helped them regain a sense of control over their lives and their health after the alarming experience of losing that control.

For many the stroke was a life-changing experience, for example for Robert. Three months earlier he had spoken of the stroke as a turning point, now he referred to the stroke as a boundary stone in life. That his life was split into a pre-and a post-stroke life, was illustrated when he said: "*Whenever I look at a photograph of mine I wonder: was this before the stroke or was it after the stroke?*"

Similar to three months earlier the stroke had a spiritual meaning for him:

Robert: Yes, you could also say [a] guardian angel you could call it, that there is something which helps you too, when something happens to you, to get over it, so that's what I actually believe.

U.I.: And that's changed since the stroke?

Robert: Yes, it somehow got more distinct.

What was only touched on earlier was more clearly stated in this conversation. The life-threatening situation seemed to have made him aware of his limitations and put him into a position where he needed help from God who heard his prayers, he got help from a guardian angel. This experience of finding spiritual meaning in the illness experience was also expressed by other participants at different points of the illness trajectories (see the next chapters).

The participants' descriptions of the stroke as a turning point - an aspect strongly emphasised by most participants at this point of the illness trajectory - have an interesting implication in terms of its meaning. If these accounts demonstrate a construction of meaning, one could assume that participants were constantly working on allocating the stroke a place in their personal stories. As described, not all participants seemed to describe the stroke as a disruption. However, all indicated that their old selves, who seemed to have taken health and life for granted, appeared

disrupted. The new selves seemed to be aware that life was unpredictable. Searching for meaning was contiguous with bridging the gap between the two selves.

Two accounts could have indicated that the search for meaning of the stroke extended the boundaries of self and included thoughts about controllability of health and life in general. Thomas pointed to this when he said that *"this can happen to anyone"*, or as Robert put it:

*Alone the conviction 'this does not apply to me' that is what
no one should ever say, that's what I had to comprehend, too,
I didn't believe that either.*

Both Thomas' and Robert's insights that no human being is in control of life and health refer to the ontology of human existence.

It is important to state here that more positive sides of the stroke seemed to be described by younger (Thomas and Stefanie) and by male participants. Bearing in mind the low number of participants, this can only be noted as a tendency. What can be stated with certainty is that the struggles or insights described by participants did not relate to any visible impairments. Thus, as stated in accounts three months earlier, impairments did not necessarily lead to problems and problems could not be explained by impairments alone. Impairments were only mentioned if their impact interfered with the view of self.

The data suggests that six months after the stroke the disruptive nature of the stroke and the need to gain meaning from it were the dominant issues. More than three months earlier many participants described how changes to their ways of doing things due to cognitive problems, problems with fatigue and with constantly changing conditions made them lose faith not only in their abilities but in themselves. The stroke seemed to have confronted all of them with limits of what was controllable in life. This represented the loss of their ontological security which led to fear of another stroke and further, to a re-definition of health and values. The

dominant issue was not *why* they had had the stroke, but *what for*- in other words, its meaning. The stroke continued to be described as the turning point, splitting their lives into pre- and post-stroke.

4.3. Twelve months later

At this point of the illness trajectory the majority of participants discussed the issue of the recurrence of stroke. More strongly than it had six months earlier, this emerged as inseparably linked with the explanation of why they had their strokes in the first place. Explanations of the cause, ways of dealing with the fear of getting another stroke and attempts to describe its meaning will be stated. The accounts fall into two main streams: descriptions of uncertainty and ways of dealing with this; and indications of relative stability and faith - faith in health and life, but also faith in one's self.

In the following a few accounts will be presented in more detail to illustrate differences in self-description. Other accounts will be incorporated into these. As some participants (Robert, Andreas, Michael, Matthias, Sofie, Judith) related their thoughts concerning another stroke to work, their accounts will be described in more detail in Chapter VI.

4.3.1. Uncertainty about another stroke

First accounts of participants who described feelings of fear concerning another stroke are presented. This fear manifested itself in various degrees ranging from constant uncertainty to great fear. Robert said that he lived with:

the uncertainty whether you get such a thing again. Before you didn't think about this.

For Karin the fear was caused not by the uncertainty, but the *certainty* of a second stroke:

Karin: It's that I expect that there will be another bang in the not too distant future and that's still so close for me, I always thought you would forget things, but that feeling how I got that stroke that's for me that's a horror vision, to have to put up with that another time... But no one can take that from me.

U.I.: But I can't imagine how you live with this prospect?

Karin: Terribly bad at the moment, I really have to tell you that [close to tears].

These two quotes mark the two extremes of participants' thoughts about a second stroke, from an uncertainty to a conviction. Most participants' feelings concerning another stroke fall in the ground between these two extremes.

As in earlier talks, most participants were dealing with uncertainty or fear by offering different explanations as to why they had the stroke. Biomedical explanations appeared far less frequently than they had earlier. Instead other factors in the constructions dominated.

An example of this is Andreas, who had earlier explained that an occlusion in his head had caused the stroke and had been the source of his problems. He had been hoping that this occlusion could be operated on and that this would solve his present problems with not being able to do things the way he had done them before. At a later date however, he stated that there had been talk of an inflammation of his heart and that he did not know why he had had the stroke. Not knowing what caused the stroke seemed to be very unsettling for him because this meant that there was nothing medical professionals could do to help him with his problems, which had been his hope three months after the stroke. Now, one year after he said:

In [hospital] they weren't able to tell me what had caused the stroke, couldn't say what made it happen. All they said was that I'd had an inflammation of the heart, and then that

something detached itself and then wandered off somewhere else, but why, they didn't tell me that. All they said was that I'd maybe had a blow to my chest which hit my heart, or I had an illness I didn't get rid of properly, they said that to me, but to this day I don't know what caused it, why I really had a stroke.

Not knowing what caused the stroke in the first place made him "kind of scared". However, the only thing for him to do was not to think about or to be reminded of the stroke, as he indicated when he said:

Because when I think about it, I remember the date, and you start thinking about it and hope it won't happen again and I just want to avoid all that. I just do not want to think about it any more, or get upset about it, I just don't want that any more... I mean like talking about it now I get this funny feeling again in here [touching stomach] and I want to avoid that.

According to him this feeling not only came back when he talked about it but also in connection with his speech and slight functional impairment. He explained the dilemma of not being able to do anything to prevent another stroke and yet being constantly reminded of the stroke because of his problems with writing and with a weakness of his arm and leg:

Andreas: ... I can, I can't do anything about it.

U.I.: I really can't imagine at all what that feels like, living with that.

Andreas: I just don't think about it, otherwise... That's why – just forget it! As long as I don't think about it it's OK. If

everybody keeps reminding me then it all comes back again and that's what I don't want.

U.I.: I have to ask a bit more, if it starts getting too much for you, just say.

Andreas: Yes.

U.I.: Because of your arm and your leg you keep getting reminded of it all, don't you?

Andreas: Yes, unfortunately.

U.I.: That can't be easy.

Andreas: No, it's not easy, and that's why I avoid writing whenever I can.

U.I.: So you avoid doing things that remind you, is that right?

Andreas: Yes, exactly.

His way out of this dilemma was to try not to think about the stroke, to "*sweep it under the carpet*", and get on with his life. The price for this was having to avoid situations which could remind him of it, such as writing. Thus he demonstrated that thoughts about the stroke, his fear of a recurrence, his way of dealing with it, and the impact of the fear on his life, were inextricably linked. After the tape recorder had been switched off Andreas told me how proud he had always been of his good handwriting, a part of his self that he had lost due to the stroke. Now he was faced with a dilemma – he either had to avoid situations which could remind him of his stroke, or he had to deal with the feelings of fear and loss that then surfaced.

Robert also presented a narrative characterised by changing bio-medically influenced explanations. Although this will be described in more detail in Chapter VI, it is important to state briefly here how it changed over the year. Three months after the stroke he was sure that his high blood fat had caused the stroke whereas six months later he was no longer sure what had caused it. Now, one year on, he still did not know the cause, but related it to stress at work.

From these examples it is important to note that bio-medical explanations of the cause of the stroke appeared to help some participants early in their illness trajectory to regain a sense of security. Later on however, participants seemed to have lost this certainty. This may have triggered feelings of a lack of control which, in these cases was dealt with by attempting to avoid situations that provoked thoughts about the stroke, or worse, could have led to another one. It seemed that this was mainly to protect the selves, although it becomes clear that it often was in connection with others that participants became aware of their problems- they were individual as much as social.

Sofie and Karin described how doctors' statements resulted in a fear of another stroke and also their methods for dealing with this fear. Both had been given a high probability of getting another stroke within one year; in the conversations twelve months after their initial stroke, both women expressed their feelings that their worst fear was imminent.

In addition to these feelings, Sofie described how her fear of getting another stroke was triggered off by stroke-like symptoms. The example she gave was a time when her arm started to feel as if the blood was no longer flowing. She felt very frightened and went out to get some fresh air. She described it as follows:

Sofie: Well I have to say, it is, like yesterday, when there is a little bit of something and then I get so nervous, and then I [breathing in deeply] well I have to say, actually I'm afraid that this will happen again. In [hospital] they said if they do

not do the surgery, well the doctor, there is a 75% chance that we'll see each other again within the coming year.

U.I.: 75%?

Sofie: Yes, within one year and that's why, now it's one year and I don't forget that, when I had just been admitted to hospital there was the issue of surgery. And then I said, well, no. And then they called, specially my husband came at three o'clock at night to [hospital] with my mother-in-law. And then I said "You're not signing anything – just like I'm not – I don't want to". And then the doctor said to me that there is a 75% chance that we'll see each other in a year or one and a half or so. That's why.

U.I.: And now it was one year, right?

Sofie: Yes, now it was a year, August, 22.

U.I.: But how is that, could you tell me how that is when he says that this could happen to you again?

Sofie: I'd say of course you think about it but yes, how is that for me? I'm simply hoping that it won't happen again.

The symptoms in her arm brought to the fore a whole cluster of thoughts about the cause of her stroke: the treatment she had been advised to undergo but had refused; the consequences of that decision for her chances of suffering another stroke; and of course her fear that this would actually happen. Sofie dealt with this fear simply - by hoping that it would not happen.

It was also a doctor who triggered Karin's fear of another stroke. She described how she was in hospital for her regular check-up one year after her stroke. According to

her this appointment left her highly unsettled; firstly because the doctor confirmed a 30% weakness of her left arm and secondly because the doctor did not offer her the hoped-for positive news regarding her prospects of not getting another stroke. On the contrary, she said he frightened her by predicting a high probability for a recurrent stroke. She described the situation as follows:

Karin: I'm really at the moment, like a living time bomb, I'm constantly waiting for something to happen. More than three months ago. Because he really unsettled me.

U.I.: He unsettled you also with regard to getting another stroke?

Karin: Yes he did, I deliberately asked him, because that was one of my main points, whether I have to reckon to get such a thing again, then he said "yeeees", with statistics, statistically speaking everyone who had one will get another one within the not too distant future.

Medically this is wrong. It is not possible to discover why the doctor said this - or why Karin heard it. The effect on Karin was to reinforce the fear she already had, not to release her from it, which is what she had hoped for. Getting a stroke in the near future meant *"for me that's within two years, and one year is already over."* Since Karin, like Andreas, did not know what caused her stroke she did not *"have anything to stop, nothing to give up, that's what, there isn't a thing I can do."* Although she was taking Warfarin to prevent another stroke, she did not believe that this was sufficient. The lack of definite cause, combined with the vivid memory of her stroke experience and the doctor's statement, had an unsettling effect and she was very afraid of getting another stroke. In her narrative time was running out before she would get another stroke.

So how did they both cope with their fear? Karin seemed to feel that she could not do anything and said *"that I see myself as a stroke patient"*. She still described herself as

being divided into an active part and a physical 'brake', indicating the continuing disruption of her self.

This was different for Sofie. She referred to the stroke as fate, presenting an explanation that ascribed the cause for the stroke to her genetic disposition:

Sofie: I say to myself it's fate, somehow.

U.I.: It's fate.

Sofie: Yes, 'cause my father, I can still remember, he was thirty three when he had a stroke, too, he was in a coma for fourteen days and then he died, he was 33 too, and yes, that's what I think, that's what happens.

For Sofie, stroke appeared as a question of inescapable destiny, as indicated when she said "*I think that's what happens*". All she could do was to hope that it would not happen to her. As with Karin, time seemed to play an important role in her rationale, firstly because the physician in hospital told her that her chances of getting another stroke within the first year were high, and secondly because she was now 25 and getting closer to the age at which her father died of a stroke. Sofie's fear of another stroke seemed to stay with her because, as she said, the only thing she could do herself was to hope and to avoid pressure. She avoided overstraining herself because she thought that stress was a major contributing factor to her stroke. However, her addition of the factor of stress to the explanation of her stroke effectively undermines her earlier concept of the stroke as fate. Whilst the latter implied that she could not do anything, the concept of stress seemed to suggest at least some possibility to influence her destiny. According to her she changed from an active and lively person into someone who sat at home and would rather have slept all the time. She related her inactivity to her fear of getting another stroke:

I mean there are days when I'm sitting there thinking "boy, now you're not doing anything" when I'm dissatisfied with

myself because that used to be the exact opposite. And I mean then I remember, well, the stroke and then I start thinking before I rush into something again [hesitating]...Firstly because of myself and secondly because of my daughter. Actually that's much more important for me.

This narrative indicates that Sofie's changes of self, her fear of a repeat stroke, her explanation of strain as a contributing factor and her way of coping were all linked. Her genetic disposition could not be changed; heart surgery, as advised by the doctor, was also unthinkable: *"that's the last thing, that would, particularly with regard of the scar, that was, no. I couldn't live with that, that's for sure"*. Avoiding stress appeared to be the only thing she could do to avoid another stroke, but this caused her to stop doing things. The dissatisfaction caused by her inactivity was countered by the responsibility she felt to avoid another stroke both for her own sake and that of her daughter. One could infer that this fear not only ruled her daily life but also acted as a catalyst, causing her to change from being a very active young woman into the exact opposite. Like Andreas, her only choice seemed to be between being active and living in fear or being inactive and giving up who she was.

The accounts presented here point to three important aspects of what stroke meant for these participants one year on. Firstly the uncertainty of getting another stroke was high for them at this point of the illness trajectory. The time-scale is crucial here, either as a result of predicted recurrences, or, as in Andreas' case, because of a need to get on with life. Secondly, attempts to cope with this uncertainty led to avoidance of situations that could trigger off another stroke and to feelings of a loss of control. Thirdly, the stroke was still very present in participants' lives; either they were reminded of it whenever they avoided situations associated with the stroke or they lived in fear. As will be described further in Chapter VI many participants saw stress, mainly in connection with work, as a cause for the stroke. The issues raised by this explanation will be explored and discussed there.

4.3.2. No fear of getting another stroke

Judith's account represents those participants who appeared to have regained a sense of stability and security after the stroke and who did not describe a fear of a second stroke. In Judith's case one could say she gained this despite the fact that she had a TIA eleven months after the stroke. Both she and Thomas were diagnosed with a TIA within the second half of their post-stroke year, and interestingly, both of them indicated that this did not impact on their regained sense of self.

Judith described that one night she could not move, felt pain, sick and dizzy and when she tried to call her son she could not speak. These symptoms lessened through the night, but when she went to her GP in the morning she was still having problems walking, her arm was weak, she felt sick and dizzy. He admitted her to hospital where she spent ten days. She described her relief that nothing worse had happened, which she attributed to Warfarin:

Judith: Thank goodness, let's say assuming I had not taken the Warfarin, then something much more terrible could have happened, you know if I said I don't want this any more, then something worse could have happened.

U.I.: How do you explain that this happened?

Judith: They assume that, one vein is still blocked or half blocked, I didn't really get that, and that something got detached and then dissolved, let's say that I've been really lucky.

U.I.: And how is the prognosis, could it happen again any time or what?

Judith: Let's say because of the Warfarin theoretically it can't happen again, 'cause they've put me on such a high dose. They themselves can't understand why I got it again.

Judith viewed the Warfarin as the factor that saved her from a more serious stroke. Her faith in the preventive effect of the medication appeared to be reinforced by the experience of having had a TIA. She seemed to believe that taking the medication was sufficient to protect her from a relapse - which is interesting because since she was on Warfarin when she had the TIA, her case could just as well prove that Warfarin was not sufficient stroke prevention at all. As described earlier (p.141) this was exactly what Karin thought.

The issue whether or not bio-medical treatment was sufficient stroke prevention appeared to be highly individual. Whilst Helene was also certain that she was safe taking her Warfarin, and Georg and Stefanie ceased to fear a second stroke after having their heart defects operated on, Michael did not believe that he was 100% safe with heart surgery. He was conscious that *"Regardless, there are so many factors that could set this off."*

Although these bio-medical explanations seemed to have a reassuring effect on most participants, they were complemented by personal explanations that included individual world-views and values. Thomas for example had the symptoms of a stroke twice during the year post-stroke, despite taking medication. Although at first he said that he had been worried about suffering another stroke each time, this changed at a later date. He explained that:

...it disappeared right away, ...actually I think it's weakness, I talked to one of my friends, it's because the nerves in my right arm are not as strong.

He simply said that he had *"to put up with it"* and to get on with life. As described earlier he explained the stroke as fate. Judith on the other hand indicated a spiritual meaning of it as she appeared to have accepted her stroke as God's will:

Listen, I don't know, I don't know, can't explain it. I don't know why I got this. All I can say is maybe He up there wanted it. That he maybe wanted me to get a sign somehow. I hope you don't think that I was mad...you know that it was God's will that I had to get this, maybe, to think things over one more time.

As in her earlier conversation, Judith interpreted the stroke as a sign from God. However, at that time she did *"not want to accept this illness"*, whereas now she appeared to have accepted it as a sign of God's will and thus integrated it into her belief system. The message to 'think things over' to her meant to think more of herself and less of others. This appeared to be addressed directly to her self. A transition seemed to have occurred: the stroke's meaning was to re-think her values, it emerged as a turning point in her life. Her health had not changed compared with how it was at the previous conversations, she said. However, she appeared to have a greater acceptance of her situation, and a more optimistic outlook on the future.

Judith gave another example of the fluidity of narrative re-construction involved in the process of coming to terms with her stroke. The transition over the year became apparent in her way of explaining the stroke: it changed from a burden sent by God which she had to bear to a sign from God to take greater care of herself. She spoke at length about her struggles, indicating how painful and laborious this process of making meaning was for her. Judith had been trying to keep her self - the strong and successful woman who used to manage everything on her own. However, she now seemed to have accepted the stroke as God's will.

Matthias also described the stroke as a sign from God which told him to change his life:

God wanted to give me a sign, tell me that I shouldn't go on living like I was before or what ever. And He thought "Listen, I have to give him a warning, so that he really, that he

actually gets it" and he virtually sent me it or gave me it or however you want to put it.

His decision to live a quieter life came about because he felt his previous way of life had been too stressful, not only at work but also in terms of his leisure activities. He described these changes as positive, saying he was "*more relaxed*", which he saw as a result of the stroke. He explained:

How should I put it? Let's say, if I'd not had the stroke then... I'd still be doing the same and due to the stroke you realise "hold on, this doesn't work any more, that doesn't work any more, you should just leave this, you should just leave that".

Matthias and others stated that they became more relaxed due to the stroke, that "*it's positive that it's changed this way*". While they would have said that having had a stroke was not positive overall, the subsequent changes they made in their lives were positive, or as Michael said, referring to his stroke and the heart surgery:

The illness itself... that's the negative part of it. And the, in inverted commas, the pain afterwards from the surgery or so, but the experience itself, you know exactly, if you hadn't had that you would have gone on living like you did and then at some point there would have been the bang [stroke]. And thus you know "hold on, you're not so invulnerable as you thought you were".

Definitions of negative and positive sides of the stroke could be regarded as indications for how people integrated it into their selves and lives. However, that these two sides of the stroke could in fact be closely linked became apparent when we compare two participants' statements. In the quote above Michael indicated his appreciation of his good health when he said that knowing that he "*is not so invulnerable*" was a positive side of the stroke. This recalls Robert's statement that

due to the stroke he now appreciated the value of good health. However, for Robert this positive aspect seemed to be linked with a negative side, namely the awareness that it could happen again. Thus he appeared to feel that the loss of health (hitherto taken for granted) contained the positive aspect of appreciating health more, yet at the same time the negative aspect of living with uncertainty and the loss of control. Whereas Robert found this uncertainty very difficult to deal with, Michael recognised a positive aspect to it - the realisation that he was not invulnerable. From these perspectives, the positive and negative characteristics of the stroke appear less as polar opposites, and more as different aspects of the same whole. What appears negative to one participant seems beneficial to another. Thus these accounts illustrate how the definition of a stroke and of the meaning it had for the selves was highly individual, created within the personal framework of values, beliefs and background.

For some participants the stroke seemed to belong to the past, for example for Thomas, who said that he was almost the same now as he was before the stroke, or Stefanie, who appeared very positive about her experience. Since her stroke, she had gone to the USA as an au pair and described herself as happy there. The stroke taught her many lessons, she said, most importantly that life is finite. She related these insights to the stroke, in her words *"I'm sure the stroke left this mark on me"*. She saw herself as changed in a positive way: she went to the USA which was a *"wish come true"*; she was not as egocentric any more; dressed differently and had had her tongue pierced. For her, the most important thing was to *"simply to be myself"*. She described her attitude to the stroke:

Stefanie: I think that it's very important to see the positive side of it and never to give up, thinking "My God I've had this, why?" but saying "Well this happened now but life goes on" and as you can see with me, I'm feeling perfectly fine. And whenever a door closes, another one opens up.

U.I.: Have you learned this because of the stroke experience or would you have said the same thing a year ago?

Stefanie: No, I think I owe this to the stroke. Really that you have to see the positive side of it and after every rain there will be sun.

Her exceptionally positive attitude towards the stroke may be due to several factors: her youth, her happy time in the States where she also found a boyfriend; her good health.

Twelve months on, the stroke appeared as an integrated part of most participants' lives. For some it represented uncertainty or fear of a relapse. In order to reach the goal of getting on with life these participants coped with their uncertainty mainly by avoiding difficult situations. Others referred to their changed outlook on life due to the stroke, describing its impact on them and on their future lives. However, all of them attempted to close this chapter at this point of the illness trajectories.

4.4. Summary

This chapter has presented accounts of participants' thoughts on what a stroke was for them. It argued that a stroke is an unexpected illness for younger people. A stroke was described as a disruption of the self in different aspects independent of the severity of symptoms. It further stated that attempts to explain the genesis of the stroke and to find meaning in it can be seen as attempts to regain control and thus to minimise the disruption of the selves and the feeling of ontological security in life and health. It thus suggested that the selves are fragile in that most participants described themselves as disrupted at some point in the illness trajectory, yet robust in that some people had managed to preserve their selves and others had tried to return to who they were before. Further data presented here indicated that bio-medical explanations of a stroke were important in easing the disruption at first but they seemed insufficient in helping to make sense of the whole illness experience in the long term.

As one would expect, participants' experience of what a stroke was changed over time. This life-threatening and potentially disabling illness was described as a turning

point and it has been argued that it cut participants' lives into a pre- and a post-stroke life. Lifetime seemed to be seen in a different light with health and life being given a higher priority by most participants.

Apart from these overall themes, changes over the year also emerged. Only three months after the stroke some participants described the stroke as something they were not conscious of or as a release. Clearly, not all younger people at this stage of the illness trajectory described the stroke as a disruption. Furthermore the question as to why participants had had a stroke was posed by most participants only at this point. At this point bio-medical causes for the stroke and related medical treatment or lifestyle changes seemed to give most participants a sense of being in control of the danger of getting another stroke.

This was different six months on when many participants seemed to indicate that the stroke had disrupted their selves, manifested in having to do things differently, instability of health, changes in appearance, loss of self-worth and of self-image. Many felt very uncertain about the possibility of another stroke. However, others spoke of the value of having survived such a life-threatening and potentially disabling illness and indicated that they learned that no human being was in control of life and health.

One year after the stroke the data suggested that participants wanted to get on with their lives. All but one participant had found some way to explain the stroke and its meaning and had thus integrated the stroke more or less into their selves. Descriptions of avoiding situations reminiscent of the stroke, explanations of the stroke as fate, as a sign from God or attempts to move on suggested that this was a point in time when most participants wanted to live a normal after-stroke life.

4.5. Reflections on my own feelings

In keeping with the hermeneutic principles described in Chapter III I have tried to understand participants from their perspective, thereby constantly assuming their otherness. I will now give an account of what I may have brought into this research.

From my own experience I empathised with all participants who described that the stroke had separated their life into a life before and a life after the stroke. Thomas' statements that the stroke was nothing special and had not left a mark on him was alien to me. Frequently I realised to what extent I was sympathising with participants when they spoke of their struggles, for example problems with concentration or with a loss of strength in an arm, or feelings of insecurity about their own selves.

From my own experience I was surprised when participants described positive sides of the stroke early in the illness trajectories. It took me over a year to become aware of the changes I had had to make due to the stroke and even longer to appreciate the chances these changes offered.

Although I was not overly afraid of getting another stroke I was surprised that both Judith and Thomas seemed not to be worried too much about their TIAs. However, I found it interesting to see how these participants seemed to integrate this experience into their lives.

Chapter V

Self and others

The last chapter focused on participants' accounts of what the stroke meant for them and how it affected them as individuals. This post-stroke individuality seemed to stem from the individual interpretation of the pre-stroke selves and the experience of the stroke in the first year following the stroke. This formed what could be called the 'internal' post-stroke selves (Jenkins, 1996). However, these internal selves do not exist as separate entities but are constantly reflected in interaction with the outside world. This chapter demonstrates how participants constantly described their self-definitions and others' responses towards them. They seemed to be continuously interpreting these interactions and indicating what feed-back they incorporated into their identity and what they rejected. They described what Jenkins calls the process of "ongoing to-and-fro of the internal-external dialectic" (1996, p.50). As he explains:

The individual presents herself to others in a particular way. That presentation is accepted (or not), becoming part of her identity in the eyes of others (or not). The responses of others to her presentation feed back to her. Reflexively, they become incorporated into her self-identity (or not). Which may modify the way she presents herself to others. And so on. As presented here, it appears simple, sequential and linear; it is multiplex, simultaneous and tortuous in practice. (Jenkins, 1996 p.50).

In Gadamer's (1996) view, in case of illness a person 'fell out' of the social situation and his or her task is to find his or her way out of this exceptional situation and back into the social life. In this process participants seemed to be greatly concerned with their normality and abnormality as someone who had a stroke at a young age. Normality appeared to be defined regarding social and cultural norms as well as in relation to what participants would have described as their 'normal' pre-stroke

selves. Residual impairment seemed to be defined as problematic only if it interfered in interaction with others. To reflect this, symptoms that are commonly described as ‘problems’ (speech, concentration, memory etc.) will be referred to in this chapter as symptoms, impairments or changes. However, should participants themselves have described them as problematic these symptoms and changes will be spoken of as health problems.

This chapter illustrates the interplay between what could be called post-stroke ‘inner selves’ and external influences. As one of many external influences, work was described as a major source of feedback and of a particular kind of interaction by all participants. The significance of returning to work and the opportunities this offered to participants to interact with their ‘normal’ environment deserves to be presented separately. It will form the next chapter of this thesis.

5.1. The first three months

Reflecting experiences with health care in this first phase after the stroke, interaction with health care professionals and in the hospital and rehabilitation environment featured heavily in the conversations. The main issues revolved around participants’ concerns about their (ab)normality as a young person suffering a stroke; around relationships; and the interference of symptoms with their relationships or social activities.

5.1.1. A stroke is a disruption of normality

Having a stroke at a younger age was deemed by all participants to be abnormal, conflicting with the cultural norm which Karin described: *"it's old people who get strokes"*. Being young and having had a stroke appeared to divert from what was normal. The fact that they had not expected that a stroke could happen to them may explain why none of the participants in this study interpreted their symptoms as severe.

This is shown in the case of Matthias, who woke up paralysed down his right side. After many difficult and mostly unsuccessful attempts to walk and hold things his wife called a doctor. He described his reaction:

When she said:

"Come on, we'll go to the doctor" then I said:

"Ach, why should I go to the doctor?",

"This side doesn't work properly", then I said:

"Ach, it's just sleeping, let it sleep, tomorrow when I have to go to work it'll be OK."

However severe the symptoms of the hemiparesis might have appeared, for Matthias they did not seem problematic. It was his wife who realised the severity of the situation and reacted accordingly. Georg also had severe symptoms which he was unaware of, driving almost a hundred kilometres to work with his right side paralysed - in his socks. It was his boss who reacted appropriately, drove him back home and finally took him to hospital.

Participants described many similar situations. Symptoms of the stroke were diverse. Stefanie spoke of a sudden weakness in one arm, and described how her *"arm dropped into the sink and I couldn't move it any more"*. She wondered what was happening but *"actually I didn't think anything of it, that it was all that important"*. Others spoke of speech problems and tiredness, or feeling sick and having to vomit or mentioned an inability to move and to speak. Regardless of the kind of symptoms, none of the participants regarded them as important and saw no reason to seek medical help although one could reasonably assume that having stroke-like symptoms at this young age would be frightening, or as Robert expressed it:

God, if you would ever have something like this, oh Jesus, then surely you'd panic and be afraid of dying.

One could infer from these accounts that participants, as active young people, did not consider themselves in any danger of suffering a severe illness, least of all a stroke.

This attitude could be a factor leading to an 'abnormal' reaction, a misinterpretation of the situation by the participants. Some of the participants said that they would have gone on with their lives as usual and all needed someone else to react for them.

As in other countries, stroke prevention has been made one of the top priorities for health care in Germany. Bearing this in mind, one would like to expect that health care professionals at least would be aware of the signs of a stroke and interpret them correctly. This was however not the case for three of the participants, who were all misdiagnosed by doctors when they sought help. Helene was treated for back problems for four weeks; she suffered repeated symptoms of weakness and "*tingling pins and needles*" in her fingers and her right arm. After she suffered an uncontrollable fit of crying and lost the ability to hear, a friend finally said "*Hey, I'm calling a doctor now*" and took her to hospital. Andreas, who had a feeling "*like pins and needles*" in his fingers was treated with a salve and injections for four days. When he fell down and suffered a slight hemiparesis, the doctor gave him another injection. Only when he woke up on the following morning and realised "*nothing worked any more*" did his girlfriend call his GP, who admitted him to hospital. Stefanie, whose arm had fallen into the sink and remained weak for a few hours, saw four different doctors (GP, neurologist, cardiologist and radiologist) over a period of four days. When she finally saw a radiologist he told her that she had a stroke. She described this situation as follows:

And he held up some x-rays and marked something and said that was a blood, what do you call it? A blood clot. And "You had a stroke. We'll make an appointment for next week" and of course I went "Yes, sure" I was totally out of it [war total daneben], hadn't grasped what he just had told me and then I took the CT- pictures...and "OK, see you next week then" and I went out and I was there with a friend and told her everything and she went "Hey, Stefanie! Why on earth are you still here? I thought you'd had a stroke, don't you have to get taken in to hospital or something?" "No idea."

Why all these health care professionals failed to react appropriately remains unclear. Neither is it possible to say why the radiologist who diagnosed her stroke sent her home. It was her friend who realised that she needed to be admitted to hospital and a colleague who finally called the stroke unit. She herself had not been able to react either. As described earlier, the problem again seemed to be with recognising the severity of the symptoms. Helene reflected this:

...you feel it then [the symptoms] and you don't know what it is, and don't react anyway.

Thus she indicated that while she realised there was something wrong she could not understand what it was nor react to it. She also described how she felt during the four weeks she experienced recurring symptoms:

Whenever this moment came then I always felt "this side doesn't belong to you at all".

Looking at this quote in the light of what other participants mentioned- for example Matthias' feeling of "...let it sleep..." or Stefanie's thoughts that it was not important – it seems these participants are referring to the same phenomenon, namely that a stroke was such an abnormal event for them that they in turn reacted 'abnormally' considering the severity of the illness. In other words, they did not understand the symptoms as severe and reacted accordingly. In addition to this Helene's quote indicates a feeling of alienation from the affected side of her body.

Another fact that contributed to the abnormality of a stroke for young people was that most of them either did not show the expected symptoms of a stroke, or recovered from them within the first few days or weeks. Stefanie described which symptoms she associated with stroke:

... you only know about strokes happening to older people and they then have, whatever, problems walking or something, some kind of problems following a stroke.

This cliché of the ‘normal stroke patient’ is not only common among the general public but also among professionals. Thomas illustrated this when he talked about a private conversation with the nurse who cared for him in the ICU:

...he then said "Come on let's go to the doctor who treated you, so that he can see you" because that would be quite funny for him to have a patient who left, just if he could see that you're well again, cause normally they see the patient when they come in and either they go out in a box or two weeks later they are gone and you never hear anything about them again. If the person was paralysed or ssst [waves flat hand to and fro in front of forehead] crazy or whatever, he doesn't see that. Then I said "OK, let's go quickly" and when he saw me he said normally this is impossible.

A person after a stroke according to Stefanie was someone who was older and had problems. Here Thomas described how a nurse added the attributes dead, paralysed or mentally disabled. The idea of a stroke leading to a form of mental handicap was mentioned by many participants, and Helene for example stated that people after a stroke were generally viewed as being "*Not quite all there*" while Karin said a stroke had "*...something to do with the brain, and if something has to do with the brain then you're not all there any more, somehow, you're a bit gaga*". Thomas who, at that point had minor problems, with speech, writing and walking had his condition described by the doctor as "*normally impossible*". Thus not only was he an ‘abnormal stroke patient’ but, exhibiting no symptoms he was also an ‘abnormal younger stroke patient’ in the eyes of others.

