

**THE ESSENCE OF STROKE REHABILITATION EXPERIENCE  
ACROSS TWO SETTINGS**

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## **Abstract**

The present research used van Manen's application of hermeneutic phenomenology as philosophy and method to explore stroke rehabilitation experience across two different settings, i.e. (i) a conventional setting (National Health Service or NHS stroke unit) and (ii) an unconventional setting (Conductive Education or CE). Interviews, observations and reflective diaries were used to collect data on 24 volunteering stroke patients' experiences. High levels of disempowerment and negative images of self as well as the nature of motivation were indicated to be thematic of stroke rehabilitation experience in the stroke unit. In the CE setting stroke rehabilitation experience was characterised by increased self-confidence, unconditional positive regard from conductors, challenging activities and body-half integration.

A juxtaposition of stroke rehabilitation experience in the CE setting with stroke rehabilitation experience in the NHS stroke unit brought to light an important difference between the physical body-split caused by stroke, and a much wider and deeper disintegration of being. The juxtaposition further indicated that (i) the approach used in the NHS stroke unit is biomedical in spite of the presence of a multi-disciplinary team, and (ii) that the one adopted by CE is a person-centred approach characterised by holistic principles, with an overall focus on mobility. A reflective evaluation of this hermeneutic phenomenological study ensues, including a discussion on the difference between person-centredness and holism. The better understanding gained regarding stroke rehabilitation experience across the two settings was then used to make recommendations regarding what could constitute a holistic approach to stroke rehabilitation.

Finally, the researcher's experience of 'being-immersed' in others' lived experiences was discussed in order to illustrate the holistic effect the research process had on the researcher's well-being, and the development of a tool which addresses researcher emotions holistically is also presented.

Key words: Stroke rehabilitation experience; Biomedicine; Holism; Positivism; Constructivism; Hermeneutic phenomenology; Person-centred approach; Researcher experience.

## **Preface**

This thesis is a description of the work carried out in the School of Applied Social Sciences, Liverpool John Moores University (United Kingdom) under the supervision of Prof. Jane Springett (Liverpool John Moores University) and Dr. Linda Gibson (Nottingham Trent University). Except where acknowledged the material presented is the original work of the author, and no part of it has been submitted at this or any other university.



*“The cure of many diseases is unknown to the physicians of Hellas<sup>\*</sup>*

*because they are ignorant of the whole.*

*For the part can never be well unless the whole is well.*

*This ... is the great error of our day in the treatment of the human body,*

*that physicians separate the soul from the body. ”*

- from “Charmides” by Plato (written 380 B.C.),

translated by B. Jowett (1892, p. 8)<sup>#</sup>

<sup>\*</sup>Greece was called Hellas in the time of Plato

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<sup>#</sup> Jowett, B. (1892). *The dialogues of Plato, translated into English with analyses and introductions*. Oxford University Press: London, U.K.

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I take this opportunity to thank my colleagues, friends and family whose great support made this study possible. First I would like to express my sincere gratitude to my principle supervisor Prof. Jane Springett, for her invaluable supervision, for offering constructive suggestions and advice, for her continuous encouragement and excitement as the project unfolded and her unshakable belief in my ability to complete this study. I am also very grateful for the help and advice from my second supervisor Dr. Linda Gibson, as well as from the following people who at one or other time in my PhD period filled a supervisory capacity: Dr. Jeff Lake, Dr. Christine Roffe and Dr. Ciara Kierans.

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## CHAPTER 1

### My personal journey through my research

#### 1.1 Introduction

“Holistic approaches to stroke rehabilitation” as the focus of my thesis, evolved from a personal experience that involved someone very close to me: my paternal grandmother. She died from the effects of a stroke in May 1998 at the age of 85, four months before my PhD journey started. It was not the first stroke she was to have. I remember about one year after her first stroke she and I played the word-game called *Scrabble* in which the players each has a limited number of alphabet letters with which to create words, with as many letters as possible. We both used to love *Scrabble* but that particular time it was different. I realised my grandmother was getting more agitated than normal when she was unable to form a long enough word. In fact, she was struggling to form words with three letters. At the time I did not understand what was going on. I now know it was the debilitating effects of her stroke that reduced some of her cognitive abilities. She also used to love letter writing and in her old age she acquired a few pen friends from around the world. After her first stroke she was suddenly not interested in writing letters anymore. I now wonder whether it was not more a case of being unable to write as well as she used to do before her stroke, than it was a case of disinterest. Here was a woman who used to love reading, writing and word games, reduced to someone who found it difficult to spell three letter words. I still get emotional when I think what it must have been like for her. What went through her head at the time? Did she think she was losing her mind? With the knowledge I now have of stroke and stroke rehabilitation I wonder whether she was given the explanation that it was one of the effects of a stroke and that she would have to learn to live with it? Or was there a health professional in her care team who tried to help her adjust

to her 'new self' post-stroke, to her changed way of being-in-the-world? A kind soul who looked at her as a whole person, and not as someone who had had a stroke and now had difficulties in some areas of her life? I will never really know how my grandmother experienced stroke and stroke rehabilitation. However my PhD journey and research gave me the opportunity to study other stroke patients' experiences of stroke rehabilitation.

In my thesis I argue that stroke patients' experiences of rehabilitation show conventional\* Western medicine to have moved its focus away from patients as being whole persons, to treating separate parts of patients in isolation from the other parts. In the process stroke rehabilitation has become focused on function and mobility, neglecting patients' non-physical needs. This is also supported by the literature on stroke rehabilitation as will be presented in chapter 2. In my argument I emphasise the need for a holistic approach which views stroke patients as whole persons with multiple levels of needs and not just patients with for example paralysed limbs. Indeed, many patients suffer from illness without showing any biomedical evidence of a disease (Reuber, et al., 2005; Carson, et al., 2000). Illness is described by Bowling (1997) as "the subjective experience of dysfunction" (p. 19), by Eisenberg (1977) as "experiences of disvalued changes in states of being and in social function" (p. 11), and by Kaufman (1988) as "the subjective response of an individual to feeling poorly" (p. 101). Wade (2006) describes illness as being an attribute of a person as a whole (a person feels ill) rather than an attribute of only a part of the person (i.e. that part which causes them to feel ill such as their brain or heart). Illness experienced by patients is often the result of a combination of factors and this should play an important role in how health professionals view and eventually treat patients (Wade, 2006). My research shows, for the first time, the important role that holistic principles are

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\* Synonyms for the term 'conventional' as I use it in my thesis are 'usual' and 'mainstream'

already playing in one setting of unconventional<sup>#</sup> stroke rehabilitation (i.e. Conductive Education), and I also provide recommendations for the development of a holistic approach to stroke rehabilitation. Uncertainties surrounding neurological recovery make it impossible to predict if and how much a patient will recover from the effects of a stroke (Becker & Kaufman, 1995). Explorative studies of stroke and stroke rehabilitation therefore can also provide information on how patients cope with such an uncertain illness trajectory. My thesis provides information on how stroke patients cope in the conventional setting of a stroke unit and, for the first time, in the unconventional setting of Conductive Education.

Influential to my main argument has also been my spiritual belief that every living being consists of not only their physical, visible parts but they are also one with their non-physical, invisible parts such as their emotions and soul/spirit. I further believe each person also exists in unison with their surroundings and the Greater Universe regardless of their awareness of this unison. Indeed, this belief in the wholeness of the Universe and in the existence of a connection between all living things, visible and invisible, has been part of a universal consciousness for centuries (Pennick, 1979). My spiritual belief is akin to a holistic view, which I believe helped me in understanding the value that a holistic approach to rehabilitation can bring to stroke patients.

The philosophy and methodology of my thesis is hermeneutic phenomenology which, as I explain later in this chapter and in chapter 3, is widely used to study lived experience. Qualitative research, including hermeneutic phenomenology, accepts that the researcher has an inevitable effect on the research and visa versa (Guba & Lincoln, 2005; Pyett, 2003; Finlay, 2002). Presentation of the researcher's own journey can therefore add to a better understanding of their assumptions and also the research itself. The aim of this chapter

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<sup>#</sup> The term 'unconventional' as I use it in my this thesis refers to that which can serve as complementary to, or as an alternative for, that which is conventional

therefore is to set the scene of how my research focus developed, what key concepts influenced its development as well as to provide information on my own personal journey.

The key concepts that influenced my research are underlined below:

- Stroke rehabilitation experience in two different settings (a conventional stroke unit and an unconventional setting namely Conductive Education)
- Biomedicine and holism as different kinds of knowledge and how they relate to stroke rehabilitation
- Positivism and constructivism as different research paradigms
- Hermeneutic phenomenology as philosophical framework as well as method

My thesis consists of a total of six chapters. Chapter 2 gives background information on the nature of stroke and conventional rehabilitation. It also provides a literature review on qualitative research in the field of conventional as well as unconventional approaches to stroke rehabilitation. The philosophical framework chosen for my thesis, namely hermeneutic phenomenology, and the way it informs the research method, is discussed in Chapter 3. Chapters 4 and 5 present patients' experiences of conventional stroke unit care as well as those of stroke survivors who attended services at an unconventional therapy centre (i.e. Conductive Education). The different approaches to stroke rehabilitation in the two distinct settings as well as recommendations for the development of a holistic approach to stroke rehabilitation and the lessons I learned concerning holistic approaches to myself as researcher, are discussed in chapter 6, the final chapter, of my thesis.

My grandmother's death made me determined to find out more about stroke patients' experiences of rehabilitation. The way in which I was to study this, however, changed a few times during the eight years in which I conducted my PhD research on a part-time basis. The only part of my focus that remained the same from beginning to end was that I would do the research in the form of two separate studies, with the first study exploring

stroke patients' lived experiences of conventional rehabilitation. It was the nature of the second study that changed quite drastically and I discuss this in more detail later in this chapter.

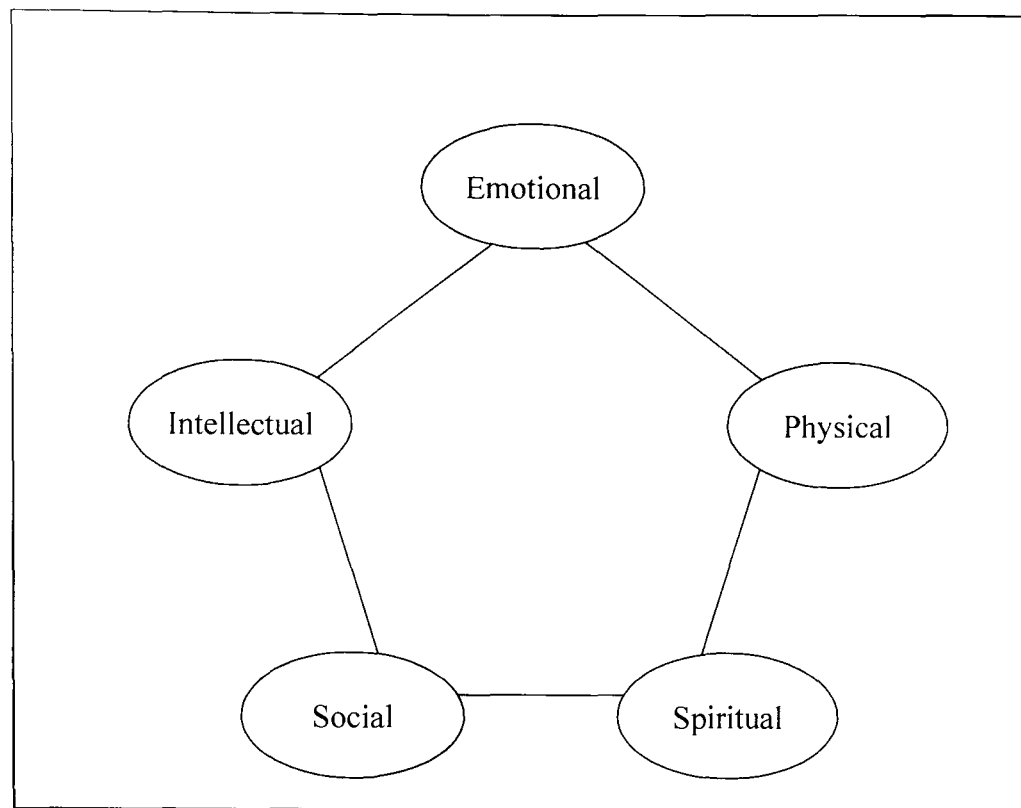
## **1.2 My research focus**

Different kinds of knowledge and views on the world guided me through the development of the focus of my research. This section discusses the kinds of knowledge and views that played an important role in this development.

### **1.2.1 Different kinds of knowledge: holistic and dualist**

There is evidence to suggest that some social groups living in the years BC believed that the earth and heavens were in harmony with each other and they tried to keep their own lives in harmony with the world around them (Pennick, 1979). They believed in a connection between themselves and their surroundings and also in a connection between their physical body and non-physical spirit. They saw connections between the cycles of the seasons and the stars, as well as between nature and their own human cycles of life and death. In the same way that there exists a uniting structure *between* humans and their environment, it was also believed that there is a uniting structure *within* humans (Dossey & Guzzetta, 2005). This uniting structure is referred to as a holistic structure. An example of a view of health informed by holistic knowledge is evident in a definition of optimal health as suggested by O'Donnell (O'Donnell, 1989) (Figure 1). This definition describes optimum health as a state of being where there exists a balance between an individual's multiple levels of being which include physical, emotional, social, intellectual and spiritual levels.





**Figure 1:** The multi-dimensional nature of a complete state of well-being (adapted from O'Donnell (1989))

On closer inspection of Figure 1 it becomes evident that a disturbance in one level of a person's well-being would cause an imbalance in the whole of a person, akin to a chain reaction. A holistic view of health states that a patient's physical, social, emotional, intellectual and spiritual aspects are interconnected, forming an integrated whole (Dossey & Guzzetta, 2005), therefore all the aspects are possible contributing factors to a patient's symptoms.

Conventional approaches to stroke rehabilitation offer patients care provided by multi-disciplinary teams (MDT's) (Stroke, 2006; Dennis & Langhorne, 1994). MDT's seem to be based on holistic principles since they consist of health professionals representing a range of different modalities in stroke care, each intended to receive an equal degree of importance within the team and working together for the well-being of patients. Despite praiseworthy physical care for patients, stroke rehabilitation services have however, as was

alluded to above, been greatly criticised for its overemphasis on physical care and lack in emotional/psychological care of patients (McNaughton, et al., 2005; Kirkevold, 2002; Bendz, 2000; Burton, 2000; Pound & Ebrahim, 2000; Dowswell, et al., 1997; Waters, 1996; Gibbon, 1993; Forster & Young, 1992). This lack in holistic approaches to rehabilitation, despite the presence of MDT's, is further illustrated by the way in which conventional medicine divides services such as mental health from those looking after patients' physical care (Wade, 2006). On closer inspection it seems this focus on the physical is to a great extent informed by the kind of knowledge practised in conventional medicine also called biomedicine (MacDonald, 1998; Bakx, 1991). The kind of knowledge that informs biomedicine stems from the teachings of the 17<sup>th</sup> century French philosopher and mathematician René Descartes (1596-1650). Up to the 16<sup>th</sup> century AD healers generally approached health from a holistic point of view (Thieme, 1993; Sheikh & Schaffer, 1979), combining it with Hippocratic principles that do relate strongly to biomedicine (Millenson, 1995). Descartes however rejected the holistic point of view and gave preference to the worldview known as dualism. This view regards the body and mind as two separate objects (Vacariu, 2005). The teachings of Descartes led to these 'objects' being treated as separate from each other. This kind of knowledge encourages a dualist way of thinking, separating patients' bodies from their mind/spirit. Indeed, biomedicine practice deconstructs a whole into its separate parts and focuses on the parts in isolation (Wade, 2006). Biomedicine has indeed brought (and still continues to bring today) remarkable advancement in many different areas of health (Frank, 2004), but it seems to have selected to focus on the parts of patients that are visible, for example the state of their organs and limbs (Dossey & Guzzetta, 2005; Hwu, et al., 2001; MacDonald, 1998; Bowling, 1997). This has contributed to the marginalisation of patients' non-physical parts, for example their emotional and social needs.

Biomedicine prides itself in using methods that have been ‘proven’ experimentally as being effective (Holmes, et al., 2006). The ways in which these experiments are conducted have however been accused of straight jacketing all health sciences, and for rejecting any health science that does not fit the exact criteria required by the biomedical experiments (Holmes, et al., 2006; Bakx, 1991). This seems to have strengthened the dominant, conventional health care system’s exclusion of “alternative forms of knowledge” (Holmes, et al., 2006, p. 180), for example non-linear knowledge that allow for multiple ways of knowing such as holism. Holistic forms of knowledge such as Chinese acupuncture\* take into consideration the relationship between different sections of a person’s life as well as between the different parts of their mind-body-soul connection (Galantino, et al., 2003; Vickers & Zollman, 1999; Magnusson, et al., 1994; Johansson, et al., 1993; Bakx, 1991).

Interestingly, when one looks at the World Health Organisation’s (WHO) definition of health it clearly reflects a holistic view, in that it addresses multiple aspects of being as part of a complete unit (Dossey & Guzzetta, 2005). The definition is as follows: health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WHO Constitution, p. 2). As mentioned above, a holistic view of a person is one which takes into consideration the whole of that person. Such a view therefore embraces the multiple dimensions of an individual’s being. The word ‘health’ originated from the Anglo-Saxon word for ‘whole’ (Hwu, et al., 2001). This therefore suggests that the conventional Western medical model has adopted a limited interpretation of the meaning of health for over 400 years since it does not approach patients in a holistic way. WHO has retained its holistic definition of health since its conception in 1948. Yet, as I argue in my thesis, biomedicine’s quest for scientific advancement seems to have

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\* I add the adjective ‘Chinese’ to differentiate it from acupuncture practised by Western biomedical practitioners. Many of the latter have discarded the original Chinese principles on which acupuncture was originally based and work purely on the physical connections between the stimulation points and organs, thus divorcing acupuncture from its original knowledge base (Vickers & Zollman, 1999).

increasingly moved its focus away from the original WHO definition of health, towards a non-holistic view of health. This seems to be the consequence of dualism, the kind of knowledge practised in biomedicine.

In the world of research there also exists different kinds of knowledge that influence the research questions and research methods. The following section addresses two main worldviews and their different kinds of knowledge.

### **1.2.2 Different views on the world**

In research people ask questions such as “What is the world? How can we come to know it?” (Lincoln & Guba, 1985, p. 14). Different research methods exist to answer these kinds of questions and these methods are all informed by specific kinds of knowledge or views of the world (Lincoln & Guba, 1985). A worldview in research is also referred to as a paradigm and consists of a set of beliefs about the world as well as methods with which to study the world. Of the many different paradigms in research today there are five main paradigms, namely positivism, post-positivism, critical theory, constructivism and participatory (Guba & Lincoln, 2005). Positivism and constructivism are the two paradigms that, when compared with each other, seem to me to give characteristics similar to those when dualism and holism are compared. It was also positivism and constructivism that influenced the development of my research focus the most. The aim of this section is to explain the similarities between positivism and dualism, and between constructivism and holism. I also explain how the two mentioned research paradigms influenced the development of my research focus.

### 1.2.2.1 Positivism and dualism

There exists several different definitions of positivism (also often referred to as quantitative research), with the following accepted as being its basic assumptions (Lincoln & Guba, 1985):

- Its ontological basis states that the world is separate from the viewer (Denzin & Lincoln, 2000; Schwandt, 2000) thus the world is “out there” (Lincoln & Guba, 1985, p. 28). Reality, according to positivism, can be taken apart into pieces after which each piece can be studied in isolation from the rest; “the whole is simply the sum of the parts” (Lincoln & Guba, 1985, p. 28).
- Its epistemological basis asserts that the observer stands separate from the observed and in fact controls the observed. Thus the researcher is believed to have no effect or influence on the subject of research and claims to be value-free and objective.
- A positivist worldview considers data to be generalisable to other settings similar to those in which the data was first obtained. Positivist questions thus aim at using large sample sizes to reach statistically significant results that can be generalised to the rest of the sample population (Brown & Lloyd, 2001).
- Positivism regards events as always taking place in a linear fashion.

These positivist assumptions are similar to those of dualist knowledge. Indeed, Polkinghorne (1989, p. 23) writes “the idea that the objective realm is independent of the knower’s subjective experiences of it can be found in Descartes’ dual substance theory, with its distinction between the objective and subjective realms.” Dualist views in biomedicine focus on individual parts of patients, in isolation from the whole of a patient (Wade, 2006). The separation between observer and the observed in positivism is similar to the separation between dualist biomedical health professionals’ views of patients and patients’ own views (McKain, et al., 2005; Bendz, 2003; Bendz, 2000). Biomedical health

professionals have been criticised for this separation, for not working more in partnership with patients and for not including patients in the decision-making process about their health. As mentioned before, many patients suffer from illness without showing any biomedical evidence of a disease (Reuber, et al., 2005; Carson, et al., 2000). Dualist biomedicine however follows the belief that all symptoms are in a linear connection with its cause (Holmes, et al., 2006; Davies, 2005), again illustrating similarities with positivism.

#### **1.2.2.2 Constructivism and holism**

The knowledge that informs constructivism and which also characterises the group of paradigms referred to as qualitative research, is on most points the exact opposite of positivism (Lincoln and Guba, 1985):

- The ontological stance of constructivism states that the observer is *in* the world (Denzin & Lincoln, 2005; Schwandt, 2000). Reality is seen as being subjective and being constructed by different observers in different ways, leading to a reality consisting of multiple levels and multiple possibilities of interpretation.
- Its epistemological basis asserts that the researcher and the researched are partners interacting with one another (Öhman, 2005). The researcher and participants co-create the research process and no single person or group has a controlling position over the others. Any effect the researcher has on the research and participants (and visa versa) is seen as part of the process. Here the term ‘reflexivity’ plays an important role (Guba & Lincoln, 2005; Brown & Lloyd, 2001). The researcher reflects continuously on their position in the research, which includes their personal biases that existed at the start of a study as well as the effect they have during the research.

- Constructivism, as most qualitative paradigms, asks questions that reach deep into human experience (Brown & Lloyd, 2001). Consequently sample sizes are small to allow for deep rather than wide exploration. Results can therefore not be generalised in the way it is done within a positivist paradigm but instead are believed to bring better understanding to human experience (Pyett, 2003). This illustrates an important difference between the objectives of positivist and constructivist questions.
- Constructivism views events as being multi-layered. Linear processes only are therefore not possible.

The whole, according to constructivism, is bigger than the sum of the parts. This is akin to a holistic view of reality, with reality seen as consisting of multiple levels. In terms of health, a constructivist/holistic view regards patients as being persons with multiple levels of needs, not only for example physical level needs. The interaction between researchers and participants also links in with a holistic view of health that there exists an interactive connection between all the different parts of a person as well as between the person and their environment (for example O'Donnell, 1989). A change in one part will inevitably cause a change in all the other parts of the whole. Using constructivism to study holistic approaches to health is in effect using holism to study holism. The following section discusses in more detail how my second study grew into its use of holism to study holism.

### **1.2.3 Developing my second study**

As mentioned before, my thesis consists of two studies with the first exploring conventional stroke rehabilitation experience. This section narrates the development of study two, with some references to Study One.

I originally come from a positivist background. My MSc studies in Music Psychology were based on quantitative methods with only a short module on qualitative methods.

During my MSc research however I became disillusioned with the way in which positivism objectified people's experiences and gave numeric values to subjective experience. Still, for the first two years of my PhD both positivism and constructivism were included in my methodology. I guess keeping positivism as part of my study kept me in a comfort zone.

During the infancy of Study One I explored different qualitative methods to use in my exploration of stroke patients' experiences of conventional rehabilitation. At the time, I attended a conference on qualitative methods in health research and met the researcher Dr. Frances Rapport (at the time she was Dr. Frances Maggs-Rapport). She was doing a hermeneutic phenomenological study on the experience of egg sharing. I was fascinated by her conference presentation and the inductive way in which hermeneutic phenomenology approaches lived experience. She suggested I read Max van Manen's book on hermeneutic phenomenology entitled 'Researching Lived Experience' (van Manen, 1990). I did, and gradually got more immersed in hermeneutic phenomenology. One could say I was converted to hermeneutic phenomenology. Epistemological and ontological similarities between the philosophy of phenomenology and qualitative research led to a strong influence of phenomenology visible in many qualitative methods (Mackey, 2005). Phenomenology involves the description of a phenomenon as it is in its natural context, akin to qualitative and holistic principles in general. Where phenomenology purely provides description of lived experience, hermeneutic phenomenology, as based on Martin Heidegger's (1889-1976) views, focuses on the interpretation of experience in order to move closer to *Verstehen* (the German word for 'understand' and often used in its German form in phenomenological writings) (Wilson & Hutchinson, 1991). van Manen (1990) states the aim of hermeneutics as being "to understand how people experience the world pre-reflectively, without taxonomizing, classifying or abstracting it" (p. 9). This also alludes to hermeneutics' constructivist nature (Guba & Lincoln, 2005) in that it allows for



study participants to each share their own view of reality without having a prescribed view of reality according to a researcher. Heidegger believed that *Verstehen* could only be reached through the quest for *Verstehen* (Wilson & Hutchinson, 1991). This suggests we can only understand experience through the seeking of understanding, which necessitates interpretation. Hermeneutic phenomenological interpretation is always informed by the natural context of a phenomenon such as its lived time and lived space (Mackey, 2005; van Manen, 1990). It constantly balances the parts with the whole which, again, is akin to holistic principles. Due to the fact that hermeneutic phenomenology is well suited to the descriptive and interpretive study of lived experience and that it is underpinned by holistic principles, I selected it as the philosophy and method for Study One as well as for, what I then thought, the constructivist part of Study Two. (See Chapter 3 for an in-depth discussion of hermeneutic phenomenology and its suitability for my thesis).

The original objective of my second study was to assess stroke patients' experiences of rehabilitation that included mental imagery exercises of their physical rehabilitation exercises, as a means to increase their participation in their own rehabilitation. I had been interested in mental imagery and the power of 'mind over matter' since childhood. Mental imagery exercises had been reported to be effective when supplementing physical performance of athletes (Heil, 1993). The research I conducted for my MSc in Music Psychology, in which I studied the effects of relaxing music, included exploration of people's images while listening to music. This also contributed to the idea for my second study. At the start of my PhD I received ethical approval to provide stroke patients in rehabilitation with audiocassettes containing recordings of a physiotherapist's voice, describing their exercises to them. The second study was to include positivist techniques with a before and after comparison study, followed by a qualitative (constructivist) exploration of how patients had experienced rehabilitation which included mental imagery.

Through continuous reflection I realised my heart was not in the positivist part of Study Two as I gradually became more interested in what patients' own images of their health would be and how they would change over time. I believed such information direct from patients was needed to inform any future mental imagery exercises provided to patients.

In order to align my study purely with qualitative principles I decided to change my second study into one using only hermeneutic phenomenology. I re-applied for ethical approval and received it to explore stroke patients' own images of their health while in rehabilitation. I intended to look at how the images changed, or remained the same, over the period of few weeks. .

My second study was well on its way when I gave an oral presentation of my research at a conference on qualitative methods in stroke research. This was four years into my PhD. The conference was to mark a significant change in the course of my PhD, initiated by one of the attending professors at the conference accusing me of brain washing patients when exploring their mental images. I defended my research during question time but despite the support I had from the rest of the conference audience as well as my research supervisors and mental imagery author Helen Graham, the professor threatened to "pull the plug" (her own words) on my PhD if I did not stop this kind of exploration. This professional and personal shock forced me to reflect on whether I wanted to continue my PhD research at all. I realised that since my MSc I had lost touch with music, which as a musician had been a lifeline for me. After deep soul searching I decided to continue my PhD but also do a diploma in the complementary therapy called Sound Therapy. It was then that I was informed that the professor now had a better understanding of my work and that I could continue my exploration of patients' mental images. Two months went by without me finding a stroke patient who met the study criteria. My spiritual belief includes the notion that if you knock on one door and it does not open after a while then it is a sign

to knock on another door. But I did not know which door to knock on. I decided to reflect again on my findings from Study One in the hope that it would guide me to this illusive door. The following is the result of my reflection. It started with a quote I came across which describes the embodied nature of illness very well:

“What happens when my body breaks down happens not just to that body

but also to my life, which is lived in that body.

When the body breaks down, so does the life.”

– Arthur Frank (Frank, 2002, p. 8)

My Study One and the literature show that a stroke is a sudden on-set illness which causes a bewildering disruption to a person’s life, as well as the lives of those around them, with often devastating consequences (Lai, et al., 2006; Faircloth, et al., 2005; Olofsson, et al., 2005; Anderson & Marlett, 2004; McKevitt, et al., 2004; Hilton, 2002; Widén Holmqvist & von Koch, 2001; Bendz, 2000; Burton, 2000; Dowswell, et al., 2000; Ellis-Hill, et al., 2000; Close & Proctor, 1999; Cox, et al., 1998; Hafsteindóttir & Grypdonck, 1997; Becker & Kaufman, 1995; Lewinter & Mikkelsen, 1995; Doolittle, 1994; Doolittle, 1991; Becker, 1993; Kaufman, 1988a, b, c). It breaks down personal abilities and throws lives into chaos. Frank’s quote above was written in the context of a cancer sufferer’s experiences of cancer. The quote can however be applied to any life-changing illness including stroke since a stroke cannot only break down a person’s body, it also breaks down the life lived inside that body. This illustrates the holistic effect of stroke and also the embodied nature of stroke. Being-in-the-world as independently mobile beings is only really appreciated when that same independence is taken away. In the *‘Absent Body’*, Miller (1982) points out that the body stays absent in our everyday lives until a part of it becomes ill and draws our attention to it, becomes present, through pain. However it is through its painless (i.e. without physical pain) absence that independence becomes salient

to stroke victims; independence becomes their holy grail as they are deprived from it by a stroke. The body becomes eclipsed. as a part of it becomes silent, affecting the whole of a person. It is therefore the whole of a stroke patient that needs rehabilitation, as I also argue in my thesis. I began to wonder what else was there for patients? When conventional medicine says ‘there is nothing more we can do for you’ (Hoffmann, 1974) what else is there for patients? I started to think about alternatives for conventional stroke rehabilitation, i.e. alternatives with a more holistic approach to their care. These thoughts were supported by what happened next.

At the time when I realised I had to get in touch with music again I also joined a classical symphony orchestra in which I played percussion. At the second rehearsal I attended, the orchestra leader looked for musicians to join a photo shoot with disabled children who attended school at the National Institute of Conductive Education (NICE\*). Since percussion instruments such as cymbals can look quite impressive on a photo, they asked me and two other musicians to go. During the photo shoot a representative of NICE told us more about their work. This included the fact that they worked with adults who had suffered strokes! After the photo shoot the representative helped me to arrange a meeting with the therapists working with stroke patients. That meeting together with what I subsequently read on Conductive Education (CE) for stroke lead to my second study changing to one exploring patients’ experiences of CE for stroke. I received ethical approval for this change, which was to be the last change to the focus of my research. A main contribution of my second study on CE for stroke has been the uncovering of patients’ experiences of CE’s person-centred care. This approach gave me the missing piece of the puzzle that links my two studies together: Study One supports previous research on stroke patients’ experiences of conventional rehabilitation lacking in holistic

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\* **Please note:** the abbreviation NICE referring to the National Institute of Conductive Education is not the same as the abbreviation NICE referring to England’s National Institute of Clinical Excellence

approaches to care, and Study Two illustrates patients' (or as CE participants are called: learners) experiences of CE for stroke providing care with holistic principles and making learners aware of their own whole bodies.

#### **1.2.3.1 Summary of the development of my research focus**

The following is a summary of the aim and objectives of the two studies that finally formed my thesis: The aim of my research was to explore the role of holistic approaches in two distinct settings of stroke rehabilitation, one being a conventional setting and the other an unconventional setting. The first objective was to explore the phenomenon of stroke rehabilitation experience in these two settings. The second objective was to discuss similarities and differences between the two settings and the third objective was to examine what the two settings could learn from each other in terms of holistic approaches to stroke rehabilitation.

I treated each setting as a single case study. A case in qualitative research can be defined as a “phenomenon of some sort occurring in a bounded context. The case is, in effect, your unit of analysis. Studies may be of just one case or of several ...” (Miles & Huberman, 1994, p. 25). In my research the first case study (Study One) explored conventional stroke rehabilitation experience in the setting of an NHS\* stroke unit at three months post-stroke. The shorter-term impact of stroke has been less researched than the longer-term impact (McKevitt, et al., 2004).

In my second case study (Study Two) I explored stroke patients' experiences in the unconventional rehabilitation setting of CE. The way in which my second study came about was explained above. My Study Two also contributes to research in that there was (and still is) a great need for more qualitative research in the field of CE for stroke.

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\* The UK's National Health Service which offers free medical care to patients

The main research question of my thesis was: Are holistic approaches evident in each of these two case studies?

- If so, how *do* they play a role?
- If not, how *can* they play a role?

Each case study also had its own main research question:

Study one:

- How do stroke patients experience conventional rehabilitation in an NHS stroke unit?

Study two:

- How do stroke patients experience unconventional rehabilitation such as CE?

These questions lead me in my exploration and also brought me to personal challenges which I explain in the next section.

### **1.3 The challenge of researching and writing about lived experience**

Morse (2002) states that there exists a contradiction in being qualitative researchers: they have to be “tough on the outside and sensitive in the inside” (p. 1019). This meant that while I was exposed to stroke patients’ often heart wrenching stories (both during interviews and analyses) I had to be tough enough to be able to listen to their stories, yet sensitive enough to these stories in order to convey the essence of their suffering to my readers. It was only after extended periods of unexplained physical and emotional suffering myself that I realised there was a link between my own suffering and the emotionally upsetting data I had been exposed to. I found a great lack in the literature in terms of advice for researchers on protecting themselves against such situations. In chapter six of my thesis I discuss the challenging effect the research had on me as researcher and as a person and share the holistic tool I developed which helped me, and which I believe could help other researchers, in dealing better with emotionally challenging research.

Apart from the emotional effect the research had on me, I also found the actual writing of my thesis challenging. In order to write about lived stroke rehabilitation experience I had to immerse myself in patients' narratives, almost as though I became one with the phenomenon I studied. This is also known as the phenomenological attitude (Spinelli, 1995). However, writing about for example general facts on stroke and rehabilitation, I felt it more appropriate to distance myself from the subject in order to achieve a more academic/positivist style of writing. Indeed, this is also the research world I originally come from. The challenge of 'voice', i.e. sharing one's research findings with others through writing and/or oral presentations, is also recognised by other researchers (Guba & Lincoln, 2005). For example Hertz (1997) argues that voice in itself is multi-dimensional since there is the voice of the author/researcher, as well as that of the research participants represented by the data. For decades, social scientists stayed with the positivist/academic way of expressing their voices (Guba & Lincoln, 2005), which distanced them from their texts. I believe that if such a way of giving voice has been imprinted first, it can make it more challenging for researchers to position themselves within their own research, as happened to me.

Reinharz (1997) writes that researchers bring multiple-selves to the research process that can be divided into three groups: research-self, brought-self and situationally-created-self. I support this idea of multiple-selves as I have come across them in own my writing styles. In my view it was my research-self that used a so-called academic voice and wrote in the style most often found in academic journals. One could describe this as a positivist style, where this self was detached from what I wrote about. My brought-self was the self with biases and assumptions as I had had before my research started. This self continued to influence and shape my views. My situationally-created-self was the self which I had

become during, and because of, my research. It is also the self that learned lessons and I believe became stronger through the research process.

In effect the writing of my thesis was a dance between different writing styles, different selves. This dance is evident as follows: chapters two and three are written in a more academic/positivist way. In the former I provide background information (facts) on stroke and stroke rehabilitation as well as a review on existing literature in the field of my research. In chapter three I discuss my methodology. I therefore felt it appropriate in these two chapters to distance myself from that which I wrote about. However, chapters four and five are hermeneutic phenomenological interpretation and writing on stroke rehabilitation experience in the two different settings. Writing about this data I found myself inside the data, giving voice to my study participants. My writing in these two chapters reflects this insider position and could be described as phenomenological writing (van Manen, 1990). The final chapter (Chapter 6) contains elements of both writing styles: I discussed the academic research relevance of my study, i.e. how holistic principles of care are evident in the one setting and not in the other, in a more positivist way, and then in the section on my own feelings and experiences I positioned myself again inside that which I wrote about.

I believe my writing in a positivist/academic way was aided by input from my research-self combined with my brought-self. Whereas the more phenomenological style of writing, i.e. being one with that which I wrote about, was due to a combination of all three the selves. All three together helped me to understand the phenomenon I wrote about. They also helped me to give something of myself through that which I wrote.

#### **1.4 Summary**

In this chapter I provided information on my own journey and how it lead to the development of my research focus. The key concepts were outlined and parallels were



drawn between the worldviews and research paradigms that played an important role in my thesis. I introduced the case for the suitability of constructivism and in particular hermeneutic phenomenology to study lived experience of stroke rehabilitation. The contribution my thesis makes to current knowledge is that, through a hermeneutic phenomenological exploration, it provides a better understanding of the role holistic principles play, and can play, in both conventional and unconventional stroke rehabilitation settings. It also provides recommendations for the development of a holistic approach to stroke rehabilitation. And it:

(i) describes and interprets lived experience of stroke rehabilitation in a conventional NHS stroke unit and for the first time also in a CE setting

And

(ii) presents the development of a tool which researchers studying sensitive topics, such as patients' experiences of illness, can use to look after themselves in a holistic way

Chapter 2 now follows with background information on stroke as well as current practice in conventional and unconventional stroke rehabilitation.

## **CHAPTER 2**

### **The nature of stroke rehabilitation today**

#### **2.1 Introduction**

Exploring stroke rehabilitation and holistic approaches to this kind of care first requires an understanding of what stroke and stroke rehabilitation are. Such an understanding not only provides background information on these key research concepts but also provides possible reasons for why stroke patients would turn to unconventional rehabilitation. This chapter aims to provide such background understanding. In the first part of the chapter I describe the prevalence of stroke in the United Kingdom (UK) as well as the nature of stroke. This is followed by a description of conventional UK stroke rehabilitation. The latter is available for free to all residents in the UK registered with the National Health Service (NHS) and is therefore the most common way in which UK stroke rehabilitation is practised. The second part is a review of qualitative research literature on the experience of stroke rehabilitation both in conventional and unconventional settings. Due to the qualitative nature of this thesis, the literature review focuses on qualitative research studies.

#### **2.2 Stroke**

##### **2.2.1 Prevalence of stroke**

Stroke is one of the primary causes of death and disability in the world today (Stroke Association, 2006a). Annually, over 150,000 people have a stroke in the UK alone, which is one person every three minutes. Men are at greater risk of having a stroke than women, with the largest percentage of people being over the age of 55, however the number of younger people being affected is on the increase (Stroke Association, 2006a). Ethnic

groups that show a higher prevalence of stroke than other groups are those from African, African-Caribbean and Asian communities, mainly due to these groups having higher numbers of people with conditions that often trigger a stroke, such as diabetes and high blood pressure. In the UK, £7billion of the annual NHS budget is spent on stroke services (NAO\*, 2005) It is predicted that by 2010 the costs of these services will have risen a further 30% since 1991. The NAO (2006) recently found that the NHS does not allow stroke the same level of attention as other serious conditions. This finding together with the predicted rise in financial costs, suggests there exists a great demand for more research in the field of stroke, and consequently also stroke rehabilitation, in order to find out more about the condition itself as well as patients' and carers' experiences thereof. My thesis aims to contribute to research that is working towards filling the gap related to patients' experiences and what holistic approaches can bring to stroke rehabilitation.

### **2.2.2 The nature of stroke**

A stroke is caused by a disturbance of the blood flow to a part of the brain (DoH<sup>#</sup>, 2006). The disturbance can be due to either haemorrhage in the brain or infarction, which leads to loss of function of the affected part of the brain. This could result in varying degrees of disability or even death (Freemantle, et al., 1992). The most common symptoms of a stroke can include sudden loss of movement on one side of the body, weakness on one side of the face and difficulties speaking. The sudden halt of normal function in the brain brings about a sudden halt in a person's life, after which that life cannot ever be the same again. The difficulties many patients experience with regards to the multiple life changes brought on by this halt, are also highlighted by my thesis.

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\* The UK's National Audit Office

# The UK's Department of Health

Physical disability after a stroke is concentrated in either the left or the right side of the body, depending on which side of the brain was damaged by the stroke (Anderson, 1992). Damage to one side of the brain will have a negative impact on the contra-lateral side of the body. Physical disability ranges from severe paralysis on one side of the body to a slight loss of control over a left or right hand side limb. It can also include (Anderson, 1992):

- weakness in the muscles on one side of the face;
- problems related to vision particularly to the extreme side of the visual field on one side of the body;
- difficulty with speaking as well as understanding others' speech;
- problems encountered when swallowing;
- urine incontinence.

