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## DOCTOR OF PHILOSOPHY

**Revisioning, reconnecting and revisiting. Facing the aftershock of stroke in the first month post-discharge: an interpretative phenomenological analysis  
an interpretative phenomenological analysis**

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Facing the aftershock of stroke in the first  
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Jan Pringle

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**Revisioning, reconnecting and  
revisiting. Facing the aftershock of  
stroke in the first month post-  
discharge:**

An interpretative phenomenological  
analysis

Submitted by

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# Contents

<b>List of Figures</b>	i
<b>Acknowledgements</b>	iii
<b>Declaration</b>	iv
<b>Abstract</b>	1
<b>Chapter 1: Background to the study</b>	
1.1 Introduction and overview	4
1.2 Stroke: the impact	5
1.3 Definition and diagnosis	6
1.4 Stroke type, incidence and prevalence	7
1.5 Stroke survival	10
1.6 Rehabilitation	11
1.7 Stroke and age related issues	12
1.8 Geographical variations	12
1.9 Gender	13
1.10 Prediction, prevention and costs	13
1.11 Transition from hospital to home	16
1.12 Summary	20
<b>Chapter 2: Literature review</b>	
2.1 Introduction	22
2.2 Background	23
2.3 Search strategy	25
2.4 Inclusion criteria	27
2.5 Key words	29
2.6 Literature review findings	38

2.7 Analysis of the studies	47
2.7.1 Location of studies	47
2.7.2 Participant numbers	47
2.7.3 Participants	48
2.7.4 Methods	49
2.7.5 Timing of studies	51
<u>The first month</u>	51
<u>One to three months</u>	53
<u>Three to six months</u>	55
<u>Longer term studies</u>	57
2.8 Discussion	58
2.8.1 Age related issues	58
2.8.2 Timing and location	59
2.8.3 Communication ability and lesion location	61
2.9 Summary	63
<b>Chapter 3: Choosing between research approaches</b>	
3.1 Introduction	65
3.2 Phenomenology as a research approach	66
3.3 Description or interpretation?	71
3.4 Bracketing	74
3.5 Insider-outsider perspectives	76
3.6 Reflexivity	78
3.7 Discussion	79
3.8 Interpretative phenomenological analysis	81
3.9 The hermeneutic circle	83
3.10 IPA and contribution to theory	84
3.11 Methodological issues	86
3.12 Sample and data considerations	87

3.13 Data collection	90
3.14 Analytical process	91
3.15 Rigour	92
3.16 Relevance to nursing and health studies	96
3.17 Summary	99

## **Chapter 4: Method**

4.1 Introduction	100
4.2 Methodology revisited	101
4.3 Method specificity	105
4.4 Data collection choices	107
4.5 Interviews	110
4.6 Diaries	116
4.7 Study sample	123
4.8 Timing	124
4.9 Diagnostic criteria	127
4.10 Homogeneity	130
4.11 Inclusive strategies	131
4.12 Carers	138
4.13 Age	141
4.14 Study location	143
4.15 Ethical considerations	144
4.16 Rigour	150
4.16.1 Sensitivity to context	151
4.16.2 Commitment and rigour	151
4.16.3 Transparency and coherence	152
4.16.4 Impact and importance	152
4.17 Transcription of data	154
4.18 Analysis	157

4.19 Summary	161
--------------	-----

## **Chapter 5: Preliminary study**

5.1 Introduction	162
------------------	-----

5.2 Participants	165
------------------	-----

5.3 Analysis and findings	172
---------------------------	-----

5.3.1 Fathoming out	175
---------------------	-----

<u>Physical limitations</u>	175
-----------------------------	-----

<u>Making comparisons</u>	176
---------------------------	-----

<u>Emotional changes</u>	178
--------------------------	-----

5.3.2 Adapting to stroke	182
--------------------------	-----

<u>Managing firsts</u>	182
------------------------	-----

<u>Balance of caring</u>	183
--------------------------	-----

<u>Back to basics</u>	184
-----------------------	-----

<u>Hope</u>	185
-------------	-----

5.3.3 Value of support	186
------------------------	-----

<u>It's good to talk</u>	187
--------------------------	-----

<u>Importance of understanding</u>	187
------------------------------------	-----

<u>Reliance on others</u>	189
---------------------------	-----

5.4 Discussion	190
----------------	-----

5.5 Researcher reflections	198
----------------------------	-----

5.6 Summary	200
-------------	-----

## **Chapter 6: Main study**

6.1 Introduction	202
------------------	-----

6.2 Main study method	203
-----------------------	-----

6.3 Sample	204
------------	-----

6.4 Geographical considerations	206
---------------------------------	-----

6.5 Inclusion criteria	206
------------------------	-----

6.6 Effects of stroke	210
6.7 Diaries	212
6.8 Interview format and considerations	214
6.9 Ethical issues	215
6.10 Communication ability	215
6.11 Analysis	219
6.12 Overview of findings	223
6.13 Data collection limitations	227
6.14 Summary	231

## **Chapter 7: Main study findings**

7.1 Introduction	232
7.2 Revisioning	233
7.2.1 Image and identity	233
7.2.2 Alternating focus and a new reality	250
7.2.3 A mortal future	261
7.3 Reconnecting	265
7.3.1 Important relationships	265
7.3.2 Choice and control	273
7.3.3 Past self and activities	283
7.4 Revisiting	284
7.4.1 The stroke event	285
7.4.2 Previous life	292
7.5 Giving advice to others	295
7.5.1 Reconnecting	295
7.5.2 Revisioning	296
7.5.3 Revisiting	296
7.6 Summary	297



## **Chapter 8: Discussion and interpretation**

8.1 Introduction	300
8.2 Revisioning, reconnecting and revisiting	300
8.2.1 Uncertain progress and biographical disruption	301
8.2.2 Psychosocial transitions	306
8.3 Revisioning	308
8.3.1 Hope as a feature of the revisioning of a new reality	308
8.3.2 Anger and depression in relation to a new reality	312
8.3.3 Alternating focus as part of revisioning	317
8.3.4 Grief and loss in relation to the revisioning of a mortal future	318
8.3.5 The revisioning of image and identity	321
8.3.6 Gender and the revisioning of image and identity	325
8.4 Reconnecting	328
8.4.1 Impact of stroke on the family unit	328
8.4.2 Close relationships	332
8.4.3 The chronic illness model	334
8.4.4 Disability and accessibility	339
8.5 Revisiting	342
8.5.1 The discharge process	342
8.5.2 Discharge support	347
8.6 Further discussion	350
8.6.1 Involvement of participants in the research and rehabilitation process	349
8.6.2 Financial issues	353
8.6.3 Levine's Conservation Principles	355
8.6.4 Poetic interpretations	359
8.7 Summary	360

<b>Chapter 9: Overview and conclusions</b>	
9.1 Introduction	362
9.2 Reflexive account	365
9.2.1 Background to the study	371
9.2.2 Selection of participants	372
9.2.3 Data generation	373
9.2.4 The impact of self and prior knowledge	375
9.2.5 The analytical process	379
9.2.6 Inclusion strategies	382
9.3 Findings in relation to the wider context	385
9.3.1 Linking findings to service provision	386
9.4 Findings in relation to further research	390
9.4.1 Research considerations	390
9.5 Dissemination	393
9.6 Limitations of the study	394
9.7 Summary	397
<b>References</b>	401
<b>List of Appendices</b>	
Appendix 1: Diary guidance notes	457
Appendix 2: Functional Independence Measure/Functional Assessment Measure (FIM+FAM) general descriptor decision tree	458
Appendix 3: Participation information sheet	459
Appendix 4: Ethical approval letter (preliminary study)	463
Appendix 5: Letter to participant's GP	464
Appendix 6: Participant consent form	465
Appendix 7: Guidance sheet: hospital staff	467

Appendix 8: Transcription format	469
Appendix 9: Examples of expression mats	470
Appendix 10: Summary report: preliminary study	472
Appendix 11: Ethical approval letter (main study)	476
Appendix 12: Mind map: main study analysis	477
Appendix 13: Worked example of transcript analysis	478
Appendix 14: Poem	485
Appendix 15: Extract from <i>Gridlock</i> (Elton, 1992)	488
Appendix 16: Details of presentations	489
Appendix 17: Details of publications	491
Appendix 18: Gantt chart	492

## List of Figures

Figure 1: Bamford Stroke Classification	9
Figure 2: Stroke risk factors	14
Figure 3: Stages in the literature review process	25
Figure 4: Databases used in the literature review	26
Figure 5: Inclusion criteria for literature review	29
Figure 6: Key words used in literature review	31
Figure 7: Summary of literature search carried out on 19/5/06	31
Figure 8: Summary of literature search carried out on 27/5/06	32
Figure 9: Summary of literature reviews	34
Figure 10: Details of research studies	40
Figure 11: The hermeneutic circle	83
Figure 12: Key features of interpretative phenomenological analysis	98
Figure 13: Essential criteria for phenomenological studies	102
Figure 14: Levels of understanding in qualitative research	103
Figure 15: Interview format	113
Figure 16: Inclusion criteria for study participants	124
Figure 17: Common types of communication difficulty following a stroke	136
Figure 18: Overview of analytical process	158
Figure 19: Preliminary study participants	167
Figure 20: FIM+FAM scores for preliminary study participants	168

Figure 21: Considerations for the inclusion of people with communication difficulties in research	171
Figure 22: Summary of preliminary study findings	174
Figure 23: Details of main study participants	207
Figure 24: Physical ability: FIM+FAM rating: main study, stroke survivors	211
Figure 25: FIM+FAM scores in relation to communication: main study participants	216
Figure 26: Super-ordinate and sub-themes: main study	224
Figure 27: Mind map of main study findings	299
Figure 28: Levine's Conservation Principles	356
Figure 29: Variants of reflexivity	370

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## **DECLARATION**

I, Jan Pringle, declare that I am the sole author of this thesis; that all references, unless otherwise stated, have been consulted by me, and that this thesis constitutes a record of the work undertaken by me. I also declare that this thesis has not been previously accepted for a higher degree.

Signature of candidate:

(Jan Pringle)

I, Dr John Drummond, certify that Jan Pringle has spent five years of part-time research under my supervision, and has fulfilled the conditions of Ordinance 39 (University of Dundee), and is thus qualified to submit this thesis for the degree of Doctor of Philosophy.

Signature of Supervisor:

(Dr John Drummond)

## **Abstract**

This study is concerned with the impact of stroke, and in particular, the experiences of patients and carers following the return of the survivor to the home environment. Given the current emphasis on reduced hospital stays and greater care in the community, supporting people once they return home is of vital importance. However, there has been limited research into patient and carer experiences during this time, resulting in a lack of information to direct and improve practice. The aim of this study is therefore to enhance understanding of the experiences of stroke survivors and their carers during the first month at home following discharge from hospital, thereby seeking to redress this knowledge deficit. By improving the body of knowledge, the provision of appropriate care can be enabled and promoted.

The support of stroke survivors and their carers is particularly highlighted by the fact that greater numbers of people are surviving: stroke mortality rates in Scotland for those under the age of seventy five reduced by 50% between 1995 and 2007. In addition to this, trials of treatments such as thrombolysis are being used for increasing numbers of patients in the UK, including those over eighty years of age. The resulting consequence is that survival rates will increase even further in future years, which will undoubtedly impact on community follow-up services. However, it has been reported that as many as 70% of patients feel inadequately supported in the community, especially in relation to speech, swallow and emotional difficulties.

A literature review undertaken during the initial part of the study showed that previous research into the experiences of stroke patients and/or their carers has often been limited to retrospective, longitudinal studies. The review also reveals the



significant fact that patients with aphasia have frequently been excluded from other stroke research. Given the fact that 25-38% of stroke survivors will have communication difficulties, such exclusion seems to be a major limitation of previous studies, and one that has not been sufficiently acknowledged.

The project involves both a preliminary study, with a purposeful sample of four patient-carer dyads, and a main study involving twelve patient-carer dyads. In-depth interviews take place one month after discharge from hospital, with self-report participant diaries also helping to provide a more immediate account of experiences, by being kept from the day of discharge. People with significant communication difficulties are included in both parts of this research. The use of pictures and diagrams to illustrate such experiences, where speech is minimal, is explored; the data contribute accounts that have previously remained unheard. The qualitative approach of interpretative phenomenological analysis (Smith et al, 2009) is used to capture and interpret these experiences, and to assist understanding of the how patients and carers make sense of their altered situation.

In the main study, the super-ordinate themes of *revisioning*, *reconnecting* and *revisiting* expand on descriptive meanings developed in the preliminary study, and illustrate the dynamic process that the participants were engaged in during this time. Revisioning of identities, either as a stroke survivor or a carer, is evidenced through their accounts; participants are also seen to be looking towards a new and different reality, with a clearer knowledge of their own mortality. Reconnecting with important relationships, past activities, and a sense of choice and control, are all shown as important in this process. Revisiting the past, and the stroke event, are also

examined as a means of helping participants to make sense of their new, altered, situation.

The study provides a great deal of information about the psychosocial transition of returning home from hospital following a stroke, and how stroke survivors and their carers make sense of their altered situation. The findings emphasise that there is much that healthcare workers can do to support people during this time, including using good communication and information provision at the appropriate time. Greater awareness of the impact of services and equipment in the home is highlighted, including considerations regarding privacy.

By gaining a better understanding of each person's family situation, and the emotions that they may be feeling (and providing opportunities for such emotions to be expressed), support that is relevant to that individual can be given.

# CHAPTER 1

## Background to the study

### 1.1 Introduction and overview

This study is concerned with the impact of stroke, and in particular, the experiences of patients and carers on the return of the survivor to the home environment. The approach of interpretative phenomenological analysis (Smith et al, 2009) is used to capture and interpret these experiences, from both a preliminary (or pilot) study, and from the main study findings. Given the current emphasis on reduced hospital stays, and greater care in the community (The Scottish Government 2009a; Dept of Health, 2010a), supporting people once they return home is of undoubted importance.

World-wide, cerebrovascular disease affects 15 million people every year (Green and King, 2007) with stroke being the major resulting condition, and most common cause of complex disability in the community (Adamson et al, 2004). Stroke is also the second leading cause of death globally in those over 60 years of age (Mackay and Mensah, 2004). However, such figures alone fail to give any indication of the impact on the individual affected, or on the people that stroke survivors may be closely connected with. It is only by exploring the individual experiences of those involved, that a true sense of the meaning can be gained.

Current UK policies emphasise the need to move the care of people with long term conditions such as stroke from hospitals into the community setting (Dept of Health, 2007; The Scottish Government, 2009a; Dept of Health, 2010a). However, the

impact of such policies on individuals is not always fully understood or explored.

This study aims to improve understanding of the experiences of stroke survivors and their carers during the first month at home following discharge from hospital.

Greater understanding of such experiences is an important aspect of providing appropriate care during this crucial time.

This chapter will examine the significance of stroke as a condition, starting with the global incidence, and relating this down to the impact on the individual, and those connected to them. Links will be made to government policies and guideline documents. Stroke definition, diagnosis, type and incidence will all be detailed.

Following on from this, survival rates, the impact of age, and geographical variations will also be discussed. Finally, risks, prevention, cost, and discharge from hospital will all be examined. The discussion will conclude by relating these issues to the situation of the individual patient, and the support that nurses can provide.

## **1.2 Stroke: the impact**

With over 120,000 people suffering a first stroke in the UK every year (British Hypertension Society, 2006), and 10,000 of these being in Scotland (Langhorne, 2010), stroke continues to have significant consequences for patients, carers, and stroke service provision. With an ageing population, the incidence of stroke has long been predicted to rise due to the increased incidence of stroke associated with age (Eaves 2002; Information Statistics Division Scotland (ISDS), 2010). The resultant consequences will have meaningful repercussions on the lives of those affected, an impact 'it would be difficult to overstate' (Dowswell et al, 2000:511). Indeed, it has been suggested that stroke has a far greater impact on an individual than other

diseases because brain function is at the very essence of what we regard as ‘humanness’ (Brauer et al, 2001: 90).

### **1.3 Definition and diagnosis**

Stroke is defined as ‘a rapidly developing episode of focal or global neurological dysfunction, lasting longer than 24hrs or leading to death, and of presumed vascular origin’ (Harwood et al, 2005:2).

As this definition indicates, the effects of a stroke can either be quite localised to one specific area or function of the body, or have a more widespread and general impact on a number of systems and functions. Such are the complex differences that may be observed or experienced by stroke survivors, that Warlow et al (2008) dedicate 800 pages to discussing the diagnosis, symptoms, and effects of different types of stroke.

Diagnosis of stroke is generally done via a Computed Tomography (CT) or Magnetic Resonance Imaging (MRI) scan, ideally ‘immediately on presentation’ at hospital (Scottish Intercollegiate Guideline Network (SIGN), 2008:4). Brain imaging is considered essential to distinguish between different types of stroke, and also to exclude certain other conditions which may have similar symptoms (e.g. brain tumours; SIGN, 2008).

Also differentiated during this early stage is whether the symptoms are consistent with a Transient Ischaemic Attack (TIA) or a more major stroke. TIA diagnosis is usually made when symptoms resolve within 24 hours (Scarborough et al, 2009).

Many patients who suffer such attacks will either not be admitted to hospital, or be sent home fairly quickly (Green and King, 2007). However, as detailed in SIGN Guideline 108 (SIGN, 2008), such episodes may be indicative of an impending

major stroke, and therefore it is vital that appropriate advice and preventative medication are initiated early.

#### **1.4 Stroke type, incidence and prevalence**

In general, stroke is divided into 2 main sub-types: ischaemic strokes (caused by a blockage due to a clot or embolus) and those caused by a haemorrhage or 'bleed'. As Warlow et al (2008) discuss, this differentiation is fundamental to initial treatment options, and on-going preventative medication. Figures relating to each type indicate that approximately 80-85% of strokes are caused by a clot or embolus, with 15% being attributed to a bleed (Warlow et al, 2008). However, as stroke statistics produced in a combined report by the British Heart Foundation and The Stroke Association (Scarborough et al, 2009) indicate, there are discrepancies and differences in the way stroke statistics are measured: for example, figures relating to haemorrhagic stroke do not always include both sub-arachnoid haemorrhage and intracranial bleed.

A further example of such differences exists in estimations of stroke occurrence, with National Stroke Audit figures (Hippisley-Cox et al, 2004) suggesting that approximately 420,000 adults in the UK have had a stroke, whereas health service figures estimate the figure at just over 1 million (Scarborough et al, 2009). Truelsen et al (2006) agree that while reliable stroke statistics are essential for calculating the burden of stroke and planning care, methodological differences can hamper comparisons of data. It would therefore seem advisable to treat statistics relating to stroke with caution, although some indications of incidence and prevalence are useful.

Incidence rates are expressed over a given period (e.g. stroke affects between 174 and 216 people per 100,000 of the UK population every year: Royal College of Physicians, 2008), and such figures are useful for allowing comparisons to be made across countries, regardless of population size. Prevalence, on the other hand, can only give information about a certain point in time, often being expressed as a percentage (Rothman, 2002). For example, early mortality from stroke was estimated to be approximately 25% in developed countries in 2000-2008 (World Heart Federation, 2010).

Early detection of stroke is being encouraged by tests such as ROSIER (Recognition of Stroke in the Emergency Room: Nor et al, 2005) and FAST observations (Face Arm Speech Test: Harbison, 2003). However, while such tests can improve speedier access to appropriate treatment and therapy (SIGN, 2008) they do not address the on-going effects and impact of stroke. It is therefore of vital importance that experiences after a stroke are listened to and understood, in order that the best possible support can be provided, and longer term outcomes optimised. This is consistent with recommendations made not only by The Scottish Government (2009a) but also by the World Health Organisation (WHO, 2010).

Regardless of whether a stroke is caused by a clot or a haemorrhage, the symptoms can be similar, and relate to the part of the brain that has been damaged (Scarborough et al, 2009). Effects can therefore vary widely, according to the area of brain injury, and precise predictions of recovery can be difficult to make (Warlow et al, 2008). Although mortality rates are improving, death within the first thirty days is currently estimated at 19% in Scotland (National Health Service (NHS) Scotland,

2009). Of those who survive, symptoms can be as wide-ranging as a minimal deficit in sensory or motor function (for example, a minor visual or limb weakness), through to a dense limb paralysis (usually one-sided) with associated loss of speech, continence and mobility. The Bamford Stroke Classification (Bamford et al, 1991) is in common use in the UK, and is summarised in Figure 1 below.

<b>Type of stroke</b>	<b>Typical symptoms</b>
Total anterior circulation infarct (TACI) (17% of strokes)	1) Weakness (with or without sensory deficit) in at least two or three body areas (face/arm/leg)  2) Loss of left or right visual field (homonymous hemianopia)  Plus  3) Higher cerebral dysfunction (e.g. speech or co-ordination deficit)
Partial anterior circulation infarct (PACI) (34% of strokes)	Two of the three components of TACI, or isolated dysphasia/co-ordination deficit
Posterior circulation infarct (POCI) (24% Of strokes)	Isolated homonymous hemianopia, uni or bilateral weakness, or sensory deficit; ataxia
Lacunar infarct (LACI) (25% of strokes)	Motor or sensory deficit only; or ataxia; or dysarthria

**Figure 1: Bamford Stroke Classification** (summarised from Bamford et al, 1991)



Poorest survival rates and greatest dependency are associated with TACI strokes, and best survival and independence rates associated with lacunar strokes (Bamford et al, 1991).