At this stage of the illness trajectories, many participants mentioned the health care environment as a central factor in determining what the stroke meant for them. The fact that they were surrounded only by older people with the same illness led at the very least to feelings of abnormality, and for some to feelings of isolation, horror and frustration.

Sofie, for example, was by far the youngest in her rehabilitation centre. She described her horror when she arrived :

I went there, I was frightened, totally scared, I have to say, I cried, I was panic-stricken. I don't have anything against older people, for heaven's sake, that was, the youngest woman was fifty-five...

She called her husband and said "*Come and get me, I'm having a major crisis, I'm definitely not staying here, for eight weeks! I won't stay here for eight weeks, no way, not even for a single day!*" Then she discharged herself.

It was not only being together with older people which was difficult. In addition to this being together with severely impaired people seemed to add to the stress of having suffered an unusual illness. Many participants described feelings of being out of place and frustration when they were together with people who had some kind of impairment. Robert's account serves as an example of these. He recalled what happened in the dining room in rehabilitation:

I came into the dining room, you are assigned to a table and there I sat, saw all the people. One at my table ate like a pig, the other at the table next to us, he didn't have a nose, you saw there was something wrong with everyone and there's me sitting in the middle of all this. I felt like getting out of it, could have wept and gone out. I kept saying "What am I doing here?", kept thinking now soon you'll wake up and see everything was just a dream. I really was, felt like I was in a

film there. It was so terrible that first weekend, no one would believe it. Yes, was really hard.

Not only was it hard for Robert to look at all the patients, he also compared himself to them and wanted to run away. In a similar vein, Matthias said that he had been frustrated seeing all the old and impaired people around him. He also described how this affected his inner view of self:

I don't have anything against older people whatsoever, but when something like this [stroke] happens and and there's only old people around you, then you feel totally out of place, then you feel like the lowest of the low...you're on the scrap heap, they want to get rid of you and that's it...this doesn't motivate you, no kick, nothing. You just kind of somehow go on living and well, my God, what the hell.

The frustration and resignation Matthias describes here contrast with the positive effect of moving to another rehabilitation clinic where:

...mostly there were younger ones and this uplifted my spirits because I said, OK, for example there was somebody in my room, he was one or two years younger than me and he had had a stroke as well but he had his right arm or the left, he had straight down [hanging] and he still had the same thing at his discharge after all the therapy, he still had that hanging... his arm then he had to lift it up. And that was not the case for me, luckily that was not the case.

While it was impossible for Matthias to identify with the older people in the first rehabilitation clinic this younger post-stroke co-patient was someone Matthias could compare himself with; in doing so he realised that he was comparatively fortunate. This raised his spirits.

So far, accounts have demonstrated how the rarity of the illness for this age group, along with the fact that they did not exhibit expected symptoms, that they were surrounded by older or visibly impaired people with a stroke added to the disruption of their feeling of normality and seemed to impact on their view of self. In addition to this, some participants described how health care professionals' behaviour could make coping with the stroke more difficult and the impact this had on their selves.

For example Robert was given a prognosis that was highly unsettling for him, as became clear when he described the "*horror scenario*" that a doctor drew in front of him and his wife. According to Robert this doctor said:

That I needn't be too hopeful that everything will be like it was before ... you simply aren't like you were before and because of the low blood pressure you're lethargic and have difficulties getting up in the morning [with a dismissive tone in his voice], and, and, and all this he told me and to ME [spoken loudly] none of this applies.

The description Robert received of a 'normal young stroke patient' did not apply to him, yet it caused great uncertainty. He explained that it was only after his concentration and memory had been checked in rehabilitation and he had proved at work that he was able to remember everything, that he felt "*...that's all totally normal*". Only then did he regain his self-confidence. Thus he indicated the power such descriptions can have in terms of threatening the ontological security of the self and of the work that needs to be done to re-establish a new sense of security. Various other examples of this kind were given by participants. Karin described how a doctor "*discouraged*" her three months after the stroke when he said, referring to her weakness "*..what hasn't recovered up to now, won't come back at all*".

It was not always what someone said that unsettled participants. What unsettled them was mostly some kind of behaviour, and its subsequent interpretation by participants. In the case of Matthias, this can be observed in his feeling that nurses did not provide

him with the care he needed. All they did was come in and bring his food three times a day. He interpreted this as meaning that the nurses were ignoring him; he imagined that they were thinking *"We don't care about that poor beggar there, we'll look after the others."*

The time it took for someone to answer the bell has been mentioned by participants as an indication of lack of interest in them as a person. Georg said when he rang the bell and no-one came, he felt the nursing staff were not interested in how he was; he gave an example of this when he described an occasion when no-one responded to the needs of the man next to him in the rehabilitation clinic:

Georg: That gets you down I'd say. When you're building yourself up, you can feel again, your hands work again, your feet work again, then you also want them to do something with you and then they let you lie there, you know in your own shit they let you lie ...that's like saying "Get stuffed", simply, I do my job and then I go home and nothing else bothers me.

*U.I.: What does this tell you as a person? [he thinks about it]
How does this make you feel as a person?*

Georg: That I'm worthless.

Here he appeared to be stating that the nurses' behaviour was sabotaging his newly built up sense of self after the stroke, leaving him with a feeling of worthlessness. He further indicated that it would have helped him build himself up if they had done *"something with"* him.

As has been said, when measured against what is considered to be normal in German society, all participants in this study were abnormal. Some of them seemed not only to see themselves as abnormal but indicated that they felt stigmatised by others because they had a stroke.

As was stated in Chapter IV (p.115/116) feelings of stigma can be related to feelings of shame and of personal insufficiency. Two participants, Karin and Thomas, spoke of shame at this point in the illness trajectory.

Karin, who had described her inner self as brain-damaged (see previous chapter) and 'stroke patients' as being seen by others as "*a bit gaga*", struggled with feelings of shame whenever she felt associated with the 'normal stroke patients'. She described how she was too ashamed to ask for help to go to the toilet, and how she did not go into the breakfast room because she was afraid that everyone would see that she had had a stroke.

U.I.: Could you tell me a little bit more about why you were actually ashamed to go into the breakfast room [to eat]?

Karin: Yes, I think you have, well actually it's old people who get strokes and what happened was that I suddenly felt old, well, yes, actually old, and ehm you could see it a bit, one foot dragging a bit, I mean if you hadn't been able to see anything, probably it wouldn't have bothered me at all because a lot of patients walk about with some kind of bandage round their heads or without hair and when I went in the first time I thought "Silly cow, you could have had a look before and seen that the patients having their breakfast in there all have some kind of weird thing" but I thought "no, you're not one of them, you don't belong to that group of patients or people, that can't be, and then it isn't". Then, as well, the first three days I was always taken to examinations in my bed. I was so ashamed that I wanted to hide under the covers, and thought "Oh no, now you're being pushed all over the place in your bed, I hope nobody I know sees me".

Here Karin described how outer circumstances and cultural attitudes corresponded with her inner self and vice versa. First she gave an account of the culturally shaped 'normal stroke patient', an older person. According to her this image was the reason why she herself engaged in the self-image of an old woman. Then she emphasised the visibility of her stigma. By identifying other people as stigmatised ("*...all have some kind of weird thing...*") she came across as constructing a sense of normality, yet in the next sentence she pointed out the difference between herself and them ("*...you're not one of them...*"). A further aspect to this is that as a nurse she was normally in the role of the one who pushed people around in their beds. Thus her role of a 'patient' and a recipient of care might have made her feel ashamed. She seemed to have struggled with this role change. To sustain a coherent biography she had to hold on to her "ideal self" (Giddens, 1991, p.68) namely Karin, the 40-year-old woman working as a nurse on night shift, a mother of four children aged between seven and eighteen, and an active person who loved to do voluntary work in the community and in church. In addition she kept a big house with a garden. Karin, like all the other participants who seemed to feel stigmatised, apparently distanced herself from the 'normal stroke patients'. However, her account seemed to suggest that feelings of normality and of stigma were negotiated. This negotiation reveals an attempt to ease feelings of stigma and to restore normality.

Thomas also described something similar. According to him the most difficult thing he had to learn when he got home after his stroke was "*that you don't have to be ashamed or so when here [right corner of his mouth] there's a drop or so hanging.*" He talked to a friend who suffered facial paralysis five or six years ago and whose face appeared to be "*falling down*" whenever he drank too much alcohol. He repeated his friend's advice:

...at some point you have to learn to live with that, to have here [right corner of his mouth] and whenever you have had alcohol, that here then is a drop hanging and that you need someone to tell you "here" but many people have that.

Thomas' friend's solidarity and his reassurance that many other people had similar problems could be seen as an act of normalising what had been perceived by Thomas as something he was ashamed of. Being normal and not disabled was very important for Thomas because *"there would be a lot (of people) who would distance themselves a bit, especially if I was disabled or something"*. The interaction with his friend helped Thomas in restoring his normal self-identity.

Accounts presented so far indicate that these participants' images of themselves as normal young people contrasted starkly with the image of a stroke as a physically and mentally impairing illness suffered by old people. Karin's and Thomas' accounts reveal that feelings of stigma and shame could be triggered if they were seen as people who had had a stroke. However, there were differences between their accounts in that Thomas seemed to negotiate his normality and thus apparently was able to restore his sense of self. Karin on the other hand described her constant struggle to maintain her old self. She seemed to feel stigmatised alone because in her little village everyone knew about her stroke.

Somehow you, it's just that you somehow don't get taken seriously, aren't considered as strong, as resilient, you get left out, you're not really as much a part of the group any more... I began to notice that people were sort of drawing back, and then I felt over there's the group and I'm an outsider. The others do look and see now and again if I'm still there, but I'm not really part of things the same any more and that was for me the first, horrible experience after I came home.

She mentioned various occasions when she felt she was being treated differently from before: for instance she described feeling left out and forgotten when not asked to participate in annual events in her village in which she used to play a central role. Another example was when her mother told her not to work so much. She interpreted these attitudes as signs of being treated differently. It is difficult to identify where

this feeling of being stigmatised started. Could her own idea that people with a stroke were mentally impaired have made her interpret the reactions of others as stigmatising? Or was it the case that being treated differently impacted on her view of herself as a brain-damaged old woman? According to her the feeling of being left out had started in hospital when nurses devoted more time to the patient next to her; the situation was made worse by the fact that she was put into the same room with an old woman who had a stroke. This made her feel as though: *"now you're on the sidelines, now they just shove you into any old room, anywhere, and that's it."*

This again indicated that being put together with someone older added to the stress of having had a stroke, which mirrors Matthias' and Sofie's descriptions of how they felt *"totally out of place...they want to get rid of you"* and *"panic-stricken"* when they had been put together with older people in rehabilitation. All these participants seemed to feel that being put together with older people made them feel inadequate. In addition the expression *"That's it"*, used by Karin and by Matthias could indicate the feeling of having been abandoned by others. Comparing Matthias' and Sofie's quotes to Karin's, one could infer that all of them, in their own way, indicated feelings of stigma, which surfaced when they were put together with visibly impaired older people. Such feelings ranged from feelings of abnormality, caused by the stigmatising attributes of a stroke, to the feeling they were being rejected by a group or by society.

One could summarise that most participants' feeling of normality was disrupted by the mere fact that they suffered from an old person's disease. In addition to this the health care environment, being put together with older highly impaired people, and being treated inappropriately all added to the disruption. Feelings of shame and of stigma were described by some of them.

5.1.2. Stroke and partnerships

The issue of relationships, as an important part of people's lives, was brought up by some of the participants. Robert's and Matthias' accounts serve as contrasting examples of how couples described the effect of the stroke on their lives and how

they dealt with this. After this, accounts are presented describing the effect of interaction of participants with health care workers.

Robert's example is that of someone who seemed to cope better with the changes due to the stroke than his wife. One could also say it is an example of how a spouse seemed to at least share, but possibly take on responsibility for a person with a stroke. As they wished, both of them took part in all the conversations.

When I first met Robert in hospital he said that his stroke was harder for his wife than for himself. She played an important role throughout the period following the stroke, ensuring that he received appropriate treatment in hospital and in rehabilitation. Once he had returned home, she monitored his stress at work and told him when his stress levels were getting too high. Robert had mixed feelings about this. On one hand he wanted her to tell him, but on the other hand he reacted impatiently. One of these situations was when his wife said that she could tell how he was by his appearance:

Wife: I can see that there was a certain level of stress or that there's something up and in his voice, I hear it right away, yes, I hear it.

Robert: Yeah, alright! [voice raised]

Wife: And I say it as well, but

Robert: Go and make the coffee now!

This short dialogue reveals a characteristic pattern which emerged throughout the conversations - Robert's wife watched over him and he recoiled from this.

She watched over Robert's health by giving him advice regarding his diet, cooking accordingly and checking his blood pressure. She pointed out problems between him and the children. When Robert talked about being angry because of the children

leaving toys lying around she said *"You know, so you can work on it, we'll work it out"*.

On his wife's initiative he decided to go to a psychotherapist. While he said he wanted to talk about the problems he had with the children she appeared to think that he needed help coming to terms with his experience of having had a stroke. This led to a short discussion:

Robert: I cope with it quite well [with the stroke]. Only what she [wife] says now, with the kids, but that was the same before, I was at the end of my tether already then too.

Wife: For me it really is important now. It maybe crystallises out of a conversation "there's a sore point here or there"...And I think there may really still be some more things which he should talk over.

Whilst Robert's wife did not state that she was unhappy with her role, one could infer from the above that she wanted him to have someone else apart from her to talk to. The conversation reflects the established pattern of her telling him what he needed and him drawing back. On the whole Robert appreciated her help and said that his wife was his main source of contact. He did not need psychotherapy, because *"Actually I could always talk to her about it and because I can speak to anybody about it."*

This example demonstrates a relationship pattern in which the couple actively negotiated to find a way to live with the stroke. As described in the previous chapter (p.117) Robert had apparently found meaning in the stroke and was able to sustain his sense of self. The interaction between him and his wife as well as the protection Robert received might have helped him to restore a sense of normality and of his self.

This relationship pattern is contrasted by the example of Matthias and his wife. Whilst Robert's wife actively took part in the conversations, Matthias' wife generally

listened to what he was saying and hardly ever commented. Other than with the previous couple, it was him, not her, who felt very insecure about himself and asked his partner for help. One example he gave illustrating this was not daring to walk his dog.

I kept saying 'Yes, next time I'll try it, next time I'll try it' but then this anxiety comes back again, or well I don't know if you can call it anxiety, the feeling you might be a failure with him...then I'd rather say 'Oh, you'd better go [with him] now, you'd better go [with him] now, I don't feel fit enough'.

He described how he needed his wife to accompany him to physiotherapy and be with him when he drove his car. Matthias' wife worked more to sustain their income and to compensate for the reduced sickness benefit. In contrast to Robert and his wife, this couple seemed much less active in negotiating and making changes due to the stroke. It was more as if the stroke had thrust changes upon them. Differently to Robert, Matthias appeared to have lost part of his old self, indicated when described himself as "...having only one side, I feel single-sided... as if I was only half a person" or three months later as feeling like a child.

Whilst it is of course important to exercise caution in detecting messages from these two examples, there appeared to be a relation between the pattern of how the couples dealt with the impact of the stroke on their lives and their expressed sense of self. One could thus say that more active and cognitive negotiation of changes and a protection of the person with a stroke seemed to be linked to a sustained sense of self, whilst a more passive and receiving attitude was linked to a threatened self.

Other participants hardly talked about the effect the stroke had on their partnerships. Helene and Sofie separated from their partners after the stroke, saying that the relationship had not been good before the stroke. Both women said that the stroke had not influenced their decision. A positive effect of the stroke on relationships was described by Robert and by Georg. Both repeatedly said during the year that going

through difficult times following the stroke strengthened their relationship and that they appreciated their wives more than before.

5.1.3. Stroke and relationships with health care professionals

Another kind of relationship was mentioned by some participants at this point of the illness trajectories: between them and health care professionals. They described mainly what had been good for them.

Helene, for example, was reassured by a therapist who confirmed that her memory problems were due to the stroke. She described her reaction:

This really was a relief for me, because you lose faith in yourself and think "Boy, have you always been this stupid?"

Here Helene indicated that she not only questioned her normality after the stroke but wondered whether she had always been like this. The therapist's reassurance that her problems were due to the stroke had a two-fold effect: firstly it seemed to communicate to her that she had been normal before the stroke - and secondly that her problems and thus her self were normal compared to other people who have had a stroke.

Apart from the reassurance of normality, cheerful behaviour and being treated as an individual were also described as helpful approaches. Andreas said that therapists *"...cheered me up and told jokes during the therapy sessions which was great"*. He continued:

They really did take an interest in people, I mean not in what a person had but just... in the person as an individual.

Encouragement, jokes and being treated as an individual instead of as a 'patient' were all beneficial for Andreas. Thomas indicated something similar when he described the positive effect of nursing care:

They simply gave you the feeling things 'll be OK and this is, at that point of time it's not certain if there'll be problems in the future and I found this brilliant, great [supergeil]. Äh, they just talked to you and "yes, yes" I couldn't speak and they simply talked a little bit to you, small talk ...so that you didn't realise how awful it actually was. I found this really good.

Nurses' behaviour appeared to convey hope for the future and distracted him from his awful situation. Participants described various attitudes and behaviours that did them good, and it appeared that this was not a question of extra work or actions that needed to be carried out, as Georg said when he talked about 'Nurse Susan' and how she cared for him:

Georg: She really looked after me.

U.I.: Could you describe a bit how she did this, how she cared for you, what she did?

Georg: For instance she shaved me every day, she could have let me go to pot. And then she rubbed my skin with oil and made sure I had something to eat, simply did what a nurse does but I don't take it for granted. Because she also cleaned my backside because I was still, I was still making a mess in my pants and did this without somehow, anything and I was very, I was embarrassed but she said "Oh, that's normal".

Here Georg indicated his feelings of shame when he had to have his bottom cleaned by a nurse. Again it was the way this particular nurse carried out nursing tasks that seemed to be a relief for him. In order to highlight his appreciation for her care he compared her to other nurses, who he said "made a face" when he needed them to clean his bottom and he ended up apologising. He described the situation as follows:

Georg: ...and I then said "I'm sorry". I was sorry indeed, but what could I do?

U.I.: Yes. And how was that for you?

Georg: Embarrassing, it was really embarrassing. They all said then "well, that's OK we're used to it".

Georg revealed how subtle the communication can be in such a sensitive situation. If shame has to do with wrong-being, and therefore bears directly on the self, the situation described by Georg takes on a critical significance in terms of the integrity of his self. He appeared to describe two different reactions to his shame and their impact. First of all 'Nurse Susan' rather than reinforcing his feeling of wrong-being, said instead "...that's normal". She left open what she meant by normal: whether it was normal for her, a normal situation for people who had had a stroke or a normal task for nurses. Secondly, the other nurses stated that they were used to this. Thus they were also indicating that it was normal, but solely in the context of nursing care. One could argue that they left him with his feeling of wrong-being.

Thus these accounts again proved to be about normality and abnormality and underline that being treated as normal and as individuals was described as most helpful by participants.

5.1.4. A stroke and remaining symptoms

As described in this chapter these younger people indicated that they were not 'normal stroke patients' because none of them conformed to the stereotype of this group of people. However, a stroke does lead to impairment and in this study all the participants apart from Stefanie suffered long-term impairments. These were invisible - manifesting as deficits in concentration and memory, as fatigue, as problems tolerating stress and noise or else with a slight weakness in their limbs. These symptoms were not always important, or even apparent, in the talks.

So when were symptoms mentioned as problematic and when were they stated as a matter of fact? There are two different aspects to the answer: firstly symptoms appeared problematic when they impacted on important social activities and, connected with this when they interfered with relationships.

Judith appeared to describe many situations in which her problems with fatigue, concentration, stress and noise toleration interfered with social activities and how she felt about herself then. For example she said:

...well when I'm in a room together with a lot of people and I can't talk to people any more and everything happens very fast, actually then I feel really superfluous.

Matthias had the same problem coping with several people talking at the same time:

If there were lots of people, let's say five, six people and they were all talking at the same time then I'd pick up what they're talking about but I wouldn't be able to concentrate on just this one person, or that one, but instead I'd hear everything at once and then a wall starts to build up in my brain and pow, that's it, the end, ...then I'd say I'm one sided.

Both Matthias and Judith described themselves as "half a person" (Judith) or "...as if I was only half a person"(Matthias). Both of them said that they withdrew from other people following the stroke. Thus symptoms that interfered with social activities seemed to not only impact on the individual selves but also cause withdrawal from others.

At this point of the illness trajectory symptoms that became problematic in relation to others seemed to be less of an issue than they would become later in the year post-stroke. This is not surprising as participants' interactions with their social environment increased as recovery progressed. As stated in the last chapter, at this

point they seemed to be more concerned to find out whether and how the stroke affected them as individuals.

In summary, three months after the stroke accounts indicated that having a stroke at a younger age and not exhibiting expected symptoms was perceived to be abnormal and some pointed to the stigmatising effect of this. Relationships were described as helpful if others treated them as normal and as individuals. Remaining symptoms of forgetfulness, concentration deficits, writing and speech seemed to be problematic if they interfered with social activities and relationships.

5.2. Six months later

Participants seemed to be more outgoing and thus increasingly confronted with their environment at this point. As Gadamer (1993) would argue, the dialogue is necessary for an understanding of the experience. Applying this argument to this study one could say that the more people interacted with their environment, the more they understood what the stroke meant for them within their world of experience, including tradition and cultural norms.

Possibly related to this, the focus of what the stroke was for participants in terms of self and others seemed to have shifted from their concerns about their abnormal status as young people who have had a stroke to issues around whether they felt different (or not) and were treated differently (or not) compared with before the stroke. Similarly as with explanations of disrupted selves and perceived meaning (as described in the previous chapter) two groups again emerged: some participants described a more stable view of self and seemed to interpret others' reactions to them more positively; others seemed to present a more threatened and unsettled view of self while describing other's responses to them as difficult.

Apart from issues of normality and difference, residual symptoms were constantly discussed by participants. Similarly to three months earlier, they appeared important not just as symptoms but in relation to their impact on social activities and on relationships.

At this point participants had very little contact with health care workers because most of them had recovered well from functional problems after the stroke. Therefore health care no longer appeared as a main issue.

5.2.1. Back to normality

As was indicated in the previous chapter, at this point of the illness trajectories some participants described the stroke as a turning point and stated their insights resulting from this. These participants were also the ones who said that they were "over it" or as Stefanie put it:

It [stroke] belongs to it [her life] but it's over and done with ...Actually I'm proud of how I dealt with it but that it happened to me, yes, well, it did happen, but it's past, finished. I won't shout it from the rooftops, it's got nothing to do with anyone else.

That Stefanie had wanted to share neither her experience of the stroke nor her pride of how she dealt with it with others could be read as her desire to pass as the person she was before in other people's eyes. Nevertheless one could infer that her pride expressed the impact the stroke had on her. This seemed to be different for Thomas who had apparently left the stroke behind. He indicated this when he said:

Thomas: It doesn't bother me in the least. That's happened, it doesn't bother me.

U.I.: mmh. Did you ever have a weird feeling because you had a stroke at your young age?

Thomas: No, never.

Thomas was the only participant who stated that he never felt abnormal due to having had a stroke at his age. This was also indicated when he said that there was *"...no difference between me and someone who hasn't had a stroke"* at his age.

It was not only some participants who wanted to *"close this chapter"* as Georg put it. Other people around them started to forget about the participants' strokes too. Robert, for example, described this when I asked him how people reacted towards him. He replied:

Meanwhile it is, most people don't think of it any more, I guess.

Sometimes someone at work would ask him how he was when they saw him eating his muesli, a dietary change which in turn reminded them of his stroke. However, normally no one would say anything about it, he said, except for people he had not seen much since the stroke, who would then ask him how he was. Similarly Thomas described how some friends he had not seen since the stroke had asked him: *"Whatever's happened to you?"* And then he would tell them, he said, sounding very unperturbed.

These accounts indicate that six months post-stroke, some participants saw the stroke as belonging to the past while people around them had apparently forgotten about the strokes. As described in the previous chapter these people had all described positive sides of the stroke for their selves, for example appreciation of health and life or taking more care of oneself. Thus, the stroke had left a mark on them. However, to the outside world they wanted to pass as the people they were before the stroke, to return to their pre-stroke identity and thus to restore normality.

Other participants seemed to indicate that their normality had not been at all restored.

5.2.2. A stroke is a disruption of normality

The yardstick all participants seemed to measure themselves against was that of their 'normal selves' before the stroke. They compared how they personally felt and how they were treated by others. Helene for instance described herself as over-sensitive at

this point and said she "...wanted to slip into an igloo". She felt that other people treated her differently. When she tried to explain how and why, her slight speech problem became quite pronounced. She started sentences, left them unfinished, indicating more than saying what she meant. However, the following dialogue emerged when I asked whether she felt she was treated differently by others after the stroke. She replied:

Helene: Yes, but I think I'm only imagining it.

U.I.: But you do have this feeling?

Helene: Yes.

U.I.: In what way?

Helene: Well, let's say how I used to be before and so "Well, Helene, she's no fun at all any more, she's so weak"... like I don't want to claim or that they didn't want me, that they didn't want to have anything to do with me any more or whatever but it is easier to deal with uncomplicated people or with unproblematic [aphasic problems pronouncing this word] people.

U.I.: Could you describe a little bit how it's changed with them or where it's changed?

Helene: After the [time in the] clinic they came and asked how I was, I'd say like empathy or emph, I'd say and after rehab nothing. Like "She's had this now and now it's her own business to deal with it". Well that's what I did feel with some of them.

For Helene it seemed to be the case that she was receiving less empathy and attention from others. What she appeared to be saying was that more consideration and attention would hence have been regarded as interest and positive feed-back for her self. In contrast to this, Judith said that above all other people's empathy and consideration was what made her feel different. She put it as follows:

...then they let you go first [in a shop], not that I would like to go first, or you know, they ask you "How are you? Are you getting along all right now, dear?" or "Let me carry this for you" or well, some other kind of things like that, sometimes I feel like I'm disabled or something, then I say then "I'm not disabled" well, sometimes it's too much for me... basically I don't want all that. I'd like to be able to say "OK, I can't manage, it's no use"...I wouldn't feel so ill then.

Here Judith equates other people's help with treatment of someone who was disabled. Getting help seemed to impinge on her view of self as a woman who had always managed everything on her own. Moreover she clearly felt that people who got help from others were seen as disabled and, as she went on to explain, this meant not being a full member of society any more. She expressed this in her own words when I asked her:

U.I.: I have to think of a woman who said to me that she didn't feel as a full member of society any more when people tried to help her only because she had this [illness]. Do you also feel like that?

Judith: Yes, actually, yes, that's probably the way to put it or a better way of saying it than how I did just now, yes they treat you as if you were disabled...as if you didn't fit into this world any more and sometimes you get angry about this and, partly, I have experienced that too much consideration, OK

it's great and good and wonderful and alright but I don't want it, not at all.

U.I.: It's a bit like, you can't manage any more?

Judith: Yes, you aren't as valuable any more.

Helene and Judith gave examples for how differently other people's consideration and empathy can be interpreted: in Helene's case as a sign of interest, and in Judith's case as stigmatising and a sign of not being as valuable any more. Helene described herself as someone who would have wanted someone else to help her or listen to her, a partner or, as she said, "...if you had some form of support or... if there was someone, I mean another daughter or son, whom you had living with you and whom you could talk to". In contrast to this, Judith did not want help from anyone and wanted to manage everything on her own. Thus it could be argued that the internal selves of both seemed to play an important role in the interpretation of societal responses. Both self-image and a participant's concept of disabled people seemed to influence how participants interpreted other's responses to them. Judith, for example, reflected the norm of societal views on disability when she described herself as less valuable. One could infer from this that participants' construction of a situation was a joint product of the self, the personal interpretation of interaction with others and societal presuppositions, in this case of disability.

Whilst Judith seemed to feel discredited because people knew that she had a stroke, Matthias' example demonstrates that the invisibility of his problems and thus of his stroke protected him from being stigmatised. After he had explained that if he got help from others and not tried to do things himself he would "*feel really useless*" I asked him:

U.I.: Recently someone else said something similar. And she also said that she didn't feel like a full member of society any more. Would you also say that?

Matthias: I don't feel like that. How should I put it? People who don't know me, someone who doesn't know me and he sees me like this, then he doesn't know that I've had a stroke. That's what she says, the one I'm walking the dog with every morning, she says: "I don't know what your problem is, you don't notice anything". But what she doesn't know is that whenever she says something five minutes later I've forgotten. And how it all used to be for me she doesn't know that either. She always says: "How you're dealing with the dog", she likes that and "you would never think that you've had a stroke". Then I'd say: "You don't know me any different", she doesn't know me any different and that's why she takes it as normal.

Like Judith and Matthias, many participants talked about the invisibility of their stroke and the effect this had at different points in the illness trajectories. It seemed that the invisibility led to a misinterpretation of the situation of people who had had a stroke; additionally, participants felt their problems were overlooked, as indicated in Matthias's account here. However, Matthias' description suggested a further dimension: this misinterpretation allowed him to pass for normal although he knew he was different. He felt that he was still regarded as a full member of society because other people who did not know him did not see that he had had a stroke. However he refers to normality in two senses. According to societal norms applied to people his age he seemed to be normal, but with regard to his normal self he felt different or abnormal. While he stated the benefits of being seen as normal by others he also seemed to indicate that he felt others misinterpreted the situation because his struggles (for example with the dog) were invisible.

All these accounts could be described as negotiations of normality of participants' selves and in the light of others' reactions. Karin brought up an additional aspect to this. Like Matthias she felt she herself had changed after the stroke, but her social environment had not:

This changed my life a lot, yes, mine. Cause I think if someone from my family had died, that would change my life too, but it would also change the [social] environment around me and this just changed me...And the environment has not changed, that's it. That didn't adopt. I'm simply, I don't fit into my environment that remains unchanged because actually I'm different.

Karin, along with Judith, indicated that she did not fit into her environment any more. However, whilst Judith described that this feeling stemmed from her treatment by others, Karin said that her normal self had changed. However accepting of these changes of herself this may sound, later on she said that she did everything she could in order to be *"the normal Mrs. Maier again who no one needs to be considerate of, well who is normal again, who neither was mad nor somehow physically disabled"*. As was said in the previous chapter, Karin described herself as schizophrenic at this point of the illness trajectory because her body wanted something different from her mind. Here was another one of her dilemmas: on the one hand she appeared to have accepted that she had changed after the stroke, yet on the other she was trying to prove to the outside world that she was her normal self. This seemed to mirror once more what she had called the schizophrenia of her head and body.

Whether participants allocated their stroke to the past or whether they indicated that they felt treated differently, the accounts presented here - like those three months earlier - could all be read as accounts concerning normality or abnormality of people after stroke. Since so many participants seemed to be concerned with this, it seems reasonable to claim that the stroke threatened their feeling of being normal as selves and in other people's eyes; the accounts would thus demonstrate attempts to reconstruct normality.

5.2.3. *A stroke and remaining symptoms*

Impairments seemed not to have changed compared to three months earlier; participants still described them in relation to memory, concentration, the toleration of stress and noise and to being over-sensitive. It is not surprising that these were often described as appearing and being problematic in the context of social activities and in relationships with others. The latter aspect appeared far stronger at this point of the illness trajectories than it had three months earlier.

Judith's description of her problems with noise and concentration was similar to the descriptions she and Matthias had given three months earlier. She illustrated them with the following situation that happened in her occupational therapist's waiting room:

In the background there were these noisy children and all of a sudden, then I noticed, now I'm totally dizzy, now you're finished off, absolutely at the limit and I almost went out and then my therapist came and then I went into the room and then she explained something to me and, I couldn't comprehend anything, I felt like the biggest idiot.

Here she appeared to be describing a correlation between her problems of tolerating noise and her physical well-being ("*totally dizzy*"), her cognitive abilities ("*couldn't comprehend anything*") and her self-image ("*the biggest idiot*"). Only in a social situation when she was together with other people did these symptoms become problematic. The problems they created had an impact on her view of self, described like Matthias had three months earlier, as "*really superfluous I feel then.*" Like then she now said she had withdrawn from other people and all she wanted was "*peace and quiet*". This signals a change from her pre-stroke self as a woman who went out a lot and dealt with customers and colleagues at work all the time. She explained that this had occurred partly because of her problems but also because she did not want that kind of life any more. However, it remains unclear whether she did not want it

any more because it was so hard for her to cope with the problems or whether she had changed fundamentally in this respect.

The wish for a quieter life was mentioned by many of the participants. Helene said that she "...wanted to slip into an igloo", others simply said that they did less and slept more than before the stroke. However, most of them described dangers in withdrawing from others as well as advantages. Here it becomes clear that there is an overlap between symptoms interfering with social activities and impacting on relationships. Sofie described something similar when she stated that she had stopped going out so much. She was worried about isolating herself from others yet at the same time mentioned the positive side:

Sofie: Because of the tiredness, I'd say I'm sitting around here and I'm tired and I think the tiredness comes from that [the stroke]. And then I'm at home, not that I was fit then, I'm still tired but thinking "Why did you not go with them now? Are you cutting yourself off from something you'd have done before?" From people and.

U.I.: Could you say the tiredness restricts you a lot in living like you used to ?

Sofie: Yes, I think so. Although I say to myself it's probably better, let's say that I'm not doing so much any more.

U.I.: What is that better for?

Sofie: Well I used to be the type of person who never went to bed or never went home and now I do, I'm doing, well that there are limits.