The physical consequences of a stroke therefore include a wide range of immense difficulties, which could possibly have an impact on all the different levels of a person's being and on how they experience the world.

Psychological responses to stroke can either be due to brain damage or could be caused by feelings of powerlessness due to physical disability (Anderson, 1992). Examples of such responses include anger, depression, mood swings, changes in personality, anxiety and reduced initiative. The latter is one of the effects that was clearly visible in my grandmother's case. A 76 year old woman's daughter describes the effects of a stroke on her mother: "I discovered that she had no idea how to wash, dress, use the toilet, or speak coherently. My clever, capable mother had become like a baby ... The partial paralysis on her right side was nothing compared with the dramatic change of lifestyle for us both" (Hollinghurst, 1998, p. 28). The changes brought on by a stroke happen without warning. All of a sudden a person has to cope with a changed body and unfamiliar psychological

and emotional characteristics, impacting on their world and how they experience their world. The effects of a stroke are all-embracing and are not just about physical disability.

### **2.3 Conventional stroke rehabilitation in the UK today**

Conventional stroke rehabilitation involves helping patients to optimally recover the abilities they lost following the event of a stroke (McLellan, 1997). The degrees of disability often vary from one patient to another and many patients do recover to a great extent. For those who do not recover well, extra care has to be taken in preparing them for their new lives without certain abilities.

At present, the effects of a stroke cannot be alleviated by drug treatment alone. Rehabilitation programmes have therefore been developed (Langhorne & Duncan, 2001). The dictionary defines the verb 'to rehabilitate' as "to restore to a former capacity ... to restore or bring to a condition of health" (Webster's ninth collegiate dictionary, 1991, p. 993). While the term 'rehabilitation' suggests a return to a prior state (i.e. prior to illness), it also implies only an approximation of a return as illustrated by the following definitions:

- through the process of rehabilitation disability is reduced or in some cases eliminated (WHO, 1995)
- rehabilitation aims to help patients recover as much as possible and adjust to any remaining disabilities (Westcott, 2001; Proot, et al., 2000)
- "Rehabilitation is an educational, problem-solving process that focuses on activity limitations and aims to optimize patient social participation and well-being, and so reduce stress on carer/family." (Wade, 2005, p. 814)

The co-operation between patients and health professionals within rehabilitation is emphasised in the following definition: rehabilitation involves communication between patients and health professionals to determine realistic goals and the activities needed for

patients to work toward achieving those goals (Bendz, 2000). This definition emphasises communication between patients and health professionals through which patients' rehabilitation is planned. Such communication therefore would seem to hold the holistic principle of partnership (Dossey & Guzzetta, 2005).

Distilled from the above, for the purpose of this thesis, conventional stroke rehabilitation is defined as the process through which stroke patients re-learn, as much as is possible for each individual patient, the skills and movements that have been lost due to a stroke, and through which they adjust to their post-stroke life on both physical and non-physical (such as emotional, psychological and social) levels. This process is facilitated by appropriate health professionals who work in co-operation with the patients. However it could be argued that non-physical rehabilitation often stays a theoretical one and does not always transpire to practice.

### **2.3.1 The organisation of conventional stroke rehabilitation in the UK**

#### **2.3.1.1 The rehabilitation setting**

In the UK, stroke patients receive conventional rehabilitation in one of the following settings:

- as in-patients on a hospital ward or in a stroke unit which is usually set on hospital premises (Moser & Ward, 2000) but could also be a mobile facility with health professionals attending to patients in a variety of settings (Langhorne, et al., 2005)
- or as out-patients receiving rehabilitation at home or making visits to a day hospital (Dennis & Langhorne, 1994)

Independent from the setting, stroke rehabilitation is provided by several health professionals often referred to as a multi-disciplinary team, which includes consultant doctors, nurses, physiotherapists, occupational therapists, speech- and language therapists.

psychologists, dieticians and social workers (Stroke Association, 2006b; Dennis & Langhorne, 1994). In this way, appropriate care for a stroke's diverse effects can be provided. The elements thus would appear to be in place for the holistic care of patients. This raises the question as to why patients' experiences of conventional stroke rehabilitation do not always reflect these elements.

A stroke unit differs from wards such as general medical wards and neurology wards, in that it offers stroke patients with specialised in-patient stroke care (Langhorne & Pollock, 2002). Already as early as 1974 there were calls for specialised stroke care as opposed to caring for stroke patients on general medical wards (Hoffmann, 1974). Modern-day research has indeed found stroke unit care to have significantly better effects on patients than a ward specialising in general neurology (Krespi, et al., 2003). It has also been suggested that staff on a general medical ward, as well as in a conventional day hospital, do not follow the same degree of teamwork as that of the staff in a stroke unit (SUTC\*, 1997). This shows yet more differences between working practices in stroke units and wards that do not specialise in stroke care.

Differences also exist amongst stroke units (Dennis and Langhorne, 1994). For instance, patients in stroke units can either be distributed around different wards in a hospital, or the unit can have a purposely-designated area in a hospital. In the former case, nursing care time is divided between stroke and non-stroke patients, in a way similar to that on a general medical ward, whereas in the latter case (i.e. a centralised stroke unit), nursing care is centred around stroke patients and their needs, 24 hours a day. A centralised stroke unit therefore holds more advantages for patients (Dennis & Langhorne, 1994). Indeed, the UK National Service Framework (NSF) for Older People (DoH, 2001a) suggests that a stroke unit's multi-disciplinary team should be located in a separate ward.

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\* Stroke Unit Trialists' Collaboration

appointed for stroke patients. My study on patients' experiences of conventional stroke rehabilitation was conducted in such a stroke unit in England.

Another setting of stroke care is that of mobile stroke units, offering care to patients in a variety of settings where a permanent stroke unit is absent. However, Langhorne et al. (Langhorne, et al., 2005) reviewed research on mobile stroke units and found no significant difference between effects on patients treated by mobile stroke unit teams and patients on general medical wards. This supports previous research showing the benefits of a stroke unit being housed in a separate, permanent hospital ward (Dennis & Langhorne, 1994).

Stroke units, in comparison to care in general medical wards, lower the risk of dying after a stroke, reduces institutionalisation, and increase the number of stroke survivors who can live independently (NAO, 2005; Stone, 2002; DoH, 2001; Rønning & Guldvog, 1998; Dennis & Langhorne, 1994; Langhorne, et al., 1993). The positive effect of stroke units on survival after stroke is still applicable up to 18 months post-stroke (Rønning & Guldvog, 1998). This shows that the care provided by stroke units can benefit patients in both the short-term and the longer-term.

Several possible explanations as to why stroke unit outcomes are better than those of wards that do not specialise in stroke are provided by Krespi et al. (2003) and Pound et al. (1999). According to the latter:

- Patients benefiting from stroke unit services spend less time lying down in bed and mobilise more than those on general medical wards
- Visiting hours in a stroke unit are not as restricted as on general medical wards, allowing patients to have more contact with family and friends, and also allowing more involvement of carers in patients' rehabilitation
- Drowsy and speech impaired patients in a stroke unit are more encouraged to interact with others than similar patients on general medical wards



According to Krespi et al. (2003) physiotherapy treatment offered on stroke units is more accentuated than even on a neurology ward and also, stroke unit patients are better monitored and treated for possible stroke related medical complications than on a neurology ward. The more intense monitoring and treatment of medical complications were also found by Rønning and Guldvog (1998) to contribute to stroke units' higher survival rate of patients when compared to those of general medical wards. In general research indicates that it is a combination of several aspects of a stroke unit, rather than one aspect alone, that leads to its apparent success (Lorenzano, et al., 2006; Pound, et al., 1999; Rønning & Guldvog, 1998). The success referred to here was based on patients' medical/functional outcomes and whether they survived their strokes, not on their experiences of what survival was like. Indeed, Pound and Ebrahim (2000) found no evidence of stroke unit care that could be termed holistic. They suggest "it might be that the better physical outcomes on stroke units are being achieved at the expense of patients' emotional well-being and that patients on stroke units have better out-comes *despite* rather than *because* of the nursing they receive there" (p. 1445; Pound and Ebrahim's own italics).

In 2001, the UK government set the target for all hospitals to have a stroke unit by April 2004 (DoH, 2001a). For a hospital ward to be called a stroke unit, it has to comply to a minimum of four of the five following criteria (ISWP\*, 2004):

- it must have a consultant stroke physician
- it has to have established links between patient organisations as well as carer organisations
- the staff in a stroke unit must hold weekly multidisciplinary meetings during which patient care is planned, with inputs from all staff members present

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\* Intercollegiate Stroke Working Party

- further information on stroke has to be available to patients
- staff must be provided with continuing education programmes

By April 2004, 82% of hospitals in England, 85% in Northern Ireland and only 45% in Wales reported to have stroke units. However, only 91% of those units in England and 64% in Northern Ireland complied with at least four of the five criteria presented above, whereas 100% of the units in Wales were fully compliant (ISWP, 2004).

It is surprising that, in spite of the evidence of the benefits stroke units hold for patients, only just over half of stroke in-patients were estimated to have spent time on a stroke unit by April 2004 (ISWP, 2004). This may be attributed to an insufficient number of beds in stroke units for the large number of annual stroke victims (NAO, 2005).

Two thirds of hospitals in England, Wales and Northern Ireland manage the numbers of their stroke unit patients through selection criteria, perhaps due to insufficient resources (ISWP, 2004). However, the use of selection criteria by stroke units has been criticised in the past (Stone, 1999). Indeed, apart from the benefit of receiving manageable numbers of patients, selection criteria also allow units to focus on admitting only so-called ‘middle-band’ patients. These are patients whose disabilities after stroke are not classed as severe and consequently have a better prognosis than patients classed as severely affected by stroke. Selection criteria could therefore influence any subsequent assessments of the success of stroke units.

### **2.3.1.2 Conventional stroke rehabilitation programmes and related issues**

A programme of stroke rehabilitation, either in a stroke unit or on a general medical ward, is set up on the basis of essentially two factors (Fraser, et al., 1999) : (i) the possible presence and nature of any co-morbid conditions, and (ii) how the effects of stroke affect a patient’s daily functional routine.

Specific aims of a programme are (Roth, et al., 2001; Fraser, et al., 1999; Wade, 1999; Reddy & Reddy, 1997; Kalra, et al., 1995):

- to help patients regain lost abilities and quality of life as much as possible
- to provide patients and their families with education on how to prevent another stroke
- to encourage and assist patients with taking up activities within their families, work and community again
- to prevent complications due to stroke (such as urinary tract infection, depression, venous thrombo-embolism, pneumonia, aspiration and musculoskeletal pain).

It is generally accepted that these aims can be achieved by incorporating a combination of several therapies (Table 1).

Most patient recovery takes place within the first few months post-stroke. It is also commonly acknowledged that the sooner the rehabilitation process begins, the more likely patients are to achieve optimal recovery (Diez-Tejedor & Fuentes, 2004; Mayo, et al., 1999). In contrast, delay in the start of rehabilitation can cause patients to acquire incorrect physiological functioning, with possible negative consequences to rehabilitation outcomes (Paolucci, et al., 2000; Laidler, 1994). Surprisingly, the UK's National Sentinel Stroke Audit 2004 report that many ambulance services do not regard stroke as a medical emergency, which can often contribute to delays in the start of rehabilitation for many patients (ISWP, 2004).

The more intense the rehabilitation a stroke patient receives, the more likely he/she is to improve (Jette, et al., 2004; Liepert, et al., 2000; Fraser, et al., 1999). This can be explained by the fact that retraining of the body helps to reorganise neural circuits in the brain, improving abilities that were lost due to the stroke. The level of retraining and recovery does however depend on the severity of the stroke (Greenwood, 2001), but it has

become apparent that early, intensive rehabilitation can have better outcomes for stroke patients (Diez-Tejedor & Fuentes, 2004; Mayo, et al., 1999).

**Table 1:** List of therapies generally included in stroke rehabilitation programmes (adapted from Fraser, et al., 1999)

Therapy provided	Patient problems
- Speech and language therapy	- Communication or swallowing difficulties
- Nutritional advice	- The need for modification of food texture / general nutritional information
- Physiotherapy	- Mobility problems & help needed to re-gain some or all independence at home
- Occupational therapy	- Help needed to cope with daily activity problems and going back to home and work
- Clinical psychology	- Cognitive problems and / or affected mood
- Specialist medical treatment	- Other problems for example bladder or bowel related

The duration of the rehabilitation process depends on several factors, such as the degree of physical disability, whether the patients suffer from anxiety (which may be caused by insecurity about their own situation, or the situation of family members, etc.) or pain (for example inflammation, traumatised joints, pressure sores) fatigue, co-morbidity, as well as patients' level of satisfaction with life in general and support from family and friends (Chung, et al., 2006; Gillen, et al., 2001; Kelly-Hayes & Paige, 1995; Laidler, 1994).

### **2.3.1.3 Measuring rehabilitation progress**

Several methods are used to monitor patients' progress. However, they tend to only measure physical elements of recovery (White & Johnstone, 2000; Lewinter & Mikkelsen, 1995). Examples of such methods are the Rivermead Motor Assessment (RMA), the Fugl-Meyer measurement of physical performance and the Barthel Index (Duncan & Badke, 1987; Adams, et al., 1997a, b). The RMA measures stroke patients' motor performance. It consists of three sections and each section is composed of a series of movements that the stroke patient is asked to perform. Examples of movements include sitting with feet unsupported for 10 seconds, climbing stairs, sitting to stand with hips at 90° and body weight through both feet, and reaching forwards and picking up a large ball with both hands (Adams, et al., 1997a, b). The Fugl-Meyer method of assessment tests the combined range of pain, movement, sensation, balance and motor function (Duncan & Badke, 1987). It looks at upper and lower body extremities in five different stages of physical movement. Finally, the Barthel Index examines stroke patients' functional status, i.e. their ability to perform activities of daily living (ADL). This tool has the advantage of being easily communicated between colleagues (Patel, et al., 1998). Compared to other ADL assessment scores, the Barthel Index is particularly advantageous because it is sensitive to

change, it can be easily manipulated statistically and it is familiar to and well implemented in clinical settings (Duncan & Badke, 1987). According to Duncan and Badke (1987), measures of stroke patients' sensory motor recovery must be objective and quantifiable (such as the three measures discussed above) so that motor problems can be identified and function recovery as well as the effectiveness of treatment can be assessed. This view is supported by the UK's *National Sentinel Stroke Audit 2004* which states that "using standardised measurement of impairments and disability after stroke helps maintain common standards and consistency of treatment." (ISWP, 2004, p.19). Such a statement however runs the risk of over-emphasising the need for measurement, and therefore also provision, of physical rehabilitation at the expense of non-physical rehabilitation (for example care of patients' emotional, social and psychological needs, experiences, and recovery). It has been suggested that the term *physical* cannot be used as an adjective for rehabilitation since rehabilitation is a problem-solving process (Wade, 2006). According to Wade (Wade, 2006) such a process cannot be described by a term from the group of adjectives in which *physical* falls. However, as the next section indicates, over-emphasis of physical elements of rehabilitation seems to create more challenges than solutions in rehabilitation, making the problem of *physical* rehabilitation very real in spite of views such as those of Wade (2006).

#### **2.3.1.4 An over-emphasis on physical elements of stroke rehabilitation**

As discussed earlier, a typical conventional stroke rehabilitation programme provides patients with physiotherapy, occupational therapy, speech- and language therapy etc. However, there is increasing evidence that these modalities are guilty of an over-emphasis on working towards and measuring physical elements of stroke (McNaughton, et al., 2005; Burton, 2000; Dowswell, et al., 1997; Waters, 1996; Gibbon, 1993; Forster & Young,

1992). Indeed, this is a common occurrence in health professionals' and society in general's, approach to people with disability including stroke patients with post-stroke disabilities (Hughes & Paterson, 1997).

The Barthel Index fulfils its role in assessing a stroke patient's ability to perform certain activities according to the Index's own requirements. However, if the Index identified a patient as being able to walk on a certain type of flooring, it does not imply that the same patient will be able to walk on a different flooring they may have at home, suggesting that patients' personal needs are not taken into account (Wade & de Jong, 2000). In the past, the little attention given to such individual needs has been found to lead to an increase in the number of patients who experience difficulties regarding their emotional, social and psychological needs (Burton, 2000; Hochsteinbach, 2000; Gibbon, 1993; Waters, 1996; Morse & Johnson, 1991). Stroke patients often suffer from a range of negative emotional and psychological conditions following a stroke, such as for example depression, anxiety and agoraphobia (Berg, et al., 2003; Harinath, et al., 1995; Ramasubbu & Kennedy, 1994; Forster & Young, 1992). Depression and anxiety have been reported to have negative effects on long-term quality of life including patients' social lives and their recovery of functional ability (Berg, et al., 2003; Åström, 1996). Services addressing the aforementioned non-physical conditions (for example care of patients' emotional, social and psychological needs, experiences, and recovery) in stroke rehabilitation have been found to be scarce (ISWP, 2004). In addition, only 25% of patients are thought to receive advice on setting up goals in relation to their quality of life, illustrating a great lack of information available to patients about their illness and possible ways forward. This is in spite of evidence of the effective role such information can play in rehabilitation (Wade & de Jong, 2000). It is also in spite of the definition of stroke emphasising cooperation

between patients and health professionals in setting up patient goals (Bendz, 2000), mentioned earlier in this chapter.

The difference in levels of attention given to patients' physical and non-physical needs seems to be determined by the framework on which a rehabilitation service provider's programmes are based. The most widely used framework is the International Classification of Impairment, Disability and Handicap (ICIDH), the first version of which was developed by the World Health Organisation in 1980 (Burton, 2000). This version addresses four concepts: disease, impairment, disability and handicap, which are viewed as being causative rather than interdependent. It illustrates a biomedical rather than holistic view of health which in fact is the opposite of WHO's definition of health as I discussed in Chapter 1 of my thesis. In the case of the ICIDH its biomedical view contributes to a linear diagnosis-treatment philosophy of rehabilitation and discards the role of factors such as environmental and behavioural factors. This shows that the ICIDH framework focuses on disease and does not cater for illness experience. A rehabilitation programme based on this framework therefore would give most attention to physical recovery and treatment of physical symptoms and much less (if any) attention to the underlying role of patients' non-physical needs. It is encouraging that in the late nineties the ICIDH framework was updated to the ICIDH-2 (WHO, 1999) to take into account the paramount role played by the environment and society in a patient's adjustment to life after a stroke. ICIDH-2 rehabilitation programmes therefore incorporate these elements together with physical recovery and treatment, indicative of a more holistic approach to rehabilitation. However, neither patients' lived experience of illness nor their quality of life was implemented in this updated framework (Wade & de Jong, 2000). The role of these concepts is paramount in patients' healing trajectories (Frank, 2002) and should therefore be included in



rehabilitation frameworks. If they were included it could create a framework with a strong holistic approach to rehabilitation, as I will discuss in Chapter 6.

As I mentioned in Chapter 1, qualitative research offers a range of methods that are appropriate for the study of multi-levelled lived experience. The remainder of this Chapter 2 is a literature review of qualitative research on lived stroke rehabilitation experience in different settings and at different time periods post-stroke.

### **2.3.2 Lived experience of conventional stroke rehabilitation**

The nature of patients' lived experience of illness is essential to their healing trajectories (Frank, 2002) since such experience provides information on multiple levels of being. Qualitative research lends itself very well to research on lived experience such as the experience of stroke rehabilitation (Öhman, 2005; McKevitt, et al., 2004; Gerhardt, 1990). One of the reasons for this is the ability of qualitative research to capture the depth of human phenomena such as patients' beliefs and attitudes that play such an important role in rehabilitation (Öhman, 2005). Qualitative research is conducted in a natural setting rather than in an unnatural experimental setting (McKevitt, et al., 2004). This enables researchers to explore their topic of study in the setting in which study participants are experiencing the phenomenon such as on a hospital ward or their own home. It enables researchers to explore previously unfamiliar areas in an inductive manner, i.e. researchers are led by the research (for example by participants' narratives on their experiences) rather than researchers leading the research with pre-formed theories, assumptions and hypotheses (Öhman, 2005; Agar, 2004; Morse & Johnson, 1991; Gerhardt, 1990). An inductive manner of research allows for research participants to initiate ideas rather than for the research to follow only *a priori* focus points.

A review of studies that used qualitative research methods to explore different elements of the experience of stroke and conventional stroke rehabilitation, follows below in sections 2.3.2.1 to 2.3.2.3. The review illustrates the usefulness of qualitative research in exploring these concepts (McKevitt, et al., 2004). In particular it demonstrates its ability to highlight the needs of stroke patients and how views on these needs often differ between health professionals, patients and their informal carers. A wide range of different qualitative methods were used in the studies reviewed, for example constant comparison method (Maclean, et al., 2002; Maclean, et al., 2000; Pound, et al., 1998), grounded theory (Folden, 1994); qualitative content analysis (Hart, 1998; Becker & Kaufman, 1995), phenomenology (Kvigne & Kirkevold, 2003; Burton, 2000; Doolittle, 1991) and hermeneutic phenomenology (Hilton, 2002; Kirkevold, 2002). The latter is the methodology used in this thesis.

The long-term illness trajectory of stroke can be divided into different phases (Kirkevold, 2002; Becker & Kaufman, 1995). Three phases determined in a qualitative study by Becker and Kaufman (1995) suggest the trajectory's first phase to be characterised by "Life disruption and the unknowable future" (p. 173). This is followed by the second phase of "Rehabilitation and the illusion of certainty" (p. 175). The final phase according to these authors can be entitled "Post-rehabilitation frustration" (178). These three phases are similar to the four suggested by Kirkevold (2002) namely (i) the on-set of stroke, starting off the trajectory and involving surprise and suspense, (ii) the first rehabilitation phase as in-patient characterised by hard physical work on the part of the patient, (iii) the second rehabilitation phase which commences when the patient is discharged from hospital, characterised by "psychosocial and practical adjustment" (p. 894) and finally (iv) the phase of semi-stability where most patients are believed to have found some way of continuing their lives post-stroke. As suggested by Becker and

Kaufman (1995) and Kirkevold (2002) the literature review below is also divided into phases. The first two correspond with those of both Becker and Kaufman (1995) and Kirkevold (2002): (i) Stroke rehabilitation experience from the moment of on-set of stroke and (ii) Stroke rehabilitation experience as in-patient in a chronic setting. Since both Kirkevold's (2002) last two phases look at life after discharge they are here merged into one integrated phase similar to Becker and Kaufman's (1995) final phase: (iii) Stroke rehabilitation experience after discharge from the chronic setting.

### **2.3.2.1 Stroke rehabilitation experience from the moment of on-set of stroke**

The on-set of a stroke is very seldom preceded by extended physical warning signals and most patients experience symptoms of stroke while they are going about their daily activities (Kirkevold, 2002; Pound, et al., 1998). It has been shown that lay people in fact find it difficult to recognise the on-set of stroke due to its widely varying symptoms (Yoon & Byles, 2002). The unexpectedness of a stroke brings about shock that lingers on in most patients, causing them to only vaguely remember the first few days post-stroke (Kirkevold, 2002). This could explain why most qualitative studies to date have been conducted after the acute phase, i.e. the seven to ten days immediately post-stroke (McKevitt, et al., 2004). An example of a retrospective qualitative study is one by Faircloth et al. (2005) which asked patients what the actual on-set of stroke was like. Words patients used to describe the symptoms of stroke were "numbness," "discomfort," "listlessness," "poor initiative," and "nervousness" (Faircloth et al., 2005, p. 936), suggesting feelings of loss of control that contributed to the shock of the event.

In this acute phase, the stroke patient plays a passive role and receives medical care to stabilise his/her physical body (Kirkevold, 2002; Bendz, 2000). Very little participation in rehabilitative activities takes place in the acute setting. Patients interviewed a few months

post-stroke on their experiences of the on-set of stroke recalled their experience of it, as well as of the rest of the acute phase, with little emotion (Kirkevold, 2002). This is in contrast to clear feelings of sadness portrayed during narratives describing their experiences at later stages post-stroke.

In the acute phase, full or partial hemi-paralysis normally takes hold over a matter of hours or days, contributing to feelings of fear, not knowing when, how and if the progressive paralysis is going to stop (Doolittle, 1991). The inability of medical treatment to offer stroke patients with a ‘quick-fix’, can cause disillusionment for many patients (Becker & Kaufman, 1995; Doolittle, 1991). They can be guaranteed neither full recovery, nor a specific time by which they would be able to go about their daily tasks in an independent manner again. While in the acute phase, patients already build up many feelings of uncertainties about their future. These feelings, including feelings of unreality (for example thoughts such as ‘this is not happening to me’), can lead to patients experiencing psychological and emotional crises (Backe, et al., 1996). Indeed, qualitative studies by Faircloth (2004), Bendz (2000) and Doolittle (1991) found a clear split between patients’ minds and their bodies. Patients objectified their bodies and talked about their paralysed limbs as ‘it’. They also talked about having to ask their body parts to move, reinforcing the absence of a sense of wholeness between the body and the mind (Doolittle, 1991). Bury (1982) refers to the sudden on-set of illness as a ‘biographical disruption’, illustrating the break between a stroke patient’s life as he/she knew it and their new life post-stroke, throwing their taken-for-granted assumptions about life into relief.

The split between mind and body mentioned above is also reflected in the way health professionals were found to see patients (Bendz, 2000). This illustrates the presence of the biomedical model in which mind and body are seen and treated as two separate entities. As becomes clear in the sections below, the separate treatment of mind and body as well as

focus on the physical body, are what patients experience to be the main features of rehabilitation. However, despite their own dualist views of themselves illustrated above, they are still coveting for rehabilitation to include emotional and psychological support as well (for example Bendz, 2000).

#### **2.3.2.2 Stroke rehabilitation experience as in-patient in a chronic setting**

The start of patients' time spent in a chronic setting such as a general medical ward or a chronic care stroke unit, is characterised by intensive rehabilitative activities that include physiotherapy and occupational therapy (Stroke Association, 2006b). This phase has been found to last on average between five weeks and three months (Kirkevold, 2002). It is in the chronic setting that patients start to realise the slow pace of recovery ahead of them, and have to learn how to cope with feelings of uncertainty about their future.

Hemi-paralysis is commonplace in stroke and is thus for health professionals a normal consequence of stroke (Burton, 2000). For patients, however, it is unfamiliar and frightening and adds to feelings of loss of control over several areas of their lives. Even though a stroke causes paralysis on only one side of the physical body, patients have been found to experience this immobilisation to arch over themselves as human beings, encompassing themselves totally and giving rise to feelings of immobilisation of self (Doolittle, 1991). A stroke necessitates patients to think differently about their bodies. Instead of acting pre-reflectively, for example where they used to simply turn a door knob to open a door and not spend time thinking about doing it, they now have to reflect on every action (Burton, 2000). This is because automatic movement had been brought to a halt (Doolittle, 1991). Spontaneous behaviour had thus become virtually impossible. Sudden loss of mobility and loss of awareness of their body as a whole, present patients with fear and uncertainty.

One of the main findings on patients' experiences of stroke and rehabilitation is that recovery from the effects of a stroke concerns much more than a patient's functional independence (Bendz, 2000; Doolittle, 1994). It affects and involves a person's whole being (Nilsson, et al., 1997). However, a study which compared patient narratives of their experiences of stroke rehabilitation, with the medical notes kept on patients' progress by their health professionals (Bendz, 2000), found that notes omitted any reference to a social context, and focused on physical functioning and impairments. Very few social and emotional issues mentioned by patients in research interviews had actually been recorded in their medical notes. This illustrates health professionals' main focus to be the functional and physical rehabilitation of patients (Ironsides, et al., 2003; Kirkevold, 2002; Bendz, 2000) and not the provision of formal emotional/psychological assistance. It is, according to Bendz (2000), evidence of the biomedical viewpoint. Ironsides et al. (Ironsides, et al., 2003) support the findings of Bendz (2000) in reporting that stroke patient narratives illustrate how professionals' opinions, even though they are well-intended, gloss over patients' non-physical needs, emphasising the gap that seems to exist between patients' and health professionals' views.

Murray and Harrison (2004) recommend post-stroke counselling to help patients cope with their adjustment and to encourage them to hold a positive regard for themselves. Support for patients' non-physical needs could help them feel more in control of their lives despite their disabilities (DoH, 2001b). The feeling of being in control, the feeling of having power is what reaches deep into individuals' being, and plays an important role in how they perceive themselves and their bodies and how they go about in their daily lives (Foucault, 1980). The absence of feelings of control can lead to a person feeling like an outsider to the events around them, staying passive (Baumeister, 1997). It follows that increased feelings of empowerment are likely to have wide-ranging positive effects on

stroke patients, including their performance in rehabilitation in a chronic setting (Bendz, 2000).

A study by Folden (1994) found that the goals patients set themselves while in the chronic setting are not necessarily the same as those set by their health care professionals. When professionals envisaged lower levels of recovery than what patients themselves believed would be the case, patients refused to accept professionals' predictions. Looking at this from a medical point of view one could argue patients were in denial and/or did not want to comply with the medical predictions. Looking at it from a non-medical point of view it could indicate patients kept on hoping for more improvement. Indeed, hope was found by Folden (1994) to be paramount in determining patients' motivation for taking part in rehabilitation activities and moving toward their goals.

Patients' motivation for rehabilitation plays a very important role in the outcome of their rehabilitation (Öhman, 2005; Kaufman & Becker, 1986). Maclean et al. (2000) and Maclean et al. (2002) explored patients' beliefs and thoughts around their own motivation. The studies illustrate that patients who had been classified by professionals as having low motivation, did not appear to understand what their rehabilitation was about. The patients' explanation for their uncertainties was a lack of information provided by the hospital staff, a shortcoming that was also identified by the UK's *National Sentinel Stroke Audit 2004* (ISWP, 2004) as well as by McKevitt et al (2004). In addition to uncertainties amongst patients in a chronic setting, Maclean et al. (2002) found that some professionals themselves had not been clear on how to determine the degree of motivation of patients. Some classed patients as being motivated when they merely exhibited an extrovert personality. This lead to some patients with an introvert personality unfairly classed as unmotivated for rehabilitation. There seems therefore to be a discrepancy between how health professionals rank patients' levels of motivation and how patients' motivation is

actually influenced. Folden (1994) found it was hope and belief in reaching their own goals that determined patients' levels of motivation.

Many patients, at some point during their time spent in the chronic setting, experience a plateau period where they do not show the same amount of improvement in their abilities as before (Page, et al., 2004; Doolittle, 1991). Doolittle (1991) reports that patients are not helped to prepare on mental and emotional levels for such periods, showing a need for health professionals to include in their information to patients the possibility of such periods and how they could manage them. The need for patients to be well informed about the length and prospects of their period in therapy during chronic rehabilitation as well as after discharge from the chronic setting is also illustrated by Wiles et al. (2002). These authors suggest that therapists ought to look into ways to improve communication between themselves and patients and ways to help patients play a more active role in their own rehabilitation. The close relationship that often develops between patients and physiotherapists, however, was found to contribute to a reluctance in therapists to share with patients news they could perceive as negative (Wiles, et al., 2004), such as the end of their treatment approaching. Wiles et al. (2004) also found that therapists had difficulties in sharing with a patient their own thoughts about the unlikelihood of the patient making further progress. Consequently, patients may have unrealistic expectations of how much they could expect to benefit from regular physiotherapy. Wiles et al. (2004) and Wiles et al. (2002) suggest that therapists should use improved communication strategies to explain realistic prospects to patients. Wiles (2002) adds that they should also guard against harming patients' will to actively participate in rehabilitation. However, this could prove to be challenging due to the biomedical framework in which stroke rehabilitation and stroke narratives are embedded (Faircloth, et al., 2004). This framework does not accommodate communication that overarches the mind and the body to include both physical and non-



physical elements simultaneously. Interestingly, Pound and Ebrahim (2000) did find evidence of communication between health professionals and patients that could be described as non-biomedical in an elderly care unit. However there was no such evidence in the stroke unit which they also studied.

An example of poor communication between therapists and patients which illustrates a biomedical influence, is reported in Wressle et al. (1999). During their research in a geriatric clinic it was observed that stroke patients were excluded from the setting of goals for their own rehabilitation. This demonstrates a division between patients' feelings and experiences and the views of therapists. Pollock (1993) argues that professionals' disregard of patients' views can lead to patients feeling that they are not in control over certain areas of their own health. These incidents in the chronic setting could determine how patients will cope once they have been discharged. Faircloth et al. (2004) suggests professionals could embed their information regarding patients' possible futures in religious or spiritual narrative instead of uncertain physical terms, however some patients could find this patronising.

Patients view recovery as a return to the way they were before the on-set of stroke, however health professionals were found to measure recovery in terms of physical progress or lack thereof (Dowswell, et al., 2000; Hart, 1998; Becker & Kaufman, 1995; Doolittle, 1994; Folden, 1994; Doolittle, 1991).

Folden (1994) recommends health professionals ought to have a clear understanding of what patients define as recovery in order to understand the ways in which patients take part, or do not take part, in rehabilitation activities. A qualitative study by Gubrium et al. (2003) looked at *how* patients measured their progress and not only *what* they defined as progress or recovery. The participants in the latter study were found to measure their own recovery and progress daily, against a set of personal benchmarks such as age, co-

morbidity, social status and self-definitions, more so than against professional benchmarks. This supports research showing the need for professionals to take into account patients' lived experiences of stroke rehabilitation if they were to increase their own understanding of patient needs and behaviours (Wottrich, et al., 2004). In cases of distinct differences between patients' and professionals' views patient feelings of confusion could increase while still in the chronic setting but also once they are discharged from hospital.

#### **2.3.2.3 Stroke rehabilitation experience after discharge from chronic setting**

Discharge from in-patient rehabilitation has been found to hold two different kinds of experiences for patients: it is a moment in time in which they can experience regained self-esteem and increased responsibilities (Olofsson, et al., 2005) and at the same time it is a moment filled with daunting prospects due to the unknown elements of their new future (Bendz, 2000; Doolittle, 1991).

Patients are normally discharged to either their old home or a new home adjusted according to their post-stroke needs, or a nursing home. Regardless of post-discharge location, many stroke patients feel left out by the health care system once they have been discharged due to a lack of sufficient community stroke services (Shannon, 2004; Sabari, et al., 2000). Indeed, the NAO (2006) recently reported that support services for stroke patients are poorly coordinated and that this can lead to many patients feeling abandoned by the very system which was put there to support them. Bendz (2000) reported that on discharge from the chronic setting stroke patients felt ill-equipped to deal with life on their own (i.e. without the constant presence of health professionals in a hospital setting). Both patients and carers have been reported to find the information provided to them post-discharge to have been insufficient (McKevitt, et al., 2004), corresponding to similar experiences while still in the chronic setting. Also, differences between patients' and health

professionals' views still existed after discharge in a study on patients' experiences in the community (Hart, 1998).

Eventual withdrawal of regular health care services post-discharge, is experienced by many patients to be abrupt and without warning (Doolittle, 1991). Physiotherapy is seen by patients as *the* therapy to help them recover after stroke (Wiles, et al., 2004; Pound, et al., 1994). Discontinuation of physiotherapy before patients reached the level of recovery they had set as goal for themselves, can therefore cause patients great disappointment and distress (Folden, 1994). Improved communication as discussed in the previous section, could help patients cope better with discontinuation of therapy. Also, for many stroke patients life post-stroke is not only affected by their stroke but also by co-morbidities such as diabetes, kidney and heart problems (Faircloth, et al., 2004; Pound, et al., 1998) which have to be taken into consideration when coping strategies are discussed with patients.

Stroke patients report that everyday tasks after discharge are time-consuming and frustrating due to the slow pace at which they have to be performed (Doolittle, 1991). Their experiences of daily activities have also been reported to be characterised by a great sense of loss, such as complete loss of certain abilities and identity (Hilton, 2002; Burton, 2000) as well as loss related to their social world (Mumma, 1986). In the case of patients being back home post-discharge, they are often tempted to experiment with their own improvement through attempting tasks they used to perform pre-stroke. Professional guidance in such experimentation is paramount to ensure patients' disheartened feelings do not take over if or when they are unable to perform pre-stroke activities satisfactorily (Doolittle, 1991). Kvigne and Kirkevold (2003) and Burton (2000) also point out the profound difficulties patients have in adjusting to their sudden inability to do daily tasks in the way/s they had been used to do pre-stroke. Fatigue was identified by Benz (2000) as another important challenge in post-stroke life, keeping patients from going about their

daily activities at a pace they would have liked and a pace they had been used to. This supports previous research which also found overwhelming feelings of fatigue to hold patients back from progressing towards reaching their goals (Folden, 1994).

Qualitative studies by Pound et al. (1998) and Faircloth et al. (2004) however suggest that ways in which stroke patients have learned to cope with their disabilities after discharge have been underreported in previous studies. They believe this has led to the general view that stroke disrupts people's lives with an immense impact, omitting many patients' views that their lives are actually 'not that bad' (Pound, et al., 1998).

Interestingly, these authors question their own findings and the possible role the coping mechanism of 'normalisation' could have played in their sample of financially poor, elderly stroke patients. This is a mechanism illustrated by Kelleher (1988) where patients' minimise the effects of an illness on their lives for various social and psychological reasons. All the participants in the study by Faircloth et al. (2004) were male war veterans. They were also argued to perhaps have adopted the coping mechanism of normalisation as far as the effects of their stroke were concerned. The findings of Pound et al. (1998) and Faircloth et al. (2004) can therefore not be widely generalised but do merit further investigation.

Kirkevold (2002) suggests that patients' feelings and the gradual processes of adjustment post-stroke should also be taken into account when working toward the development of improved stroke services. This is supported by a study by Faircloth et al. (2004). These authors suggest that by "listening to the patients, drawing out the narrative themes that help make life meaningful, then applying these themes to the construction of a recovery plan, health care, and rehabilitation, practitioners can ensure that the designed rehabilitation strategy encompasses patient-centered needs and concerns" (p. 410).

The above literature review illustrates how wide-ranging the effects of a stroke and patients' experiences thereof may be. Stroke units have been described as the most effective stroke care settings (Langhorne, et al., 1993), but they are still falling short in their care of patients as whole persons with physical as well as emotional/psychological needs (Pound & Ebrahim, 2000). Ferguson (1987) states that the biomedical model does not encourage the active involvement of patients in their own health care. By implication real partnership tends to be found with approaches that have a more holistic perspective.

As mentioned in Chapter 1, due to stroke rehabilitation not always being very effective, many patients are tempted to look for alternative approaches to stroke rehabilitation (Sze, et al., 2002). Many of these approaches do not follow the conventional biomedical model focusing on symptoms, but rather an approach that looks at a patient as a whole person. Indeed, Bendz (2000) suggests that the biomedical perspective used by the multi-disciplinary team providing stroke rehabilitation, in combination with a sub-ordinate role played by patients, does not offer space for issues other than biomedical issues. The fact that the members of a team cover multiple disciplines therefore does not guarantee a holistic approach to patients. The separate disciplines still seem to act as separate from each other.

The following section discusses unconventional approaches to stroke rehabilitation available to patients today. They are approaches that do not use a biomedical view of health but rather hold views that correspond with holistic principles.

## **2.4 Unconventional approaches to stroke rehabilitation**

### **2.4.1 Alternative options to conventional stroke rehabilitation currently available**

In the UK the only alternative therapy for stroke currently available on the NHS, and therefore for free, is acupuncture (Stroke Association, 2005). Research on the effectiveness

of acupuncture in stroke rehabilitation is discussed below. Two other approaches that also offer alternative methods to stroke rehabilitation but are not available on the NHS are the Feldenkrais Method and Conductive Education. There are no clinical studies on the effectiveness of other alternative approaches such as Alexander Technique, sound therapy, reflexology and aromatherapy in stroke rehabilitation. One study on reiki used in stroke rehabilitation showed no benefits to patients (Shiflett, et al., 2002). Given the lack of published research generally on unconventional therapies only the three aforementioned approaches will be reviewed. All three focus on the external physical body and its manipulation. Oral treatments such as herbal medicine are excluded.

#### **2.4.1.1 Acupuncture as part of Traditional Chinese Medicine**

Acupuncture originally developed as part of Traditional Chinese Medicine (TCM) and dates back more than 2,000 years ago (Gong & Sucher, 1999; Vickers & Zollman, 1999). TCM views the human body and its environment as being inextricably linked (Kane, 2006; Gong & Sucher, 1999). Diseases (including stroke) are believed to be the result of an imbalance between factors intrinsic to a person as well as external factors. This suggests a holistic view of health. Treatment takes into account a combination of factors believed to play a role in this holistic view and normally consists of acupuncture and/or herbal medicines (Kane, 2006).