### **1.5 Stroke survival**

Mortality rates for stroke have reduced dramatically in the UK over the last fifteen years, with deaths in Scotland for the under 75 age group being reduced by 50% between 1995 and 2008 (The Scottish Government, 2009a). The introduction of specialist stroke units in UK hospitals has undoubtedly had an impact on these statistics, with figures showing increasing survival rates and fewer immediate complications amongst patients admitted to such units (National Audit Office, 2010). As Langhorne et al (2010) discuss, since 1990 stroke units have gone from being virtually non-existent to becoming well established, and of proven benefit.

In addition to this, trials of treatments such as thrombolysis are being used for increasing numbers of patients in the UK, including those over 80 years of age (Lindley et al, 2010). The resulting consequence is that survival rates will increase even further in future years, which will undoubtedly impact on community follow-up services. However, Saha et al (2010) report that only 30% of patients in their study received community rehabilitation support. They also report that as many as 70% of patients felt inadequately supported, especially in relation to speech, swallow and emotional difficulties, and that patients who had community support had 'significantly less emotional difficulties in coping with their stroke' than the cohort who did not (Saha et al, 2010:i45).

Given that Haun et al (2008) consider that inadequate emotional support diminishes the ability to recovery, it would therefore seem important to access the narratives of stroke survivors and their carers, to more fully understand their experiences at significant times, such as the period immediately following discharge from hospital. Indeed, The Scottish Government (2009a) has set listening to people's views as a priority, arguing that evaluation and future planning of services needs to be shaped by patient experiences.

However, in further relation to this, Mold et al (2006) consider that those with complex cognitive and communication problems following a stroke may be amongst those at risk of not receiving adequate follow-up care. It is also these patients whose views may be at risk of not being heard, or accessed, as part of either research or evaluation programmes (Pringle et al, 2008). The Scottish Government (2009a) conclude that the focus of evaluation needs to be on more than medical and financial outcomes, particularly if their vision of Scotland becoming a world leader in tackling stroke issues is to be achieved.

## **1.6 Rehabilitation**

As Warlow et al (2008) describe, stroke rehabilitation can be a complex and lengthy process, with over 60% of survivors being left with a degree of neurological and functional disability that requires intense rehabilitation (Sit et al, 2004). Cott et al (2007:1567) consider rehabilitation as 'a status passage in which clients are transitioning from the status of non-disabled to disabled person'. However, Harwood et al (2005:154) take a more positive view, seeing rehabilitation as 'a restoration to rights or former ability' which aims to maximise functional ability and increase

choice. Despite these differing viewpoints, there is common agreement that stroke recovery is a challenging time.

### **1.7 Stroke and age related issues**

Although stroke is considered an ‘age-dependent illness’ (SIGN, 2008:1), stroke incidence is still seen in a significant number of younger people, with approximately 25% of strokes occurring in people under 65 years of age (National Audit Office, 2010). While greater numbers of ‘older old’ (over 80 years of age: SIGN, 2008:1) are seen as having an impact on future morbidity predictions (SIGN, 2008), increasing obesity rates, lack of exercise and poor nutrition in younger people could mean that the impact of stroke may be increasingly spread over a wider age span (Lu et al, 2005; The Scottish Government, 2009a).

The particular needs of younger people following a stroke in Scotland are addressed by Banks and Pearson (2003) and The Scottish Government (2009a). However, whether such an emphasis is justified is a debatable issue, and one which this thesis will consider, along with other age specific factors.

### **1.8 Geographical variations**

Although overall mortality from stroke is falling in Western Europe and America, trends in other countries are less clear (Lewsey et al, 2009). Globally countries with the highest stroke incidence have traditionally included China, India and Russia (Mackay and Mensah, 2004). However, according to the World Heart Federation (2010), stroke incidence and mortality rates in developing countries (e.g. Latin America, the Middle East, and sub-Saharan Africa) have recently been found to be higher than in developed countries for the first time.

Even within the UK, the impact of stroke can vary. For example, stroke mortality is 50% higher in Scotland than it is London (Scarborough et al, 2009). This figure relates to The Scottish Government's (2009a) focus on the need to reduce this trend. The National Audit Office (2010) also reports on the correlation between stroke and deprivation, and within individual UK regions, mortality is greater in areas of more marked poverty. This highlights the need for services to be improved in such areas (Scarborough et al, 2009; Scottish Executive, 2006).

With regard to race and ethnicity, people from Afro-Caribbean and South Asian backgrounds are at greater risk (National Audit Office, 2010), regardless of which country they actually live in.

### **1.9 Gender**

With regard to gender differences, although stroke is more common in men, women are more likely to die following a stroke (National Audit Office, 2010). This is due to the fact that women are generally older at the time of the stroke, and in poorer health (National Audit Office, 2010).

Hilton (2002) discusses the fact that haemorrhagic and cardio-embolic strokes (e.g. those resulting from bleeds or a dysfunction in cardiac rhythm) are more common in women, and ischaemic strokes are more likely to happen in men. However, whilst these issues may impact on occurrence, adjustment in the aftermath may be equally difficult, regardless of cause or gender.

### **1.10 Prediction, prevention and costs**

Although age is considered to be the single biggest predictor of stroke (Information Statistics Division Scotland (ISDS), 2010), there are many other factors that increase

stroke likelihood. These include inherent factors such as race or ethnic background, and lifestyle risk factors such as smoking and diet (The Scottish Government, 2009a). Risk factors are summarised in Figure 2 below.

<b>Stroke: common risk factors</b>
<ul style="list-style-type: none"><li>• Raised blood pressure</li><li>• Raised cholesterol levels</li><li>• Atrial fibrillation (irregular heart rhythm)</li><li>• Diabetes Mellitus</li><li>• Smoking</li><li>• Unhealthy diet</li><li>• High alcohol intake</li><li>• Lack of exercise</li><li>• Previous stroke or transient ischaemic attack (TIA)</li><li>• Obesity</li><li>• Afro-Caribbean and South Asian background</li></ul>

**Figure 2: Stroke risk factors** (Summarised from the National Audit Office, 2010)

Across the UK, there are action plans in place with specific targets relating to stroke prevention, particularly regarding modifiable risk factors (Dept of Health, 2007).

These guidelines address issues of lifestyle choice, and when the use of preventative medication for hypertension or high cholesterol levels is indicated. With regard to diet, although similar nationwide advice exists for fat and salt intake, at the time of writing Scotland is the only UK region to have specific targets relating to the limitation of alcohol consumption (The Scottish Government, 2009a). However,

while organisations such The Stroke Association and Chest, Heart & Stroke Scotland are doing on-going work to raise much needed awareness of stroke issues, The Scottish Government (2009a) concludes that understanding of stroke remains low amongst the general public.

Wiles and Giallombardo (2010: i44) discuss stroke patients as a ‘complex and resource intensive’ population. In relation to preventative medication alone, the number of prescriptions for both cardio and cerebrovascular disease has increased by 73% in the last decade (ISDS, 2009). These medications tend to be grouped together, because many will act to prevent both heart disease and stroke. However, while such prescribing will have a positive effect on reducing mortality rates in the longer term, the immediate and associated costs are high (£187 million in 2008-9: ISDS, 2009).

With further regard to finance, it is estimated that the cost of stroke to the UK health and social care system was over £4.5 billion in 2006/7 (Scarborough et al, 2009).

Although 80% of these costs were for hospital and residential care, the vast majority of stroke survivors are being cared for in their own homes (Saha et al, 2010). Saka et al (2009) argue that the real cost rises to £8.9 billion per year if indirect costs, such as income loss and benefit payments, are taken into account. They refer to these figures as relating more accurately to the ‘societal perspective’ of stroke burden (Saka et al, 2009: 27). However, as Scarborough et al (2009:101) conclude ‘looking only at the cost of stroke and TIA to the health and social care systems of the UK grossly underestimates the true cost of these conditions’. Indeed such figures give no indication of costs in terms of the impact not only on the stroke survivor, but also on their position within their particular family and social situation.

With the trend for increasing numbers of patients being cared for at home likely to increase (Dept of Health, 2007; The Scottish Government, 2009a), the need to look closely at stroke care provision and experiences has never been more important. As argued by Carlsson et al (2004) and Rochette et al (2007), even people with limited deficits from their stroke can still have considerable adjustments to make in the aftermath. Green and King (2007) also consider that people with a mild stroke may have important yet unaddressed issues, on their often more rapid return to the community.

### **1.11 Transition from hospital to home**

It has been estimated that up to 80% of stroke survivors will return home to continue their recovery (Han and Haley, 1999; Rittman et al, 2004). Recommendations encouraging community care and early supported discharge for conditions such as stroke have been emphasised for a number of years (Langhorne et al 2005, Scottish Executive 2005, The Scottish Government, 2009a), with hospital stroke units being recognised as only ‘the platform on which to *begin* the recovery and adjustment process’ (Young, 2001:787; emphasis in the original).

An increasing emphasis on early discharge schemes, which will continue to be highlighted by this shifting locus of care, may mean that more recovery will be taking place at an even earlier stage within the home (Langhorne, 2003). According to Smith et al (2004), however, this has not been matched by research into the impact on carers and families of such shifts in care-giving. Jenkinson and Ford (2006) also argue that there has not only been too little in the way of support post-discharge for

patients and carers, but that they have not been included sufficiently in stroke research.

The time of transition from hospital to home has long been recognised as a period of great uncertainty (Doolittle, 1991; Snape and Burton, 2002; Ellis-Hill et al, 2009; Greenwood et al, 2009). Olofsson et al. (2005) suggest that this is because it is only once home that patients and carers really start to understand the full consequences of the illness. Brazil et al (2000) comment that, even with good discharge planning, needs can become more complex after discharge. With regard to traumatic brain injury patients, for example, Fleming et al (2006) report that self-awareness can increase significantly following discharge from hospital, and that this may have a detrimental impact on mood.

Pound et al (1995) and Brauer et al (2001) suggest that patients and carers can welcome being able to hand over responsibility for decision-making during the acute hospital phase. However, discharge home involves the process of taking back that responsibility (von Koch et al, 1998; Mayo et al, 2000; Olofsson et al, 2005) with patients starting to exit the 'sick role' and becoming more independent (Palmer and Glass, 2003:257). The time of discharge home can therefore be seen as period which may raise many issues for patients and carers.

According to the Department of Health (2010a) there are sound reasons why earlier discharge of patients is beneficial: a protracted length of hospital stay can not only increase the risk of infection and depression, but loss of independence and confidence may also impede recovery and rehabilitation. With further regard to



costs, discharging patients earlier also has important resource implications: not only do more hospital beds become available, but the financial cost of community services is considered to be less (Langhorne, 2003).

Despite this, Ytterberg et al (2000) identify that some patients may deteriorate or cease to improve following discharge from hospital. A number of studies, in a variety of countries, have also indicated high readmission rates (Claesson et al, 2002; Langhorne et al, 2005; Torp et al, 2006). This raises questions about the causes of readmission, and the type of support available (Moyer, 2006). Although Claesson et al (2002) conclude that it is more dependent patients who tend to be readmitted, they also found that stroke severity was not necessarily related to readmission. New and unforeseen problems can arise within the first week following discharge, and carer stress may also be a factor (Claesson et al, 2002). Brereton and Nolan (2000:498) argue that although community care aims to reduce cost, whilst still ensuring good quality of life, the reality of the situation is that 'community care equates largely with family care', and that there is still too little recognition of the impact on carers. The time of discharge home is also a period when patients are at risk of 'falling through the net' of stroke care, particularly if survivors have cognitive or communication problems (Mold et al, 2006:349).

In general, the time of discharge home has been recognised as an unsettling time for many patients, regardless of diagnosis (Michels, 1988). Rydeman and Tornkvist (2006) argue that many older people, in particular, can be left vulnerable and exposed in the discharge process. In a similar way to the circumstances which might apply to stroke survivors, as an amputee patient, Giles (2007:2) describes the need for a 'temporary set of stabilisers' by way of support, following discharge home.

With regard to the assistance that is available once people are back in the community, a meta-analysis of early supported discharge services (Langhorne et al, 2005) discusses the benefits such schemes can offer in terms of reduced risk of mortality, dependency, and adverse outcome. However, interventions to support people at home following a stroke have not always shown great benefit (Forster and Young, 1996; Boter, 2004). As will be discussed later in the thesis, this may be due to the type of intervention: in the study by Boter (2004), for example, intervention was standardised as part of a randomised controlled trial, rather than being adapted to individual need. As Luker and Grimmer-Somers (2009) conclude, post-discharge support needs cannot be easily predicted, and it would therefore seem more appropriate that a flexible and responsive system of support is provided, rather than a rigid, fixed intervention.

While disabling illnesses such as stroke can be discussed in terms of crises and stresses for those involved, Parkes (1971) considers such descriptions to be negative, limited, and possibly indicating an outcome that does not actually occur. For example, an event that for one person may indeed be a crisis, could be viewed as an opportunity by another. As Parkes (1971:102) states, a crisis 'can lead to the stars as well as to the grave'; he argues that it is coping ability which defines how a crisis will be dealt with.

Parkes (1971:103) therefore offers the term 'psycho-social transitions' to better explain changes which are 'lasting in their effects, which take place over a relatively short period of time and which affect large areas of the assumptive world'. From the earlier descriptions mentioned above, stroke must surely fall into such a category.

Assumptions about the future may become less certain as a result, and it is important that the effects on the individuals concerned are understood in order to provide the best support. As Hilton (2002:21) stresses, lack of understanding regarding experiences following stroke may result in 'inappropriate and inadequate care by nurses'. In the words of one participant in a study by Brereton and Nolan (2000:504) 'it's a totally different ballgame when you get home'. This quote refers to the fact that advice given by hospital staff may bear no relation to the actual home environment. The transition can therefore be seen as 'a complex process, unique to each family' (Brereton and Nolan, 2000:505).

### **1.12 Summary**

This chapter has given a broad overview of stroke as a condition, including definitions, diagnosis and incidence. The overview gives indications of the scale of the issues being dealt with, and the related costs. A stroke usually happens suddenly, and without prior warning. However, with increased community, rather than hospital, care and rehabilitation, survivors may be discharged home at a time when the true impact of the situation is only just being realised.

The Scottish Government (2009a) emphasises the value of listening to the experiences of those affected by stroke. It was against the backdrop of increasing stroke incidence and greater likelihood of survival in the UK, that this study was planned. As an initial step towards exploring what was already known about stroke experiences, especially during the period immediately following discharge from hospital, a literature review was carried out to inform and situate the proposed study.

The thesis unfolds as follows: details of the method, results and conclusions of the literature review are given in chapter 2; chapter 3 discusses methodological choices, and in particular interpretative phenomenological analysis; chapter 4 considers the particulars of method for the study as a whole; chapter 5 discusses the preliminary study findings; in chapter 6 the main study method is detailed; chapter 7 presents the main study findings, while chapter 8 considers a more in-depth analysis and discussion around the findings; chapter 9 summarises the study, giving recommendations for both clinical practice and further research, as well as including a reflexive account.

## **CHAPTER 2**

### **Literature review**

#### **2.1 Introduction**

*When the person is removed from his/her environment and is changed greatly by illness, an uncomfortable incongruence between the person and their environment might be anticipated upon his/her return. (Davidson and Young, 1985:127)*

This chapter reports on the findings of a review of research literature which was undertaken relating to the early discharge experiences of stroke patients and their carers, from a qualitative perspective. The aim of the literature review was therefore to identify the scope of previous research in relation to this aspect of stroke recovery. It was felt that greater awareness of these experiences might help to better inform and improve service provision. The review was carried out during 2006, and examined research available at that time concerning the particular focus of the transition from hospital to home. In this chapter, explicit details of how the review was carried out are given, and limitations detailed.

Findings from the review are used to support and highlight the need for the particular emphasis on discharge experiences, and to help situate the proposed study in terms of what was already known from other research at that time. However, over the course of the planned study, further relevant studies were accessed, and these are referred to, as appropriate, throughout the thesis, and in particular in the discussions in chapter 8, where relevant literature is related more specifically to the distinct

findings of this research. A shortened version of this literature review has been published in the *Journal of Clinical Nursing* (Pringle et al, 2008).

## **2.2 Background**

According to Hek et al (2000), the aim of literature reviews is to provide an overview of work already carried out in a specific area of interest. However, they also acknowledge that a full systematic review may involve more resources (e.g. time, cost, or personnel) than are available. In addition to this, Knipschild (1995:11) cautions that electronic databases alone may not yield the best or most comprehensive results, and that ‘only fanatical collectors’ can expect to identify more than 75% of relevant material, even when ‘grey’ or unpublished literature is included.

Dochartaigh (2007) asserts that the most relevant, reliable and best quality academic sources are beyond the scope of popular search engines such as Google, Yahoo or MSN Search. He advises using subject-specific databases which, as Hendry and Farley (1998) conclude, can help to link theory, research and practice in disciplines such as nursing. Hendry and Farley (1998) also suggest that it is helpful to develop a questioning approach to the whole review process.

Dochartaigh (2007) further discusses the increasing amount of information available on the internet. It is therefore inevitable that restrictions to any literature review have to be set, to make the task in hand achievable. If such boundaries are made clear, alongside the particular aims of the review, then the reader will be able to assess the findings and conclusions on their merits, within the stated limitations. That said, there is still a need for authors to ensure that the review has been conducted and

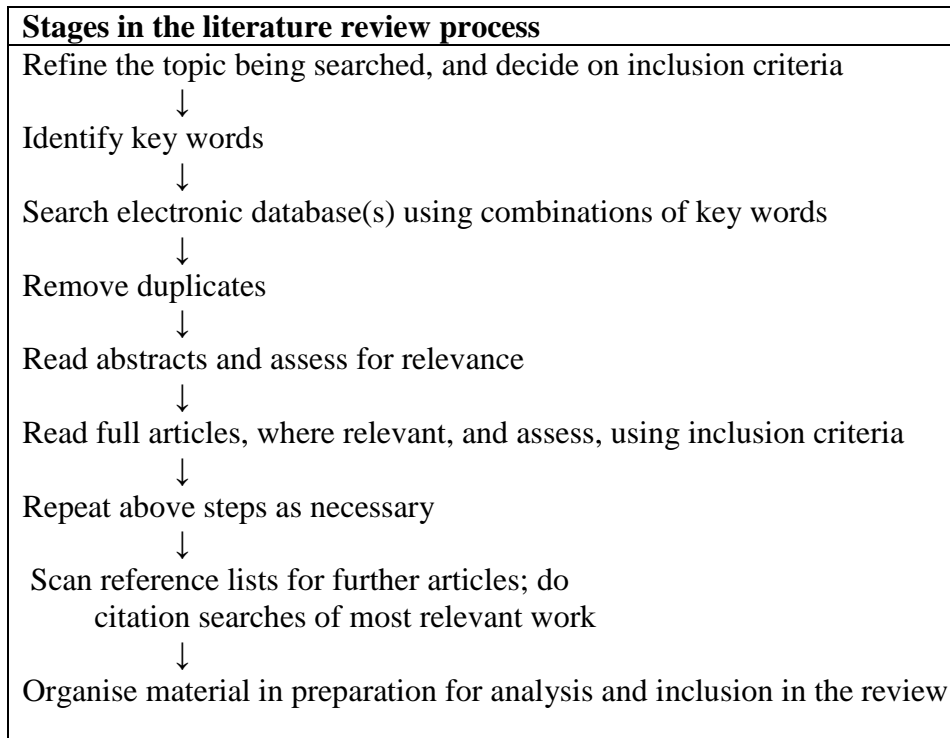
constructed in a transparent, logical and thorough manner in order that findings can adequately identify and summarise central arguments, main issues, and gaps in knowledge, that are credible and legitimate. Such detail is necessary because, as Sandelowski (2008:105) reports, the ‘vagaries’ of databases can make searches very difficult to reproduce, even using identical criteria. As time passes, and more up-to-date information becomes accessible, the likelihood of producing similar results or conclusions seems even slimmer.

Although Hek et al (2000:42) discuss the fact that many systematic reviews aim to include studies with a low susceptibility to bias, such as randomised controlled trials, they later acknowledge that studies having greater susceptibility to bias can still offer ‘extremely important insights into the whole area of investigation’. Decisions therefore have to be made about the type of literature the search will be aiming to identify.

Timmins and McCabe (2005) detail the different purposes that a literature search may fulfil, such as guiding evidence-based practice, or identifying gaps in research. The aim of the literature review detailed here was therefore to explore what was already known about the time of going home from hospital, from the experiential viewpoint of both stroke patients and their carers. The objective was to discover potential gaps in knowledge or awareness in relation to this time, and therefore to focus and inform the proposed study further, and judge where it might sit and contribute, in relation to other research.

However, although guidelines can be followed (Hek et al, 2000), Timmins and McCabe (2005) argue that the procedure is rarely a linear set of steps, and searches

may need to be revisited and repeated many times during the process. From this aspect, although the strategy used here was adapted from Polit al (2001), and detailed in Figure 3 below, flexibility was also considered a key necessity.