Withdrawal because of tiredness as mentioned here by Sofie seemed to involve cutting oneself off from others with the consequence, as Helene said, that "...you're alone". Thus how to deal with their own limitations seemed to be a delicate issue.

Some participants did describe the impact symptoms had on their relationships with their partners. Accounts of three participants will serve as examples regarding this issue.

According to Matthias his memory problems appeared and became problematic mostly in interaction with his wife:

When she tells me to do something in the morning before she goes to work or whenever
"Remember to do that!"
"Yes, yes, yes, yes." When she comes home:
"Have you done it?"
"Why should I have?"
"I told you to do it!"
"You didn't tell me!", I can't remember a thing, everything seems to have vanished.

The extent to which his memory problems troubled him were his main concern six months after the stroke. Both he and his wife said the problems often caused arguments and put a strain on their relationship. Furthermore, they impacted on Matthias' view of self, as he described:

I feel like a little child. Cause ... when she [wife] says: "I told you this", "no, you didn't say that", "yes, I did say that" then you lose faith in yourself. That's how I would put it, faith in yourself.

By describing himself as a child and as having lost faith in himself, Matthias seemed to have incorporated the memory difficulties into his self. Every interaction in which

his memory problems appeared and every situation in which he did not manage to do something (e.g. setting up his new computer) seemed to reinforce this lost sense of self. On the basis of this, one could argue that his self after the stroke was constantly being formed and re-formed by self-reflection and in interaction with others.

However, as indicated three months earlier similar symptoms had different effects on people. In contrast to Matthias, the changes in Michael's memory did not seem to cause any self-doubts. In answer to my question whether he was the same as before the stroke he replied as follows:

Michael: Well, as I told you last time, sometimes it is that I forget things.

U.I.: That's still the same?

Michael: Yes but that's relatively little. For example appointments. Some I do know: "You must remember this, you must remember this". And some: "Right then, got it" and that was that.

U.I.: And that used to be different?

Michael: It wasn't this bad. I don't know whether that's only the ageing process, don't know. [laughing] I didn't notice it as bad. And now it is the case that I've to write down more things.

Michael seemed to explain his memory problems as part of the ageing process and he bore them with humour. Whether his problems were less severe than those of Matthias is debatable. However, the way in which the two men regarded their memory problems was very different. While Matthias appeared devastated because of them Michael seemed indifferent. For example when he forgot each of our

appointments for these conversations he did not seem to be unduly worried. These two contrasting accounts seemed to reinforce the earlier statement, namely that symptoms only seemed to be felt as problematic if they interfered with important aspects of life, that is with social activities, or in Matthias' case with his marital relationship. Only then it seemed did they impact on the sense of self. Participants' descriptions of this also indicate that this pattern emerged independently from the type of symptoms or from their severity.

Two contrasting examples regarding speech impairments may illustrate this further. As described earlier Thomas had minor speech problems but these did not impact on his view of self. His speech problems were apparent in our conversations; sometimes he had problems saying a word and needed three or four attempts to say it, or when he wanted to use foreign words, as he described them, he was unable to spell them. Andreas also spoke of speech problems. However, he described them as having a strong impact on his life in that they caused problems in his relationship with his girlfriend. According to Andreas she wanted him to be at home more and to give up seeing his "*mates and playing darts and to simply be there solely for her.*" He said this had changed since the stroke and he saw a connection between these changes in the relationship and his speech problems. He explained:

At the beginning after the stroke because of my speech defect I just wasn't able to react or operate in such a way that I could give her tit for tat, I mean I imagined it alright, but it didn't somehow, come out.

He felt that his inability to speak up for himself was directly related to his speech problems. As revealed in his comparison between before and after the stroke he saw his girlfriend's behaviour as related to his inability to speak up for himself:

Andreas: And I think like, that she then took advantage of that. Before, if she had done that with me before, I wouldn't have hesitated very long, I'd have sent her to hell right

away....And now it's just not so, it's no longer so easy, to just throw her out, even though I really wanted to...to throw her out.

U.I.: Why is it now no longer so easy for you to just throw her out?

Andreas: I don't know [resigned] perhaps I haven't the courage to do that. The determination, I don't know, I can't say. I could, every time, when she starts going on about my friends, erm, I could erm I could take her by throat and strangle her and say "Make sure that you get to hell out of here".

His train of thought seemed to be that his speech problems impacted on his ability to express himself and this in turn caused his girlfriend to demand things from him which he was not willing to give. Again it was his speech problems that left him unable to "give her tit for tat" or to express his anger because he felt discouraged and had lost his determination. Thus he appeared to relate indirectly his discouragement to his speech problems and thus to his stroke, because they were the reason for his inability to speak up for himself. However, he went on to explain that all this had an impact on his girlfriend's view of him. She now saw him:

Andreas: As helpless perhaps? I'm saying like, I would never have put up with that before.

U.I.: Do you also feel helpless, or how do you feel about yourself?

Andreas: Yeaah, I wouldn't exactly say helpless, wavering perhaps.

U.I.: Mmh - more than before?

Andreas: Yes, more than before yeah.

Andreas demonstrated how his speech problems impacted on his girlfriend's view of him and on their relationship. In interaction with her it appeared he had created a view of self, which he described as discouraged and wavering. While his speech problems caused a change in his view of self, it was only in interaction with his girlfriend that they appeared problematic. Describing interaction with his friends at darts he never mentioned his speech impairment causing problems. Thus whether speech problems appeared problematic seemed to depend on the situations in which they occurred.

In summary, six months after the stroke, participants' accounts of themselves seemed to fall into two major categories: some who had a more positive view of themselves and other people's responses, and others who struggled with their changed image of self and others' responses. Why some participants appeared to leave the stroke behind whilst others struggled with it is an interesting area. Factors that could influence this are on many different levels. The data seemed to suggest that neither the severity of symptoms nor relationships could explain this. All participants had some impairment (Stefanie had just undergone heart surgery) and most participants lived in more or less stable relationships. If they did not (Helene and Sofie) they said this did not have to do with the stroke. As described in the last chapter there was a tendency for younger and male participants to present a more positive outlook on their strokes and on other people's responses to them. However, this is not to suggest that gender and age determined what a stroke was for these people. At this point factors that could have explained the different approaches to the stroke remained unclear.

The controversy of the invisibility of the stroke, of consideration towards people and of the impact of residual symptoms emerged from the data. The invisibility of the stroke led to misinterpretations, with the positive consequences of passing as normal and the negative consequence of lack of consideration from others. However, Judith

described the consideration shown towards her as stigmatising. Furthermore residual speech and memory impairments or concentration problems were variously seen as problematic or unproblematic by individuals, depending on whether they interfered with meaningful social activities and/or relationships.

5.3. Twelve months later

At this point of the illness trajectories most participants had gone back to work and thus talked much more about themselves in interaction with others at the workplace. This issue will be explored fully in the next chapter, thus for presentational purposes here only accounts that viewed the impact of the stroke in the light of self and others and outside of work will be discussed.

The idea described six months earlier that the stroke belonged to the past for some participants does not appear any more. This is because their responses at this point have either been described in the last chapter or will be in the next. For example, Stefanie and Michael's positive statements about the insights they gained from the stroke and Thomas' view that it belonged to the past were all described in the last chapter.

5.3.1. A stroke is a disruption of normality

Normality at this point of the illness trajectories seemed to mean for most people in this study that they were treated by others similarly to how they had been before the stroke. Being seen and treated as people who had had a stroke seemed to cause feelings of stigma in them. Matthias and Karin talked most about other people's presumed perception of them as people who had had a stroke. Interestingly these two participants felt accepted at work as the people they were, not as people who had a stroke (see next chapter). Here their accounts will be used as examples of how they perceived and interpreted other people's reactions towards them as stigmatising and how this seemed to influence their image of self. Some other participants' accounts will be fed into these.

For Matthias having less visitors than before the stroke meant that he was treated differently from before. He said:

Matthias: Well, in my opinion we get even less visitors than before...How should I put it? Last year it was the case that I said if someone wanted to come [to visit], call before and then not more than two, three people so to let me know and if they come I need to call others off. And nothing, simply nothing any more. My brother, I don't know when it was that my brother was here the last time. OK, he has a lot to do and whatever, that's possible but

U.I.: Somehow you're thinking that it had to do with it [the stroke]?

Matthias: Somehow I've got the feeling, yes. Particularly with her [wife] friend I'm thinking that it could have to do with it, I'd say in inverted commas.

U.I.: What might keep them from coming?

Matthias: Somehow, I'd not say fear but reservations that I wouldn't be able to get it when the room was full [of people] or so, I don't know, I couldn't tell.

Here Matthias mentioned having less visitors as an indicator of change in relationships. When he tried to explain why this could have been the case he produced two reasons. First he connected the change to the first period after the stroke when he had restricted the numbers of visitors. The second explanation he mentioned was twofold: other people might not have trusted his cognitive abilities any more, or they did not come out of consideration that it could be too much for him. The point made here, that other people did not believe in his cognitive abilities any more and thus he possibly felt stigmatised, was mentioned repeatedly by him, for example when he said that no one asked for his advice any more. He said:

Well in the past it used to be like people came to me and said "My motor bike isn't working" or "the car doesn't do what it's supposed to". Nothing at all like that any more, nothing any more, just like: he has had a stroke, he doesn't know anything any more anyway.

In this example he interpreted others' failure to ask his advice any more as a clear indicator that others thought of him primarily as someone who had had a stroke and therefore, as someone of reduced cognitive abilities. Karin mentioned the same aspect when she tried to explain how other people treated her differently. She expressed it thus:

...people treat me more cautiously, like "this woman is crazy somehow or she has a defect, you know, she's had something with her head".

As described earlier, Karin suffered from the self-image of an old and brain-damaged woman and she had indicated feelings of stigma before, at three and six months post-stroke. What she described in the above quote seemed to correspond with her self-image. One situation when she felt this was at a church event. Unlike previous years she had not been asked to contribute a salad. She described the change:

...I always used to be the second or third on the list of people who had to do something with the salad. And now I had to find out from the back that they're in urgent need for people who help making the salad... and someone said "We still need to be a bit easy on Karin" and actually that is what I don't want. That adds to my uncertainty cause I think when I'm struggling with my self-doubts and other people as well, then there must be something true in it. Somewhere your defect must be more than you want to admit yourself.

Here Karin indicated that her self-image of having a defect was being reinforced by others. She described herself as fighting against this image. However she also felt that the fact that she was forgotten by others reinforced her self-doubts. In her eyes not appearing on people's list any more was a form of enacted stigma. Another example she gave was being told by her mother or her husband to work less. She did not want other people's consideration, she said. That made her feel that she was *"...not a full member of society any more"*, indicating that she felt left out and was not being taken seriously.

However, like six months earlier it needs to be pointed out that consideration was not always felt as stigma. For example Michael interpreted other people's consideration as protection and interest in him as a person. He described this as follows:

Michael: Well my acquaintances or friends they're still saying "Hey, that's nothing for you, let us do the work." Well they do still, how should I put it, they still protect me. They still help me with it. Or "Stop, that's to much strain for you, don't do that, we'll do it, no problem."

U.I.: Yes. And what do you think about them still doing this?

Michael: Great, they think of me. If no one cared then you'd know exactly they had not cared or they were not interested in knowing what happened to me. I think this is nicer...Absolutely, that's no problem.

As had been indicated earlier, Michael did not appear to have any self-doubts. His memory problems did not make him question his cognitive abilities and he felt that he was the same as before, only that he was more conscious of living and was more appreciative of things. This positive self-image could have formed the basis for his interpretation of other people's responses to him. Although Michael's and Karin's

quotes can be interpreted to mean that their self-image determined how they interpreted other's responses, this seemed not to be the case for Matthias.

He spoke of himself as being "*more relaxed*" and said the stroke had changed him positively (see previous chapter). Yet at the same time he felt that other people treated him as if he was cognitively impaired and felt overlooked and stigmatised. He described his feelings when he said:

... contact gets limited only to the essential and it's well like "Don't have anything to do with him, don't have anything to do with him".

and

...you feel like they shoved you in the corner, whoops, there you go, there you are now, that's it, finito. You had a stroke, that's it, end of story.

Here Matthias, like Karin, indicated that he was not being taken seriously any more. Moreover, he felt that other people avoided having anything to do with him because he had had a stroke. All these accounts indicate that having had a stroke was at least a perceived stigma for some participants for up to one year afterwards in that other people treated them according to a profile of people who had suffered a stroke, not according to their old and normal selves. Interpreting the data highlighted two components to this: participants felt that other people behaved differently than before towards them, and participants interpreted this behaviour as stigmatising. Most accounts remained ambiguous as to whether the differently perceived behaviour was interpreted as stigma or whether assumed attitudes really were acted out. Karin gave an example of this:

...what hurts me most and sticks out for me is that they don't take me as a full member any more... she, she, somehow she's a little crazy. And I mean that really hurts cause I know that mentally it is, I don't have a defect. But it doesn't make sense to tell that anyone, actually they don't understand this. And

then they also have, everyone knows someone who had a stroke or who got a stroke³⁶... The image of a stroke, you have certain [problems], then you can't move properly, mostly you're demented or restless and older... you're put into that scheme and I don't know if you ever have a chance to get out of it, supposedly you can try as hard as you want. Rather you're getting more and more aggressive and that's then for other people the confirmation "Well we knew it, didn't we"... I do have the constant feeling of having to prove that you're normal. And I mean it makes you feel a bit lonely, that I have to say. Somehow, ahm, people withdraw a little because they can't deal with it.

Is it important to know whether Karin imagined others' stigmatising features or whether they actually had them. It is more important to acknowledge that stigma appeared to be an ongoing issue for some of these younger people who had had a stroke and to acknowledge the struggles involved with this. Karin's example demonstrates this well, as she described her great efforts to lead her post-stroke life in order to prove that she was as physically and mentally capable as she had been before. She wanted to pass for the woman she was before, however felt herself that she did not pass as normal and she seemed resigned to this.

In contrast to participants who wanted to go out and be accepted as normal, others preferred to stay at home. This was a sensitive issue because as Helene indicated, this involved the danger of becoming lonely. As she put it:

I have to be careful with this a little bit, I mustn't seclude myself completely because afterwards you'll be alone very quickly although you don't want to be.

³⁶ she used the word Schlag = short form for stroke but means also "bang" in German. It could be that she referred more to the meaning of a "bang" here.

This statement indicates a common issue about the balance between social life and solitude. It could be from anyone and seemed not specific for someone who had a stroke. However, what Helene could have been indicating was that the stroke put this issue into another perspective. Feeling left out by others as she, Karin and Matthias indicated, seemed to lead to the feeling that they needed to make an effort if they wanted to be accepted in the same way as before. Matthias summed up what would have been best for someone who had had a stroke when he said:

And well if you see it like that then it's always best if no one knows what was wrong with you because people treat you completely differently if they don't know than if they do know.

Here Matthias highlighted something that was true for most of the participants: they did not want to be treated as people who had a stroke but as 'normal' young people. Andreas referred to this, saying "*Actually people don't talk about what I've had any more. And that's OK, I wouldn't want that.*" As indicated in the last chapter participants' accounts seemed to suggest that particularly one year after the stroke they put the stroke in the past and get on with their normal lives. It must be added that they wanted to pass for the people they were and this included not being treated as people with a stroke by others.

5.3.2. The need to talk

Another aspect concerned with sustaining a stable self or bearing the consequences of the illness expressed by many participants was being able to talk to someone. In particular the dialogues for this study were considered helpful and important by most of the participants. Stefanie for example said:

Well I have to say that it helped me a lot to talk about it, I'd never have thought that. ... that I could talk to someone who did recognise me, whom I didn't just tell my problems but whom I could tell, yes, how it really was. That helped me a lot.

For some it was also important not to put a strain on their friends or family by telling them their problems about the stroke. Helene indicated this when she said:

I mean now [in these conversations] I can talk about it, which I wouldn't do with everyone, well, it is a bit of a relief...as I said I don't want to put a strain on my daughter and my friend.

Or in Karin's words: “[in the conversations for the study] *I've unburdened something I can't unburden on anyone else.*” For her it was important to sustain her old self in interaction with others, including in relation to her husband:

Well I didn't put this strain on him but pretended to be fine... Actually I'm not such a feeble woman. I said no one needed to come and visit me. I'll deal with this all by myself.

As Karin had done three and six months after the stroke she seemed to be holding on to her 'ideal self', a woman who managed everything on her own. However, she like others, indicated that they felt more at ease after the talks, as Andreas put it: "*I do feel relieved when I talk to you about it*".

Only a few participants said that they talked to friends or partners about their feelings concerning the stroke. Robert was one of the few who said:

I think you have to talk about it, particularly at the beginning or so. Then you overcome it better... we [he and his wife] continuously talked about it.

Here Robert seemed to emphasise the helpful aspect of talking about the experience for himself, particularly as help to overcome "it".

It was surprising that so many participants said they did not talk to anyone else the way they did in the conversations for the study. When I asked them whether they would have wanted a professional to talk to, for example a psychotherapist, they all answered in the negative. Sofie, for example, described how above all my questions had helped her to reflect on her experience. She said that she would not have wanted to talk to someone on a regular basis. For Karin it would have been unacceptable to talk to a psychotherapist because *"that would have enhanced my mood of now they really don't regard you as being normal any more."*

These accounts seemed to indicate that talking about the experience of having had a stroke was important for most participants but they appeared to demonstrate that apart from the talks in connection with the research most of them did not talk about it, partly because they did not want to be a burden to others, not be seen as different or because they did not want to appear weak.

5.3.3. A stroke and remaining symptoms

As had been stated throughout the year symptoms appeared to become relevant and impact on participants' view of self when they interfered with their social activities or interaction. However, at this point in time participants did not indicate that health problems impacted on their view of self as much as they had appeared to earlier in the year. Accordingly, in this part of the chapter the emphasis will be on how some participants described their remaining impairments and how they dealt with these. Since not all participants described impairments as relevant in interaction with others a few accounts will illustrate this issue.

Symptoms had not changed much compared to earlier in the year. Participants continued to describe speech and memory impairments, deficits in concentration and of fatigue or of slight weaknesses in an arm or leg.

Thomas still described a slight speech problem and problems with writing. His narrative arguably pointed to the stigmatising effect of having a stroke at a younger age and indicated how he and his friend managed this information and thus avoided to be stigmatised. Due to the stroke Thomas had lost the ability to speak English. He

described how his friend filled in for him when they wanted to talk to girls they met on holidays. Thomas' friend said:

"It's not that he can't speak English" but that I still have problems with pronunciation because I had an accident.

This short description indicates two important aspects in dealing with stigma. Firstly was clearly an agreement between Thomas and his friend (tacit or otherwise) that they would conceal the fact that he had a stroke. Instead his friend expressed what had happened to Thomas as something acceptable for a man of 25 - an accident. This explanation allowed Thomas to appear normal in the eyes of these girls. Secondly, in this situation, in which his impairment could have become problematic for his self, his friend protected him. Supposedly the two friends had not discussed this before and thus it could be read as an example of how people acted to stay within cultural norms and thus protected the self and avoided stigma.

In the case of Andreas, his speech impairment did not lead to problems in his relationship any more than it had earlier (see p.185). He said that he spoke up to his girlfriend and then *"...it finally came out again, that's what I used to do in the past."* Smiling, he indicated that this had changed the relationship in that *"I'm wearing the trousers again"*. However, his speech impairment seemed to have remained the same. He said:

It's just that I need longer until I can interpret certain things correctly, when I listen to the others they speak away fluently, one sentence after another, totally fluent, they don't have to think about it, and with me, well, it takes me a while to think about things, until I've got it all right, and then until I can say it... Or well you know in our club I'm, that is they elected me, there's eighteen of us and they voted me boss... Yes, well, what I notice is that if we have a meeting and I want to take notes then I can't manage to keep up.

His speech impairment had an impact on his interaction with others. However, unlike six months before he did not indicate that he felt he was "*wavering*" any more because of it. Thus he, like others who described symptoms that appeared in interaction with others, did not indicate that these problems had an impact on the self any more, earlier described as an idiot (Judith) or as a little child (Matthias). In contrast to this, at this point participants described their impairments but appeared to be more accepting of them and of the stroke in general in their lives. Georg described how his repartee was not as good any more due to the stroke. With a smile he said that his wife would refer to this, saying that his "*cheeky tongue*" was still missing. However, while he only now said that he admitted that changes were due to the stroke (see next chapter, p.229) now he accepted that he had to "*live with it*".

It is interesting to consider why participants were dealing so differently with remaining symptoms than earlier in the year. Thomas' account already indicated one possible answer to this. He and his friend seemed to be managing the potentially stigmatising information that he had a stroke and this allowed him to pass for normal and to avoid stigma.

Another way of dealing with residual impairment was indicated by Helene who described what had changed as a result of the stroke, saying that she "*became so sensitive, I mean that's true, that's the way it is*". When I asked her whether this had to do with the stroke she answered in the negative and explained:

People say you don't get older, you become more mature, you become more considerate and you don't put up with things any more.

Here she attributed changes in her self to the ageing process. This was a mode of explaining difficulties that some other participants also engaged in. Earlier in the year Michael had done so. Now Thomas also said that he could not party as much any more. However, for him this had nothing to do with the stroke but "*...maybe it's because of getting older.*" Whether these participants were accepting changes in their

selves as part of the normal ageing process or whether like Georg they did not want to admit the effects of the stroke on their selves remains unclear and is not important. What *is* important is that they explained changes after the stroke in a way that was culturally acceptable – as normal ageing. Like Thomas' example earlier, this could be read as a way to manage the stigma of having had a stroke at a younger age and to seem normal- to themselves and in other people's eyes. And it is also important to note that these culturally acceptable explanations seemed to change the meaning symptoms had for the individuals. Thus what all the accounts presented here appeared to indicate was twofold: firstly, they indicated the fluidity of narrative reconstruction. Secondly they demonstrated the development of strategies to help them accept remaining symptoms and possibly to integrate them into the selves.

It is fair to summarise that accounts presented about the meaning of symptoms in interaction with others mainly concerned the effects of symptoms on relationships and the stigmatising aspect of having had a stroke at a younger age. Two factors emerged that could have helped to deal with changes at this point of the illness trajectories. Firstly the period of time which had lapsed could have allowed participants to develop adaptive strategies to cope with the effect of the symptoms in interaction with others. One of these strategies was to manage the information of having had a stroke and thus to avoid stigma. Secondly, the invisibility of symptoms mentioned earlier could have protected them from stigmatising responses.

Another factor that could have influenced why participants appeared to be more accepting of their symptoms at this stage was recovery. If symptoms appeared less severe it would most likely have been easier to deal with them. However, none of the participants said anything that could have indicated recovery as a factor in being able to accept changes of the stroke.

5.4. Summary

Accounts presented here demonstrate that participants' main issues in interaction with others in their year post-stroke seemed to revolve around normality and abnormality and around symptoms and their impact.

Accounts indicated that a stroke is a disruption of normality. The normality referred to is what was considered to be normal for younger people, what was a 'normal'

person with a stroke as well as what participants perceived as their normal pre-stroke selves. The stroke appeared to disrupt normality in all these aspects and to lead to feelings of being different, which resulted in some participants feeling stigmatised. This required strategies to manage feelings of being sidelined as well as to manage the information of having had a stroke.

The interpretation of other people's responses seemed not to be determined by the response alone (for example consideration) but interpreted individually.

Symptoms were invisible in all participants and thus seemed not to draw stigmatising responses from others. However, they could also lead to a lack of consideration and understanding. Whether or not impairments became problematic seemed to depend on whether they interfered with interaction and with relationships.

Three months after the stroke participants appeared to feel that they were considered to be abnormal in a double sense: as younger people who suffered from an old person's disease, a stroke, and as people who had had a stroke but did not show any visible symptoms. Some participants described feelings of shame and stigma.

While three months after the stroke societal norms of people with a stroke seemed to be the yardstick against which participants appraised their (ab)normality, six months after their accounts seemed to suggest that they reflected on how they were seen by others compared to before the stroke, in other words whether they were treated as the 'normal' Karin, Matthias and so on. Participants now fell into two groups: those who presented a positive view of self were more likely to feel supported by others, and those who struggled with a changed view of self seemed to feel stigmatised and excluded by others. Several accounts seemed to indicate that the invisibility of participants' problems led to a misinterpretation of their situation.

A further six months later most participants indicated that they preferred other people not to refer to their strokes any more - which seemed to have happened in most cases. However, some of them indicated that they felt stigmatised as people with a stroke. Some of these had adopted strategies to deal with this such as proving that they were capable and managing the information of having had a stroke. Residual impairments

impacted less on the view of self than they had earlier in the year. The period of time, together with having developed strategies to deal with effects of the symptoms, emerged as factors that could have helped participants to deal with symptoms at this point of the illness trajectory and to appear normal.

5.5. Reflection on my feelings

While writing this chapter I was particularly surprised about the extent to which societal norms appeared to be relevant for participants' image of selves. I had not thought about this connection - which, as it emerged, was strong - between cultural norms of younger people, profiles of people who had had a stroke and the impact on the view of selves. However, I did expect participants to feel out of place in rehabilitation clinics because it is a fact that mostly older people are to be found there; I remember having distanced myself from the older people when I was in rehabilitation.

Thomas again surprised me when he said that he never had any uneasy feelings about having a stroke at his age. As I had noted in my reflective diary this had already been the case at our first contact in hospital. Then he had major difficulties speaking, often needing four or five attempts to say a word and not speaking in sentences. In my diary I noted:

I said to him that it must be difficult for him not to be able to say things he wanted to say. He answered in the negative, said that this was not a problem for him. I could kick myself for having done this, to read something into him that he had not said nor felt at all.

He helped me realise my own prejudice, namely that a stroke must be terrible for such a young man and not being able to express himself must be absolutely horrible. He taught me that this is one of many possible reactions shown by a young person to a stroke.

I empathised more with participants who described changes in memory, speech, concentration and so on as problematic in interaction with others than with

participants who did not. I was convinced that it must be hard not being able to interact with others in the same way as before the stroke.

The more I worked with the data the more I became aware of my own presuppositions and the more open I became to participants' experiences with the stroke.

Chapter VI

Self and work

In keeping with Gadamer's principle of openness, participants' accounts have led me to grant the issue of work a separate chapter, although in reality work is an inextricable part of social life, of 'self and others'. This chapter does justice to the fact that in this study work was mentioned as a major issue of increasing importance throughout this year by participants. Who they were without being able to fulfil their professional role, when they faced changes to this role or when they were going back to it seemed of particular importance. So why did work appear as such an important issue?

As Herzlich and Pierret (1987) suggest, health, the ability to work and to be active are all tied together and enable participation in society. Thus "...illness has the character of a forced disruption of day-to-day life, which puts and end to the individual's professional, familial, or political activities" (p.177). The authors continue to explain that in the past:

...an essential connection between the individual's occupational activity and his or her identity has become established. As a result, the enforced inactivity of illness has become unbearable, for by destroying the ties that make it possible to be integrated into society and thereby to exist, illness has become tantamount to social exclusion. It isolates the sick from the world and from other people and encloses them within a solitude that cannot be shared. This breakdown of social ties is perceived all the more negatively for the subject is deeply committed to, and totally identified with, a social role. (p.177/178)

It seems that illness and related inactivity lead to loss of the professional role and to social exclusion and as a consequence to loss of identity. The particular difficulties

of the loss of the professional role for people has been described by Babad et al. (1983). They state that a role can become a person's identity, pointing out that: "This happens often in the work domain, where people identifying so strongly with their professional role and invest so much mental energy in it that it becomes a salient socio-identity" (p.224/225). The authors argue that this shift to an identity tied in with work is a personal choice which is experienced positively. However, following Herzlich and Pierret's quote above, the loss of this role would then mean a loss of this identity.

It was of great concern to participants whether they could return to work or not. In this respect the anti-discrimination legislation in Germany (Behindertengleichstellungsgesetz – BGG) was important for them. As in many other countries, laws against discrimination regulate rights for people with impairments³⁷ with the aim to avoid socially created disability. In terms of work the German law says that people with impairments are not to be discriminated against people without, for example in job allocation, and that employers have to make 'reasonable' efforts to adjust workplaces to take account of people's special needs. Whilst Degener (2002), who is part of the 'Enquete Kommission' 'Right and Ethics in Modern Medicine' in the German government acknowledges these regulations, she criticises Germany for still following the principle of 'separate but equal'. This means that people with impairments in Germany are more likely to be referred to specific institutions (for example special schools or specific workplaces) than integrated into society.

This chapter explores what the stroke means for participants in the light of themselves at work. As described in Chapter III all participants had been employed before the stroke, so going back to their previous jobs was an issue affecting all of them. However, it appeared to have the greatest significance for most of them at the point one year on from their strokes.

The question of who they were and what had changed compared to before the stroke was paramount for participants in connection with work. Issues concerning sameness and difference revolved around work. One year after the stroke, normal demands at

³⁷ The German language does not differentiate between impairment, disability and handicap, but all is described with the word "Behinderung".

work, stress and the fear of getting another stroke were all of major importance for participants.

6.1. The first three months

At this point in the illness trajectories six participants were still off sick (Andreas, Matthias, Stefanie, Georg, Judith, Michael). Of those who had gone back to their previous jobs, three had a reduced workload (Helene, Sofie, Thomas) and two had the full pre-stroke workload (Robert, Karin). At this point work was not an issue for all participants. Some did not mention it at all. Those who had gone back to work were examining whether they had the same abilities compared to before the stroke or whether they had changed. Some of those who had not gone back talked about what would be different if they did.

6.1.1. Sameness and difference

As had been indicated in the previous two chapters, the yardstick against which participants measured themselves was that of their pre-stroke selves. For those who had returned to employment, work seemed to be a place of particular importance in terms of finding out about their abilities in comparison to before the stroke. Robert was one of the few participants who had gone back to his previous job very soon after the stroke and was working there full time. He said work was especially important for him because a doctor had described a "*horror scenario*" at the onset of the stroke. Amongst other things the doctor said that:

...most young people don't settle back in at work again and have problems with their private life...

Robert said that this caused him great feelings of fear and uncertainty and that he had only regained confidence in his abilities once he was back at his work as a clerk. He was pleased to discover that he still knew important things, like all the necessary codes, and could manage his work well. Work provided a mirror for him in which to view his abilities and to compare them to before the stroke. As he explained:

It shows you that everything's OK, and, you haven't actually forgotten anything, or how to do something because of the illness, you still remember, that's actually quite comforting. And it shows that you've got over it quite well, the whole thing.

His ability to work not only confirmed his mental and cognitive functioning but showed him that he had managed the strains of the illness. Being able to work was a significant point for Robert in terms of proving to himself that he was back to his normal self.

Not having lost one's abilities mostly provided reassurance for participants themselves, as Karin indicated when she said she had to "*prove to myself that I can do it again*".

Thomas had also gone back to work. He was in the reintegration phase at work and was happy with it. Although he reported several remaining impairments such as problems with writing and with fine motor movement, he felt that their impact on his work was minor. He felt the same despite these difficulties.

Apart from the confirmation of abilities, work also provided distraction from the stroke. This was indicated by Sofie who worked in her own pub, although on a reduced basis:

Sofie: Then I talk to the guests and this gets somehow [pushed] to the sidelines gets repressed, as I said before. I mean if I was only at home or housewife or would only be sitting at home, I don't know how I would, don't know.

U.I.: The distraction is good for you.

Sofie: Yes.

Sofie felt she needed to be distracted from sitting at home and thinking about her stroke. Although she did not say it, one could infer that working in the pub serving guests gave her a sense of normality and sameness. The first two talks took place in her pub and I saw how she greeted the customers by name. It seemed she had not merely returned to a workplace, but also to a valuable social environment, albeit on a reduced basis. It helped her protect herself from thinking about the consequences of the stroke.

However, for Karin being back at work had the opposite effect. As a nurse working night shifts on a medical ward she was not distracted from her stroke but constantly reminded of it. This was very stressful, as she described when she said: *"day in day out, seeing them all the time, these stroke patients, I just can't cope any more"*. She went on to describe how seeing all *"these stroke patients"* reminded her of herself. She gave an example of what she felt was most important for her:

At the moment the most important thing is for me to cope with working, and my symptoms, to handle that. To just manage better... at the moment I'm looking for another job, where I don't have to work with stroke patients although I could, I would have, I could actually identify with them closely, but, no, I just can't.

Karin gave an example of a blind woman who reminded her of herself. She had been unable to see anything for the first few hours after her stroke. Here she pointed to a different aspect, namely that sameness made her aware of her own difference compared to before the stroke. Aiming to be the same as before, she needed to distance herself from other people who had had strokes, saying that she was *"...not one of them, you don't belong to that group of patients or people"*. Her words suggest that part of her self-protection broke down whenever she was confronted with *"...these stroke patients"* at work. She seemed to feel the need for another form of protection and as a consequence she started looking for another job.

Both Sofie and Karin indicated that being confronted constantly with their illness and thus with the differences to their pre-stroke life would have been too much. It could

be claimed that distraction from the reality of having had a stroke was a form of self-protection in that it allowed them to try to be the same as before.

These accounts indicate that work provided a place where participants were able to compare themselves before and after the stroke. Robert, Karin, Thomas and also Sofie seemed to find confirmation that work after the stroke could be the same as it was before. At the same time it highlighted differences, for example for Karin.