In TCM a stroke is referred to as ‘wind stroke’ (Kane, 2006; Gong & Sucher, 1999; Hopwood, 1996) due to the belief that the Chinese element of wind plays an important role in the cause of stroke. This relates to the Chinese school of thought which works with the five elements of wind, water, air, fire and ether. Both Chinese herbal medicines and acupuncture for stroke include focus on bringing back balance between the body and the element ‘wind’. In acupuncture the use of the term ‘wind’ also refers to an acupuncture

point at the nape of the neck called ‘Wind Gate’, which is commonly included in acupuncture treatment of stroke patients (Kane, 2006).

A traditional Chinese doctor would insert fine needles into different stimulation points on the body, including the ‘Wind Gate’, in order to improve the flow of Qi (pronounced ‘chee’) or life force believed to flow through the body along meridians (Vickers & Zollman, 1999).

Conventional Western health professionals readily use acupuncture today, however many have discarded the notion of Qi and work purely on the physical connections between the stimulation points and organs (Vickers & Zollman, 1999). Studies have found acupuncture to be effective in for example the management of pain (Stroke Association, 2005) and in particular chronic low back pain (Manheimer, et al., 2005), however the effectiveness of acupuncture in the rehabilitation of stroke patients seems to be a contentious topic. Some studies show clear benefits of acupuncture for stroke (Galantino, et al., 2003; Magnusson, et al., 1994; Johansson, et al., 1993) whereas other studies are sceptical about it and found little if any benefits (Zhang, et al., 2006; Mitchell, et al., 2005; Wayne, et al., 2005; Sze, et al., 2002). Interestingly, Johansson et al. (2001) indicates acupuncture to not be effective for stroke, negating their own research of 8 years before (i.e. Johansson, et al., 1993). While Moffett (2006) goes as far as to argue in favour of suspending research on acupuncture for stroke due to the little evidence in favour of it. There is some debate concerning the research methodology used in such studies, including the appropriateness of the application of traditional western clinical research methods to types of interventions that adopt more holistic approaches. All the studies referred to have used quantitative approaches, none have used qualitative.

#### **2.4.1.2 The Feldenkrais Method**

The Feldenkrais Method (FM) is an educational approach to body movement developed by the Ukrainian scientist, physicist and engineer Dr. Moshe Feldenkrais (1904-1984) (Lyttle, 1997). FM is not a technique for diagnosis, treatment or cure (Rywerant, 1983). Rather, it is described as an approach with which to ‘unlearn’ bad movement habits that have lead to physical discomfort, and to relearn movement habits that are conducive to good quality of life (Lyttle, 1997). FM is believed to stimulate the body’s aspect of neuroplasticity and “to explore and fill in gaps and missing links in a person's neuromuscular self-image through sensory-motor awareness” (Lyttle, 1997, p. 262). This method of body work provides its users with two interrelated modes of teaching, either as (i) group sessions called ‘Awareness Through Movement’ (ATM) or (ii) one-to-one sessions called ‘Functional Integration’ (FI). Sessions are referred to as ‘lessons’ and users as ‘pupils’, emphasizing the educational philosophy of FM. In ATM lessons pupils are verbally guided through structured yet explorative movements that range from simple to very complex, depending on the needs and abilities of each individual. The FI sessions provide pupils with hands-on treatments by the FM instructor in order to improve body and movement awareness (Batson & Deutsch, 2005; Lyttle, 1997). However, the ATM sessions include very little, if any, hands-on manipulation except in cases where a pupil might seem to be at risk. Dr. Feldenkrais argued that by involving the brain in a conscious way, movement can improve significantly. For this reason all exercises are performed at a slow pace to encourage inner awareness of each movement (Birkell, 1998). Awareness of the body and the full movements performed suggests holistic principles of incorporating the whole body.

FM is widely used by disabled people as well as by able-bodied people with physical injuries, however research evidence for the efficacy of FM for stroke is very limited



(Wildman, et al., 2005). An extensive bibliography on FM by the Feldenkrais Guild of North America last updated in August 2005 reveals three quantitative research studies on this subject were presented at a conference in 2004 (Batson, 2004; Burkhardt, et al., 2004; Connors & Grenough, 2004). Only one of these was published in a peer-reviewed journal (Batson & Deutsch, 2005). The latter found that FM'S ATM mode of instruction was effective in improving stroke patients' balance. Indeed, for many stroke patients regaining control over balance is either impossible or proves to be very challenging (Batson, 2004; Zorowitz, et al., 2002). However, Batson and Deutsch (2005) used a very small sample (only four stroke patients) in their study, the data of which they analysed quantitatively. Therefore even though the results seem promising, the sample was too small to make any substantial recommendations about the usefulness of FM for stroke. As with acupuncture there have been no published qualitative studies.

#### **2.4.1.3 Conductive Education for stroke**

Conductive Education (CE) is an educational approach to the “habilitation and rehabilitation” (Lodge, 2004, p. 474) of both adults and children who suffer from motor disorders such as stroke, cerebral palsy, dyspraxia, multiple sclerosis, and Parkinson's disease, as well as people who have had head injuries. The process of learning, which is also widely accepted to be the aim of CE, encourages active participation by attendees in CE sessions and is termed *orthofunction* (UKFCE\*, 1998). Orthofunction is described as being a process of “integrated cognitive performance” (Hári, 1997, p. 2) through which an individual moves closer to their potential (UKFCE, 1998). It is believed that once a person has achieved orthofunction they have achieved cognitive growth and not only the ability to

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\* UK Federation for Conductive Education

perform certain physical activities (Hári, 1997). This suggested more holistic view since CE seems to incorporate multiple levels of being.

The therapists providing CE are referred to as conductors, emphasising the nature of CE being conductive, i.e. people are “led into learning” (Sutton, 2000, p. 6). People attending CE sessions are called learners, reiterating the educational process inherent to CE. Learners each attend an initial assessment session in which conductors can determine not *whether* a person is able to perform certain movements, but rather *how* they execute movements and *how* learners can improve on their movements (Kinsman, 1986). Based on the outcome of the initial session learners are placed in groups of approximately 5 to 8 co-learners, all with the same or similar motor disorders. As is the case with the Feldenkrais Method, CE takes place in both individual and group settings however in CE more time is spent in the group setting.

Conductors apply a combination of skills derived from conventional rehabilitation’s multi-disciplinary teams, in that their educating of learners encompasses techniques from for example physiotherapy, educational psychology, occupational and speech therapy (Read, 1998; Beardshaw, 1989). However, manual facilitation is a last resort (Brown & Mikula-Toth, 1997), indicating another similarity with FM, in this case specifically FM’s Awareness Through Movement sessions. CE conductors first facilitate activities through demonstration, motivation and direction. CE overtly gives equal attention to learners’ non-physical and physical needs since equal emphasis is put on mobility skills and development of self-esteem and self-confidence (Gombinsky, 2004). This is further evidence of the holistic approach applied by CE. Indeed, Hayward (1985, p. 3) wrote “The conductors do not specifically look at one part of the person, they look at the whole person and a way for that person (to) achieve what he (*sic*) had not been able to achieve before because of his (*sic*) disabilities.”

CE originated from Hungary after the Second World War and was the brainchild of an Austrian-Hungarian physician András Pető (1893-1967) (Read, 1998). Pető argued that people with motor disorders were not victims of their physical disabilities but were able to learn (or re-learn) how to improve effective use of their own bodies and in this way solve mobility problems encountered in their everyday lives (Lodge, 2004). This, he believed, could lead to increased independent living for disabled people. The re-learning aspect of CE seems to be similar to the philosophy held by the Feldenkrais Method discussed above. The encouragement of autonomous living is akin to the epistemology of holism where the health professional and patient are seen as being in an equal partnership.

During the 1980's a group of British students trained at the Pető Institute for CE in Hungary. On their return they created a charity called The Foundation for Conductive Education. Through the Foundation they began to adapt some of Pető's original approach to suit the British culture, due to the fact that CE was partly the product of social and political circumstances that were different from those in the UK (Beardshaw, 1989; Read, 1994). However, the central idea of teaching people with motor disorders "how to achieve control over bodily movements and coordination" (Lodge, 2004, p. 474) remains the principle concept behind CE practiced in Britain today. Another important concept in CE is the belief in life-long learning (Brown & Mikula-Toth, 1997). Neurological damage does not necessarily mean to a CE conductor that a learner does not have the ability to learn anymore or indeed that they would reach a plateau where no further learning would be possible. On the contrary, according to Brown and Mikula-Toth (1997) CE regards every person as having a life-long capacity for learning, and programmes for learners are based on learners' individual pace of learning.

Practice of CE includes vocal chanting of movements and counting out loud. This is to bring about rhythmical intention which is believed to aid control over movements through

focusing attention on body parts and body position, and through encouraging planning and visualisation of movement before executing the movement (Lodge, 2004). An example of vocal chanting of a movement is the following: “I put my right foot flat 1 – 2 – 3 – 4 – 5” (Brown & Mikula-Toth, 1997, p. 47). In CE, vocal chanting is believed to also contribute to speech development. The verbalisation of the movement takes place prior to implementing the movement itself. It is believed verbalisation helps to set the intention for the movement (Brown & Mikula-Toth, 1997). The actual implementation of the movement only takes place during counting. It is the counting which is said to instil control through rhythm. Aphasic learners however are still believed to benefit from CE in that the vocalisation is not the focus of CE activities (Brown & Mikula-Toth, 1997). Indeed, activities include a vast range of whole body aspects and do not limit its focus to isolated parts. The conscious awareness of movement also seems to be similar to principles of the Feldenkrais Method (FM). A main difference between CE and FM however seems to be the fact that CE is purely for people with motor disorders and FM is for able-bodied people as well as for people with motor disorders.

CE is not without its critics. Oliver (1989) argues that CE’s “insistence on adapting individuals rather than environments flies in the face of ... the expressed wishes of many disabled people who want society to change, not themselves” (p. 198). He supports his argument by reminding the reader that disability groups have been campaigning for a rejection of the biomedical model due to its focus being solely on “cure, normalisation and adaptation by the disabled person” (Read, 1998, p. 283) and not on attending to their non-physical needs. Oliver’s (1989) criticism includes specific disagreement with the use of the word ‘normal’, said to feature prominently in the writings of one of the founders of CE in the UK, namely the late Hungarian Mária Hári (former director of the Petö Institute in Hungary and former trustee of the UK Foundation for Conductive Education). However,

there are two facts which Oliver (1992, 1990, 1989) does not seem to acknowledge: (i) Hári's English was self-taught (Sutton, 2001) which could have led her to use words in English which native English speakers might not normally use; and (ii) CE grew out of Hungarian culture where children who could not walk were not allowed to go to school. this includes special education schools (Sutton, 1986). CE therefore developed in such a way that mobility without the use of aids is strongly encouraged, for both children and adults. On its arrival in the UK, it seems people assumed that the British application of CE would include an almost bullying culture of 'making' disabled people as 'normal' as possible (Read, 1998). This seems to have been partially due to a misunderstanding of the cultural differences between Hungary and Britain. Reports from parents whose children attended CE sessions reveal UK CE to be everything but harsh and coercive and indeed allow learners to use aids such as wheelchairs (Read, 1998).

A practice which develops in different countries with widely different cultures does however make generalisation of the effects of the practice difficult (Read, 1998). The second study in this thesis which looks at CE, focuses on the practice of CE at the UK headquarters of the National Institute for Conductive Education (NICE) in Birmingham and was also the setting of my research on stroke survivors' experiences of CE. It is believed the way in which CE is practised at NICE in Birmingham is representative of how it is practised in Western Europe due to the fact that CE for application in the UK was originally piloted and culturally adjusted at the NICE (formerly known as the Birmingham Institute for Conductive Education) headquarters by the Foundation for Conductive Education during the 1980's (Read, 1998). It was from here that the adjusted CE practice was passed on to other practitioners who wanted to learn how to use CE.

A search of internet databases revealed a burgeoning of research on CE for children, in particular for children with cerebral palsy. However, there is a clear lack of research on CE

for adults and even less available on CE for adults with stroke. There are only three peer-reviewed publications that report research studies in which CE was applied to stroke rehabilitation, namely Howard and Verrier (1989), Endres et al. (1990) and Brown (2006b). In 1997 a paper on CE for stroke appeared in one of NICE's own publications, namely Laver and Brown (1997). None of these studies used qualitative methodology only.

Stroke patients in a chronic rehabilitation setting who appeared to have reached a plateau in their rehabilitation (see section 2.3.2.2 on the occurrence of a plateau in stroke rehabilitation) took part in a study on the possible effectiveness of nine months of CE sessions for stroke (Howard & Verrier, 1989). The study was analysed quantitatively and revealed that despite the plateau they had reached in conventional rehabilitation, they showed measurable physical changes in activities performed as well as retention of motor performance after the series of CE sessions. The study did not however explore whether CE brought improvement to their daily experiences post-stroke, something which could have been studied qualitatively. Howard and Verrier (1989) conclude their paper with setting out the advantages CE holds for stroke survivors, based on their research:

- Stroke patients' ability for motor learning could be enhanced by including use of language in rehabilitation. This could also increase patients' active participation in their own rehabilitation process
- The skills taught by CE provides patients with strategies to approach further acquisition of skills, suggesting advantages for the combining of CE with conventional rehabilitation

Howard and Verrier's (1989) study was not followed-up with further research on CE for stroke.

Endres et al. (1990) studied the difference between the Barthel index and Rivermead Motors Assessment (as mentioned earlier in this chapter, both are accepted measures of

rehabilitation progress in conventional stroke rehabilitation) after stroke rehabilitation which consisted of a combination of elements from the Bobath concept (a widely used approach in conventional stroke rehabilitation) and elements from CE. The authors did not compare the use of the Bobath elements with those of CE. It is however encouraging to note a case of stroke rehabilitation where the use of a conventional method, such as Bobath, was combined with that of CE.

A research project which combined quantitative and qualitative methods in the study of stroke patients' experiences of CE is reported by Laver and Brown (1997). Stroke patients with a wide-ranging number of months since their stroke received three weeks of a CE intervention. The authors do not specify how many CE sessions were attended during the three weeks, making full assessment of the contribution of the study difficult. Nevertheless, on comparing study participants' pre- and post-CE intervention data, both the quantitative and qualitative study results reveal an overall positive change in study participants' performance and personal satisfaction.

A recent pilot study on CE for stroke (Brown, 2006b) used quantitative scales, such as the Barthel index and Quality of Life scale, and observation of a ten metre walk to determine stroke survivors' health-related quality of life before and after a series of ten CE sessions. The results from this study show a fifty percent plus improvement in patients' quality of life. This pilot is part of a larger on-going study on the benefits of CE for adults with stroke, multiple sclerosis and Parkinson's disease (Brown, 2006b).

Overall there are few existing research papers on CE for stroke, indicating the need for further work both quantitative and qualitative.

## 2.5 Summary

In this chapter I provided background information on the prevalence and nature of stroke as well as a literature review of qualitative studies on the lived experience of conventional and unconventional stroke rehabilitation. The literature review included discussion of papers reporting on stroke rehabilitation experience in a chronic rehabilitation setting. The first of my two studies for this thesis was conducted in such a setting using hermeneutic phenomenology which has been used rarely in this type of research.

Most of the studies on stroke rehabilitation experience are retrospective only and/or longitudinal. A main contribution from my Study One lies in the fact that it gives a snapshot of experience in a chronic setting. Study One's findings are presented and discussed in Chapter 4 of my thesis.

In this Chapter 2 I also discussed the nature of and research literature on three unconventional approaches to stroke rehabilitation, namely acupuncture, the Feldenkrais Method and Conductive Education. Evidence was given for the holistic nature of each approach as well as the need for more research in the use of these approaches in the rehabilitation of stroke patients. In Chapter 1 of my thesis I explained how it came about that I studied CE for stroke. The findings of that study are presented and discussed in Chapter 5 of my thesis. The main contribution from my CE study (i.e. Study Two) is two-fold: it provides more information on CE for stroke, an area of study that needs more research as pointed out above; the second contribution is the fact that it is a qualitative study where most of the other existing studies on CE for stroke are quantitative.

Hermeneutic phenomenology was the philosophy and method which I used to explore lived experience of stroke. The next chapter, Chapter 3, provides an in-depth discussion of hermeneutic phenomenology and how I used it in my research.



## **CHAPTER 3**

### **Researching lived experience of stroke rehabilitation across two different settings: philosophy and research design**

#### **3.1 Introduction**

Chapter 1 of this thesis outlined the main reasons for the choice of hermeneutic phenomenology for the exploration of stroke rehabilitation experience in two distinct settings. The aim of chapter 3 is to provide more in-depth information on hermeneutic phenomenology, its origin in the philosophies of phenomenology and hermeneutics and its use as research tool. It outlines the research design including the research context, study participants and data collection tools used.

#### **3.2 Philosophy**

A study's philosophy influences the research questions and the choice of methods used to gather and analyse data (Mays & Pope, 1995; Mackey, 2005; Maykut & Morehouse, 1994). The present study focuses on the exploration of stroke patients' experiences in rehabilitation in two different settings. Chapter 1 discussed the suitability of constructivism for this exploration. A philosophy congruent with constructivism is one that primarily focuses on the nature of human experience and one such philosophy, the principles of which are also widely used in qualitative research on lived experience, is phenomenology (Mackey, 2005; Öhman, 2005; Lopez & Willis, 2004; Kvigne, et al., 2002; Walton & Madjar, 1999). This section aims to provide background information on phenomenology as well as hermeneutic phenomenology, in order to explain the latter's appropriateness for the current research.

### 3.2.1 Phenomenology

“I see your behaviour.

You see my behaviour.

But I do not and never have and never will see your experience of me.”

(Laing & Esterson, 1973, p. 15)

The above quote illustrates the personal and unique nature of experience. One can attempt to understand someone else’s experience, but never claim one knows exactly what experience is like for the other. Phenomenology is a philosophy which has been widely used by researchers in healthcare to explore patients’ experiences of health and illness (Lopez & Willis, 2004). Phenomenology is the study of *phainomenon* with the latter meaning ‘appearance’ or “that which shows itself” (Spinelli, 1995, p.2). It is the study of subjective experience of phenomena or as Hammond et al. (1991, p.1) puts it “phenomenology involves the description of things as one experiences them, or of one's experiences of things ...”. Phenomenology is thus also called the philosophy of experience (Valle, 1998). It explores experience as a whole and acknowledges that experience does not only occur via sensory (i.e. seeing, hearing, smelling, tasting, feeling through touch) perception but also via for example remembering, imagining things, feeling angry at things, etc. (Hammond, et al., 1991). These authors, as well as Ehrich (1999), also argue that phenomenology is opposed to Cartesian dualism\* since phenomenology sees experience as always being experience of something. Therefore a Cartesian split between a person’s inner experience and an outer object or event is an impossibility. In terms of healthcare research, a phenomenological approach could be said to be in contrast to positivism in which ‘outsiders’ (i.e. non-patient researchers) only investigate a part of illness experience, for example the experience of bodily pain, and neglect the concept of

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\* See Chapter 1 of this thesis for a discussion of Cartesian dualism

‘lived experience’ or ‘felt world’ that implies a unity between bodily, emotional and societal experience (Hughes & Paterson, 1997; Kleinmann, 1988). Phenomenology therefore follows a holistic approach to the study of experience. This is one of the reasons why phenomenology was seen as a possible philosophy and method suitable for the current research. Thus a potentially holistic approach is being used to study holism.

The next section explains the main concepts of phenomenology that also form the basis of many different branches of this philosophy such as hermeneutic phenomenology (Mackey, et al., 1996; Maggs-Rapport, 2001). Hermeneutic phenomenology is discussed in section 3.2.2.

### **3.2.1.1 Husserl’s phenomenological method**

The German philosopher and mathematician Edmund Husserl (1859-1938) is regarded as the father of phenomenology (for example Maggs-Rapport, 2001; Spinelli, 1995; Hammond, et al., 1991). He was opposed to the way positivism was infiltrating psychology and social science (Ehrich, 1999). As a result he was interested in finding an empirical method to study experience with, one that was not informed by dualist knowledge. He consequently developed his so-called phenomenological method which contains the following key concepts on which most methods using phenomenological techniques, are based. Even though the concepts are here presented in a linear way they are in effect all interrelated (Gearing, 2004; Maggs-Rapport, 2001; van Manen, 1990).

#### **- Epoché**

Husserl argued that when philosophers/researchers study phenomena they should, at the same time, suspend their own preconceived assumptions of the phenomena (Maggs-Rapport, 2001; Ehrich, 1999; von Eckartsberg, 1998; Spinelli, 1995; Moustakas, 1994; Hammond, et al., 1991). Epoché, also called phenomenological reduction, refers to this

practice of suspension or bracketing of pre-assumptions. It asks researchers to practise reflection in order to become aware of their own thoughts and ideas concerning a phenomenon and then to push the thoughts and ideas aside to prevent them from influencing their description of the phenomenon under study (Lopez & Willis, 2004; Ehrich, 1999; Spinelli, 1995). This is in order to describe a phenomenon for what it is. However, a criticism of Husserl's method is that to be completely 'value\*-free' when encountering another person's narratives, is virtually impossible (Le Vasseur, 2003; Denzin, 1994; Rutan & Groves, 1992; Lincoln & Guba, 1985). An attempt to be free from all values can be compared to positivism's division between the researcher and the researched (Lincoln & Guba, 1985). One might find it surprising then that a philosophy which holds description of the whole with such high regard, would endeavour to obtain value-free description and thus imply a positivist attitude (Le Vasseur, 2003). Spinelli (1995), a fervent supporter of Husserl's method, however argues that even though it might be difficult to put one's own values and thoughts/ideas aside it is possible to bracket a large number of one's assumptions. One should however not be blinded by bracketing's similarities with positivism since the rest of Husserl's phenomenology is overtly the contrast of positivism, for instance the phenomenological study of experience includes "the full range of conscious experience" (Le Vasseur, 2003, p. 411) and not only a part of it. Indeed, it has been reported that throughout his life Husserl himself struggled with the idea of bracketing and what it implied (Spiegelberg, 1975), suggesting that even the father of phenomenology was unclear about this concept. Beech (1999) therefore warns qualitative researchers who claim to be using phenomenology to explicate their understanding of bracketing due to its contentious nature. Under the heading of Epoché, one can also put Husserl's notion of 'natural attitude' versus 'transcendental attitude'. According to Spinelli

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\* Here the term value implies assumptions, hypotheses, perspectives, social or cultural norms as well as personal or individual norms (Lincoln & Guba, 1985)

(1995), Husserl argued that in everyday life people are unaware of the interdependence that exists between themselves and their surroundings. Instead, they tend to think more of themselves as being independent from the world around them, corresponding to dualist thought. Husserl termed this way of thinking or attitude, the 'natural attitude'. A contrasting attitude, one with which one sees a phenomenon for what it really is, without judging it, is termed the 'transcendental attitude'. In phenomenology, through the bracketing of one's pre-assumptions, one attempts to understand a phenomenon for what it really is (*Zu den Sachen* – see the concept 'Description') (Spinelli, 1995). The process of bracketing of assumptions often leads to the discovery of more assumptions that need to be bracketed. Husserl termed this continuous movement from bracketing to re-bracketing, a movement from the 'natural attitude' to the 'transcendental attitude' (Spinelli, 1995). This movement is a process similar to that involved in the hermeneutic circle, discussed in this chapter's section on hermeneutic phenomenology.

- Description

A core feature of Husserl's phenomenology is the issue of *Zu den Sachen* which is the German for 'to the things themselves' (von Eckartsberg, 1998; Cohen & Omery, 1994). This indicates the focus on the phenomenon purely for what it is, without being judged - a focus which one applies when adopting the 'transcendental attitude', discussed above. The essence of phenomenological description is "describe, don't explain" (Spinelli, 1995, p.17), reminding researchers that one ought to keep one's focus on the *Sachen* (the things/phenomenon under study) and refrain from speculation and explanation which could 'contaminate' the data. The German word *Lebenswelt* is used in phenomenology to refer to a person's life-world – i.e. the world as experienced by the person which is then described by phenomenology (Ehrich, 1999; Spinelli, 1995). The notion of *Zu den Sachen* connects with the notion of *Lebenswelt* in that a description of experience while bracketing pre-

assumptions, reveals to us the world as experienced by another individual or group of individuals, without contamination by the researcher's pre-assumptions and judgements (Ehrich, 1999).

- Horisontalisation and Free Imaginative Variation

Both these concepts take place during different stages of the concept of Description. Horisontalisation is about treating all parts of the data as equal parts of the whole (Spinelli, 1995). Thus, for the most part of Description, no parts of the phenomenon are put in hierarchical levels. This is also akin to holistic principles. Once analysis is complete the phenomenological researcher applies Free Imaginative Variation to the themes that emerged from the data (Maggs-Rapport, 2001; Ehrich, 1999; van Manen, 1990). This is an activity aimed at determining which themes are essential to the essence of the phenomenon and which are only incidental. Essential themes are those that “make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1990, page 107). Incidental themes are those whose absence from the description of a phenomenon would not change the essence of the phenomenon and are regarded as not being unique to the phenomenon. Such themes are either discarded from the description or a group of incidental themes could create a new essential theme (van Manen, 1990). I find Horisontalisation and Free Imaginative Variation to be in effect the opposite of one another, with the former treating the whole and all its parts with equal importance and the latter choosing which parts of the description are the most essential (important) to the phenomenon. However, together they bring the phenomenological researcher closer to the essence of the phenomenon under study.

- Intentionality

This phenomenological concept conveys the idea of consciousness being intentional, meaning that consciousness is always directed to something (Le Vasseur, 2003) and ‘of

something' (von Eckartsberg, 1998), as experience is also always 'of something' (Hammond, et al., 1991). From this follows the term known in phenomenology as 'intentionality' and emphasises the inter-relationship between the world around people and their conscious experience of it (Spinelli, 1995).

As discussed above, Husserl's phenomenology is useful for determining what the essence of lived experience is, however, it does not allow for interpretation of the essence (Lopez & Willis, 2004; Mulhall, 1996; Cohen & Omery, 1994). Interpretation can uncover characteristics of phenomena that might have stayed hidden if it were presented to the reader through description only (Rather, 1994). For this reason it was thought fitting to use an interpretive phenomenology to interpret the essence of lived stroke rehabilitation experience in order to inform the role of holistic approaches to stroke rehabilitation practice. The next section describes such an interpretive phenomenology, namely hermeneutic phenomenology.

### **3.2.2 Hermeneutic Phenomenology**

The philosopher and researcher credited with being the father of interpretive or hermeneutic phenomenology is Martin Heidegger (1889-1976). He was an assistant of Husserl at Freiburg University, Germany, and succeeded him as Chair of Philosophy in 1928. Heidegger therefore came into close contact with Husserl's phenomenological ideas (Mulhall, 1996). The following is a discussion of the main concepts of Heidegger's hermeneutic phenomenology (as with phenomenology, the following concepts are also all interrelated despite their linear presentation):

- Being and the importance of interpretation

Heidegger's focus was on questions about the meaning of 'Being' and he saw Husserl's method as useful for the study of situated being or everyday being-in-the-world

(Mulhall, 1996; Cohen & Omery, 1994). The existentialist\* views of Heidegger can be described as ontological, in contrast to those of Husserl which are epistemological (Annells, 1996; Cohen & Omery, 1994). Heidegger was interested in the question – “what is being?” (Cohen & Omery, 1994, p. 142), whereas Husserl worked with the question – “what do we know as persons?” (p. 142). Heidegger agreed with Husserl’s emphasis on *Zu den Sachen*, i.e. seeing a phenomenon for what it really is. However, Heidegger considered description to be of no use on its own (Mulhall, 1996; Cohen & Omery, 1994). Indeed, he thought it to be impossible for description to exist without some degree of interpretation (Koch, 1996; Mulhall, 1996) and argued that meaningful understanding of being is to be found in interpretation (Lopez & Willis, 2004; Mulhall, 1996). For this reason he developed the interpretive phenomenology called hermeneutic phenomenology. The term ‘hermeneutics’ originated from the Greek word *hermeneia* which refers to the understanding of language (Annells, 1996). It was originally associated with the interpretation of biblical texts (Lopez & Willis, 2004; Ehrich, 1999) however in the twentieth century philosophers and researchers started using this term to indicate the interpretation of the life-world as though it were a text.

- Being-in-the-world or *Dasein*

An additional Husserlian view which Heidegger did not agree with was the one which regarded the philosopher/researcher as separate from that which he/she studies (Draucker, 1999; Mulhall, 1996). This separation is reflected in Husserl’s concept of Epoché where the attempt to bracket all pre-assumptions could be compared to the positivist division between the knower and the known (Le Vasseur, 2003; Draucker, 1999). Heidegger believed one makes sense of the world one is in through *being* in it, and not through being detached from it (Maggs-Rapport, 2001). Indeed, one of the main concepts of Heidegger’s

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\* Heidegger’s focus on Being lead to terms such as existentialist and existentialism often used to describe his and his followers’ teachings.



hermeneutic phenomenology is that of 'Being', or 'Being-in-the-world'. He described pre-reflective 'being-in-the-world' with the German word *Dasein* (Mackey, 2005; Maggs-Rapport, 2001; Draucker, 1999; Annells, 1996; Mulhall, 1996). *Dasein* cannot be translated into a single English word but its literal translation is: "the fact that something is" (Mulhall, 1996, p.6). This refers to the existentialist view of existence as essentially 'being-in-the-world' (Valle, et al., 1989). Heidegger believed an understanding of *Dasein* should always include an understanding of the experience of time and space in the context of *Dasein*, because, he believed, temporality and spatiality help give meaning to *Dasein* (Mackey, 2005; Mulhall, 1996).

- Co-constitution

Heidegger argued that since there is no separation between the observer and the observed (or the person and their life-world), bracketing of thoughts is impossible (Le Vasseur, 2003; Draucker, 1999; Mulhall, 1996). As Le Vasseur (2003) says: "we are already thrown into our world and cannot extricate ourselves from it" (p. 418). *Dasein* further conveys the notion that all our relationships are also inseparable from what goes on around us, our life-world (Lopez & Willis, 2004; Maggs-Rapport, 2001), i.e. our 'being-in-the-world' influences all our relationships and visa versa. Human beings and their life-worlds are therefore co-constituted (Annells, 1996). Consequently in Heidegger's hermeneutic phenomenology one's pre-assumptions are seen as an important part of the hermeneutic phenomenological interpretation (Lopez & Willis, 2004; Maggs-Rapport, 2001) and the interpretation of a hermeneutic phenomenological study on lived experience is then an interpretation co-constituted by the researcher/s and participant/s (Lopez & Willis, 2004). This is strongly akin to constructivism as well as the holistic principle which states that there is a connection between every part of the whole, as discussed in Chapter 1 of this thesis.

- Hermeneutic circle

A hermeneutic phenomenological inquiry into experience, most often transcribed into narrative text, takes on a cyclical and open-ended approach to the text (Mackey, 2005; Mulhall, 1996). This cyclical approach is called the 'hermeneutic circle' and involves the continuous reading and re-reading of the text in order to get a sense of the whole of the text and not only of certain parts of it. Through the hermeneutic circle, one gets immersed in the text (van Manen, 1990). All the time spent in the circle, reflection takes place on what one's own assumptions were before reading the text (Mackey, 2005; Le Vasseur, 2003; Mulhall, 1996; van Manen, 1990; Valle, et al., 1989). The researcher's own history and his/her 'being-conscious-of' their own pre-assumptions, are all part of the hermeneutic process. Considering and making explicit one's own pre-reflective assumptions both on their own and in the context of the research data, is a constant movement to and 'fro, within the hermeneutic circle (Mackey, 2005). As mentioned earlier, the hermeneutic circle seems to be similar to the process Husserl described when he spoke about the movement between the 'natural attitude' and the 'transcendental attitude'. The continuous reflection on one's own assumptions while in the hermeneutic circle makes 'arrival' at an ultimate understanding impossible since arrival would merely indicate another stage of pre-understanding (Le Vasseur, 2003). According to Le Vasseur (2003, p. 418) "the ongoing project of reflective questions keeps the possibility of new experience and understanding alive".

Hermeneutic phenomenologists admit that a description and interpretation of a text is not the ultimate description and interpretation of that specific text (Lopez & Willis, 2004; Churchill, et al., 1998; van Manen, 1990). Other readers reading it might describe and interpret it differently. Therefore the results of a hermeneutic study are only possible interpretations of data (Churchill, et al., 1998; van Manen, 1990). The question - what is

the use of only ‘possible’ interpretation? - comes to mind. In hermeneutics the merit of the results does not depend on whether they are the absolute truth, but whether they help people to reach better understanding of everyday being-in-the-world (Churchill, et al., 1998; van Manen, 1990). This is supported by Wilson and Hutchinson (1991) who also state that “conclusions of hermeneutics are not considered the ultimate ‘truth’ but rather an open-ended presentation of informants’ realities. Instead of a prescriptive outcome, a hermeneutical study ends with common themes and shared meanings” (p. 274). Criteria used to evaluate the rigour of a hermeneutic phenomenological study are therefore different from those used in quantitative research and even from those generally used in qualitative research (de Witt & Ploeg, 2006; Guba & Lincoln, 2005). Chapter 6 will discuss this in more detail.

### **3.2.2.1 Hermeneutic Phenomenology as research method**

Further expansion of phenomenology, and the philosophies that have their roots in phenomenology, include the development of three main schools of thought, namely the Dutch and the French schools (Gearing, 2004) as well as the Duquesne school based in Pittsburgh in the United States of America (Ehrich, 1999). The Dutch school combined Husserlian elements with those of Heidegger’s hermeneutics, whereas the French school mainly continued their focus on Husserl’s phenomenology. The Duquesne school brought a strong psychological focus to hermeneutic phenomenology and their main method is known as existential phenomenological psychology (Ehrich, 1999). For the current research it was decided to use a method from the Dutch school since they use methods that include both descriptive and interpretive phenomenology (i.e. hermeneutic phenomenology). The French school’s Husserlian focus was therefore not appropriate. Indeed, in recent years many researchers of patient experiences also prefer interpretive

approaches since they provide one with a better understanding, rather than just an explanation, of experience (Mackey, 2005). Methods from the Duquesne school were not suitable to the current research either due to their strong psychological orientation, which is not in keeping with my study's social scientific context.

Heidegger did not provide researchers with a single standardised method with which to perform hermeneutic phenomenological inquiry (Mackey, 2005; Ehrich, 1999; Annells, 1996; Robertson-Malt, 1999; van Manen, 1990) because he believed it to be difficult to consign oneself to one method only (Mulhall, 1996). Juxtaposed with this view is his own description of phenomenology in terms of method (van Manen, 2006). Since research needs to be guided in its quest for understanding experience, researchers have developed different sets of guidelines for research which uses hermeneutic phenomenological principles. Also, for researchers using phenomenological principles it is common practice to adapt existing phenomenological techniques/methods to their own research questions (Maggs-Rapport, 2001; van Manen, 1990).

Methodological guidelines for a hermeneutic phenomenological study that have already been widely used in different areas of social science research is that of the Dutch phenomenologist and pedagogue Max van Manen (Maggs-Rapport, 2001; Ehrich, 1999). van Manen (1990) writes in an undemanding way that helps to unfold the world of hermeneutic phenomenological inquiry for the reader, a fact supported by other hermeneutic phenomenological researchers as well (Maggs-Rapport, 2001). For these reasons van Manen's (1990) guidelines were chosen to inform the method for the current research.

van Manen's (1990) method synthesises hermeneutic phenomenological principles into six so-called research activities. The activities can be used as a guide to "select or invent appropriate research methods, techniques, and procedures for a particular problem or

question” (van Manen, 1990, p. 30). There exists interplay between the six activities and they are not a set of rules to be followed blindly. They are:

- i. turning to the nature of lived experience;
- ii. investigating experience as we live it;
- iii. hermeneutic phenomenological reflection (reflection on essential themes drawn from the data);
- iv. hermeneutic phenomenological writing and rewriting, describing the phenomenon;
- v. maintaining a strong and oriented relation to the phenomenon;
- vi. balancing the research context by considering parts and whole (again a link with holism)

van Manen’s (1990) six activities show many similarities with the phenomenological methods developed by well publicised researchers such as Colaizzi (Beck, 1992) and Giorgi (1989). For example, all three authors follow the principle of the hermeneutic circle, reading and re-reading text after which they extract significant sentences from the material and then describe it. The main difference between van Manen and the other two authors, Colaizzi and Giorgi, is that the latter two stop the process after having reintegrated the significant themes into the whole, whereas van Manen takes it further and allows for interpretation of the phenomenon. This is again an illustration of the main distinction between phenomenological and hermeneutic phenomenological methods of inquiry.

Diekelmann et al. (1989) are also researchers who developed a hermeneutic phenomenological method. Theirs is a seven stage analysis process which involves major contributions from a research team and application of multiple stages of interpretation that is to act as a means of bias control (Diekelmann, et al.. 1989). This is in contrast with van Manen’s (1990) method which can be applied by a single researcher, increasing its suitability for the current research.

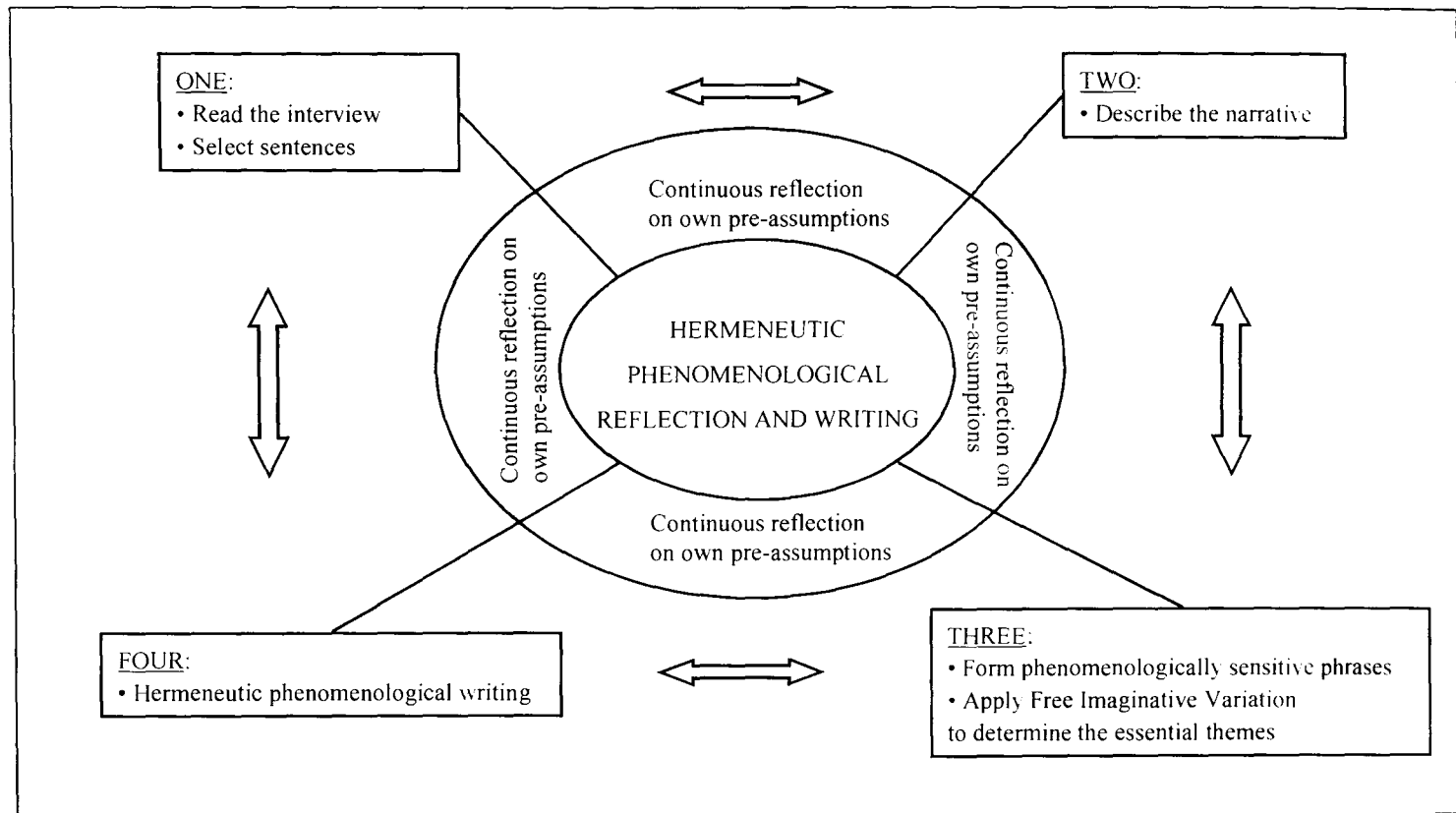
### **3.2.2.2 Applying hermeneutic phenomenological principles to the method used in the current research**

As mentioned above, van Manen (1990) encourages researchers to draw upon his proposed research activities and to adapt them to the needs of their own studies. This could be however used to criticise van Manen's approach since it encourages an always-evolving method. On the other hand, the hermeneutic circle is evidence of an always-evolving interpretation, which is then in keeping with an always-evolving method as well. I feel however that it is paramount for continuous evolvment to stay in keeping with the principle concepts of hermeneutic phenomenology discussed earlier in this chapter to prevent it from becoming a completely different philosophy.