**Figure 3: Stages in the literature review process** (Adapted from Polit et al, 2001)

### **2.3 Search strategy**

It was recognised that the period following discharge home was a topic of potential interest to a number of disciplines and services, ranging from medicine, nursing, and therapeutics, through to non-statutory volunteer agencies. Barbour and Barbour (2003) also emphasise that certain databases, such as Medline, may have a distinct clinical or subject-specific focus, and because of this fact, results may be restricted. Therefore, in order to cast as wide a net as possible, a broad range of electronic databases were accessed, as detailed in Figure 4 below.



<b>Database</b>	<b>Dates</b>	<b>Details</b>
AARP Agerline	1978- 2006	An on-line bibliographic database produced by the American Association of Retired Persons (AARP). Focus is on aging, middle age and older adults - in particular social, psychological and health issues
AMED	1985- 2006	Allied and Complimentary Medicines Database, with a focus on complimentary medicine, palliative care and professions allied to medicine
ASSIA	1970- 2006	Applied Social Sciences Index and Abstracts; includes literature from psychology, sociology, medicine, anthropology, politics and law
BNI	1985- 2006	British Nursing Index covers articles from core nursing and midwifery titles
CINAHL	1982- 2006	Cumulative Index to Nursing and Allied Health Literature. Includes nursing journals from 1982; books and dissertations also included
EMBASE	1980- 2006	Excerpta Medica Database covers biomedical and pharmacological literature
EBM reviews	All listed	Evidence-Based Medicine contains reviews of research from over 7,500 journals
ERIC	1965- 2006	Education Resources Information Center (ERIC); described as the world's largest database of educational literature
MEDLINE	1950- 2006	Also known as PubMed; covers approx. 3,200 health related journals world-wide, focusing on evidence/research based work
PsycINFO	1806- 2006	Abstract database providing systematic coverage of psychological literature as far back as the 1800s
Social Work Abstracts	1977- 2006	Produced by the National Association of Social Workers; contains more than 45,000 records relating to social work and other related topics on welfare, aging, and communities

**Figure 4: Databases used in the literature review**

As can be seen from Figure 4 above, unlike Hek et al (2000), date limitations were not set by the researcher, with the only restriction being the date from which each

database had entries recorded. This helped to ensure that early seminal works would not be excluded (Timmins and McCabe, 2005).

As Hek et al (2000) identify, when using a number of different databases, the likelihood of duplication can be high. However, Hek et al (2000) also conclude that it is not always possible to eliminate duplicates through electronic means (e.g. bibliographic software programmes), and therefore manual checks were also carried out.

The databases were accessed either via the university learning and resource centre database or the NHS e-library (now known as the NHS Knowledge Network) using an Athens password, which allows free retrieval of certain resources for NHS staff. It was considered that this strategy might allow a greater number of articles to be accessed directly, rather than using one network alone.

#### **2.4 Inclusion criteria**

In relation to inclusion criteria, Dowswell et al (2000), Burton (2000), and Murray et al (2003), all argue that traditional quantitative outcome measures are not appropriate if patient and carer experiences are to be fully understood, and services tailored more effectively. While the use of standardised outcome measures could be viewed as improving the robustness of a study (Low et al 1999, Barbour, 2008), and have been of immense benefit in measuring the functional aspects of stroke recovery, Mumma et al (1986) and Burton (2000) assert that qualitative approaches lead to a richer and more total impression of stroke experiences. The view that a comprehensive understanding might not be captured by standardised measures is shared by Pound et

al (1998) and Hart (1999). It was therefore decided to focus the search on studies that had some inclusion of the qualitative, experiential aspects of stroke recovery.

Earlier qualitative stroke studies and literature reviews encouraged the development of longitudinal as opposed to cross-sectional approaches (Folden, 1994; Hafsteinsdottir and Grypdonck, 1997; Low et al, 1999). While studies examining the longer term trajectory of stroke recovery (e.g. Hilton, 2002; Kvingne et al, 2002; Smith et al, 2004; Murray and Harrison, 2004) have added a great deal to the pool of understanding relating to the longer term impact of stroke on patients and carers, the period of discharge home is also recognised as a critical time in the shorter term (Burton, 2000; Olofsson et al, 2005). It was therefore decided to further screen for studies that included some reference to the early days at home. No consensus or definition of what constitutes this period of time could be found, however Rittman et al (2004) identify the first month as the main transition period, and Grant et al (2004) also suggested that this period is a crucial time for stroke carers. In addition to these studies, Johnston et al (1999) suggest that patient's mental conceptions of recovery prospects at one month following discharge may predict their future progress. The research literature was therefore examined for references to the first month at home.

Due to translation difficulties, non-English language articles were excluded. It is also acknowledged that 'grey' or unpublished literature has been excluded from the review, due to potential access difficulties and resource limitations, as discussed above. Whilst Benzies et al (2006:55) acknowledge the advantages of including grey literature in 'state-of-the evidence' reviews, they also acknowledge that such a strategy is challenging, and suggest ways to determine if such inclusion is

appropriate. For example, if available research evidence is of low quality and volume, then it may be necessary to access grey literature to more fully evaluate the current state of knowledge. Since a few trial searches indicated that this did not apply to the chosen area of investigation, the search aimed to include only published and peer reviewed studies. However, Dochartaigh (2007:6) cautions that while such literature may be considered as quality assured, that does not make it flawless, and potential articles still need to be approached with a ‘critical eye’.

Inclusion criteria are summarised in Figure 5 below.

<b>Inclusion criteria for literature review</b>
<ul style="list-style-type: none"><li>• Qualitative/experiential studies</li><li>• Research based</li><li>• Published/peer reviewed studies</li><li>• English language</li><li>• Early weeks at home examined</li></ul>

**Figure 5: Inclusion criteria for literature review**

## **2.5 Key words**

The choice of key words is considered to be ‘the cornerstone of an effective search’ (Timmins and McCabe, 2005: 44), and adequate thought in relation to their use may help to define and focus the information retrieved (Dochartaigh, 2007). Databases will often give suggested linked key words in their thesaurus. For example, CINAHL

suggests the use of the word stroke, instead of cerebrovascular accident (CVA); however using the key word CVA in the same database does still generate numerous results. A flexible and varied approach was therefore taken, with words being truncated with key symbols to expand on different possibilities. For example, phenomeno\$ might generate phenomenological, phenomenology or phenomenon.

Such an adaptable approach was considered necessary because, as Hek et al (2000) acknowledge, a search strategy that is too sensitive and specific may have high precision, but may still fail to capture many relevant articles. Likewise, the process was not viewed in terms of the 'logical progression' suggested by Hek et al (2000:41), but rather as an on-going process that would continue to be revisited throughout the proposed research. As Wilkinson and Wilkinson (1995:30) advise, 'the significant difference between the early and later searches in a literature review is that in the former the emphasis is on topic clarification, data collection and familiarisation, whereas in the latter, specific elements of topic are focused on'. In this respect, although Hek et al (2000:50) discuss 'literature review saturation', no such concept was considered appropriate or possible in a project where new and relevant literature might be continually being produced or made available; neither did the review set out to be exhaustive, although it was hoped that a broad range of available literature would be accessed.

Key words and phrases are noted in Figure 6 below.

<ul style="list-style-type: none"> <li>• stroke/CVA</li> <li>• acquired brain injury</li> <li>• discharge home</li> <li>• discharge planning</li> <li>• transitions</li> <li>• rehabilitation experiences</li> </ul>	<ul style="list-style-type: none"> <li>• patient experiences,</li> <li>• carer/caregiver experiences</li> <li>• life after stroke</li> <li>• phenomenology/phenomenological research</li> <li>• qualitative studies/research</li> </ul>
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**Figure 6: Key words used in literature review**

Combined searches of the key word terms using Boolean strategies (Wilczynski et al, 2007) were used to expand and explore as many combinations as possible, and also to focus the search where too many non-specific items were found. Boolean strategies are named after the mathematician George Boole, and involve the use of the terms ‘and’, ‘or’ and ‘not’, and can help to either widen the search, or make it more specific, depending on the results (Timmins and McCabe, 2005). From this aspect, different combinations of key words were used on numerous occasions, and notes kept of the results. Two sample searches and the results are given below in Figures 7 and 8.

Search number	Search history	Results
1	Stroke	9933
2	Patient\$ experience\$	2447
3	Combine 1 and 2; limit to English	75
4	Remove duplicates and scan for relevance	1

**Figure 7: Summary of literature search carried out on 19/05/06**

Search number	Search history	Results
1	Cerebral Vascular Accident	10,305
2	Phenomenological Research	3,576
3	Combine 1 and 2; limit to English	38
4	Remove duplicates and scan for relevance	9

**Figure 8: Summary of literature search carried out on 27/05/06**

The keywords used were sought anywhere in the article, rather than just in the title, unless a specific article was being sought that had already been identified. Terms relating to the clinical condition of stroke were also omitted in some searches in order to locate studies referring to discharge experiences relating to other medical conditions. It was felt this might add further information to compare and contrast later in the study. Titles of articles and abstracts were read, and if considered potentially relevant, the full article was accessed for further consideration.

Although the main focus of the search was on qualitative studies, primary sources of information (e.g. policy documents and statistical reports) that were highlighted during the review were useful in providing background information (as detailed in Chapter 1), as were studies evaluating discharge support schemes and services from a more quantitative viewpoint.

Reference lists of relevant articles were screened, and citation searches carried out on the most pertinent studies. Hand searches of library journals were also carried out, according to the publications most commonly noted as containing relevant papers (*Journal of Advanced Nursing; Disability and Rehabilitation; Rehabilitation Nursing*). As Barbour and Barbour (2003:184) conclude, ‘serendipity’ can yield

articles from unexpected sources through browsing in libraries, or discussions with colleagues. Reference lists from existing stroke literature reviews were also searched (Hafsteinsdottir and Grypdonck, 1997; Han and Haley, 1999; Low et al, 1999; Brauer et al, 2001; Snape and Burton, 2002; Palmer and Glass, 2003; Murray et al, 2003; McKevitt et al, 2004; Lui et al, 2005). These reviews were useful in that they gave an overview of literature as assessed by other parties. A summary of the focus of these reviews is given in Figure 9 below. However, none of the reviews that were found focused on the early discharge period or experiences during that time.



<b>Authors</b>	<b>Date of review</b>	<b>Focus of review</b>	<b>Number of studies reviewed</b>	<b>Summary of findings</b>
Hafsteinsdottir and Grypdonck	1997	Patient's experience of stroke over a broad time frame	4	Patient and professional recovery goals differ
Han and Haley	1999	Evaluating the impact of stroke on family caregiver well-being	20	Caregivers have elevated levels of depression, both in the acute phase and longer term
Low et al	1999	The impact of stroke on informal carers	31	Carers ability to cope was influenced by positive coping strategies
Brauer et al	2001	Previous studies synthesised to form a model of stroke recovery	9	Stroke recovery involves deterioration, recovery and re-synthesis
Snape and Burton	2002	Nursing contribution to stroke rehabilitation	Not specified	Nursing practice can support the social and psychological consequences of stroke
Palmer and Glass	2003	Family function and stroke recovery	78	Studies have tended to view the stroke patient or carer in isolation
Murray et al	2003	Long term problems for stroke patients and their carers	23	Problems relate mainly to social and emotional consequences
McKevitt et al	2004	A review of qualitative stroke studies	95	Problems remain in the delivery of best quality stroke care
Lui et al	2005	Care-giver problem-solving skills	11	Problem-solving skills are rarely measured, and require more acknowledgment

**Figure 9: Summary of literature reviews**

In addition to the search strategies mentioned above, some studies were located that had been commissioned by the major UK stroke charities: Chest, Heart & Stroke Scotland (CHSS and Scottish Association of Health Councils, 2001; Banks and Pearson, 2003), and The Stroke Association (Wolfe et al, 1996). Although the studies by these bodies had not necessarily been peer reviewed, their contribution to overall findings was considered important due to their focus on service user perspectives, and being authored by field experts.

Due to the diversity of impact a stroke can have (Harwood et al, 2005), the review found a wide range of studies from various disciplines including nursing, psychology, allied health professions, social services and the voluntary sector. Likewise, as McKeivitt et al (2004) also report, articles may be published in journals that are not often read outside the specific discipline, and therefore are not more generally available, but may still be of interest to other disciplines.

Studies that combined quantitative and qualitative methods were reviewed, and the searches that were carried out did not always specify a method keyword (e.g. phenomenology or qualitative) in order to capture as many potential studies as possible.

Knipschild (1995) found that electronic databases can yield as few as one third of published resources. He therefore advises that using a snowballing technique to check reference lists, and references from these references, can be much more rewarding, yielding up to 75% of available literature. Such a technique is also referred to as a 'network' approach by O'Connor (1992: 44).

With further regard to published literature, it was decided to focus on research-based studies and to exclude books or articles relating to personal stories. Although Barbour and Barbour (2003:184) consider that such omissions may limit the scope of a search, they also admit that such literature may ‘not make a significant contribution to the evidence base’. In addition to this, in an analysis of personal story publications, Easton (1999:71) discusses the fact that these are frequently written by authors of ‘above average’ education, and also written from a longitudinal, retrospective perspective, some time after the event. This may present a pre-meditated and edited version of events, and it was felt that much of the detail relating to the early discharge experience may have been forgotten or re-interpreted in these types of publication.

It was considered that although not all the work identified in the search would be relevant to the review, as discussed above, such literature could still potentially add additional information and valuable perspectives that might be of benefit to the comparisons that might be made in later discussions. However, it was accepted that this prior knowledge of other research, whilst a necessary part of the process of evaluating what was already known about the topic of proposed study, might also have the potential to influence the analysis and findings (Lowes and Prowse, 2001). An intentional focus on the specific data produced during the proposed study would therefore have to be made, and such tensions acknowledged. These issues will be further explored later in the thesis, but an awareness of such prior knowledge is also necessary during the early stages of a research proposal (Lowes and Prowse, 2001; Smith et al, 2009).

Although Baker et al (1992:1357) regard a literature review prior to a phenomenological study as only requiring to be 'sparse', Smith et al (2009) conclude that knowledge of other research is required, not only to specify the contribution the proposed study may make to the existing body of knowledge, but also to help the researcher be explicit about what it is they wish to achieve in their own study. A tension therefore exists between making a case for the proposed study, and not allowing knowledge of existing research to influence findings, which need to develop inductively from participant accounts in a phenomenological study. As Brocki and Wearden (2006:92) conclude, 'it seems unlikely that researchers could embark upon a project without having at least some awareness of the current literature and issues surrounding the area'.

Although, as discussed above, literature searches were to be continued throughout the project, there came a point at which the available studies had to be critically examined, and conclusions drawn, in order that the research proposal could be finalised. Paper copies of many relevant articles were therefore accessed, either directly on-line or through the university inter-library loan system. Some articles had to be sourced from further afield (mainly via the British Library), and in this respect much helpful support was given by the university library staff and study supervisory team. As acknowledged by Hek et al (2000) as an occasional likelihood, there were a few papers that were unobtainable, and therefore could not be included in the review.

Having paper copies proved beneficial in that notes could be made on the articles, and relevant sections highlighted, for subsequent speedier retrieval of information. The copies were also available for repeated revisiting throughout the research project.

## **2. 6 Literature review findings**

After initial searches involving many hundreds of titles and abstracts, eighty three articles were located for further appraisal. More thorough screening using the inclusion and exclusion criteria resulted in a total of twenty eight relevant studies being selected for in-depth review at this stage in the research. Since the purpose of the review was to find out what was already known about early discharge experiences, rather than specifically critically reviewing the quality or rigour of the actual research, issues of relevance in relation to this time were the main areas of appraisal. In this respect, a tool such as the Qualitative Assessment and Review Instrument (QARI: Lamb et al, 2008) was not used, and it is acknowledged that within the confines of journal articles, sufficient information to form such judgements may not be available (Maggs-Rapport, 2001).

The studies were quite diverse, but specific aspects such as the aim of the research, and methods used, are detailed in a summary grid, as suggested by Polit et al (2001). In addition to information about the participants, timing of data collection and location of the studies are also given. As such, the review answers questions in relation to when, why, how, who, where, and what was found or concluded. Whilst the review was done in a systematic fashion, as Sandelowski (2008) considers, the use of inclusion and exclusion criteria still make the process more subjective than is often acknowledged. However, as Maxwell (2006: 28) discusses, although this review included an overview ‘of research’, the main purpose was aimed at making a case ‘for research’, and it is important that such a difference is specified.

The findings of this review are detailed below in Figure 10, and will be discussed further in the latter part of this chapter. The studies detailed here will also be revisited, as appropriate, later in the thesis, and in particular in relation to issues such as stroke severity and ethical approval.

Author/date	Research aim	Method	Study participants	Ages	Location	Findings
Davidson and Young 1985	To investigate problems after stroke rehabilitation and how survivors interact with their environment up to 18 mths post-discharge	Grounded theory interviews/mixed methods (qualitative and quantitative) 1-7 and 12-18 months post-discharge	29 patients and carers	Age range: pts 40-64 and 65-82;  Carers ages not specified	USA	Much energy is spent planning and timing activities. Survivors want a challenging but not over stressful environment
Kaufman 1988	To investigate the phenomenology of the chronic illness experience during the first year after a stroke	Open-ended interviews; timing of interviews unclear, but carried out over the course of the 1 <sup>st</sup> year post-stroke	64 patients and 50 carers; the paper discussed 2 case studies from this sample	Age range:  pts over 45; carers ages not specified	USA	Assumptions exist about the boundaries of medical authority for both survivors and carers
McLean et al 1991	To discover perceived service needs amongst stroke survivors and their carers; to pilot interview techniques and evaluate a counselling intervention	Semi-structured interviews; timing since discharge not specified, although participants approached just prior to discharge	20 patients and their carers	Age range:  mean female pts 78, male 69; female carers 59; male 52	UK	More information about stroke, and counselling in relation to carer problems, are needed by carers
Doolittle 1992	To discover the experience of lacunar stroke during the first 6 months post-stroke	Descriptive approach: structured and unstructured interviews; 1 <sup>st</sup> interview 72hrs post-stroke; timing of other interviews not standardised	13 patients	Age range: 50-88	USA	Survivors continue to experience a very objectified body with loss of pre stroke automaticity and smoothness of movement

Author/date	Research aim	Method	Study participants	Ages	Location	Findings
Folden 1994	To explore how stroke survivors manage multiple deficits during the first months after a stroke (pre and post-discharge)	Grounded theory interviews; 1 <sup>st</sup> interview 2 weeks post-stroke (in hospital); 2 <sup>nd</sup> interview 3-4 weeks post-discharge	20 patients	Age range:65-78	USA	Stroke survivors face a very different illness trajectory from other disabling illnesses
Thomas and Parry 1996	To research user views of stroke services; participants 4 months to 9years post-stroke	In-depth, loosely structured interviews; time since discharge not made explicit	15 patients and carers	Age range: pts 45-77; carers not specified	UK	User view research does not necessarily equate to empowerment. More partnership working required
Nilsson et al 1997	To elucidate the experience of stroke during the first 3 months post-stroke	Narrative interviews 1 and 3 mths post-discharge; open-ended questions. Deductive approach related to the theory of developmental crisis	10 patients (with a 1 <sup>st</sup> stroke)	Age range: 53-81	Sweden	Phenomena signifying developmental crises found in all cases in the study
Sisson 1998	To investigate and describe the meaning of stroke to patients in the first 6 months post-stroke	Thematic approach; qualitative interviews 1wk and 1, 3 and 6 months post-stroke. Time since discharge not specified	11 patients with R hemisphere strokes	Age range: 33-70	USA	Major changes in mood and cognitive function found, which vary over time



Author/date	Research aim	Method	Study participants	Ages	Location	Findings
Pilkington 1999	To elicit descriptions of QoL during acute care stay, and 1 and 3 months post-stroke	Loosely structured interviews, interpreted using Parse's human becoming theory (health as a lived experience); time since discharge not specified	13 patients	Age range: 40-91	Canada	Themes relating to quality of life found to provide insight into living with a stroke
Ellis-Hill et al 2000	To explore perceived life and identity changes post-stroke	Life narrative interviews and outcome measures in hospital and 6 and 12 months post-discharge	8 couples (survivors having no previous disability)	Age range: 56-82	UK	Self-body split found up to one year post-stroke and remained a focus of life. Emphasis on physical recovery discussed
Burton 2000	To explore the lived experience of recovery from stroke over time	Phenomenology/ grounded theory interviews – monthly for 1 <sup>st</sup> yr post-stroke; time since discharge not specified	6 patients (with 1 <sup>st</sup> stroke)	Age range: 52-81	UK	No end point to recovery identified 12 months post-stroke and the social impact of recovery is emphasised by survivors rather than physical function
Brazil et al 2000	To assess the needs of family caregivers of stroke; study looked back at 1 <sup>st</sup> year of transition	Semi-structured telephone interviews; qualitative and quantitative; interviews carried out after 1 <sup>st</sup> year since discharge	34 carers; 53 professionals	Average age 61	Canada	Great importance is placed on education about stroke and recovery by carers and professionals. Service providers underestimate difficulties and carers not sufficiently involved in discharge planning