Those who had not gone back to work did not have the chance to make this comparison between before and after. They talked about work only in terms of what it had meant to them before and what it meant to be off work. Two said how important it would be to go back for them because that would give them the feeling that they were needed. For Andreas being needed at work had been a very positive thing before the stroke. At present, the only time he felt needed was by a friend to help paint his flat. He articulated how much he missed being needed at work when he said:

Andreas: I'd say that from his point of view he needs me and it's good that I know that...[and at work] I used to do everything and at times I'd do without a holiday just because of work.

U.I.: Because you were needed?

Andreas: Yeah, exactly, actually for a long time I was the only one who could drive or manage the lorry and they simply needed me. And that, that was good.

For Judith being needed gave her meaning in life, indicated in her answer to my question about what gave her life meaning:

God, I think that I'm needed, yes, that I'm needed. Now I'm needed less cause I'm not fit but then I'll be needed more once I'm fit again.

Andreas had mentioned his special talent for driving the lorry and Judith mentioned serving customers as reasons for being needed at work. The value that others placed on their abilities contributed towards this feeling of being needed. Therefore these accounts point to what they described as meaning for them. In addition work offered the possibility for socialising, indicated by Judith when she said that it was "...being with the people" that she missed most.

Various other aspects linked to work were mentioned by Matthias who was also still off sick: his self-image, the stigma of being off sick, feelings of shame and his own prejudices against people who were off sick. His account will be presented in more detail because it serves as an example of many cultural issues related to work in Germany and probably in other Western countries.

Matthias said that he had always liked his work as an electroplater and would have preferred to go back to it at this point. However, this decision lay not with him, but with his GP. As he explained:

[then] I go to the GP again, then he does his examinations and then "We have to sign you off sick again, this still isn't alright", then "Shit", yes it is always the disappointment then, ...the feeling you're always ill, always beneath the, not up to it.

His disappointment indicated how important work was for him. Despite the weakness of his arm he wanted to go back to work because being on sick leave was to be "...not up to it" which implies he felt excluded from normality. He also expressed this in his description of his emotional response when other people talked about him being off sick:

...a lot of people say "You should be glad to be off sick, you get money and everything" but you are always disappointed, get the feeling you're always sick, always on the side, on the sidelines, when you go out, that's why I don't like to draw attention to it,... I would rather keep it secret.

Here Matthias linked sickness benefit to the stigma of receiving benefits and, connected with this, of being excluded from the normal community of working people. However, he not only felt excluded by others, but excluded himself from others. He illustrated this with the example of a situation which happened whenever he saw his neighbour, who was also one of his workmates:

...[he is a] colleague of mine and he sees me day after day, how I, I feel embarrassed, then I think "Oh, there he is again, I'd better make sure I stay inside" or something because he always sees me and I don't know what he thinks, but I always think he thinks "Ah, I have to go to work and that guy is sitting around, sitting around on his own, having a great time and" [voice raised] because he doesn't know about my arm and so on.

The invisibility of the reason he had for being on sick leave, namely the weakness of his arm, played an important role in his feeling of embarrassment. His assumption of what his neighbour could have thought about him is important for two reasons. Firstly it indicated the felt stigma of being off sick and secondly it evoked an image of self as someone who purposefully stayed away from work instead of really being ill. This self-image reflected Matthias' own prejudice regarding people who were off sick for a long time, as emerged in his response to my question of what he would have thought of someone else who had had a stroke at his age. He replied:

Matthias: At my age? Then I would have thought, it's hard to say, but if he would have been off sick for as long as I've been

now, then I'd have said that's a, how do you say, ehm, he's stretching this out this isn't possible.

U.I.: He's malingering?

Matthias: Yes, he's malingering, this can't last that long... [if] someone at work was sick for one or two weeks, or if it's bad for three weeks off sick, then I always say "he knows how to get three weeks of holidays, right?" Now it's me who meanwhile... it's almost four months since I've been to work.

Matthias' presupposition here stems in part from his personal prejudice against people who went on sick leave while not showing any visible signs of their illness. However, it could also arise from a cultural prejudice against people who violated the norm of being healthy and productive, a norm that exists in modern societies (Crawford, 1984). In either case, Matthias described his feelings of shame as coming from his invisible problems. As has been stated in the last chapter, feelings of shame can indicate feelings of personal insufficiency. Thus Matthias' struggle with the issue of not being able to going back to work can be read as a testimony of such feelings. His desire to conceal himself from others might then be rooted in his shaken self, with the wish to cope with this feeling as the motivation for his desire to go back to work as soon as possible.

In summary at this point work was an issue for some of the participants. For those who had gone back it was important to prove that their abilities to work were the same as before - that they had recovered. Additionally, it provided distraction, but also highlighted differences to before. Some of those who had not gone back mentioned that they missed being needed as well as the social contacts. Matthias highlighted cultural issues of being off sick, related to feeling abnormal and excluded.

Participants experimenting with who they were at work and talking about the value of work for one's position in relation to others and in society continued to be the core issues six months after the stroke - but with a slight shift.

6.2. Six months later

Six months after the stroke many participants who had gone back to work were confronted with the 'normal' demands of working life. This confronted them with their 'normal' pre-stroke selves as well as with social and cultural expectations.

At this point of the illness trajectories six participants were back at work. Four of them had their pre-stroke workload (Thomas, Robert, Karin, Georg) and two were undergoing reintegration into the work process (Helene, Sofie). The other five were still on sick leave (Matthias, Andreas, Judith, Stefanie, Michael).

6.2.1. Sameness and difference

As described in the previous chapter, at this point of the illness trajectories most participants seemed to compare themselves to what was considered to be normal in a social sense and not so much to their own pre-stroke selves, which had been their focus three months earlier. Thus being 'the same' at this point meant not only attempting to be the same as before but also to 'fit in'.

Thomas, one of those participants who worked full time, indicated this. As three months earlier, he had no problems with work, stating that his problems with writing and sometimes with foreign words did not cause problems at work at all. He said that there was no difference between him and someone who has not had a stroke. The stroke belonged to the past.

In a similar vein Georg appeared to be convinced that the stroke was "*...a closed chapter for me, that it's over, we have to look ahead.*" At the same time he mentioned memory problems. This was not a new issue, but whilst three months earlier he said that they had nothing to do with the stroke, now he appeared not so sure any more. He reasoned whether or not his memory problems led to difficulties he had working on a machine he had worked on before:

Georg: ... he put me on the machine I worked at two years ago and I don't know whether you could trace that back to the stroke or whether it's normal forgetfulness, I didn't remember much, I have to say... and there I had a crash last week, well I've ruined the machine to put it bluntly and at first I didn't notice it and then I had tears in my eyes and then I called the master, that was nine or ten at night, I called him and said "I've had a crash"...then he came and told me what I've done wrong and then I remembered it. And that, this mistake I do blame on the stroke cause this was what I didn't know any more and when I told him about it then it came back. That's with everything, when I learn it, then it comes back...

U.I.: But I don't understand. You said earlier that the stroke was no issue for you any more but ...I would imagine as quite shocking to notice that there is something you always used to do and now you can't do it any more. Isn't that the case for you?

Georg: No, cause I say to myself it can also be the years, that I've been off sick for a long time and before that I've worked on another machine and then I was off sick for a quarter of a year, respectively four months, half a year that I've not worked on that machine and that could be the reason. And when he explained it to me it all came back. I don't know whether it's from the stroke or from the time I've not worked on it.

Georg's different explanations of the disaster with the machine could be read as attempts to protect his old sense of self. The switch between explaining his memory problems as due to the stroke and not believing that they had anything to do with it seemed to lead to the supposedly more acceptable explanation of normal

forgetfulness as the cause of the problem with the machine. Thus he restored not exactly his pre-stroke self, but still a self that was not affected by the stroke. As he explained half a year later, his way of dealing with the stroke (and also with this situation) was to avoid confrontation with the reality of the effects of the stroke. According to him it took him a year to "...admit what it was" (see also previous chapter). Thus his account demonstrates that the issue at stake was not whether the accident was due to the stroke. What is truly important is instead how he protected himself at this point and how it took him one year to become aware of the consequences of his stroke and to admit their effect on his abilities and on his self. Sofie presented a way to protect her self at this point of the illness trajectory. She was just about to give up ownership of her pub. Tenants were going to take it over, and when I asked her how it felt to give it up she replied:

I have to say that feels similarly unreal as it had with the stroke... I've to say, first of April and then when there are the new tenants, maybe it'll be only then that I realise it. Now it's like in a film, as if this all passed me like a movie, yes.

By comparing the situation of giving up her pub with the process of becoming conscious of the fact that she had a stroke, Sofie indicated that she was experiencing a similar feeling of unreality regarding both issues. Sofie referred to this feeling of unreality in the last chapter, indicating that it was her way of protecting her self from the strain of the illness.

As three months ago, those participants who had not gone back to work reflected on what it would have meant for them to be able to return. Andreas for instance said that being able to work meant "a lot" to him. He explained why:

I just don't want to sit at home twirling my thumbs anymore, I am simply a guy who likes working and, works hard and, yeah, I mean, I have now been at home for six months and like, out of professional life and now it's really about time,

that I did something... The most important part is, I'm simply fed up to the back teeth sitting around at home and having nothing to do, I really feel so superfluous.

Here Andreas related his ability to work to his self-worth. Not being able to work marked a difference in the contribution he could make to others.

Matthias often indicated that going back to work would have meant going back to his normal old self. Three months earlier he had indicated how important work was for his self-image and for his social position. At this point he felt very insecure because of his memory problems (see Chapter IV, p.179), and he feared failure if he went back to work. Thinking about work made him aware of the potential impact of his impairment on work and thus of the difference to before. However, this would not hold him back if he was signed off sick by the doctor, indicated when he said "*... in any case I would try it*".

Judith raised the same issues when she described her fear of failing at work:

Actually I'm afraid of not being able to do it any more, let's say I really did like it a lot and I was good at it, the customers keep asking for me.

Apart from reassurance, Judith also missed the social position work used to provide her with:

Judith: I want to know where I stand, like in the past I was right up there, in the front row and now I'm probably somewhere here at the very back of the queue and now I really need to know, what, where I am.

U.I.: You're saying... that this is connected, your position in society and what you're able to do.

Judith: Well it is, you know customers call me and ask for advice, and [they ask] when I've got time or when I'm in Freiburg, they ask me to come by and you know, you know I do get recognition from the outside world that I am someone, it's not that I'm now a nobody.

Judith had lost her social status due to the illness. Other people's recognition appeared vitally important in that it reassured her that she was 'not a nobody'. She needed this feedback for her self-esteem and for the creation of her post-stroke self. All these accounts indicate that not being able to work reminded these participants of their difference whilst they aimed to regain their old feelings of self-worth and old social positions.

6.2.2. Normal demands and changed priorities

Being the same meant also that participants were confronted with the same pre-stroke demands and thus with the normality of work life, or more explicitly, how to manage stress. However, as was described in Chapter IV the stroke marked a turning point in that some participants changed priorities. For some of them the desire to make themselves and their health top priority clashed with the reality at work, particularly stress. Robert was one of them. He said that the stress at work was what he wanted to avoid because he had given work too much priority before the stroke:

...I've intended this, ehm, that I don't take the stress any more, that there are more important things than work, this I've seen clearly when I was lying there.

Sticking to this intention appeared to be difficult at work. He explained why:

My colleague was on holiday and then it was also, it's the end of the year and that's always when the pressure and the stress

is highest and that was when I had to start my full workload and that really was a bit unfortunate.

Robert seemed to enter a vicious circle of managing stress in the workplace. Part of this circle was formed by his intention to give other things in life higher priority over work and also of explaining the cause of the stroke with stress "*because I don't see any other causes*". (Interestingly, three months earlier Robert said that his high blood fat caused the stroke.) Thus what he needed to do was to avoid stress. This itself seemed to create new stress, particularly when he was confronted with 'normal' demands at work, which sometimes included being under stress. In the situation described above he seemed not only to have had to deal with the stress at work but also with the frustration of not being able to stay true to his insights. In addition, he had to cope with the fear that he could get another stroke due to being under stress. There are thus two parts to what he indicated. Firstly work confronted him with his pre-stroke normality at work, yet as this normality had partly caused the stroke, it was not entirely desirable to go back to it. Secondly the stress at work reminded him of his vulnerability and lack of control over his health and life.

These were not only his issues. Helene, for instance, who had described three months earlier that she could not "*..take this*" stress at work any more raised the same issue. She was still working on a reduced basis, gradually being reintegrated into the work process. She described her situation:

Helene: ...I'm falling under the same spell again.

U.I.: Like before the stroke?

Helene: Yes, yes.

U.I.: Could you describe how that is?

Helene: Yeah, well like doing everything. Always doing, doing and ehm, I don't listen to myself.

In the course of the conversation she gave several descriptions of her situation, as for example when she said: *"I don't know whether I can't keep control of myself so that I've you know the feeling I have to do all this?"* Later she said: *"I have to say, I'm not coping"*, referring to the situation at work. As stated in Chapter IV at this point of the illness trajectory, Helene, like Robert, had identified her way of life and the stress as the cause of her stroke. Now living almost as she had before was causing feelings of helplessness and vulnerability and making her afraid of getting another stroke.

These last two accounts of people who had gone back to work described how the fear of getting another stroke was related to work if the stroke had been explained as being caused by stress. As was argued in Chapter IV, explaining the stroke was similar to coming to terms with it and giving it meaning. Judith added another dimension to this, although her account is different in that she had not gone back to work. Thus she reflected not on the basis of her actual situation at work but on the pre-stroke situation when she explained how work and getting a stroke were related to each other:

Judith: Listen, actually I think He up above [points with her finger upwards] said: "You there, listen, you can't go on like this, you've been working too much." Or "think of yourself now and slow down a bit", like putting on the brakes.

U.I.: This means there is another dimension?

Judith: Because I actually think, looking back, I did work a lot, yes and I really enjoyed it and still, sometimes I might have overexploited my body. That I simply, OK, that actually it was too much and that but for me it wasn't. And that the body said: "That's enough now".

U.I.: The body or He up above?

Judith: Both I think, so I'd say both. Actually I'm quite religious although I don't run to church all the time but I think it was too much.

Here she differentiates between the self who liked to work a lot and the body told by God by means of the stroke that it had all been too much. Her self appeared to be what she described as the active, successful and wealthy woman who felt she could achieve anything by will and effort. Her body appeared to communicate God's message that she should be doing less. It put on the brakes. Here she appeared accepting of this message, yet at the same time she seemed to fight against it: *"I don't want to take on this illness, I really don't want it"*. However, her attitude was changing. Before she had described getting a stroke as fate; now her account seemed to indicate that she was fighting against accepting it. Thus, like Robert and Helene, she voiced a conflict between identifying the cause of the stroke as too much work and the decision to therefore work less. They were all thinking about the meaning of the stroke for their lives and struggling to absorb this meaning into their everyday reality and into their selves. However, as opposed to Robert and Helene, Judith did not have to struggle with translating her insights into the reality of work. While she appeared to be fighting against accepting the stroke, Robert and Helene seemed to be more concerned with the practical consequences of their interpretation of the stroke's meaning for work. Since the stress at work was intertwined with the experience of the stroke, stressful situations reminded them of their vulnerability and mortality and gave rise to the fear that it could happen again. Therefore stressful situations at work added to the inner stress of trying to translate new insights into the reality of work.

These accounts demonstrate that explaining a stroke as a consequence of stress at work created a dilemma for some of the participants who had gone back to work in that it clashed with the priorities of putting themselves and their health first, not work. Their insights into their own vulnerability also sat uneasily with their need to be strong at work.

Participants who had not gone back to work also found themselves confronted with normal expectations regarding work, both in terms of expected appearance and of being fully capable and healthy.

Stefanie for instance was off work because she was recovering from heart surgery of the patent foramen ovale. Her training as a pharmaceutical assistant was finished and she was organising her stay as an au pair in the USA. As described in Chapter IV, at this point of the illness trajectory she had her tongue pierced as a sign that she had 'got over it'. Now she faced the difficulty of finding a family that would take her. She speculated whether this had to do with her piercing:

You start to doubt about yourself. If one said no, although if it was only the piercing of my tongue then I'm sorry. Cause they have photographs of me, they have documents, they can get an idea of me, I think they could judge me and just because of the piercing, that's no difference.

While she saw the piercing of her tongue as a positive sign of her recovery she felt she was being judged by others and rejected as a person. Self-doubts started to grow and she wondered whether she should take the stud out but said that "...this is a sign for me and if I took it out, that's not what I want." Taking it out appeared to be like denying what had changed for her after the stroke. She interpreted her failure to find a family as a direct result of her piercing, but it is unclear whether this was in fact the case. However, this feeling led her to negotiate with herself whether to give up a part of her self related to the stroke, or whether to fight the consequent difficulties and doubts.

In contrast to her feeling of being unwanted and arguably of being stigmatised on grounds of the piercing (as the sign for her coping with the stroke) Michael felt that he was discriminated on grounds of his changed health situation. He had been advised by his doctor not to do the same strenuous job any more because of his heart surgery. Michael was very disappointed after talking to the head of the personnel department, who gave no indication that he was willing to give Michael another job.

Instead he felt as if "...it was sort of like "look for another job ". He said that he did not understand how there could be a problem finding another job for him "in a company with 1100 employees". Michael described the various options he had. One was to go back to the old job and try to avoid heavy work. However, he rejected that and described what it might be like if someone (in this case him) were not able to do a full workload:

To start with it would be alright, then they'd say "Well, you're still ill, we can take on some of your work" but at some point you'd hear "come on, get a move on!" And then you come and say "I'm not allowed to lift this" then they say "why did they send us a cripple like that?" That's the way it is.

While he understood his colleagues' presumed discriminating point of view to an extent, his bosses' standpoint had made him feel that they wanted to let him go. He said:

Michael: It's really hard when you cannot work, the whole thing, because then they want to see and get rid of you, to put it bluntly.

U.I.: But how is that for you as a person if they wanted to get rid of those who can't work as much?

Michael: Hey you feel as if you were useless, of no use for anything, and you think in the past you were good enough for them and now, now they want to get rid of you, no "Thank you", nothing. "You haven't done a full workload? We'll look for someone else then" something like that.

Here he indicated that the work environment was unforgiving towards people who could not meet expectations. His feeling of being unwanted at work made him feel

useless, or as Andreas had said, superfluous. Michael's and Stefanie's accounts told of their difficulties in dealing with felt prejudices, mercilessness and strain of a normal work environment. These participants felt unwanted either because of the fact that they could not keep up with the requirements at work or because of prejudice. However, whilst Stefanie related her feeling of being discriminated to her piercing, Michael described his boss's behaviour and his unwillingness to deal with people who did not fulfil the demands of a productive and healthy work environment.

Three months earlier, participants had described work as particularly important for them in terms of an opportunity to compare the pre-and the post-stroke selves. Confirmation of abilities and thus of being the same at work were central to those who had gone back to work at that stage. Although three and six months after the stroke only half of the participants were back at work, the emphasis seemed to have shifted. In these second talks some appeared to talk about the demands of normal work and how they clashed with the insights these participants had distilled from their experience. Working less, as well as doing a less strenuous job, or showing a piercing as 'abnormality' all seemed to be unwanted in the world of work. Work was important for these participants because they defined it as their meaning in life. A few participants seemed to feel normal at work despite remaining impairments.

Karin's account does not fit into any of these described categories. Working as a nurse she felt she had to educate her colleagues in care for people after stroke, as she indicated when she said that she would *"...go home with a guilty conscience if I ignored the same things that had been wrong in my own case."* Work confronted her with her experience of care and the care at her workplace. Out of her professional role, she was trying to change this for the better. A possible interpretation of her efforts could be that she took on the responsibility to fight for better care. They can also be read as efforts to come to terms with her experience and thus to integrate the stroke into her self.

6.3. Twelve months later

As had been indicated in the previous two chapters this point in time appeared to mark the desire to return to normality and not be treated as a person with a stroke any

more. This was also reflected at work. Work had become an important issue at this point of the illness trajectories. Most of the participants had returned to their former workplaces and were working the same workload as before the stroke. Two participants were on sick leave (Judith, Sofie) and one was working within the framework of the reintegration process (Matthias).

6.3.1. Back to normal

For the majority of the participants being back at work meant that they were back to 'normal'. This normality however raised various issues. On one hand there were feelings of regret when they realised that their goals of leading a different life than before the stroke seemed unattainable. On the other hand this normality seemed to raise their self-confidence as normal young people who were part of a productive society.

As six months earlier Robert was one of those who regretted his return to the normal way of things:

I think that I've adapted to the old thing again, a colleague of mine just said to me at the beginning I wasn't like I had been before...When I started to work then I was somehow, well how should I put it, like muted, didn't laugh like I did before and somehow everything was a bit slower and a bit unhurried and I don't know. And now everything came back, that you've fallen back into the same old rut.

'Falling into the same old rut' meant for Robert he might "get angry about things that aren't worth it, that you have to say to yourself "stop, this isn't all that important". Thus it seemed that he was not able to remain true to his inner self, who had learned that there were more important things than work. However, he also described how outer influences at work made it hard not to fall back into old habits:

...in my department many people weren't there, also off sick for a longer time... we were so decimated and then always the

management they don't do anything and you don't know how to manage all the work and and and, one thing leads to another. And then I had an argument about this whole thing and that was it then.

"That was it" meant that he called his doctor and asked him to sign him off sick, which as he said was something he had never done before. Thus Robert indicated that it was not only difficult for him personally to stick to his intention and not to allow work to be as important as before the stroke, but that the circumstances also made it difficult for him. Apart from the personal dimension a cultural dimension emerged: demands of normal work that seemed to allow no consideration of individual needs. Like Helene and Georg, he said he wanted to avoid living as he had before the stroke (see Chapter IV, e.g. p.119). All of them indicated that they had not been able to keep to this promise they had made to themselves. In Georg's words:

I'm totally caught up in everything again. Claudia [his wife] says it as well, or she tells me off sometimes but on the other hand, everyone comes up to me and wants me to do something, you're meant to do everything.

Georg related this to his situation at work but also to his life in general. Three different kinds of pressure come across in this quote. Firstly he did not want to fall back into the same routine as before the stroke. Secondly his wife told him off because she felt that was what was happening. And thirdly other people put pressure on him by demanding "everything" of him. One year after the stroke, both Georg and Robert found themselves confronted with the same expectations regarding work as before the stroke. Being treated like before conflicted with their post-stroke selves which did not want to live up to the expectations of others or to take the strain any more.

Being back to the normal state of things did not only have a difficult side. For some this normality was existentially important. Judith, who had not gone back to work,

and Matthias, who was in the reintegration process working three hours per day, both expressed this importance. Judith said:

Judith: I'm looking forward to being able to going back to work again... I'd like to try it after the rehab, such a reintegration I want to try it and I'm granting myself this time out, I'm really allowing it myself and [then] I'd like to try it again...

U.I.: This question is almost superfluous, but I'm going to ask it anyway: How important is it for you for things to be OK so, that you can go to work again?

Judith: Listen, that is very important. Actually just as important as eating and drinking.

The extreme importance Judith attached to work makes sense when we consider her struggle with her lack of self-esteem after the stroke. She described this in various contexts, one of which was her inability to work. This lack of self-esteem emerged in her description of herself: "...how should I put it, simply not as valuable any more, I simply cannot do as much any more." While Judith emphasised her desire to work as linked to her self-esteem, Matthias brought up another dimension. He described work as most important for his future:

Matthias: First of all my future consists of my ability to work the seven and a half hours that I've to work, that I manage that, that I get that off the ground.

U.I.: To reach that goal.

Matthias: Yes, once I've reached that goal then personally I feel, then the world is my oyster, then I can reach everything. When I've reached that goal then I can get anything I want.

Being back at work, even if only for three hours a day, led him to describe himself as "very healthy" and he appeared to be happy despite remaining symptoms of weakness in his arm and memory problems. Matthias had not returned to normal. He worked less and still had his impairment. However, these differences seemed to be overridden by the benefit of being back in the employment process:

I have to say, what I think now, that what really got me going so I was brave enough to start doing things again was me being back at work again, working for three hours a day.

Matthias detailed what he meant by "what really got me going again":

I only imagine if, you're at home for ten months or whatever, you're at home, have to fend for yourself, can't really go out and so on and so forth, then this somehow gets limited [gestures to his head]. And now you're going to work, then you're meeting colleagues and him and him and him and as it was with me at the beginning "Is it better?" and "How was it?" And then you've to tell and tell and tell and you start to talk here to someone and there to someone and there you've totally different possibilities than if you're just like when I was sitting at home, I didn't have any possibilities at all...I always thought about myself. "Why did this have to happen? Why me of all people? Why am I so ill now?" and and about all your symptoms. This is what you're doing day after day, you can't get out of it. One day you're saying "Tomorrow, tomorrow things will change, tomorrow everything will be different" but the next day it's exactly the same old game. And

now when I know that I've to work... then I can talk to one about the motor bike, or to the other I talk about women or about that and that or about motor races and everything you could possibly imagine.

Here Matthias mentioned beneficial aspects of work that can be summarised as social contacts with his colleagues, cognitive stimulation through talking to others, and finding distraction from "the same old game" of constantly thinking about his symptoms and why he had had a stroke. Furthermore he felt that being back at work meant the end of being stigmatised for him:

...what I meant is if you had something like that, then you get "There was something wrong with him, he can't go to work any more, there was something wrong with him", whatever, no matter, you're put away in the corner, you're out, that's it, end of story, matter's closed. Gone, simply gone.

In this quote Matthias describes how he felt he was regarded by others before he had gone back to work: put in a corner, socially excluded - stigmatised. However, as described in the previous chapter, he had experienced feelings of stigma at this point of the illness trajectory. He indicates here that these were however not related to work.

Whilst both Matthias and Judith talked about the prospect of work and neither had yet been confronted with the reality of the strain of a full workload, Karin, who had always worked her full workload after the stroke, similarly felt more accepted at work than outside. According to her, people at work were the only ones "who accept me for who I am." She described the situation:

...for my colleagues I'm the same as I always had been and the same for the patients and I'm just as capable and I know about my abilities.

While she described herself as feeling "100% insecure" she said that work was "another area, there I don't constantly have the feeling now you're falling down having a stroke". Here insecurity about herself seemed to be related to her fear of getting another stroke. Being treated the same way as before the stroke and feeling confident about her abilities provided her with a feeling of security, which extended to not getting another stroke.

Looking at these narratives one could infer that work meant for participants, either theoretically or in reality, social integration, distraction from thinking in circles and cognitive stimulation. It could be said that the beneficial aspects of work as described by these participants touched on participants' images of themselves as individuals and as social beings.

Feeling accepted for who they were played an important role in re-building participants' self-confidence. Work provided a particularly important place for this. Andreas said that it was most important for him: "*Just being accepted at work again, I was accepted before too, but now it's more important to me.*" Like others, Andreas described himself as feeling insecure outside of work. Thus some participants indicated the reassuring effect of work on their shaken selves.

6.3.2. Normality despite changes

As described in the previous chapter remaining impairments did not impact on the participants' view of self at this point of the illness trajectories. This was particularly true at work. For example, Andreas described how his leg started to shake when he climbed up and down the lorry's ladder. However, while his writing problems troubled him (see previous chapter, p.179) the shaking of his leg was not an issue, in his words "*my leg, I can live with that*". Another example of dealing with remaining impairment was given by Georg. As mentioned earlier, Georg spoke of his memory problems in each of our talks. However, it was not until this point that he related his changed memory abilities to the stroke. This became clear when we talked about the incident with the machine six months earlier. Then he had explained the incident as a result of forgetfulness. Now he described it differently:

U.I.: To me you used to say the stroke was no issue for you any more, that was only two weeks and then it was over.

Georg: Yes, with regard to the illness, indeed. But with regard to thinking I really do have like that it's sitting somewhere else, that I've thought you haven't done this for a long time.

U.I.: Yes. I did read the story about what happened with the machine again, and I wanted to ask you how you're looking at that now: do you think this had anything to do with the stroke?

Georg: That's for sure, yes.

U.I.: That's what you're thinking now?

Georg: Yes.

Here Georg separated the symptom of changed memory abilities from the illness, the stroke. He used technical terms to describe his memory problems, saying he needed "...to start everything up in here [brain] as well" and that it was "sitting somewhere else" in his brain. However he, like most of the other participants, appeared to describe this in a matter of fact way, not as something problematic. This also held true with the accident with the machine. Georg saw no problem with being unable to handle a machine and destroying it because of a lapse in memory due to the stroke. One could infer from this that although participants spoke of remaining symptoms that emerged in the work situation, these did not seem to impinge on their view of self at one year after the stroke.

For Karin the symptoms she noticed at work also appeared insignificant when compared to her feeling of being stigmatised (see previous chapter, p.192/193). As she described:

...whenever I have to put strain on myself or have to push beds, then I notice it. But I think I could live with that. But what hurts most and sticks out most is that they don't take me as a full "member" any more.

One can see from several accounts that for many participants the benefits of being back at work outweighed the problems of remaining symptoms. Furthermore these accounts suggest that fulfilling their former occupational roles gave them self-confidence and a feeling of normality. As was described in the previous chapters feeling normal and not being treated as post-stroke people were stated by all participants as being very important at this point of the illness trajectories. Karin and Matthias, who had both felt that they were treated as abnormal by others, stated that only at work this was not the case.

However, as much as work provided a place for confirmation of normality, there were a few participants who described how the fact that they had a stroke impacted on their work. For these the issue of whether to conceal or to disclose effects of the stroke at work led to some difficulties.

6.3.3. Disclosure and concealment

Here a few participants' accounts will serve as examples of disclosure and concealment of the information of having had a stroke and remaining problems. Georg's case will demonstrate what happened when the fact that he had had a stroke was not revealed.

Helene had to deal with a difficult situation at work at this point of the illness trajectory. She said her boss kept pressurising her to work 100% when she was being reintegrated. Additional pressure, said Helene, was put on her because her boss

"...seemingly had decided on someone to replace me". She described her remaining problems with concentration and blackouts at work. She had gone back to work full-time as a playschool teacher at this point. In the following dialogue she described how she felt about her problems and the consequences with regard to her boss' behaviour:

Helene: Well, ehm, I need a bit more time, I've become slower.

U.I.: You make a movement with your hand towards your head, you mean slower in thinking?

Helene: Yes. Well, ...with concentration.

U.I.: Mmh. This has remained.

Helene: Yes, well I really have problems there [at work]. I don't need to tell everyone, but I notice it then. There I also had [the] feeling, I mean I really was too honest and did say this and I mean, then I noticed that then she [boss] wanted to get rid of me because I, for her I am not a full worker...[it is] more difficult, not so easy as it used to be.

U.I.: And this is mainly concentration. How does this show itself?

Helene: It deteriorates, I forget a lot, I really somehow have total blackouts well mainly in stressful situations everything just drifts by and maybe it's a kind of protection, a defence you create yourself, I don't know.

Here Helene described how she felt her boss wanted to get rid of her when she revealed her problems with concentration. She came to the conclusion that she should not reveal problems at work any more, as indicated when she said that she had been "...too honest". As a consequence she said she tried to reduce the stress at work by working with smaller groups of children (going for walks or reading a book to them). Helene had dealt with her blackouts in stressful situations on her own and it seemed she was not granted any kind of protection from her employer. The only relief, she said, was when she got a disability certification which protected her from dismissal.

Helene indicated that concealing health problems due to the stroke was one possible way of trying to protect oneself from discrimination at work. Georg's example illustrates the opposite extreme. His employer tried to protect him by hiding the fact that Georg had a stroke, to the extent that a colleague who had to train him for his new job did not know about it. This led to difficulties:

Georg: At first he had to explain everything four, five times and he did not know that I've had a stroke, well my boss didn't tell him and although he knew it he consciously hid it so that he [the colleague] would not [treat me] with the attitude "he won't get it anyway".

U.I.: Right. And then he expected too much of you?

Georg: Exactly. And then he went in [to the boss] and said "Mr Müller doesn't get it right away, we need more time" and then Mr Schmidt, the boss, told him that I'd had a stroke and then he really went wild.

Here Georg described a preconception surrounding someone who had had a stroke, namely that such a person "...won't get it anyway". It appeared as if there was an agreement between the boss and Georg that hiding the fact he had had a stroke was

appropriate in order to protect him from prejudice at work. This protection however proved useless when Georg's concentration problems affected the training. At this point the protection strategy changed; the disclosure of the fact that he had had a stroke was then viewed by the boss as more protective for Georg, presumably in order to explain the difficulties to the colleague. However, this disclosure resulted in discriminating behaviour on the part of another colleague who sometimes said to Georg:

Did you not get that? I think you're needing some time out again, you can go back to the machine for half a day.

To Georg, having to go back to working on the machine, that is, working in a less qualified position, meant a step downwards - he was a master mechanic. His colleague's reaction, telling him that he lacked the cognitive abilities to do more complicated jobs, must be read as a form of stigmatising behaviour. Georg certainly understood it this way, but he seemed not to take his colleague's comments too seriously, as indicated when he said that this man "*talks rubbish*".

These examples demonstrate the sensitivity of the issue of disclosure and concealment. Helene and Georg both gave examples of feeling discriminated when they disclosed the fact that they had had a stroke or mentioned their difficulties at work. However, Georg's account suggests that concealment could also lead to colleagues having 'normal' expectations of him which he could not meet. The question of whether or not to disclose the fact that they had had a stroke arose for participants because of the fact that their symptoms were invisible. At one year after the stroke, when other people had forgotten about their strokes (see previous chapter), it appeared it was entirely up to the participants to deal with expectations towards them at work, and to decide themselves whether to disclose their difficulties or not. In Goffman's (1968) terms they needed to manage the information of having had a stroke. Thus they can be read as accounts of how to deal with the stigma of stroke at work. Robert also referred to this when he said:

At work, well I mean, whenever there is a situation where I somehow, I try to give the personal manager an understanding of it, that I still have to overcome this [stroke].