In the current study, van Manen's (1990) guidelines were adapted as follows:

- i. It focused on the phenomenon of stroke rehabilitation experience in two different settings;
- ii. It investigated the phenomenon within a stroke unit where patients received rehabilitation and explored patients' accounts of their experiences. It also investigated the phenomenon within a Conductive Education setting where stroke survivors' experiences of Conductive Education for stroke were explored;
- iii. It drew on hermeneutic phenomenological principles while reflecting on themes;
- iv. It drew on hermeneutic phenomenological principles while describing and interpreting patients' experiences;
- v. It followed the hermeneutic circle's cyclical principle, staying immersed in the data and staying aware of own pre-assumptions and their influence;
- vi. It considered all extracts of the material and themes on their own, as well as in context with the bigger picture of the study.

During the research activities of hermeneutic phenomenological reflection and writing (i.e. numbers iii and iv), the research was guided by four stages based on van Manen's writings (van Manen, 1990). I present these, for the first time, around a circle in Figure 2.



**Figure 2:** Hermeneutic phenomenological reflection and writing

This circular representation emphasises the non-linear process followed during analysis in keeping with the hermeneutic circle, including constant reflection\* on own pre-assumptions. The following is a description of the four stages as illustrated in Figure 2 and is a clear example of the Dutch school's combination of Husserlian and Heideggerian concepts:

*Stage One:* The process began by carefully reading and re-reading a data transcript in order to become immersed in the data (see section 3.3 for information on the research design.

\* Chapter 6 of my thesis contains a section on the rigour of the current research which includes details on how constant reflection was practised.

setting and study participants); sentences and phrases that were identified as thematic of patients' experiences in the particular setting were selected and underlined.

*Stage Two:* The material was described in the third person.

*Stage Three:* The selected material was re-read in both its original and described forms.

This was followed by an activity called "Composing Linguistic Transformations" (van Manen, 1990, p. 96). This is a creative, hermeneutic process that aims at transforming the selected statements into phrases that are phenomenologically sensitive. Through the Husserlian process of Free Imaginative Variation as also suggested by van Manen (1990), themes considered to be an essential element of stroke rehabilitation experience, and those that related more incidentally to it, were separated from each other. Incidental themes were discarded and essential themes were kept for further analysis. Imaginative variation of themes can also create new essential themes (van Manen, 1990), for example when a group of incidental themes are incorporated into one already existing or new essential theme. The rationale behind Free Imaginative Variation according to van Manen (1990) is that not every theme that emerges from hermeneutic reflection on the data is unique to the phenomenon under study. Indeed, this part of the research process is concerned with revealing "aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is" (van Manen, 1990, p. 107). Questions asked to facilitate this process were: Is theme X an essential theme of stroke rehabilitation experience? Can one imagine the experience of stroke rehabilitation without theme X? Would stroke rehabilitation experience still be the same if one imaginatively changed or deleted theme X from it? (questions adapted from van Manen (1990, p. 107).

*Stage Four:* The phenomenological textual description based on the hermeneutic phenomenological interpretation of stroke rehabilitation experience took place during this fourth stage. "The problem of writing is that one must bring into presence this



phenomenon that can be represented only in words - and yet escapes all representation.” (van Manen, 2006, p. 6). The act of writing phenomenologically takes this into account and, as mentioned before, does not claim to hold the ultimate understanding of a phenomenon, in my case stroke patients’ experiences in two different settings. However, such writing does add to a global understanding. In order for phenomenological writing to fulfill its goal (i.e. add to global understanding), van Manen (1990) encourages a seeking of “a sense of organisational form and organic wholeness consistent with the methodical emphasis of the research approach” (p. 168). He suggests five possible ways with which to achieve organisational form, namely:

- Thematically: use the themes that emerged from the data as guides for writing
- Analytically: analyse interview transcripts to find anecdotes with which to reconstruct life stories
- Exemplificatively: start with a description of the phenomenon under study and then systematically extend the description by taking into account other modalities of the phenomenon
- Exegetically: organise one’s writing around those of other authors who wrote about the same / a similar phenomenon
- Existentially: weave “one’s phenomenological description against the existentials” (van Manen, 1990, p. 172). The existentials are temporality (lived time), spatiality (lived space), corporeality (lived body) and sociality (lived relationship to others).

The choice here was thematical writing as it was felt that this will provide a better understanding of stroke patients’ experiences as represented by the themes since the themes emerged from the data itself. The phenomenological textual description of stroke rehabilitation experience and experience of Conductive Education for stroke in Chapters 4 and 5 of thesis, is therefore based on the essential themes that emerged from the data.

The fifth of Van Manen's (1990) research activities discussed earlier under point v. entailed a two-fold process of becoming immersed in study participants' narratives and at the same time being reflective and aware of my own pre-assumptions and emotions. The latter corresponds to the phenomenological practice of bracketing and the hermeneutic phenomenological viewpoint that pre-assumptions cannot be set aside but do play an important role in the research process (Lopez & Willis, 2004; Maggs-Rapport, 2001).

Ways in which I undertook bracketing in the hermeneutic process included the following:

- I did not do an extensive literature search on the experience of stroke rehabilitation prior to commencing data collection and analysis. This was to minimise the possible effect information in the literature could have had on my interview prompts and analysis.
- Prior to starting interviewing study participants I attended a three month part-time course on the use of Rogerian counselling skills (see 6.4.1) to improve my interviewing and listening skills. One of the skills entails having unconditional positive regard for the client. In applying this during interviewing I regarded each interviewee as a unique human being with a unique story to tell me. I treated each interview as a "blank canvas" and refrained from asking an interviewee a question based on what I had learned from another interviewee lest it would influence the remainder of that particular interview.
- In Chapter 6 of this thesis I relate the effect of the research on me as a person, especially how it affected me emotionally during Study One (see 6.4). Emotions I experienced during interviewing and analysis at first included anger and deep sadness. On combining this knowledge with the application of bracketing and reflective practice I realised the need to re-analyse the interviews from Study One. On comparing the second analysis with the first I noticed in a first-analysis-theme such as "Patients

talking themselves down (due to being angry with their limbs)” that I had mistaken patients’ feelings of helplessness and frustration for that of anger. This was most probably due to the fact that I had allowed my own anger with their helplessness to colour my judgment. I also noticed how my own eagerness for patients to receive more care emerged in a first-analysis-theme such as “Not enough physiotherapy” rather than “Eagerness to re-learn”. The second analysis was done at a stage where I was much more aware of my own reactions to the research and it was also at a point when more time had lapsed since my being in the stroke unit and experiencing patients’ sorrow on a daily basis. I believe this fact together with my continuous practice of hermeneutic phenomenological reflection lead in the second analysis to an improved interpretation of patients’ experiences of stroke rehabilitation in the stroke unit.

More information on the research participants who contributed to a better understanding of stroke rehabilitation experience, as well as the research setting and research design as a whole, is presented in the next section.

### **3.3 Research design**

As explained in Chapter 1, my thesis consists of two separate case studies entitled Study One and Study Two. Study One was conducted in the setting of a conventional stroke unit and Study Two in a Conductive Education (CE) setting. The aim of this section is to discuss the design as well as the characteristics of the research setting and participants of each individual study. The section begins however with a discussion of the reasons why interviews were chosen as one of the data collection tools. The sections on Studies One and Two explain how the interview data was supplemented by observations and in the case of Study Two also by participant diaries.

The stories study participants tell researchers about their life experiences are very effective in conveying their experiences (Gubrium & Holstein, 2002). The research interview was therefore one of the data collection tools chosen for this thesis. Other reasons for this choice were: (i) it is the method of choice for a non-directive, phenomenologically aware interviewer (Plummer, 1995), (ii) it is a commonly accepted means for exploring and collecting accounts of lived experience (van Manen, 1990), and (iii) it facilitates a non-hierarchical relationship between the interviewer and the interviewees (Edwards, 1993). The latter reason overlaps with principles of a holistic view, strengthening the research interview's suitability for this thesis.

In the interviews of both Study One and Study Two flexible interview schedules were used (see Appendices A and B). It covered broad themes to meet the research aims, but also allowed the patients to introduce issues for discussion. As interviewer I adopted a phenomenological approach, i.e. I listened and responded to interviewees without being guided by my own pre-formed structured focus points and assumptions. This is akin to hermeneutic phenomenology's interpretation of bracketing (van Manen, 1998).

The overall focus that exists in experience methods (i.e. methods used to gather data on experience) is multi-directional (Clandinin & Connelly, 1994), allowing for a holistic view of experience. The four directions in the multi-directionality of experience methods are: *inward* (internal processes involved in experience, for example internal conditions of feelings and hopes); *outward* (environmental factors influencing experience); *backward* and *forward* (temporality: past, present and future). Inquiry into experience must address its multi-directionality (Clandinin & Connelly, 1994). Indeed, the interviews conducted in my thesis were multi-directional in that topics discussed in the interviews included both internal feelings of patients and external factors that influenced their experiences, as well as patient narratives on their past, present and future.

A non-hierarchical relationship between the patients as interviewees and myself as interviewer was encouraged by my application of client-centred counselling skills\*, as developed by the humanistic psychologist Carl Rogers (1951). Such a relationship is believed to facilitate verbal interaction between interviewer and interviewee (Rogers, 1951). The client-centred approach is consistent with the hermeneutic phenomenological principles of accepting someone for who they are, allowing them to be who they are while listening to their stories (van Manen, 1990). Rogers (1951) developed the following conditions by which a person-centred approach is recognised and which I also applied during interviewing:

1. empathy
2. congruence
3. unconditional positive regard

1. Empathy: This condition has been described by Rogers as “the ability to sense the client’s world *as if* it were your own, without losing the ‘as if’ quality” (Sanders, 1998, p.66). Showing empathy is thus to gently try and understand someone else's circumstances and experience. It is not however claiming that you know how the other person feels (Sanders, 1998), similar to a phenomenological attitude as discussed above.
2. Congruence: Being aware of, and in touch with, one’s own feelings while being a counsellor (or in my case an interviewer), is what Rogers meant when he spoke about congruence (Sanders, 1998). Congruence is akin to the phenomenological principle of constant reflection and the practice of bracketing. Pretending to be who you are not can easily be picked up by the interviewee and they could lose trust in you.

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\* In 1999 I completed a three month part-time course on the use of counselling skills.

3. Unconditional positive regard (UPR): Rogers viewed every human being as being essentially good and valuable, even though it was difficult to see such qualities on the surface (Burnard, 1994). This third condition (UPR) means accepting the interviewee in a warm and non-judgmental way and reminds one to be open for whatever is brought up during a session and to accept it for what it is - without judging it due to personal biases. This is again akin to phenomenology and I believe my practice of UPR helped me to be as non-judgmental as possible when I conducted the interviews.

### **3.3.1 The research setting and participants: Study One**

This part of the research drew on unstructured interviews with elderly stroke patients in a stroke unit in Staffordshire, a county in the northwest of England, (UK). The practical part of the research for this study (i.e. interviews and observations) took place during the period May to October 2000. The UK's National Health Service (NHS) manages the unit, taking care of stroke patients of all races and social classes. At the time of the study this particular unit received patients aged 65 years and older. The unit consisted of two wings (one for females and one for males) with 10 beds in each wing. It also had a dining room, lounge (where patients could socialise amongst themselves as well as with friends and family), bathrooms, kitchen and staff office. Stroke patients stayed there for an average period of three months to receive rehabilitative care from a multidisciplinary team. This team included medical doctors, nurses, physiotherapists, psychologists, dieticians, social workers and occupational- and speech therapists.

After ethical approval was received from Liverpool John Moores University Ethics Committee as well as the Ethics Committee of the stroke unit's NHS Trust, letters of invitation to take part in the research were given to patients in the stroke unit (see

Appendix C for a copy of the letter of invitation) who met the participant criteria as explained below.

Previous studies on stroke in which interviews were conducted with patients after discharge from the chronic setting, revealed that many patients had adjusted to their post-stroke lives (Faircloth, et al., 2004; Pound, et al., 1998), and referred to their lives as not ‘being that bad’ (Pound, et al., 1998). This indicates an acceptance of, and adjustment to, any residual post-stroke disabilities. In order to obtain a snapshot of patients’ experiences of rehabilitation in a stroke unit, it was therefore decided to interview patients for the current study while they were still in the stroke unit setting receiving daily rehabilitative therapies. This was also in order to preclude a range of research variables that may have been created by a transfer from hospital to home. Examples of such possible variables are: more support from family members than would have been the case while in hospital, and less interaction with hospital staff at home than while in hospital. Such variables could have influenced patients’ views of rehabilitation as they had experienced it in the stroke unit. As a consequence this could have influenced their narratives shared with me in interviews. Another advantage of interviewing patients while they were still in the stroke unit is that it helps build understanding of the shorter-term impact of stroke which has been less researched than the longer-term impact (McKevitt, et al., 2004).

All interviews were conducted in a private room in the stroke unit, to ensure confidentiality. Interviews were recorded onto audiotape with the consent of the participants, and transcribed *verbatim*. At any point the interviews could be terminated or the tape recorder switched off at the request of the participants. The interview transcripts were then analysed using the hermeneutic phenomenological principles of van Manen (1990) as described above.

During a set of pilot interviews with three male\* and four female patients (average age: 77 years) it became apparent that patients less than an average of three months post-stroke had not yet received sufficient rehabilitation to be able to provide substantial accounts of their experiences. Also, McKevitt et al. (2004) postulate that the lack of lived experience studies on stroke patients in the acute phase post-stroke is due to their state of shock, reducing their ability to share experiences with researchers. According to the stroke unit records at the time of my study, three months was an average length of hospital stay for stroke patients. Therefore it was decided to interview patients three months post-stroke. Since the majority of study participants would have been discharged after the three months, a longitudinal study of stroke rehabilitation experience in the unit, which could have included multiple interviews and the keeping of diaries, was not feasible. Only one interview per participant was therefore conducted, providing a snapshot of experience in a stroke unit. Criteria for stroke unit participants are presented in Table 2.

**Table 2:** Participant criteria, stroke unit

- |   |
|---|
| <ul style="list-style-type: none"> <li>- able to communicate verbally</li> <li>- ca. 3 months post-stroke</li> <li>- receiving rehabilitation in the NHS stroke unit<br/>where the study was conducted</li> </ul> |
|---|

12 stroke unit patients (five females; seven males) were interviewed for the main part of Study One. Their average age was 78.6 years. At the time of the research all the available participants were of white Caucasian origin and mainly from middle class

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\* The numbers of male and female participants are provided purely to help the reader form an idea of the group of participants and not with the purpose of comparing male and female responses.



backgrounds. Participants were recruited through purposive sampling. This technique does not depend on statistical formulae but involves the selection of participants bearing a study's research questions in mind (Mason, 2002). It enables researchers to satisfy their “specific needs in a project” (Robson, 1993, p. 142) and to “respect the specificities of each subject's response and the meanings of the response to the subject” (Banister, et al., 1994, p. 12). In the current research, the consultant in the unit introduced me to patients in the stroke unit. They were then asked whether they would like to take part in the study and were assured that participation was voluntary. This was re-iterated in the consent forms they signed (see Appendix D for copies of the consent form signed by patients).

In-depth studies are time consuming and complex and “with high complexity a study of more than 15 cases or so can become unwieldy. There are too many data to scan visually and too many permutations to account for” (Miles & Huberman, 1994, p. 30). These authors add that numbers of participants should be decided upon whilst keeping researchers’ own limits of their time and means in mind. Within the timeframe available for my research, a number of 10-15 participants was aimed at. The final number of interview participants in the stroke unit was 12.

The interview data was supplemented with observations conducted of activities on the stroke unit. Observation in qualitative research involves the systematic recording of people’s behaviour and talk (Mays and Pope, 1995). Indeed, according to Pound and Ebrahim (2000) non-participant observation in particular lends itself very well to the study of care in a health setting. In the current research it involved sitting in on, but not taking part in, so-called case conferences where the multi-disciplinary team discussed patients’ conditions, standing in stroke unit corridors and rooms observing activities taking place, and sitting in on patients’ physiotherapy sessions. The latter only took place when both therapist and patient agreed to it. The observer in a research study has to be aware of their

influence on the setting they observe (Cooksy, 2006; Mays and Pope, 1995). In the case of a ‘fly-on-the-wall’ observation the observer stands completely outside the activities being observed. During the observations conducted in the stroke unit I never interacted with patients or staff since they had been told I was there purely to see what happens in a stroke unit. Interaction only took place at the end of each observation period. I was therefore able to be a ‘complete’ observer (Cooksy, 2006) since I did not directly influence the setting. Observations took place at different times during the six months of interviewing patients. Staff and patients therefore had time to get used to my presence, therefore any influence my presence, during observations on the ward, could have had on staff and patient behaviour can be regarded as negligible.

### **3.3.2 The research setting and participants: Study Two**

The Conductive Education (CE) research setting was the headquarters of NICE (National Institute for Conductive Education) in Birmingham, West Midlands, UK. The practical part of the research for this study (i.e. interviews, observations and patient diary keeping) took place during the period April to October 2003. NICE is housed in a renovated Victorian house with a modern purpose built extension to the side of the house. CE services for children take place in the modern building and those for adults take place in the renovated Victorian house. The latter consists of a reception hall, small lounge where learners (the term given to people attending sessions at CE) can relax, and several rooms of different sizes used for offices and activity rooms. Students studying CE at Wolverhampton University (Wolverhampton is a town near Birmingham, England, U.K.) receive placements at NICE for their practical experience. The research focused on adult stroke survivors attending CE sessions, however CE services at NICE also include sessions for children suffering from cerebral palsy and dyspraxia, as well as sessions for adults

suffering from conditions such as multiple sclerosis, cerebral palsy, Parkinson's disease and head injury other than stroke.

Criteria for study participants in the CE setting were similar to those in the stroke unit (Table 3), however the wide range in the time since CE participants' strokes made it difficult to set a cut-off time post-stroke. This has already been mentioned as being a problem with CE research (Brown, 2006b). Therefore a certain time post-stroke was not included in the criteria for study participants from NICE. Also, CE strongly encourages members of participants' families and/or carers to attend the sessions with them so that they can help participants with their movements at home. The carers' presence during interviews and their help with the keeping of diaries, made it possible to allow participants with communication difficulties to take part in my study.

**Table 3:** Participant criteria, CE setting

- |  |
|--|
| <ul style="list-style-type: none"><li>- able to communicate verbally, or being accompanied by a carer who could help with their communication</li><li>- attending CE sessions for stroke at NICE in Birmingham</li></ul> |
|--|

After having received ethical approval from Liverpool John Moores University Ethics Committee as well as approval from the director of stroke services at NICE, letters of invitation to take part in the research were given to adults attending CE stroke sessions (see Appendix E for a copy of the letter of invitation). Through the process of purposive sampling described earlier in this chapter, a total of twelve CE participants (seven female and five male) were recruited to take part in the study. Each participant also signed a form of consent before taking part (see Appendix F for a copy of the consent form).

Group CE sessions for stroke are presented over a two week period (2.5 hours per day, five days a week), after which participants may return for weekly classes if they so wished and can afford it financially. Data collection tools for my study in the CE setting were:

(i) diaries\* kept by participants during such a two week block of CE sessions. Participant diaries reflect on issues relevant to the research and are often used as method of data collection in health care research, helping participants reflect on their experiences (Milligan, et al., 2005; Rancour & Brauer, 2003; Campbell, 1992). Each participant in my study who had agreed to keep a diary was provided with a letter outlining the focus of the diary (See Appendix G for a copy of this letter).

(ii) observations of the participants during their group CE sessions. As mentioned before, the observer in a research study has to be aware of their influence on the setting they observe (Cooksy, 2006). In the case of the research in the CE setting I sat on a chair outside the part of the room where the CE activities were taking place, while I took notes of what I observed. As in the stroke unit, I was again able to be a complete observer and did not directly influence the setting.

(iii) relatively unstructured interviews with stroke survivors having attended the CE sessions.

Eleven of the twelve participants had an average age of 60 years and the twelfth participant was 34 years old. Nine of the twelve were willing to be interviewed, six kept diaries and nine agreed for me to observe them during their CE sessions (Table 4). Nine participants were attending CE for the first time during the period of the research and three participants had been attending weekly sessions for more than one year.

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\* The fact that participants attended a series of ten CE sessions made it possible to include the data collection tool of diary keeping which takes place over a period of time.

**Table 4:** Numbers of CE participants and data collection tools

	Total number in study	Interviewed	Observed	Kept a diary
Number of Males	5	3	4	3
Number of Females	7	6	5	3
Total	12	9	9	6

As in Study One, all interviews in Study Two were conducted in private rooms to ensure confidentiality. Interviews were recorded onto audiotape with the consent of the participants, and transcribed *verbatim*. At any point the interviews could be terminated or the tape recorder switched off at the request of the participants. The interview transcripts were then analysed using the hermeneutic phenomenological principles of van Manen (1990) as described above.

In six of the nine interviews conducted with participants, their carers were present to help with any communication difficulties. One of the participants who agreed to be interviewed as well as keep a diary (Ian - pseudonym) was unable to speak or write. His fiancée, who was also his carer, therefore sat in with him during the interview to answer questions on his behalf and also kept the diary for him. Indeed this was not ideal since the information received was second-hand, however it was felt that via his fiancée he still had an important voice that could be added to the study's experiential data. Another one of the six participants who kept a diary, Beatrice (pseudonym), was also unable to write. Her husband therefore kept the diary on her behalf as well.

### **3.4 Summary**

This chapter presented information on the origins of the philosophy hermeneutic phenomenology which underpins the method used in the current research. The different concepts of phenomenology and hermeneutic phenomenology were discussed as well as van Manen's (1990) guidelines for a hermeneutic phenomenological method. The way in which the latter was applied to the current research was presented. In addition this chapter gave information on the research design of the study and explained the research context, data collection tools and research participants of the two different studies that constitute the current research.

The next chapter, Chapter 4, presents the data from Study One as well as a hermeneutic phenomenological discussion on the data. Chapter 5 presents the data and hermeneutic phenomenological discussion for Study Two.

## **CHAPTER 4**

### **Lived experience of stroke rehabilitation in a conventional stroke unit**

#### **4.1 Introduction**

As explained earlier in this thesis, the research consists of two main studies. This chapter focuses on Study One which explored the lived rehabilitation experience of stroke patients in a conventional stroke unit. The findings are divided into two sections:

- Section 4.2 provides the results of the composing of linguistic transformations, i.e. transformation of the statements that were identified as essential to patients' experiences in the stroke unit, into phrases (themes) that are phenomenologically sensitive (see stage 3 presented in Figure 2, Chapter 3). Each theme and its sub-themes are supplemented by examples of representative transcript quotes which they emerged from.
- In section 4.3 the themes are developed into hermeneutic phenomenological writing on 'being-in-stroke-rehabilitation' in a conventional stroke unit.

In chapter 6 the findings in relation to the broader literature on stroke rehabilitation experience will be discussed.

#### **4.2 Phenomenologically sensitive themes essential to lived stroke rehabilitation experience in a conventional stroke unit**

Hermeneutic phenomenological analysis of the interviews with stroke patients in the stroke unit, together with the observations undertaken in the unit, revealed eleven themes as essential elements of stroke patients' rehabilitation experience. These could be merged into three main themes that provide a better understanding of the essence of the patients' experiences:

- A high level of disempowerment
- A high proportion of negative images of body and self
- Nature of motivation

Table 5 provides a summary of the three main themes mentioned above and their related sub-themes.

**Table 5:** Sub-themes organised next to the three main themes

Themes	Sub-themes
A high level of disempowerment	<ul style="list-style-type: none"> <li>- Feelings of powerlessness</li> <li>- Need for mental and social stimulation</li> <li>- Feelings of insecurity</li> <li>- Poor communication between patients and health professionals</li> <li>- Role of rehabilitation location</li> </ul>
A high proportion of negative images of body and self	<ul style="list-style-type: none"> <li>- Having to cope with changes in way of being</li> <li>- Using negative language in reference to self</li> </ul>
The nature of motivation	<ul style="list-style-type: none"> <li>- Eagerness to re-learn</li> <li>- Importance of emotional support and encouragement from family and friends</li> <li>- Feelings surrounding rate of own progress</li> <li>- Hope that future will bring healing</li> </ul>

The three main themes, as well as their sub-themes, are further described below. Each is supported by a representative selection of quotes from the patient interviews and stroke unit observations. The quotes are typed in a different font from the rest of the text to



facilitate differentiation between quotes and their description. Words in *italics* were added during analysis to put quotes into context; words **in bold** were emphasised by patients during interviews; names in brackets at the end of quotes are pseudonyms. All the patients were close to three months post-stroke, therefore their individual number of months post-stroke are not provided as is the case in Chapter 5.

#### **4.2.1 A high level of disempowerment**

Definitions for the root of the word disempowerment, namely empowerment, are highly contested (Koelen & Lindström, 2005; MacDonald, 1998; Raeburn & Rootman, 1998). Already in the 1980's Rappaport (1988) considered an all-encompassing definition of empowerment to be virtually impossible since it contains both psychological and political elements that imply it would manifest differently for people in different contexts. It is therefore essential to explain the understanding of the term 'empowerment' in the context of this thesis. Individual empowerment has to originate in the individual person and cannot come directly from an outside person's input (MacDonald, 1998). The latter is termed 'impowerment' and does not free an individual from an authoritative person's prescriptions (MacDonald, 1998). An outside person can only encourage empowerment to develop inside another person through for example their behaviour. Empowerment enables an individual to act autonomously and consequently increases self-confidence (Pibernik-Okanovic, et al., 2004). There are two separate definitions of empowerment (Koelen & Lindström, 2005; MacDonald, 1998) applicable to an individual person, that could supplement each other, namely: empowerment refers "to the cultivating of a person's self-esteem to such a degree that they assume power over some aspect of their life, without reference to higher authority" (MacDonald, 1998, p.10) and empowerment is also "a process by which people gain mastery (control) over their lives, by which they learn to see

a closer correspondence between their goals and a sense of how to achieve these goals, and by which people learn to see a relationship between their efforts and the outcomes thereof” (Koelen & Lindström, 2005, p. S12). These two definitions together define the nature of empowerment as understood in this thesis.

The exploration of patients’ experiences in the stroke unit provides numerous narratives characterised by feelings that lie towards the opposite of empowerment as defined above. These lead to the theme title of ‘a high level of disempowerment’ as being a key element thematic of stroke rehabilitation experience in a stroke unit. The following sub-themes gave rise to this theme.

#### **4.2.1.1 Feelings of powerlessness**

The disabilities brought on by a stroke most often contribute to feelings of powerlessness that are associated with disempowerment (Koelen & Lindström, 2005):

- “Take such a thing as eating. I can’t pick up a knife properly, I mean I know I can’t write with it but I couldn’t do a, I wouldn’t even know how to hold a pen, never mind anything else ... Yes I do (*exercise my affected\* hand*), occasionally, but then again, I don’t know, at the end of the day you lose a lot of interest, you know in doing these things, and you can’t keep it up.” (*Malcolm, 57 years old*)

Post-stroke disabilities also most often necessitate dependence on others and their time, which can be embarrassing for patients:

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\* The term affected in this context refers to the limb/s affected by the stroke.

- "I fell out of the settee, just over a week ago ... this (*affected arm*) happened to slide and the pillow went with it, and I tried to catch the pillow. I moved forward and I ended up on the floor ... then I moved over to the shoulder, and I had to shout for the nurses ... I felt like a damn fool because it's as they say, if something falls don't pick it up, call for somebody, but it's an automatic reaction to go after it ... it's so frustrating now, being stuck in one of these things " (Donald, 76 years old)

- "I do cope. I cope very well thank you, except at times, you know, when once or twice that I've been, I had diarrhoea and like, or similar to, you know. Once it starts, it comes out quick. Especially, especially the busy. If I, you know, it comes, the feeling comes on and within two minutes it's all out. Then they've got to change me. (*It makes me feel*) terrible, other people get to know about it and the same with the water. You see if I have a cold drink in the morning, it goes right through me. Immediately. I'd have a drink and about five minutes afterwards I'm running to the toilet.

Interviewer: Do you get there in time?

Peter: I did, (*but*) once or twice I haven't." (Peter, 84 years old)

- "Patients have no privacy. They lie in beds next to each other. On the ward round there are 2 doctors and 1 nurse walking from patient to patient. Arriving at a patient's bed: the doctors examine his files and the nurse informs the doctors about the patient, in front of the patient. They use medical jargon while they discuss something about the patient as 'being low'. I feel for the patient: what if he also overheard them and starts guessing what they meant and puts together an even more distressing scenario for himself. Everything about the patient is discussed in front of him, clear for everyone to hear. The doctors and nurse whisper at times.

The doctor walks over to the patient, greets him and says: "I hear you've been having problems with your waterworks". "Yes doctor". "Well I've asked nurse (*name*) here to increase the dose of your medication and we'll see if that helps, OK?" "Yes, thank you doctor." Dr walks away without a further word, no opportunity given to patient to introduce another subject of concern to himself." (Observation b\_1)

- "Sometimes the curtain is drawn around a patient's bed in the case of a private procedure. However everything said behind the curtain can still be heard by all the other patients – thus no real privacy." (Observation b\_2)

Asking for help sometimes leads to insensitive behaviour from hospital staff, making patients feel as though they do not have a say in matters regarding the care they receive. They could perceive it as though their existence is not fully acknowledged, as illustrated by the following:

- "I mean it's not fair to push people, in a wheelchair, into a room or their own bedroom, where they have no facilities to be able to do anything to occupy their mind. And very often that happens and then if you can't reach your bell you're stumped ... they're so busy that they in fact turn a blind eye or a deaf ear many times. Needs a lot to be desired really." (Lily, 73 years old)

- "Patient X calls a nurse to be taken to the loo. A nurse walks past and says 'just a minute' ... It is now 30 minutes ago, the patient is still waiting. (Observation d\_2)

- "I've completed my interview with patient Y and asked a nurse who did not look too busy to return him in his wheelchair to the Day Room so that he can socialise with the others. I've asked the nurse 20 minutes ago but still patient Y is stuck in her wheelchair, alone in the room where I interviewed her." (Observation d\_3)

#### 4.2.1.2 Need for mental and social stimulation

Hospital staff appear to mainly give attention to patients' physical needs. Non-physical needs such as emotional support and needs for mental and social stimulation receive little, if any, attention. This leads to great boredom and frustration for patients and feelings of frustration seem to increase their sense of powerlessness:

- "That is one of the problems here, there is not enough going on to stimulate us ... and we need some to get (*our heads*) working probably, don't we? Oh yes, yes (*it does get boring here*), you can imagine yourself, you're sitting here looking at four walls ... That's very frustrating. You just have to put up with it. There's not much you can do about it ... (*We need*) something going on, that would activate the mind more ... because we sit in the room there, and look around you, there's four walls and windows."  
(Donald, 76 years old)

- "It (*our free time*) is very boring in it's the same thing everyday." (Brian, 76 years old)

- "Sometimes I wish I could, you know, **do** something, instead of just lounging about. It is very boring." (Molly, 78 years old)

#### 4.2.1.3 Feelings of insecurity

The on-set of a stroke is sudden. Patients' lives were unexpectedly interrupted and post-stroke they have to come to terms with often bewildering changes. Many participants reveal feelings of insecurity concerning areas of their lives that were secure before their strokes, and areas they used to have control over:

- "I don't know. I'm hoping to read again. I certainly think it's a good thing to be able to read, but hmmm whether I'm achieving anything, I don't know."  
(Fiona, 81 years old)

- "When you think about how you are and you might never recover from it ... that's depressing." (Donald, 76 years old)

- "It's a feeling of hmmm not being in control of your own **self** again, and hmmm ... uncertainty as to what the future is going to hold for me." (Lily, 73 years old)

Loss of physical abilities often necessitate having to make adjustments to patients' existing houses or having to move into new accommodation altogether. This creates even more uncertainties, and also contributes to feelings of powerlessness:

- "I have a lot of doubts for the future. See, the house that I live in is not suitable for this (*wheelchair*). One step in the front. My wife's an invalid, she couldn't get the wheelchair in. She has difficulty even pushing me a few yards." (Donald, 76 years old)

- "I think what's going to happen to me ... because I've got to get out of me flat. The people that are on (*my case*) say that I can't stop there, if I can't do nothing for meself I've got to get out ... so ... I feel, it makes me feel sad and, and unhappy, because I've been there for ten years." (Molly, 78 years old)

Feelings of despair initiate a negative spiral effect and patients get frustrated and impatient with the whole process and with themselves:

- "There's other people in the same predicament as yourself, it doesn't lift you up at all. In fact when you see someone, someone getting on a bit better than you, it's more frustrating than uplifting. I wish it were me of course. If someone comes in the room who has been faster, and he's walking, even with a frame, and you're not doing that, it makes you feel: what's wrong, why aren't I like that?" (Donald, 76 years old)

- "(*Once*) I was left sitting on the loo and reached out for something and slid onto the floor and hit my forehead. A huge lump came up very quickly and I had a black eye all down the one side of my face, and that was really only through leaving me. They (*hospital staff*) shouldn't have left me at that time but they were very apologetic and rang my husband up straight away and did what they could, but nevertheless it shouldn't have happened. So it is, as a result it's made me very nervous since, for being left even for a few minutes, because my balance is not right yet, you see, and you grab for the nearest thing you can reach and that's often not very safe." (Lily, 73 years old)

- “Then I was taken off the Zimmer frame and told to use a stick. And **that** was my downfall ... (*because*) my balance is not so good and I sort of bend in the middle.” (Mary, 89 years old)

#### 4.2.1.4 Poor communication between patients and health professionals

The kind of relationship between patients and health professionals is greatly revealed in the quality of communication amongst them. Patients seem to experience poor communication from the health professionals in the stroke unit, and therefore lack in knowledge about their own situation. This seems to commonly lead to confusion and uncertainty for patients – another possible cause for feelings of powerlessness:

- “They (*hospital staff*) just come and say: so and so, and then they’re off. Well I suppose I could (*have said something in return*), but I wasn't **sharp** enough, I was so surprised (*when told I can go home*). I seemed to be, a bit **flustered**, if you know what I mean, ‘cause it was first one (*nurse*) and then another coming to me and I mean, I’m not as bright as I used to be ... so that’s **one** thing I’m a bit concerned about. It’s just that ... I’m hoping I’m going to be all right.” (Mary, 89 years old)

- “I feel there’s something there, as though there’s pressure (*in my head*), like a sort of numbness, since I had the stroke, yes. I tried to tell (*the nurses and doctors*) what it feels like there. They just made a note of it, they didn’t say anything.” (Donald, 76 years old)

“Interviewer: ‘If there’s anything that you would have liked to change in the hospital, if there was anything and if you could change that, what would that be?’