Author/date	Research aim	Method	Study participants	Ages	Location	Findings
CHSS and Scottish Association of Health Councils 2001	To examine the experiences of patients and families of acute and rehab stroke services	Qualitative interviews and focus groups; time since discharge not specified. Constant comparison analysis	114 patients and their carers	Ages not specified	UK	The need for stroke specialist units and stroke training for staff is highlighted, as well as information and liaison staff post-discharge
Bakas et al 2002	To determine needs, concerns and strategies of stroke caregivers during the first 6 months after hospital discharge, and advice they would offer others	Telephone interviews/open-ended questions; exact timings of interviews not specified	14 female carers	Age range not specified	USA	Family caregivers need information not only about how to care for the stroke survivor, but also how to care for themselves. 5 major categories of caregiver need identified
Brereton and Nolan 2002	To gain an appreciation of the needs of new stroke carers and consider how these needs change over an 18 month period	Grounded theory / semi-structured interviews every 2-3 months, up to 18months post-stroke; time since discharge not made explicit	14 carers	Ages range: carers 32-93 Pts ages not specified	UK	'Seeking' information is identified as a key activity of new carers of stroke survivors, esp during the acute hospital phase
Eaves 2002	To examine rural African American stroke patients and caregivers satisfaction with care provided by professionals and family	Narrative analysis of interviews; patients had suffered a stroke in previous 4 months and were recruited on discharge	8 patients and their carers	Age range: pts 56-79; carers 21-70	USA	Caregivers are dissatisfied with the assistance they receive and most needed more help

Author/ date	Research aim	Method	Study participants	Ages	Location	Findings
Banks and Pearson 2003	To investigate the experiences of younger stroke survivors and their families (up to 18 months post-discharge) in relation to service availability particularly	Qualitative interviews/ self report diaries/mixed methods, 3-6 months post-discharge and 3-9 months later	50 patients, their carers and professionals	Age range: pts 18-49; carers 20s-80s	UK	Variations in service provision identified, as well as poor communicationlack of information and understanding, and gaps in post-discharge and longer term support
Röding et al 2003	To investigate young stroke survivors experience of the rehabilitation process in hospital and community at 2 yrs post-stroke	Grounded theory/ in-depth thematic interviews; time since discharge not explicit	5 patients	Age range: 37-54	Sweden	Core categories identified; young survivors feel frustrated and invisible and that the different needs of younger patients are not acknowledged
Bendz 2003	To investigate the ways stroke survivors and health professionals understand the implications of having a stroke during the 1 <sup>st</sup> yr of rehabilitation	Phenomenology / open-ended questions/ interviews and professional records; 3,6 and 12mths post admission; time since discharge not specified	15 patients and professionals	Age range of pts: under 65	Sweden	Patients and professionals share some basic conceptions, but interpretation and goals differ between the two groups
Alaszewski et al 2004	To explore stroke survivors, carers and professionals views of the impact of stroke 1 year post-stroke	Semi-structured naturalistic (person centred) interviews/self-report diaries and focus groups; time since discharge not specified	31 patients and their carers, plus professionals	Age range: 40-89	UK	The bereavement model is used by professionals to explain the impact of stroke, but is absent from survivors/carers accounts

<b>Author/ date</b>	<b>Research aim</b>	<b>Method</b>	<b>Study participants</b>	<b>Ages</b>	<b>Location</b>	<b>Findings</b>
Faircloth et al 2004	To analyse the sudden illness onset of stroke in relation to biographical disruption over the first year after discharge home	In-depth interviews 1,3 and 12mths post-discharge	57 patients (war veterans)	Age range: 46-88	USA	Findings suggest a biographical flow rather than a biographical disruption in relation to stroke patients experience of recovery
Rittman et al 2004	To investigate dimensions of the experience of time during the transition from hospital and the first month at home	In-depth semi-structured interviews 1 month after discharge	51 male service veterans and their carers	Age range: pts 46-84; carers 40-81	USA	Changes in the temporal order of life are related to functional impairment and bodily disruption; strategies for managing idle time are identified
Grant et al 2004	To identify problems experienced by family carers of stroke survivors during 1st month home	Telephone thematic interviews 1 month after discharge	22 carers	Age range: carers 42-70; pts 63-89	USA	The first month of caregiving is dynamic and distressing for new caregivers and telephone contacts are beneficial to coping
Smith et al 2004	To describe the experience of caring for a stroke survivor during the 1st year post-stroke	Semi-structured interviews 1yr post-stroke; patients had been home 3-11 months	90 carers	Age range: Pts 35-90; Carers 19-84	UK	Carers lacked knowledge and skills, and did not feel adequately prepared for role
Olofsson et al 2005	To investigate the experiences of stroke patients and carers concerning acute care and homecoming	In-depth interviews; 4mths post-stroke; time since discharge not specified	9 patients 5 carers	Age range: pts 64-83 Ages of carers not specified	Sweden	3 main categories identified; patients get their most important insights once home; carers views not noted

Author/date	Research aim	Method	Study participants	Ages	Location	Findings
King and Semik 2006	To identify the most difficult times and unmet needs during the first 2 years of stroke caregiving and the resources used	Semi-structured interviews / mixed methods; data collected 2 years post-discharge	93 carers	Age range: carers 22-85; pts 24-85	USA	The hospitalisation period and the first months at home are the most difficult for the majority of caregivers
Rochette et al 2006	To improve understanding of appraisal and coping post-stroke by investigating personal experiences	Phenomenologically orientated in-depth interviews 3 weeks post-stroke, and 3 and 6 months later; time since discharge not specified	10 patients	Age range: 61-86	Canada	7 themes relating to appraisal and 5 themes relating to coping found 3 and 6 months post-stroke
Pierce et al 2006	To examine the perceived problems of new caregivers and how they alter during a three month period following discharge	Bi-monthly telephone interviews for 1 <sup>st</sup> 3 months following discharge/open-ended questions (following a web-based intervention programme)	9 Carers	Age range: carers 51-68; patients 54-87	USA	Problems are related to self-care requirements of patients, and although they decrease with time, 'balancing it all' increases for carers; carers also need care

**Figure 10: Details of research studies**

## **2.7 Analysis of the studies**

### **2.7.1 Location of studies**

Of the twenty eight studies, twelve were undertaken in the USA, nine in the UK, four in Sweden and three in Canada. While there may be parallels in human experiences following stroke, and some studies have certainly discussed the similarities across geographical boundaries (Stone 2007), it must also be remembered, however, that health care services and provision can be very diverse in different regions, let alone countries. As Low et al (1999) discuss, it is not only differences in lifestyle and culture that need to be taken into account, but also how provision is financed or paid for by service users. Whilst Stone (2007) found marked similarities in experiences across the geographical boundaries of several countries, care therefore still needs to be taken when comparing findings across continents, and differences acknowledged.

Although European guidelines serve to direct the standard of acute hospital stroke healthcare provision across Europe (Brainin et al, 2000), there is still no consensus concerning the follow-up care of patients in the community (Torp et al, 2006). As Langhorne (2003) concludes, the primary care services that are available in the location of a research study can impact on findings, and even if specified, can make it less clear how results may be relevant to another area.

### **2.7.2 Participant numbers**

The number of participants in the twenty eight studies varied between five and one hundred and fourteen. In most of the studies the number of participants tended to reflect the in-depth, qualitative nature of the research, where large numbers are neither necessarily required, nor sought (Robson, 2002). In this type of research, a

fairly small sample will still generate a large amount of data (St John and Johnson, 2000; Barbour, 2008). However, of the twenty eight studies, eleven studies involved more than twenty participants. Of the studies that did include larger numbers, three involved telephone interviews and two focus groups, both of these methods presumably accounting, in part, for the larger numbers. It is often considered that small study numbers can make findings less generalizable (Robson, 2002), but so can many other factors in the sampling process: for example, choosing participants from a minority group. For the purposes of examining in-depth experiences, a smaller study cohort concentrating on a shorter period of time may give the necessary depth of insight that broader studies, with larger numbers, lack (Smith et al, 2009). Regardless of sample size, however, limitations relating to participants do still require to be acknowledged.

### **2.7.3 Participants**

Palmer and Glass (2003) argue that the prevailing tendency in past stroke research has been to study the patient or carer in isolation, rather than in the context of their whole community situation, which may involve several support people. McKeivitt et al (2004) also argue that finding solutions to problems in providing appropriate stroke care requires an understanding of the wider social situation in which the survivor exists. This involves including not only carers and wider family networks, but also taking account of social involvement and responsibilities. Glass et al (2000) argue that patient's goals are often linked to their social roles within the community, and therefore rehabilitation requires to be linked to their wider social network to be meaningful to their lives.

The health and well-being of patients and carers are also inextricably linked, with the well-being of carers potentially affecting the health and recovery of the stroke patient (Lui et al, 2005). As one of the studies examined here concluded, contributions from close family may well have ‘widened and deepened’ their research results (Olofsson et al, 2005: 438). It could therefore be argued that carer views, and acknowledgement of social circumstances, should be included in all stroke research.

Since the Carers Act (Dept of Health,1995) came into operation, there is also a requirement that nursing care will include the views of, and support for, carers. However, as Brereton (1997:426) concludes, this can represent a ‘significant challenge’, and Smith et al (2004) suggest that the needs of stroke carers are still not always fully understood.

Of the studies examined, ten involved patients, six carers, and twelve studies involved combinations of carers, patients and professionals; the majority therefore did not include perspectives from both patients and carers.

#### **2.7.4 Methods**

With regard to the method employed, twenty four studies referred to semi-structured, in-depth or loosely-structured interviews as methods to elicit the information sought. Some studies detailed more specific research approaches, such as grounded theory, phenomenology or narrative analysis. However, the overarching aim was similar, in that there was a desire on behalf of the researchers to understand stroke experiences in greater depth. Pound et al (1995) and Barbour (2008) certainly argue that free-flowing accounts yield insights not attainable through more quantitative, structured approaches. Wiles et al (2002) also discuss the value of qualitative approaches in



identifying understandings and expectations, in order to improve care. As Hafsteinsdottir and Grydonck (1997:580) conclude, previous research has taken the rather narrow view that ‘recovery is analogous to the improvement of physical recovery’, and it is only in more recent years that a wider focus, incorporating psychological and social aspects of recovery, has been acknowledged.

With further regard to the methods used, four studies employed telephone interviews to obtain data, which may have restricted the amount of information obtained, and cannot necessarily be claimed to be a true reflection of participants’ experience: as Neuman (2000) points out, open-ended questions, which are largely used in qualitative research, are difficult to use in telephone interviews. The method may be useful for participants without speech difficulties or, for example, where participants live in very rural or inaccessible areas (Pierce et al, 2006). It should be remembered, however, that some additional information like gestures and facial expressions may be lost to the researcher. As Pilkington (1999) and Yow (2005) discuss, meaning is not only expressed through speaking and silence, but also through movement, tears, sighs, and facial expressions. Such factors are of particular importance to stroke survivors with speech impairments, and may play a large part in their ability to communicate their emotions and experiences, if verbal communication is restricted.

Focus groups were used in two of the studies, in addition to individual interviews. Although a potentially valuable method of data generation, such groups may also exclude those participants with aphasia, and those with greater disability, who may have difficulty accessing venues (Kroll et al, 2007). For stroke carers, there may also be issues with finding suitable substitute carers to allow attendance at an external location (Simon and Kumar, 2002). Because of such difficulties, it would seem

appropriate that an understanding of discharge experiences might be best achieved by using in-depth, face-to-face interviews at a thoughtfully chosen location.

With a carefully selected study sample, some more general conclusions may be allowed to emerge. Nevertheless, study samples still have limitations which require acknowledgement to make the findings credible (Barbour, 2008). In addition to this, if thought is given to the venue, and to facilitating the inclusion of stroke survivors with communication difficulties, then people with a variety of stroke related deficits can be included in a study. These issues will be discussed in greater depth later in the thesis.

### **2.7.5 Timing of studies**

As has already been stated, the early days at home following discharge may be a crucial time for stroke survivors and their carers. The studies were therefore reviewed in relation to their emphasis on the immediate discharge experience for patients, carers, or both, which was taken to include the first few weeks at home.

#### The first month

Of the twenty eight studies, six specifically involved research within the first month following discharge. These were: Folden (1994), Nilsson et al (1997), Faircloth et al (2004), Rittman et al (2004), Grant et al (2004), and Pierce et al (2006).

The study by Folden (1994) concentrated on the experiences of twenty American stroke survivors who had undergone a comprehensive in-patient rehabilitation programme. Participants were interviewed in hospital and again at three to four weeks post-discharge. Analysis and conclusions were largely related to rehabilitation

therapy over time, rather than examining the impact of being home on the participants.

Nilsson et al (1997) examined the experiences of ten Swedish stroke survivors at one and three months post-discharge. The impact of these early months was studied using a deductive approach, relating to the theory of developmental crises. The study concluded that during these months, individuals were in the middle of grasping their new situation and how this was changing over time. Again, the specific impact of being home was not the main focus of the study, but rather a comparison of changes over time.

The studies of Faircloth et al (2004) and Rittman et al (2004) appeared to be related to the same study sample of American war veterans, with several of the authors being named in both papers. Faircloth et al (2004) took a more longitudinal approach, interviewing participants at one month, and up to one year post-discharge. Rittman et al (2004) focused on results from the first month, relating findings to the temporal order of life. Both studies emphasised the disruption to life and functional ability caused by the stroke. The limitations of the sample group (American war veterans) are briefly acknowledged in each study, with no female participants in Rittman's study and only two in Faircloth's study. The results of these studies cannot therefore be considered to be necessarily similar or related to other stroke survivors.

Grant et al (2004) and Pierce et al (2006) studied the experiences of American caregivers. Both studies used telephone interviews, the limitations of which have already been noted. The study by Grant et al (2004) focused on the impact of

problem-solving telephone partnerships as a way of providing support for carers. Pierce et al (2006) examined problems that new carers face, and how they altered over a three month period. The carers in this study were enrolled on a web-based intervention programme, a technique which would presumably exclude those who were not computer literate, although no acknowledgment of this is made in the publication. The study examined the feasibility of this intervention method. Both studies identified the main problems experienced by carers, with the participants suggesting interventions that might be helpful to the coping ability of other carers. Although interviewing carers at one month following discharge, neither study specifically examined the impact that survivors coming home had on the carers. The focus was rather on evaluating the impact on the carers of specific types of support intervention.

#### One to three months

Researchers in a further eight studies reported on the experiences of participants at one to three months: Davidson and Young (1985), McLean et al (1991), Sisson (1998), Pilkington (1999), Burton (2000), Brereton and Nolan (2002), Bendz (2003) and Rochette et al (2006) .

In only one of these studies (McLean et al, 1991) were the participants just interviewed once. The remaining studies involved longitudinal approaches, with researchers interviewing participants at various stages, including this period, and making comparisons. The aim of the study by McLean et al (1991) was primarily to test and refine methods for a larger study, and therefore an in-depth analysis of the

results was not the main focus. The study did conclude, however, that a counselling intervention for carers might be beneficial.

Of these eight studies, only one specified the time since discharge from hospital (Davidson and Young, 1985). In the remaining studies, timing was specified as post-stroke rather than post-discharge. This made it difficult to assess the extent that the effect of being home had on the findings, since the timing of discharge was not known. Nevertheless, some of the findings did relate to the early days at home: Davidson and Young (1985), for example, discussed the implications of the home environment on recovery, comparing the periods of one to seven, and twelve to eighteen months post-discharge. The results were related to coping ability and adjustment over time.

Similarly, Burton (2000), Bendz (2003) and Rochette et al (2006) also examined the adjustment process over one to twelve months. Participants were interviewed at various intervals after their stroke. All three studies commented on the need for professionals to acknowledge the goals of stroke survivors and their role in post-stroke adjustment. The emphasis in all of these studies was on longer term needs, rather than the specific needs during the early discharge period. The research of Bendz (2003) was also limited to patients under 65 years of age. Such age restrictions will be considered later in the discussion section of this chapter.

Sisson (1998) and Pilkington (1999) both identified changes with regard to quality of life and mood during the first months post-stroke, and concluded that it is important that these elements are taken into greater account by nurses. Both studies included data from the acute hospital stay and home, although again time since discharge was

not specified. Sisson (1998) further limited her study to include only participants with right hemisphere strokes. The deficits associated with this type of lesion location were examined, such as emotional changes and verbal/visual memory loss. The study found emotional and behavioural tendencies not previously associated with right hemisphere lesions. However, other studies have examined the impact of lesion type or location (Schulz et al, 1988; deHaan et al, 1995; Brauer et al, 2001) and found no strong links between lesion type and quality of life, experiences, or carer burden.

The study by Brereton and Nolan (2002) was the only one of these eight studies to examine the needs of carers; the period from stroke onset until eighteen months afterwards was the focus of the study. 'Seeking' behaviour and the need for more information for carers were both highlighted but, again, over the longer term (Brereton and Nolan, 2002:22).

### Three to six months

Six studies focused on this period of time: Doolittle (1992), Thomas and Parry (1996), Bakas et al (2002), Eaves (2002), Banks and Pearson (2003) and Olofsson et al (2005).

Of these studies, Doolittle (1992) examined people affected by lacunar infarcts, which account for approximately 20-25% of strokes (Bamford et al, 1991). However, the reason behind this decision was not made explicit, and it is therefore unclear whether the results can be related to other stroke survivors. This study reported that the participants experienced a very objectified and sometimes passive body, when appraising their recovery.

Olofsson et al. (2005) reported a similar theme, discussing the re-personalisation of the depersonalised body. Although the emphasis in this study was on patient's perception of how things would be when they returned home, surprisingly the time since discharge for participants was not specified.

Banks and Pearson's study (2003), carried out for the charity Chest, Heart & Stroke Scotland, studied stroke survivors under 50 years of age. Participants engaged in interviews and focus groups three to six months post-discharge, and then again six to nine months later. This study identified gaps in service provision, but took a longitudinal approach with a group of younger stroke survivors.

Another study which focused on a minority group was Eaves' (2002) study of African American families. This study found marked dissatisfaction with assistance offered to patients and carers following discharge home, but it is debatable whether the findings are relevant to other communities. Bakas et al (2002) also studied American carers, but this time including white and African participants. The information needs of carers were highlighted, but with the interviews being carried out by telephone, wider information about the experience of care-giving may not have been gathered.

Thomas and Parry (1996) researched user views about stroke services, and concluded that user research does not necessarily equate to user empowerment. Although participants were asked about their views on hospital discharge and life at home, with survivors having been home for anything from four months to nine years, the focus was on a much broader picture than the immediate discharge experience.

### Longer term studies

The eight remaining studies all looked at stroke recovery from a longer term perspective: Kaufman (1988), Ellis-Hill et al (2000), Brazil et al (2000), Chest, Heart & Stroke Scotland (CHSS, 2001), Röding et al (2003), Smith et al (2004), Alaszewski et al (2004), and King and Semik (2006).

For example, although discharge from hospital had been some three to eleven months previously, the study by Smith et al (2004) mainly emphasised carer experiences one year after the stroke event. Brazil et al (2000) also concentrated on carer needs during their first year as carers. Both studies identified the difficulties carers face in obtaining information and assistance in the community.

Kaufman (1988) and Ellis-Hill et al (2000) similarly examined experiences up to one year post-stroke and post-discharge respectively. Kaufman (1988) suggested that some of the dilemmas facing patients and carers were responses to the medical model of care. Of the sixty four patients and fifty carers in the study, however, only two cases are reported upon in this paper, with no information on why these two participants were chosen, and virtually no reference to the other participants. This limited any wider conclusions that could be drawn from the details provided.

Ellis-Hill et al (2000) also discussed the emphasis on physical recovery, and argued, like Kaufman (1988), that practitioners should move beyond treating the physical body out of the context in which it is required to operate (i.e. home and the community). Although both studies acknowledged the importance of discharge home, the emphasis was again on longer term adaptation and responses, with little focus on the immediate situation being faced on return home.



Of the last four studies to be discussed, only King and Semik (2006) specified the length of time their participants (carers) had been in their new situation. In this study, although the first two to three months at home were identified as difficult, many changes in views and experiences can occur even during this period of time.

Both the studies by CHSS (2001) and Alaszewski et al (2004) likened the return home to a bereavement experience. However, although this emotional impact is acknowledged, it is only as part of the wider context of overall stroke recovery. The emotional repercussions of stroke were also referred to in the study by Rödning et al (2003: 867), who reported younger stroke survivors as feeling ‘frustrated and invisible’. Like the studies of Banks and Pearson (2003) and Bendz (2003), this study by Rödning et al (2003) only examined the experiences of younger patients, with all participants being under 55 years of age.

## **2.8 Discussion**

### **2.8.1 Age related issues**

Three of the twenty eight studies therefore researched the specific experiences of survivors under the age of 65 years. According to Benz (2003), however, only 20% of strokes occur in those below that age. Harwood et al (2005) also state that an even smaller number (10%) of strokes occur in those under 50 years of age. This places the younger patients in these studies in the minority. It is debatable whether the results from these studies can necessarily be considered relevant to all stroke survivors, or whether the issues identified are specific to the age groups involved.

To examine this further, of these three studies, Banks and Pearson (2003) argue that the particular needs of younger patients and their carers are often neglected, because service provision is geared towards the older majority. Bendz (2003) and Röding et al (2003) also discuss particular issues relating to employment and family responsibility that younger stroke survivors face. It cannot necessarily be assumed, however, that younger patients have greater issues than those in an older age bracket. For example, deHaan et al (1995) found quality of life to be negatively associated with older age in their stroke study. Faircloth et al (2004) also discuss the compounding effect that age and co-morbidity can have on difficulties post-stroke. Indeed, O’Kelly (2002) concludes that many difficulties post-stroke are shared between different age groups.