Compared to six and nine months earlier the issue of disclosure and concealment at work was new. Obviously the invisibility of symptoms in combination with the fact that participants were confronted with the expectation of being able to cope with a 'normal' workload led to conflict as to whether to conceal or to disclose. Since this emerged now, it seems that participants were granted consideration and protection only for a certain time. Michael had described this six months earlier and he said it again in this talk when he explained that his colleagues still accepted that he could not lift heavy weights. However, "...this will work for a period of time and later they'll say: "You could just as well help here, what do we have you here for." For some of the participants this period of protection seemed to be over at one year after the stroke.

One of the further dilemmas described by participants was the issue of stress at work and participants' related fear of getting another stroke. It is to this issue that this chapter now turns.

6.3.4. Work, stress and getting a stroke

As indicated in Chapter IV, the fear of getting another stroke appeared a dominant issue at this point of the illness trajectories. Apart from explaining it individually in medical terms or spiritually, at work many participants presented another explanation: stress. Robert indicated his thoughts about a second stroke in the following dialogue:

Robert: [in stressful situations at work] ...then you really are somehow, I'm afraid that something's going to develop out of it, out of this whole situation. And I also used to, now I catch myself again at thinking about work, as well at night and so on, I didn't have that for some time.

U.I.: Well, do you have the feeling this could lead to a stroke, living like this? It almost sounds like that.

Robert: hää, I always say to myself then, I'm actually taking medication, it's unlikely to happen again, but when I start feeling nervous and I'm like I never actually used to be then I say to myself you must get out of that somehow.

U.I.: Was that the same before the stroke?

Robert: No, I was never shaky like that, and I notice it now, my voice becomes hoarse and she [wife] is more likely to notice it than me, when it, when I'm under great stress...

U.I.: I mean that's a point I'd like you to say a little more about, why that fear comes back whenever you're put under strain, although that had nothing to do with your stroke, that's how I understood you?

Robert: No, the causes remain unclear... if you look what you're meant to do to avoid a stroke, they say apart from being overweight and from smoking, that you should avoid stress. And because I wasn't really overweight and I didn't smoke, and well, the only thing was I had high blood pressure and now and then stressful situations and because I now notice when I'm in a stressful situation, how I get hoarse, then of course I feel anxious and I know exactly, that's what it was like after the stroke, I was hoarse.

Robert's description of work and his fear of getting another stroke turned into a narrative about the genesis of his stroke. His explanation of why he had a stroke

changed over the year. While at first he appeared certain that his high blood fat caused his stroke, he later said that the stress at work and his high blood pressure might have led to the stroke. Stressful situations at this point as well as six months ago heightened his fear of suffering another stroke because in connection with hoarseness such situations reminded him of the stroke and thus of his vulnerability. In addition to this he described an idea about what had caused his stroke related to his knowledge of prevention. Thus he seemed to be demonstrating that his rationale was formed through his experience of stress at work- which reminded him of his stroke- and a related fear of a relapse - which was based on his experience and on his knowledge of stroke prevention. He was not the only participant who demonstrated an interplay between stressful work situations, the fear of getting another stroke and common knowledge about stroke prevention. Andreas struggled with similar feelings when he described how his lifestyle could lead to another stroke. His GP also played a role in this because, according to Andreas, in order to avoid stress his doctor had forbidden him to drive and work with a cement pump. He now drove a cement lorry instead. Andreas said:

Andreas: I suppose, if I continue to lead my life like I'm doing, you know my diet, and stress, and I think just now at work, well we've got a lot of work, stress too, not like with the cement pump but there still is stress and well because of that I maybe am afraid it could happen again.

U.I.: So you think these are the reasons why you had a stroke?

Andreas: Yes, I do. In [hospital] they weren't able to tell me what had caused the stroke... to this day I don't know what caused it, why I really had a stroke.

He, as well as Robert, filled in the gaps in his knowledge about the causes of his stroke with a personal narrative about stress at work and his diet leading to the

stroke. Stress as described here was something both of them were exposed to at work. Furthermore, it did not seem to be under their control. However, Andreas, like Robert, had not always described the genesis of the stroke like this. Three and six months before, Andreas had related his stroke to an occlusion in his head.

Narratives concerning stress at work in the case of both of these participants became narratives of the attempt to explain the genesis of the illness and to deal with the fear of getting another stroke. As has been stated in Chapter IV, only participants who had had heart surgery were not afraid of another stroke. The idea of the heart defect being 'repaired' seemed to be sufficient to assure most of them that they would not suffer another stroke. However, this simplicity of cause and effect did not work for the majority of participants, who had to compensate in some way for not knowing what had caused their stroke. In stroke prevention programmes in Germany and other countries stress is mentioned as one of many risk factors. Many participants in this study used this knowledge to gain control over their situation and keep the uncertainty about a possible further stroke in check. One could thus say that participants needed to do so in order to regain a sense of ontological security. This then would give a sense of control over circumstances, particularly at work. Michael illustrated this:

The first thing to prevent all this is to avoid stress. If you did everything, how should I say, see it from a distance then you can control stress a little bit. Or make sure there is not that much stress. Stress in many respects. One gets stressed because of this, the other because of that. But you really can channel it properly.

In this explanation Michael claimed that it was possible to control stress. However, the logical conclusion to this train of thought is that people who were unable to control stress and thus unable to prevent another stroke have themselves to blame. As has been described earlier Robert and Andreas perceived stress as something that was beyond their control. In their cases this seemed to go hand in hand with

returning to the 'normal' routine at work, something that Michael had not experienced at this point of the illness trajectory. Although he was working full time as a worker in civil engineering he explained that he still avoided heavy work.

More participants talked about stress as a factor leading to a stroke at this point in time than before. One could infer from this that thoughts about stress were related to the demands of a normal work life. As indicated by these accounts narratives about stress became narratives about the genesis of the stroke. Both had changed over time and whilst stress was mentioned as the cause for a stroke by two participants six months ago, now one year post-stroke many more participants seemed to relate stress and their strokes to each other. It also seemed to be more of an issue for men than for women.

Matthias provided another example of how stress came into play as an explanation for his stroke. His narrative was particularly interesting in this respect because he spoke of what could have caused his stroke in the first and in the third dialogue, but gave different explanations. To demonstrate how his narrative developed I will depart from the structure of presenting the talks chronologically, and present the relevant parts of his accounts at three and twelve months after the stroke at once. Three months post-stroke he and his wife had the following dialogue about what could have caused his stroke:

Matthias: Stress, we've, I've said this to her [wife] before, that maybe that I've had stress, but I didn't perceive it as stress, I felt it was normal.

Wife: Well, we had a relaxed day that Saturday.

Matthias: I worked that Saturday till two pm, we went to buy a mobile phone.

Wife: We had a totally relaxed day, then we went out with him [dog], ate cake, in the evening we were relaxed too and at night it happened.

Matthias: If someone asked me today about the whys and the wherefores, why the whole thing happened, then I'd have no idea. Except for this one thing with the heart I can't imagine why this whole thing happened.

Here Matthias indicated that stress was something he thought of as a cause of his stroke but he did not regard it as relevant. Twelve months post-stroke Matthias' explanation of why he had a stroke had changed. He said that God sent him the stroke to tell him to change his life (see Chapter IV, p.146/147). I asked him what he was thinking of changing. He described how he used to come home from work and hurry to get on his motorbike. Then he said:

Matthias: ...And I reckon somehow this must have been too much stress, although I didn't think of it as stress myself but somehow it must have been too much stress.

U.I.: What, riding the motor bike?

Matthias: Yes but not only that. Like, when I used to come home, like that Saturday when it happened [stroke], we usually come home from work or we go shopping directly from work, then you go shopping here, shopping there, do this, do that and that, then you come home, then you go out with the dog, walk the dog and after that there is something else, whatever, a colleague comes by or something different, I simply think that this was too much stress.

This was different from nine months before; Matthias appeared to explain the occurrence of his stroke as entirely due to the stress he had had that day, mainly related to his leisure activities. However, he also related it to his stress at work as an electroplater when he compared his way of working before and after the stroke. This was indicated in the talk as it continued:

... I already gave up riding the motor bike, yes and then I let myself, before it was like "Oh, these orders!" [urgent] and this and that and I tried everything to get the orders ready. And when I go to work now, I'll do tomorrow what I can't do today. If I don't have time or then I do it tomorrow, well then, bad luck, then I can do it just as well tomorrow. It never used to be like that...

U.I.: What do you think -, why could stress lead to a stroke? Why do you believe that?

Matthias: Well I just imagine that because of stress your blood pressure, well I don't know if you'd say blood pressure, that your blood becomes thicker, you see? And then somewhere there's not enough blood and then you get the stroke.

Matthias said this was his own idea of how stress led to a stroke and that no one had explained it to him like this. This whole narrative suggests various aspects related to the issue of stress, work and the occurrence of a stroke for Matthias. Firstly he, like other participants, came up with his own reason for his stroke in the absence of any firm medical explanation: stress. He presented a linear model with stress leading to high blood pressure, which in turn led to inadequate provision of blood and ultimately to a stroke. Secondly he indicated that any form of stress could lead to this. Thirdly he seemed convinced that taking things easy at work and taking medication would prevent him from getting another stroke "...this can't happen again

cause I'm taking medication". He, like Michael, appeared to think that he was able to control the danger of getting another stroke by controlling stress and taking medication.

Sofie also tried to avoid the danger of another stroke by avoiding stress. In her case this resulted in a lack of job prospects. She had given up her pub and was waiting to hear about her disability pension. Sofie was sure that stress had caused the stroke:

Let's say for me in retrospect it was stress, that's for sure. That's absolutely sure... Not because the doctors said that but, the irregular sleeping hours or something, that's what I would say myself now. When I think, I'd come home, at four or five in the morning, at seven I had to get up, get the little one ready, take her to playschool at half seven and then I'd go back home, lie down for another hour, but that was [stops speaking].

As described in Chapter V Sofie rejected medical advice to undergo heart surgery in order to prevent another stroke. Like other participants she created a narrative that described stress as the cause of the stroke. However, this narrative put her into a position where she had to avoid stress in order to avoid another stroke. She seemed to control her fear of getting another stroke by trying "...to avoid anything exhausting". At this point of the illness trajectory she was still having problems with weakness of her arm and with back pain and she did not seem to have any perspective regarding work.

So far accounts have shown how narratives about stress at work turned into narratives about the genesis of the stroke and about how to control the danger of getting another stroke. As will now be described, thoughts about how too much work could cause the stroke also seemed to turn into narratives about the spiritual meaning of the illness. The ways in which participants came to talk about the meaning of the stroke for themselves has been described in Chapter IV. What is important here is how participants related stress or too much work to the spiritual meaning of the

stroke for their selves. Matthias for example said that the stroke was a warning for him not to "...go on living like I was before or whatever". By this he meant what has just been described above: avoiding stress at work as well as stress in his free time. Judith spoke of too much work having led to the stroke at six months post stroke (see Chapter IV and this chapter). Here she has interpreted it as a sign from God "...to think things over one more time." She described the message she found in this illness experience in almost identical terms to six months previously:

Not long ago, or before this happened last year I was just slaving away, did nothing but work, you know, I only was there for others, never thought of myself. Only there for others and maybe He up there said: "Hey, you, listen, start to think a little bit of yourself." That's how I see it, that well a hand brake was put on.

These narratives give an account not of what caused the stroke but of its spiritual meaning for the people. Both participants seemed to describe how they had been overdoing the activities that had been meaningful for them before the stroke- Judith working and being there for others, Matthias working and participating in leisure activities. There is a sense that they all felt that they had 'misbehaved' in that they did too much; then came the stroke. All of them regarded the stroke as a sign that it was time to put an end to their 'misbehaviour'. Some participants said that this sign came from God, for others it was a "*lesson*" they learned (see Chapter IV, e.g. p.132). However, one could say that thinking about stress at work led to thinking about what caused the stroke; thinking about causes for the stroke in turn led to thinking about work as an important part of life. Pursuing this train of thought one could say that thinking about the cause of the stroke and its consequences for participants' lives appeared to constitute a search for the sense and meaning of the stroke. The gap described earlier would then not be a gap due to not knowing the cause of the illness but instead a gap caused by a lack of meaning in the stroke. This issue had already emerged six months before. However, it appeared to be much more distinct and important for more participants at this point of the illness trajectories. Thus with

regard to stress and work, one could claim that the process of making sense of the stroke was a major issue for many participants at one year after the stroke, whether they had gone back to work or not. It seems that work provided a particularly important opportunity for this, maybe because participants were confronted inescapably with normal expectations of working in Germany. Work thus emerges as a place where participants could reflect on who they had been before, what they had made of the illness experience, how they wanted to live their post-stroke lives and who they wanted to be after the stroke. Andreas' example illustrated this when he said that he had always liked to work hard (pre-stroke self); at this point he mentioned that stress at work could lead to another stroke (illness experience). That was why he now wanted to avoid stress (live his post-stroke life) and at the same time he wanted to be accepted at work as he had before (who he wanted to be). Viewed in this light, narratives about stress at work have shifted into narratives about the struggle to integrate the stroke into the post-stroke selves and to pass as normal in other people's eyes.

Two participants' accounts have not been mentioned in this part of the chapter. Both said they were more or less happy with their work. Stefanie had gone to the USA as an au pair and said she was very happy there. She intended to stay on and study there when her time as an au pair was over. Thomas said that he was working full time as a printer and it was all *"totally normal"*. When I asked him about the alternative training he had intended to undergo to become a clerk he said that he would *"have to learn how to write properly"* before he could start it. He was the only of the participants who seemed to feel work was not that important. This was indicated when I asked him about his prospects for the future. He replied: *"It'll be OK. Tomorrow with the 32 million"*. He meant that he hoped to win the lottery and that if he won this time he would never have to work again.

In Germany people who are signed off sick are entitled to the full salary for six weeks only. After this time sickness benefits of 65% are granted for up to eighteen months. These structural issues clearly play a role for those participants who had to live with 35% less than their normal salary. However, these financial issues were

rarely brought up by participants throughout this year, with only Matthias and Michael mentioning them. Judith said that she had lost a lot of money because in addition to her work as a saleswoman she used to work on a freelance basis sewing curtains for customers. This she could no longer do. There is no clear explanation why these structural problems were almost absent in these talks. Perhaps participants did not regard financial issues as important for these talks, or they did not want to talk about them. Perhaps they were indeed not important issues for participants throughout this first year after their strokes.

In summary, this part of the chapter reveals that at work participants were inescapably confronted with every aspect of their illness. Stress at work was a major issue for many participants. Thinking about stress at work led to thoughts and fears connected with getting another stroke, or else to looking for some kind of meaning. The consequence was the desire to prevent another stroke by avoiding stressful situations through making lifestyle changes. It was argued that this process could be described as a vicious circle of managing stress at work but also as a process of making sense of the illness and of integrating the stroke into participants' selves.

Thus it was argued that work provided an important opportunity for reflection on and stabilisation of participants' selves. In addition to this social contacts and the interaction with others were described as helpful. A particular difficulty was the issue of disclosure and concealment, affecting a few participants. Accounts demonstrate that disclosure of one's problems could lead to discrimination. Concealment however could lead to high demands being made of a person which also caused problems. The issue of how to manage the information of having had a stroke was a sensitive one for these participants.

Two participants did not describe any work-related issues. Financial issues were raised only by a few people in this study.

6.4. Summary

In this chapter participants' accounts provided insights into their experience of the stroke with regard to work. The dominant issues have clearly changed over the year. Several reasons for the particular importance of work were mentioned. Firstly, it

allowed them to compare their pre-and post-stroke abilities and in addition provided social contacts, interaction with others, cognitive stimulation and social interaction. Secondly, work gave participants meaning in life. Thirdly, people who had gone back to work raised different issues than those who had not. It seemed that being back at work meant being the same as before. This could lead to difficulties in meeting normal expectations but also to more self-confidence when abilities and social position were confirmed. Participants who had not gone back to work talked about what they missed or reflected on the significance work had had for them before the stroke.

Three months post-stroke participants who had gone back to work described the relief of being able to do the same things as before. Work seemed to provide distraction from the stroke as well as confrontation with it. Participants who had not gone back indicated that they missed the meaning that work gave them as well as the social contacts.

At six months after the stroke some of those who had gone back appeared to create sameness by not being conscious of differences or by justifying them. Others who had gone back told of the downside of being back in the same routine, namely the fear of getting another stroke. It was argued that these narratives revealed a search for meaning of the stroke and for coping with feelings of vulnerability. Some of those who had not gone back doubted their abilities and missed the social position work had provided them with before the stroke. Two participants struggled with the feeling that they were unwanted in the world of work as the people they had become; as someone with a piercing and someone with reduced abilities. These are examples of stigma.

Twelve months post-stroke most participants were working their former workload. This created feelings of normality which again had two sides: for some there was a clash between the need to fulfil the demands of 'normal' work and not being able to realise their intention to work less. Other participants felt they were accepted as they had been before the stroke.

Normal expectations also meant confrontation with stress and this led to thoughts about the genesis of the stroke and to challenges connected with integrating the stroke into the post-stroke selves. Narratives demonstrated in particular the temporal nature of reconstructing the genesis of the stroke. This seemed to consist of several factors: the pre-stroke selves at work, demands at work after stroke, public knowledge about stroke prevention, personal belief systems and existential questions to do with faith and a personal world-view.

Two participants struggled with whether to disclose or to conceal their problems due to the stroke, with their accounts suggesting that both strategies could lead to problems.

Structural issues such as sickness benefits did not appear an important issue in these talks.

6.5. Reflection on my feelings

That work appeared to be such an important part of participants' recovery process and that the feelings and experiences attached to it were so diverse surprised me initially. However, at the same time it made me conscious of the major role that work plays in Germany in self- and of group-identification. Germans are said to be hardworking ("*fleißig*") and I think this is part of our national identity. From this point of view it is hardly surprising that participants strive so hard to get back to work and that the benefits of returning outweighed the difficulties. Personally speaking I learned most from participants' accounts about their thoughts concerning stress at work, in particular the description of stress as 'misbehaviour', which led to the stroke and needed to be changed. This revealed its value for making sense of the illness. This was a new way of looking at it for me.

I was surprised when Georg said that the incident with the machine, related to his stroke, was something he could refer to in such an offhand way. I felt sorry for Sofie who was 24 years old and seemed to have no work prospects. However, I am certain that my consciousness of these feelings prevented their potentially manipulating effect on my interpretation.

Chapter VII

Perspectives of younger people on their experience of having a stroke

This chapter discusses the findings of this study and brings them together with the literature on younger people after stroke and the theoretical frameworks of chronic illness, crisis and coping. The ultimate goal is to draw conclusions for nursing and health care of younger people after stroke. As Gadamer (1997) points out, theory must be tested in praxis and proven to withstand the demands of human life; without this, any theory is useless. In Chapter I, literature on younger people after stroke was outlined focusing on different perspectives. It was argued that this group of people has been neglected by nursing research. However, studies from other fields emphasise a stroke as a crisis and a difficult event that leads to impairment and age-specific problems in younger people, raising needs that are extremely inadequately met by services. In addition to these perspectives, a stroke is also seen as a chronic illness and thus Chapter II explored selected theoretical frameworks in this field, complemented by Lazarus et al's theory of emotion-generating processes and coping structures. It is however questionable whether these younger people would describe themselves as chronically ill. Since having a stroke is considered to be abnormal for younger people the issue of stigma deserved closer attention. The concept of the *Leib*, in which human beings are seen from all possible dimensions, provided an alternative to the dualistic viewpoint of the self and the body employed in much of the literature.

This research aims to compensate for the lack of studies that investigate how younger people experience their stroke. It enhances understanding of issues and concerns that this raises and provides grounds for the development of nursing interventions.

This chapter firstly gives an overview of this study's findings. It then describes the stroke as a fundamental disruption of these people's life-times, cutting it into a pre- and a post-stroke one. Notwithstanding this, having a stroke at a younger age must be individually appraised and dealt with. The stroke is however as much a social

experience as an individual one. Feelings of being abnormal and of being treated differently by others leads to feelings of stigma. The difference between 'being normal' and 'sameness' and the vicious circle some of the participants found themselves in when they tried to cope with the same stress at work as before the stroke is then described. In the following, participants' explanations of the stroke and of the meaning of symptoms suggest that this experience goes beyond what can be intellectualised and objectified in everyday language. Having a stroke at a younger age affects the rhythm of individual human life, and confronts the person with the limits of life- it is an experience of the *Leib*. Finally, the concrete implications of this for nursing and health care, including implications for policy, research and teaching are stated. It is argued that younger people after stroke often feel abandoned, particularly where work problems and stigma are concerned, and that long-term support must be made available if these people are to achieve their main goal and get on with their post-stroke lives.

7.1. Overview of findings

This section gives a brief summary of the findings of this study. The most fundamental finding is that having a stroke at a younger age is not, as the literature generally suggests, a devastating experience per se. It can range from a catastrophe to simply a difficult life experience to a release. Furthermore, how it is defined changes over time. The stroke which is at first seen as a release from a difficult pre-stroke life can turn into a major struggle; what seems a catastrophe at first can be transformed into a life experience that can be surmounted. Thus it does disrupt people's lives and selves. It throws them off balance individually, socially, spiritually and metaphysically. However, the consequences of this can vary greatly. In Gadamer's (1996) terms one could say that this is a thesis about the back and forth movements that people make in order to understand what happened to them, redefine themselves in their world of experience and regain balance or retune themselves with life.

The stroke affects people's being. It forces them to question who they are and who they were. This disruption of self happens on two levels: firstly on what Leder (1990) calls the body-for-me. This relates to changes of self that are apparent without

interaction and without action. These are almost impossible to describe and are thus often hidden in metaphors, for example descriptions of half a person who is cut down the middle (but who does not have any signs of a hemiplegia) or of a small body and a long neck with a big head. It is as if these people are describing an innermost part of their selves that is affected by the stroke. Secondly, and much more common, are descriptions of effects on the self that only appear in interaction with others or in doing things. It is then that people are confronted with a changed ability to remember, with exhaustion when they try to do things, with concentration problems or problems with stress and noise. In other words, others confront them with what is different to before the stroke and they appraise what these differences mean for them. As interaction and action increase over time, people become more aware of the disruption of self and life-time throughout the year post-stroke.

Of course the disruption of self cannot be separated from the disruption of identity. The self is constantly recreated, mainly in interaction with others, as is identity. Younger people after stroke are confronted with the prejudice that this illness only affects older people and suffering it at a younger age is seen as abnormal. The efforts that they make to prove their normality can be highly stressful. Participants' accounts describe how they become sensitive to other people's responses, how they interpret them, reject or accept them and reflect on the consequences this rejection or acceptance has for their lives. Whilst this can be seen as a normal process of identity-building, for younger people after stroke this happens in the context of a disrupted feeling of self and of insecurity about who they are. Immediately after the stroke it is absolutely uncertain whether they will be able to regain their pre-stroke professional roles and whether or how the stroke will affect their relationships with others. As interaction with others increases, people find their feelings of being abnormal or normal confirmed in other people's responses. Being treated as a person who has just had a stroke is frustrating. Being treated as 'normal' is needed to restore a sense of security. Participants rejected the identity of a chronically ill post-stroke person and wanted to be seen as the individual they are.

Work constitutes a place of particular importance for questions of self and identity. Most participants had a strong desire to rejoin the world of work as soon as possible. It is there that they were inescapably confronted with those abilities they had regained after the stroke and those they had lost. Thus while for a few it was confirmation that they were able to do the same things as before, others became more aware of their impairment and thus of the impact of the stroke on their lives. At twelve months post-stroke, when most of them had returned to work, social contacts within the work environment seemed to be most important for participants. It suggested normality for all the participants, not only for those who had gone back, and provided a sense of social inclusion, of being accepted and respected as the people they were. It allowed them to pass as normal in the eyes of outsiders, although for some of the participants this was at the expense of concealing difficulties. Dilemmas that resulted from this for some of the participants are explored in more detail later.

The stereotypical image of a stroke is not only that it only affects older people but also that it causes certain symptoms, for example hemiplegia and speech problems, which are clearly visible to others. Visible symptoms are a legitimisation for taking on the sick role (Bury, 1997). Moreover, it is often assumed that the more severe the symptoms look, the more disruptive this illness is for the self – and this assumption is found not only amongst the general public but also in nursing literature (see for example Backe et al., 1996). None of these assumptions is warranted. Younger people also have strokes and their strokes can be invisible to others. This does not mean, however, that they do not have problems. Visible impairments are only the tip of the iceberg. Underneath lies the disruption of self and of identity - of the *Leib-* that needs to be dealt with. It is thus clear that the problems which stroke causes need to be individually appraised.

One of the main problems for participants is issues of uncertainty. The stroke teaches them that life and health are not to be taken for granted and that life could change from one minute to the next. It makes them aware of the danger that it could happen again and for many it was their first experience of not being in control. The question

is then how to regain control over health and life and thus how to regain a sense of ontological security. Explaining why the stroke happened is an attempt to make sense of it and to rebalance feelings of certainty and uncertainty. Whilst in the first phase after the stroke, these explanations followed a biomedical model of cause and effect, these lost their power later on. Explanations began to incorporate descriptions of a personal worldview, of psychological states, of knowledge about stroke prevention, of spiritual beliefs and of social and cultural aspects. However, explanations were not always sufficient to restore a feeling of security and for some the fear of getting another stroke remained throughout the year.

At six and at twelve months after the stroke participants fell into two groups: those who struggled with having had a stroke and the effects this had for them and others who described the stroke in more positive terms. Overall there was a tendency for the younger participants and for the male participants to describe the stroke more positively. However, this tendency could be due to many factors and an assumption that age or gender markedly influence the experience would not be warranted by the accounts. Different types of ischaemic stroke do not seem to relate to different experiences either. Demographic aspects such as ethnicity, social class and socioeconomic status do not apply since participants had similar backgrounds in this respect. Thus what a stroke is for people resists assumptions based on linear thinking. Later Lazarus' theory of emotion-generating processes and coping is employed to enhance understanding of these highly complex and individual processes of appraisal.

An orientation on Gadamer's philosophical hermeneutics for this research has proved to be of great benefit. The key point of his humanistic orientation is related to basic questions of what it means to be a human being. This and the ethic of assuming the otherness of the dialogue partner forced me to reflect constantly on my own presuppositions and to question my assumptions. Gadamer's work is phenomenologist in that he looks at issues of being, for example exploring health and illness. However, in his sense these would never be seen as objectively describable phenomena but rather as ones which need to be individually defined and understood,

mainly in dialogue with a text (which can also be a conversation or work of art). In this sense he is close to social interactionist standpoints. However, he differs from this school of thought in that he emphasises the historicity of understanding - understanding is always already there *and* it is created in interaction.

His many aspects of interpretation and of understanding of human life, including the *Leib*-perspective have broadened my view and understanding of what it can mean to have a stroke at a younger age and they have led me to think beyond theoretically derived boundaries.

Overall I found that Gadamer's philosophy covers many issues that participants raised and also articulated ideas that they struggled to express in words. Most importantly his metaphysical thoughts on the indescribability of aspects of illness experience on the *Leib* paralleled participants' descriptions. Although other writers (for example Charmaz, 1991; Good, 1994) talk about indescribable aspects of illness experience, the English language often employs dichotomous expressions, for example the division of a whole being into "body" and "self". By contrast, inherent to German culture – which is not only Gadamer's native culture but also that of myself and the participants – is the more inclusive concept of the *Leib*. This concept allowed me to gain a more complete understanding of the participants' experience and to express it in terms that have a meaning in German culture.

7.2. A stroke as a disruption of life-time

No one would ever expect to have a stroke at a younger age. The interpretation of accounts presented in this thesis reveals that for all participants it was the first confrontation with a life-threatening illness and jolted them out of their comfortable assumptions that health and life could be taken for granted. The experience of life's capriciousness confronted them with the limitations of existence and forced them to reconsider their pre-stroke values, as well as their ideas about life, in the future as well as the present and past. Life-time became separated into two parts: a pre- and a post-stroke part. The concept of time in relation to life and the self in this time both took on another meaning. This happened on both the level of the individual self and on a social level. Throughout this thesis, I will refer to life-time. This is a concept quite distinct from "lifetime", or the total timespan of a single life. "Life-time" here

refers to the concept of time individuals use to interpret and demarcate stages of their lives.

7.2.1. Disruption over time

Due to its longitudinal nature, an important finding of this study is the temporality of the illness experience. Physiologically speaking a stroke is a sudden event. A vein is blocked by a thrombus or embolus and this immediately affects the person, mainly noticed in malfunction. The body *dys*-appears (Leder, 1990). However, looking at these younger people's descriptions of their first symptoms and what happened before they went into hospital the stroke does not appear at all sudden. Accounts reveal that a stroke in younger people can be misdiagnosed and that up to four weeks can pass before someone is admitted to hospital.

Thus the awareness that a younger person has had a stroke needs time to be processed. In spite of the nature of their symptoms, whether they were unusual such as a hemiplegia or more common such as hoarseness or tingling sensations in fingers, people in this study did not seek medical help, not thinking they had a stroke. People's decisions to seek medical help or not were thus not due to the nature of symptoms, or in Zola's terms (1973):

Neither the mere presence nor the obviousness of symptoms, neither their medical seriousness nor objective discomfort seems to differentiate those episodes which do and do not get professional treatment. (p.678/679)

In this study it was mainly other people who forced participants to seek help, a pattern that Zola (1973) calls 'sanctioning'. Apart from this, having a stroke at a younger age is such an unexpected event that the younger people themselves might well be unable to read the signs and to recognise them as a stroke. This suggests that symptoms of a stroke themselves must not necessarily, and in this study did not, cause disruption for participants. It was only in retrospect that most participants defined the onset of the stroke as the point in time when their life changed.

The stroke is a marker for these younger people's life-time, described as a 'turning point', a 'boundary stone' or a 'kick in the shins'. Most often referred to was the fact of having survived this life-threatening and potentially disabling illness. The stroke was a "reminder of mortality" (Charmaz, 1991, p.213). In this light, pre-stroke values were reflected upon and people defined what was worth consideration in face of impairment and death. A time shift occurred: many said that they now lived in the present and had given up planning into the far future. However, this is not what Charmaz (1991) calls "living one day at a time" (p.178ff) because its purpose was not to gain control and to get through hard times in illness. It was the awareness that all plans can be useless as life changes from one day to another, accompanied by a new gratitude for the beauty of nature, for 'little things' and the appreciation of the 'gift of life'. It is this what made the stroke a 'turning point'.

After this experience of the limitations of what is controllable in life, the first three months after the stroke were characterised by a sense of relief about rapid recovery from symptoms, suggesting that returning to the pre-stroke self and life would soon be possible and thus the disruption of time and of self would be limited to this initial phase. The experience of the stroke in this early phase was influenced strongly by a cultural factor, namely by the medical procedures of diagnosis, defining a cause for the stroke and undergoing related treatment. These "real payoffs" (Frank, 1995, p.148) of modern medicine helped these younger people to explain their strokes and gave them a sense of security by suggesting that causes could be controlled by taking medication, undergoing heart surgery or changing lifestyle. The time perspective was firmly on current problems and on regaining the pre-stroke status. This is not surprising, for as Frank (1995) says "Anyone who is sick wants to be healthy again" (p.77).

However, six months after the stroke, long-term effects were apparent, recovery had slowed down and biomedical knowledge could only offer unsatisfactory explanations of causes and treatments of invisible problems with fatigue, concentration or toleration of stress and noise. In addition to this, contradictory biomedical knowledge led to uncertainty. The realisation that it was not easy to return to the pre-stroke self

and the feeling of not being in control increased, as did the associated fear of getting another stroke. Thus the time between three and six months after the stroke marked another point at which these people became aware of the disruption of their life by being confronted with the long-term impacts of the stroke. Their concerns at this point were mainly coping with present fears and problems and returning to work as soon as possible.

This research suggests that younger people after stroke did not see their conditions as chronic but tried to 'close the chapter' of the stroke one year later, thus limiting the time of the disruption. The first anniversary was an important marker of recovery and of returning to the old self - or at least aiming to - although with new insights gained through the illness experience. On an individual level, this can give hope, direction and a sense of control (Charmaz, 1991). As will be discussed later, the desire to make the stroke a past experience is also socially motivated by the desire to pass as normal in other people's eyes. However, as Frank (1995) says, illness does refuse to consign itself to the past; although a person might no longer be ill, he or she "remains marked by illness" (p.118). Strategies to try and pretend that the stroke belonged to the past included avoiding situations reminiscent of the stroke, or those that could cause another stroke, for example stressful situations. Another strategy was to explain long-term effects, for example concentration and memory problems, as normal weaknesses such as ageing, or to point out that things could have been worse. The illness was described as an important aspect, but it was more important to go on and live a normal life, to look into the future and "to remain in the world of the healthy" (Radley, 1994, p.154).

It is important to note that one account did not fit into the pattern of shifting time perspectives described here. Whilst the participant indicated that the stroke disrupted his life for a short time, a mere six months after the stroke, he was 'almost' the same as before. This leads to another important aspect: the disruption of life-time not only occurred gradually over time but the extent to which the stroke was disruptive for people depended on the individual appraisal.

7.2.2. Disruption individually appraised

Accounts described in this study suggest that the meanings that a stroke can have for an individual vary considerably and also change over time.

So what led participants to describe the stroke in the way they did? Lazarus' (1991, 1993, 2000) cognitive-motivational-relational theory of emotions, particularly primary and secondary appraising, throws light on this question.