Fiona: I think they should have a book that tells you all the ins and outs how to go on, with information on what to do after the stroke ... I think it would (*help*)” (Fiona, 81 years old)

- “I went to say hello to a patient I interviewed last week and the following happened: While I am talking to her the doctor comes in to tell her she is to be discharged the following day. This comes as a blow to her since she’s not yet able to walk independently. The tears start to roll down her cheeks and the doctor just walks away followed by the nurse. She receives no emotional support. No-one consoles her and it is left to me to try and say something. Nothing I can say will change her reality.”(Observation j\_1)

- “During the ward visit the doctor tells M that because she’d had a successful home visit she could be discharged. M is delighted. The doctor and accompanying nurses leave her bedside. M is bursting with joy but she has no-one but me to share her joy with. Health professionals do not seem to realise the immense importance of these moments for patients.”  
(Observation j\_2)

#### **4.2.1.5 Role of rehabilitation location**

Patients do not have fond memories of their time spent on the acute ward, i.e. the part of the hospital where they were first taken care of after their strokes. They report having felt like numbers and don’t feel they were well cared for there. Patients therefore consider the stroke unit to be much better, as far as rehabilitative care is concerned, than the acute ward:

- "It didn't take me long to adjust to (*the stroke unit*), mostly because I was scared of being sent back to (*the acute ward*). It wasn't very nice." (Molly, 78 years old)

- "(*I was*) not very well (*taken care of on the acute ward*). I didn't like it. I didn't like the hospital ... I don't know (*why*), there's something about it I didn't like. Noise for one thing, a noisy hospital." (Peter, 84 years old)

- "I came here (*to the stroke unit*) from Ward X (*acute ward*) down at C. (*hospital*). And there of course when you get up you have to sit by the side of your bed all day. Now of course here it's more, well more like a **home**, isn't it? ... it's more hospitalised at C. (*acute ward*). The therapists come round, it's sitting by your bed all day ... And you're stuck with it, you know." (Joseph, 76 years old)

- "Well they've got more time (*in the stroke unit than in the acute ward*), anybody would come to you immediately ... It is really, it is really I mean all the food really, I mean it shouldn't be as good as, well it's very good here. You know at breakfast time at the other hospital (*acute ward*) I just got a drink of orange in the morning, and a knob of butter wrapped in polythene and a dried-out piece of toast. They had it dry and cold, now if you've only got there and you can't spread it, nobody spreads it for you so you never ate it, did you, you just had the cornflakes and left the toast. Well you couldn't eat it, I couldn't spread it and nobody would come and do it for me. See they would do everything here for you, even cut it for you." (Anthony, 75 years old)

- "Well it's the comfort and the nursing staff (*in the stroke unit*), it all helps. It's much better here than what it was when I was in A. (*the acute ward*) when I had me stroke. You can't compare it at all with this ... The nurses didn't seem to bother." (Isaac, 72 years old)

## **4.2.2 A high proportion of negative images of body and self**

### **4.2.2.1 Having to cope with changes in way of being**

'Being' before the stroke and 'being' after the stroke are significantly different from each other due to the effects of a stroke. In many cases participants' rehabilitation experience include having to adjust to a new way of being, a new way of being-in-the-world. This adjustment is most often accompanied by negative images apparent in the following quotes:

- "I don't think I shall be good enough to do what I did. I don't think I shall come to that place, you know, I hope, like I was beforehand. I don't think I shall ever do that again ... I feel a bit despondent at times about it, thinking I shan't be able to do what I did. Difficult to put up with it ... I've got to adjust all together, yes, in everything actually ... I've got to adjust me whole life. Well (*the stroke*) stopped me doing things that I'd like to do (*at this point he became emotional*). I've just got to try and get back to where I was ... I mean after years, doing different things, it's awkward." (Peter, 84 years old)

- "(*My appetite is*) not the same. It isn't the same, no, I mean hmmm I don't know, it's a different life entirely. I can't be interested in anything really, all you're interested in is thinking about going home, what could be." (Malcolm, 81 years old)

- "It's awkward starting walk at first, you're like a tin soldier. The stroke, it's like being back to your childhood, you can't dress, you can't, you can eat, just about. There's lots of things you've gotta learn and do again. And you feel so incapable, that's the trouble ... that's, that's the worst trouble, it's the frustration, trying to do things you used to, you knew you could, but your limbs don't answer the same as they used to do." (Isaac, 72 years old)

#### **4.2.2.2 Using negative language in reference to self**

The loss of ability as a result of a stroke, seems to cause anger and despondency in patients. Patients often use negative language in reference to themselves in general, or their body parts, after the stroke:

- "You can't hold a book, you need to shut it with the other fingers. I never used to do anything with my left hand. I did all with me right. I tell you, you're only one-handed, you know. I mean my hand does move but my forearm doesn't move at all, it just lies limp, but it does shift about, but as I say it doesn't do any good when you eat, when you touch the plate, the food or anything, it's all over the place, you know, you can't control yourself." (Anthony, 75 years old)

- "*(after the stroke)* I became useless." (Fiona, 81 years old)

- "It's awkward starting walk at first, you're like a tin soldier. The stroke, it's like being back to your childhood, you can't dress, you can't, you can eat, just about. There's lots of things you've gotta learn and do again. And you feel so incapable, that's the trouble ... that's, that's the worst trouble, it's the

frustration, trying to do things you used to, you knew you could, but your limbs don't answer the same as they used to do. I can move this hand (*his left, affected hand*) now but hmmm it's not as adaptable as this one (*his right hand*). I mean I can pick up something with that (*right hand*) but I shall have a job with this one (*left, affected hand*)." (Isaac, 72 years old)

It appears, through their use of negative terms, as though patients direct their anger and frustration towards their affected body part/s:

- "It doesn't come very easily, and the same with my bad leg that doesn't function as I'd like it to. You get one leg and one arm goes haywire ... and the leg, getting that going, has been most difficult." (Lily, 73 years old)

- "I want to walk you see. I look at it this way: in life, if you've got two legs you're independent ... Even if you've got a bad arm, you're still independent if you've got two legs. If you've got one bad leg it doesn't matter how the rest of your body is, you have to rely on someone, and there's no way 'round it." (Joseph, 76 years old)

### **4.2.3 The nature of motivation**

#### **4.2.3.1 Eagerness to re-learn**

The willingness to get better and be independent again, brings about an eagerness, a motivation to (re)learn those things patients need in order to work towards their goals:

- "When I could walk, I could, I walked **a lot** with the Zimmer frame, so much so that two or three nights my knees were really off and even my elbows, with holding, you know. It's a strain 'cause you use your muscles

that you don't normally use, don't you. I was doing that very well there but I really over did it, but I mean you know how, what it's like if you're trying to get better, you want to get better quickly, don't you." (Mary, 89 years old)

- "You see the trouble with me is I'm trying to run before I can walk. I want to walk you see. I look at it this way: in life, if you've got two legs you're independent." (Joseph, 76 years old)

- "I said (*to myself*): I'm going to learn. I'm open for learning, yes that's what I'm open for. And I'm eager to learn **more**, you know." (Susanne, 82 years old)

- "If I can walk I can do the rest. I think so, 'cause I've got the will to do it."  
(Malcolm, 81 years old)

#### **4.2.3.2 Importance of emotional support and encouragement from family and friends**

Visits from patients' family and friends are often described as being the highlight of their days in the stroke unit, increasing levels of motivation. Visitors seem to represent a link to the outside world, to 'normality':

- "I'm not short of visitors ... it's like being back home, you know." (Brian, 76 years old)

- "And then the support of your family, you know. If they don't want to know you, you'd be very lonely. But I think visits and visitors really make your day ... I always say the days drag, if there's no visitors." (Joseph, 76 years old)

- “The people who **visit** the patients, you’d be surprised how, ooh, friendly they are. I can’t quite think of the word, but they have, they’re sympathetic with you. You know, the staff and the, not the staff, the patients’ relatives, yeah, and you get to know them so well when you’ve been in hospital for three months. See because they come in here from hmmm ooh about four-o-clock ‘till ten, you see, and they come in anytime. So there’s always somebody popping in. And then you get to know them and you say: oh hello, as they come in and they go to find their relatives. It’s, very, it’s nothing like a hospital atmosphere. It’s, well it’s really a rehab place, isn’t it?” (Mary, 89 years old)

- “I hope I can, I hope I do get better ... I mean when I tell me grandchildren ... they’re so, it’s lovely to see their faces and you know, they say: nan work on hard, work hard on.” (Molly, 78 years old)

#### **4.2.3.3 Feelings surrounding rate of own progress**

Most patients seem to be eager to learn and progress. For those making good progress rehabilitation is accompanied by feelings of joy, which seem to contribute to increased self-belief and motivation:

- “I think I’m going the right way. Well I think I am, I’m not going backwards I mean there are some in here who’re not going the right way at all. I compare myself to them and I think: you’re all right, Anthony, you’re all right, you keep going.” (Anthony, 75 years old)

- “I **get** things and then I think: well that’s sort of coming right. (*Makes me feel*) happy (*laugh*).” (Suzanne, 82 years old)

- “Before, I couldn’t move me hand, I couldn’t move me leg. You see the, I can feel that it’s swollen but I can move me leg now. But the weight of it of course is, is stopping me a bit, but I can lift me leg up like a normal leg and hmmm no I’m getting on very well, I’m quite pleased.” (Joseph, 76 years old)

Slow progress (or no progress at all) on the other hand is also sometimes experienced. This seems to decrease levels of motivation and increase more negative feelings in patients such as frustration (lack of patience) and other forms of emotional pain:

- “My visitors that come, they keep telling me I’m looking a lot better and seem a lot better, yes, which helps, so I must have improved a bit ...  
(*Progress*) is slow, it seems very slow and one must have endless patience.” (Lily, 73 years old)

- “I’ve realised from the start that it’s going to be a long, long job. I know I’ve got over a few small things but it’s a long, long job, it’s not a rush job, it’s a long, long, painful job.” (Brian, 76 years old)

#### **4.2.3.4 Hope that future will bring healing**

Many patients hold faith in the future to bring them healing or at least partial healing (such feelings may contribute to increased motivation to work hard in rehabilitation in order to reach a better future, therefore they are categorised under the main theme of motivation):

- “I think it will work out. It’s just that I’m **hoping** it will work out, shall we put it that way.” (Mary, 89 years old)



- "I hope I can, I hope I do get better." (Molly, 78 years old)

- "Well I hope I win. Underneath me round chest, you know I hope I win. I shan't tell them any of it but I hope I win. I shall be me old self then (*laugh*), that'll be all right for me. I look out of the present and I've got a goal, I've got **that** you see, but I haven't got the present that I **want**." (Suzanne, 82 years old)

- "So my balance hasn't gone right yet, that's the biggest problem. Maybe one day it will right itself. We just hope so ..." (Lily, 73 years old)

#### **4.3 Hermeneutic phenomenological writing on 'being-in-stroke-rehabilitation' in a conventional stroke unit**

A hermeneutic phenomenological exploration of stroke rehabilitation experience in a conventional stroke unit at three months post-stroke, provides a snap-shot of the essence of this phenomenon. Study One's more holistic approach to lived experience addressed several distinct elements of stroke rehabilitation experience, including physical, emotional and social experience. This is in contrast with previous research which tends to only focus on one pre-determined area at a time for example experience of physiotherapy (Pound, et al., 1994), eating (Jacobsson, et al., 2000) and assistive devices (Gitlin, et al., 1998).

The hermeneutic phenomenological interpretation of the data below has been written with reference to the phenomenological literature, and is guided by the main and sub-themes that emerged from Study One. This is in keeping with the suggestions of van Manen (1990) as discussed in Chapter 3 of my thesis.

### **A high level of disempowerment**

‘Being-in-the-world’ for stroke patients in rehabilitation, or rather: ‘being-in-stroke rehabilitation’, is revealed to be weighed down by feelings of powerlessness. The sudden loss of the familiarity of their own bodies, and the inability to act independently from medical assistance, threw patients’ lives into a chaotic sea of insecurity. ‘Being-in-the-world’ as independently mobile beings is only really appreciated when that same independence is taken away. Normally we go about our daily tasks in a virtual un-awareness of our physical bodies (Sartre, 1956). Miller (1982) points out in the ‘*Absent Body*’ that the body stays absent in our everyday lives until a part of it becomes ill, draws our attention to it and becomes present, through pain. van Manen (1998) supports this in saying that once the well-being of a person is disturbed, that person moves into an intense awareness of their body and, in a way, they then discover their own bodies, albeit different from before their illness. For the stroke patients in Study One it was through its physical *painless* but emotional *painful* absence that independence became salient to them, making them painfully aware of their inability to cope with life in the manner they used to. Some patients also had to deal with the fact that they needed to be fed, bathed and dressed - as one patient said it was like being back in his childhood. The function of eating and bathing, which ought to be comforting and most often pleasurable, had been turned into embarrassing moments by the stroke.

Patients’ bodies became eclipsed, as a part of them became silent, leading to a disintegration of the integrated whole of the body where its separate parts work together. Indeed, hemi-paralysis can cause patients to feel they have a “divided body” (Kvigne, et al., 2002, p. 64). The participants in Study One therefore did not only lose their sense of integration with the world around them, but also their sense of integration that existed within their own bodies. They could not trust their bodies the way they used to. They seem

to have lost their sense of belonging and searched for explanations and ways to cope with the changes in their being. The connection between mind and body illustrated by research into psychoneuroimmunology suggests that such stressful feelings have negative effects on the body as a whole (Vitetta, et al., 2005), linking in with the concept of holism referred to earlier in my thesis. With this knowledge at hand, it becomes even more paramount for health professionals to address patients' minds and bodies as a whole, and also help patients to regain a sense of integration within their bodies and within society.

Feelings of disempowerment in 'being-in-stroke rehabilitation' seem to also be characterised by a lack of patients' knowledge regarding their own situation. They have to learn to manage life when their own lives had been altered so radically (Frank, 2002). They have to get to know themselves as they would a stranger, without the support of more knowledge about the strangeness staring them in the face. Indeed, "illness is something to recover from if you can, but recovery is worth only as much as what you learn about the life you are regaining" (Frank, 2002, p. 2). According to van Manen (1998) explanation of an illness situation can help healing take place, in that it reduces part of a patient's anxieties. Patients' narratives on 'being-in-stroke rehabilitation' revealed a thirst for explanations and knowledge, something to hold on to in the insecure future they were facing.

For patients, suffering is a crises of the spirit but for many health professionals suffering is "a problem of management" (Frank, 2002, p. 131). In order to make sense of their spirit's suffering, patients experiencing 'being-in-stroke rehabilitation' thought and wondered about their situation, increasing the numbers of questions created by this wondering. On asking questions related to their spiritual suffering they often only received managerial answers, more aimed at helping them at that moment but it was not enough to have alleviated fears for the future. This poor communication between themselves and

health professionals clearly did not lighten the load of questions lying heavy on patients' minds.

Patients kept on searching for recognition of their emotions such as fear and low self-esteem. The cliché 'sorrow shared is sorrow halved, joy shared is joy doubled' (Anonymous) comes to mind. However it is possible that health professionals looking after the participants in Study One felt uncomfortable with patients' emotions because they (the professionals) could not control the emotions. "Those who provide treatment give patients cues as to the emotions that are appropriate to express. Because patients are dependent on medical staff, they tend to accept these cues" (Frank, 2002, p. 100). This quote supports an experience I had with a consultant doctor in the stroke unit early on during my research for Study One:

The consultant introduces me to a patient called Rob. I start talking to him and say "I would like to hear your story, about your experiences here". Rob becomes tearful and says yes, he would like to talk to me. At this point the consultant calls me to one side and says: "use a different tone of voice when talking to patients, be more matter-of-fact. This will prevent patients from becoming emotional and floodgates opening. You might find that you can steer the interviews better when patients don't get emotional." I am stunned and at first at a loss for words. Such a comment is like a bucket of cold water thrown unexpectedly at someone: shocking and cold. I decide not to acquiesce but to stand up for what I believe in. I reply by saying: "the interviews are guided by the patients. If a patient starts to cry I ask if they want to stop the tape and do so if they want and we continue later, if they

want\*. But I follow the patient and allow them to be who they are at that moment in time.” The consultant just looked at me and smiled.

This experience illustrates the way in which patients’ emotions are not recognised in order to protect staff rather than acknowledge patients’ being. The ability and opportunity to share your own losses with someone else is often the most peaceful way to live with your losses (Frank, 2002). It is plausible that even if a health professional would simply take the time to sit with a patient and allow them to cry, it could contribute effectively to the patient’s moving through emotions.

Stroke rehabilitation is a series of rehabilitative therapies for patients that have been found to focus mostly on patients’ physical recovery (see Chapter 2 of my thesis). The findings in Study One revealed that the patients did indeed experience these therapies to provide them with neither enough mental and social stimulation nor enough emotional support. Patients “experience and live with their problems in a different, sometimes deeply personal and unique manner” (van Manen, 1998, p. 1) as is very well illustrated in the following quote by a stroke victim-turned author<sup>#</sup> shortly before he died: “ ‘You can handle the wheelchair,’ said the occupational therapist with a smile intended to make the remark sound like good news, whereas to my ears it had the ring of a life-sentence. In one flash I saw the frightening truth ... (*the therapists*) all left.” (Bauby, 1998, p. 17). In this case the therapists completed their tasks for that day, however for Jean-Dominique Bauby and an infinite number of other stroke patients in the same situation, it came as a severe reality-check: having to constantly deal with an unpredictable and strange body, entering an unpredictable and strange future with this unfamiliar part of themselves, i.e. their bodies. It illustrates a difference in views between therapists and patients, for example: the

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\* One of the hospital ethics committee’s requirements for Study One was to provide patients with information and contact details of a local counselling service if they needed to talk about issues that came up during the interview. Further emotional support was therefore provided for them if they needed it.

<sup>#</sup> He was not a participant in my study.

former might believe they have completed their task when they verified the level at which a patient can perform a specific movement. However for the patient their ability or inability to perform would have opened up more questions than just ability or inability and they might be in great need to talk their feelings through with staff. It is at this point however where 'being-in-stroke rehabilitation' seems to fall short.

### **A high proportion of negative images of body and self**

It is evident that the physical consequences of a stroke can include a vast range of difficulties (Anderson, 1992), all having an impact on 'being-in-stroke rehabilitation' and on images patients have of themselves : 'Weakness on one side of the face' could impact negatively on a person's self-esteem through feelings of embarrassment about the way they look; 'difficulty in seeing out of one side of each eye' could cause confusion in a person's visual perception, and also in their experience of their world; communication problems could increase feelings of distress and could make a person feel isolated, misunderstood and unable to connect with the world around them; 'difficulty in coughing or swallowing' could increase feelings of anxiety about the possible occurrence of choking, a life threatening occurrence at the most and a social embarrassment at the least; 'incontinence of the bladder' could contribute to already existing feelings of helplessness and could also bring about feelings of embarrassment and loss of dignity.

Exploration of 'being-in-stroke rehabilitation' as a phenomenon revealed that patients did indeed hold a large number of negative impressions of themselves and their physical bodies. A body eclipsed by a stroke most often does not answer to the requests made by its operator, i.e. the person living in that body, in the way it used to do. In fact, the way in which the body does answer is often described with using images of inability and loss. This was exemplified by participants in Study One and the apparent ways in which they referred to their changed 'being-in-the-world'. Their illness experience commenced without any

warning and changes brought on by stroke arrived unannounced in their 'being-in-the-world'. A stroke throws one in at the deep-end and does not provide time to first adapt to the idea of the possible causes of stroke. Patients referred to the stroke having stopped them from doing the things they were used to do and that in fact they had to adjust their entire lives. They had difficulties imagining themselves coping with life easily again. Frank (2002) states that the "mind also thinks through the body (which) it is a part of" (p. 87). We perceive the world through our bodies. van Kaam (1966, p. 22) wrote "my body makes the world available to me; it is in and through my body that the world becomes-for-me, becomes mine, my world." The sudden on-set of a stroke causes a sudden change in patients' bodies and therefore also in the way the world "becomes" for them. It follows that stroke patients need a new frame of reference for when they think of their bodies, and in effect of their own 'being-in-the-body'. Strategies for development of such a new framework, for example general coping strategies, were not overtly provided to patients in Study One. This most probably lead to their feelings of frustration and anger, the symptoms of which included use of words with negative connotations when they talked about themselves post-stroke. One patient compared his body to that of a tin soldier. This image revealed he thought of his body as being stiff and unable to perform free movement. Of itself the image of a tin soldier is not negative but in associating one's own body with it creates an image which is the opposite of what a patient would like, which is free movement. Their limbs affected by the stroke were described with negative terms such as lying 'limp' or that a specific limb just 'shifts about'. In describing how eating had become a challenge with disabled limbs, a patient arched the uncontrollability of limbs over his whole self by stating 'you can't control yourself'. Negative images of body parts therefore seem to have enveloped the whole of his 'being-in-stroke rehabilitation'. One patient even went as far as saying she 'became useless' after her stroke.

Stroke patients often described their unaffected sides as their ‘good sides’ and their affected/disabled sides as ‘bad’, illustrating a dualism in the way they thought of themselves. The repetitive use of words such as ‘bad’ may lead them into a snowball effect of using more and more words with negative connotations, later in effect expecting disablement from their bodies. Research has indeed shown that repetitive use of such words does not contribute positively to patients’ recovery (Graham, 2004).

It could be suggested that dualism is also visible in the way health professionals and patients think of patients’ bodies as separate from their minds when talking about parts of their bodies (Frank, 2002). This is apparent in the way patients refer to ‘*the* leg’ or ‘*one*’s leg’ rather than claiming back their affected limbs and talking about their limbs as ‘theirs’. Having to cope with an estranged body, ‘cut’ into two by a stroke, cannot be easy.

### **The nature of motivation**

‘Being-in-stroke rehabilitation’ is enveloped by an air of working towards independence, freedom. Viktor Frankl (1905-1997), Austrian psychiatrist and survivor of Nazi concentration camps, developed the view that “all freedom has a ‘from what’ and a ‘to what’” (Frankl, 2000, p. 59). This reflects the Husserlian concept of intentionality, which states that consciousness is always directed to something (see Chapter 3). Working towards the start of freedom while ‘being-in-stroke rehabilitation’ could also be said to have a ‘from what’ which is the stroke. However its ‘to what’, i.e. freedom, is more difficult to describe since it lies in an unknown future. Patients could not be guaranteed that they would get to the ‘to what’ of freedom, and if they were meant to reach it health professionals were unable to guarantee the level of freedom they would reach. The unpredictable nature of patients’ illness trajectories therefore played a determining role in the ‘to what’ of their ‘being-in-stroke rehabilitation’. Despite this uncertainty patients still



showed motivation for working towards freedom. Frankl (2000) describes motivation as people's intrinsic search for meaning in life. This search is seen as the essence that keeps them moving towards their goals. In the case of 'being-in-stroke rehabilitation' it seems that patients' search for meaning in their post-stroke lives moved them, motivated them to keep on working towards their goals. It follows that if a patient is unsure of their goals or future in general, their levels of motivation may suffer. Indeed, "he (who) knows the 'why' for his existence ... will be able to bear almost any 'how' (Frankl, 1962, p. 80).

Motivation for working towards recovery while 'being-in-stroke rehabilitation' seems to have been influenced by both internal and external sources of motivational energy. An internal source was patients' willingness to re-learn. Lack of independent movement encouraged patients to 'want to' re-learn execution of movement. Their own progress towards re-learning can then be recognised as a secondary internal source of motivation which built on their willingness to re-learn. However, when patients saw others progressing well when they themselves did not progress well, they experienced feelings of discouragement, the opposite of motivation.

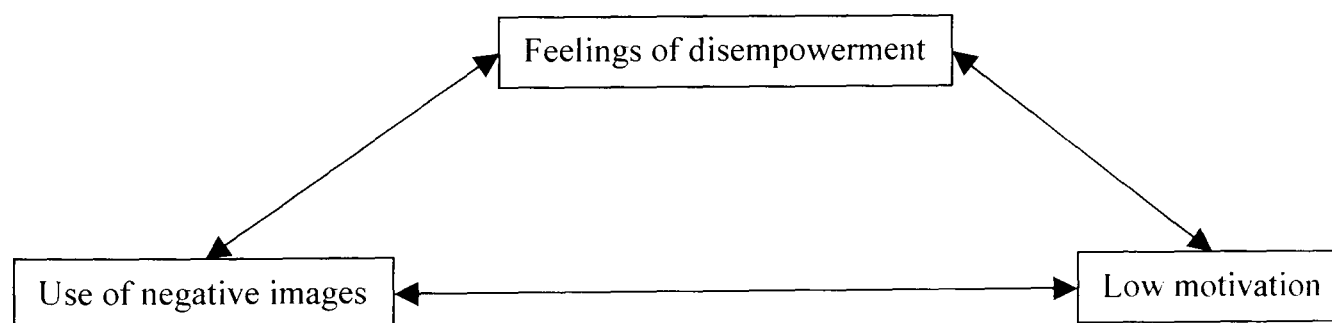
Support from family and friends, encouraging patients to 'do better', and rejoicing with patients when progress had been made, were external sources of motivation. Visits from patients' family and friends were often described as being the highlight of their days in the stroke unit. Visitors seem to also have represented "fragile threads" (Bauby, 1998, p. 111) that linked patients to the outside world, to 'normality'. These threads most probably also helped patients in their search for meaning in their post-stroke lives.

Keeping in mind Frankl's (Frankl, 2000) view of motivation as being one's search for meaning, stroke patients' expressions of hope for healing can be seen as part of their search. It is as though their flames of hope kept alight possibilities of a future free from disability and dependence, a future that would return meaning to their disrupted lives.

Patients hoped they would return to independence even though the unpredictable course a person's body takes after a stroke could not give strong ground to base this hope on. It became clear in Study One that visits from patients' family and friends and the emotional support and encouragement received from them, helped to keep their flames of hope burning inside them, keeping them motivated. Some patients did relate how their own hope sometimes dwindled, often due to the slow rate of progress, but was then reignited by their families' hopeful words and facial expressions.

#### 4.4 Summary

This chapter provided a better understanding of 'being-in-stroke-rehabilitation'. It presented the themes and sub-themes essential to this phenomenon and discussed them within a hermeneutic phenomenological framework. On closer inspection, the three main themes of disempowerment, negative images and motivation, reveal a possible interaction between themselves (Figure 3).



**Figure 3:** The possible interaction between the three main themes essential to 'being-in-stroke rehabilitation'

Patients' levels of motivation could be strongly influenced by the first theme, i.e. feelings of powerlessness. The latter may reduce patients' interest in finding meaning and

therefore their levels of motivation could be negatively affected. Low levels of motivation may in turn increase feelings of disempowerment. But combined with feelings of powerlessness low levels of motivation may also contribute to the second theme, i.e. use of negative images. The use of negative images may contribute to more feelings of disempowerment but also in turn to low levels of motivation. The essence of 'being-in-stroke rehabilitation' as revealed in Study One reveals an experience characterised by negative elements (i.e. the three main themes). If health professionals could prevent even only one of these negative elements, 'being-in-stroke rehabilitation' may be a more positive experience.

The next chapter, Chapter 5, presents the data and hermeneutic phenomenological discussion for Study Two, which explored the lived experience of Conductive Education for stroke.

## **CHAPTER 5**

### **Lived experience of stroke rehabilitation in a Conductive Education setting**

#### **5.1 Introduction**

This chapter focuses on Study Two which explored the lived rehabilitation experience of stroke patients in a Conductive Education (CE) setting. Since it is customary in CE to call its attendees learners, the participants of Study Two will also be referred to as learners, or stroke learners.

As with Chapter 4, Chapter 5 is also divided into two sections:

- Section 5.2 provides the results of the composing of linguistic transformations, i.e. transformation of the statements that were identified as essential to learners' experiences of CE for stroke, into phrases (themes) that are phenomenologically sensitive (see stage 3 presented in Figure 2, Chapter 3). Each theme and its sub-themes are supplemented by examples of representative transcript quotes which they emerged from.
- In section 5.3 the themes are developed into hermeneutic phenomenological writing on 'being-in-CE for stroke'.

In chapter 6 the findings in relation to the broader literature on CE for stroke, as well as CE in general will be discussed.

#### **5.2 Phenomenologically sensitive themes essential to lived experience of CE for stroke**

Hermeneutic phenomenological analysis of the interviews with learners attending CE for stroke, as well as their diaries and my observations in the setting, revealed twelve themes as essential elements of learners' experiences of CE for stroke. These could be

merged into four main themes which provide a better understanding of the essence of the learners' experiences:

- CE increases self-confidence
- CE conductors show Rogerian unconditional positive regard\* for learners. treating them as individuals and not as numbers
- CE activities are often experienced to be challenging, requiring perseverance from learners and carers
- CE encourages body-half integration, leading to awareness of the body as a complete unit

Table 6 provides a summary of these three themes and their related sub-themes.

The four main themes, as well as their sub-themes, are further described below. Each is supported by a representative selection of quotes from the learners. It is important to note that many learners who took part in Study Two referred to CE as being what rehabilitation in the conventional setting was not. Quotes from their narratives therefore include references to both the conventional and CE setting.

The quotes are typed in a different font from the rest of the text to facilitate differentiation between quotes and their description. Words in *italics* were added during analysis to put quotes into context; words **in bold** were emphasised by learners during interviews; names in brackets at the end of quotes are pseudonyms, followed by learners' age and number of months or years since their stroke. As with the gender information provided in Chapter 3, the latter information is provided only to help the reader form a better idea of the learners, since their individual time post-stroke varied greatly. Some of the quotes from Study Two tend to be longer in length than those from Study One. This is

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\* Also see Chapter 3 for a discussion on Rogerian unconditional positive regard

simply because learners at CE talked more during the interviews than the patients in the stroke unit did.

**Table 6:** Sub-themes organised next to the four main themes

Themes	Sub-themes
CE increases self-confidence	<ul style="list-style-type: none"> <li>- Conductors apply a positive approach to learners</li> <li>- Focus on ability rather than on disability</li> <li>- CE increases feelings of independence</li> <li>- CE facilitates formation of a new / adjusted identity for learners</li> <li>- CE's group ethos facilitates an increase in self-confidence</li> </ul>
CE conductors show Rogerian unconditional positive regard for learners	<ul style="list-style-type: none"> <li>- Learners feel valued</li> <li>- Learners feel nurtured</li> <li>- Learners perceive commitment from conductors</li> </ul>
CE activities are often experienced to be challenging	<ul style="list-style-type: none"> <li>- CE is hard work and requires perseverance from both learners and carers</li> <li>- CE activities sometimes create frustration due to their degree of difficulty</li> </ul>
CE encourages body half integration, leading to awareness of the body as a complete unit	<u>N/A</u>

### **5.2.1. CE increases self-confidence**

The findings from Study Two revealed that learners experienced an increase in self-confidence due to their participation in CE for stroke sessions. Sections 5.2.1.1 through 5.2.1.5 provide more information on this particular part of ‘being-in-CE for stroke’.

#### **5.2.1.1 Conductors apply a positive approach to learners**

Suggestions of CE’s positive effect on learners’ levels of confidence can be found in their narratives in which they describe the conductors’ positive approach as early as during their first assessment in the CE setting. The quotes below also reveal a sense of surprise and appreciation:

- “When we came up for the assessment, we walked out and we both looked at each other, and I could see he felt the same way as I did, it was just confidence, wasn’t it? We just felt a high when we came out ... it was just the whole environment, and they just gave (*him*) confidence in what (*he*) could do”. (Fiancée of Ian, 58 years old, 1 year post-stroke)
- “The first time I came here, (*the conductors*) put me on a frame and said ‘walk’, and I walked across the room, (*made me feel*) absolutely bloody wonderful.” (Harold, 58 years old, 1 year post-stroke)
- “First time I came was for the evaluation and I realised nobody was, it wasn’t they weren’t going to help me, but they were waiting to see how much I could do myself, so I did. And I like that attitude, the help was there if I needed it but it wasn’t forced on me. Nobody grabbed me by the elbow and hoisted me up.” (Phyllis, 59 years old, 3 years post-stroke)

The data reveal that conductors' positive approach always include the provision of a sense of hope, regardless of a person's physical disabilities. This overt provision of hope seems to encourage learners in working towards reaching their goals as far as possible:

- "In normal physiotherapy I would say that all that happened was that they got me a little bit mobile. They got me up onto a Zimmer frame or they got me onto a stick and at the same time they said, you know: we can't treat you anymore, good bye. Whereas here (at CE) it's: 'we are working with you, you are going to do as much as we can make you do'. And they present you with a challenge. It's up to you whether you take up the challenge, but they present you with a challenge and say: try this, try this, try this. And I like this because giving me something to go for, giving me a goal, giving me the next step. I'm working towards something. If I go in to normal physiotherapy I know that in a couple of weeks, maybe if I'm lucky a month, it's going to be: well we've got other patients, we're very busy, we can't treat you anymore. And you're out on your ear again, and it's so frustrating and it hurts. It's almost heartbreaking because you work so hard and then suddenly it's gone." (Phyllis, 59 years old, 3 years post-stroke)

- "They've got hope, the people here (at CE). I always said (*while in conventional setting*): this can't be it, you can't just leave me here, this isn't me for the rest of my life, but they just wouldn't take it any further. Now these (at CE) do. They have that little bit of hope that you can do it, and they get you to believe it. They've (CE) given me a lot more hope than I had. I really thought that was it and this was it for the rest of my life. but I



don't think it's going to be anymore. They (*conventional therapists*) told me, and I couldn't believe it, when they told me: this is it, you're not going to improve, this is your life, I couldn't believe it, I just wanted to die. Well, the lady (*conductor*), she explained to me how I felt, and I felt so good, somebody's actually thinking like me, which made me feel good. You see they (*conventional setting*) told me that I'd have my splint on for the rest of me life but (*the conductor*) told me that I can learn a little bit at a time to walk with that and train me foot without me splint, so I can buy nice shoes (*laughs*)."(Laura, 57 years old, 2 years post-stroke)

- "The conductor tells the group not to worry if they don't experience immediate results and that it **will** come gradually. Illustrating provision of hope" (Observation 8/7)

- "The conductor gives them advice on how to improve their walking and shows them how. She says to them that the fine-tuning of movements does take longer but no doubt they will come" (Observation 15/7)

#### **5.2.1.2 Focus on ability rather than on disability**

Learners report having been surprised by their own abilities observed and commented on by the conductors. They compared this with what could be described as the conventional settings' focus on disability:

- "I wouldn't have dreamt of (*walking*) before I came here (*to CE*). Well they (*professionals in conventional setting*) said I've got no balance, but when I came (*here*), M and A (*conductors*) saw me and they said: 'you have got a bit of balance or else you wouldn't be able to sit up in the (*wheel*)chair'. I've

come on leaps and bounds. It's been three and a half years now. I mean it takes a long time. And I know, I don't think I'll ever be able to walk all by myself, you know, like I did before. But the achievement is just to be able to walk with (*my husband*) with a stick. You know what I mean. You just feel so much independent." (Violet, 63 years old, 4 years post-stroke).

- "They (*professionals in conventional setting*) said I wouldn't get anymore movement in my arm, they were more positive here (*at CE*), saying I would be able to get some movement, they gave me a bit of an incentive because the physio had just sort of written me off (*and*) said: 'you won't get any more movement from that arm', so that's it." (Jason, 57 years old, 2 years post-stroke)

- "Much against my expectations I have learned that even at this late stage I have been able to achieve greater movements in my left arm, and integrate better habits. Increased awareness of affected (*left*) side and greater movement than I would have anticipated. Left foot more stable when walking, reduced inclination to turn in. Greater balance due to putting more weight through left hip ... gradually became more aware of my left side (*which I'd*) ignored for years. " (Simon, 57 years old, 18 years post-stroke)

Many learners remarked that the word 'cannot' does not exist in the CE setting.

Conductors and learners together always appear to find a solution if a problem arises. This ability approach seems to help learners in increasing their focus on their own abilities as opposed to their disabilities:

- "The whole ethos of NICE is built around 'can do' so 'do it.'" (Harold, 58 years old, 1 year post-stroke)

- "There's not such a word as 'you can't' is there? 'Yes, you can'. And it makes you feel as if you can do everything." (Violet, 63 years old, 4 years post-stroke).

- "(*At CE*) it's the well-being part, and it was ill-being in physio and the hospitals. (*At CE*) they want you to be well and they want to do more for your being even if you can't do it, they try it and let you, leave you to do it, but physio's and hospitals are just: oh you've got a stroke, well that's it then, you know, there's a bit of physio, just so you're not going to be too tight in your hand, but not anything else. (*At CE*) they, I mean even my, the (*special*) shoes, they'd say: have you got the shoes yet? You know, they're interested in things like that ... I know we're all disabled (*at CE*) with the stroke things but it doesn't feel like one of the ill people. It's positive vibes here, and it's never (*like that*) on the hospital trips anywhere ... It's just negative vibes all the time and I hate them. Here (*at CE*) it's positive. Not like the out-patient clinics (*where*) everywhere it just drains you, it's so negative all the time, the doctors, the people in the clinics. (*At CE*) even if you can't do it, you can try it and even if it's a little thing they go: ooh yes, yes!" (Andrea, 34 years old, 4 years post-stroke)

- "(*The conductor*) encourages all the learners to walk or stand, depending on their individual abilities, without their splints (*for those who wear them*) over the weekend. If they don't wear a splint they're encouraged to walk bare feet. If they feel safe they're told to really try to give a few steps. The conductor explains this is to encourage weight bearing on their affected

feet and also increase their control over their affected feet.” (Observation 10/7)

Learners report feeling encouraged and motivated, often due to the belief conductors show in learners’ abilities:

- “I’d say from the different (NHS) groups I’ve been to they all seem to have the same problem: motivation ...

Interviewer: Do you feel motivated here (at CE)?

Jason: I certainly do”. (Jason, 57 years old, 1 year post-stroke)

- “The group ethos has developed as one of the main strengths. Expectations are high, lots of good feedback for progress, however small.” (Simon, 57 years old, 18 years post-stroke)

- “I’ve had the best care here (at CE) because everybody is totally dedicated. Everybody is working to the same. They’re not distracted by an influx of people off a ward. It is appointments, people come in, they do their bit, then they go away again. And you get 400 percent attention and I feel I’ve had a lot of improvement here and I want it to continue. I feel that here (at CE) I am doing really well. But I don’t want to just reach, I want to do as much as I can and if I can do more at the end of this course I am happy to carry on. Because I feel there is still more I can do”. (Phyllis, 59 years old, 3 years post-stroke)

- “I think when you look at the staff here and the staff at home (conventional setting), they just teach you the basic, mind you they probably don’t know any more. But when you come here, as far as they’re

concerned it's always possible, your body can go that bit further."

(Husband of Laura, 57 years old, 2 years post-stroke)

- "Positive reinforcement takes place all the time. The conductor repeats she is very proud of the learners. The group encourages each other and give applause when someone managed to do something they couldn't do before." (Observation 9/7 )

- "Ian manages to move his affected toes by himself for the first time. The whole group rejoices with him and his fiancée. After that he moves his toes up further with every attempt." (Observation 14/7 )

Conductors are observed to remind learners that whenever a movement causes them pain they have to report it so that the movement can be adjusted in accordance with their abilities to reduce the physical discomfort. Focus is therefore removed from inability to ability:

- "Learners are encouraged to remember that no movement should be forced, they shouldn't feel any pain. If they do feel pain then they're given an alternative movement." (Observation 8/7)

- "Further stretching, without hurting themselves, is encouraged to everyone." (Observation 14/7)

- "The conductor repeats again that if ever a movement hurts they should stop a bit." (Observation 15/7)

- “The conductor bends Harold’s affected wrist for him and asks whether it hurts. Harold replies that it does hurt but tells the conductor not to worry about it. Still the conductor releases the pressure on his wrist. This reminds me of what conductors often say: that if learners feel any pain they should stop a moment to adjust the movement.”(Observation 17/7)

Learners in CE sessions for stroke often report having been told by professionals in conventional settings that they had to accept their disabilities, since it was unlikely they would improve any further. However, during CE sessions for stroke such learners frequently experience improvements in their physical conditions despite the prognosis of conventional rehabilitation professionals:

- “I always said: this can’t be it, you can’t just leave me here, this isn’t me for the rest of my life, but they (*conventional setting*) just wouldn’t take it any further. Now these (*CE*) do ... I really thought that was it and this was it for the rest of my life, but I don’t think it’s going to be anymore. Yes, they (*conventional setting*) told me and I couldn’t believe it, when they told me: this is it, you’re not going to improve, this is your life, I couldn’t believe it, I just wanted to die ...” (Laura, 57 years old, 2 years post-stroke)

Laura’s husband: “... It’s like with Laura’s hand now, the wrist, there’s never been movement there and yet now there is. Her foot, before she came here I can honestly say there was no movement at all, nothing, and after 5 days (*at CE*) it started to, the movement was there. And the speed of (*her*) walking was slow, whereas (*now*) you’ve got to keep up with her.”

- “I wouldn’t have dreamt of (*walking*) before I came here (*to CE*). They (*professionals in conventional setting*) were brilliant there and they tried so

hard, they tried me walking on one of these high frames but I could only do a couple of steps and then I'd be over this that and the other. They said I've got no balance, but when I came (*here*) they said: 'you have got a bit of balance or else you wouldn't be able to sit up in the wheelchair. (*Since then*) I've come on leaps and bounds.'" (Violet, 63 years old, 4 years post-stroke)

- "They (*professionals in conventional setting*) said I wouldn't get anymore movement in my arm, they were more positive here (*at CE*), saying I would be able to get some movement, they gave me a bit of an incentive because the physio had just sort of written me off (*and*) said: 'you won't get any more movement from that arm, so that's it.'" (Jason, 57 years old, 2 years post-stroke)

- "We had been told there's nothing, it's dead (*his left arm*). (*After CE sessions*) I managed to get my hand onto the neck of my guitar, so I'm a lot happier. I couldn't hold my hand there before, it just fell off. So that in itself is a marvellous thing for me." (Harold, 58 years old, 1 year post-stroke)

#### **5.2.1.3 CE increases feelings of independence**

Learners' narratives indicate that CE increased their levels and sense of independence, adding to their self-confidence and feelings of empowerment. Learners are delighted about the feelings of independence they experience when succeeding in performing physical movements according to guidance received from CE. Also, every learner manages to make progress to some degree:

- “Yeah. It’s (CE) made my life easier at home as well because I can get out of bed. Before, B (*her husband*) used to have to pull me up (*from the bed*). But now I roll on my side and I push myself up and sit on the end of the bed and B stands in front and I get myself up and then he just holds me one-to-one to the bathroom. Whereas before Conductive Education, he had to pull me out of the (*wheel*)chair and everything, but I do it myself now. Oh it’s wonderful. It has made such a difference ... Oh I couldn’t believe it, the confidence it’s given me ... I just feel a new person, coming here (*to CE*). I’m so happy. There’s not such a word as ‘you can’t’ is there? Yes, you can. And it makes you feel as if you can do everything.” (Violet, 63 years old, 4 years post-stroke).

- “I can climb stairs, as long as I can hang on to the railing. But perhaps, that’s because, I think they are so good, they’ve given me the confidence back ... I’ve walked over the road for the first time, it was Monday, no it was Friday last week. ‘Cause they’re quite wide roads, I thought: I’m going to walk over there, and I really steeled myself to do it right. And I charged over the road ... Oh it was good, it really was good.” (Lisa, 65 years old, 5 years post-stroke).