Stroke incidence increases with age (Hilton 2002), and as has already been noted, we live in an ageing society. With varying retirement ages and people becoming parents later in life, the issues that previously concerned stroke survivors under the age of 65, such as employment and family responsibilities, may not be limited to that age group. There is an argument, therefore, not to assume that age is necessarily a defining feature of stroke experience or recovery. This will be discussed further later in the thesis.

### 2.8.2 Timing and location

With regard to timing, it can be seen that as the period since discharge from hospital increases, the focus of studies tends to divert from the more specific to the wider on-going rehabilitation and adjustment process. That said, where interviews were carried out within one month of discharge, none had a specific focus of examining

the impact that arriving home had on the participants, or the meaning it held for them. Useful observations relating to this time were made, however, with Nilsson et al (1997:954) describing it as 'critical', and Rittman et al (2004:261) acknowledging the 'psychosocial transition' of returning home. Grant et al (2004:105) also identify the first month as 'dynamic and distressful' for carers.

Whilst all of the twenty eight studies made some reference to the time of discharge home, many did so from a retrospective, longitudinal standpoint, with participants having been home for some time when the studies were carried out. In the case of Thomas and Parry (1996), for example, one participant had been home for nine years. Although Banks and Pearson (2003) did use the Lifegrid Method (Blane, 1996) to assist with recollection, this tool is more useful for assisting memory in relation to a time frame, rather than the specific detail of events. There are still acknowledged difficulties where the recollection of emotionally laden episodes are concerned, with significant recall bias being a possibility, even if such tools are used (Moss and Goldstein, 1979).

As Blane (1996) discusses, emotional events are particularly likely to be remembered inaccurately. The closer to the occurrence that data is collected, therefore, the greater the likelihood of accuracy. Following discharge, it is the emotional state of patients, in particular, that Driscoll (2000) argues has not been well researched previously, regardless of diagnosis.

A literature review carried out by Hafsteinsdottir and Grypdonck (1997) stated that even by evaluating patients at set intervals along their stroke recovery, a thorough description of the recovery is missed. This view is shared by Kvigne and Kirkvoid

(2003:1308), who conclude that if their informants had been interviewed more frequently, then the process of change across time might have been identified in a more 'nuanced' way. It is as a result of considering this perspective that Hafsteinsdottir and Grypdonck (1997:581) argue that more in-depth accounts of the recovery process are 'badly needed'.

Although, as has been previously discussed, the point of discharge home is acknowledged as a crucial point in time, sixteen of the twenty eight studies examined failed to clarify how long the patients had been home. Most studies took as their point of reference the number of weeks post-stroke the patient was, rather than identifying the length of time since discharge. Given the wide range of times that stroke patients may be hospitalised for, this made it difficult to assess the extent that the impact of being home had on the findings in these studies. As Han and Haley (1999) argue, time intervals can be critical variables, with short-term coping strategies possibly being very different from those used in the longer term.

Of the studies specifically carried out during the first month, none took place in the UK. As has been previously discussed, the experiences of participants in other countries may bear little similarity to experiences in the UK, under the NHS system of care.

### 2.8.3 Communication ability and lesion location

With between 25% and 38% of stroke patients having some type of communication deficit (Gordon et al, 2009), inclusion of this group of people in stroke research would seem to be an important factor. However, it is worth noting that of the twenty eight studies examined, only one (CHSS, 2001) made a point of actively including

people with aphasia, seeking advice from a speech and language specialist in order to do so. The other studies either excluded participants with aphasia, or included only those with mild communication problems. Even in the CHSS study, particular details of the extent of communication difficulty that participants had are not given.

Kvigne et al (2002) argue that where verbal responses are difficult to interpret, body language may be much more clearly expressed, providing valuable supplementary information. Even if such strategies fail, carers may provide useful data on behalf of survivors, thereby giving them some form of 'voice' (McLean et al, 1991; Sneeuw et al, 1997; deHaan et al, 1995). However, as deHaan et al (1995) also caution, findings from carers may be difficult to evaluate as being truly representative of the views or experiences of patients.

With regard to stroke lesion location, communication difficulties are more often associated with left brain hemisphere damage (Harwood et al, 2005). However, as Brauer et al (2001) conclude, regardless of the type or extent of the lesion, stroke is considered to be a life transforming event by those it affects. Pilkington (1999) agrees that despite considerable diversity in the effects of a stroke, survivors can still experience shared meanings and patterns. Secrest and Thomas (1999) found common themes regardless of age, impairment or location of stroke lesion, and argue that nursing practice needs to focus on the individual, rather than being based on generalisations relating to lesion type, or location of stroke. It can therefore be concluded that although some studies examined here had such specific foci, this specificity does not necessarily add a great deal to inform nursing practice.

## 2.9 Summary

This literature review has identified that there has been little research specifically into the early post-discharge experiences of patients and their carers following a stroke, particularly in the UK. Most studies that have included these experiences did so some time afterwards, when recollection may not have been accurate, and other more recent concerns may have altered the focus. The literature reviewed suggests that although factors such as age or stroke lesion and location can have some impact on symptoms and recovery, they are not necessarily related to the experience and emotions resulting from a stroke. In addition to this, the need for research to include those patients whose stroke lesion has resulted in communication problems has been highlighted.

Recognition of the impact of stroke on caregivers has been demonstrated to be improving, especially in relation to longer term consequences. The importance of acknowledging the stroke patients' wider social circle and community networks, in conjunction with the main caregiver(s), has also been discussed.

It is clear, therefore, that these issues must be acknowledged alongside the continuing shift towards care in the community. Although some of the literature does discuss the significance of the early days following discharge home in general terms, in many of the studies post-discharge experiences are discussed as part of longitudinal studies, rather than being the specific focus of the study. The conclusion from this literature review is that it is necessary to investigate the phenomenon of early discharge experiences in greater depth, and as a specific focus in its own right. Following weeks or months in hospital, a stroke patient may be returning to their

home and family a very different person to their pre-stroke self. It is not clear what it feels like from the patient's or carer's perspective when the survivor returns to their own surroundings, or what sense those involved make of their altered situation.

Greater understanding of experiences during this important period may allow more informed preparation for going home, and assist follow-up services to operate with greater awareness. As Clark (2006:173) concludes 'the focus of stroke recovery still remains largely on the physical recovery, and the emotions or behaviours of persons with stroke receive little attention. Therefore, caregivers are not well prepared to respond to these changes when trying to manage at home'.

The importance of the individual in this process, whether they are a stroke survivor or a carer, has been highlighted by this literature review. Taking these issues into consideration, the next chapter will examine the best methodological approach to achieve the aim of the proposed study, which is to gain a greater understanding of such experiences during the first few weeks after discharge from hospital. The following chapter will therefore discuss methodological issues, and provide details of how the specific choice of approach was made from within the alternatives available.

## CHAPTER 3

### Choosing between research approaches

#### 3.1 Introduction

The literature review in the previous chapter highlighted the importance of gaining improved understanding of patient and carer experiences, particularly in situations that are potentially uncertain or stressful, such as the period following discharge from hospital. In order to improve support for people in such circumstances, healthcare workers need to first develop ways of accessing what is actually being experienced. Due to the nature of data being sought, which had an emphasis on experiential accounts, rather than statistical or standardised outcome measures, a qualitative approach seemed most appropriate.

Although many options are open to the qualitative researcher, it is still important that the proposed method is well matched to the overall aims of the research project (Barbour, 2008). Bearing this in mind, phenomenology, with its emphasis on experiential understandings, seemed to provide a good ‘fit’ in terms of what the developing research proposal was hoping to achieve. Other approaches, such as ethnography (with its emphasis on field work, and the understanding of cultural worlds and activities) or grounded theory (with its emphasis on theory generation from data, and social processes) did not have the necessary focus on experiential understandings from the perspective of the individual that the research sought to attain.



This chapter will explore the concept of phenomenology, concentrating initially on the dilemmas and challenges faced in the search for an appropriate approach from the choices available within phenomenology. The specific approach of interpretative phenomenological analysis (IPA) will then be further considered and critiqued.

Two articles from these discussions have been published (Pringle et al, 2011a; Pringle et al, 2011b).

### **3.2 Phenomenology as a research approach**

Phenomenology is an ‘umbrella term’ used to describe both a philosophical movement and a range of research approaches (Finlay and Ballinger, 2006:261).

Understanding human experiences is the basis of a phenomenological approach to research, a concept introduced by the German philosopher Husserl in the early 1900s (Jones, 2001). Husserl’s stance, which was essentially ‘a rigorous descriptive science of consciousness’ (Baker et al, 1992:1356), was further developed into a more interpretive form by Heidegger (Koch, 1999; Smith et al, 2009). Heidegger considered that Husserl’s approach to ‘knowing’ from a scientific standpoint should be replaced by ‘understanding’ (Fleming et al, 2003:115). Fleming et al (2003:114) also argue that within Heidegger’s interpretation of ‘Dasein’ (or ‘being there’), broader concepts relating to one’s being, belonging, and relational attitudes to others are not always fully appreciated by nurse researchers.

Although the concept of experience is in itself complex, it is normally when an experience takes on a particular significance, or when something important has happened in a person’s life, that the experience becomes the topic of research (Smith et al, 2009). McGee (2001:289) refers to ‘aporia’ as ‘being stopped’ in life by

something that puzzles, and requires reassessment and re-evaluation of previous assumptions. The word 'aporia' stems from the Greek 'a poros', meaning 'without passage'. According to McGee (2001) such moments can inspire, and lead to broadening perspectives, especially when the experiences become the focus of research. Such a questioning examination of views and experiences is an important part of reflexivity, as will be discussed later in the thesis.

Phenomenology stems from the Greek word 'to bring into the light', but according to Fleming et al (2003) the present definition encourages an approach which looks beyond initial and obvious appearances. Jones (2001:65) describes this as allowing a researcher 'to go beyond factual accounts to look at common life experiences'. As McNamara (2005:697) argues, our natural attitude 'conceals the extraordinary in the ordinary; the strange in the commonplace; the hidden in the obvious'.

Alvesson and Sköldbberg (2000:36) discuss the fact that phenomenologists are critical of natural science for having distanced itself too far from everyday life, without having 'sufficiently analyzed the foundations of ordinary human experience upon which it rests'. Indeed, Snape and Spencer (2003:12) consider the aim of phenomenology to be understanding the 'constructs' people use in everyday life to make sense of their world.

In recent years phenomenology has become an increasingly recognised approach for investigating experiences in health related research (Sadala and Adorno, 2002; Mackey, 2004). However, as a research philosophy it is not without problems, due to

differing methods of interpretation (Mackey, 2004). As Koch (1999) and Dowling (2004) discuss, even the definitions and terminology can sometimes be unclear and confusing. In addition to this, Lawler (1998:105) claims that many nurse researchers have failed in the past to report 'the means by which the gap between philosophically related theory and research practice is resolved'.

While there is a tendency on behalf of some researchers to increase the legitimacy of their work by 'publicly avowing its theoretical location' (Filmer et al, 2004:34), Seale (1999) suggests that engaging too intensely in methodological awareness can hinder the practice and progress of a research project. Barthes (1986:318) asserts that 'there is no surer way to kill a piece of research and to send it to join the great scrap heap of abandoned projects than method'. A balance must therefore be struck, that not only allows philosophical approach and method choices to be clearly articulated, but that also supports the project to proceed with a reasonable degree of direction. As Lopez and Willis (2004:726) argue, implementing a method without examining philosophical backgrounds can result in ambiguity in 'purpose, structure, and findings'.

Variations and arguments surrounding the use of phenomenology in research are well documented (Hallet, 1995; Giorgi, 2000; Jones, 2001; Fleming et al, 2003; Mackey, 2004; McNamara, 2005). Hallet (1995: 58) suggests that the term 'method' is applied incorrectly to phenomenology, arguing that the approach used 'is as much dependent on the way in which the researcher's mind deals with the data, as in the way in which the data were collected'.

One only has to read Giorgi's criticism of Crotty (Giorgi, 2000) to gain a sense of the differences of opinion that surround the subject of phenomenology. Giorgi himself acknowledges these difficulties, and suggests that confusions can exist because researchers fail to clarify the type of approach they are using (Giorgi, 2000).

Giorgi (2000) stresses the importance of differentiating between philosophical and scientific phenomenology. He considers philosophical phenomenology as involving reflections on one's own experience, and scientific phenomenology as describing a more general essence, based on the experience of others. However, Caelli (2001) and Dowling (2007) consider that both philosophical and scientific approaches are relevant to nursing research and practice, and that it would be difficult to make a distinction between the two.

Norlyk and Harder (2010:420) discuss phenomenology as a philosophy rather than a scientific research method, and suggest that adopting the approach as a framework for nursing research is 'challenging'. Similarly, other guidelines appear to offer researchers conflicting advice: for example, while Webb (2003) suggests that phenomenology is not compatible with the validation of interpretation by participants, Ploeg (1999) asserts that this is a frequently used strategy. Potential researchers could be left wondering how to proceed with their research proposal with regard to this.

Hallet (1995) questions attempts to simplify phenomenology by presenting it as a step-by-step method. However, this is certainly the way in which many researchers appear to operate. Giorgi himself (Giorgi, 2000) seems to simultaneously suggest

and criticise such steps, but does give further guidance emphasising the importance of reduction and imaginative variation in the search for the essence of meaning, rather than a reliance on the more rigid steps he initially appears to be suggesting (Giorgi, 1985).

As Giorgi (2000) explains, the more complex and less schematic elements of his approach, such as reduction, imaginative variation, the search for essence, and the role of description, are ignored by authors such as Crotty (1996). Indeed, this next level of analysis appears to be missing from other studies claiming to be following Giorgi's method (Theobald, 1997; Friedrichsen and Erichsen, 2004). Although Rochette et al (2006) do give greater detail about how these issues are addressed in their study, they still do not make claim to be achieving a purist approach, the attainment of which (given the complexity of the elements involved) must be difficult to prove, verify, or indeed accomplish, in studies which appear to be claiming to use a true phenomenological approach.

Given the arguments and criticisms that exist, it may be realistic to consider that many studies are in fact following the example of Rochette et al (2006:247) by using a 'phenomenological orientation' without being explicit about it. As previously stated, although they may be 'publicly avowing' phenomenology as the theoretical location (Filmer et al, 2004:34), Giorgi (2000:11) considers that closer scrutiny may reveal more 'naïve applications'. Rochette et al (2006) seek to avoid such criticism by not claiming to be purist in their approach. However, by still detailing the rigorous method used, they do not totally avoid the issue of clarity either - whether this is still a naïve application is debatable.

According to Baker et al (1992), Husserl considered there to be four fundamental concepts involved in phenomenological research:

- Intentionality: this involves an intentional focus on, and consciousness of, the subject/experience of interest
- Description: involves a rich description of the experienced phenomenon
- Reduction: firstly involves the setting aside, or 'bracketing', of preconceptions; the second process involves looking at the phenomenon imaginatively, to identify characteristic attributes
- Essence: through the above processes, the essence of the phenomenon becomes apparent

Variations and arguments surrounding these concepts will be discussed further below.

### **3.3 Description or interpretation?**

Jones (2001:65) considers that in its 'purest form' phenomenology is not interpretive. Webb (2003), however, appears to suggest that only certain types of phenomenology are interpretive, while van Manen (1997) considers that all phenomenological descriptions have an interpretive element. This raises the question of whether it is possible to describe something without interpreting it. Indeed, Paley (1998) asserts that as human beings we are, by our nature, naturally self-interpreting.

Van der Zalm and Bergum (2000) describe hermeneutic-phenomenology as having both descriptive and interpretive elements. According to Bäckstöm and Sundin (2007), while phenomenology uncovers meanings, hermeneutics interprets the meaning. To a certain extent, therefore, studies which are interpreting results must be using a degree of hermeneutics.

According to van Manen (1997:179) hermeneutics is the ‘theory and practice of interpretation’. The word itself is derived from the Greek god, Hermes, who had the task of communicating messages from the Gods to mortals, in a comprehensible form. In further relation to this, hermeneutics began as a theory to assist with the interpretation of biblical texts (Smith, 2007). As Smith (2007) also explains, the use of hermeneutics has expanded from this original intent, firstly into the reading of historical, legal and artistic literature, and more recently into human sciences.

However, in similarity to phenomenology, there have been arguments over the nature of the hermeneutic process (Smith, 2007). Smith (2007) discusses the fact that Schleiermacher’s views on understanding were contested by Gadamer (2004), in relation to their differing views on the interpretation of meanings and intent within texts. Smith et al (2009:37) also debate the issues involved, and in particular the view of Gadamer that ‘when reading a text we are trying to make sense of the text rather than the author’. Smith (2007) is in agreement with Schleiermacher (cited in Smith, 2007) that analysis should be an holistic approach that tries to make sense of the words used, and the person who has uttered them. This view would certainly seem to be more congruent with nurses’ need and desire to better understand their patients.

Similar discussions exist in relation to the work of Heidegger (Paley, 1998).

Although an interpretive approach is commonly associated with Heidegger, Paley (1998) asserts that hermeneutic studies are incompatible with Heidegger's approach to what can be known about the nature of the social world.

Such historical arguments further serve to complicate attempts at seeking clarity, and do little to help the nurse researcher either make sense of the situation, or apply hermeneutics and phenomenology with confidence to qualitative studies. Sadala and Adorno (2002: 282) agree, being of the opinion that in the past phenomenologists have 'neither defined or clearly described a research method'. Other researchers, such as Jasper (1994:309), claim to limit a description of their approach for the sake of 'clarity'. However, this in itself may be an admission that descriptions of the approach can either over-complicate or over-simplify its use.

Dowling (2004:30) comments on the fact that the terms 'hermeneutics' and 'phenomenology' are often wrongly used interchangeably. However, both she and Koch (1999) observe that there are many different types of terminology used to describe both, further adding to potential confusion. As Smith et al (2009:37) argue 'without the phenomenology, there would be nothing to interpret; without the hermeneutics, the phenomenon would not be seen'. It would therefore seem that there is an inter-dependency between the two that perhaps needs greater acknowledgement, and a differentiation between the use of phenomenology as an approach to discovering meanings, and the use of hermeneutics to interpret the meanings that are uncovered. As Sundin and Jansson (2003:108) conclude, there is a 'mutual belonging' between phenomenology and hermeneutics. Lopez and Willis



(2004:731) also consider hermeneutic enquiry to be 'emancipatory' due to the possibility of viewing reality in a more illuminating way. However, Smith (2007:11) concludes that hermeneutic theory still does not uncover all the mystery of interpretation, and that 'when one person tries to make sense of what another person is saying, I would suggest there is still a great deal that remains unknown'.

In practical terms, Norlyk and Harder (2010) consider that advice on how to apply a phenomenological approach, whether descriptive or interpretative, is not easy to come by, especially as many published authors appear to be unclear about the approach themselves. Koch (1999: 31) offers an explanatory summary of approaches, and useful advice for nurse researchers in this respect, cautioning that phenomenological readings are best approached 'under the guidance of a mentor or within a specific study program'.

### **3.4 Bracketing**

In a similar manner to the above arguments, the extent to which setting aside preconceived ideas or understandings is possible or necessary, also generates much discussion. Researchers such as Giorgi (1985), following Husserl's philosophy, suggest the need to put aside or 'bracket' past knowledge or experience. Other researchers question whether this is possible (Paley, 1998; Wimpenny and Gass, 2000; Finlay, 2008), acknowledging instead that close involvement is expected as part of the research process.

Fleming et al (2003: 115) describe the aim of bracketing as being 'for researchers to put aside their preconceptions of the phenomena being studied so they do not distort

it'. Although Theobald (1997) agrees about this need, she also acknowledges Crotty's (1996) view that this can be very difficult to achieve.

Alvesson and Sköldbberg (2000:36) discuss bracketing in terms of the real world being 'cut off' and refer to this as the first stage in 'phenomenological reduction'. They argue that rather than subjective or objective views, there is another alternative: 'the lived'. They go on to describe the second stage as being to reach the 'essence' – something common to a whole group of phenomena, while not being detached from the original experience. The third step involves investigating how these essences are constructed and linked.

Certainly, how these issues are dealt with in practical terms is not very often made explicit in individual studies. Indeed, Hallet (1995) argues that bracketing is a process of reasoning within the mind of the researcher, rather than a paper or computer exercise. However, it could also be argued that all research requires the setting aside of preconceptions to avoid the pit-fall of trying to fit findings into researcher expectations. Rose et al (1995: 1126) describe how pre-conceived ideas can influence and alter research analysis in this way, and suggest that when made explicit, bracketing can assist against 'compromising the rigor of research in respect of its credibility'.

While Dowling (2004) considers bracketing to be an effort to maintain objectivity, it is subjective experiences that phenomenology is trying to capture (Van der Zalm and Bergum, 2000). The important distinction to be made here is that while phenomenology may be describing or interpreting subjective accounts, the researcher can remain 'objective' by either bracketing preconceptions or acknowledging them as part of the research process. According to Fleming et al (2003), objectivity in

hermeneutic research can be achieved by faithful representation of texts, although even this may be partial, as readers may reach their own, differing, interpretations.