Lazarus (2000) informs us that primary appraising depends on whether an event seems relevant for a person's goal (goal relevance), whether the event facilitates or threatens this goal (goal congruence) and whether the ego, for example in relation to self- and social esteem, moral values, meanings and ideas is taxed (ego involvement). Secondary appraising concerns the options a person has to cope with an event, if this event is appraised as relevant and caused emotions in the first place. It includes judgements about who is responsible for a threat, challenge or benefit; what can be done about it (coping potential) and what is to be expected in the future (future expectations). The author points out that appraisal and emotion are intertwined, that appraisal is always constructed by the individual and that coping is an integral part of the process.

In light of this theory, descriptions of a stroke can be seen as personal constructions. There is a theme behind the expression of emotions, for example if someone expresses gratitude. According to Lazarus (2000) gratitude is the appreciation for a gift, for example the gift of life, that provides personal benefit. Feelings of shame exhibit a threat to the ego ideal, and guilt the feeling that one has transgressed moral values (p.219).

Two examples taken from this study illustrate the emotion-generating process regarding feelings of shame. Using Lazarus' theory, one can explain the occurrence of feeling too ashamed to go to the breakfast room after stroke as follows: for a person whose goal is to exhibit an ideal self to the outside world (goal relevance and ego involvement) exhibiting symptoms of a stroke is incongruent with this goal (goal congruence), and as a result this person might feel ashamed. In the secondary appraising this person might blame him- or herself and feel that there is nothing he or she can do about this (coping potential) and that this will not change (future

expectations). The result of this might then be sadness as an expression of "an irrevocable loss" (Lazarus, 2000, p.219), but only if what was supposedly lost, in this case the ego ideal, is still appraised as relevant for well-being. Depending on this new appraisal the emotion-generating process will continue.

On the other hand a person who feels ashamed because of saliva hanging at the corner of his or her mouth as a result of the stroke also exhibits the violation of the ego ideal that is to be seen as the ideal self by others. Assurance from a friend that this is normal and happens to other people as well might lead to the secondary appraising that no one is to blame for this and nothing can or needs to be done. The situation remains the same, but it is not appraised as problematic any more.

These two examples indicate that whether an event contributes to a reappraisal of self and of life-time depends on the individual within his or her environment. What is relevant for one person is of course not necessarily so for another; similarly, coping strategies that work for one person must not work for others. These examples also indicate that emotion, appraisal and coping do not occur in a vacuum but that other people's reactions are part of the emotion-generating process in that their potential or actual response is part of the appraisal. However, this analysis still suggests that the experience of a stroke is highly dependent on the individual and thus neglects social and cultural aspects. Why have people internalised the idea that it is stigmatising to dribble, or look different? The issue of stigma will be more fully explored later. Here it is important to note that as much as coping is individually created, it is also socially and culturally influenced.

This exploration of emotions, appraisal and coping also casts doubt on the assumption found in some literature that a stroke precipitates a crisis similar to bereavement and that younger people's patterns of coping with this can be characterised by phases (Kallert, 1993, Frank et al., 1985). These models might be useful for highlighting the temporal nature of managing the consequences of a stroke at a younger age; simultaneously, they point to some difficult aspects. As these authors acknowledge, there is a danger of treating people according to a stereotypical pattern. However, accounts from this study suggest that there were difficult points in

the lives of younger people post-stroke, but these did not follow a clear temporal pattern.

The situation that most participants described as extremely difficult was the hospital-rehabilitation interface. Emotions mentioned included horror, anxiety, fright, sadness and shame. If anxiety is an expression of existential threat and uncertainty, fright of "immediate, concrete and overwhelming physical danger", sadness of irrevocable loss and shame of failing to live up to the ideal self (Lazarus, 2000, p.219), then this situation poses an existential threat for the selves. Again, the appraisal of this situation is not only individual but is influenced by the environment. Being put together with older people with severe impairments, together with the lack of facilities suitable for younger people with a stroke were distressing influences described in these accounts as well as in another study (Banks et al., 2002). Whilst this could be seen as evidence of an ageist view, accounts in this study suggest that there was another theme behind these expressions, namely the need for other people to identify with. Only other younger people with the same illness seemed to provide such options for comparison and identification of what it meant to live as a younger person post-stroke.

Other situations were described by some participants as difficult but not by others. These were the change from the stroke unit to the post-stroke ward, the rehabilitation-home interface, the return to work and attempts to complete tasks that were routine before the stroke or coping with demands at work. The findings of this study thus suggest that the stroke can lead to situations that are appraised as crisis situations and coped with individually. A process following a pattern of phases is not apparent. It was not the aim of this study to explore a stroke as a crisis and indeed, the design with long time-spans in between the investigations is not suitable to capture this fully. However, accounts interpreted in the light of Lazarus' theory offer sufficient evidence for the conclusion that a stroke at a younger age is not a crisis per se, but precipitates individually appraised crisis situations. Golan (1978) also emphasises the individuality of a crisis:

different persons faced with the same situation, or the same person at different stages of life or in other sets of interacting

circumstances, may not necessarily display the same reactions or be similarly affected. An a priori assumption that a crisis exists may be unwarranted. (p.62)

Some participants in this study indicated that the stroke led to a crisis, but others did not. However, to some extent it threw all of them off balance for a certain period of time. This is why accounts in this study led to describe the stroke as a disruption but not as a crisis.

7.2.3. Disruption of self

Although people described and handled the experience of having had a stroke individually, all of them described it as a disruption of their life-time in the sense that there is a life before and a life after the stroke. The consciousness that this event could have ended their life as active young people made them question who they were before, who they were now and who they wanted to be in the future. Thus it is a disruption of self. It is from this disrupted 'inner space' (Craib, 1998) that participants appraised their world after stroke and integrated aspects of it or not. The self is both robust and fragile:

Fragile, because the biography the individual reflexively holds in mind is only one 'story' among many other potential stories that could be told about her development as a self; robust because a sense of self-identity is often securely enough held to weather major tensions or transitions in the social environments within which the person moves. (Giddens, 1991, p.55)

Younger people with a stroke clearly indicate the fragility as well as the robustness of their selves in that their view of self can change drastically into that of an old woman, a child or half a person, yet at the same time they do hold on to the Karin or Matthias they were before the stroke. As Kelly (1992) says, people want to carry on

as normal although their normal self as well as their identity might be disrupted by illness. It is this tension in younger people after stroke that is now explored.

7.3. A stroke as a disruption of normality

The terms that participants in this study used most often to describe what they wanted most for their post-stroke life were to be 'normal' or to be 'the same' as before. When they spoke of normality they referred to what was their 'normal self' or the self as they knew themselves, as well as 'being normal' in other people's eyes. Thus normality is concerned with self and with identity. Their normal being, meaning the self they used to be, is not similar to being the same. It is to their different foci that this chapter now turns.

7.3.1. Normal self, sameness and stress

At three months after the stroke difference and sameness were important issues: people talked about how they were different to how they had been pre-stroke; those who were back at work found that they were able to do the same things in the same way as before. Difference caused distress and concerns about whether it would ever be possible to be the same again. Apart from one woman who felt better after the stroke than before, the goal was to be the same and the reference point for being the same was the pre-stroke self.

At the six-month stage, this had changed. As described earlier, the time perspective was now on present problems and participants were beginning to focus on thoughts about how to translate their insights into the future. Many people spoke of their consciousness of having survived a life-threatening illness and some were relieved that they had escaped with relatively little impairment. These people wanted to keep this consciousness and along with it they wanted to lead another life-style and live according to changed values. They did not want to get back into 'the same old rut' any more yet at the same time they wanted to be what they knew as their normal self, the Robert or Judith, who had integrated the new insights into his or her being.

Contrary to expectations, this was different at work, to which six of the participants had returned at this point. Managing the same workload with the same strength and the same ability to cope with stress created tension for many of those who were back at work. There was a tension between the need to be the normal self, although with remaining difficulties such as concentration problems, and the need to fulfil role obligations at work. Kelly (1992) rightly says that this task of having to cope with the tension between the demands of illness and normal role obligations is a normal human experience. It does however have specific implications for younger people after stroke because of the additional need to translate new insights from having survived a life-threatening illness into the reality of work. As described earlier, the fear of getting another stroke was particularly apparent at this point. Maintaining a lifestyle in keeping with the new insights meant preventing another stroke. Maintaining the view that work is not as important as life and health, managing to avoid stress, thinking more of oneself and less of others all became vitally necessary. It was people's attempts to regain a sense of control over the threat of another stroke. The tension described above is between the need to follow a lifestyle determined by the desire to prevent another stroke on the one hand, and the need to meet the demands of a role at work which take no account of the stroke on the other. There was a further conflict between a post-stroke self and a demanding work environment that reflects German cultural values – hard-working, efficient and productive. Since occupational activity is closely linked with people's identity (Crawford, 1984, Babad et al., 1983, Herzlich and Pierret, 1987) it could also be described as a tension between self and identity.

At twelve months on, when stress was the most commonly mentioned aetiological factor for a stroke, many of those who were back in their roles as employees described this tension in even stronger terms. A pattern of a vicious circle emerged from participants' descriptions: if stress was seen as a cause of the stroke, participants tried to avoid stress as a result; however, demands at work made it impossible to avoid stress and thus the desire to avoid stress actually created more stress itself. Moreover, as described earlier, work suggested sameness and allowed participants to pass as normal in other people's eyes. As was suggested by the example of being too

ashamed to go to the breakfast room, difference created stress in itself. Thus although the ability to work was vitally important for participants' identity, some form of stress was unavoidable for the majority of participants. The situation could be made even worse if attempts to avoid stress were unsuccessful, because there was then the additional stress of dealing with the fear of getting another stroke. Yet another source of stress was participants' inability or unwillingness to talk about the entire situation - linked to the issue of concealing or disclosing difficulties due to the stroke. They "carried on regardless" (Kelly, 1992, see for example pp.52, 105) in that they concealed their difficulties and kept the conflict internal. An example for this is the person who did not ask his doctor to sign him off sick until twelve months after the stroke although he had already described the tension between trying to stay true to his insights and still perform as best as he could at work six months earlier.

Williams (1984) argues that the concept of stress is 'attractive' because it serves as an umbrella for many different factors, "anything from excessive noise to bereavement" (p.188). In this study however, 'stress' refers also to a specific situation - the fear of losing one's job. Stress as the cause for the stroke can thus be seen as an expression of the demanding work situations of younger people in Germany, where unemployment and the related pressure created by the fear of losing one's job is relatively high. Accounts indicate that participants who described this dilemma at work were alone with their difficulties, most of them preferring to conceal their problems than risk the negative consequences of discussing them.

In summary, one could say that the major desire three months after the stroke was to reach a state of sameness. Later, when most participants did not want to be the same but rather incorporate new insights into their normal selves, sameness at work led to conflicts and tension for many of those who had returned. However, it needs to be pointed out that there were participants who were back at work but did not describe any tension between their 'normal self' and role obligations. For these individuals, being back at work was most important as it was there that they felt accepted and included as normal.

This is what other participants who had not gone back to work or who were not yet working a full workload also wanted. They wanted to fulfil their professional role

and in doing so return to their former identity. Whilst they obviously did not face any tension at work, they saw work as a chance to be socially included again. For them it offered a way out of being abnormal.

7.3.2. Being normal, being different and stigma

Having a stroke at a younger age is not only a disruption of the life-time and of the self, it is also a disruption of being normal in other people's eyes. It is having an old person's disease at an abnormal age. According to Rolland (1988) "clinicians and researchers generally agree that there exists a normative and nonnormative timing of chronic illness in the life cycle" (p.66). In case of having a stroke at an age when people usually have the greatest responsibilities, not only for themselves but also for people around them, "the timing is off; it is out of sync" (Herz Brown, 1989, p.464). Younger people experience being different: firstly as younger people with a stroke and secondly as 'stroke sufferers' who do not present the expected picture. Most participants described both the feeling of being abnormal and the experience of being treated different by others. The experience of being abnormal, the issues it raised and the ways participants used to cope changed over time.

As Gadamer says, we experience and understand within the framework of tradition and of culture (Gadamer, 1990, 1993, 1997). Crawford (1984) argues that in cultures in which health is a central concept for modern self and identity, being healthy combines values of being in control, good, productive, respectable, responsible and being a normal self. Unhealthy people pose a threat to this ideal and:

...illness represents a danger both to the individual and to the social order and thus is a symbolically charged event.
(p.1355)

The controllability of health and body is clearly brought into question for younger people who have had a stroke. A stroke at a younger age is a reminder of mortality and vulnerability - for people who suffer it and for others around them alike. What happens according to Crawford is that people who are 'momentarily free of illness'

protect themselves by projection: the sick are made responsible for their illness and made different - they are stigmatised.

The mechanism described here suggests that people who had a stroke are almost automatically stigmatised by others because they violate the norm of being healthy. And there is another important point: the younger people who have a stroke are part of a culture that advocates the healthy self and are likely to have incorporated this ideal. If this is the case then it is logical that in case of serious illness they feel discreditable for being ill and they are discredited by others (Goffman, 1968). Some of the participants described feeling marginalised by society. Having a stroke at a younger age is a stigma and being discredited because of this was already indicated by some participants at three months after and throughout the year post-stroke.

Although at three months after the stroke, most participants' main goal was to be the same as before, this was also the point in time when other people around them still thought of them as being different - as post-stroke people. Some participants described feelings of being pushed to the sidelines; not being part of the group any more; feeling out of place or feeling that others want to get rid of them. These all indicated feelings of being stigmatised. Coping with these feelings was difficult. For example returning to work as quickly as possible was used by some participants to demonstrate normality. Most people were still signed off sick and hence social contact was limited. Most participants stayed within their family circles and were thus able to limit or avoid feelings of stigma. As social activity increased, stigma became more pronounced and were mentioned by more participants at six months after the stroke.

At this point a few participants said that they were normal, but most others indicated that they felt different: treated differently by others and feeling different at work. Other people's behaviour was recognised and interpreted individually. A good example of this is consideration: the lack of consideration caused feelings of 'being left out'. On the other hand, when consideration was shown, it caused feelings of 'being treated as disabled', but was also interpreted as an expression of interest. In most cases consideration was interpreted as stigmatising. Being treated differently by

others was hurtful, causing feelings of not being as valuable any more, not being taken seriously and being seen as crazy. These are all expressions of how participants interpreted interaction with other people as stigmatising. In Scambler and Hopkins' (1986) terms they are expressions of felt stigma. The authors' propositions developed in terms of epilepsy and stigma (see p.38) can thus be applied here. In terms of having a stroke at a younger age this would mean three things. Firstly, people perceive their status as younger people with a stroke as socially undesirable and come to define their stroke as stigma. The fear of enacted stigma predominates in this point of view. Secondly, this fear causes them to conceal problems concerning the stroke and try to pass as normal. Thirdly, this concealment reduces the rate of enacted stigma. It is thus the fear of enacted stigma which causes the distress, not the enacted stigma itself.

This model is problematic for two main reasons. Firstly it reflects an individualistic viewpoint in which the reality of being stigmatised is constructed by the individual. It does not take into consideration the cultural side, namely that having a stroke at a younger age is a stigma because these people are different from others. It does not talk about the stress created by the desire to be seen as normal. It also neglects the fact that other people do not want to be reminded of their vulnerability and wounds and thus exclude unhealthy others to protect themselves and society, as described for example by Crawford (1984) or Frank (1995). Secondly it separates stigma into objectively definable stigma, which are enacted and can be operationalised or observed, and subjectively felt and interpreted stigma. Scambler and Hopkins' (1986) question "To what extent is felt stigma justified?" (p.38) reflects this view.

Findings in this study challenge this view and the following propositions in terms of the stigma of having had a stroke are advocated as an alternative. Firstly, a stroke in younger people is a stigmatising illness because it is brain-damaging and it is abnormal for this age group. Secondly, people who suffer it not only violate the norm of being healthy and remind others of the uncontrollability of health and life, they also disrupt their view of self as being healthy, invulnerable and in control. Thirdly, there is a constant interplay between the disruption of self and life-time, the feeling of abnormality, cultural norms and other people's responses. All these aspects

contribute to the feeling of being stigmatised. Fourthly, feeling stigmatised is a major issue for many younger people after stroke. Because they do not disclose their problems, the self-doubts and questioned self-worth that come with stigma are hidden. Whether stigma is felt or enacted is not important at all and the question should not be to what extent felt stigma is justified, but what psychological problems stigma generally causes and how it is possible to assist these people in difficult areas such as information management and coping with stigma.

Accounts at twelve months after the stroke indicated that stigma was an ongoing theme for some participants. Feelings of having less visitors than before, of not being asked for advice any more, of not being on people's lists any more and not being accepted as a full member of society were all described. How to handle the information of having had a stroke was a major issue. This is firstly because others 'forgot about the stroke'. Remaining symptoms were invisible and did not remind others or identify participants as people post-stroke. Secondly, participants wanted to be seen as normal and close the chapter of the stroke. At this point it was possible to pass as normal in many situations and most participants described this. However, for some it was not easy.

It is a matter of maintaining an impression of oneself as ordinary ('just like other people'), against the background of evidence that one is clearly not so. Minimizing the seriousness of the condition in communications with others is part of this presentation. (Radley, 1994, p.158)

Some participants described clearly how they tried to be regarded as normal. Remaining problems, for example with concentration or with not being able to take the strain at work were concealed. Efforts were made to pass as normal, but this often involved withdrawal from others. In order to avoid becoming lonely, participants had to balance their withdrawal with social activities.

7.4. A stroke as an experience of the Leib

What has been said so far indicates that the stroke affected participants on many levels: as individuals within their life-time and selves; on a social level in their feeling of being abnormal and stigmatised; culturally in that it confronted them with cultural norms of being in control of life and health and with the high demands of work. Yet other dimensions of the experience are revealed when we look at some people's descriptions of why they had a stroke and also some of their attempts to explain why they were different now.

At six and at twelve months after the stroke many of the participants no longer stayed within biomedical explanations of the genesis of their stroke as most of them had done at three months on. They all now included social, cultural as well as spiritual and metaphysical aspects in the reconstruction of the genesis of their illness.

Some participants explained the stroke as a message from God, sometimes combining this with the concept of stress. This meant that they had an unquestionable authority – God – who alone had the power to determine their destiny. As such, this can be liberating from the task of looking for causes and can lead to acceptance of the stroke. Thus it can appear as the end point of narrative reconstruction of the genesis of the stroke. Moreover, seeing the stroke as a message from God transforms it into a spiritual experience and gives it an important value in a person's life.

However, there is a problem with describing the stroke as spiritual, mainly because of this term's various meanings and because of its relatedness to religious or other meanings of life. McSherry and Cash (2003) point out that this term is not clearly defined and they describe many different layers of meanings, always dependent on the individual worldview of the person who defines it. In their literature review the authors explore many of these different meanings. They state that whilst the traditional meaning of it relates to religion, a post-modern understanding of the term is more existentially determined relating to purpose and meaning of life, attitudes, values and beliefs that shape and guide people's faith. Both these definitions express what Williams (1984) calls *telos*- the ultimate goal and meaning of life. As he rightly says, in face of such a *telos*, sociological questions, for example how illness impacts

on someone's self-worth, become meaningless. This is where Gadamer's philosophy becomes particularly beneficial in that it forces us to look beyond categories of social, cultural and spiritual explanations and into fundamental metaphysical questions of human existence, which consist of but also transcend these categories.

It was when participants wrestled for words to describe why 'it's different, everything' or why 'nothing works any more' that these questions were raised. Mostly they attempted to capture this by rationalising the impact of the remaining symptoms on their lives. However, the reasons why a speech impairment creates problems in a relationship and leave a person with a changed view of self at one point in time but not in another defy easy definition. The same is true in the case of the bodily feeling of being only the left half of oneself, yet not exhibiting any symptoms of paralysis. A further example is the case of trying to define whether the problem was in the agile head or in the weak body, yet realising the stroke happened in the head. This all seems beyond the scope of objective and logical explanation, or as Jackson (1996) says, the experience (in her study of pain) goes beyond what can be described by everyday language.

The difficulty for these younger people was that the stroke was often not felt in the body, but in a changed life- in their *Leib*. To recap: etymologically *Leib* has the same roots as 'life' and includes all aspects of being. It is the lived object of feelings about oneself (Duden, 1987). In Gadamer's (1996) terms it is a person's constant rhythm of life, of sleep and being awake, of being ill and healthy and of life and death within his or her world of experience, thus including all dimensions of human being. As opposed to the *Körper*, the experiencing *Leib* extends what can be objectively described and measured. Moreover, particularly in experiences of limitations of what is controllable such as illness much of it cannot even be described (Gadamer, 1996).

Having a stroke confronts younger people with limitations of what is controllable. Logical explanation is not sufficient for some of them to describe why they had a stroke, what it means and why they cannot go back to the status quo - although objectively speaking this still seems possible. Their narratives are constructions of personal feelings, interpretations of social relationships, of cultural values, for

example work, and many include spiritual and metaphysical aspects, thus explaining the meaning of the stroke and of its symptoms for their lives. Although they might talk about their experience in dualistic terms such as head and body or a healthy half and an unhealthy one, it seems that these are unsuccessful attempts to rationalise the root of the problem. Having a stroke as they describe it transcends dualism to become an experience of the *Leib*. Some of them indicate that being confronted with the limitations of life offers the chance to touch on and to learn about the limitations of human existence in general, which according to Gadamer (1996) is one of the aspects of *Leiblichkeit*³⁸.

Separating the experience of having a stroke at a younger age into its individual, social, cultural, spiritual and metaphysical aspects is necessary for analytical and presentational purposes- it theorises, categorises and thus systematises the experience. However, since the aim of this thesis is to gain insights into the experience of having a stroke at a younger age which will be useful for nursing it is important to translate this theoretical knowledge into the praxis. In Gadamer's (1996) words there is no choice:

We have to learn to bridge the gap between the theorist, who knows about the commonalties and the person working in praxis who needs to respond to the ever unique situation of a worrying patient. (p.124)

In praxis nurses face a younger person who can not be seen in different parts such as the personal, the social and so on but who experiences the stroke in all its individually relevant dimensions. The conclusion drawn from findings of this study for nursing translates aspects of the experience of the *Leib* into nursing for younger people after stroke.

³⁸ Gadamer, 1996a: translated as 'bodily life' (for example in p.79) and thus not quite capturing the meaning of *Leiblichkeit* which is more like 'the embodied life'.

7.5. Towards nursing and health care for the Leib

This chapter has argued that a stroke at a younger age is a disruption of life-time and self and of normality. The temporal nature and the individuality of this disruption have been emphasised. It was argued that for some participants it was particularly difficult to cope with the tension created by trying to stay true to new insights into life and being confronted with the same stress at work. Furthermore the abnormality and stigmatising nature of a stroke was underlined.

To sum up the main aspects raised in chronological order: in the first three months, diagnosis and treatment helped to regain a sense of security and control. Time perspectives shifted. At three months after the stroke people wanted to be the same as they were pre-stroke. Between three and six months on, the long-term impacts became apparent. These were however not always negative - some participants also spoke of new insights they had gained from the illness.

Six months after the stroke marked a difficult time for many participants, who worried about present problems and how to translate new insights into the future life. Some feared another stroke. This created a tension between the post-stroke self and demands due to role obligations, particularly at work. There was also a tension between the desire to prevent another stroke and to manage a normal life. Many people felt abnormal because they had a stroke at an abnormal age and did not exhibit the expected symptoms.

Twelve months on, people wanted to put the stroke behind them, get on with their lives and be seen as normal in other people's eyes. At the same time the fear of another stroke caused by leading a normal life was considerable for some of them. The vicious circle of normality and stress, stress avoidance and creation of new stress was extremely difficult for some participants. 'Closing the chapter' had its costs – some participants had to avoid things that were reminiscent of remaining symptoms as well as explaining difficulties as ageing or normal forgetfulness. Being considered normal was achieved for some at the expense of concealing problems and trying to 'carry on regardless' and by withdrawal from others. Feelings of stigma were an issue for most participants at all times of the illness trajectories, but increasingly so as they had more social contact.

Within this a stroke was described as an individually appraised experience, fluid, variant and complex. It was argued that it is an experience of the *Leib* - it does not appear in the body or head but in individuals' lives, potentially touching on every aspect of human existence.

Something which is of major importance for the nursing profession is the fact that none of the participants saw a nurse after the first two or three weeks following their stroke. All the health care they reported in rehabilitation and afterwards was delivered by therapists and medical doctors. This fact alone has much to say about the image and the reality of nursing in Germany: as long as 'physical' and 'technical' care in the sense of assistance with daily activities or managing a busy schedule of diagnostic tests and treatment was needed, there were nurses. As soon as people were independent of this and in the recovery phase, nurses no longer appeared. This indicates that nursing in Germany is still suffering from a view that limits care to delivering of 'physical' or 'basic' and 'technical' care. This distinction was criticised by various scientists who studied nursing; more than twenty years ago in Britain (see for example Melia, 1979, p.62) or more recently in Germany (see for example Wittneben, 1998). It is clear that there is a long way to go before a Leib-perspective can be translated into nursing practice – but I would argue that this is absolutely necessary.

This research is based in Germany and the implications that will be drawn from it need to be explored within the nursing tradition in this country. Nursing in Germany was and still is strongly influenced by the religious tradition. As in most countries it is traditionally women's work, undervalued, underpaid and low status (Bischoff, 1994). However, the situation in Germany is also unique as a result of the Second World War and the Hitler regime. In her well-known work about nursing between 1933 and 1945, Steppe (1996) describes the difficult role of nursing at that time. Every stance nurses took was political, with the choice being between dangerous and often fatal opposition, and complicity. Consequently, after the war the nursing profession shied away from being political and from being regulated centrally by the government. As a result various nursing associations developed and still exist which

all have their own focus and interest. As Arndt (1996) points out, a self-organised nursing association with political power is still to be established. These are all reasons why nursing research and academic qualifications for teachers and managers in Germany only started a little more than ten years ago, mainly concentrated in universities of applied sciences and in five universities only.

The situation in nursing in Germany today might be comparable to how Dingwall and McIntosh (1978) describe the situation in Britain more than twenty years ago: basic nursing education is isolated from higher education, nurses have to deal with shortened hospital stays, more chronically ill people pose different demands on nursing and more unskilled workers are employed - for economic reasons and to compensate for the shortage of qualified nurses. As the authors describe in relation to Britain, nurses in Germany complain about the increasing distance to the ill people caused by paper work.

Similar to Bradshaw's (1997) criticism that different nursing models and theories were simply adopted from the United States into British nursing in the seventies, in Germany the same happened fifteen to twenty years ago. Nowadays nurse scientists, for example Schaeffer (1999), call for German nursing to build up its own body of knowledge, thereby not ignoring available resources but translating the knowledge generated in Germany into the German situation. Aspects within the perspective of the *Leib* which appeared so strongly in participants' accounts in this study fit in with current attempts to develop specific implications from this perspective for nursing (Uzarewicz, 2002³⁹). This study's findings could contribute importantly to this development.

For this reason and in order to keep within Gadamer's call for a translation of theory into praxis the aim is now to formulate implications from findings of this study for nursing care, research and teaching. Political implications will be woven into these.

Nursing as seen from the *Leib* perspective prohibits a separation of the person into a self and a body or an engagement into any other dualism such as severely impaired/not severely impaired or healthy/ill. It requires an understanding of health

and illness, or to speak in Gadamer's (1996) terms, one in which health and illness are in constant motion. Illness appears when the balance between it and health is lost. The task for the person who is ill is to regain the balance and to 'tune' oneself back into life. Gadamer emphasises that this is a constant human task, not an exceptional case. From this follows that the task for the doctor (and the nurse) is to assist and to provide *Beistand*⁴⁰ for individuals in their process of finding a new balance.

Such an understanding of health and illness requires an approach that is open and inquiring about the individual meaning of the illness:

In order to understand the human being it is vitally important that the nurse ascertain from the individual *his* appraisal of his health status. (Travelbee, 1971, p.10, italics in original)

Findings of this study underline this claim by clearly demonstrating that the problems, the level of distress and gains are not visible according to exhibited bodily symptoms. Since visible impairments are the tip of the iceberg, not only for younger people in this study, but generally in the experience of stroke (Doolittle, 1994, Ellis-Hill, 2000, Hart, 1998) nursing and care plans cannot focus only on functional and visible problems and must go beyond this. Any separation of a view of nursing, be it into 'basic' and 'technical' or into 'physical', 'psychological', 'emotional' or 'spiritual' care makes it impossible to understand what is off balance as seen from the perspective of the person with a stroke. This study as well as another recent one (Röding et al., 2003) suggests that people without visible impairments tend to be overlooked by nurses because they do not show obvious needs. Thus basing nursing on the appraisal of the meaning of illness for the individual is a goal that is still to be reached. Lazarus (1992) provides a framework for assessing the appraisals of the meaning of illness for an individual including personal agendas, circumstances, illness and prognosis, life stage and others. He points out that only the individual defines in primary and secondary appraisal what the stroke means for him or her; that

³⁹ Personal conversation in Nürnberg, Fourth International Conference for Nursing Research, September, 2003

⁴⁰ Best translated as 'to attend somebody' or as presence

this meaning is likely to change over time and according to changing circumstances. MacHaffie (1992) points out that in order to be able to understand individuals, nurses as well as other health care professionals need to be knowledgeable of theories of coping. Unfortunately she does not go into the practical implications this has for nursing.

A further implication follows on from this, inherent in the first: in order to gain an understanding of the individually appraised experience of illness, nurses and other health care professionals need to enter a dialogue with the person after stroke, including verbal and non-verbal communication. The ethical principles for this dialogue are provided by Gadamer (1990, 1996): openness and assuming the otherness of the dialogue partner, acknowledging the limitations of what we can ever know about another person. He emphasises that the dialogue is not preparation for treatment and therapy, but it *is* therapy and *is* part of healing.

Lazarus (1992) argues along the same lines when he points out that:

Intervention should depend on listening to the patient [person] carefully, discovering his/her sources of threat, harm and distress. This is something now almost absent in medical practice, namely, a great concern and awareness of the patient's [person's] emotional life. (p.28)

From this study it must be added that listening is a valuable way of discovering sources not only of the harm but also of the benefits of the illness. Gratitude for the gift of life or change of values can give perspectives on a better future (Charmaz, 1991) and thus become resources for recovery- the dialogue takes on a therapeutic meaning. It is important that:

this dialogue is only really successful when it takes place almost if it were a normal conversation....through such

conversation [it is] that the other is to be led to a point where he is able to see things for himself. (Gadamer, 1996, p.172)⁴¹

This means firstly not treating people according to a standard profile of a 'younger stroke patient' but as normal young people. Participants indicated clearly what they needed: to be treated with an interest in the person as an individual, having conversations in a way that reflects common conversations between younger people, joking and gaining hope that things would improve. As Green (2003) argues, regular and sustained conversations between people with and without impairments can decrease feelings of stigma in people with impairments and empathy in people without. An understanding of humans as "all living beings are impaired- that is, frail, limited, vulnerable, mortal" (Shakespeare and Watson, 2001, p.25) avoids labelling people who are ill as abnormal. This normality can be conveyed in 'normal' conversations. Other possibilities that have been indicated in younger people's statements described in the literature review include being given the opportunity to listen to their own music, or eating the food they like. Wherever possible the ability to get out of the hospital environment has been described as increasing a feeling of being normal. Participants in this study wanted to be seen and treated as, what Frank (1995) calls "fellow-humans", or in Travelbee's (1971) words they wanted to be cared for in a human-to-human relationship.

Another implication relates to provision of an appropriate environment, in Banks et al.'s (2002) terms, it needs to be motivating and suitable for younger people. Findings from both this and Banks et al.'s study suggest that the hospital-rehabilitation interface was of particular difficulty. The lack of options suitable for younger people in addition to being put together with elderly, severely impaired people is damaging. This gap points to a structural problem with political implications of lack of services suitable for younger people in both countries, Scotland and Germany. It indicates the need to raise political awareness that such services and institutions are needed. In the given circumstances much can be done to improve the situation by taking account of

⁴¹ see Gadamer, 1996a, p.137

the need of younger people to be together with other younger people as much as possible.

Due to the longitudinal design of the study two very important implications must be stated. The first is the need to address different issues at different times and the need for long-term follow-up services.

Particularly during the first three months, professionals can provide reassuring medical information for younger people after stroke. Naming the cause of the stroke, providing appropriate treatment and advice for making lifestyle changes suggest that something can be done and that the situation is under control. Thus it increases a sense of security and decreases uncertainty. Telling people that things will not improve or that the probability of a recurrent stroke is high is likely to be incorrect and frustrating information and should not be given unless there is a clear medical foundation for this.

Many difficult issues arose later in participants' illness trajectories and data suggests that they dealt individually with often distressing problems such as the tension between the fear of getting another stroke and the desire to live a normal life, experiences with stigma or issues to do with work. Together with Banks et al.'s (2002) findings, these findings call for long-term support for younger people after stroke. All of the participants in this study said that telling their stories was beneficial but that they would not have wanted to see a psychologist. Instead nurses could provide this service:

Attention should be paid to standardising the role of stroke nurses... A case could be made for a liason/advocacy role which would draw on many aspects of current practice- including the provision of accessible specialist information and linking different agencies, such as health, social services, employment, education, housing, the benefit agency, and voluntary organisations. (Banks et al., 2002, p.144/145)

Indeed, as has already been described in Chapter I and as also emerged from the data, nurses could be seen as being in a particularly important position to assist people after stroke in coping with the effects of their illness. However, Banks et al's proposal would be difficult to translate into the German health care system for two main reasons. Firstly, the German health and care insurance policies currently do not allow visits to be offered to younger people after stroke if they do not have any specific needs. Unfortunately – and this has been heavily criticised – the insurance policy focuses on either medically defined problems (health insurance) or on problems with daily activities (care insurance). Secondly it does not apply to the German situation because in Germany there are hardly any specialised stroke nurses. Despite these structural and political difficulties the need for long-term support for (younger) people after stroke must be addressed. A practical and realistic first solution to this could be telephone nursing. Following Cox's and Wilson's (2003) statement in their literature review about follow-up for people with cancer, such a service could be an efficient way of providing follow-up for people with a stroke. The advantages stated by the authors are that it allows access to a large number of people and allows nurses to give immediate medical and psychological advice. Furthermore, the possibility for early interventions and thus the potential reduction of re-admissions or the option for giving information and emotional support are encouraging findings from their review.