Another factor which seems to play an important role in increasing learners’ confidence is the way in which conductors communicate with them and convey knowledge to them. Learners talk about the fact that their sessions at CE give them the knowledge of *how to* perform physical movements. They often say they now “know how”. It seems that this kind of knowledge contributes to their increased sense of self-confidence experienced at CE :



- "I was given a booklet 'An introduction to Conductive Education'. The introduction was written in clear speak ... The writing of the CE introduction most certainly filled in blanks in my own experience, and I felt so much more able to cope with the process of something about myself that I hadn't realised was altered until I read about the situation." (Harold, 58 years old, 1 year post-stroke)

- "I said (*to the conductors*): I didn't know we'd come for miracles (*laughs*) and what we were then told was that he probably could have moved (*his arm*) in the previous week or so, but he didn't know how. So here they showed him how to move it. (*Here they're*) showing you how you do these things." (Fiancée of Ian, 58 years old, 1 year post-stroke)

- "And then you see, you get another thing hmmm at home when Laura (*his wife*) was walking, never once did they (*conventional setting*) correct it, but she was walking out of the room here one day in the first few days and I. (*a conductor*) came to her and all he said was: take a short step with that one and wobble with your weight and your right leg will come through. And it did! ... (Husband of Laura)

Laura: My walking became so easy." (Laura, 57 years old, 2 years post-stroke)

#### **5.2.1.4 CE facilitates formation of a new / adjusted identity for learners**

In the process of increasing their confidence, learners also seem to find CE helps them to regain parts of their pre-stroke personality and sense of identity:

- "I'm a completely different person, aren't I? (*she looks at her husband*). My personality's gone back to nearly what it was before (*my stroke*). I just

feel a new person, coming here. I'm so happy. There's not such a word as 'you can't', is there? And it makes you feel as if you can do everything."  
(Violet, 63 years old, 4 years post-stroke)

- "I was an active person (*before my stroke*), I used to go to rock concerts and I used to go walking with me animals, and driving, I was on the go. And after the stroke it really hit me hard and I couldn't accept it at all. I hated meself, I hated the world, I hated everything and I hated me body, it was like a black thing inside, one side ruining me life and I just couldn't cope. And me son heard about this CE and they've been wonderful, as you see: I'm laughing and I'm happy and I'm so proud of myself. And I hated myself **so** much (*before CE*) ... Before Conductive Education I was a nobody. I am now a somebody." (Laura, 57 years old, 2 years post-stroke)

#### **5.2.1.5 CE's group ethos facilitates an increase in self-confidence**

As mentioned in Chapter 2 of this thesis, most CE sessions for stroke are conducted in a group setting. This was also the case for the learners in Study Two. Evidence of the benefits of doing group work, such as sharing in each other's success and learning through watching others, can be found in the data. It is likely that these benefits could also increase learners' self-confidence:

- "The group ethos has developed as one of the main strengths. Expectations are high, lots of good feedback for progress, however small."  
(Simon, 57 years old, 18 years post-stroke)

- "The group encourages each other and give applause when someone managed to do something they couldn't do before ... the conductor repeats she is very proud of the learners." (Observation 9/7)



- *"Ian manages to move his affected toes by himself for the first time. The whole group rejoices with him and his fiancée. After that he moves his toes up further with every attempt." (Observation 14/7)*

The opportunity to see other group members carry out exercises seems to be helpful when a learner does not succeed immediately:

- "One learner looks a bit lost, as she does not seem to understand the instruction just given by the conductor. After watching the other learners she seems to know how to continue. She now performs the exercise correctly." (Observation 14/7)
- "Simon struggles with lifting his affected arm's elbow while his hands are clasped together. He notices Claire keeps her clasped hands directly underneath her chin, touching her chin and manages well. He tries to do the same and manages better." (Observation 10/7)

## **5.2.2 CE conductors show Rogerian unconditional positive regard for learners**

### **5.2.2.1 Learners feel valued**

Learners' narratives reflect feelings of being valued for who they are during experiences of CE sessions for stroke. It seems that learners are each treated as an individual and not as a number, revealing Rogerian unconditional positive regard from conductors (Rogers, 1951):

- "With NICE\* the relationship is far more natural and represents a joint effort to overcome current problems. Decisions have been made by the

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\* The abbreviation NICE referring to CE's National Institute is not the same as the abbreviation NICE referring to the UK's National Institute of Clinical Excellence

NHS about me, totally without my knowledge. The arrogance of this stinks. There is talk of teamwork however this does not exist. There certainly is an exchange of recorded information between therapists but communication and this exchange do not include the patient ... you see when I came here (to CE) I had a complete physical. M and A (*conductors*) examined me with a fine toothpick, didn't they, and we had a four to five page report of what I must do health-wise. When I walked out of here that evening we were very pleased about it. There in black and white hard copy was something that represented me. Not that we want to hold on to it, or point at it or whatever, but it was a record. Also then we could understand how to deal with things, you know, what's wrong and what's right, you know, 'cause if you're not told anything ...” (*he left this sentence like this, rhetorically*) (Harold, 58 years old, 1 year post-stroke)

- “I welcome the increased level of individual attention with a greater number of conductors.” (Simon, 57 years old, 18 years post-stroke)

- “I've had the best care here, because everybody is totally dedicated. Everybody is working to the same. They're not distracted by an influx of people off a ward. It is appointments, people come in, they do their bit, then they go away again. And you get 400 percent attention / and I feel I've had a lot of improvement here”. (Phyllis, 59 years old, 3 years post-stroke)

#### **5.2.2.2 Learners feel nurtured**

The value of being treated with unconditional positive regard was also evident in learners' narratives describing how they felt cared for and nurtured at CE, creating a feeling of belonging there:

- "You really feel as if you're part of a family, whereas in the hospital, I mean they were brilliant, I don't know what I'd have done (*had they not been there for me*) but you're a number. You don't feel a number here (*at CE*). You feel, well you feel like a family, don't you?" (Violet, 63 years old, 4 years post-stroke)

- "Before Conductive Education I was a nobody. I am now a somebody."  
(Laura, 57 years old, 2 years post-stroke)

Feelings of being nurtured and valued as an individual are present despite activity sessions taking place in groups. It seems being in a group contribute to the enjoyment of taking part in CE activities, and as mentioned before it also provides learners with opportunities to see how other learners perform exercises:

- "I think (*CE is effective*) perhaps because you are working in a class so you're all doing things together, it helps considerably. 'Cause you're all working together, aren't you, for the same thing." (Jason, 57 years old, 2 years post-stroke)

- "The group encourages each other and give applause when someone managed to do something they couldn't do before." (Observation 9/7)

### 5.2.2.3 Learners perceive commitment from conductors

Learners also remark on the high level of involvement from the conductors in the care provided to learners. They particularly comment on how they experience the conductors to be committed to everyone's individual progress:

- "And another thing that's nice about it, and you've probably noticed, the moment you come out of that room (*where learners do the exercises*) they're (*the conductors*) not separate from you. They watch you in the coffee room, how you sit down, and they see what you do in the car park and it doesn't matter where A. (*a conductor*) is, she'd call 'hold your back up', or do this or do this. (Husband of Violet)

Violet: Yes you never finish it. I mean I've only been here a few months and I was going out from the back way and they came running up and said 'you're doing this and that'. I mean, it's brilliant. You really feel as if you're part of a family." (Violet, 63 years old, 4 years post-stroke)

- "You feel that the conductors put a lot of effort into what they do so you feel you need to do the same, not to disappoint them. They are also very caring and very keen for you to do well." (Jason, 57 years old, 2 years post-stroke)

- "I've had the best care here because everybody is totally dedicated. Everybody is working to the same. They're not distracted by an influx of people off a ward. It is appointments, people come in, they do their bit, then they go away again. And you get 400 percent attention and I feel I've had a lot of improvement here and I want it to continue." (Phyllis, 59 years old, 3 years post-stroke)

### **5.2.3 CE activities are often experienced to be challenging, requiring perseverance from every learner**

#### **5.2.3.1 CE is hard work and requires perseverance from both learners and carers**

The physical exercises practised in CE prove to be challenging for some learners. The exercises are sometimes described as hard work, requiring perseverance and dedication from learners:

- “Well, it’s very tiring to start, I don’t think the weather’s helping, is it? (*very warm summer*) (Claire, 71 years old, 6 years post-stroke)

Claire’s husband: She doesn’t like the arm bit, you know, where they say: do that (*lift arm*). That’s hard.

Claire : Yes because it’s like a heavy weight, you know, it’s so tiring and that, isn’t it, you know.

Husband: It’s been great, I think (*but*) it’s been tiring for her.

Claire : Yes, it has been for us all.

Husband: It’s trying to do so much in so little (*time*).” (Claire, 71 years old, 6 years post-stroke)

- “I think the first couple of days were difficult. (Husband of Laura)

Laura: Oh I was terrible, I’d give up on meself, I wanted to go home ‘cause I always expect 110 percent from meself. Me dad always drummed it into me: you should have 110 percent, and he expected it from me, you see. So I’ve always wanted 110 percent off meself and I wasn’t getting it when I first came here. And I went back to the hotel and I cried and I wanted to go home and it wasn’t working and (*I felt*) I was the only one that wouldn’t get through it.” (Laura, 57 years old, 2 years post-stroke)

- “Relief when session ended ... Not enjoying course and wouldn’t choose to do it again but know it is doing me good. Very hard work ... After ¾hr felt exhausted – would have given up if given the chance. Left wrist hurting still

from yesterday. Shoulder was hurting but did stretches last night and this a.m. and ache eased after C.E. Walking with splint but without stick - good today." (Ian, 58 years old, 1 year post-stroke)

Family members and/or carers of learners are encouraged to be present at learners' CE sessions to observe how exercises are to be performed. In this way the learners have some help at home with challenging exercises:

- "From a rehab point of view, they do a lot better here (*at CE*) in involving the family and carers to do things. In H. (*the conventional setting*) I went to a couple of physio sessions but was not allowed to watch. But there's lots of things you could be doing but nobody tells you, like massaging the feet. His feet were in an awful state, swollen and hard-skinned and another thing is like massaging the hands. I'm sure there's lots of things, you spend a lot of time in the hospital when you could be doing things. And even more so when you come home. But they just don't want to show you anything, or well, they showed him on his hands but often he got confused with the instructions they'd given him. And we'd been doing things the wrong way, haven't we (*she turns to face her husband*), for a while but sort of coming here (*to CE*), they do involve the carers and show you the right way to do things, and that stops bad habits forming. We (*as carers*) have to look after them 24 hours a day but we were never told how to do anything (*in the conventional setting*)." (Wife of Harold, 58 years old, 1 year post-stroke)

Observations of sessions also witnessed involvement of carers and family members:



- “Carers are encouraged to try the movements for themselves.”

(Observation 8/7)

- “Carers are also shown how to safely help learners to sit up in case of low energy, such as times when they have a cold. The way to lift them has also been designed to protect the carers’ backs.” (Observation 9/7)

- “The conductor emphasises importance of carers’ involvement in learners’ work at CE.” (Observation 10/7)

- “The conductor reminds Harold of all his exercises and also shows his wife how to support him while he walks.” (Observation 15/7)

#### **5.2.3.2 CE activities sometimes create frustration due to their degree of difficulty**

Learners’ behaviour illustrated their frustration when they did not succeed in performing the exercises at times:

- “Simon becomes frustrated and hits his left hand with his affected right hand. I wonder how he feels about having a very good job but being a student at CE.” (Observation 8/7 )

- “Learners have to draw on the paper, moving both hands together at the same time, drawing circles in a mirror fashion. Their carers are told to push learners’ affected hands over the paper, while learners move their unaffected hands by themselves. Harold gets frustrated. He cannot do it but also, he does not allow his wife to help him. In stead he continues to

draw cartoons with his unaffected hand ... he then gives up completely.

His wife looks frustrated too, she looks up at me and sighs.” (Observation 17/7)

#### **5.2.4 CE encourages body half integration, leading to awareness of the body as a complete unit**

Learners’ narratives reveal an increased sense of body-half integration, i.e. awareness of their bodies moving as a unit as opposed to two separate sides, one affected by stroke and one unaffected:

- “(At CE) you always do the brain things like the speech as well, that is better for me, it’s like learning the brain again (*about*) both sides as well, (*before*) they were just thinking: left, left, left for the physio (*her left side was affected by the stroke*). (At CE) it’s better.”(Andrea, 34 years old, 4 years post-stroke)
- “When they’re training you here (at CE), they go for your central bit and they bring your left (*affected*) side more into it. (Husband of Laura, 57 years old, 2 years post-stroke)
- “Whole body movement encouraged; affected and unaffected sides move together. Learners are encouraged to use their affected side more, and then help with the unaffected side.” (Observation 8/7)
- “Greater balance due to putting more weight through left hip ... gradually became more aware of my left side (which I’d) ignored for years.” (Simon, 57 years old, 18 years post-stroke)

CE exercises were indeed observed to work towards increasing awareness of the body as a whole. Learners were continuously reminded to give attention to their affected limbs as well as their non-affected limbs, encouraging concurrent movement of bilateral limbs and in effect involving both sides of their bodies:

- "Learners have to lie on their backs on the beds, bend their knees and lift their bottoms up. The conductor says this encourages weight onto both feet simultaneously". (Observation 15/7)
- "The conductors check whether learners' bodies are each in alignment. They notice very small details, even so small as keeping their wrists together at the same height when their hands are clasped together ... Simultaneous use of hands is regularly encouraged." (Observation 14/7)
- "When lying down Simon is encouraged to keep his head in the middle in order to increase his awareness of his midline ... Conductors often emphasise that it is important for learners to keep their feet parallel while sitting. They say this ensures learners to put their body weight as equally as possible onto both feet when they stand up. Again: emphasis on working both sides of the body together ... The chanting of the name of limbs used in movements seem to facilitate awareness and concurrent movement of bilateral limbs." (Observation 10/7)

### **5.3 Hermeneutic phenomenological writing on 'being-in-CE for stroke'**

In Study Two stroke survivors were given the opportunity, as part of a hermeneutic phenomenological study, to express their views and feelings surrounding their experiences of CE for stroke. Hermeneutic phenomenological exploration of their experiences provides more information on the essence of this phenomenon. Hermeneutic phenomenological

writing guided by the four main themes, as well as elements from their sub-themes, is presented below. This is in keeping with the suggestions of van Manen (1990) as discussed in Chapter 3 of my thesis.

### **CE increases self-confidence**

‘Being-in-CE for stroke’ was revealed to lighten the weight of ‘being-in-the-world’ for learners post-stroke, partly through increasing confidence in themselves and their own abilities. The biographical disruption (Bury, 1982) that sets the effects of stroke into motion had come as a shock to learners and imposed onto them adjustment to a new way of being. Many learners had before been told by conventional rehabilitation professionals they could not and should not expect further relief from their disabilities. They had to accept their fate and had not been granted any hope, causing stroke patients to settle for a “restricted future self” (Ellis-Hill & Horn, 2000, p. 286), i.e. a life overshadowed by disabilities and lack of confidence. Revelations of conductors’ belief in learners’ abilities were met by feelings of surprise from learners since they were still within a sense of a future restricted by disabilities. In demonstrating belief in learners’ abilities, conductors did not shy away from overt provision of hope. Indeed, their view was that “hope is what gets most of us out of bed in the morning; it is what gives us a lift in our day to day lives” (Brown, 2003, p. 27). This implies that without hope and dreams there is no use even in trying to achieve better. Such hopelessness and apathy can be compared to what Viktor Frankl (2000) refers to as an ‘existential vacuum’. CE seems to have facilitated learning in such a way that learners could lift themselves out of such an existential vacuum where they had had no hope or dreams. CE links in further with Frankl’s teachings concerning humans’ search for meaning: Frankl (2000) defines the perception of meaning to be the sudden awareness “of a possibility against the background of reality” (p. 141). CE’s ability

approach seems to have made learners aware of possibilities against the background of their post-stroke lives.

CE's belief in learners as being unrestricted except for having to learn how to use their changed central nervous system (Brown, 2003) seems to have facilitated an improvement in learners' progress and movement towards independence. In turn this seems to have increased not only confidence in themselves and motivation to continue their renewed relationship with their bodies, but also helped them to get in touch with a sense of self-identity again, albeit often a new identity of self. The CE activities taught them ways in which to (re)-acquaint themselves with their bodies, the vehicles for their inner-being. They became less estranged from their post-stroke bodies and suddenly their future selves did not look that restricted anymore. Learners were continuously provided with detailed explanations of how to carry out activities. Such communication between conductors and learners lead to an increase in knowledge about their post-stroke bodies, in effect aiding the reconnection to themselves and an increased sense of self-identity. This could also have contributed to their growing self-confidence experienced in 'being-in-CE for stroke'.

CE's approach could be referred to as an ability-approach, an approach which increases awareness of what *can* be done, as opposed to one that continuously focuses on inability or disability, i.e. what *cannot* be done. The language used in CE sessions reflected this focus on ability, since negative statements such as 'you can not do this' were never uttered. Instead, there seemed to be an impetus to always find a solution to an apparent challenge. Indeed, Brown (2003) states that it is the duty of the conductor to always find a way in which to teach a learner, even if at first it appears impossible. CE's philosophy therefore includes that the conductor's teaching style is always based on the individual learner's learning style, with the conductor adapting to the way in which the learner presents him/herself. This ability approach could be compared to a modern method used in change

management, called *Appreciative Inquiry* (Cooperrider & Whitney, 2005). *Appreciative Inquiry* (AI) is based on the principle that every organisation is positive at its core. AI focuses on tapping these positive resources and therefore on what an organisation *can do*, and not on what it *cannot*. In the same way CE seemed to tap the positive resources in learners. CE's ability-approach increased learners' awareness of how their bodies could work *for them* rather than *against them*. This in turn facilitated feelings of being in control and feelings of self-empowerment. CE's characteristic of showing them *how to* execute movement seems to have put them in touch with the inherent abilities individual learners still had post-stroke.

Support from other learners in the same CE group were also identified as an aid to the progress, and resultant increased self-confidence experienced while 'being-in-CE for stroke'. This was partly through watching other learners perform activities and finding such observations helpful to their own execution of activities. Indeed, Werner et al. (2003) found that women with chronic musculoskeletal pain who attended treatment groups (which included physical exercises and emotional and social support) reported feeling stronger in themselves and more able to handle their everyday pain-filled lives. Also, the camaraderie observed that existed within the stroke learner group in Study Two, most probably contributed to the positive experiences learners described. Such camaraderie was characterised by the support received when learners experienced exercises to be challenging and also the sharing in joy experienced when learners succeeded in performing a previously challenging activity. The latter in itself could have added to feelings of being valued and nurtured. Being-recognised for who they were by the other CE group members could have contributed to learners' positive experiences about the group and general increase in confidence.

### **CE conductors show Rogerian unconditional positive regard for learners**

Learners reflected on feelings of 'being-valued' for who they were while 'being-in-CE for stroke'. They were recognised for being people with potential first, and their disabilities were not the focus. Conductors' belief in learners' highest potential regardless of the disabilities they presented with forms part of basic CE philosophy (Brown, 2003). CE overtly teaches conductors to view learners not as being disabled and therefore restricted, but rather as people with no restrictions except for their need to learn how to use their new<sup>\*</sup> central nervous system to enable them to keep on moving forward, both figuratively and literally. This is akin to the views of well-known endocrinologist and mind-body medicine author Deepak Chopra MD when he says : "Every doctor must make an inner journey, taking his understanding beyond the limits of the physical body and into the heart of a deeper reality" (Chopra, 1990, p. 4). The physical limits a patient/learner presents themselves with do not necessarily mean they have no potential for further recovery, and CE conductors seemed to work within this awareness. This awareness can also be compared to a client-centred counselling skill developed by humanistic psychologist Carl Rogers (1951). His counselling skill entitled unconditional positive regard (UPR) entails acceptance of the client in a warm and non-judgmental way and reminds the counsellor to be open for whatever is brought up during a session and to accept it for what it is - without judging it due to personal biases. Indeed, Rogers viewed every human being as being essentially good and valuable, even if it was difficult to see such qualities on the surface (Burnard, 1994). The importance of experiencing 'being-valued' is highlighted by Riemen (1986), suggesting that people who feel valued in effect experience 'being-cared' for. Such feelings were strengthened by the general care learners received at CE which also made

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\* The term 'new' here refers to the state of their nervous system after their stroke, therefore new to themselves.

them feel nurtured. They felt they belonged in that space where learning was encouraged and where the tools were provided to experience more learning.

CE seemed to have succeeded in getting the message of nurturing and value across despite the fact that sessions took place in a group setting. Indeed, from learners' narratives it seems that 'being-with-others in CE' complemented their own experiences and at times enhanced them, creating a sense of 'being-part of a family' and thus belonging there.

**CE activities are often experienced to be challenging, requiring perseverance from every learner**

Up to this point of the discussion the reader may be forgiven for thinking CE to be a miracle working therapy, holding only positive experiences for learners. Further exploration of learners' narratives, as well as session observations, however revealed CE activities to be very challenging at times. This called for perseverance from every learner as well as their carers who were part of the learning process. Previous criticism of CE (Oliver, 1989) dwelled on the challenging nature of CE and claimed it to be coercive and forceful. Read (1998) however warns against equating a challenging technique with being coercive or forceful without having consulted people who have experienced CE themselves. As mentioned earlier, being-valued in the CE setting would inevitably have lead to patients feeling 'being-cared' for (Riemen, 1986). Yonge and Molzahn (2002) argue that a certain degree of being-hard, as some learners experienced CE and conductors to be at times, form part of caring as a whole. From the experiences of participants in Study Two it seems possible that the challenging nature of CE in fact added to growth in self-confidence when learners succeeded in overcoming the difficulties. This suggests that caring sometimes hide behind a strict facade. Viktor Frankl (2000) found there are three ways in which one can find meaning in life. The first is through doing something creative



and the second is through loving someone. He believed the third way to be the most important, i.e.: “Facing a fate we cannot change, we are called upon to make the best of it by rising above ourselves and growing beyond ourselves, in a word, by changing ourselves ... (to) see in life’s transitoriness an incentive to take responsible action” (Frankl, 2000, p. 142). Study Two suggests that CE provided learners with an opportunity for Frankl’s (2000) third way, in that CE activities were challenging the way of being which learners got acquainted with post-stroke, and offered them further challenges through which they could move beyond that restricted way of being, towards finding meaning in life again. The participants in Study Two did relate how at times they hated the activities, how frustrated they sometimes felt and wanted to return home. But a combination of inner confidence brought on by the philosophy of CE as well as encouragement from carers, conductors and other learners, seems to have contributed to learners’ perseverance and dedication.

CE conductors overtly involved carers in learners’ activities. This enabled the carers to help learners once they went back home, increasing their ability to support learners’ journeys through the challenging nature of CE. It possibly also helped to create a bond of ‘working-together’ between carer and learner. This reminds of a holistic approach where health professionals do not only work with the ‘patient’ but also with the carers.

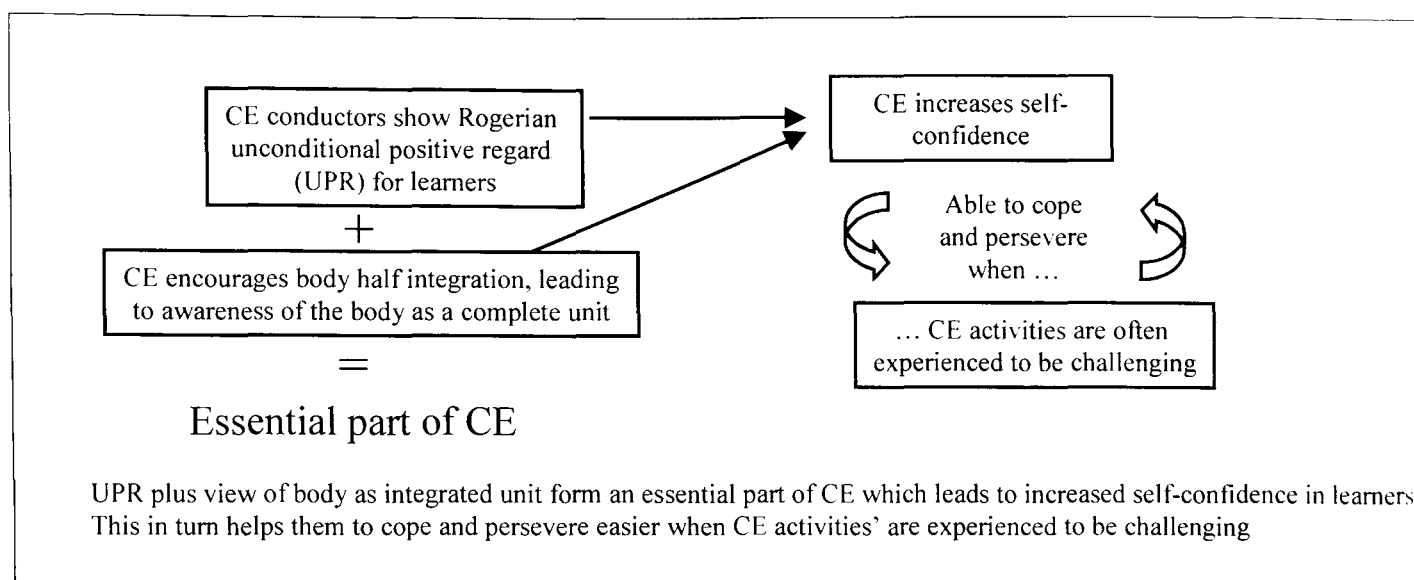
### **CE encourages body half integration, leading to awareness of the body as a complete unit**

The biographical disruption (Bury, 1982) which characterises a stroke does not only halt a person’s independence and their integration in society but it also halts their sense of having an integrated body with two halves that work together (see Study One). As mentioned in Chapter 4, van Kaam (1966, p. 22) wrote “my body makes the world

available to me; it is in and through my body that the world becomes-for-me, becomes mine, my world.” We perceive the world through our bodies, which implies that the eclipsed body brought on by stroke would also change someone’s perception of the world. Study Two revealed learners were continuously reminded to give attention to their affected limbs as well as their non-affected limbs, encouraging simultaneous movement of bilateral limbs and in effect involving both sides of their bodies. One could therefore reason that CE works toward removing the perception of a divided body, even though the side of the body affected by stroke may never recover completely. Learners’ stated that in their lives before attending CE for stroke, therapy focus was mostly on the side of the body affected by the stroke, which would have reinforced feelings of a divided body. The findings of Study Two indicate that ‘being-in-CE-for-stroke’ altered the perception of a body being divided into two halves and lead to an increased sense of body-half integration. Such a sense coupled with greater knowledge of how their bodies could work *for them* rather than *against them* could also have contributed to increased self-confidence and self-identity.

## **5.4 Summary**

This chapter provided a better understanding of ‘being-in-CE for stroke’. It presented the themes and sub-themes essential to this phenomenon and discussed them within a hermeneutic phenomenological framework. It could be suggested that the four main themes, that emerged as being the essence of ‘being-in-CE for stroke’, together form a process (Figure 4):



**Figure 4:** The process revealed by the themes essential to ‘being-in-CE for stroke’

In Figure 4 the Rogerian unconditional positive regard shown by conductors as well as their belief in learners’ abilities, facilitated an increase in learners’ belief in themselves, i.e. their self-confidence. Included in CE’s approach is its regard for the body as being an integrated unit regardless of any disabilities. Learners’ increased sense of their bodies as a whole also facilitated an increase in self-confidence, which seems to have helped them to cope and persevere easier when they found CE activities challenging.

Study Two revealed that the essence of ‘being-in-CE for stroke’ is mainly characterised by positive elements (i.e. the first, second and fourth main themes). The third main theme is not negative in itself, as is evident from Frankl’s (2000) description of what is needed in the search for meaning, but at the time of ‘being-in-CE for stroke’ learners could experience it as negative. The presence of the first, second and fourth main themes however seem to overshadow any negative elements, supporting learners in their quest for a new meaning in post-stroke life.

Chapter 6 addresses the differences and similarities between Studies One and Two and particularly looks at the possibilities for holistic approaches to stroke rehabilitation in both these settings.

## **CHAPTER 6**

### **Reflections**

#### **6.1 Introduction**

Studies One and Two explored the experience of stroke rehabilitation across two different settings. This chapter reflects on the findings from these individual studies and their implications and then asks the question: What makes something holistic and to what extent were either these settings adopting a holistic approach to rehabilitation. In doing so the difference between person-centredness and holism is discussed. Finally recommendations for the development of a holistic approach to stroke rehabilitation are given.

Chapter Six also further reflects on the method I used for my thesis and discusses its soundness and rigour in terms of de Witt and Ploeg's (de Witt & Ploeg, 2006) criteria. This is followed by a reflection on the study's strengths and limitations.

To complete the chapter I reflect on my own position in the research. I discuss the holistic effect the research had on me as human being and how I subsequently coped with the challenging nature of this research topic.

#### **6.2 Reflection on the findings from Studies One and Two**

##### **6.2.1 Study One: Stroke rehabilitation experience in a conventional stroke unit setting**

A clear emphasis on physical recovery and simultaneous lack of attention to patients' non-physical needs while receiving conventional stroke rehabilitation was evident from Study One. This was highlighted by patients' feelings of disempowerment especially when health professionals did not recognise their fears and insecurities, and did not realise the impact of negative imagery. The observation from the literature mentioned in Chapter 2,

that emotional and social recovery following a stroke is often neglected (McNaughton, et al., 2005; ISWP, 2004; Burton, 2000; Dowswell, et al., 1997; Waters, 1996; Gibbon, 1993; Forster & Young, 1992) is therefore supported by these findings. The discussion below looks at how the biomedical approach continues to dominate in conventional stroke rehabilitation. It is divided according to the three main themes that were found, in Study One, to be the essence of stroke rehabilitation experience in a conventional stroke unit.

- High level of disempowerment:

Patients revealed feelings of powerlessness and confusion about their condition and altered future. These feelings were magnified by the poor communication and lack in sharing of information between patients and health professionals. Evidence of poor communication between stroke patients and health professionals was also found by McKain et al. (2005), Anderson and Marlett (2004) and Wressle (1999). This signifies the dualist separation between health professionals and patients that exists within a biomedical approach. Rodgers et al. (2001) and Wiles (2002) found that cases where patients were given information, the information-giving was ineffective. The problem therefore seems to be two-fold: on the one hand information is not provided and on the other hand where it is provided, ineffective methods are used for the sharing of information. This two-fold problem exists despite: (i) the fact that the importance of providing patients with information has already been acknowledged (Hoffmann, et al., 2004; Wiles, et al., 2002) and (ii) that studies show improved communication between patients and health professionals do lead to better health care outcomes (Little, et al., 2001). These improved health outcomes also include higher levels of motivation (Cott, 2004; Maclean, et al., 2000) and feelings of empowerment (Nordgren & Fridlund, 2001). The latter may improve the level at which patients take part in rehabilitation, as well as improve their quality of life

in general (Proot, et al., 2000). Indeed, the UK Department of Health supports the implementation of so-called 'Expert Patients Programmes' that can assist the public in managing their own illnesses (DoH, 1999). These programmes aim at the development of patient confidence and motivation to help patients become more empowered in the management of their own conditions (DoH, 2001b). An example of such assistance is easy access to knowledge regarding their own health. Such easy access was however not the case for the stroke patients reported in Study One, nor was there any provision of a formal 'Expert Patient Programme' to help patients increase feelings of empowerment.

Recovery after stroke is difficult to predict (Anderson, 1992). This renders provision of information on stroke patients' possible futures, very challenging. Indeed, Becker and Kaufman (Becker & Kaufman, 1995) report on health professionals shying away from giving patients information on their condition within the first few weeks after stroke due to their own uncertainties, as well as due to not wanting to upset patient morale. Also, Wiles et al. (2002) report that therapists found it difficult to keep a balance between motivating patients to take part in rehabilitation and discouraging over-optimism in patients for their uncertain future. Therapists felt uncomfortable with discussing patients' future since they themselves were unsure as to what to tell patients regarding the future they worked towards. However, as suggested by Study One, little or no information has a negative effect on patient morale and motivation. Communication between health professionals and provision of information to patients therefore needs serious reconsideration.

Lack of sufficient time available and focus on physical rehabilitation have previously been reported to prevent hospital staff from discussing uncertainties in-depth with patients (Close & Proctor, 1999). Interestingly though, some patients in Study One perceived stroke unit staff to have had more time for them than those on the acute ward. It does however seem as though this time was not spent on emotional support for patients. Quantitative

studies by Andersen (2001) and Glass and Maddox (1992) revealed functional and social improvement in stroke patients who received formal emotional support. Andersen (2001) specifically found interventions such as counselling sessions and general information provision, improved quality of life. Again the subject of information provision emerges, suggesting patient education in the form of improved communication to be a golden thread that could be of great benefit to increase feelings of empowerment and motivation for patients in a stroke unit. This does however seem to create a paradox: more information about what patients could expect in the future is difficult to provide since each patient's case is unique. However provision of as much information as possible could help patients in coping with the present 'being-in-stroke-rehabilitation'. It follows a balance has to be found, between accepting that information provision cannot answer all patients' answers and still providing them with as much information as possible, as well as with ways to cope with the sensitive information, such as the possibility of not walking again.

- A high proportion of negative images of body and self:

Bury (1982) refers to the effects of chronic illness as causing a biographical disruption. Stroke patients need support in dealing with this disruption not only in terms of disruption to their physical body but their whole sense of being. Patients' ways of coping with the disruption, as shown by Study One, often included anger and frustration directed at their disabled body parts. The use of negative terms when referring to themselves and their bodies was common in their narratives. People's belief systems and the vocabulary they use to express their thoughts have a far-reaching effect on their different levels of holistic being, including physical and emotional levels (Vitetta, et al., 2005; Graham, 2004; Brigham, et al., 1994). Body and health images people carry in their belief systems play an important role in the development of illness. In the case of the stroke patients in Study One

it could also have affected their progress negatively. Finset and Andersson (2000) found that patients who used negative coping techniques such as dwelling on negative emotions showed signs of depression. These authors advised especially occupational therapists to be aware of the impact of such negative emotions. It is suggested here that all the members of a stroke patient's multi-disciplinary team (MDT) ought to be made aware of the possible effects of negative emotions and not only one therapist. White and Johnstone (2000) argue in favour of formal post-stroke counselling to help patients deal with the effects of stroke. Such counselling could also make patients themselves aware of the impact of negative images and could support them in working more with positive images. Byrne et al. (2002) however found that when it was suggested to cancer patients to work with positive imagery, some patients, while focusing on positive imagery, concealed their emotions and put on a brave face to adopt a 'fighting-the-cancer' attitude. Byrne et al. (2002) found this reaction to be unhelpful to patients in the long-term, since they had not been given the opportunity to first work through their emotions such as fear and grief before health professionals suggested they adopt a 'fighting' attitude. According to these authors this lead to patients feeling disempowered instead of empowered. They warn that improved communication between health professionals and patients is necessary to help patients work through their emotions before expectations of positive imagery are put in place. This should also be kept in mind if stroke patients are made more aware of the value of positive imagery. Byrne et al. (2002) also shows the problems created by poor communication between patients and health professionals, as found in Study One.

- The nature of motivation:

Motivation is said to be one of the most important factors in determining the outcome of rehabilitation, including stroke rehabilitation (Öhman, 2005; Cott, 2004; Gubrium, et al.,



2003; Lennon & Ashburn, 2000; Becker & Kaufman, 1995). Wiles et al. (2002) found that patients' levels of motivation were directly related to how much they took part, and were able to take part, in rehabilitative activities. This is supported by the findings of Study One, which indicate that support from family and friends greatly contributed to patient motivation. Patient motivation however seems to be a complex subject for therapists. Patients classified as showing low motivation for rehabilitation, sometimes simply because they were more reticent than other patients, received less intense attention from health professionals than those classified by professionals as being motivated (Maclean, et al., 2002; Pound, et al., 1998).

Study One's themes showed 'being-in-stroke rehabilitation' in a stroke unit to be fraught with feelings of disempowerment, use of negative imagery and issues around motivation, all of which could be described as symptoms of a lack of meaning in life (Frankl, 2000). This was also illustrated by the hermeneutic phenomenological discussion in Chapter 4. Such symptoms often contribute to poor health (Sobel, 1995; Brigham, et al., 1994) and in the case of stroke patients may also contribute to poor progress and outcome of rehabilitation. The care provided to stroke patients seems to be falling short of that which patients ask for. Study One shows the essence of stroke rehabilitation experience to be related not only to physical matters, but also to emotional, social and environmental matters, showing the importance of a holistic approach to stroke rehabilitation. It could be argued that biomedicine constrains the opportunity for such a holistic approach because of its inherent nature as a specific mindset.

A longitudinal study by Kirkevold (2002) followed stroke patients from the acute phase up to one year post-stroke. Her description of the intervals at which interviews were held with patients is as follows: "frequently during the first 2 months (at 1, 2, 4, 6 and 8 weeks).

gradually lengthening the intervals as the situation stabilized (at 3, 6, 9, 6, 12 months)'' (p. 889). This suggests that the author classified patients at three months post-stroke as being at a point in time where their condition had been stabilised and where they would already have been discharged from the hospital environment. She reports that while stroke patients are still in hospital for rehabilitation (i.e. up to 8 weeks), the hospital itself gives patients a focus and purpose which is, according to her, their physical recovery. Study One revealed however that at three months post-stroke patients who were still in a stroke unit (i.e. hospital environment) already struggled with issues other than pure physical recovery. Their days were clouded by thoughts of their uncertain future, indicating the holistic effect of stroke to be already present. Kirkevold (2002) further reports that social activities are put on hold while in hospital so that they do not interfere with physical recovery, and also that while in hospital patients do not yet show realisation of the impact of stroke on the rest of their lives. Study One found that patients at three months post-stroke in a stroke unit already longed for social and mental stimulation and that they were indeed preoccupied with the impact of the stroke on their future. This was despite being in a hospital environment where, according to Kirkevold (2002) patients are mainly preoccupied with their physical recovery. In the case of Kirkevold (2002) patients showing realisation of the impact of their stroke had already been discharged, suggesting it was only after discharge that patients' realisation became more concrete. Study One suggests that the patients' realisation of the impact of stroke on their lives is not determined by the rehabilitation environment, but rather by the time-period post-stroke. Three longitudinal studies on post-stroke experiences (Dowswell, et al., 2000; Ellis-Hill, et al., 2000; Kaufman, 1988a) found the lack of emotional support and negative feelings surrounding self, as highlighted in Study One, characterised the essence of patients' experiences for at least one year post-

stroke. This supports the need for holistic support in rehabilitation already while in a hospitalised environment.

### **6.2.2 Study Two: Stroke rehabilitation experience in the unconventional setting of Conductive Education (CE)**

According to Study Two, ‘being-in-CE for stroke’ involves participation in challenging activities supported by conductors’ unconditional positive regard for learners’ being. The CE activities and conductors’ attitude seem to contribute to an increase in self-confidence and a sense of re-integrated self. This section uses the four main themes as headings to discuss the findings from Study Two. Themes 1, 2 and 4 are discussed together under one heading, followed by theme 3 under a separate heading.

- CE increases self-confidence, CE conductors show unconditional positive regard for learners, and CE encourages body half integration:

Prospective CE participants attend an initial assessment session in which conductors and the participants together determine whether and how CE could be of benefit to them (Brown, 2003; Kinsman, 1986). Here CE shows a sharing relationship, rather than separation, between the knower (in this case conductors) and the known (in this case learners). During this assessment, conductors focus on what participants are able to do, and how their abilities can be developed further. Study Two participants reported on such an ability-approach being present from the start and all through their time spent at CE. Their experiences were characterised by a continuous encouragement of the skills they already had, celebrating their successes rather than only focus on their disabilities. Indeed, teaching in CE is said to take place in such a way that learners leave the CE premises celebrating what they could do that day, rather than feel negative about the activities they could not do (Brown, 2003). This has also been reported in the general CE literature (for example

Brown, 2003; Beardshaw, 1989) as well as literature on parents' experiences of CE's services for their children with cerebral palsy (James & Taylor, 1997).

Experiences of 'being-in-CE-for-stroke' revealed conductors held unconditional positive regard for learners as persons first, stroke survivors second. Self-confidence of learners could have increased partly due to this unconditional positive regard and the strong belief conductors showed in their still invisible abilities. "The keys to a quality life after stroke are support, guidance, rehabilitation and, most important of all, the will to get well" (Hinds, 2000, p. 2). The findings from Study Two suggest that CE provided learners with tools to reacquaint themselves with self-confidence and a will to recover as much as they could. The participants in Study Two revealed joy and amazement at conductors' irrevocable belief in their abilities. Indeed, CE has been described as "being about high expectations" (Beardshaw, 1989, p. 297), increasing learners' motivation regardless of their health conditions. CE's high expectations were also evident in the overt encouragement of hope. The latter seems to have contributed to an increase in learners' self-confidence, general mobility improvement and increased sense of self-identity. Indeed, hope has been reported to play an important role in patients' abilities to cope in the face of tragedy (Elliot & Olver, 2002).

Participants in Study Two spoke about how they appreciated conductors' commitment to their progress. They felt conductors were more committed to them as learners than conventional health professionals had been to them as patients in rehabilitation. This finding supports parents' experiences of conductors' commitment to their children with cerebral palsy (James & Taylor, 1997).

In CE the aim of the process through which knowledge is conveyed to learners is known as *orthofunction* (Hári, 1997; Kinsman, 1986). Orthofunction refers to a person's "ability to solve problems and to apply solutions learnt in one situation to another" (Coles

& Zsargo, 1998, p. 71). CE's demonstration of *how to* rather than *what* conveys the belief that every learner has the ability to learn how to solve their own movement problems, and then will also be able to transfer this knowledge (Brown, 2003). The CE literature on orthofunction often refers to the situation during the 1980's where the term orthofunction was mistaken to imply forcing someone to go about their daily life without the assistance of any physical aids such as a walking stick and wheelchair (Read, 1998). This misconception lead to negative comments on CE such as criticism from disability groups (Oliver, 1989). The origin of the misconception lies in the absence of aids in CE's country of origin, Hungary, which was later explained to have been due to the lack of funds for such aids and not due to any banning of aids by CE (Forrai, 1999; Coles & Zsargo, 1998; Read, 1998). During the 1990's orthofunction came to be accepted as solely referring to the autonomy CE learners reach through building on their abilities which include ability to transfer skills to other areas of their lives.

CE's integration of educational methods with medical knowledge seems to give learners with neurological disorders a better understanding of their medical condition and equally understanding of, and support for, the psychological and social impact their condition has on their lives (Brown, 2006a). András Pető, founder of CE, is said to have included principles from the philosophies of Rudolf Steiner as well as Gestalt therapy in his work (Forrai, 1999). Study Two does however show that CE's focus is on teaching learners physical mobility.