Jasper (1994) emphasises that conclusions reached from research should arise from the data, and not from concepts imposed by the researcher. However, Jasper's (1994) paper is criticised by Walters (1995) for failing to distinguish between differing phenomenological approaches. Likewise, while Jasper's notions of validity relate to the possibility of an objective truth (Husserlian tradition), Walters (1995) argues that this does not acknowledge the differing stance of Heideggerian approaches, where an interpretation is not considered an absolute or objective truth. In interpretative approaches, the reader should be able to judge the 'correctness' of the interpretation, according to Walters (1995:797), from the information provided by the researcher. In this respect, it should be made clear how conclusions are reached, for example by including text from the data in the findings. Further issues relating to rigour will be discussed later in this chapter.

### **3.5 Insider-outsider perspectives**

The extent to which objectivity is possible, when researchers are studying in fields close to their area of practice, similarly generates much discussion. Jasper (1994) discusses subjectivity as one of the key differences between phenomenology and other research approaches. Kanuha (2000), while acknowledging this, considers a critical analysis of the researcher's prejudices as necessary, especially with groups one identifies with.

The value of researching within a group one has knowledge of, or belongs to, as an 'insider' has frequently been contrasted to the benefits of stranger or 'outsider' research (Wilde, 1992; Hanson, 1994; Kanuha, 2000). Kanuha (2000: 443) questions whether an insider researcher's knowledge enables or obscures the research process, describing such knowledge as 'both an asset and a liability'. Asselin (2003) discusses the fact that prior knowledge may result in important pieces of information being overlooked, because both the researcher and the researched can assume they share a common understanding of what is meant (possibly mistakenly) without it being made explicit.

Borbasi et al (2005:499) also discusses the 'duality' that might exist for a nurse entering the research field in an area he or she is already familiar with. On the one hand, possible preconceptions have to be considered and acknowledged, while on the other, there is the benefit of a shared understanding of 'health, illness and body' (Borbasi et al, 2005:498) between the nurse and participant. Asselin (2003) suggests several strategies to overcome these difficulties, including continuing self-reflection, outsider verification and member-checking. As discussed earlier, there are differing opinions as to the appropriateness of the latter.

In this respect, the researcher in this proposed study would arguably fit into neither insider nor outsider category: by being unknown to the participants in any other capacity prior to the research taking place, nor having had a stroke herself, she does not fulfil Kanuha's (2000) definition of an insider. However, the wider understanding the researcher has from her role as a community stroke specialist, although potentially helpful in terms of empathy and knowledge, may also limit her ability to be totally without preconceptions, and thereby not fully an 'outsider' either.

In addition to this, is the knowledge gained through the literature search, which had the potential to influence what was subsequently 'heard' in the research findings.

As Norlyk and Harder (2010:427) discuss, arguments exist about whether reviewing the literature should wait until after the analysis, or whether it is 'impossible to perform phenomenological study without knowing something about the phenomenon' first. Finlay (2009:11) argues that it is the 'intersubjective interconnectedness' between the researcher and participants that characterises phenomenology, and allows deeper understandings to emerge that go beyond previous knowledge.

In order to address some of these issues in this current research project, it was therefore considered important that reflective notes be kept by the researcher to record any such related thoughts and ideas. Regular discussions with the research supervisory team formed another part of the overall analysis process. As Thomas et al (2000) discuss, having people such as supervisors, who are outside or not closely connected with the immediate research subject or environment, can help to broaden perspectives and potential interpretations. However, whilst there may be many different interpretations, the principal investigator must decide on which to highlight and give main emphasis to, acknowledging that supervisory perspectives are also not without bias (Lowe and Prowse, 2001).

### **3.6 Reflexivity**

The value of reflexivity throughout the whole research process is discussed by Mauthner and Doucet (2003). However, they caution that it may not always be possible for researchers to be conscious of their own biases. As Larkin et al

(2006:109) argue ‘what is objective and what is subjective cannot be teased apart in any simple fashion’. Using reflexivity can therefore assist, but cannot completely ensure that preconceptions are avoided.

Finlay (2008:21) relates the ability to being open to hearing experiences in a new way to Husserl’s stages of reduction, where bracketing of pre-knowledge or preconceptions is ‘followed by a process of examining the phenomenon in a fresh way that enables new understandings to emerge’. However, Finlay (2008) also suggests that such understanding is founded in the previous knowledge of professionals and, in keeping with the stances of Heidegger and Gadamer, this cannot be fully bracketed out, and needs to be acknowledged. She describes this as the tension between ‘striving for reductive focus and reflective self-awareness; between bracketing pre-understandings and exploiting them as a source of insight’ (Finlay, 2008:1). It would therefore seem that by using reflexive skill it is possible to combine these seemingly opposing phenomenological concepts. However, Giorgi and Giorgi (2003:28) caution that while phenomenology allows a better understanding than one would have ‘spontaneously in everyday life’ the process itself should not ‘transform the original situation beyond recognition’. This also highlights the importance of the process of continually relating findings back to the original transcripts (Smith et al, 2009), as will be demonstrated and discussed later in the thesis.

### **3.7 Discussion**

There are therefore many dilemmas, and potential for confusion, facing researchers drawn to phenomenology as a research approach. This may result in what Wimpenny

and Gass (2000:1491) refer to as ‘muddling, slurring and blurring’ due to a lack of clarity, perhaps based on misunderstandings about the approach. Baker et al (1992:1355) also stress the importance of ‘specificity in methodology’ to avoid this blurring of distinctions.

Caelli (2001) discusses the double difficulty of not only finding information on how to utilise a phenomenological approach in practical terms, but also the challenges of understanding the philosophical underpinnings of such research. In its favour, however, Jasper (1994) considers that phenomenology provides nurses with an approach which focuses on the experiences of patients, thereby identifying needs, which can in turn be used to plan and justify care. Rose et al (1995, p1128) also consider that phenomenology has ‘theory-generating’ power through identification of concepts, which allows applicability of the knowledge generated to nursing practice. However, ambiguities in the guidelines, and the academic arguments about how to apply phenomenology in an appropriate way, do little to recommend the approach. Perhaps the time has come to put aside historical differences of opinion and move towards an approach which offers greater ease of use to modern researchers, whilst still retaining and acknowledging some of the philosophical roots. As Rose et al (1995:1128) state ‘phenomenology clearly has the potential to generate knowledge for practice from practice’ and it would be a pity if potential researchers were deterred from its use by the complexity of its historical past.

Seale (1999:18) cautions that while researchers should not abandon attempts to find a ‘strong authorial presence’, valuable lessons can be learnt from a variety of schools. Barbour (2008: 25) is of a similar opinion, stating that ‘there is nothing shameful about developing hybrid approaches’. That said, for purposes of clarity and

robustness, some clear indication of approaches and methods must be given (Koch, 2006).

As previously discussed, several authors have suggested that phenomenological writings lack sufficient advice or information about the practical application of the approach (Taylor, 1995; Lawler, 1998; Caelli, 2001; Sadala and Adorno, 2002).

However, in more recent years detailed guidelines have been improving (Smith et al, 2009). Taking all these elements and arguments into consideration, the researcher therefore proposed to follow the path of Smith (2004) and Smith et al (2009), and use the approach of interpretative phenomenological analysis (IPA), which will be discussed next.

### **3.8 Interpretative phenomenological analysis**

IPA is a research approach which has been developing over the last 15 years, having its roots in psychology, and recognising ‘the central role for the analyst in making sense of that personal experience’ (Smith, 2004:40).

The approach is described in Finlay and Ballinger (2006:260) in the following way:

*‘This variant of phenomenology aims to explore individuals’ perceptions and experiences. Taking an idiographic approach, the focus is on individuals’ cognitive, linguistic, affective and physical being. IPA involves a two-stage interpretation process as the researcher tries to make sense of participants’ sense making’.*

Smith (2004:40) refers to this as a ‘double hermeneutic’, given the two-fold sense-making process. As discussed earlier, IPA combines both descriptive and interpretive



elements of phenomenology, which can enable ‘inter-subjective understanding’ to develop (Standing, 2009:30). In a sense, IPA therefore allows for many of the differing phenomenological stances to be incorporated together with hermeneutics, in one approach.

With further regard to the description-interpretation debate, talk of themes ‘emerging’ or ‘being discovered’ in more descriptive accounts may be considered solely to ‘bear witness’ to experiences (Barbour, 2008:15). However, in doing so, this could be seen to deny the active role the researcher can play in the analytical process (Braun and Clarke, 2006). It could be argued that without this active involvement in the analysis, accounts may not more fully uncover or ‘bring into the light’ the meanings phenomenology is seeking to achieve (Pringle et al, 2011a:8).

IPA, when considered in relation to other forms of phenomenology, tends to adopt an interpretation of belief and acceptance of participant’s stories, albeit in a questioning way. This is again different from the ‘interpretation of suspicion’ (Smith et al, 2009:201) or critical analysis advocated by Langdrige (2007), who was influenced by the phenomenological writings of the French philosopher Ricoeur. However, although interpretation and increased understanding are important in IPA, and a degree of ‘questioning’ (Smith et al, 2009:36) is considered beneficial to depth of analysis, IPA does not follow the critical interpretive framework discussed by Koch (1999). Implications stemming from IPA therefore need to be firmly rooted in what the participants are actually saying, with direct quotes being used widely to substantiate findings.

According to Hammond (2010:378), IPA draws from the school of ‘philosophical hermeneutics’, which differs from earlier forms of hermeneutics by recognising researcher subjectivity, and acknowledgement of the interpretation as one of many possible versions. IPA therefore draws together human experiences and human meaning.

### 3.9 The hermeneutic circle

The hermeneutic circle involves ensuring that the parts are related to the whole, and the whole to the parts. According to Smith (2007), this involves a dynamic relationship between the parts, with neither part nor whole being fully understood in isolation. Figure 11 below illustrates this relationship.

<b>The part</b>	<b>The whole</b>
The single word	The sentence in which the word is embedded
The single extract	The complete text
The particular text	The complete oeuvre
The single episode	The complete life

**Figure 11: The hermeneutic circle** (Smith, 2007:5)

Fleming et al (2003) consider that unless detailed discussion takes place between the researcher and the researched, the hermeneutic circle will not be fully experienced.

According to Smith (2007:6) this requires not only ‘an intense attentiveness to and

engagement with the participant as he/she speaks' but also an awareness of one's own preconceptions.

Hammond (2010) is critical of Smith et al (2009) for not making further elements of the hermeneutic circle, such as the dialogue between researcher and participant, more explicit. However, the questioning and probing elements of an IPA interview, as advocated by Smith et al (2009), should ensure that a co-construction occurs, rather than (as Hammond claims) accounts merely being of participants' making. The careful balance that is required between not leading or influencing the interview process to too great an extent (Baker et al, 1992; Hilton, 2002; Smith et al, 2009), while still gaining greater insight through questioning and probing, is perhaps one of the more challenging skills required by the IPA researcher.

### **3.10 IPA and contribution to theory**

The idiographic or individual nature of the analysis in IPA studies is something which is highlighted by Smith et al (2009). Malim et al (1992:74) consider such idiographic research as addressing 'the wholeness and uniqueness of the individual' aiming to give a complete and in-depth picture. However, this could also be seen as a weakness of the approach: as Malim et al (1992:74) point out, generalisations are largely not feasible, and idiographic studies could be considered to be 'subjective, intuitive and impressionistic'. This, in turn, can make it difficult to establish which variables are important, especially given the small numbers advocated for most IPA studies (Smith et al, 2009).

However, although broad generalisations may not be possible, Reid et al (2005:23) consider that commonalities across accounts and 'analytic commentary' may well

lead to useful insights which have wider implications. Caldwell (2008:1) argues that whilst ‘Theory’ with a capital ‘T’ is not the purpose or remit of IPA studies, findings can nevertheless influence and contribute to theory in a broader ‘lower case’ sense. As Caldwell (2008:2) discusses, the ‘theoretical dialogue’ resulting from IPA studies can contextualise the contribution the research is making to the wider literature, thereby arguably making a contribution to ‘Theory’ seem more valid than perhaps some quantitative researchers, for example, would possibly acknowledge. Therefore, by gaining insight into the individual situation, insight into the whole may also be achieved. In this respect, Smith et al (2009:51) advise IPA researchers to think in terms of ‘theoretical transferability rather than empirical generalizability’.

As Biggerstaff and Thompson (2008) discuss, once healthcare professionals become aware of the potential of qualitative approaches like IPA, they can then value the real contribution that such research makes to understanding illness and healthcare interventions from the patient perspective. Jasper (1994:313) also suggests that findings from phenomenological studies can be used to guide further research from an ‘informed starting point’.

Although IPA seeks to understand personal experiences rather than social processes (Brocki and Wearden, 2006), there is still acknowledgment that ‘meanings are constructed by individuals within both a social and personal world’ (Smith and Osborn, 2003:52). This is presumably why Smith et al (2009) discuss the links that IPA has with social constructionism.

### **3.11 Methodological issues**

Smith et al (2009) stress the non-prescriptive, adaptable nature of IPA. Whilst this may seem alien to researchers of a more positivist persuasion, as has already been discussed, Giorgi (2000) is openly critical of trying to represent phenomenological research methods as a fixed set of prescribed stages. Having said that, Smith et al (2009:81), while describing the approach of IPA in a series of ‘steps’, also continually acknowledge that such guidelines are only just that, and are open to adaptation in the given research situation, and in particular to more experienced IPA researchers. It is the very complexity of such openness which may baffle those used to operating in the more rigid world of scientific experimentation and randomised controlled trials.

Both Giorgi and Giorgi (2008) and Smith et al (2009: 200) seek to ‘operationalize’ phenomenology, moving it from its philosophical roots through to a more user-friendly approach. Nevertheless, Smith et al (2009) do also emphasise the need for researchers to appreciate and acknowledge the philosophical background in order to fully understand the subtleties of the method.

In contrast to Giorgi’s descriptive approach (Giorgi, 1985), IPA stresses the interpretative and hermeneutic elements, seeking to capture examples of convergence and divergence, rather than having a focus solely on commonalities, which Giorgi’s approach foregrounds (Smith et al, 2009). Similarly, as Finlay (2009:9) discusses, whilst descriptive approaches to phenomenological analysis, like Giorgi’s, may mean that ‘idiographic details are thus discarded or typified and

generalised', IPA takes a different approach, with individual accounts being accentuated.

In further relation to bracketing, Smith et al (2009:100) consider that 'the rigour of systematically following the steps outlined should ensure that there is scope for this to happen', while still acknowledging that previous researcher experience will be part of the interpretative analysis. Again, although authors such as Giorgi (2000) would argue against a rigorous set of steps, Smith et al (2009) advocate a clear, auditable, systematic process, rather than a rigid, prescriptive one.

Having such 'practical and accessible guidelines' (Smith, 2004:40), is one of the strengths of IPA, especially when considering the previously mentioned dilemmas and arguments that exist around the application of phenomenology as a research approach. Taking this approach also answers criticisms regarding the lack of advice about technical aspects of conducting a phenomenological study (Caelli, 2001). As Larkin et al (2006: 102) state, IPA offers more than a 'simply descriptive' methodology, and through 'bypassing the closed systems of borrowed hypotheses and theories, it can instead provide meaningful and unexpected analysis of psychosocial issues' (Reid et al, 2005:23). It was for these reasons that the approach was considered appropriate and well-suited for the proposed project.

### **3.12 Sample and data considerations**

As has already been discussed, IPA accounts do privilege the individual and therefore tend to use smaller sample sizes. As such, the approach offers a different

perspective from approaches such as grounded theory, which frequently uses larger sample numbers to substantiate theory (Barbour, 2008). However, although Giorgi (2008:37) argues that variations in accounts are needed in order to identify a 'typical essence' of the experience, he also considers that this can be achieved with as few as three participants.

Whilst smaller sample sizes might be seen as a limitation of IPA studies, Smith et al (2009) consider that reduced participant numbers allows for a richer depth of analysis, which might be inhibited with a larger sample. Again, a deeper and more interpretative analysis might be considered to be drawing the analyst away from the original meanings, and indeed Smith et al (2009:186) encourage researchers to 'go beyond' immediately apparent content. However, as already discussed, the approach of IPA seeks to illustrate and inform themes and master themes, and thereby firmly anchor findings in direct quotes from participant accounts (Smith et al, 2009).

Quotes and metaphors used by participants can also be used in theme titles or descriptions, to further root the analysis directly in their words. In this respect, IPA aims to go beyond a 'standard thematic analysis' (Brocki and Wearden, 2006:89).

Although Braun and Clarke (2006: 78) argue that thematic analysis is 'a method in its own right', which provides core skills for other forms of qualitative analysis, they also consider methods such as IPA to be constrained by their theoretical roots.

However, it could be argued that theoretical roots add a sense of depth and purpose which thematic analysis lacks. Smith (2004:42) cites Warnock (1987) as emphasising that 'delving deeper into the particular also takes us closer to the universal'.

With further regard to the study participants, Smith et al (2009:49) advise researchers to find a 'fairly homogenous sample'. However, they also conclude that the effectiveness of an IPA study is judged by the light it sheds in a broader context (Smith et al, 2009). This might seem difficult to achieve if the sample group is too specific or unique. To overcome this, Smith et al (2009) suggest that if the research account is rich and transparent enough, and sufficiently related to current literature, the reader should be able to assess and evaluate transferability themselves. This further emphasises the skill required when the account is written up and contextualised, but might also suggest that too narrow and homogenous a sample could make transferability judgements and links more difficult. This would seem to be an inevitable tension within IPA studies, which can be overcome if limitations relating to participants are acknowledged and clarified by researchers.

To consider potential limitations further, Brocki and Wearden (2006) discuss the merits and drawbacks of various data collection methods across a range of IPA studies. The studies examined by Brocki and Wearden (2006) used interviews, written narrative accounts, diaries, e-mail discussions and focus groups. Brocki and Wearden (2006) conclude that IPA offers sufficient flexibility to allow such diversity of data collection methods; however, they also argue that limitations are not always reported in sufficient detail, and caution researchers to acknowledge and discuss the advantages and drawbacks of their chosen collection methods.



Willig (2008:69) asserts that IPA allows ‘more room for creativity and freedom’ than other approaches, which may be of particular importance when less usual groups, situations, or means of data collection, are being contemplated. This might be of particular relevance in healthcare research, if the views of difficult to reach groups are being sought, or where beliefs and expectations may be ‘outside the perceptual field’ of health professionals (Biggerstaff and Thompson, 2008:216). As Reid et al (2005) also discuss, IPA has been used to explore experiences even in situations where lucidity is compromised due to mental health conditions. This further illustrates the scope and adaptability of the approach.

### **3.13 Data collection**

Smith and Osborn (2003:5) discuss semi-structured interviews as the ‘exemplary’ data collection method in IPA studies. However, interview formats have also been referred to as ‘in-depth’ (Smith et al, 2009:57), ‘loosely structured’ (Smith, 2007:10), and ‘unstructured’ (Brocki and Wearden, 2006:91). It would therefore seem that the degree of structure may be dependent on such variables as the topic, ability of the participants, and overall study setting. For example, slightly greater structure may be required where the topic is sensitive, and not one the participants would normally discuss in everyday conversation. That said, Smith et al (2009) do advise that too much structure may inhibit spontaneity and freedom of expression. As Smith and Osborn (2003) argue, the advantage over more structured formats is that a more detailed engagement with the experience can be explored and shared during the interview with such a degree of flexibility. Although other means of data collection (e.g. focus groups or diaries) may be used, the in-depth interview remains the most frequently chosen method (Brocki and Wearden, 2006).

### **3.14 Analytical process**

Thorne (2000) describes data analysis as the most complex part of qualitative research, requiring inductive reasoning processes to uncover meaning from the data.

In a similar way to other phenomenological studies (Nilsson et al, 1997; Burton, 2000; Rochette et al, 2006) interview transcripts in IPA are transcribed verbatim.

These transcripts are then read, and tapes listened to again, to grasp the global content and gain what Burton (2000:304) refers to as an initial 'naïve interpretation'.

Following on from this, the analyst will make notes and form ideas relating to potential themes. From these beginnings, the more complex analytical elements can then be drawn out. As Braun and Clarke (2006:91) conclude, it is necessary to 'capture the contours' of the data within the themes, and this process will be discussed more fully later in the thesis.

In further relation to the process of analysis, earlier IPA discussions suggest that themes may be carried forward from the first participant account to be built on, or added to, with subsequent accounts (Smith et al, 1999). However, later discussion by Smith et al (2009:100) gives greater emphasis to the need to approach each case 'on its own terms, to do justice to its own individuality', whilst also acknowledging the difficulty of bracketing the ideas that may have emerged from earlier transcripts. This perhaps shows the evolving nature of the approach, with earlier ideas being superseded by enhanced and developing guidance.

### **3.15 Rigour**

According to Maggs-Rapport (2001) research studies need to display the standards of best practice with which they have been carried out in order to meet the requirements of critical appraisal. Not doing so can result in criticisms in relation to rigour (Seale, 2004). However, whilst criteria for judging rigour in quantitative research are well established, the same cannot be said for qualitative enquiry (Yardley, 2000). Yardley argues that this is compounded by the diversity of method within qualitative research, and that the ethos behind many qualitative methodologies is incompatible with the rigid procedures and standards used to judge quantitative research; it is therefore necessary to avoid the mistake of evaluating qualitative research according to the standards that might be used for quantitative studies (Elliott et al, 1999; Sandelowski, 2006).