Younger people's need to talk about their problems after stroke has been addressed already in establishing a self-help group under the Deutsche Schlaganfall-Hilfe.⁴² As stated in Chapter III this group grew out of this research. We have currently started to develop our own homepage with the aim to build up a support system for younger people after stroke equivalent to '*different Strokes*' in the UK. This is hoped to be a useful forum for younger people, particularly for those who have problems with speaking on the phone. Apart from this the Deutsche Schlaganfall-Hilfe gives my phone number to younger people after stroke who seek advice. This is not an officially announced service, however, I do get phone calls from people all over Germany. This indicates that there is a need for people to receive help and advice.

⁴² equivalent of Chest, Heart and Stroke Association

Given the stigmatising aspects of having a stroke the telephone provides an anonymous and convenient way for people to ask questions and to approach help.

7.5.1. Implications beyond nursing

A further implication goes beyond the realm of nursing but is nevertheless vitally important: issues concerning the return to work. Accounts suggest that decisions as to when to go back, for how many hours and how to deal with the problems involved in this are left to chance. That these decisions are mainly influenced by the GP's assessment and the employer's demands does not take account of the fact that:

Return to work is a complex issue necessitating a broad understanding. When the subjective perceptions of the meaning of disability and return to work relevancy are understood, a better understanding of the variations in return to work experiences is realized. Furthermore, the importance of individuals' appraisal of personal, societal and environmental issues, evident in these constructs, promotes the need for more research. (Shaw et al., 2002, p.194)

The findings of this study show that not only is return to work poorly understood, participants are also left alone to cope with the tension between the self after stroke and the demands of the occupational role or with how to deal with the information of having had a stroke. In this research, work appeared as a dominant theme at six and mainly at twelve months after the stroke. In the light of these findings it is striking that there are no longitudinal studies investigating return to work specifically from the view of the person after stroke and the employer.

7.5.2. Implications for further research

The longitudinal design of this study is a strength in that it highlights the changes and emotional struggles over time. The gaps identified indicate that much is to be done in terms of researching the experience of having a stroke at a younger age.

It raises several questions, for example whether findings of this study conducted in Germany would also apply in the context of other cultures and other health care systems, including other options for treatment and care.

Further studies are needed to gain insight into younger people's experience with haemorrhagic strokes and the implications this has for nursing.

The importance of work for restoring normality of self and identity calls for further longitudinal studies to capture problems as seen from the perspective of the younger people and the employers. This study indicates that problems to do with work were of increasing importance throughout the year, and, one would expect, for some time after.

Longitudinal studies are also needed to capture emotion-generating processes (Lazarus, 2000, p.204) in these younger people. A greater understanding of this could lead to better interventions, for example in response to crucial feelings such as shame and to better identify crucial points in the illness trajectories.

Participants in this study presented a homogeneous picture in terms of their long-term symptoms: none of them exhibited what are thought of as 'typical' symptoms post-stroke (hemiparesis, speech defects, problems with mobility). This is a limitation of this study since it prohibits the comparison of how visible and invisible impairments impacted on participants' lives. More narrative approaches are needed to capture "social as well as perceptual processes" and "phenomenological dimensions of illness experience, as well as to narrative and ritual dimensions of efforts to reconstitute the world unmade" (Good, 1994, p.134).

However, these suggestions could be accused of neglecting the reality of research policy. In Luker's (1997) words, they seek to promote "nursing as it should be practised rather than nursing as it actually is practised" (p.261). She argues that the call for research that focuses on the individual and holistic care is in direct opposition to economically driven research policy. Therefore researching younger people's needs after stroke needs to be placed within the strategic development of appropriate service provision for these people with the goal of ensuring the best possible chances for them to live a healthy life. Within this various studies are needed, of which a specific study could be the implementation of a telephone follow-up service run by nurses for (younger) people after stroke in south-west Germany.

7.5.3. Implications for teaching

Last but not least if nursing is to continue to aim to care for people according to the concept of *Leib*, illness must be taught as a common human experience, as a sign of disruption of an equilibrium and not as the opposite of health. As Gadamer (1996) says, there is no illness without health. The individuality of the experience of health and illness implies that teaching must be narrative-based. This is what Frank (1995) calls "the pedagogy of suffering" (p.145). This approach places people's experience of illness in an equal position to professionals' expertise, pointing out that these people have much to teach society. Frank's idea behind this is manifold: multiple voices would be heard about illness, a new ethic could humanise administrative systems and it would personalise medicine. This personalisation is what contributes to individualised care that acknowledges the *Leib* in all its individually relevant dimensions.

The claim made here is not new:

The want is nearly as old as the world, nearly as large as the world, as pressing as life or death. It is that of sickness. And the art is that of nursing the sick. Please mark- nursing the sick; not nursing sickness. (Nightingale, 1954, p.355)

From this study I would like to add a further aspect to this concept of nursing: nursing a person not only in terms of aspects of sickness but also in order to re-balance their being, themselves in their world. However, the scientific knowledge gained by research is not automatically translated into nursing. Didactic models, such as Wittneben's (1998) "critical-constructive didactic" that focus on the person who is ill and help nurses to apply scientific knowledge are needed. Such an approach needs structures - of nursing education and an appropriate hospital environment. The Robert Bosch Stiftung (2000) has developed a new curriculum that is to reform nursing education and teaching in Germany until 2020. This advocates a person-centred approach to nursing that does integrate ever-changing social, cultural and

political circumstances. They call for 'learning organisations', hospitals as well as schools of nursing that allow these high demands to be met.

7.6. Conclusions

The *Spiel* of dealing with having had a stroke takes place in younger people's lives - they experience it in all aspects of being, in their *Leib*. Their task is to rebalance themselves and to find their place within their environment. Nurses can best assist these people if they move beyond dualistic thinking and beyond categorising people according to the visible impairments of their *Körper*. Nursing needs to view everyone as a fellow human and accompany this individual for a certain period of time with professional knowledge, inquiring about the individual meaning of the illness for this person. This is not a call for omnipotent nurses but for people who, in Gadamer's sense, acknowledge the cultural, social and personal prejudices that they bring into the relationship. In the 21st century it is the ideal of being healthy and in control which marginalises people who threaten this ideal. To merge the ever-present call to care for people who have touched on the limitations of human existence with the best available scientific knowledge of the time and to enter an open and unique dialogue with each individual is what makes nursing an art.

Literature

- Albert, A. (1995) *Aktuelle Diagnostik zerebraler Ischämien bei jungen Patienten; Nachuntersuchungen an jungen Erwachsenen in Freiburg und Basel*, Neurologische Kliniken, Universität Freiburg, MD thesis
- Anderson, R. (1992) *The Aftermath of Stroke*, Cambridge University Press, Cambridge, New York.
- Annandale, E. (1998) *The Sociology of Health and Illness; A Critical Introduction*, Polity Press in ass. with Blackwell Publishers Ltd., Cambridge, Oxford, Malden.
- Annells, M. (1996) Hermeneutic phenomenology: philosophical perspectives and current use in nursing research, *Journal of Advanced Nursing*, **23**, 705-713.
- Arndt, M. (1996) Berufliche Pflege und Ethik- Pflege als moralische Notwendigkeit, In *Ethik denken- Maßstäbe zum Handeln in der Pflege* (Ed. Arndt, M), Georg Thieme Verlag Stuttgart, New York, pp.7-15.
- Babad, E. Y., Birnbaum, M. and Benne, K. D. (1983) *The social self, Group influences on personal identity*, Sage, Beverly Hills, London, New Delhi.
- Backe, M., Larsson, K. and Fridlund, B. (1996) Patients' conceptions of their life situation within the first week after a stroke event: a qualitative analysis, *Intensive and Critical Care Nursing*, **12**, 285-294.
- Banks, P., Pearson, C., Riddell, S. and Roy, C. (2002) *Are Services Meeting the Needs of Younger Stroke Survivors?*, Strathclyde Centre for Disability Research University of Glasgow, Unpublished Report.

- Barbotte, E., Guillemin, F., Chau, N. and The Lorhandicap Group (2001) Prevalence of impairments, disabilities, handicaps and quality of life in the general population: a review of recent literature, *Bulletin of the World Health Organization*, **79**, 1047-1055.
- Bauby, J.-D. (1997) *The Diving-Bell & The Butterfly*, Fourth Estate Limited, London.
- Bendelow, G. and Williams, S. (1995) Pain and the Mind-Body Dualism: A Sociological Approach, *Body & Society*, **1**, 83-103.
- Benz, M. (2000) Rules of relevance after a stroke, *Social Science & Medicine*, **51**, 713-723.
- Bergum, V. (1991) Being a Phenomenological Researcher, In *Qualitative Nursing Research. A Contemporary Dialogue* (Ed, Morse, J. M.) SAGE Publications, London, New Delhi, pp. 55-71.
- Bischoff, C. (1994) *Frauen in der Krankenpflege; Zur Entwicklung der Frauenrolle und Frauenberufstätigkeit im 19. und 20. Jahrhundert*, Campus Verlag GmbH, Frankfurt.
- Black-Schaffer, R. M. and Lemieux, L. (1994) Vocational outcome after stroke, *Topics in Stroke Rehabilitation*, **1**, 74-86.
- Blumer, H. (1969): The methodological position of symbolic interactionism, in: *Symbolic interactionism; Perspective and Method*, University of California Press, Berkeley, London.
- Bogousslavsky, J., Devuyst, G., Nendaz, M., Yamamoto, H. and Sarasin, F. (1997) Prevention of stroke recurrence with presumed paradoxical embolism, *Journal of Neurology*, **244**, 71-75.

- Booth, B. (1994) The knowledge nurses need to educate patients about stroke, *Nursing Times*, **90**, 32-34.
- Böhme, H. (2002) , *Der sprechende Leib*, access. April 2003, <http://www.culture.huberlin.de/HB/texte/natsub/leib.html>.
- Bouchet, C., Guillemin, F., Paul-Dauphin, A. and Briancon, S. (2000) Selection of Quality-of-Life Measures for a Prevention Trial: A Psychometric Analysis, *Controlled Clinical Trials*, **21**, 30-43.
- Boynton De Sepulveda, L. I. and Chang, B. (1994) Effective Coping with Stroke Disability in a Community Setting: The Development of a Causal Model, *Journal of Neuroscience Nursing*, **26**, 193-203.
- Bradshaw, A. (1997) The Ethics of Nursing Care, *Ethics & Medicine*, **13**, 49-55.
- Brammer, L. M. (1991) *How to Cope With Life Transitions: The Challenge of Personal Change*, Hemisphere Publishing Corporation, New York, Washington, London.
- Brereton, L. and Nolan, M. (2000) 'You do know he's had a stroke, don't you?' Preparation for family care-giving- the neglected dimension, *Journal of Clinical Nursing*, **9**, 498-506.
- Bucher, J., Smith, E. and Gillespie, C. (1984) Short term group therapy for stroke patients in a rehabilitation centre, *British Journal of Medical Psychology*, **57**, 283-290.
- Bugge, C., Hagen, S. and Alexander, H. (2001) Measuring stroke patients' health status in the early post-stroke phase using the SF36, *International Journal of Nursing Studies*, **38**, 319-327.

- Burton, C. R. (2000) Re-thinking stroke rehabilitation: the Corbin and Strauss chronic illness trajectory framework, *Journal of Advanced Nursing*, **32**, 595-602.
- Bury, M. (1982) Chronic illness as biographical disruption, *Sociology of Health and Illness*, **4**, 162-182.
- Bury, M. (1991) The sociology of chronic illness: a review of research and prospects, *Sociology of Health and Illness*, **13**, 451-468.
- Bury, M. (1997) *Health and Illness in a Changing Society*, Routledge, London, New York.
- Camerlingo, M., Castro, L., Censori, B., Ferraro, B., Caverni, L., Manara, O., Finazzi, G., Radice, E., Drago, G., Tommasi, S. M. D., Gotti, E., Barbui, T. and Mamoli, A. (2000) Recurrence after first cerebral infarction in young adults, *Acta Neurol Scand*, **102**, 87-93.
- Charmaz, K. (1991) *Good days, bad days: the self in chronic illness and time*, Rutgers University Press, New Brunswick, New Jersey.
- Christine P., P. (1993) Meine Erfahrungen mit dem Schlaganfall, *Pflegen ambulant*, **4**, 30-32.
- Coffey, A. and Atkinson, P. (1996) Concepts and Coding, in: *Making sense of qualitative data; complementary research strategies*, SAGE Publications, London, New Delhi, pp. 26-53.
- Conrad, P. (1990) Qualitative Research on Chronic Illness: A commentary on Method and Conceptual Development, *Social Science Medicine*, **30**, 1257-1263.

- Corbin, J. and Strauss, A. L. (1987) Accompaniments of chronic illness: Changes in body, self, biography, and biographical time, *Research in the Sociology of Health Care*, **6**, 249-281.
- Coubrough, F. (1992) On the Receiving End, *Nursing Times*, **88**, 28-29.
- Cox, K. and Wilson, E. (2003) Follow-up for people with cancer: nurse-led services and telephone interventions, *Journal of Advanced Nursing*, **43** (1), 51-61.
- Craib, I. (1998) *Experiencing Identity*, Sage Publications Ltd, London, New Delhi.
- Crawford, R. (1984) The boundaries of the self and the unhealthy other: reflections on health, culture and AIDS, *Social Science Medicine*, **38**, 1347-1365.
- Crossley, M. C. (2000) Narrative psychology, trauma and the study of self/ identity, *Theory & Psychology* **10** (4), 527-546.
- Crotty, M. (1998) *The Foundations of Social Research; Meaning and Perspective in the Research Process*, Sage Publications, London, Thousand Oaks, New Delhi.
- Darbyshire, P., Diekelmann, J. and Diekelmann, N. (1999) Reading Heidegger and interpretive phenomenology: a response to the work of Michael Crotty, *Nursing Inquiry*, **6**, 17-25.
- Davis, K. (1997) Embodiment Theory; Beyond Modernist and Postmodernist Readings of the Body In *Embodied Practices, Feminist Perspectives on the Body* (Ed., Davis, K.), Sage Publications, London, New Delhi, pp.1-23
- De Bernardi, J. (1994) Social aspects of language use, In *Companion Encyclopedia of Anthropology*, Vol. 1st (Ed, Ingold, T.) Routledge, London, New York, pp. 861-890.
- Degener, T. (2002) *Antidiskriminierungsgesetze für Behinderte weltweit*,

Beauftragter der Bundesregierung für die Belange behinderter Menschen,

<http://www.behindertenbeauftragter.de/gesetzgebung/behindertengleichstellungsgesetz/texte/impulsreferate>.

Department of Health (1994) *Stroke. An Epidemiological Overview*, The Health of the Nation Report, London.

different Strokes (2000) *Work after stroke- Project update (unpublished)*,

<http://www.differentstrokes.co.uk/>.

Dingwall, R. and McIntosh, J. (1978) Introduction, In *Readings in the Sociology of Nursing* (Eds, Dingwall, R. and McIntosh, J.) Churchill Livingstone, Edinburgh, London, pp.1-15.

Doolittle, N. D. (1990) *Life After Stroke: Survivors' Bodily and Practical Knowledge of Coping During Recovery*, University of California, Nursing, PhD thesis, unpublished

Doolittle, N. D. (1994) A Clinical Ethnography of Stroke Recovery, In *Embodiment, Caring, and Ethics in Health and Illness* (Ed, Benner, P.) SAGE Publications, San Francisco, pp. 211-223.

Dowswell, G., Lawler, J., Dowswell, T., Young, J., Forster, A. and Hearn, J. (2000) Investigating recovery from stroke: a qualitative study, *Journal of Clinical Nursing*, **9**, 507-517.

Draucker, C. B. (1999) The critique of Heideggerian hermeneutical nursing research, *Journal of Advanced Nursing*, **30**, 360-373.

Drummond, J. (1997) *Encyclopedia of Phenomenology*, Vol. 18 Kluwer Academic Publishers, pp. 304-307.

- Duden, B. (1987) *Geschichte unter der Haut*, Ernst Klett Verlage GmbH u. Co. KG, Stuttgart.
- Ebrahim, S. and Harwood, R. (1999) *Stroke. Epidemiology, evidence, and clinical practice*, Oxford University Press, Oxford, New York.
- Ellis-Hill, C. S. (2000) Change in identity and self-concept: a new theoretical approach to recovery following a stroke, *Clinical Rehabilitation*, **14**, 279-287.
- Ellis-Hill, C. S., Payne, S. and Ward, C. (2000) Self-body split: issues of identity in physical recovery following a stroke, *Disability and Rehabilitation*, **22**, 725-733.
- Everson, S. A., Lynch, J. W., Kaplan, G. A., Lakka, T. A., Sivenius, J. and Salonen, J. T. (2001) Stress-Induced Blood Pressure Reactivity and Incident Stroke in Middle-Aged Men, *Stroke*, **32**, 1263-1270.
- Fleming, V., Gaidys, U., Robb, Y. (2003) Hermeneutic research in nursing: developing a Gadamerian-based research method, *Nursing Inquiry*, **10**, 113-120.
- Frank, A. W. (1995) *The Wounded Storyteller. Body, Illness and Ethics*, University of Chicago Press, Chicago.
- Frank, A. W. (2000) The Standpoint of the Storyteller, *Qualitative Health Research*, **10**, 354-365.
- Frank, R., Fischer, V., Kittner, P. and Jacobi, P. (1985) Krankheitsverarbeitung und Persönlichkeit: zur psychotherapeutischen Beeinflussung von Krankheitsverleugnungsstrategien bei Schlaganfall-Patienten, *Psychotherapie, medizinische Psychologie*, **35**, 281-289.

- Fritschi, W. (1988) *Ich bin jetzt wie ein Acker. Die Geschichte eines Hirnschlags*,
Radio Vorarlberg "Focus", 9/5/1988, Dornbirn.
- Gadamer, H.-G. (1967) *Kleine Schriften*. Bd.2, Interpretationen, , Tübingen.
- Gadamer, H.-G. (1989) *Truth and Method*, The Crossroad Publishing Corporation,
New York.
- Gadamer, H.-G. (1990) *Wahrheit und Methode. Grundzüge einer philosophischen
Hermeneutik*, J.C.B. Mohr (Paul Siebeck), Tübingen.
- Gadamer, H.-G. (1993) *Wahrheit und Methode. Ergänzungen, Register*, J.C.B. Mohr
(Paul Siebeck), Tübingen.
- Gadamer, H.-G. (1996) *Über die Verborgenheit der Gesundheit*, Suhrkamp,
Frankfurt am Main.
- Gadamer, H. G. (1996) *The enigma of health*, Blackwell, Polity Press.
- Gadamer, H. G. (1997) Reflections on my philosophical journey, In *The philosophy
of Hans Georg Gadamer* (Ed, Hahn, L. E.) The Library of Living
Philosophers, Illinois, pp. 3-63.
- Geanellos, R. (1998) Hermeneutic philosophy. PartI: implications of its use as
methodology in interpretive nursing research, *Nursing Inquiry*, **5**, 154-163.
- Gerhard, U. (1990) Qualitative Research on Chronic Illness: The Issue and the Story,
Social Science Medicine, **30**, 1149-1159.
- Giddens, A. (1991) *Modernity and self-identity: Self and society in the late modern
age*, Blackwell Publishers, Cambridge.
- Goffman, E. (1968) *Stigma: notes on the management of spoiled identity*, Penguin,
London.
- Golan, N. (1978) Identifying and Defining the Crisis Situation, In *Treatment in*

- Crisis Situations* (Ed, Golan, N.) The Free Press. A Division of Macmillan Publishing Co., Inc., New York, London, pp. 61-79.
- Good, B. J. (1994) *Medicine, rationality and experience. An anthropological perspective*, Cambridge University Press, Cambridge, New York, Melbourne.
- Green, S. E. (2003) "What do you mean 'what's wrong with her?': stigma and the lives of families of children with disabilities, *Social Science & Medicine*, **57**, 1361-1374.
- Grondin, J. (1997) Gadamer on humanism, In *The Philosophy of Hans Georg Gadamer* (Ed, Hahn, L. E.) The Library of Living Philosophers, Illinois, pp. 157-172.
- Habel, M. (1997) , *Management of the patient with a stroke*, Vol. 2003, <http://www.nurseweekce.com/courses/nurseweek/NW0200d/Coursebook.pdf>.
- Hafensteinsdóttir, T. B. and Grypdonck, M. (1997) Being a stroke patient: a review of the literature, *Journal of Advanced Nursing*, **26**, 580-588.
- Hager, K. and Ziegler, K. (1998) Stadien der Krankheitsverarbeitung nach einem Schlaganfall, *Zeitschrift fuer Gerontologie und Geriatrie*, **31**, 9-15.
- Hammersley, M. (1995) On Feminist Methodology, In *The politics of social research*, Sage Publications, London, New Delhi, pp.45-65.
- Harrison, J., MacGibbon, L. and Morton, M. (2001) Regimes of Trustworthiness in Qualitative Research: The Rigours of Reciprocity, *Qualitative Inquiry*, **7**, 323-345.
- Hart, E. (1998) Evaluating a pilot community stroke service using insights from medical anthropology, *Journal of Advanced Nursing*, **27**, 1177-1183.
- Hartke, R. J. and Brashler, R. (1994) Assessment of the needs of the young stroke survivor, *Topics in Stroke Rehabilitation*, **1**, 15-24.

- Heim, E. (1998) Coping- Erkenntnisstand der 90er Jahre, *PPmP Psychotherapie, Psychosomatik, medizinische Psychologie*, **48**, 321-337.
- Heinemann, L. A. J., Lewis, M. A., Thorogood, M., Spitzer, W. O., Guggenmoos-Holzmann, I. and Bruppacher, R. (1997) Case-control study of oral contraceptives and risk of thromboembolic stroke: results from international study on oral contraceptives and health of young women, *bmj*, **315**, 1502-1504.
- Herrmann, M., Britz, A., Bartels, C. and Wallesch, C.-W. (1995) Bedingungen und Möglichkeiten der Krankheitsverarbeitung im ersten Jahr nach Schlaganfall, *Neurolinguistik*, **9**, 23-39.
- Herz Brown, F. (1989) The Impact of Death and Serious Illness on the Family Life Cycle, In *The Changing Family Life Cycle* (Eds, Carter, B. and McGoldrick, M.) Allyn and Bacon, Boston, London, Sydney, pp.662-669.
- Herzlich, C. and Pierret, J. (1987, translation of 1984) *Illness and self in society*, John Hopkins University Press, Baltimore, London.
- Homma, S., Tullio, M. R. D., Sacco, R. L., Sciacca, R. R., Smith, C. and Mohr, J. P. (1997) Surgical Closure of Patent Foramen Ovale in Cryptogenic Stroke Patients, *Stroke*, **28**, 2376-2381.
- Hyman, M. D. (1971) The stigma of stroke, *Geriatrics*, **5**, 132-141.
- Immenschuh, U. (2000) Ein Schlaganfall ist eine Katastrophe für die Betroffenen- (Wie) wird die Pflege den Bedürfnissen jüngerer Betroffener gerecht?, *Pflege*, **13**, 180-186.
- Isayev, Y., Chan, R. K. T. and Pullicino, P. M. (2002) "Economy Class" stroke syndrome?, *Neurology*, **58**, 960-961.

- Jackson, D., Thornton, H. and Turner-Stokes, L. (2000) Can young severely disabled stroke patients regain the ability to walk independently more than three months post stroke?, *Clinical Rehabilitation*, **14**, 538-547.
- Jackson, J. (1994) Chronic pain and the tension between the body as subject and object, In *Embodiment and experience; the existential ground of culture and self* (Ed, Csordas, T. J.) University Press, Cambridge.
- Jacobs, B. S., Boden-Albala, B., Lin, I.-F. and Sacco, R. L. (2002) Stroke in the Young in the Northern Manhattan Stroke Study, *Stroke*, **33**, 2789-2793.
- Jacoby, A. (1994) Felt versus enacted stigma: A concept revisited, *Social Science Medicine*, **38**, 269-274.
- James, S. (2000) Feminism in philosophy of mind: The question of personal identity, In *The Cambridge companion to feminism in philosophy*, Vol. 1 (Eds, Fricker, M. and Hornsby, J.) University Press, Cambridge, pp. 29-48.
- Janesick, V. J. (1994) The Dance of Qualitative Research Design. Metaphor, Methodology, and Meaning, In *Handbook of Qualitative Research* (Eds, Denzin, N. K. and Lincoln, Y. S.) SAGE Publications, London, New Delhi, pp. 209-219.
- Jenkins, R. (1996) *Social Identity*, Routledge, London, New York.
- Joachim, G. and Acorn, S. (2000) Stigma of visible and invisible chronic conditions, *Journal of Advanced Nursing*, **32**, 243-248.
- Jones, A. (1995) Utilizing Peplau's psychodynamic theory for stroke patient care, *Journal of Clinical Nursing*, **4**, 49-54.

- Kallert, T. W. (1993) Ausgewählte Aspekte der Krankheitsverarbeitung und der psychotherapeutischen Behandlung von Schlaganfallpatienten, *Rehabilitation*, **32**, 99-106.
- Kean, S. (2000) Focus Group Interviews: Ein qualitativer Forschungsansatz in der Pflege, *Pflege*, **13**, 145-151.
- Kelly, M. P. (1992) *Colitis*, Routledge, London, New York.
- Kelly, M.P. (1992a) Self, Identity and Radical Surgery, *Sociology of Health & Illness*, **14** (3) 390-415
- Kelly, M.P. and Field, D. (1996) Medical Sociology, Chronic Illness and the Body, *Sociology of Health & Illness*, **18** (2) 241-257
- Kelly, P. T. (1994) Observations of a young stroke patient, *Topics in Stroke Rehabilitation*, **1**, 87-90.
- Kempers, E. (1994) Preparing the young stroke survivor for return to work, *Topics in Stroke Rehabilitation*, **1**, 65-73.
- Kersten, P., Low, J. T. S., Ashburn, A., George, S. L. and McLellan, D. L. (2002) The unmet needs of young people who have had a stroke: results of a national UK survey, *Disability and Rehabilitation*, **24**, 860-866.
- Kidel, M. (1988) Illness and meaning, In *The Meaning of Illness* (Eds, Kidel, M. and Rowe-Leete, S.) Routledge, London, New York.
- Kirkevold, M. (1999) Die Rolle der Pflege in der Rehabilitation akuter Hirnschlagpatienten, *Pflege*, **12**, 21-27.
- Kirkevold, M. (2002) The unfolding illness trajectory of stroke, *Disability and Rehabilitation*, **24**, 887-898.
- Kittner, S. J. (2002) Stroke in the young; Coming of age, *Neurology*, **59**, 6-7.

- Kitzinger, J. (1994) The methodology of Focus Groups: the importance of interaction between research participants, *Sociology of Health and Illness*, **16**, 103-121.
- Kleinman, A. (1988) *The illness narratives. Suffering, healing and the human condition*, Basic Books, United States of America.
- Koch, T. (1992) Establishing rigour in qualitative research: the decision trail, *Journal of Advanced Nursing*, **19**, 976-986.
- Koch, T. (1996) Implementation of a hermeneutic inquiry in nursing: philosophy, rigour and representation, *Journal of Advanced Nursing*, **24**, 174-184.
- Koch, T. (1998) Story telling: is it really research?, *Journal of Advanced Nursing*, **28**, 1182-1190.
- Koch, T. and Harrington, A. (1998) Reconceptualizing rigour: the case for reflexivity, *Journal of Advanced Nursing*, **28**, 882-890.
- Korpelainen, J., Nieminen, P. and Myllylä, V. (1999) Sexual functioning among stroke patients and their spouses, *Stroke*, **30**, 715-719.
- Kristensen, B., Malm, J., Carlberg, B., Stegmayr, B., Backman, C., Fagerlund, M. and Olsson, T. (1997) Epidemiology and Etiology of Ischemic Stroke in Young Adults Aged 18 to 44 Years in Northern Sweden, *Stroke*, **28**, 1702-1709.
- Kvigne, K., Gjengedal, E. and Kirkevold, M. (2002) Gaining access to the life-world of women suffering from stroke: methodological issues in empirical phenomenological studies, *Journal of Advanced Nursing*, **40**, 61-68.
- Kyriazis, M. (1994) Developments in the treatment of stroke patients, *Nursing Times*, **90**, 30-32.

- Lamy, C., Giannesini, C., Zuber, M., Arquizan, C., Meder, J. F., Trystram, D., Coste, J. and Mas, J. L. (2002) Clinical and Imaging Findings in Cryptogenic Stroke Patients With and Without Patent Foramen Ovale; The PFO-ASA Study, *Stroke*, **33**, 706-711.
- Laska, A. C., Hellblom, A., Murray, V., Kahan, T. and Arbin, M. v. (2001) Aphasia in acute stroke and relation to outcome, *Journal of Internal Medicine*, **249**, 413-422.
- Lawler, J., Dowswell, G., Hearn, J., Forster, A. and Young, J. (1999) Recovering from stroke: a qualitative investigation of the role of goal setting in late stroke recovery, *Journal of Advanced Nursing*, **30**, 401-409.
- Lazarus, R. S. (1991) *Emotion & Adaption*, Oxford University Press, New York.
- Lazarus, R. S. (1992) Coping With the Stress of Illness, *WHO Regional Publications. European Series*, **44**, 11-31.
- Lazarus, R. S. (1993) From Psychological Stress to the Emotions: A History of Changing Outlooks, *Annual Review of Psychology*, **44**, 1-21.
- Lazarus, R. S. (2000) Evolution of a Model of Stress, Coping, and Discrete Emotions, In *Handbook of Stress, Coping and Health; Implications for Nursing Research, Theory, and Practice* (Ed, Rice, V. H.) Sage Publications, London, New Delhi, pp. 195-222.
- Leder, D. (1990) *The absent body*, The University of Chicago Press, Chicago, London.
- Leys, D., Bandu, L., Hénon, H., Lucas, C., Mounier-Vehier, F., Rondepierre, P. and Godefroy, O. (2002) Clinical outcome in 287 consecutive young adults (15 to 45 years) with ischemic stroke, *Neurology*, **59**, 26-33.

- Lofland J. and Lofland L.H. (1995) Developing Analysis. In: *Analysing Social Settings: A Guide to Qualitative Observation and Analysis*, Wadsworth Publishing Company, London, New York, pp. 181-204
- Lui, M. H. L. and Mackenzie, A. E. (1999) Chinese elderly patients' perceptions of their rehabilitation needs following a stroke, *Journal of Advanced Nursing*, **30**, 391-400.
- Luker, K.A. (1997) Research and the configuration of nursing services, *Journal of Clinical Nursing*, **6**, 259-267.
- MacLeod, M. L. P. (1990) *Experience in Everyday Nursing Practice: A Study of 'Experienced' Surgical Ward Sisters*, University of Edinburgh, Nursing Studies, PhD thesis, unpublished.
- MacHaffie, H. (1992) Coping: an essential element of nursing, *Journal of Advanced Nursing*, **17**, 933-940.
- Martin, P., Enevoldson, T. and Humphrey, P. (1997) Causes of ischaemic stroke in the young, *Prostgrad Med J*, **73**, 8-16.
- McCrum, R. (1998) *My Year Off. Rediscovering Life After Stroke*, Picador, London.
- McSherry, W., Cash, K. (2003) The language of spirituality, *International Journal of Nursing Studies*, in press.
- Medline Plus Medical Encyclopedia (2002) , U.S. National Library of Medicine and the National Institutes of Health,
<http://www.nlm.nih.gov/medlineplus/ency/article/001113.htm> .
- Meier, B. and Lock, J. E. (2003) Contemporary Management of Patent Foramen Ovale, *Circulation*, **7**, 5-9.

- Melia, K. M. (1979) A sociological approach to the analysis of nursing work, *Journal of Advanced Nursing*, **4**, 57-67.
- Melia, K. M. (1997) Producing 'Plausible Stories': Interviewing Student Nurses, In *Context & Method in Qualitative Research* (Eds, Miller, G. and Dingwall, R.) Sage Publications, London, New Delhi, pp.26-36.
- Mikula Jr., N. (1998) The Plight of the One-Armed Paperhanger, In *After Stroke; Enhancing Quality of Life*, (Ed, Sife, W.) Haworth Press, Binghamton NY, pp. 201-204.
- Mishler, E. G. (1986) *Research Interviewing. Context and Narrative*, Harvard University Press, Cambridge, Massachusetts, London.
- Monks, J. and Frankenberg, R. (1995) Being Ill and Being Me: Self, Body, and Time in Multiple Sklerosis Narratives, In *Disability and Culture* (Ed, Benedicte Ingstad, S. R. W.) University of California Press, Berkley, Los Angeles, London, pp. 107-134.
- Morse, J. M. (1991) Strategies for Sampling, In *Qualitative Nursing Research. A Contemporary Dialogue* (Ed, Morse, J. M.) SAGE Publications, London, New Delhi, pp. 126-145.
- Munts, A. G., Genderen, P. J. J. v., Dippel, D. W. J., Kooten, F. v. and Koudstaal, P. J. (1998) Coagulation disorders in young adults with acute cerebral ischaemia, *Journal of Neurology*, **245**, 21-15.
- Naess, H., Nyland, H. I., Thomassen, L., Aarseth, J., Nyland, G. and Myhr, K.-M. (2002) Incidence and Short-Term Outcome of Cerebral Infarction in Young Adults in Western Norway, *Stroke*, **33**, 2105-2108.