The importance of the educational side of CE is clear in the language used: participants at CE are not referred to as patients, i.e. passive recipients of health care, but as learners, therefore people learning skills and techniques to perform movements that able-bodied people take for granted (Brown, 2003). CE's integrated technique includes elements practised in conventional rehabilitation by separate professions namely occupational

therapy, physiotherapy, speech therapy, general teaching and educational psychology (Brown & Mikula-Toth, 1997; James & Taylor, 1997; Cotton, 1994; Beardshaw, 1989). In this multi-levelled process it is claimed that learners are taught how to restore control over their own body movements as much as possible (Brown, 2006a). They are taught the rules of movement so that they can transfer their knowledge to other situations (Brown, 2003). The experiences of the participants in Study Two provide evidence for this process through which they regained a sense of independence and autonomy, often referring to the fact that they now know *how*.

Prior to each physical activity CE learners were encouraged to practise conscious intention of their next movement, coupled with rhythmic verbal expression of the intention. Intention is believed to facilitate learners in the execution of previously difficult or impossible movement (Hári, 1997; Howard & Verrier, 1989). CE holds the view that the overt verbal expression of an intended movement, utilising an external rhythmic pattern, will later become covert when the rhythmic movement becomes internalised (Howard & Verrier, 1989). Accordingly, CE tasks have been described as “containing the simultaneous interconnections of thoughts, feelings, intention, harmony and dynamics” (Hári, 1997, p. 5). Indeed, research on the power of mental imagery (i.e. visualisation) of movement, indicates movement to become more integrated with the self, when one holds a mental image of the movement prior to execution (Graham, 2004; Heil, 1993). Focused intention could also have contributed to what learners referred to as now *knowing how*: they first imagine (intend) a movement and in the process integrate the movement more into their whole being. Inner structure and representation of movement depends partially on a person’s neurological state (Hári, 1997). A stroke changes a person’s neurology and in some cases drastically (Anderson, 1992). Mental imaging of movement may therefore

facilitate neurological re-learning in that a learner can become reacquainted with an inner representation of movement, taken away by the stroke.

Getting re-acquainted with an identity of self was evident in the narratives of learners in Study Two. This finding supports a similar experience reported by adults suffering from other neurological conditions who have attended CE services, such as people with Parkinson's disease (Mikula-Toth & Brown, 1997) and multiple sclerosis (Samuelson, 2003). Positive changes in disabled children's attitudes to life, were also reported by their parents (Read, 1998). As was the case in the latter three studies, participants in Study Two seem to have regained a sense of self through the higher levels of self-confidence and independent movement experienced in CE.

The integration of learners' left and right sides of their physical bodies was evident in Study Two. This supports Brown and Mikula-Toth's (Brown & Mikula-Toth, 1997) outline of CE specifically for stroke. They emphasise the importance of including all possible movement in a session and not only that of affected limbs. One of the methods used to encourage awareness of an integrated body is the simultaneous use of both hands (Cotton, 1994) which was observed in CE sessions for stroke on numerous occasions in Study Two. Another method found in the CE literature and which was also observed in Study Two is that of encouraging awareness of one's midline. Again, not focussing on one side alone, but on that which connects the two sides, namely the midline. Such methods could also have increased learners' awareness of their bodies as being an integrated whole.

Study Two participants' experiences of improvement in CE were reported to have been despite having been told by conventional rehabilitation professionals that they had reached a learning ceiling or plateau. This supports a similar finding by Howard and Verrier's (1989) study on the effect of CE for stroke on patients previously told in conventional rehabilitation that they had reached such a plateau. The authors found measurable evidence

for motor learning after regular CE sessions over a period of nine months. Parents' experiences of CE for their children with cerebral palsy also include reports on how their children progressed in CE in spite of having been told by main stream health care that further improvement was not to be expected (James & Taylor, 1997). Even though there is a discrepancy between the neurological conditions, age and the length of time that learners had attended CE sessions for, there is a similarity between these studies in that their findings illustrate the concept of life-long learning which is indeed an important part of CE philosophy (Breakwell, 1994; Brown, 2003; Brown, 2003; Russell & Cotton, 1994). It entails the belief that there exists continuous opportunities for learning regardless of one's neurological condition. Indeed, according to Brown (Brown, 2003) "... of course there will be problems faced, but when searching for a solution we must always lead people into the realm of potential and not keep them in the realm of despair" (p. 29). This is akin to Appreciative Inquiry's (Cooperrider & Whitney, 2005) focus on what an organisation (in this case, learners) *can do* rather than *cannot* do.

The importance of the group in CE was clear from participants' narratives, revealing how 'being-part-of-a-group' helped them to see how others performed exercises if they had not grasped it themselves immediately. They also shared in each other's successes. Indeed, the latter is a benefit of group work in CE also underlined in a textbook on CE by Russell and Cotton (1994). It is likely that these benefits could also have increased participants' self-confidence. Brown (2003) provides an additional benefit of the group which is the fact that someone who does not suffer from a certain condition, can not know what daily life is like for someone with such a condition. Sharing learning in a group with others who have the same or similar condition as oneself contributes positively to the learning experience. Also, learning together in a group may contribute to a feeling of belonging, something else Study Two participants shared in their narratives. They found the atmosphere to be



familial, leading to feelings of being nurtured and valued. Conductors' commitment, as reported by learners, also contributed to these feelings. Indeed, CE handbooks refer to a family atmosphere present in CE sessions (Cottam & Sutton, 1986). It therefore seems the experience of learners 'being-in-CE-for-stroke' is consistent with the philosophy CE wants to convey.

Carers in Study Two received hands-on advice on how to help learners. The parents in James and Taylor's (1997) study on parents' views of CE, also related the value of being involved by CE and the increased knowledge they received about their children's conditions and abilities. A study by Laver and Brown (1997) showed consistent positive changes in families' abilities to support stroke learners. The provision of 'know-how' by conductors most probably contributed to these authors' findings as well as those from Study Two.

#### - CE activities are often experienced to be challenging

The finding from Study Two regarding the experience of CE being hard work which can lead to frustration for learners, removes any doubts that CE could be an approach that offers learners miracles. CE's aim to facilitate development of orthofunction seems to go hand-in-hand with dedication and perseverance from learners themselves as well. This links in with CE's view of participants as active learners as opposed to passive patients. Learners' attitudes may change for the better, as was indicated to have been the case for many learners, but they are covertly, and sometimes overtly, expected to work at keeping a positive attitude and one of perseverance rather than quitting when activities prove too challenging. Interestingly the other available literature on users' perspectives do not mention the frustrations learners experience when they have difficulties with CE activities.

It is unknown whether study participants did not mention it, were not questioned about it or whether the report authors decided not to include it in their findings.

Study Two suggests that learners are not ‘molly-coddled’ (or overprotected) which could hinder building of character. It seems that CE’s ability-approach nurtures learners’ growing self-belief in their own mobility, which they could draw strength from when activities are frustratingly challenging.

The founder of CE András Pető, was quoted to have said that in CE they worked *in order to* reach a goal and not *because of* existing symptoms in learners (Cotton, 1994). Paradoxically CE is also said not to be result driven but rather the activity itself should be the goal (Forrai, 1999). This paradox could be challenging to conventional Western thinking. I believe it alludes to keeping a balance between working towards a goal but not putting all importance on the goal itself which is reaching one’s potential as much as possible. Rather, focus is on the activities needed to reach the goal. This brings to mind the well-known Zen viewpoint: the most important part of a journey is not the destination, but the journey itself (Varian, 2005).

### **6.2.3 A reflection on two different approaches to stroke rehabilitation**

The above two reflections on Studies One and Two provide a better understanding of stroke rehabilitation experience across two different settings. On juxtaposing\* experience in the stroke unit with experience in the CE setting an important difference between the physical body-split caused by stroke, and a much wider and deeper disintegration of being post-stroke comes to light. In the stroke unit a strong emphasis on the visible physical

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\* It is important to note that this is not a direct comparison of experience in the one setting with experience in the other setting. Juxtaposition implies the laying of the collective experience in the stroke unit next to that of the collective experience in the CE setting to see what can be learned from stroke rehabilitation experience across the two settings.

body-split was prevalent. This was illustrated by for example reference to patients' paralysed sides as their bad sides and their non-effected sides as their good sides, with therapy being focused on the former. Such focus and vocabulary seem to have added to the agony patients experienced being in a strange body. Patients often referred to their limbs as though they were not theirs, e.g. *the* hand or *that* leg. On deeper examination their narratives revealed that the visible physical body-split (i.e. split into two) went beyond the physical into a disintegration of being. Sentences such as "I became useless" and "you can't control yourself" illustrate more than just the experience of being split into two, but actually experiencing disintegration of their whole being. The latter also included frustration and feelings of powerlessness due to their sudden inability to cope as they used to, and fear of an unknown future due to these inability. Their physical body-split could therefore be described as only the tip of the iceberg of their life post-stroke. In the CE setting experience revealed a move back to a sense of an integrated self. Focus was on learners' abilities rather than their inability. Feelings of re-integration were present despite lasting symptoms of a physical body-split.

This difference evident from the juxtaposition of experience across the two settings encouraged me to delve deeper into the difference between the two approaches used in the settings, as revealed in studies One and Two. The salient principles of these two approaches are here juxtaposed (Table 7) and afterwards discussed in greater detail.

**Table 7:** A juxtaposition of the two different approaches to stroke rehabilitation evident from stroke rehabilitation experience across the two settings

CE setting	Stroke unit setting
<ul style="list-style-type: none"> <li>- A sharing relationship between conductors and learners</li> <li>- Ability approach; physical focus but still believing in the unseen possibilities of learners and encouraging hope</li> <li>- Overt integration of left and right sides of the body</li> <li>- Learning is non-linear and infinite</li> <li>- Learners are taught in a way so that they are able to apply what is learned in CE, in other areas of their lives</li> <li>- Integration into a group and involvement of carers</li> <li>- Positive language used: emphasis on positive images combined with verbal expression, increasing learner's role in own healing trajectory</li> <li>- Increase in self-confidence and sense of self</li> <li>- Teamwork amongst conductors and part-MDT knowledge held by each conductor</li> </ul>	<ul style="list-style-type: none"> <li>- A clear separation between health professionals and patients</li> <li>- Functional approach; physical focus while shying away from provision of hope lest it would be false hope</li> <li>- Overt focus on parts of body affected by stroke and neglect of unaffected parts</li> <li>- Learning is linear and finite</li> <li>- Learning is limited to the rehabilitation setting and patients find it difficult to transfer skills to other areas of their lives (Wade &amp; de Jong, 2000)</li> <li>- Mostly individual therapy sessions and no involvement of carers</li> <li>- Negative language not discouraged and also used by health professionals. Patients stay passive in their own healing trajectories</li> <li>- Decrease in self-confidence and sense of self</li> <li>- MDT only present in theory since its effect was not experienced by patients</li> </ul>

In the CE setting participants experienced a relationship of sharing, akin to a partnership, between themselves and conductors concerning their progress. In the stroke unit there was a clear separation between patients and health professionals with very little information provided to patients.

CE learners were taught to focus on what they *could* do rather than what they *could not* do, while still being aware of where their challenges lay. This suggests awareness in CE of a person with abilities behind their disabilities. CE's focus on the physical body as an integrated whole was evident in their encouragement of body-half integration, also promoting in learners an integrated sense of self. In the stroke unit focus was on affected limbs, and thus patients' inabilities, only. This could be described as a restricted or limiting view of a person (Cooperrider & Whitney, 2005).

In the CE setting life-long learning was endorsed and conductors argued that it was impossible to predict whether or how much a stroke patient would progress. In contrast it was believed that the likelihood of a patient still progressing after having reached an apparent learning-plateau was very small.

CE skills were revealed to be easily transferable to settings other than the CE setting. This could also be a reason why learners experienced feelings of independence. CE's transferability of skills seems to take into account learners' individual lives outside the CE setting. Also, CE integrated individual learners into groups of learners and involved their carers/family members, indicating further awareness of learners as persons that live amongst other people and have families. In the stroke unit, patients' therapy was provided in one-to-one sessions only and their carers/family members were not involved in patients' rehabilitation. This suggests patients' social needs were not part of the stroke unit's rehabilitation focus.

In the CE setting there was an emphasis on learners' use of positive as opposed to negative language. This suggests awareness of the influence of one's thoughts on one's own attitude and eventually one's own healing trajectory. It could further indicate a cultivation of greater self-responsibility within a healthcare setting. In the stroke unit vocabulary was characterised by the use of negative concepts and patients did not seem to play an active role in their own healing trajectories.

As mentioned in Chapter 2, health professionals in a stroke unit form part of a multi-disciplinary team (MDT) consisting of a wide range of different therapeutic modalities including consultant doctors, nurses, physiotherapists, occupational therapists, speech- and language therapists, psychologists, dieticians and social workers (Stroke Association, 2006b; Dennis & Langhorne, 1994). In theory an MDT therefore embraces all the different modalities needed in stroke care. From Study One it is however evident that such collective care did not realise itself for patients in practice. The non-physical parts of patients' experiences were not addressed, illustrating that the different modalities within the MDT did not provide equal degrees of care. Teamwork between CE conductors is a fundamental standard (Quicke, 1986). *Within* one conductor one also finds skills comprising of a mixture of some of the stroke unit MDT members' knowledge such as physiotherapy, social work and psychology (Read, 1998; Beardshaw, 1989). Indeed, Study Two participants did report care provided for both their physical and non-physical needs such as emotional and social needs. However, the overall focus of CE still seems to have been physical mobility, since all activities were based on physical movement albeit accompanied by learners' verbal expression thereof. Indeed, CE is based on the theory that once a person has achieved orthofunction\* they have achieved cognitive growth and not only the ability to perform certain physical activities (Hári, 1997), implying focus on more

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\* *Orthofunction* is described as a process of "integrated cognitive performance" (Hári, 1997, p. 2) through which an individual moves closer to their potential (UKFCE, 1998).

than the physical level of being. CE's physical focus could therefore be argued to have a rehabilitative effect on learners' emotional and psychological levels of being. Still, this does not make CE's approach a holistic one: any positive effects on levels of being other than the physical, could therefore have been because of physical progress within an educational model that provides learners with information on their condition, and not because of direct effects of focus on non-physical levels.

Keeping in mind the discussion of biomedicine and positivism in Chapter 1 of this thesis, it is clear that the approach used in the conventional stroke unit is biomedical. The approach used in the CE setting shows principles of a nature opposite to those of biomedicine. The opposite of biomedicine/positivism, as was also discussed in Chapter 1, is holism/constructivism. Two questions now arise:

i) What makes a health approach holistic?

And:

ii) If the approach used in CE cannot be described as holistic, what can it be described as?

The next section addresses these two questions.

#### **6.2.4 Reflection on what makes a health approach holistic**

In Chapter 1 of this thesis I refer to the existence of different kinds of knowledge in healthcare. I provide arguments for the fact that today's conventional medicine is based on dualist biomedical knowledge, whereas more unconventional practices in medicine show principles from non-linear holistic knowledge. In revisiting a clarification of biomedicine one sees an obvious focus on parts of the whole only, and in particular on symptoms. I would like to compare this to a condition known as tunnel vision, where a person cannot see objects in her/his peripheral visual field, only those within a tunnel-shaped field that stretches out in front of them. Often people who refuse to see other viewpoints are referred

to as having tunnel vision. Taking this analogy over to the concept of holism one could say a holistic view represents one which sees beyond the ‘tunnel’ into the peripheries, allowing for more than what is apparent and in front. The South African statesman Jan Smuts coined the term ‘holism’ (Smuts, 1926) to refer to such a holistic view of systems and life in general. Indeed, he saw holism as a natural trend present in life that always forms ‘wholes’ that are bigger than the sum of their parts, and argued that this trend was the result of creative evolution. This suggests that holism and the search ‘to-be-whole’ are inherently part of every living being. To deny this search for ‘being-whole’ would then imply gross disrespect for all life.

Table 8 provides more detail on the principles fundamental to a holistic approach to health. It is the first half of the last principle in Table 8 that has contributed strongly to a critique of a holistic approach to health. This critique includes two main arguments: (i) holism is based on a philosophy of victim-blaming where the individual is seen as being responsible for the state of their health, rather than the social system; and (ii) holism is individualist in that it focuses on ways in which the individual can change but disregards social and environmental influences (McKee, 1988). It could be argued that this criticism is based on a limiting view of holism since (i) the very essence of holism is to include the individual *as well as* their society and environment and (ii) in a true holistic approach the social system and the person form part of the bigger whole and work together for the benefit of all involved. The focus therefore of the criticism should be that many of the approaches are not in fact truly holistic.



**Table 8:** Principles of a holistic approach to health (compiled from Dossey & Guzzetta, 2005; Bell, 2003; Galantino, et al., 2003; Kim, 1999; Vickers & Zollman, 1999; Bakx, 1991; O'Donnell, 1989)

- A person comprises multiple levels of being and therefore has multiple health needs, relating to their different levels of being. These different levels include emotional, physical, spiritual, intellectual and social/environmental.
- The whole of a person is larger\* than the sum of those individual levels.
- There is no hierarchy between the different levels of a person's being. All is of equal importance.
- There exists an interactive connection between all the different levels within a person's being as well as between the person and his/her environment/society.
- A change in one level of a person's being causes a change in all her/his other levels.

Caroline Myss, well-known medical intuitive, author and public speaker, goes as far as to say that health and healing occurs in a holographic way (Myss, 1996). This suggests that the multiple levels of personhood interact with each other holographically, the latter being indicative of non-linear processes happening simultaneously on different levels.

- A person accepts a more responsible role in her/his healing trajectory, in partnership with his/her health professionals.

As stated in Chapter 1 of this thesis, evidence suggests that some social groups living in the years BC held a holistic view of life for many centuries (Pennick, 1979). This was

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\* This does not indicate a quantifiable size, rather a metaphysical dimension of magnitude.

before a dualist view was introduced by influential thinkers such as Descartes (1596-1650), which formed the foundation of most knowledge bases in modern life, including that of conventional Western medicine. This suggests that something fundamental about 'being-human', which could be argued to be a humanistic and also holistic view that sees a person as a multi-levelled being integrated with their surroundings, was in the seventeenth century replaced by a limiting and therefore unnatural dualist system. This could further be argued to have led to public services offering care in a way that was, and still is, limiting and unnatural. Indeed, looking at Study One's participant responses it is clear that the dualist, mechanistic view upheld by conventional biomedicine falls short in many ways. Stroke patients yearn to be viewed as holistic beings with holistic needs that ought to be addressed in a truly holistic way.

Bearing in mind this discussion of holism and in particular the contents of Table 8 as well as that of Table 7, it is clear that the CE approach indeed holds many principles that are akin to holistic principles, for example: CE encourages awareness of the body as an integrated whole. It also encourages awareness of the importance of the role of carers/family members. Transferability of physical skills to areas outside CE form an important part of CE activities. CE promotes a partnership between learners and conductors and encourages more self-responsibility for learners' own healing trajectories.

However, as mentioned above CE's holistic principles are mostly applied with an overall goal of physical mobility. CE does not include activities specifically focused at levels of learners' lives other than the physical. Claims such as the one of Gombinsky (2004), that CE puts equal emphasis on learners' physical progress and improvement of self-esteem, should therefore not be read as an indication of a holistic approach. It could rather be argued that CE's application of holistic principles, with an overall physical focus,

puts it under the umbrella term of a person-centred approach. The next section clarifies the latter concept.

#### **6.2.4.1 A person-centred approach to health**

The consumer-led society we live in today has been said to have entered the world of health care as well (Kravitz & Melnikow, 2001; Guadagnoli & Ward, 1998; McKee, 1988). Consumers' knowledge of products and possibilities has increased together with increased access to information. In the same way, many patients' lay knowledge of health and medicine has increased as well, leading to expectations of more choice from their health care system. Many patients would also like to play a more active role in their own health care (Michie, et al., 2003; Mead & Bower, 2000). Indeed, research indicates that increased patient education (Johansson, et al., 2003) and the involvement of patients in decisions regarding their own health (Ford, et al., 2003) lead to increased feelings of empowerment in patients, which then lead to better health outcomes. An approach to health of which the main aim is to give patients more choice and allow them greater participation in their own health care, is called the person-centred\* approach (Ford, et al., 2003; Fossum & Arborelius, 2003; Michie, et al., 2003; Epstein, et al., 2002; Little, et al., 2001; Bensing, 2000; Mead & Bower, 2000). The literature indicates that there is not one sole definition for the concept of person-centred care (Michie, et al., 2003; Stewart, 2001; Mead & Bower, 2000). The following is extracted from a selection of definitions:

- "It has a basically humanistic, biopsychosocial perspective, combining ethical values on the 'ideal physician', psychotherapeutic theories on facilitating patients' disclosure of real worries, and negotiation theories on decision making" (Bensing, 2000. p. 17).

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\* also sometimes referred to as client-centred or patient-centred. From a literature review it seems that the prefix 'patient' is more often used by health professionals in a biomedical arena and 'client' and 'person' are more often used by social scientists and counsellors/psychologists.

- It takes “into account the patient’s desire for information and for sharing decision making and responding appropriately” (Stewart, 2001, p. 445).
- It contains 6 interconnected elements namely i) an exploration of both the patient’s disease and their own experiences thereof; ii) an understanding of the whole person; iii) the finding of a shared understanding of management; iv) the inclusion of prevention as well as health promotion; v) the improvement of the patient-doctor relationship; vi) the acceptance of limitations in terms of own abilities, time and resources (Stewart, et al., 1995).

Indeed, the above definitions overlap with holistic principles, and those of CE’s approach (Table 7) seem to correspond well with the person-centred approach. CE learners’ wishes were assessed in their first session, together with input from conductors, revealing a partnership between learners and conductors. CE could be said to hold a biopsychosocial perspective in the MDT elements present within and between conductors. Learners reported conductors shared information in a way that was accessible to learners. The emphasis on patient education in the person-centred approach is also paramount in the CE philosophy.

Two principle criticisms of such an approach are i) its need for longer doctor-patient interaction time (Little, et al., 2001) and ii) the fact that not all patients care for more information nor does everyone want to play a more empowered role in their own healthcare (Ford, et al., 2003; Guadagnoli & Ward, 1998). It seems that CE overcomes the first criticism through a system that intrinsically allows more time for patients/learners to reveal their needs to conductors. However it is not known how CE would manage the second criticism. It could be argued that stroke patients with very little or no inner motivation to accept some level of self-responsibility in their own healing trajectory might not consider attending CE sessions at all, and would prefer to accept the conventional

passive patient role. It is therefore very important in a person-centred care approach that health professionals first determine to what level a patient wants to be involved in their own healthcare (Ford, et al., 2003). Again, it is possible that stroke patients attending CE sessions already made the decision to take a more responsible role for their own progress.

Research indicates that the person-centred approach is better developed as a theory than a practice (Bensing, 2000). This could be a reason for its lack of a central definition (Stewart, 2001). It could also explain why the concept of a person-centred approach is often erroneously used in conjunction with the term 'holistic' (Barrett, et al., 2004). A holistic approach seems to go beyond the person-centred approach. Despite the one definition which includes a focus on the whole person (Stewart, et al., 1995), in practice the person-centred approach is mostly concerned with whether patients are heard in the doctor-patient relationship in terms of what their most prominent health needs are at the time (Fossum & Arborelius, 2003; Byrne, et al., 2002) and whether patients are part of the decision-making process regarding their own healthcare (Fossum & Arborelius, 2003; Deyo, 2001; Charles, et al., 1999; Close & Proctor, 1999). As with CE it seems that effects on patients' levels of being such as spiritual and social is more likely to be because of management of patients' presented health needs at a certain time than an exploration of all individual levels of being. Therefore it could be argued that if a patient does not present with a problem on a spiritual level, that level would not be addressed. A holistic approach however highlights the importance of addressing all levels of being and not only those presented by a patient at a certain time. The next section provides recommendations regarding the development of a holistic approach to stroke rehabilitation, thus one that goes beyond a person-centred approach.

### **6.2.5 Recommendations regarding the development of a more holistic approach to stroke rehabilitation**

A holistic approach to stroke rehabilitation would be one that adheres to all the principles of holism, not only a few. Nor will it have an overall focus on only one part of the whole. It would have a “profound respect for the power of the individual to choose or act” (Benner, 2000, p. 16) and simultaneously show an understanding for the person’s embodied experiences that give rise to this power. In this section the holistic principles that were evident in the two settings studied are recommended for a holistic approach to stroke rehabilitation, together with further aspects of holism.

In the stroke unit the only biomedical principle that alludes to holism is that of the MDT but, as mentioned earlier, the holistic aim of this concept did not realise itself for patients. Neither did it realise in full for CE learners. Patients’ experiences illustrated that the different modalities within the MDT did not provide equal degrees of care. It reminds one of the well-known sentence from the 1945 novel ‘Animal Farm’ by George Orwell: “all animals are equal, some animals are more equal than others”. In the case of the current research it could read: “all health professionals are equal, some health professionals are more equal than others”. This problem with MDT’s is also highlighted by Sharma (1992) who wrote that “in the most willing partnership divergent interests will surface and make themselves felt” (p. 110), and also by Quicke (1986) who stated that MDT’s “may be all right in theory, but in practice they are fraught with tensions due to different professional interests” (p. 305). It could also be argued that this is due to a tension between excellence and general ability. In CE, teamwork between conductors however is a fundamental standard (Quicke, 1986). It seems that the philosophy of an MDT, albeit in one conductor or amongst a number of CE conductors, can indeed operate holistically in practice. Interestingly a holistic approach to patients has already been advocated by one modality

represented in the conventional MDT, namely nursing. Florence Nightingale advocated care for the “whole patient” (Kim, 1999, p. 87), an approach described as a consideration for a patient’s mind, body and spirit, also in relation to their environment (Benner, 2000; Kim, 1999). The concept of holistic nursing has grown and there are today peer-reviewed journals and text books (for example Dossey, et al., 2005) focusing on this topic.

Unfortunately it could be argued that due to the overall biomedical knowledge base of the conventional MDT, the holistic voice of its nursing members is not heard. Diller (1990) suggests that instead of a *multi*-disciplinary team, health professionals could form an *inter*-disciplinary team which “involves members who are engaged in problem solving beyond the confines of their particular knowledge base” (p. 277). He argues that such an approach would suit rehabilitation in particular due to patients’ individualised problems that “cannot be solved by cookbook approaches” (Diller, 1990, p. 277). A first recommendation for a holistic approach to stroke rehabilitation could therefore be the formation of an Inter-Disciplinary Team (IDT) in which the members are aware of the value of their own contributions as well as those of the other members. This would also suggest awareness of the non-hierarchical nature of the IDT.

Further recommendations, as was evident in CE, are as follows:

- An awareness of each patient as a whole person with potential, as opposed to a patient with symptoms that limit their potential, will form the core of the holistic approach to stroke rehabilitation.
- A non-hierarchical partnership between health professionals and patients, akin to the sharing relationship between the knower and the known in holism, will be pursued at all times.
- This approach will foster an intrinsic belief in non-linear life-long learning, equating to non-linear thinking in holism.

- The importance of the transferability of skills to other areas of stroke patients' lives. reminding of the holistic principle of interaction between all levels of being, will exist in theory as well as in practice.
- The involvement of patients' carers/family from the point of on-set of stroke will be strongly encouraged, as well as ways to help patients and their carers/family members adapt to patients' changed levels of being.
- This approach will encourage a positive attitude as well as self-responsibility in patients' own healing trajectories.

In the latter recommendation patients will be supported at all times through an awareness of the important role of their emotions and mental images within this empowerment process. As mentioned in the reflection on Study Two, it is very important for health professionals to give patients the opportunity and support to work through their emotions before work with positive imagery is started (Byrne, et al., 2002; Epstein, et al., 2002). This is to prevent patients from hiding their true emotions lest they were seen as being negative.

It is suggested here that a holistic approach to stroke rehabilitation would go beyond a person-centred approach and overtly include all levels of being. On a physical level the conventional biomedical acute care will be encouraged, combined with CE's person-centred approach. The attention paid to patients' emotional/psychological and mental levels in a person-centred approach could be supplemented by overt attention to their spiritual level through awareness and conscious application of the flow of universal life force or 'qi' (pronounced 'chee'). The latter forms an important part of many holistic therapies (McKee, 1988). A personal awareness of the flow of qi, as well as ways to manipulate it oneself, could be beneficial to stroke patients as well. Different self-help techniques such as mental imagery and/or meditation combined with a holistic therapy



such as acupuncture could be used to increase this awareness. The practice of meditation involves becoming quiet and focusing one's mind on one thought or image (Glasscock Barnes, 2004; Roland, 2003). Apart from the spiritual benefits of meditation, it has also been shown to have more holistic results in that it effects a person's physical body in positive ways (for example it lowers blood pressure and reduces heartbeat in times of stress) as well as their emotional/psychological 'bodies' (increasing a feeling of inner power which can help people in times of personal difficulties) (Glasscock Barnes, 2004).

Some people however might equate meditation to religion and therefore shy away from it. A practice akin to meditation but without a religious context is commonly known in psychology as mental imagery (Graham, 2004; Brigham, et al., 1994; Heil, 1993; Schaub, et al., 1991; Smith, 1991; Kunzendorf & Sheikh, 1990; Achterberg, 1985). Mental imagery involves the visualisation of an image in a person's mind, the aim of which could range from increasing awareness of bodily movement to increasing personal autonomy (Graham, 2004; Heil, 1993). Mental imagery has been shown to be beneficial in areas such as relaxation (Graham, 1992) and sport injury rehabilitation (Heil, 1993) and has been suggested to be applicable to rehabilitation (Warner & McNeill, 1988) and stroke rehabilitation\* as well (van Leeuwen & Inglis, 1998; Weiss, et al., 1994; Weiss, et al., 1994). Difficulties with motor functioning post-stroke are largely due to damaged neural pathways (van Leeuwen & Inglis, 1998). Such damage decreases the control patients have over some muscles. The neural system however has a characteristic called "plasticity" which enables the body to produce changes in neural connections, compensating for damaged connections. Retraining greatly influences such neural "reorganisation". Results indicating that mental imagery activates brain areas similar to those activated through physical practice, suggest that neural reorganisation can be influenced by mental imagery.

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\* Indeed, the effectiveness of mental imagery in stroke rehabilitation was one of the initial focuses of my PhD, as discussed in Chapter 1.

even if patients cannot do physical exercise (van Leeuwen & Inglis, 1998). Indeed, research indicates that when stroke patients performed a mental imagery task, their brain patterns were similar to those of able-bodied people performing the same task (Weiss, et al., 1994; Weiss, et al., 1994). In both sport injury rehabilitation (Heil, 1993) and cancer treatment (Graham, 2004; Achterberg, 1985; Achterberg & Lawlis, 1978) mental imagery is often included to address patients' emotional, physical and mental needs. The use of images in the mind's eye to address such needs is widely regarded as important for positive reaction to conventional treatment (Bell, 2003; Heil, 1993; Schneider, et al., 1991; Smith, 1991; Markham, 1989; Achterberg, 1985; Shorr, et al., 1980; Achterberg & Lawlis, 1978). Also, mental imagery for stroke patients links in with the already-practised activity of verbal intention in CE discussed earlier. The importance of the role that mental imagery could play in a holistic approach to stroke rehabilitation therefore needs to be considered.

These recommendations for a holistic approach to stroke rehabilitation are believed to include all levels of a person's being. Such an approach may however also be accused of taking too much of health professionals' time. Charles et al. (1999) provides a counter-argument: if a new approach "turns out to require more time on average than other approaches in order to facilitate interaction and to build consensus, then physicians may respond by either advocating for increased fees or seeing fewer patients. However, there may also be costs for not involving patients, in the form of repeat visits, second opinions and doctor shopping" (p. 659). Indeed, research is needed to assess the workability of such an approach in the evidence-driven health service of today. However the encouraging results of research on a person-centred approach could be seen as indicative of possible similar effective results from a holistic approach to stroke rehabilitation.

### **6.3 Reflection on method**

This section assesses the soundness and rigour of the method I used in my thesis. In quantitative research statistical formulae are used to determine the validity of a study and the trustworthiness of its findings (Robson, 1993). Qualitative research needs different ways in which to determine this (de Witt & Ploeg, 2006; Guba & Lincoln, 2005; van der Zalm & Bergum, 2000; Mays & Pope, 1995; Robson, 1993). Also, qualitative research studies do not search for ultimate truth (Guba & Lincoln, 2005), rather for understanding. It could therefore be argued that the term ‘validity’ does not suit an assessment of a qualitative study’s value. A term such as ‘soundness’ (Trochim, 2006) seems to be more appropriate.

An intense debate started in the 1980’s on the need for separate criteria for determining the value of qualitative research, which lead to the development of sets of generic criteria (for example Sandelowski, 1986; Lincoln & Guba, 1985). These have since been widely used to assess qualitative studies’ rigour and soundness. Interestingly, Guba and Lincoln (2005) refer to their criteria of 1985 as methodological only and present arguments in favour of the development of criteria more applicable to phenomenological and interpretive research. Indeed, de Witt and Ploeg (2006) recently introduced a set of such criteria specifically applicable to interpretive research, and specifically to hermeneutic phenomenological studies. According to these authors the hereto widely used generic criteria are both philosophically and methodologically inconsistent with hermeneutic phenomenology. The aim of this section is to present the difference between generic and specific criteria and to reflect the current research method and process against the criteria of de Witt and Ploeg (2006).

The section concludes with a discussion on the study’s limitations and strengths.

### **6.3.1 Generic versus specific criteria for determining rigour and soundness of hermeneutic phenomenological method**

The criteria developed by Lincoln and Guba (1985) which are criticised by themselves as being methodological only (Guba & Lincoln, 2005) and by de Witt and Ploeg (2006) as being too generic are credibility, transferability, dependability and confirmability.

Sandelowski (1986) developed these further and replaced ‘transferability’ with ‘fittingness’ and ‘dependability’ by ‘auditability’. The following is a discussion of Sandelowski’s terms from which de Witt and Ploeg (2006) developed theirs. The current study will then be reflected against the latter authors’ criteria.

- Credibility: The credibility of a study lies in the fact whether the readers of the study findings would recognise the experience conveyed. People who have had or are having the experience might recognise the experience as their own. and those who have not had the same experience might recognise it after reading about it in the study findings.
- Fittingness: This concept describes the way in which a study’s participants fit the experience that was studied and assesses whether they are representative of those having the experience under study. It also describes how the findings of a study would transfer to other settings in which a similar experience could take place.
- Auditability: The auditability of a study refers to whether the path of thinking and reasoning the researcher followed throughout the research, is made to clear to the reader.
- Confirmability: This concept assesses the degree of freedom from bias in the study and entails confirmation of the above three criteria.

de Witt and Ploeg (2006) argue that Sandelowski’s generic criteria fall short when used in interpretive research as follows:

‘Credibility’ conceals the depth of the effect study findings can have on the reader. Readers *feel* rather than just *recognise* experience. ‘Fittingness’ as relating to study participants’ being well-suited (‘fitting’) for the research and representative of the group of people under study, is inconsistent with hermeneutic phenomenology’s approach to sampling. The only criterion for sampling in hermeneutic phenomenology, according to de Witt and Ploeg (2006) “is that participants are willing and able to articulate their experience of a phenomenon” (p.223). It therefore does not aim at obtaining a representative sample through, for example, theoretical sampling as most often suggested by Sandelowski (1986). ‘Confirmability’ is to me most obviously out of harmony with hermeneutic phenomenological principles. The fact that researchers cannot be unbiased and value-free is an important part of the philosophy of hermeneutic phenomenology. de Witt and Ploeg (2006) supports this, as well as Sandelowski’s criterion called ‘auditability’. They agree with Sandelowski’s call for the need of explication of researcher thought patterns but at the same time an awareness by the interpretive researcher not to get caught up in rules and techniques but to remember the creativity involved in hermeneutic phenomenological research.

The five criteria suggested by de Witt and Ploeg (2006) follow below. Simultaneously, the current research is reflected against these criteria.

- **Balanced integration:** This concept assesses whether the philosophy of the study is intertwined within the study methods as well as the findings. In the case of the current research hermeneutic phenomenology was the philosophy which is clearly evident in the study method used (i.e. adaptation of van Manen’s (1990) six research activities based on hermeneutic phenomenological principles) as well as the findings where hermeneutic phenomenological concepts such as ‘being’ are included.

- Openness: This criterion is equivalent to Sandelowski's 'auditability' and verifies whether the researcher provides information on the development of their thoughts and decisions made during the research. In the current study such information is indeed given, for example in Chapter 1 I discuss the development of the focus of my research, how my study came to be two-fold, i.e. consisting of two separate studies and also how it came about that I decided to use hermeneutic phenomenology as philosophy and method. In Chapter 3 I provide information particularly on how Study One's participant criteria developed into those stating that patients had to be three months post-stroke. I will discuss my own feelings and experiences later in this chapter, revealing my emotions during the research process. Regarding the latter I admit that I re-analysed the data from Study One in an attempt to reduce the effect my emotions could have had on my analysis.
- Concreteness: The concreteness of a study is measured against how real the reader might feel an experience through reading the study findings. It therefore refers to how well a study's findings reflect the lived experience that was studied. van Manen (1997) uses the terms 'lived throughness' which lead to de Witt & Ploeg's (2006) criterion of 'concreteness'. He describes this concept as follows: "Lived throughness means that the phenomenon is placed concretely in the lifeworld so that the reader may experientially recognize it" (van Manen, 1997, p. 351). In Chapter 1 I refer to the dance I had to do between different writing styles. In Chapters 4 and 5 I discussed the study findings in a hermeneutic phenomenological way in order to make the lived experience of stroke rehabilitation more concrete, than if I had only presented it as a general discussion in the style of Chapter 6.
- Resonance: 'Resonance' refers to whether the reader literally resonates with the study findings when reading them. van Manen (1997) writes about such resonance as "the

sudden perception or intuitive grasp of the life meaning of something. This experience is so strong that it might stir us at the core of our being” (p. 364). I was continuously aware throughout writing my study findings that the reader might not know anything about stroke rehabilitation experience. Therefore I attempted to make this phenomenon as vivid as possible in my choice of language combined with study participants’ own words. Simultaneously I was aware of the fact that the reader might know the experience very well. I therefore felt a great responsibility in my attempt to convey this phenomenon to the best of my abilities so that the reader can resonate with it.

- Actualisation: This criterion is in fact not measurable at the first appearance of a study’s findings since it refers to the way in which future readers will resonate with them. de Witt and Ploeg (2006) therefore suggests that readers of research findings should increasingly send feedback on their feelings about interpretive studies’ findings to the authors, in order to help researchers determine the actualisation of a study.

In summary the current research meets the first four of the above criteria namely balanced integration, openness, concreteness and resonance. Whether it meets the last criterion of actualisation will only be known in the future after feedback from readers.

It is important to also mention two general qualitative standards applicable to interpretive research, which could also be used to assess the soundness and rigour of the current study. They are reflexivity and participant validation. The former relates to de Witt and Ploeg’s (2006) criterion of ‘openness’ but I feel the importance of reflexivity in hermeneutic phenomenological research warrants a thorough discussion of how it can be used to increase a study’s soundness and rigour:

- Reflexivity

A critique of researchers using hermeneutic phenomenology as method is that they are not explicit enough about their own pre-assumptions and how they contributed to the forming of the research (Draucker, 1999). The researchers often provide the voices of the participants but omit or neglect a section on their own perspectives. This reduces the degree of understanding possible through hermeneutic phenomenology (Draucker, 1999). Indeed, van Manen (1990) encourages researchers to be sincere about their pre-reflective assumptions and to view them as co-constituting the descriptive and interpretive process. Le Vasseur (2003) identified the concept of ‘persistent curiosity’ which could be used to interpret bracketing as practised in hermeneutic phenomenology. Through being curious one acknowledges ignorance about a certain phenomenon and then ask questions of one’s own pre-reflections in order to understand the phenomenon better (Le Vasseur, 2003). According to Le Vasseur (2003) this correlates with the thoughts of Merleau-Ponty, an existential phenomenologist, on being astonished by the world and that which one studies. Le Vasseur’s (2003) concept of persistent curiosity could contribute to making Husserl’s bracketing\* more congruent with hermeneutic phenomenology, instead of rejecting it outright. As apparent in Figure 2, I was constantly aware of my own pre-reflections and assumptions while being immersed in the research process. Chapter 1 explained my position in terms of being in favour of a holistic approach to health. This orientation therefore most probably influenced the way in which I analysed the data. Also, as mentioned before, the way in which the research affected me as human being would also have had a reciprocal effect on the research process. I believe my practice of reflexivity contributed to the ‘Openness’ (de Witt & Ploeg, 2006) of my research and therefore increased the soundness and rigour of my study.