With further regard to this, Barbour (2001) cautions against using a checklist approach to demonstrate the rigour and credibility of qualitative studies, without more critical awareness of the rationale behind such strategies, and acknowledgement that one approach may not suit all methods. Thought therefore needs to be given to how this can be practically achieved, without either resorting to 'technical fixes' (Barbour, 2001:1115), or compromising the creativity Seale (2004) argues is necessary for good quality qualitative research.

With regard to selecting a means of ensuring or assessing rigour, Norlyk and Harder (2010) argue that even within phenomenological studies, assessment of rigour needs to be matched to the specific approach being used. For example, according to Walters (1995) traditional evaluations of validity are based on the scientific concept of objective truth. While such notions may fit with Husserlian phenomenological

approaches, they are not consistent with interpretative approaches, where no such objective truth is sought or considered appropriate.

Yardley (2000:219) proposes that broad principles for evaluating quality in qualitative research should include an assessment of sensitivity to context, and details regarding the commitment and rigour with which a study has been carried out. She also stresses the importance of transparency and coherence in the writing up process, which should include indicators as to the impact and relevance that the findings may have to other fields or areas.

Smith et al (2009) detail ways in which such criteria can be fulfilled in IPA studies, and also discuss how being open to external audit can enhance rigour. This is similar to the 'decision trail' advocated by Koch (2006:91) and, as Smith et al (2009) discuss, is an important aspect of validity. In addition to these measures, Koch & Harrington (1998:882) assert that reflexive accounts play a vital part in displaying whether the findings are 'believable or plausible'.

From the above discussions, it is clear that adequate detail regarding the way a study has been carried out must be given to facilitate assessments of rigour. The use of IPA as an approach to phenomenological research is supported by many accounts (e.g. Flowers et al, 1997; Smith and Osborn, 2003; Hunt and Smith, 2004; Dean et al, 2006) which give the clarity and depth of analytical detail that other phenomenological studies have been criticised for omitting. These accounts fulfil the need for rigour by leaving their unique 'decision trail' of detail (Koch, 2006:91), and also help to give guidance to researchers new to the approach about how other studies have carried out their analysis.

In further connection to rigour, is the topic of validation of findings by research participants. As has already been discussed, this is not always considered relevant or necessary in phenomenological research (Sandelowski, 1993; Webb, 2003). Indeed, Norlyk and Harder (2010:428) go so far as to state that 'if the final word is going to be given to the individual undergoing the experience, then there are no arguments for an analysis to take place'. However, although the approach of IPA does not exclude going back to participants as a possibility, Giorgi (2008) considers the tensions that might arise from trying to determine which perspective should take priority, if a discrepancy of views exists,

Smith (2007:9) considers the process of verification by participants as more of an 'extension of the interpretative process' rather than just the member validation that has been discussed above. Having said that, Giorgi (2008) does differentiate between the natural attitude a participant may have towards their experience, and the phenomenological attitude a researcher should have in trying to uncover meanings within texts, from an exploratory research standpoint. From this perspective, it would seem likely that meanings may be uncovered that participants are not fully aware of themselves, and this therefore adds to the case for not necessarily seeking participant verification.

To expand on previous discussions regarding insider-outsider perspectives, Reid et al (2005:23) consider that within IPA, while a researcher may start from an 'emic' (or insider) position, due to previous knowledge or experience, this is balanced by the need to look at the 'etic' (outsider) viewpoint, where a broader more interpretative

perspective is sought. Relating the etic view back to the emic perspective forms part of the hermeneutic circle examined earlier.

In IPA studies the analysis account is also, by its very nature, the interpretation of one researcher (or research team). As has already been discussed, this may give rise to doubts about claims regarding the significance of findings. However, according to Smith et al (2009:183), audit is there to ‘ensure that the account produced is a credible one, not the only credible one’. Although this concept may again seem alien to more quantitative researchers, qualitative approaches such as IPA are not seeking to find one single answer or truth, but rather a coherent and legitimate account, which is attentive to the words of the participants. Narratives should ‘strike a chord’ with the reader (Van der Zalm and Bergum, 2000: 216), and as Finlay (2009:14) argues, there must be a place for both ‘rigour and resonance’ in research findings.

From a practical aspect, reflection, team discussion, and method triangulation can all help to achieve coherence and rigour. Casey and Murphy (2009:41) discuss the fact that using more than one method of data collection (for example, interviews combined with diaries) can achieve triangulation ‘within method’ by improving the completeness of data, as well as acting to enhance findings. According to Smith et al (2009:185), IPA studies should aim to go beyond an analysis which is just ‘good enough’ requiring, therefore, more explicit detail regarding the commitment and rigour with which the study has been carried out. In situations where data may not be as rich and detailed as desired by the researcher (for example, due to the ill health of participants, or sensitive timing of data collection) having an additional method of data collection may enhance the data sufficiently to allow a more elaborate analysis.

As Braun and Clarke (2006:98) consider, producing a good analysis from poorer quality data is more demanding, but ‘can potentially be performed by a skilled and experienced analyst’.

There are therefore a variety of measures that can be used to achieve, display and assess rigour within qualitative research studies. How this is accomplished more specifically within the proposed study will be discussed in further detail, where relevant, in the following chapters.

### **3.16 Relevance to nursing and health studies**

Husserl considered phenomenology from a scientific and philosophical standpoint, and was not seeking to specifically deliver a research method that might be meaningful in a health context, where understanding behaviours is at the crux of influencing health promotion. As Lawler (1998:106) discusses, these historical methodologies were ‘not necessarily designed to deal with people who are ill and outside their normal contexts and surroundings’.

With regard to quantitative research results, theory tends to be generated from the mean or middle ground of the findings, with less emphasis on findings which fall out-with these perimeters. It could be argued that in health care it is those who fall out-with the ‘norm’ who are the very people in greater need of our attention as nurses. According to Munhall (1994), unless we understand meanings, we cannot alter health behaviour and lifestyles, and it is surely only by maintaining an open, adaptable approach that we are able to truly reach, hear, understand and access our participant’s experiences, particularly those who may be in greatest need of our

support. Expansive, honest and reflective accounts may be less forthcoming and more difficult to attain from such participants if a rigid set of questions or more structured interview technique is used; this argument could well extend to the data analysis process, which also requires to be flexible.

As has already been discussed, IPA is grounded in psychology, which could be seen to lessen its applicability to other disciplines, such as nursing. However, Smith et al (2009:45) argue that analysis should be informed more by a general psychological interest, rather than being approached from a 'pre-existing formal theoretical position'. This would therefore potentially allow for different disciplines to use IPA beneficially, and draw on theories from a number of sources during interpretive discussions, whilst still grounding the interpretation firmly in the text of the participants' words. According to Smith and Osborn (2003:52), IPA assumes there is a 'chain of connection' between the way participants' talk, their thoughts, and their emotional state, even if this connection is not always overtly known or expressed by participants themselves.

It is by understanding, and bringing to the fore, individual accounts, that we can begin to understand 'life worlds' in a phenomenological sense that is meaningful to nursing (Munhall, 1994). As Warren (1994: 252) argues, individual accounts and understandings offer 'one clear way of demonstrating that human beings are the subject of nursing, not their medical condition'. Phenomenological approaches such as IPA can make previously unheard accounts 'vivid' (Hilton, 2002:21). Making phenomenology accessible and usable in such circumstances is one of the aims and strengths of IPA (Smith et al, 2009), and answers criticisms that psychology has a



‘tendency to overgeneralize about people’ resulting in ‘over simple statements that actually apply to no one’ (Lazarus, 2003:174).

Key features of IPA are summarised by the analyst in Figure 12 below.

<b>Summary of key features of interpretative phenomenological analysis</b>
<ul style="list-style-type: none"><li>➤ Ideographic – focuses on individual accounts throughout the process, although commonalities across a group of participants can be identified</li><li>➤ Interpretative – hermeneutics of belief and questioning, rather than suspicion</li><li>➤ Roots in psychology and psychological meanings</li><li>➤ Double hermeneutic – the researcher attempts to make sense of the participant’s sense-making</li><li>➤ Contributes to theory, rather than theory building</li><li>➤ Inductive – ‘bottom up’ approach, building themes and super-ordinate themes from the transcripts</li><li>➤ Uses the hermeneutic circle to relate the parts to the whole, and the whole to the parts</li></ul>

**Figure 12: Key features of interpretative phenomenological analysis**

### **3.17 Summary**

This discussion has focused on many of the dilemmas and confusions that may face a researcher considering phenomenology as a research approach. It is of undoubted importance that the historical roots and methodology are understood, if the approach is to be applied in an appropriate and meaningful way. However, more recent movements towards combining some of the seemingly opposing schools of thought in phenomenology, as achieved in studies using interpretative phenomenological analysis, are proving to be helpful.

To summarise, IPA can be seen to offer an adaptable and accessible approach to phenomenological research, while still adhering to guidelines relating to rigour and validity. It is an approach which, by emphasising the importance of individual accounts, has much in common with nurses' desire to offer holistic care. Just as nursing seeks to deliver care which is evidence based, the findings of IPA studies are firmly rooted in the 'evidence' of the words of participants. IPA has already been seen to be of value in other health related research studies, and would therefore seem well suited to greater use in phenomenological nursing research; the use of IPA seems certain to expand in coming years. As the number and diversity of studies using this approach increases, its application and benefits can be further assessed.

Having discussed the overall concept of phenomenology as a research approach, and the individual merits of IPA, the following chapter will focus on the more distinct choices being faced as part of the planned research study. Methodological issues that are relevant to the particular nature of the proposed study will also be revisited in the light of the specific method.

## CHAPTER 4

### Method

#### 4.1 Introduction

This chapter will detail the specific method choices and decisions relating to the proposed research project. The reasoning behind the decisions will be explored, and the planned method will be summarised, ahead of the actual findings from the study, which was divided into two parts: a small preliminary study, to trial methods and evaluate data, and a larger main study, which would take the analysis to a more interpretative level. Results from each part of the study will be given in the following chapters.

It was recognised that any necessary adjustments to method for the main study would be able to be made in the light of the preliminary study findings, if appropriate or necessary. This will be discussed later, before the main study findings. With regard to terminology, since the study was carried out as part of a higher degree by research, the interviews and analysis were all carried out by one person, albeit with supervisory support. To that extent, the words ‘interviewer’, ‘researcher’ and ‘analyst’ are all used interchangeably, referring to the same person, but with different roles.

As already stated, the aim of the study is to gain an understanding of experiences during the first month at home following a stroke, and to include the perspectives of both patients and carers. Unlike other studies, for example the study by Ellis-Hill et al (2009), which focused more on functional recovery and mobility, the emphasis was planned to allow participants a free reign to discuss their experiences, in order to

gain a phenomenological understanding. Such an approach requires greater participant involvement, and decreases the impact or lead of the researcher. Whilst not going as far as some of the approaches advocated by McFadden and McCamley (2003), who discuss participants as potentially shaping every aspect of the research process, participants in this current study were enabled to collaborate and co-construct their accounts (Elliot, 1997), and be significantly involved in the research process, by the emphasis placed on their individual narratives in the interview process. As Smith et al (2009:58) stress, the participant is the ‘experiential expert’ in this type of enquiry, and Brocki and Wearden (2006:100) conclude that interpretative phenomenological analysis (IPA) is ‘entirely congruent with the increase in patient-centred research’.

#### **4.2 Methodology revisited**

To briefly revisit and summarise methodological issues, according to Webb (2003), method within phenomenology in general needs to fulfil certain essential criteria, as noted in Figure 13 below. These points will be addressed further during the following discussion, with particular reference to method within IPA.

### Phenomenology – essential criteria

- Statement of which form is being used
- If relevant, discussion of bracketing and how this was used
- Focus on the meaning of experience (if Husserlian) or the interpretation of meaning (if hermeneutic)
- Unstructured data collection e.g. interview starting with a very open question, followed up by general probes to continue
- Use of appropriate and systematic data analysis method or an appropriate adaptation of an established, credible process
- Transparency about the research process e.g. use of reflexive journal data, discussing how the author's horizon of understanding and pre-understanding operated
- Attention is paid to representation (e.g. use of participant's words in the text)
- Identification of the essence of the phenomenon, not just 'themes' or 'categories'

**Figure 13: Essential criteria for phenomenological studies** (summarised from Webb, 2003)

In addition to this, Porter (1996) also describes four levels of understanding in relation to qualitative research. These levels of understanding are noted in Figure 14 below, with specific reference to the proposed study. The figure has also been adapted to add an additional level (level 5), to illustrate the contribution a study using IPA can make to the body of research knowledge.

<b>Level</b>	<b>Details</b>	<b>Questions to be addressed</b>	<b>Specifics relating to the proposed project</b>
1	Ontology	What is reality? (Concerned with the subject matter of the research)	What constitutes the 'reality' of the discharge experience?
2	Epistemology	What counts as knowledge?	What counts as knowledge of the discharge experience?
3	Methodology	How can we understand reality?	What means are at our disposal for accessing knowledge about the reality of discharge experiences for participants?
4	Method	How can evidence be collected about reality?	How can data be generated about discharge experiences?
5	IPA	How do participants make sense of reality?	How do participants make sense of their experiences following discharge from hospital?

**Figure 14: Levels of understanding in qualitative research** (Adapted from Porter, 1996)

The previous chapter considered ontological, epistemological and methodological issues. This chapter will consider the specifics of method, with particular reference to a study using IPA.

With regard to the emphasis on the individual narratives that are the focus of an IPA study, to be successful in allowing participants to take a lead role in the interview process, they could be considered to need to have very good communication and reflective abilities, as well as a certain degree of physical stamina (McNamara, 2007). The fact that this study was proposing to include participants with significant stroke related communication and physical restrictions posed not only notable challenges, but also opportunities that have not been widely taken up in other stroke studies (Pringle et al, 2008). Even in a study by Shadden and Hagström (2007:325), which specifically aimed to examine life participation and aphasia, the participant selected to illustrate key themes was chosen for his ‘articulateness’. Such strategies illustrate the assertion by Connect (the communication disability charity) that people with communication problems after stroke are still being ‘unjustly excluded’ in many areas (Connect, 2011:1).

Given that communication problems alone affect up to 38% of stroke patients (Gordon et al, 2009), their exclusion could result in the views of a significant number of potential participants not being heard, contributing to what Law et al (2007:1) describe as the ‘doubly disadvantaged’ situation many aphasic people find themselves in. Failing to include such participants could be viewed as an important limitation of other stroke research, but is one that has not always been fully acknowledged (Pringle et al, 2008).

In further relation to this, there was a possibility that by including people with communication difficulties, less detailed accounts might be obtained, and meanings might also not be as readily understandable. According to Smith and Osborn (2003), in such cases, the analyst must participate in a detailed and sustained engagement

with the data in order to obtain the necessary insight. Careful planning would therefore have to be given to how this was going to be achieved.

The following discussion will detail how many of these issues were proposed to be dealt with in the overall study method.

### **4.3 Method specificity**

According to Caelli (2001) due to the confusions that can exist in phenomenological research, it is particularly important to make the distinction between the methodology (philosophical framework), and the method (research technique), and to ensure that the specific process matches the philosophical position that guides the study. While the approach of phenomenology has been discussed in general terms in the previous chapter, this chapter seeks to link these discussions to the specifics of method.

As already stated, having a philosophical backdrop such as phenomenology against which to place and guide the research process, can also assist in forming a richer, more directed analysis. However, from the review of literature carried out at the beginning of this study, not all studies do detail any guiding methodological principles. Greenwood et al (2009), for example, although examining the stroke experiences of carers up to 3 months post-discharge, do not go beyond the production of descriptive themes. As previously discussed, vague statements can also sometimes be used, such as ‘phenomenological orientation’ (Rochette et al, 2006: 247) or ‘draws on ethnography’ (Greenwood et al, 2009:1124), with little specific detail of what this entails.



Other studies can also give confusing accounts of methodology. For example, although presenting a very informative and detailed account of stroke experiences over a broad time range, Burton (2000:301) details his study as ‘phenomenological’ whilst later describing a grounded theory approach. As Wimpenny and Gass (2000) discuss, there are distinct differences between the aims of the two approaches, and lack of clarity with regard to the method used is not helpful in understanding the purpose of the research. Bradbury-Jones et al (2009a: 663) argue that it is important that nurse researchers not only ‘develop critical awareness of research methodologies’ they propose to use, but that they are also able to explain and defend the choices they make.

As Smith et al (2009:192) discuss, IPA is particularly useful in presenting a case for more unusual participants, who might ‘easily disappear in the aggregates of statistical analysis’ in quantitative studies, and who may also have been excluded from contributing to previous qualitative research. The purpose behind the study was therefore to gain a greater understanding of participant’s experiences, thereby assisting the provision of more appropriate care, both in terms of discharge planning, and follow-up support. Lawler (1998) argues that unless nurses understand the meanings people attach to events which disrupt their lives, they have a limited capacity to help. Burton (2000:301) also considers such understanding as ‘essential’ if services are to be ‘effective and appropriate’. The approach of researching experiences in this way is described by Clarke and Iphofen (2006:6) as gaining ‘practice generated’ evidence.

The study being detailed here hopes to add to the pool of stroke knowledge from a more interpretative slant, situated in the phenomenological approach of IPA (Pringle

et al, 2011b). The study also hopes to build on previous IPA stroke studies, which have examined the hospital experiences of stroke carers (Hunt and Smith, 2004) and stroke survivors in the longer term (Murray and Harrison, 2004; Salisbury et al, 2010).

#### **4.4 Data collection choices**

In further relation to methods, focus groups were considered as a possibility during the conceptual stage of the research project, due to their ability to be a 'rich source of information' (McLafferty, 2004:187). Such focused group discussions on a predefined topic were traditionally employed in the field of marketing (Murphy et al, 1992), although their use and value in health related research has increased in recent years (Barbour, 2008). However, the use of focus groups in phenomenological studies is the subject of differing opinions: for example, although some authors suggest they are incompatible with phenomenology (Webb, 2003), Bradbury-Jones et al (2009a) argue that such forums are not as inconsistent to gaining phenomenological insights as other researchers might suggest. Whilst there may be an inhibitory element to talking more personally in a group situation, Smith et al (2009) consider that in some cases participants may interact well, allowing multiple voices and views to be heard, a view that is in agreement with Flowers et al (2001). Alaszewski et al (2004:1069) certainly offered their stroke survivors the choice of individual interviews or focus group participation, to ensure that 'those people who might feel uncomfortable in an individual setting' were included. However, they offer no further discussion regarding how this strategy may have impacted on the type of data generated.

Bradbury-Jones et al (2009a) consider that focus group discussions may further the interpretation of experiences by participants during the group interaction. However, it could also be argued that there is a risk that such interpretations may be too far removed from the original individual experience, and that participants may change their stories in the light of the narratives of others, which Bradbury-Jones et al (2009a) do not acknowledge.

In addition to this, Bowler (1997:76) argues that within focus group discussions it may be more difficult to access 'muted' groups or individuals, who do not form part of the 'dominant communicative system'. As Murphy et al (1992) conclude, opinionated participants may dominate (and thereby alter) the discussions, and it takes a skilled group facilitator to manage this.

Bradbury-Jones et al (2009a) also discuss the fact that researcher interpretations may be productively challenged by participants during a focus group encounter. However, it could also be argued that in the true spirit of phenomenological research, participants should not be aware of any researcher views or interpretations during the data gathering process. It may be that Bradbury-Jones et al (2009a) are referring to the internal researcher reflections and interpretations that are being challenged by listening to the group discussion, but this is not made clear.

In further relation to this, Smith et al (2009) discuss the fact that convergent and divergent views do need to be harnessed and explored during the interpretative analytical phase of the research; a group consensus about an experience during the data gathering stage may inhibit divergences that are of importance and relevance to the experience (Brocki and Wearden, 2006). It is therefore vital that all these

potential influences and conflicts are acknowledged by researchers, particularly during their reflexive writings.

There also needs to be consideration of whether participants can give the same depth of account, or whether there is sufficient opportunity for probing by the interviewer, in focus group forums (Barbour, 2008; Smith et al, 2009). Participation in a group setting could also be considerably more difficult for anyone with a communication difficulty (Barrett and Kirk, 2000), and those with greater disability could have difficulty accessing venues (Kroll et al, 2007). As already identified, for carers there may be issues with finding suitable substitute carers to allow attendance at an external meeting (Simon and Kumar, 2002).

Taking these arguments into consideration, along with the nature of the proposed study, although focus groups would have been very interesting forums, individual interviews and diaries were considered to be the best means of gathering the data for the study, to allow greater ease of participation. The use of participant diaries, alongside interviews, was felt to give an opportunity for data from mixed sources to be included, and is certainly a direction encouraged for future IPA studies by Smith et al (2009). These choices of data gathering methods will be discussed further below.

With more specific reference to the terminology used, it was considered that data would be *collected* in the form of interview tapes and diary entries; data would be actively *generated* during these interactions and processes, and data would also be *gathered* more generally in terms of the field notes, and overall impressions and reflections made by the interviewer in her research diary. Collins (1998:3) considers

that unstructured interviews in particular involve an ‘interactional situation’, and that it is more useful to refer to ‘data generation’ than data collection, because of the construction of accounts that is taking place. However, Collins (1998) also considers that even the most unstructured interview will be structured to a certain extent, albeit subtly, and that researcher reflexivity can assist in identifying the influence of the interviewer in forming such structure. As well as these considerations, Collins (1998) discusses the fact that interviewees can have their own agenda, which may control the information they divulge. Such issues in relation to interview format will be discussed next.