- Nightingale, F. (1954) *Sick Nursing and Health Nursing*; A paper read at the Chicago Exhibition, 1893, In *Selected Writings of Florence Nighingale* (Ed, Seymer, L. R.) The Macmillan Company, New York, pp. 353-376.
- Northcott, N. (1996) Cognitive mapping: An approach to qualitative data analysis, *NTRResearch*, **1** (6), 456-463.
- Norton, I. (1993) Altered Circumstances, *Nursing Times*, **89**, 62-64.
- O'Connor, S. E. (1996) Stroke units: centres of nursing innovation, *British Journal of Nursing*, **5**, 105-109.
- Oehring, A. K. and Oakley, J. L. (1994) The young stroke patient: A need for specialized group support systems, *Topics in Stroke Rehabilitation*, **1**, 25-40.
- Parahoo, K. (1997) *Nursing Research. Principles, process and issues*, Macmillan Press LTD, London.
- Pascoe, E. (1996) The value to nursing research of Gadamer's hermeneutic philosophy, *Journal of Advanced Nursing*, **24**, 1309-1314.
- Petty, G. W., Brown, R. D., Whisnand, J. P., Sicks, J. D., O'Fallon, W. M. and Wiebers, D. O. (2000) Ischemic Stroke Subtypes; A Population-Based Study of Functional Outcome, Survival, and Recurrence, *Stroke*, **31**, 1062-1068.
- Pound, P., Gompertz, P. and Ebrahim, S. (1998) Illness in the context of older age: the case of stroke, *Sociology of Health & Illness*, **20**, 489-506.
- Pound, P., Ebrahim S. (2000) Rhetoric and reality in stroke patient care, *Social Science & Medicine*, **51**, 1437-1446.
- Powers, B. A. and Knapp, T. R. (1995) *A Dictionary of Nursing Theory and Research*, Sage Publications, Thousand Oaks, London, New Delhi.

- Radley, A. (1994) *Making Sense of Illness; The Social Psychology of Health and Disease*, Sage Publications, London, New Delhi.
- Robert Bosch Stiftung (2000) *Pflege neu denken; Zur Zukunft der Pflegeausbildung*, Schattauer, Stuttgart, New York.
- Robinson, R. G. (1998) *The Clinical Neuropsychiatry of Stroke. Cognitive, behavioural and emotional disorders following vascular brain injury*, Cambridge University Press, Cambridge, New York.
- Röding, J., Lindström, B., Malm, J. and Öhman, A. (2003) Frustrated and invisible-younger stroke patients' experiences of the rehabilitation process, *Disability and Rehabilitation*, **25**, 867-874.
- Rolland, J. S. (1988) A Conceptual Model of Chronic and Life-Threatening Illness and Its Impact on Families, In *Chronic Illness and Disability; Families in Trouble Series*, (Eds, Chilman, C. S., Nunnally, E. W. and Cox, F. M.) Sage Publications, London, New Delhi, Vol. 2, pp. 17-68.
- Sacco, R., Ellenberg, J., Mohr, J., Tatemichi, T., Hier, D., Price, T. and Wolf, P. (1989) Infarcts of undetermined cause: the NINCDS Stroke Data Bank, *Annals of Neurology*, **25**, 382-390.
- Sandelowski, M. (1993) Rigor or rigor mortis: The problem of rigor in qualitative research revisited, *Advanced Nursing Science*, **16**, 1-8.
- Scambler, G. and Hopkins, A. (1986) Being epileptic: coming to terms with stigma, *Sociology of Health and Illness*, **8**, 26-43.
- Schaeffer, D. (1999) Entwicklungsstand und -herausforderungen der bundesdeutschen Pflegewissenschaft, *Pflege*, **12**, 141-152.

- Scheidt, C. E. and Schwind, A. (1992) Zur Psychodynamik der Krankheitsverarbeitung bei Schlaganfall- Erfahrungen einer psychotherapeutischen Gruppe, *PPmP Psychotherapie, Psychosomatik, medizinische Psychologie*, **42**, 54-59.
- Schumacher, J. and Reschke, K. (1994) , Theoretische Konzepte und empirische Methoden der Bewältigungsforschung, access 1999, <http://www.uni-leipzig.de/~gespsych/coping.html>.
- Shakespeare, T. and Watson, N. (2001) The social model of disability: an outdated ideology?, *Exploring Theories and Expanding Methodologies*, **2**, 9-28.
- Shaw, L., Segal, R., Polatajko, H. and Harburn, K. (2002) Understanding return to work behaviours: promoting the importance of individual perceptions in the study of return to work, *Disability and rehabilitation*, **24**, 185-195.
- Silverman, D. (2000) *Doing Qualitative Research*, Sage Publications, London, New Delhi.
- Skultans, V. (1998) Anthropology and narrative, In *Narrative Based Medicine; Dialogue and discourse in clinical practice* (Eds, Greenhalgh, T. and Hurwitz, B.) BMJ Books, London, pp. 225-233.
- Sokolowski, R. (1997) Gadamer's theory of hermeneutics, In *The Philosophy of Hans-Georg Gadamer* (Ed, Hahn, L. E.) The Library of Living Philosophers, Chicago, pp. 223-234.
- Steiner, M. M., Tullio, M. R. D., Rundek, T., Gan, R., Chen, X., Liguori, C., Brainin, M., Homma, S. and Sacco, R. L. (1998) Patent Foramen Ovale Size and Embolic Brain Imaging Findings Among Patients With Ischemic Stroke, *Stroke*, **29**, 944-948.

- Steppe, H. (Ed), (1996) *Krankenpflege im Nationalsozialismus*, Mabuse Verlag, Frankfurt.
- Stopczyk, A. (1998) *Sophias Leib- Entfesselung der Weisheit*, Carl-Auer-Systeme Verlag, Heidelberg.
- Tacke, D. (1997) *Auswirkungen professioneller Hilfe auf Menschen mit Aphasie*, University of Applied Sciences Osnabrück, Nursing, Diplomarbeit (equivalent to MSc dissertation).
- Talal, A. (1986) The Concept of Cultural Translation in British Social Anthropology, In *Writing Culture: The Poetics and Politics of Ethnography. A School of American Research advanced seminar*, (Ed. Clifford, J., Marcus, G.E.) University of California Press, Berkley.
- Teasdale, T. and Engberg, A. (2001) Suicide after a stroke: a population study, *Journal of Epidemiology and Community Health*, **55**, 863-866.
- Teasell, R. W., McRae, M. P. and Finestone, H. M. (2000) Social issues in the Rehabilitation of Younger Stroke Patients, *Arch Phys Med Rehabil*, **81**, 205-209.
- The Collins German Dictionary (2001) HarperCollins Publishers, Glasgow.
- The Compact Oxford English Dictionary, University of Edinburgh Homepage
- The Concise Oxford Dictionary (1995) Clarendon Press, Oxford.
- Thompson, I. E., Melia, K. M. and Boyd, K. M. (1988) *Nursing Ethics*, Churchill Livingstone, New York.
- Thorne, S., Paterson, B., Acorn, S., Canam, C., Joachim, G. and Jillings, C. (2002) Chronic Illness Experience: Insights From a Metastudy, *Qualitative Health Research*, **12**, 437-452.

- Travelbee, J. (1971) The Nature of Nursing, In *Interpersonal Aspects of Nursing*, F.A. Davis Company, Philadelphia, pp. 1-22.
- Tully Farzan, D. (1991) Reintegration for Stroke Survivors, *Nursing Clinics of North America*, **26**, 1037-1048.
- Uexküll, T. v. (1991) Psychosomatik als Suche nach dem verlorenen lebenden Körper, *PPmP Psychother. Psychosom. med. Psychol.*, **41**, 482-488.
- Uzarewicz, C. (2002) Das Konzept der Leiblichkeit und seine Bedeutung für die Pflege, In *Das Originäre der Pflege entdecken. Pflege beschreiben, erfassen und begrenzen*. Mabuse Verlag, Frankfurt a.M., Berlin, pp. 13-26.
- Vance, B. (1998) Stroke! This Isn't the Script I Was Writing!, In *After Stroke; Enhancing Quality of Life*, (Ed, Sife, W.) Haworth Press, Binghamton, NY, pp. 149-160.
- VanderZee, K. I., Buunk, B. P. and Sanderman, R. (1995) Social comparison as a mediator between health problems and subjective health evaluation, *British Journal of Social Psychology*, **34**, 53-65.
- Warlow, C. P., Dennis, M. S., Gijn, J. v., Hankey, G. J., Sandercock, P. A. G., Bamford, J. M. and Wardlaw, J. M. (2001) *Stroke, A practical guide to management*, Blackwell Science Ltd, Oxford, Edinburgh, London, Malden.
- Watson, G. (1987) *Writing a thesis; a guide to long essays and dissertations*, Longman Group UK Limited, London, New York.
- Weaver Moore, L. and Miller, M. (1999) Initiating research with doubly vulnerable populations, *Journal of Advanced Nursing*, **30**, 1034-1040.
- Williams, G. (1984) The genesis of chronic illness: narrative re-construction, *Sociology of Health and Illness*, **6**, 175-200.

- Williams, S. J. (1996) The Vicissitudes of Embodiment Across the Chronic Illness Trajectory, *Body & Society*, **2**, 23-47.
- Wittneben, K. (1998) *Pflegekonzepte in der Weiterbildung zur Pflegelehrkraft: über Voraussetzungen und Perspektiven einer kritisch-konstruktiven Didaktik der Krankenpflege*, Lang, Frankfurt, New York, Paris.
- Wolcott, H. F. (1994) *Transforming qualitative data- description, analysis and interpretation*, Sage, Thousand Oaks California, London.
- Wolcott, H. F. (2001) *Writing up qualitative research*, Sage Publications, Thousand Oaks, California, New Delhi.
- Wolcott, H. F. (2002) Writing Up Qualitative Research. Better, *Qualitative Health Research*, **12**, 91-103.
- World Health Organization (2002) *Towards a Common Language for Functioning, Disability and Health*, access June 2003,
<http://www.who.int/classification/icf>.
- Wozniak, M. A., Kittner, S. J., Price, T., Hebel, J. R., Sloan, M. A. and Gardner, J. F. (1999) Stroke Location Is Not Associated With Return to Work After First Ischemic Stroke, *Stroke*, **30**, 2568-2573.
- Zola, I. K. (1973) Pathways to the doctor- from person to patient, *Social Science & Medicine*, **7**, 677-689.

Appendices

List of people participating in the study

| <i>Name</i> | <i>age</i> | <i>date of stroke</i> | <i>gender</i> | <i>partnership and children at the time of the stroke</i> | <i>change in partnership after the stroke</i> | <i>occupation</i> |
|-----------------|------------|-----------------------|---------------|---|---|------------------------|
| Andreas | 35 | Jan.00 | male | single, in a relationship, no children | same (problems in the relationship) | lorry driver |
| Georg | 31 | May 00 | male | married, no children | same, relationship became stronger | mechanic |
| Helene | 51 | March 00 | female | widowed, in a relationship, one grown up daughter | broke up the relationship | play school teacher |
| Judith | 48 | May 00 | female | divorced, in a relationship, one grown up son | same | specialised saleswoman |
| Karin | 40 | July 00 | female | married, four children | same | nurse |
| Matthias | 35 | May 00 | male | married, no children | same | electroplater |
| Michael | 38 | Dec. 00 | male | single, in a relationship, one daughter | same | car-mechanic |
| Robert | 40 | May 00 | male | married, two children | same, relationship became stronger | clerk |
| Sofie | 24 | August 00 | female | married, one daughter | divorced, living with her daughter | owns a pub |
| Stefanie | 18 | March 01 | female | single, no children | same | pharmacist's assistant |
| Thomas | 26 | May 00 | male | single, no children | same | printer |

- four people have children, one of them does not live with his daughter
- two are single, not in a relationship with a partner
- no one has a higher education, ten were employed as skilled workers, one was self-employed

Impairments of participants (as described by them)

| Name | Type of ischaemic stroke | impairment immediately after stroke | impairment three months after | impairment six months after | impairment twelve months after |
|-----------------|---------------------------------|--|--|--|--|
| Andreas | A. media | semi-paralysis, problems with speech and with writing | invisible weakness of his arm and leg, speech problems, problems with writing | as three months after | as three months after |
| Georg | A. cerebri anterior left | semi-paralysis, limited field of vision, speech impairment, dependent on care in all daily activities for first days | memory problems (according to him not related to stroke) | memory problems (according to him not related to stroke) | memory problems (according to him related to stroke) |
| Helene | A. media | problems with hearing and with speech | no problems | problems with concentration, with toleration of stress and noise | problems with concentration and with toleration of stress |
| Judith | A. media | no problems | fatigue, problems with concentration, with toleration of stress and noise, invisible weakness in her hand, problems with fine motor movement | as three months after | as three months after |
| Karin | brain stem | invisible weakness of her arm and leg | invisible weakness of her arm and leg | as three months after | as three months after |
| Matthias | thalamus | semi-paralysis, speech problems, dependent on care for first days | invisible weakness of his arm, memory problems | memory problems predominant, invisible weakness of his arm | slight memory problems |
| Michael | thalamus | speech problems | memory problems | as three months after | as three months after |
| Robert | brain stem | hoarseness, speech problems | no problems | no problems | no problems |
| Sofie | thalamus | semi-paralysis, limited field of vision, speech impairment, dependent on care in all daily activities for first days | problems with walking, a limited field of vision and weakness of her arm | problems with walking, a limited field of vision and weakness of her arm | problems with walking, a limited field of vision and weakness of her arm |
| Stefanie | A. media | weakness of her arm | no problems | no problems | no problems |
| Thomas | A. media | semi-paralysis, speech problems, problems with writing | speech problems and with writing, problems with fine motor movement | speech problems and with writing | speech problems and with writing |

Informationsblatt zur Studie **“Krankheitserleben nach Schlaganfall”**

Mein Name ist Ursula Immenschuh. Ich bin Krankenschwester und bin sehr daran interessiert, die Pflege von Menschen zu verbessern. Aus diesem Anliegen heraus führe ich eine wissenschaftliche Studie mit jüngeren Menschen, die einen Schlaganfall erlitten haben durch.

Um was für eine Studie handelt es sich?

Die wichtigsten Fragen, die die Studie leiten sind

- Wie ergeht es jüngeren Menschen (bis 55 Jahre) nachdem sie einen Schlaganfall erlitten haben?
- Was sind wichtige Fragen für diese Menschen?
- Was brauchen diese Menschen von Pflegenden?

Diese Studie wird Ihre Pflege nicht direkt verbessern, aber die Ergebnisse werden in der Zukunft anderen Menschen, die einen Schlaganfall erleiden, zugute kommen.

Was heißt es für Sie an der Studie teilzunehmen?

Eine Teilnahme an der Studie hat keinerlei Einfluß auf Ihre Pflege oder Behandlung. Ich habe langjährige Erfahrung als Krankenschwester, stehe aber in keinerlei Anstellungsverhältnis mit Kliniken oder Rehabilitationseinrichtungen.

Ich bitte Sie um die Bereitschaft, an drei Gesprächen (Interviews) teilzunehmen.

Wenn Sie sich zur Teilnahme an der Studie bereiterklären, werde ich mich ca. zwei Monate nach dem Schlaganfall wieder mit Ihnen in Verbindung setzen und einen Termin für ein erstes Gespräch vereinbaren, das ca. drei Monate nach Ihrem Schlaganfall stattfinden soll. Um weitere Gespräche bitte ich Sie sechs und zwölf Monate nach dem Schlaganfall.

Wie steht es mit der vertraulichen Behandlung Ihrer Daten?

Ihre Daten und Informationen werden absolut vertraulich behandelt, nicht an Dritte weitergegeben und in schriftlichen Arbeiten und Veröffentlichungen anonymisiert. Es wird nicht möglich sein, dass Sie als Person identifizierbar sind.

Und wenn Sie Ihre Entscheidung ändern?

Zu jeglichem Zeitpunkt können Sie Ihre Entscheidung, an der Studie teilzunehmen, widerrufen. Dies hat keinerlei Auswirkungen auf Ihre Pflege oder Behandlung.

Was passiert nun?

Ich werde ca. zwei Monate nach unserem ersten Gespräch wieder Kontakt mit Ihnen aufnehmen. Falls Sie in der Zwischenzeit Fragen haben, können Sie sich gerne an mich wenden.

Consent form (participation)

Meine Teilnahme an der Studie "Krankheitserleben nach Schlaganfall"

Name und Adresse

.....
.....
.....
.....

Alter

Beruf

Der Schlaganfall passierte am.....

Einverständniserklärung

Ich habe die Informationen gelesen.

Ich hatte ausreichend Möglichkeit, bezüglich der Studie Fragen zu stellen und mich zu informieren.

Ich habe verstanden, was es heißt, an der Studie teilzunehmen.

Ich weiß, dass ich jederzeit mein Einverständnis, an der Studie teilzunehmen, ohne Angabe von Gründen widerrufen kann.

Ich weiß, dass es keinen Einfluß auf meine Pflege und Behandlung hat, ob ich an der Studie teilnehme oder nicht.

Ich erkläre mich einverstanden, an der Studie teilzunehmen.

.....

Unterschrift

.....

Datum

Letter of consent for patients records

Ursula Immenschuh, Staufenerstr. 52, 79115 Freiburg ☎ 0761/ 292 7544

An Frau

Freiburg, den 15.03.01

Liebe Frau ,

wie ich Ihnen bereits angekündigt habe würde ich gerne im Rahmen meiner Forschungs-arbeit "Krankheitserleben jüngerer Menschen nach Schlaganfall" Einsicht in Ihre Krankenakten beim... nehmen. Diese Maßnahme wird von ärztlicher Seite unterstützt, was Herr Dr.Hetzel mit seiner Unterschrift bestätigt.

Ich versichere Ihnen, dass die in den Krankenakten enthaltenen Daten und Informationen von mir absolut vertraulich behandelt, nicht an Dritte weitergegeben und in schriftlichen Arbeiten und Veröffentlichungen anonymisiert werden. Es wird nicht möglich sein, dass Sie als Person identifizierbar sind.

Ich bitte Sie deshalb darum, dass Sie sich schriftlich damit einverstanden erklären, dass ich

- Einsicht in die gesamten Unterlagen nehmen darf, einschließlich pflegerischer, ärztlicher und diagnostischer Berichte
- die Unterlagen zum Zwecke der Auswertung fotokopieren darf.

Falls Sie sich damit einverstanden erklären können werde ich mit Ihrer Unterschrift die entsprechenden Unterlagen von der Pflegedienstleitung der neurologischen ... ausgehändigt bekommen, sie fotokopieren und zusammen mit den Unterlagen über unsere Gespräch aufbewahren und auswerten.

Ich wäre Ihnen sehr dankbar wenn Sie mir eines der Exemplare der beiliegenden Einverständniserklärung zurückschicken würden. Wenn Sie noch Fragen haben können Sie mich gerne anrufen unter 0761/292 7544.

Vielen Dank.

Mit freundlichen Grüßen

Ursula Immenschuh

Dr. Andreas Hetzel

Consent form (patients records)

Name und Adresse

.....
.....
.....
.....

Geburtsdatum:.....

Einverständniserklärung

Ich habe die Informationen gelesen.

Ich erkläre mich damit einverstanden, dass Frau Ursula Immenschuh zum Zwecke ihrer Forschung "Krankheitserleben von jüngeren Menschen nach Schlaganfall" meine Krankenakte, die von meinem Aufenthalt nach dem Schlaganfall im Jahr 2000 an der ... existiert, ausgehändigt bekommt. Dies gilt sowohl für pflegerische als auch ärztliche und diagnostische Berichte. Ich bin damit einverstanden, dass sie diese ausschließlich zur Verwendung für die Forschungsarbeit fotokopiert.

.....
Unterschrift

.....
Datum

Text of the radio broadcast

I wrote an account of my own experience of the stroke, weaving into it anonymised stories of participants. It was produced and broadcast by the public radio Südwestrundfunk 2 in April 2002. I used a pseudonym.

Life, interrupted

Young people after a stroke

By Ursina Rosenberger

Narrator/person with a stroke

When you're thirty years old, committed to your job, full of plans and brimming with energy the last thing you think of is having a stroke. All the more incredible, then, when it happens to you. I am sitting on the sofa one evening when I suddenly feel a funny swooshing, a roaring in my head. I want to say something to my husband but can't get a word out. I want to drink something, but can't swallow. Even my attempt to open a bottle of mineral water is unsuccessful. My husband is shocked to see my face is all „squint“. Panicking, I run into the bathroom in the hope cold water will help me. Something strange is happening to me. I'm not in pain, I don't feel sick. I'm just – stunned. As if something has come undone in my head.

Whenever I try to speak only unintelligible sounds come out. My husband looks at me, horrified. He asks me what's wrong and tries to understand from the outside what's going on inside me. Minutes pass before I manage with great effort to get my first words out. Am I mentally ill? My husband wants to go to the hospital. I refuse. Things that begin in such an unreal way must surely go away again soon. I end up just going to bed and think that when I wake up the next day everything'll be OK again. And the next day's Friday, I'm on duty over the weekend at the clinic, and I want to be there, definitely.

That night is pure hell. Not a wink of sleep. I pace up and down in the living room, feeling uneasy. I'm afraid. Can I still write? I pick up a pen and see that the letters I manage to write on a scrap of paper bear no resemblance to my usual handwriting. All I can do is start to write a word, but after a couple of letters everything just stops. My hand won't do what my brain wants it to. I start diagnosing myself. It must be something to do with my brain. As a trained nurse that's clear to me. My guess is a brain haemorrhage. It's the middle of the night – should I go to the hospital after all? Unable to decide I wait until the next morning. I still can't speak properly. My husband has to phone the clinic for me to say I can't come into work. All attempts to speak fail. Either I get stuck in the middle of a word, or else I say something that isn't at all what I wanted to say. Despite this I'm convinced I'll be able to work at the weekend. My husband and I get on our tandem and cycle to the doctor's – we don't have a car. Pedalling is no problem, although I can't feel my right side.

Radio journalist:

How can anyone – let alone someone with medical training - suffering such drastic symptoms so completely misunderstand a situation? This is not an isolated case.

Thomas, 35 years old. One morning it's almost impossible to wake him up. It takes a huge effort – and help from his wife – to get himself to the breakfast table. Once he sits down he keels over, slumps to one side and goes back to sleep. He is unable to pick up a piece of bread with his right hand. He doesn't feel worried. „My hand, my leg – they're just tired,“ he says. „Tomorrow when I have to go to work it'll all be OK again.“ His wife takes him to a doctor, against his will. It takes days before he can walk properly again, and is more awake. His memory of all this is incomplete.

Not only stroke victims fail to recognise what's happening. Brigitte, 51, was treated for four weeks by an orthopaedic specialist for back trouble. She suffered from a recurring feeling of numbness on her right hand side. These attacks lasted about ten minutes. She said she always felt as if that side didn't belong to her at all. But it's not until she's unable to speak properly that a friend drives her to the hospital.

Narrator

My GP suspects a brain haemorrhage and sends me straight away for a CT. The radiologist reveals the result of the examination to me. „You've had a stroke.“ He points to a dark area on the X-ray. Not a haemorrhage, then, but a blocked blood vessel. I've often heard about young people having brain haemorrhages, but I wasn't expecting this diagnosis. „And now?“ I ask. The radiologist advises me to go home and rest. There's nothing anyone can do just now, anyway. He says I should go to my GP the week after. I ask him to phone her. I feel unable to make any decisions. My GP sends me to the neurology clinic. I phone my mother and tell her what's happened. When I utter the word „stroke“ for the first time I burst into tears, but pull myself together immediately. This will be typical in the weeks to come.

Soon I'm able to move normally again, although writing's still difficult and I have to concentrate very hard when I'm speaking. Otherwise I don't have any physical problems. But I've lost my inner balance. On the outside I'm brave, make a big effort to appear unchanged, and by doing so protect my friends and family who visit me in the clinic. Anything else would scare them, and me, too much.

Being a nurse makes it extremely hard for me to swap sides and be a patient. Before, I was the one who looked after people, I gave advice when someone wasn't sure what to do next. Now I've lost my feeling for myself. There are no visible symptoms, but inside I'm struggling, caught between hope and despair. In hospital it's one check up after another. They're trying to find out what caused the stroke. When the doctor tells me during the ward round that my blood tests were inconclusive I'm relieved and disappointed at the same time. Relieved because there's no negative result, and disappointed because the reason for my stroke still hasn't been found. As a nurse I'm aware there is an increased danger of having another stroke within the first couple of weeks of the first one. The uncertainty is unbearable. I'd never realised before how exhausting uncertainty is. I feel weak, I withdraw a bit, I feel I'm standing next to the person I used to be. My husband and a good friend, who visit me every day, help me so I don't disappear completely. Every little gesture helps. My five year old nephew paints me a picture: on one side of the picture the sun is shining, on the other it's raining. A vertical line divides the picture into two halves, one sunny and one rainy. Just like me after the stroke.

Radio Journalist

Manfred suffered a stroke when he was 40. Since then he has been preoccupied with the question of what life is worth living for. He intends changing several things. Work, money and material things are not as important any more. He wants to pay more attention to his own needs.

Since her stroke, Stefanie, 25, has been paralysed down her right side. No medical reason for the stroke has been found. Stefanie herself is convinced that her stroke was caused by work, sleep deficiency, stress and too much responsibility. She definitely wants to change this when she gets home. But first she has learn to walk again properly. Stefanie says that she's actually quite optimistic. If she wasn't paralysed she'd feel full of beans.

Michael, 31, is forced to experience what it's like to be fully dependent on others. After his stroke he's paralysed down one side and unable to wash himself or go to the toilet unaided.

This embarrasses him. In the clinic there's a nurse (Stefanie) who gives him the feeling that this is something quite normal and that she enjoys helping him. The fact that Stefanie takes the time to help him encourages Michael. He's able to think positively again „Things are getting better – life goes on.“

Narrator

Three weeks since my stroke and I'm still in the clinic. I feel uneasy, I want to go home. The days seem endless. The exact cause of the stroke is still unknown. A blood clot might have developed due to a hole in the cardiac septum between the atria. The blood clot then ended up in my brain. The doctors recommend an operation to close the hole. But it's not urgent. My biggest problem is my right shoulder. Two weeks after my stroke I have terrible pains, day and night, which cannot be relieved by medication, by resting nor by moving and exercising. Up until now post stroke shoulder pain was just something I'd read about in medical text books. Now I realise how harmless it sounds. This pain wears me out. Sometimes in the middle of the night I'll have a bath or listen to music to take my mind off it. It's not until a specially-trained physiotherapist starts treating me that the pain gradually becomes bearable. Increasingly I have the feeling that I can't trust my own body. It's as if the sunny side is observing the rainy side and keeps getting surprised again and again by some new pain or uncertainty. Sometimes I feel really angry with that side of my body, the right side, which has distanced itself so much from me.

Radio Journalist:

The problems faced by young people after a stroke vary considerably. Reactivating the side of their body which is paralysed is the top priority for some. Others who have no outward symptoms must come to terms with invisible changes. Elizabeth, 48, is one of those stroke patients without any noticeable outward symptoms. She describes herself three months post stroke as half a person. One half functions normally, the other half could easily be put away into a corner, she says. She feels exhausted. After she cooks herself a meal she has to lie down and rest to recover before she can eat because the preparation costs her so much energy. Her condition is unpredictable. One day she feels fit, the next she's exhausted, for no apparent reason. She used to enjoy company and had a demanding job, but now she finds herself retreating more and more. What she likes best is to be alone. However she has retained her strong will and is still ambitious. She hasn't given up and hopes that at some point she'll be able to live like she used to before her stroke. Elizabeth suffers from an inferiority complex. Not being able to do as much as she could do before means – to her – not being worth so much. Being able to work again is to her like breathing.

Narrator

Home at last. The sun's really warm. I can feel it when I sit out on our balcony, which faces south. I savour those things you tend to take for granted: sleeping in your own bed, surrounded by your personal possessions. I have to go for blood tests several times a week; twice a week I go to physiotherapy and thermal baths. Before the stroke it was normal for me as a senior nurse in charge of things to plan and organise, to keep track of a lot of tasks still to be done. Now I feel it's too much if I have more than two appointments a day. I'm thin-skinned, sensitive – about noise too. I need a lot of time, I need peace and quiet. I need to be alone. At the same time I feel lonely. My husband gives me a lot of support, as do a few especially good friends. But now there are new places in my life. No one can follow me there, because I have no words to describe these places. I

can't share the experience. This frightens me. I have to integrate the experience of having had a stroke into my life. A difficult task, and one which is a long way from being fulfilled.

Radio Journalist:

A stroke is a turning point, a milestone in the life of the victim. After the stroke the victim's biography is distinctly divided into two parts: life before the stroke, life after the stroke. Not only the stroke victims feel insecure after a stroke, asking themselves just who they are. Their environment treats them differently too. Before her stroke Silvia, 40, played an active part in the community and was well known for her commitment and imaginative ideas. Whether it was baking a cake or organising a big festival in the village, she was always the one who was asked for advice and for help. After her stroke that all stopped. When she found out that the people in the village were saying she needed a rest and shouldn't be asked to do too much she was hurt. She felt she no longer belonged and that no one expected anything of her any more. That was the worst thing she experienced after she came out of hospital. She didn't only have to come to terms with having had a stroke, she also felt she had to prove she was a „whole“ person, still able to do all the things she could do before.

Elizabeth also describes how too much consideration makes her feel she's incapable in some way, handicapped. Her wish, quite simply, is for people to help her when she asks them to.

On the other hand it's just as bad when little or no consideration is shown. Herbert is scared of losing his job. After his stroke doctors advised him to do less strenuous work. However the personnel manager indicated there was little chance of that being possible. Herbert can't believe that the company he works for – which employs several hundred people – doesn't have a suitable job for him any more. He now feels „useless“, no good for anything. He's 38.

Narrator

I'm still signed off sick. My GP is really supportive. Not just because she signs me off to make sure I get a proper rest – she also takes time to talk to me. About my work, and what's going to happen there, or about how the stroke is affecting my marriage. She also writes the clinical assessment I need for my application for rehab treatment.

I'm scared about the future. Will I be able to cope with everything? How will I change? Will my relationship with my husband bear the strain of all this uncertainty? Will friendships survive? Having a stroke confronted me with limits. With the limits of my own strength. The limits of what can be achieved through effort. The limits of planning and organising. The stroke shook my life to the very foundations. What – if anything – is still valid? Who am I?

Radio Journalist:

Looking back, many people who suffer a stroke see it as something that was necessary. A necessary about turn in their lives. Brigitte, 51, is now aware of the fact that before the stroke she lived more for others and neglected her own needs. She wants to change that. She now only keeps in touch with people who also give her something, and don't just take. Work and the welfare of others are no longer her top priorities. She spends more time on her own now, and only goes out if she really feels like it. Even if there's a danger of ending up all alone one day. She knows she has to be economical with her strength.

Michael, 31, used to manage on only 4 hours' sleep because he had to work so much. He had his job, he was building a house and on top of that was completing vocational training. Now, after the stroke, the relationship with his partner is much more important. They want to start a family.

All these people have changed their priorities. Top priority now is health, followed by good relationships. Everything else - work, career, money - is no longer as important. At the same time they're afraid of getting back into a rut – of being unable to put their good intentions into practice. Most of them have to live with the fact that they might suffer another stroke. None of them ever thought they'd have a stroke. But experience has shown them that anyone can have a stroke. Out of the blue. Even young people.

Narrator

It's been eight years since I had my stroke. A year after that I had the heart operation. I needed a lot of time to get over the feeling of loss experienced in connection with the stroke. At the same time new perspectives, previously unthought of, opened up. Free of obligations I was able to accompany my husband to the USA for a year. During that time I made a good recovery and did lots of things I'd never had time for before: relaxing, travelling, cooking, meeting people, doing pottery..... I also got interested in health care in the US and came upon the idea of doing post graduate studies. I started to study at the Department of Nursing Studies, Edinburgh University.

In my future professional life I want to improve care and treatment for younger people who have suffered a stroke. This is also the subject of my PhD thesis.

My stroke has taught me, though, that my profession is only one part of my life. I'm sitting listening to an organ recital in the Freiburg Münster, a beautiful gothic cathedral. I see the last few rays of that day's sun light up the big round window. I'm fascinated by the intensity of colour in the stained glass. Isn't my life a little like this mosaic pattern? Dark and light fragments create a pattern of shapes and colours and make me think of my stroke. The stroke added a lot of new elements to my personal mosaic, rearranging the way it used to look, disturbing the pattern. This in turn gave rise to a need to be creative, but that need was also a chance.

There were times when I wrestled with the dark fragments added to the mosaic of my life by the stroke. I hadn't been planning on being confronted at 30 with such a drastic experience. I watch the window slowly getting darker. Outside the sun has set. I listen to the music, look inwards, study my own mosaic. It's not static like the round, stained glass window. It's moving, it's always in motion, like the pattern in a kaleidoscope.