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\* see Chapter 3 for a discussion on Husserl’s concept of bracketing.



- Participant validation

To meet this standard researchers return to their participants with data transcripts and/or the analysed data to allow their input on whether the transcripts and/or analysis correctly reflect their experiences (Barbour, 2001). A difficulty inherent to this standard is that qualitative researchers work towards an overall view of an experience whereas individual participants focus on their own experiences (Mays & Pope, 2000). According to Lapadat (2000) transcripts reflect interviewee's narratives at a certain point in time and place. Returning data to them at another time implies participants could have 'moved on' and might not totally agree anymore with what they had said at the time of the interviews. This standard could therefore complicate matters a great deal for most kinds of qualitative studies, especially when a study explores snapshots of experience. It could however be more appropriate in for example an action research study where participants take part in the research on a continuous basis over a length of time (Barbour, 2001). In the current research, which was done on a part-time basis, interviewing took place over a period of six months in the stroke unit after which I started analysis. In the CE setting interviewing, observation and the keeping of diaries took place during the two week CE course after which I commenced analysis of this second case study. For both Study One and Two analysis took place over periods of six months and longer. Study participants' verifications six months or more after interviewing were likely to have been coloured with experiences they had had outside the research settings, adding irrelevant data to the original stroke unit data. Verification from interviewees was therefore inappropriate for the current method of research.

## **6.4 Reflection on the researcher experience**

The aim of this section is to reflect on the effect the research had on me, and how I dealt with the challenging nature of my research topic. Emotion is affected by multiple levels of interaction with oneself and one's environment (Denzin, 1983). This points to the holistic nature of being of which emotion is one level. Interaction between researcher and research participants is an example of a social situation in which emotions of different kinds and degrees are bound to realise. The kinds and degrees of emotion would depend on the level of interaction between researcher and research participants. The nature of hermeneutic phenomenological inquiry is such that researchers immerse themselves deeply into the phenomenon they study (van Manen, 1990). This was no different from my own PhD research and the way in which I immersed myself in stroke patients' and CE learners' experiences of rehabilitation. This section discusses my experiences of 'being-immersed' in others' lived experiences to illustrate the holistic effect of research on the researcher. I also present how, after my experiences in Study One, I developed a tool which addresses researcher emotions holistically and how it helped me in Study Two to deal better with my emotional reactions to patients'/learners' often upsetting narratives. I conclude the section with a suggestion that other researchers studying sensitive topics could also use this tool to take care of themselves in the research process.

### **6.4.1 Taking care of interviewees ... neglecting own emotions**

Studying sensitive topics (i.e. topics that deal with questions of a private, stressful, and/or sacred nature (McCosker, et al., 2001) such as stroke rehabilitation experience, and interviewing people who have experienced profound events, such as stroke, creates the possibility for more than just superficial sharing of experiences. It creates the possibility for intense, emotional narratives that could affect both interviewer and interviewee. In

longitudinal studies even more intense emotions could emerge since the relationship between researcher and participant inevitably grows deeper over time (Gatenby & Humphries, 2000). There is a burgeoning number of papers that provide interviewers with guidelines on how to take care of interviewees in emotional distress (for example Tee & Lathlean, 2004; Koivisto, et al., 2001; Coyle & Wright, 1996; Cook, 1995; Parkes, 1995; Cowles, 1988). Good technical interviewing skills are an important part of such guidelines and form the subject of many articles (for example Corbin & Morse, 2003; Chenail, 1997; Coyle & Wright, 1996). Interviewers are encouraged to use techniques such as counselling skills in order to be a good listener and to create an atmosphere where interviewees could feel safe enough to share their experiences with the interviewer (Chenail, 1997; Coyle & Wright, 1996). Interviews with patients are not counselling sessions (Hutchinson & Wilson, 1994) but the characteristics of counselling interactions have many elements in common with those of qualitative unstructured interviewing. They both ask for an unbiased approach from the interviewer, and an openness to whatever the interviewee might say or do.

Prior to starting interviewing my study participants in Study One, I therefore attended a three month part-time course on the use of counselling skills to improve my interviewing and listening skills. In retrospect I realise that the skills I had learned and used during interviewing focused on and recognised only the comfort and emotions of the patients and not those of myself. The literature on interviewing skills contribute little to the recognition of interviewers' own feelings - to the contrary, the literature mostly deals with technical aspects of interviewing, such as the use of counselling skills as mentioned above, to put the interviewee at ease (Rowling, 1999), moving attention away from the human aspects of 'being-an-interviewer'. Client-centred counselling skills (Rogers, 1951) which I used in my interviews with study participants required empathy, congruence and unconditional

positive regard (UPR) from myself as interviewer. It now appears that showing empathy, 'moving into' another person's experiences, contributed to my negative emotional reactions to the research, especially in Study One when I was still unaware of this impact. Also, in having had UPR for the interviewees it appears I had not given enough recognition to myself as an individual person and the ways in which interviewees' narratives affected me. Indeed, patients often revealed despairing concepts through sharing their personal emotions with me. Despite the fact that I only conducted one-off interviews with participants, emotional involvement with their narratives was prolonged during transcription and interpretation of the interview data. For example, one patient in the stroke unit revealed a high level of anxiety and feelings of powerlessness in the following quote (names in brackets are pseudonyms):

- "I mean it is not fair to push people in a wheel chair, into a room or their own bedroom, where they have no facilities to be able to do anything to occupy their mind. And very often that happens and then if you can't reach your bell you're stumped." (Lily, 73 years old)

In another stroke unit patient's account, similar feelings of powerlessness and negative images of his own body were unveiled:

- "It's awkward starting walk at first, you're like a tin soldier. The stroke, it's like being back to your childhood, you can't dress, you can't, you can eat, just about. There's lots of things you've gotta learn and do again. And you feel so incapable, that's the trouble ... that's, that's the worst trouble, it's the frustration, trying to do things you used to, you knew you could, but your limbs don't answer the same as they used to do. I can move this hand (*his*

*left, affected hand*) now but hmmm it's not as adaptable as this one (*his right hand*). I mean I can pick up something with that (*right hand*) but I shall have a job with this one (*left, affected hand*)." (Isaac, 72 years old)

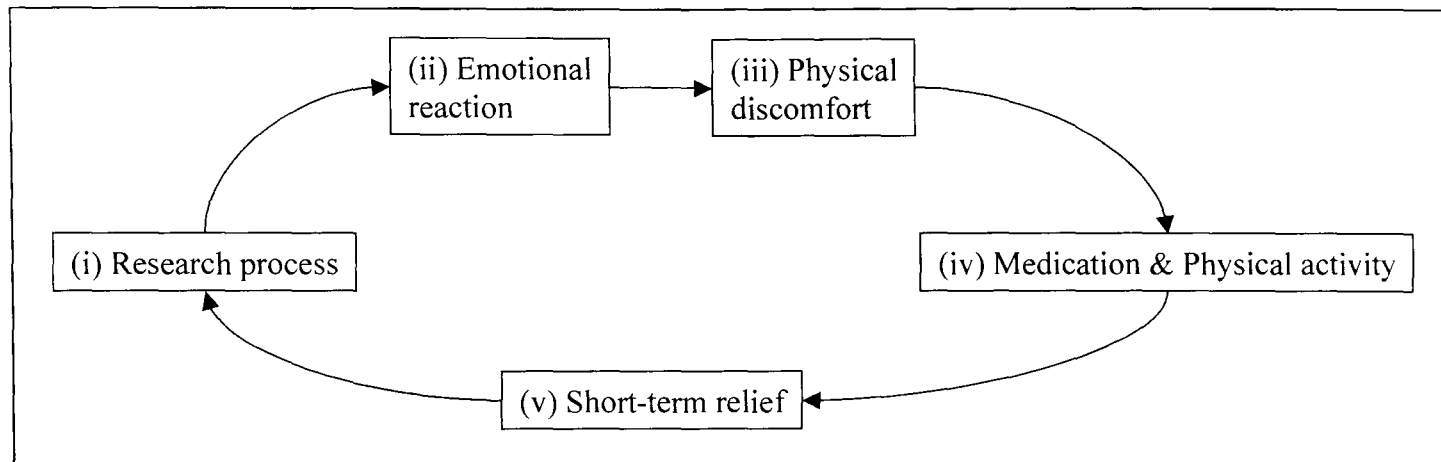
I had never contemplated how far I was prepared to immerse myself into interviewees' narratives. During the conducting of the interviews I found it difficult to keep an emotional distance from the patients in fear of being perceived as 'cold', and not really listening. To achieve a balance between 'cold' and 'too immersed' was indeed very challenging.

Shortly after having started the interviews for Study One, I began to experience an imbalance of health suggested by sudden unexplained symptoms which I had seldom experienced before. At first I identified this imbalance by the on-set of unexplained physical responses. Typical physical reactions I experienced after an interview with a stroke patient were recurrent headaches accompanied by neck and shoulder pain, general muscle pain, irritable bowel syndrome, tenseness around my throat area and episodes of intense crying. I quickly linked these responses to the nature of my research, since (i) they had first appeared shortly after I had started conducting interviews with stroke patients, (ii) the rate at which they recurred had increased with the increasing number of interviews in which I was exposed to patients' intense emotions, and (iii) I experienced corresponding responses during transcription, analysis and interpretation of the data. In order to understand what was happening to me I searched the literature for researcher experiences. I found that researchers' emotional responses, and the impact these may have on them and on the research outcome, were commonly revealed in presentations at research conferences and amongst research colleagues (Moch & Gates, 2000). Yet such emotional distress was an issue that was seldom acknowledged in the peer-reviewed scientific literature (Rowling, 1999; McCosker, et al., 2001). This was surprising to me, since other researchers working

on sensitive topics had also experienced physical reactions similar to mine (for example headaches and insomnia (Cowles, 1988; Dunn, 1991); gastrointestinal upsets and neck and shoulder pain (Dunn, 1991); crying (Dunn, 1991; Burr, 1996; Rowling, 1999)). What I deduced from my literature search was that there existed (and still exists) a contradiction in being a qualitative researcher: we have to be “tough on the outside and sensitive in the inside” (Morse, 2002, p.1019). Thus we have to be tough enough to be able to listen to people’s often painful stories, yet hold a sensitive approach to these stories in order to convey the essence of people’s suffering to the readers of their research (Morse, 2002). It is surprising then that there is a very limited account in the literature of adequate strategies for assisting qualitative researchers in coping with their own emotional distress when exposed to people’s suffering. The most commonly encountered suggestions were: (i) journal keeping (Rowling, 1999; McCosker, et al., 2001), (ii) debriefing sessions with colleagues (Cowles, 1988; Burr, 1996; McCosker, et al., 2001), (iii) improving the scheduling of interviews, for example limiting the number of interviews per week, conducting interviews in the morning only, shortening the length of the interviews (Cowles, 1988) and (iv) allocating the interviewing and transcribing tasks to two different researchers (McCosker, et al., 2001). As I discuss later, I found these guidelines to be inadequate.

For a while I treated my physical symptoms with medication and the practice of physical activities such as gym exercises. However, the need to take repeated doses of pain-relief tablets over a period of several months and the short-term relief they provided convinced me that I had to find an alternative and better approach to dealing with my physical responses. The inefficiency of the way in which had I treated my physical responses was easily understood in terms of the cyclical nature of my experience (Figure 5), i.e. exposure to sensitive research topics, followed by physical discomfort, treatment of





these physical reactions using medication and physical exercises only. and re-exposure to despairing concepts during the research process, etc. However, I soon found that this cyclical illustration provided only part of the whole picture.



**Figure 5:** The cyclical nature of the researcher's experience, based on the sole treatment of physical discomfort

Gradually through the course of Study One I also experienced unexplained anxiety prior to starting new interviews. As feelings of anxiety were not something I normally felt when communicating with others, I suspected a potential causal link between the research and my anxiety. I then became more aware of my every reaction to the research, both physical and non-physical reactions, and noticed that different instances in the research gave rise to different emotional responses, leading to different physical responses (Table 9).

**Table 9:** My double-sided response (emotional and physical) to the research process

Instances in the research process which I experienced as emotionally upsetting	Emotional response	Physical response
Listening to patients describing their sudden loss of mobility, and when a patient's progress regressed or reached a plateau	Overwhelming sadness	<u>Muscle tension</u> 
Inability to do something for the patients to help them improve their seemingly hopeless situation	Feelings of powerlessness and frustration	Physical fatigue 
The thought of having to transcribe an interview which contained a patient's descriptions of brash handling by health professionals and patients generally not being acknowledged as human beings	Anxiety	Stomach churning 
When patients related how they received insufficient emotional and physiotherapy support, mostly due to staff shortages	Anger	Headaches 

Overwhelming feelings of sadness contributed to muscle tension while listening to patients describing their sudden loss of mobility, and also when a patient's progress regressed or reached a plateau. I felt physical fatigue after having experienced feelings of powerlessness and frustration due to the inability to do something for the patients to help them improve their seemingly hopeless situation. Anxiety contributed to stomach churning at the thought of having to transcribe an interview containing a patient's descriptions of brash handling by health professionals and generally not being acknowledged as a human



being. Headaches developed due to anger felt when patients related how they had been provided with insufficient emotional support.

All of these led to the awareness that my previously unexplained physical and non-physical symptoms were either directly or indirectly linked to my exposure to the patients' grief. By not regarding acknowledgement and management of my own emotions as researcher to be of great importance, and by focusing only on the good conduct of the research, I had neglected my own emotional health. I had fostered the idea that a researcher should be able to 'handle' sensitive issues in research. Also, that researchers should be able to step away from their research and not get over-involved in participants' personal issues. I thus perceived my own emotional reactions to patients' narratives without recognising their significance. According to Gadamer (1996) this is a natural, human reaction. "It is part of the balancing act of life that one learns to forget what is causing a disturbance, or at least succeeds in regarding it with indifference. One of the means for sustaining this skill of balancing is precisely intelligent behaviour, including, for example, self-deception or the knowing refusal to accept the truth of one's own illness" (p. 55). It was my physical symptoms that drew my attention more and more to the fact that in order to maintain an equilibrium within my research I had to address the source of these symptoms.

It became clear to me that my emotional reactions brought about my physical discomfort and formed a critical part in the cyclical illustration of my research experience (Figure 5). If I had confronted my emotions already in Study One, understood them and worked out ways to manage them, they might have had less of an impact on my health, both physical and non-physical. I realised that addressing my emotional reactions first was vital in the effort to reduce physical discomfort during my research process.

#### **6.4.2 The relationship between emotion and health**

Indeed, research shows that emotional reactions can have a profound effect on people, both physically and non-physically, even though they may not consciously be aware of such a link. For instance, emotional distress may increase the quantity of acid released into the stomach, without a person being consciously aware of this happening (Williams & Bendelow, 1996). Continuous stress of this kind could lead to gastro-intestinal disorders, all mediated by emotional responses to external stimuli, as was also illustrated by the symptoms I experienced, triggered by my emotional reactions.

The essence of good qualitative research revolves around holism (Noblit & Engel, 1991). This implies addressing the research process, participants and researchers from multiple perspectives. However, there seems to exist a lack of approaches that address the links between the physical and non-physical needs of researchers studying sensitive topics, in a holistic way. This lack of holism is evident in for example guidelines for a protocol for researcher safety (Paterson, et al., 1999). The guidelines include only physical elements of personal safety, such as how researchers could protect themselves against possible physical attacks from interviewees. While I do not deny the importance of direct physical protection, it is surprising that their protocol does not include elements such as emotional protection, since researchers may be more commonly exposed to emotionally risky situations than to direct physical risk. I would like to suggest further that denying and/or omitting researchers' emotional experience from research reports and peer-reviewed papers may intentionally deprive qualitative research of its holistic nature. Therefore, acknowledgement of the researcher experience and its disclosure must be regarded as prime requirements for the conduct of sound qualitative research.

Awareness and acknowledgement of one's own emotions as researcher and interviewer, which result from the interviewees' narratives, are also essential since

emotions may have detrimental effects on both the health of the researcher and the validity of the data (Rowling, 1999; Burr, 1996; Dunn, 1991; Cowles, 1988). It is therefore imperative that ways to process researcher emotional reactions are established in order to minimise these negative effects.

My discussion up to this point supports a call for a holistic approach to researcher experience and well-being. In the following sub-section I suggest, for the first time, a management programme I developed and used in Study Two of my PhD research, that uses such a holistic approach.

#### **6.4.3 Coping strategies – the EPSSI management programme**

As mentioned earlier, the suggested strategies I found for encouraging emotional well-being for researchers included journal keeping, debriefing sessions with colleagues, improving the scheduling of interviews and allocating the interviewing and transcribing tasks to two different researchers. However, the last two strategies concern the logistics of interviewing and do not address the researchers' emotional reactions directly. The first two strategies (journal keeping and debriefing sessions) take place after exposure to research participants' narratives. They are reflective and therefore not pro-active. Indeed, reflective practice is an important part of qualitative research methods such as hermeneutic phenomenology (Ironsides, et al., 2003), but it is my belief that already prior to starting a study (i.e. prior to interviewing, transcription of interviews, interview data analyses), as well as prior to every possible exposure to emotional upsets within a study, researchers who know they are vulnerable emotionally should prepare themselves emotionally. They should be aware of strategies to manage their own emotional reactions whilst within an emotionally upsetting situation such as an interview on a sensitive topic.

I suggest researchers treat their own health holistically. In most cases, as mentioned before, the coping strategies offered by the literature may not be sufficient to overcome the often overwhelming emotional distress experienced by qualitative researchers, since they do not pursue a holistic description of the researcher's health. Gadamer (1996) writes that already in the days of Plato, Greek doctors realised the human body cannot be fully treated without knowledge of the whole of the body's being-in-the-world. Description of researchers' health should therefore address the health of the researcher as a multi-dimensional phenomenon (Figure 1), which can be defined as the complete state of physical (for example fitness, relaxation, nutrition, medication), emotional (for example care for emotional distress, stress management, relaxation), social (for example families, friends, colleagues, environment), spiritual (for example love, hope, meaning in life) and intellectual (for example educational, achievement, career) well-being (O'Donnell, 1989). High levels of well-being for the researcher may therefore not be attainable without a balance between these five interdependent and mutually supporting domains of health.

I needed therefore a holistic management programme which includes pro-active strategies as well as strategies to be implemented during and after data gathering. I developed such a programme and called it the EPSSI-management programme. This programme includes strategies that address health holistically, and therefore it includes all five health domains illustrated in figure 1, i.e. the **E**motional, **P**hysical, **S**ocial, **S**piritual and **I**ntellectual domains. The suggested programme could enable researchers to manage their own emotional distress while also taking into account the link between their emotions and the other four health domains.

#### **6.4.3.1 Development of the EPSSI-programme: Links between emotion and the other four health domains**

Optimum health requires for all levels of health, such as represented by the five domains figure 1, to be in balance with each other (O'Donnell, 1989). Also, as is the case with holism mentioned before, an imbalance in one of the domains will have an effect on one or more of the other domains, causing an overall health imbalance. It is very important that while experiencing emotional distress researchers stay aware of how it influences the other domains of their health. Repeated listening to people's heart-rending narratives can have emotional effects such as sadness, anger and frustration on interviewers. As I have experienced and as the literature also suggests (Williams & Bendelow, 1996), these emotions can have a number of different effects on the physical body for example headaches, muscular pain, nausea and fatigue. In combination, the emotional and physical effects may have effects on the three remaining health domains in the following ways:

- Social domain: Fatigue and/or feelings of depression often contribute to decreased motivation to socialise (Butler & Hope, 2004). This may lead to social isolation.
- Spiritual domain: In the current context, this domain does not refer to religion but rather to one's relationship with one's inner self, and the images and thoughts researchers convey to themselves. Many people benefit and draw strength from some kind of spiritual belief (Sims, 1992). Continuous negative emotions and physical discomfort may decrease interest in and motivation for pursuing such beliefs.
- Intellectual domain: Physical pain and discomfort can decrease concentration span (Apkarian, et al., 2004), as well as motivation for intellectual processes such as logical thinking.

In applying this programme I realised that identification and understanding of my emotional and resulting physical reactions, and ultimate management of such reactions,

may prevent the cycle illustrated in figure 5 from moving through prolonged emotional distress and physical discomfort. As my primary response to the research process was most often an emotional reaction, I suggest that researchers first address and manage their emotional reactions, in order to attain some or complete relief from physical discomfort brought about by their emotional distress. Below is a discussion of how I addressed my emotions through the other four domains in figure 1.

#### **6.4.3.2 Development of the EPSSI-programme: Addressing and managing emotion through the other four health domains**

I found addressing and managing my emotional responses through activities related to the other four health domains in the EPSSI-model to be very valuable, once I had realised the significance of my own emotional responses to the research. As mentioned earlier, high levels of well-being for the researcher are not attainable without a balance in the interdependent and mutually supporting domains of health. Over-attention to one or more of these levels can lead to lack of attention in one or more of the others, resulting in an overall imbalance of health. The following are examples of how I addressed and managed my emotions through the other four health domains in figure 1 and in this way kept a balance in my overall well-being:

- Physical domain: Physical activities such as yoga, general gym exercises and progressive muscle relaxation helped to release stress present in my physical body. Popular complementary therapies, such as aromatherapy and sound therapy, also helped me to relax.
- Social domain: I sought regular contact with like-minded friends and family (they did not have to be qualitative researchers themselves) and found such regular social contact prevented me from getting too focussed on, and overwhelmed by, my research.

- Spiritual domain: Popular self-help techniques which I found helpful in keeping a positive outlook included repetition of positive affirmations coupled with quiet times (meditation). The latter was practised both before and after interviews. Quiet times related to interviewing mostly entailed relaxed deep breathing and mental preparation for a possible encounter with grief.
- Intellectual domain: Debriefing sessions with my research supervisors and other colleagues who understood how emotionally distressing research on sensitive topics can be, were indeed helpful in order to keep perspective. Activities for this domain may also include the keeping of a journal in which researchers can express their thoughts and feelings (Lyons, 1999). Such activities may contribute to a releasing process for emotional distress as opposed to a blocking process created by keeping emotions to oneself.

#### **6.4.4 Practical application of the EPSSI-management programme**

The following is an illustration of how and when I practically applied the EPSSI-management programme to my research, during Study Two:

- Prior to meeting with an interviewee for an interview, I spent a few minutes alone, practising deep breathing and progressive muscle relaxation to induce emotional and physical relaxation. I visualised the interviewee in for example a therapy session, enjoying the activities – such visualisation reinforced in me the belief that it could still be possible to experience good quality times despite having had a stroke. Reinforcement of positive thoughts helped me to not focus only on the sadness stroke survivors experienced. These activities together with those from both the physical (progressive muscle relaxation) and the spiritual domains (breathing and positive visualisation), pro-actively supported possible emotional reactions. I practised the same

activities before transcription of interviews as well as before commencing analysis of interview data.

- During an interview I sat on a chair, placing my feet firmly on the ground. I kept that position for the duration of the interview as it contributed to a feeling of being ‘grounded’. The feeling of ‘groundedness’ is generally encouraged in meditation practice to centre one’s awareness and create a sense of inner balance, including at times of emotional stress (Glasscock Barnes, 2004; Roland, 2003). In the case of an interview becoming emotionally upsetting, I immediately resumed deeper breathing. The latter is known to prevent muscles from tensing up due to stressful situations (Chaitow, 2004). I did this as softly as possible lest I would reveal my feelings to interviewees. Visualising a golden light enveloping both the interviewee and myself also assisted me in feeling more in control of my own emotional responses to interviewees’ narratives. The latter is a technique commonly used in colour therapy to increase levels of vitality in the human system (Wills, 2000) and in meditation practice to release tension (Glasscock Barnes, 2004). These activities addressed my emotional well-being from both the spiritual (colour therapy and meditation) and physical domains (breathing). During transcription and analysis of data I practised the same activities when I felt emotionally upset.
- Following an interview and prior to leaving the research setting, I’d go to the cloakroom, wash my hands and visualise taking off a coat and hanging it at the front door of the setting. This kind of visualisation created a sense of closure and helped me not to take emotional ‘baggage’ home with me. Visualisation techniques may help a person in that they focus mental energy in order to deal with stress (Roland, 2003).
- On arriving home I’d write down notes about my own feelings and the interview itself, a sort of personal journal keeping, therefore addressing any emotional issues from the



intellectual domain. Journal keeping is advised to help a person focus their thoughts as well as analyse their insights (Roland, 2003). I would then spend half an hour practising self-care techniques such as yoga, gym exercises and/or taking a bath with aromatherapy oil, prior to resuming my family- and home-related activities. Supporting my emotional well-being through the social domain of health, I regularly made and kept contact with like-minded friends and family. I found this to be particularly helpful in keeping a balance between work and home life. Debriefing sessions with my PhD supervisors provided valuable intellectual support.

In general the EPSSI-management programme helped to increase my feelings of empowerment and self-worth, consequently enabling me to contribute to the research in a more effective way, i.e. still being immersed in the research as required by the hermeneutic phenomenological approach but being able to distance myself emotionally from the data. This programme may be used as an empowerment tool for qualitative researchers to enable them to deal effectively with their emotional responses to the research process, if and when they occur. Management strategies can however differ from researcher to researcher and should be tailored to the needs and personalities of individual researchers (McCosker, et al., 2001; Driscoll, et al., 1997). The details of the activities I practised in each domain were my personal choice, and other researchers might find different activities more effective. In this case researchers could find activities relating to each domain that suit their own personalities. Further research will be necessary to determine the usefulness of this programme for qualitative researchers in general.

#### 6.4.5 Researcher emotions and their management

I propose that safeguards, for example programmes such as the EPSSI-management programme, are implemented for researchers working on sensitive topics, be it officially set in place by an ethics committee or at least planned and performed by researchers themselves. In the same way as providing for participant safety, pre-planning of researcher safeguards could prevent many researchers from being caught off-guard by their own emotions due to the sensitive nature of their research, in stead of identifying strategies “by trial and error” (McCosker, et al., 2001, paragraph 34). Prior to embarking on research that studies people’s experiences of sensitive issues, qualitative researchers ought to be encouraged to be acutely aware of the following: they must respect the participants in their studies, but should also respect themselves and their own emotions, be aware of them, acknowledge them and manage them holistically.

Branches of qualitative research such as feminist methods and also hermeneutic phenomenology, see the researcher as “always and inevitably present *in* the research” (Stanley & Wise, 1993, p. 179). During in-depth interviewing the research process therefore does not only depend on the participant’s narrative but also on how the interviewer understands her-/himself, his/her own thought patterns, and integrity (Johnson, 2002). It follows that it is not only difficult for researchers to separate their own emotions experienced during a research study from their research, but it is actually impossible (Lowes & Prowse, 2001; Gatenby & Humphries, 2000; Ahern, 1999; Stanley & Wise, 1993). The principles of hermeneutic phenomenology support these realistic guidelines and take a researcher’s presuppositions for granted and as part and parcel of the whole research process (Le Vasseur, 2003). In retrospect my emotions could have affected early analysis of interviews on the stroke unit in Study One, which could have lead to a more negative reflection of patients’ narratives in the emerging themes. I therefore re-analysed the

interviews once I had realised the effect of my emotions and once I had implemented use of the EPSSI-management programme. The latter was also used all through Study Two.

I believe that discussions on the researcher experience should be encouraged in the author guidelines of peer-reviewed journals, in order to make more researchers aware of the impact their experiences may have on themselves and their research outcomes. However, as my search of the literature showed, researcher experiences and emotions are mostly kept covert and seldom overtly discussed in research articles. It may be argued that scientific journals prevent inclusion of researcher experiences for several reasons. Perhaps paramount amongst these is the prominence of objectivity in positivist research methodologies (Horsburgh, 2003; Sword, 1999; Cowles, 1988). These methodologies emphasise objectivity, exclude emotion, and most of them regard subjectivity as being biased and of limited scientific value. However, the very nature of qualitative research asks of researchers to immerse themselves in the research process. Total objectivity is therefore not realistic (Horsburgh, 2003; Sword, 1999; Schutz, 1994) and may not even be beneficial to qualitative research (Ahern, 1999; Rowling, 1999). The recognition and acceptance of subjectivity, personal experience and emotions may help to elicit deeper meaning to experiential data (Schutz, 1994; Rowling, 1999) and to underline one's integrity as qualitative researcher (Sword, 1999).

## **6.5 Reflection on the study strengths and limitations**

The aim of a hermeneutic phenomenological study is not to reach an ultimate result but rather to reveal new understanding of a phenomenon (Ironsides et al., 2003; van Manen, 1990). The study of experience through hermeneutic phenomenology is a process characterised by reflection and a circular motion “with interpretations being continually held open” (Ironsides et al., 2003, page 175). The contribution of such a study, including

my PhD research reported in this thesis, therefore lies in the attainment of greater understanding which is left open to further exploration. The exploration and interpretation presented in my thesis should therefore be viewed as provisional and not as an ultimate exploration and interpretation. This continuous evolvement of knowledge is reflected by de Witt and Ploeg (2006) in their criteria for rigour in hermeneutic phenomenological research namely “actualisation”. The latter is a conscious allowance for further development of the interpretation presented by a study. From a positivist point of view an evolving method with provisional “outcomes” would be a limitation. However, from a constructivist point of view it could be seen as a strength in that it admits that no data collected on human experience could ever provide an ultimate picture of that experience. The value of studying experience through hermeneutic phenomenology could also be said to lie in its honesty and openness on how the understanding gained was co-created by both the researcher/s and the researched. Indeed, in the case of my own research my interest in the experience of stroke rehabilitation was triggered by the illness and death of my paternal grandmother. From the start of the research my reasoning, be it consciously or unconsciously, would have been affected by the emotions I felt surrounding her death and the possible treatment she did or did not receive. This in turn would have affected the way in which I interviewed participants and analysed the study transcripts. Another person with no personal experiences related to stroke would have been able to give an account of lived stroke rehabilitation uncontaminated by the personal feelings I had and still have. However, the nature of hermeneutic phenomenological inquiry is such that the researcher’s emotions and feelings are part of the creation of the research process (de Witt & Ploeg, 2006; van Manen, 1990). Therefore I feel the limitation just described was also in effect a strength in that I had an understanding of what patients might have been going through which another researcher, without the same experiences as me, could not have had.

The fact that I did not have the opportunity to study the same patients I interviewed in the stroke unit, in a CE setting could be seen as a limitation. The two groups of participants in Studies One and Two could therefore not be directly compared with each other.

Hermeneutic phenomenology's inclusion of the researcher's experiences brought a strength to my study: the findings do not only provide better understanding of lived stroke rehabilitation experience in two different settings and how we could move closer to holistic approaches to stroke rehabilitation, but it also brings better understanding of the researcher's own experiences which other qualitative researchers might find invaluable.

## **6.6 Final reflection**

I began this thesis with reference to my grandmother and how her possible suffering lead to the focus of my PhD journey. In Chapter One I explained how my research developed over the last eight years of study and presented in Chapter Two background information on the nature of stroke and stroke rehabilitation in the UK. Chapter Three explained the origins of hermeneutic phenomenology as research method as well as the way in which I applied it in my research. In Chapters Four and Five I presented the findings of two separate hermeneutic phenomenological studies on the lived experience of stroke rehabilitation, in two different settings. In this final chapter of my thesis, Chapter Six, I reflected on different areas of my PhD, namely:

- the findings from Study One and Two which I then evaluated them in terms of a holistic approach to health
- recommendations for the development of a more truly holistic approach to stroke rehabilitation which could be studied in further research
- the soundness and rigour of the hermeneutic phenomenological method I used

- a holistic tool for researchers to take care of themselves, which I developed as a result of my own emotional reactions to the research
- the strengths and limitations of my study

My original aim of exploring the role of holistic approaches in two distinct settings of stroke rehabilitation brought better understanding of stroke patients' experiences in a conventional stroke unit and in a CE setting, and showed that neither setting used a truly holistic approach. It is hoped that the recommendations for a more truly holistic approach to stroke rehabilitation will be followed-up and their feasibility assessed.

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## **Appendix A: Interview schedule in stroke unit**

As you know this is a stroke unit providing stroke rehabilitation. I would like to know what your experiences have been since you came here.

Prompts:

- What things do you identify as your rehabilitation?
- What support do you think do you need being here?
- What do you think about the rehabilitation you have received up to now?
- What would you say is the most effective?
- Do you think you have made progress?
- Has the stroke changed your life? How?
- How do you cope with the changes?
- Do you think about the future / your future?
- Do you have goals for yourself?
- What advice would you give to other stroke patients on how to cope during rehabilitation?
- Good life? Again?

## **Appendix B: Interview schedule in CE setting**

I would like to know what your experiences of the sessions here at CE have been.

Prompts:

- What do you think about the sessions you have attended up to now?
- What would you say is the most effective?
- Do you think you have made progress/are making progress?
- Has the sessions changed your view on your own situation after the stroke? How?
- Do you think about the future / your future?
- Do you have goals for yourself?
- What advice would you give to other stroke patients on how to cope after a stroke?
- Good life? Again?

**Appendix C:** Letter of invitation (stroke unit participants)

Hallo!

I am a research student from John Moores University in Liverpool and I would like to know how you experience your rehabilitation. Not many stroke patients have the opportunity to really talk about their experiences. You now have the opportunity to be part of a research project looking at stroke rehabilitation through the eyes of the patients themselves.

If you would like to be part of this project, please write your name on this paper and give it to your physiotherapist. I will contact you shortly afterwards and give you the opportunity to talk about your experiences. Everything you tell me will be treated anonymously - in other words your name will never be associated with anything you tell me. Your stories could help future stroke patients.

See you soon!

Best wishes,  
Wilna

Wilna Dirkse-van-Schalkwyk  
Research student  
Liverpool John Moores University

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Please contact me to arrange a date on which I can tell you about my experience of stroke rehabilitation

Name and surname (printed): \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

**Appendix D:** Consent form (stroke unit)

**NORTH STAFFORDSHIRE HEALTH AUTHORITY**

**RESEARCH ETHICS COMMITTEE**

**FORM OF CONSENT FOR A PATIENT IN A CLINICAL RESEARCH PROJECT**

**Study title:** An investigation of stroke patients' experiences of rehabilitation with particular reference to the use of mental imagery.

**Main Investigator:** Ms. Wilna Dirkse-van-Schalkwyk

**Study Responsible Clinician:** Dr. C. Roffe

The aims and procedures of the clinical investigation in which I have been asked to take part have been explained to me by

.....

I have read and understood the patient leaflet set out overleaf, and have been informed about reasonably foreseeable risks or discomfort. I understand that the procedure is to be carried out solely for the purpose of medical research.

I have had the opportunity to ask questions and to consider the answers given.

I understand that participation in the study is voluntary and that I may withdraw from the study at any time of my own accord. If I do withdraw it will not affect the future care and attention which I will receive from my doctors.

**I hereby give my fully informed consent to taking part in this clinical investigation.**

Patient's name: ..... Address: .....  
.....

Signature: ..... Date: .....

**I confirm that I have explained the purpose and the nature of this procedure and the risks involved.**

Investigator's name: ..... Signature: .....

Date: .....



**An investigation of stroke patients' experiences of rehabilitation with particular reference to the use of mental imagery.**

**Why is this study being done?**

We know very little of how stroke patients in rehabilitation experience rehabilitation. This study is being done to learn about the experience of stroke rehabilitation through the eyes of the patients.

**What is my part in the study?**

I would like for you to tell me about your experience of rehabilitation.

**How would this research affect me?**

You might feel tired due to talking to me for a while and/or you might get emotional when you share certain experiences with me. Remember you are allowed to stop or postpone the interview whenever you want to. The interview could also have a positive effect in that you will be able to share your experiences in rehabilitation and contribute to health professionals' better understanding of stroke patients' own individual experiences. Thus helping future stroke patients.

**What are the results used for?**

The results will be used to inform us on how to improve stroke rehabilitation for future stroke patients. By obtaining information from you how you experience it, we could shape future stroke rehabilitation programmes more according to patients' needs.

**Do I have to say yes?**

No, you can refuse to take part in the study. No one should feel forced to agree.

**What will happen if I say no?**

You will receive your normal medical care.

**Can I change my mind?**

Yes, of course, at any time. If you would like to withdraw for any reason, just let us know.

**Who can I contact if I have any other questions?**

Ms. W. Dirkse van Schalkwyk (main investigator) Tel: (01782) 310634

Dr. C Roffe (consultant in stroke medicine) Tel: 552267 (secretary)  
or (01893) 323485 (pager)

**Appendix E:** Letter of invitation (CE participants)

**Letter of invitation to the Conductive Education participants:**

Dear Madam / Sir,

I am a doctoral research student from Liverpool John Moores University and I am doing a study on how people who had a stroke experience their rehabilitation. Since you take part in Conductive Education for stroke, I would like to hear more about your experience of Conductive Education, as well as your experience of stroke rehabilitation in general. You now have the opportunity to be part of a research project looking at Conductive Education and stroke rehabilitation through the eyes of the participants themselves. More information is printed overleaf.

If you would like to be part of this project, please complete the section below and give it to Dr. Melanie Brown, who will arrange for us to meet and discuss your experiences. All our discussions will take place in a private room at the National Institute of Conductive Education (NICE), Cannon Hill House, Moseley, Birmingham, before or after your stroke sessions. Your participation might help people suffering from stroke in the future.

Many thanks in advance.

I look forward to meeting you.

Sincerely yours,

Wilna Dirkse van Schalkwyk  
Doctoral research student  
Institute for Health  
Liverpool John Moores University

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Yes I would like to tell you about my experience of stroke rehabilitation and Conductive Education.

Name and surname (printed): \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

## **An investigation of stroke patients' experiences of rehabilitation with particular reference to the use of approaches aimed at individual independence**

### **Why is this study being done?**

Very little is known of how stroke patients experience rehabilitation. This study is being done to learn about the experience of stroke rehabilitation through the eyes of the patients themselves. The study also explores people's experiences of participation in Conductive Educational sessions for stroke.

### **What will your part in the study be?**

I would like to meet you and give you the opportunity to tell me about your experience of rehabilitation and Conductive Education. Your identity will always remain confidential in the study.

### **How would this research affect you?**

Talking to me may have a positive effect in that you will be able to share with me your experiences. Your contribution to knowledge of rehabilitation and Conductive Education experience, might lead health professionals to a better understanding of stroke patients' own individual experiences. Thus you might help people suffering from stroke in the future.

Sharing with me your past and present experiences might make you feel tired or emotionally upset. Dr. Melanie Brown will be available for you to discuss with her any such feelings if you wished to do so. Remember you are allowed to stop or postpone our meeting whenever you want to.

### **What will the results be used for?**

The results of this study will help to further identify the specific needs of individual stroke patients, as well as any shortcomings in current conventional stroke rehabilitation programmes.

Participation in the study is voluntary. You are therefore under no obligation to take part. Your decision whether to take part or not will not affect the services you receive from NICE in any way.

### **People to contact if you have any other questions?**

Ms. Wilna Dirkse van Schalkwyk (main investigator)	Tel: 07940 - 872770
Dr. Melanie Brown (senior conductor, NICE)	Tel: 0121-449-1569
Prof. Jane Springett (research project supervisor)	Tel: 0151-231-4055

**Appendix F:** Consent form (CE)

**FORM OF CONSENT TO TAKE PART AS A PARTICIPANT  
IN A RESEARCH PROJECT**

**Title of project:**

**An investigation of stroke patients' experiences of rehabilitation with particular reference to the use of approaches aimed at individual independence**

I, ..... agree to take part in the  
(**Participant's** full name)

above named project, the details of which have been fully explained to me and described in writing.

Signed..... Date .....  
(Participant)

I, ..... certify that the details  
(**Investigator's** full name)

of this project have been fully explained and described in writing to the participant named above and have been understood by him/her.

Signed..... Date .....  
(Investigator)

I, ..... certify that the details  
(**Witness's** full name)

of this project have been fully explained and described in writing to the participant named above and have been understood by him/her.

Signed ..... Date.....  
(Witness)

**NB** The witness must be an independent third party.

**Appendix G:** Information letter for keeping of diary

Please keep a diary of your experiences over the eleven days (weekends included) of the NICE course. I would be very grateful if you could specifically mention experiences related to the following:

- Any challenges you may experience caused by the stroke, whether it is physical, emotional or spiritual of nature, and how you cope with it
- Your experiences of your sessions at the Institute for Conductive Education
- What role Conductive Education plays in your day-to-day life

You are free to write as much or as little as you want.

Please remember to bring your diary with you to the National Institute for Conductive Education on the last day of your two-week course when I will collect it from you. Your identity will always remain confidential in the study.

If you have any questions related to my research please do not hesitate to ask Dr. Melanie Brown or myself.

Many thanks for your help with my research.

Sincerely yours,

Wilna Dirkse van Schalkwyk