#### **4.5 Interviews**

Jasper (1994) discusses the fact that the lived experiences phenomenology seeks to explore are most commonly achieved by audio-taped interview. As Wimpenny and Gass (2000) observe, the relationship between researcher and participant distinguishes this type of interview from other forms, moving from the observational in quantitative research, to dialogical in qualitative research, and then to reflective in phenomenological studies. Therefore, in order to capture these experiences, a study design incorporating audio tape-recorded, in-depth interviews was used; according to Fleming et al (2003:118), recording is necessary to capture ‘the historical moment’ of the encounter.

The purpose of such interviews is therefore to develop ideas and understanding, rather than generate facts and statistics. Oppenheim (1996:67) refers to this approach as essentially ‘heuristic’, which stems from the Greek word meaning ‘to discover’. The focus is on how people think and feel about the topic of concern to the

researcher, and in studies using the approach of IPA, the aim is also to gain an understanding of how participants make sense of their situation or experience.

The issue of how much direction the researcher should give to the participant by the type of questions asked is an important point for consideration. Wimpenny and Gass (2000: 1488) discuss this as being ‘the tension between having a frame of reference and the naivety identified as essential by many phenomenological researchers’.

Smith et al (2009) certainly advocate a non-directional approach to allow maximum freedom of expression for the interviewee, and offer practical guidelines for the phrasing of suitable questions. As Collins (1998:3) argues, rather than being objective and detached, the interviewer requires to be ‘engaged’. Oppenheim’s (1996) heuristic approach to depth interviewing also offers clear guidelines to the researcher on how to avoid the pitfalls of the interview process. For example, according to Wimpenny and Gass (2000) many researchers, although considering their studies to be phenomenological, are mistakenly using more structured or guiding interview techniques.

Smith and Osborn (2003) discuss the fact that, even for loosely structured interviews, advance thought needs to be given to wording and the overall format of the interview, in order to more fully engage with participants during the actual interview itself. Smith and Osborn (2003) also consider it important to strike a balance between being too general and too specific: if too many specific questions need to be asked, they suggest that perhaps the participant is not sufficiently engaged in the interview process. However, as Hafsteinsdottir and Grypdonck (1997) argue, questions set by the researcher may not be relevant to the participant and their situation, and therefore data relating to their viewpoint may not be acquired. This

stresses the importance of forward planning, and Collins (1998) further advises that if interviewers control their urge to interrupt, a more fluid account may be achieved.

In keeping with IPA guidelines (Smith et al, 2009), the interview format was therefore to be kept as unstructured as possible. A process of ‘funnelling’ (Smith et al, 2009:61) is suggested as a means of moving from a general to a more personally focussed mode of enquiry, by making questions gradually more specific.

Following initial informal welcoming comments, according to recommendations from the local ethics committee, the interview should begin with the researcher reiterating their name, and place of study, as well as ensuring that the participant still wishes to continue. Further issues in relation to ethics will be discussed later in this chapter.

Typically, once the equipment has been set up, and a few initial reminders given about the purpose of the visit, the interviewer can then ask each participant about the more specific details of the study. Probes and prompts can be made as necessary.

The interview guidelines used in this study can be viewed in Figure 15 below.

## **Interview Format**

### **Introduction and explanation**

My name is Jan Pringle. I am carrying out this research as part of my studies at the University of Dundee.

I am interested in hearing about your experiences since you (your relative/friend) returned home following the stroke. The interview will be tape recorded and I may take notes while you speak.

(Re-iterate confidentiality and freedom to withdraw).

We can start whenever you feel comfortable to do so.

**Start tape:** re-iterate ‘ I am interested in...’ if necessary

### **Suggested prompts:**

‘please go on’; ‘can you say a little bit more about that?’

‘uhuh’; ‘yes’; ‘I see’; ‘do continue/carry on’; ‘what makes you say that?’

### **Other strategies:**

Summarise/repeat back what has just been said

Use of expectant silence or expectant expression

Acknowledge any hurt/upset – offer to stop interview

**End:** ‘Thank you very much for taking part in this interview. Do you have anything else you would like to add or ask me?’

**Figure 15: Interview format** (Adapted from Oppenheim, 1992)

For most people, being interviewed is an unfamiliar experience, and they may have little idea of what to expect (Graham et al, 2007). From that respect, they may be looking to the researcher for guidance. As Smith et al (2009) advise, it is helpful if



the format of the interview is explained to potential participants ahead of time, and therefore this was discussed at the time of recruitment.

With regard to the planned location of interviews, according to Pashley and Henry (1990) a quiet situation, and allowing plenty of time, are important considerations when interacting with older participants, in particular, who may have difficulty processing multi-person conversations. As Mathieson (1999:117) also observes, there is a 'world of difference between interviewing the ill and the healthy', and special considerations therefore need to be made with regard to the participants and their medical condition. Interviews with people who have communication difficulties, for example, may especially be considered to be better suited to a quiet location.

Adding to these issues, are the concentration difficulties many stroke patients may have (Rudd et al, 2000), especially so soon after the event, and it may be advantageous if potentially distracting stimuli can be minimised. These suggestions are consistent with advice given by Murphy et al (2005) and the UK communication charity Connect (2007). It was therefore planned that interviews would take place in the homes of the participants, at a time that was mutually agreed upon between the interviewer and the individuals concerned. It was also hoped that by carrying out interviews in their homes, participants would feel more at ease and comfortable. As Wilson (2009:31) discusses, having interviews taking place in participant's houses can shift the balance of power in favour of the participant, which may assist in accessing a more 'private account'. Hilton (2002:21) also considers that such a strategy may help to preserve the 'naturalistic setting'.

It was planned that interviews would be conducted with only the individual participant and the interviewer present, if possible, and this will be discussed further below.

With regard to rapport, this is acknowledged as being of undoubted importance in the interview process (Yow, 2005; Smith et al, 2009). However, as Mathieson (1999) discusses, rapport is a difficult concept to define. Mathieson (1999:128) suggests rapport concerns a 'personal engagement' with the research participant, which can be built up by the use of patience, humour, and showing respect and appreciation.

Rapport is also important because it may increase the amount of information divulged during the interview (Graham et al, 2007).

The establishment of trust between the interviewer and interviewee is therefore vital, and Clarke and Iphofen (2006) suggest engaging in the three core conditions of a person-centred approach to facilitate this: congruence, unconditional positive regard and empathy. When thoughts, ideas and feelings are shared through the use of such an approach, the possibility of participants becoming co-constructors increases; as has already been identified, this is an important aspect of phenomenological enquiry (McNamara, 2005). Indeed, Giorgi and Giorgi (2003) consider empathy to be a vital component of phenomenological research, in order to truly reach the essence of the experience. It is therefore important to make time to address these aspects of the interview process, and to try and make the interaction as relaxed and informal as possible.

Interviews were all conducted by the same person, giving what Smith et al (2004:242) call 'internal consistency'. In addition to this, although Flowers (2008) considers that multiple interviews with each participant can offer greater opportunity

for disclosure, there are also practical considerations that need to be made in terms of participant and interviewer availability. It was therefore considered that diaries might be beneficial in acquiring additional data without the intrusion of further interviews.

The use of research diaries will be discussed next.

#### **4.6 Diaries**

Participant diaries are becoming an increasingly recognised data collection method (Alaszewski, 2006). According to Bryman (2004) diaries in research tend to fall into 3 main categories :

- those used by the researcher to keep field notes
- unsolicited diaries which are included in research analysis at some stage after their completion
- diaries actively solicited for the purposes of the research

Whilst the first two categories above are fairly common, solicited diaries have been less commonly used in qualitative research (Elliot, 1997; Clayton and Thorne, 2000; Alaszewski, 2006). Where they have been used, they can vary quite considerably in form, structure and instructions to the participants (Alaszewski, 2006). Thought therefore requires to be given to how detailed the instructions to diarists ought to be, with some advocates considering that guidance needs to be quite structured to acquire adequate data, and to ensure diary completion (Alaszewski, 2006). However, where the structure and data sought is more unstructured, and more about feelings and emotions, diaries can still provide rich data. Clayton and Thorne (2000), for example, consider that too much structure may influence the focus of diary entries by defining the agenda, thereby potentially reducing the fullness of entries. They

suggest a semi-structured format to allow an equal balance between the researcher and participant agendas'. Having very little structure can allow the diarist significant freedom of expression, and certainly allowing such scope, at least in the preliminary study, could be used to determine if greater detail of structure would be considered necessary for the main study.

As already discussed, whereas retrospective interviews rely on memory, and can produce 'generalised and idealised accounts' (Alaszewski, 2006: vi), diaries can reduce the possibility of recall distortion (Clayton and Thorne, 2000). Morse (2007: 864) argues that details recorded after an event can be more valid because the participant has been able to put events into perspective, without the feelings of being 'overwhelmed' by the trauma of the immediate situation. However, this view could deny the importance of that overwhelming, and potentially traumatic, experience. Diaries therefore allow for the immediacy of the situation to be captured, in what Zimmerman and Wieder (cited in Jacelon and Imperio, 2005:993) call 'the view from within'.

Diaries certainly give the opportunity for experiences to be recorded as they occur, to a greater degree than interviews alone, which can involve a much greater time lapse. Furness and Garrud (2010:263) are in agreement that diaries can capture the adaptation process as it happens, and help to reduce the 'telescoping effects associated with retrospective accounts'.

With further regard to these issues, Flowers (2001:24) discusses recall as being 'a complex sense of the past as seen through the lens of the present'. Elliot (1997) also considers that diaries can help to avoid such memory distortion, and allow access to behaviour that may be inaccessible by other means, particularly in the case of illness.

However, according to Piasecki et al (2007:28) it is important to recognise that diaries are not immune from bias or error, and that diaries may be ‘backfilled’ by participants some time after events have actually happened.

In further relation to memory and recall, although Banks and Pearson (2003) used the Lifegrid tool (Blane, 1996) to reduce recall bias in their stroke study, the validity of such tools has been criticised by Dawson et al (2003: 865) as being ‘risky’ and requiring ‘considerably more evidence’ to assess their contribution. As Dawson et al (2003: 865) conclude, just because accounts can be considered reliable due to being ‘replicable’, does not necessarily imply validity: ‘they could still have been under or overestimates of reality, or simply wrong’. However, it was felt that diaries would at least go some way to reducing the impact of memory and recall variations. Further issues relating to recall and rigour will be considered in greater detail later.

Narratives captured in diaries are therefore perhaps less likely to have been rehearsed or re-interpreted, which Smith et al (2009) consider as a possibility when there has been a time delay between events and data collection. Although diaries were used in the stroke studies of Banks and Pearson (2003) and Alaszewski et al (2004), they were used at later stages in the stroke recovery process. In Banks and Pearson (2003) there is also little detail reported on the purpose or data produced from the diaries in their research. As Alaszewski (2006) argues, it is important that sufficient detail is provided to allow the contribution of diary data to be assessed by others.

Furness and Garrud (2010:267) caution that the researcher has ‘less power over the direction, nature, and quality’ of diary data, but they also consider that differences between participants’ entries can be equally informative. For example, if there

appears to have been only a few problems being experienced by some participants, then their diary entries may reflect this.

As has also been discussed, diary data can be used to triangulate and expand on data from other sources. Burns (2000) considers this combination of data collection to be an approximation to participant observation, but without the intrusion and resource implications. The linking of diaries with interviews also allows for the potential lack of tone and mood indicators in the diary to be addressed.

However, drawbacks in the use of diaries are that participants may become less diligent over time, or give up altogether (Bryman, 2004). Although Alaszewski (2006) suggests that keeping in regular touch with diarists can improve completion, he also concedes that such intervention may alter the diary-keeping process. It was therefore decided not to contact participants with regard to their diary during the time they were keeping it. Contact was made, however, to arrange a suitable interview date and time, and this might have acted as a less explicit reminder in relation to diary entries.

Clarke and Iphofen (2006) argue that in contrast to interviews, diaries can provide more reflective accounts. Jacelon and Imperio (2005) certainly noted that diary entries became more reflective as the completion progressed in their study, and suggest that this may be as a result of participants becoming more comfortable and less self-conscious about the process. However, asking diarists to keep their contributions going for too long may also have an inhibitory effect. Jacelon and Imperio (2005) suggest one to two weeks as an optimum time to maintain interest and prevent participants from running out of things to say. Clarke and Iphofen (2006:64) asked their participants to keep their diaries for a month-long period, and

suggest that an interview at the end of this period can be used to allow ‘closure’ after their commitment.

Clearly a balance is required between keeping the diary long enough to allow the entries to potentially develop the necessary reflective depth, but not so lengthy a commitment as to be off-putting. In this study, it was therefore proposed to ask participants to complete the diary for a four week period, but with the concession that they write ‘as much or as little as you feel able’. The value of the preliminary study was that it allowed this strategy to be tested, and adjustments made, as necessary, ahead of the main study.

Diaries were also offered to carers/other family members. To facilitate freedom of expression, participants were asked to respect the privacy of other people’s diaries, and assurances given that entries would be treated with sensitivity and anonymity in the writing up process.

Another issue that required to be taken into account was the fact that diary-keeping requires a degree of literacy, physical ability, hand co-ordination, and vision in order to allow participation (Jasper, 1994). This had the potential to exclude stroke patients with difficulties in these areas. Strategies to increase the inclusion of people with such limitations therefore needed to be considered. It was decided to offer those who were unable to write a tape recorder to record their thoughts and feelings verbally, if they desired to participate. Those who had lost both the power of speech and writing, were offered the loan of a picture communication system similar to ‘Talking Mats’<sup>TM</sup> (Murphy et al, 2005), plus a film camera to record particular feelings or emotions (on the mats) on any given day of diary-keeping, or during their interview. By using these practical measures, which will be discussed in further detail below, the

exclusion of participants with verbal or physical difficulties could be reduced. Problems relating to the use of such aids would also have the opportunity to be addressed at an early stage in the preliminary study, thereby allowing for even greater inclusion strategies in the main study.

In common with the interviews, the diary format was to be kept as open as possible. A blank A5 sized notebook came with guidance (see Appendix 1) and, in brief, participants were asked to record their thoughts, feelings and emotions as they (or their relative/friend) returned home, and for three to four weeks afterwards. The words 'feelings' and 'emotions' were both mentioned to encourage both physical and mental states to be included. This is in keeping with the suggestions of Furness and Garrud (2010), who also discuss the fact that having an open forum can encourage other life events that may be of relevance to be included in the diary accounts. As Dewar et al (2010:30) argue, if methods focus solely on attitudes, or statements about what is good or bad, as tends to happen in surveys and questionnaires, then a limited amount of information may be 'gleaned', especially in relation to experiences.

Asking participants to focus on feelings and emotions can also help to move accounts more quickly from simple description to the individual meaning of the experience, according to Dewar et al (2010). Race (2001:5) also considers that 'feelings are as much about what it is to be human as any other aspect of humanity'.

Although some data of less relevance might also be recorded, Elliot (1997) considers that having an open format allows participants the freedom to write about things that are of importance to them, and to structure the entries as they wish. Unlike Furness and Garrud (2010), examples and suggestions of diary entries were therefore not



given to participants, as it was felt such a strategy might lead or influence the participant entries to too great an extent. Diaries were also clearly marked as private and confidential to increase the likelihood of participants feeling able to be open in their writings.

Piasecki et al (2007) argue that electronic diaries, rather than paper diaries, can increase the quality of data in terms of timely completion and reduction of recall bias through electronic prompts or reminders to complete. However, their use was considered more difficult for the participants in this study, due to the timing of data collection and a lack of opportunity in which to explain or train participants with regard to their use. In addition to this, greater manual dexterity might be required to operate such devices. Although back-filled data was a possibility, participants were asked to date their diary entries, to give an indication of when the entry was made; also, because experiential rather than experimental information was being sought, a more open forum for diary completion was considered appropriate.

Clarke and Iphofen (2006) acknowledge that because keeping a diary can be a very personal experience, participants should be given the right to change their mind about parting with the diary at the end of the period. However, as they also conclude, it can be a unique way of acquiring 'a truly reflective, honest and often emotional insight' (Clarke and Iphofen, 2006; 73). Participants were therefore given the option of not parting with their diary at the end of the month, or being offered the original, with the researcher taking a copy. Diaries were planned to be collected on the day of the interviews.

#### **4.7 Study sample**

Numbers of participants in phenomenological studies tend to be small (Braun and Clarke, 2006), and in studies using IPA, an even smaller number of participants can allow the full richness and meanings within data to be examined in great depth (Smith, 2004). Sample selection can therefore be small and purposeful. Purposeful sampling is defined as allowing ‘access to a particular perspective on the phenomenon under study’ (Smith et al, 2009:49).

To a certain extent, however, the sample to be included was also somewhat of a convenience sample, in that the research had to be led by the time frame available, and the participants who were willing, able, and available to take part during that period. That said, a reasonable time frame was set for both the preliminary and main stages of the proposed study, with data to be gathered for each part over a six to nine month period.

A purposeful sample of four stroke survivors and their carers/family was therefore planned for the preliminary study, with twelve patient/carer dyads planned for the main study. Patients were to be identified as eligible by the hospital multi-disciplinary stroke teams, whilst they were still in hospital. Suitability was gauged by the use of inclusion criteria (see Figure 16, below) and the team’s judgement of the patient’s fitness to participate. Permission to approach potential participants was sought from the stroke consultant, who was also made aware of, and supported, the proposed study at the planning stage.

<b>Inclusion Criteria</b>
Over 18 years of age
Confirmed diagnosis of stroke (CT scan), or their carer/family
Medically fit to participate
Willing to be audio tape-recorded or use other communication aids
In-patient for at least one week
Discharged to home environment

**Figure 16: Inclusion criteria for study participants**

These criteria will be discussed further, under the relevant sections below.

#### **4.8 Timing**

With regard to the timing of the study, Wellwood et al (1995) discuss the need to research experiences whilst they are still fresh in participant's minds. However, as has already been noted, many studies that report on experiences following discharge from hospital fail to detail the time since discharge, or may collect data a long time after discharge. For example, in the study by Murray and Harrison (2004) participants were an average of nine years post-stroke, and in the study by O'Connell et al (2001) participants ranged from two months to fifteen years post-stroke.

Although King and Semik (2006) collected data from stroke caregivers relating to four time-frames (ranging from the period of hospitalisation though to the second

year following discharge) the data were all collected at the end of that second year.

King and Semik (2006) do conclude that recall may have been aided by more frequent data collection.

Such time differences give further rise to questions about memory and recall, especially since stroke survivors and elderly participants may be more prone to memory difficulties (Warlow et al, 2008). As Gardner (2001:193) concludes ‘individuals rarely remember, store and recall information and life-events in the form of a text which remains inert and unchanged’ and it may be unrealistic for researchers to expect otherwise.

As has already been discussed, although Blane (1996) claims that recall can be assisted by the use of certain tools, there are other accounts which support the fact that recall bias is a significant factor that may not be so easily dealt with (Clarke et al, 2008; Schmier and Halpern, 2004). Smith (2003:181) similarly discusses the fact that people may alter the accounts they tell over time, and that events in subsequent accounts may be ‘reinterpreted more positively’. Smith (2003) suggests this may be part of a coping strategy to deal with an unpleasant event, or a desire to think more positively about a situation. It would therefore seem more likely that the earlier an account is heard after the event, the more likely it may be to contain frank admissions about the reality of a situation, rather than including ‘considerable reflexive reconstruction’ (Smith, 2003:181). From this perspective, the fact that data were to be collected in the form of on-going diary entries, closely followed by in-depth interviews, might help to access more immediate and less altered accounts of the experiences and events taking place at that time, as discussed above.

In addition to this, accounts were also planned to be heard from two perspectives (patients and carers), which was considered as potentially giving access to a more complete story, rather than the ‘highly partial’ accounts discussed by Gardner (2001:191). However, as Gardner (2001:189) also discusses, it is more helpful to think in terms of imperfect accounts, rather than considering that one has accessed ‘the truth’. These arguments contributed to the decisions to ask participants to keep their diary accounts from the day of discharge, and to have interviews taking place approximately four weeks after discharge.

Triangulation, as discussed in the previous chapter, through the use of interviews and diaries, was also felt to be a means of increasing the fullness of data collected.

Whilst Barbour (2001:1116) argues that data from differing sources ‘defy direct comparison’, this was not the purpose of the dual methods of data collection proposed here. As Barbour (2001:1116) goes on to conclude, data gathered from different sources may increase comprehensiveness and ‘crystallisation’ of findings. Casey and Murphy (2009) also discuss the fact that such an approach, within the same method, can achieve a triangulation which increases the completeness and credibility of the study.

With further regard to timing issues, the criterion of having been an in-patient for at least one week was decided upon to exclude those participants who may have had very short hospital stays, and whose adjustment to returning home might not be particularly marked. Cowdell and Garrett (2003) agree that a minimum hospital stay is necessary when researching stroke patient’s experiences of rehabilitation in particular, and although Rochette et al (2007) argue that even a mild stroke (and the

possibility of only a short hospital stay) can still have an important impact, this criterion was decided upon for the preliminary study. It was also felt that this length of time would allow an adequate period for potential participants to consider whether or not to take part in the study, and ask any questions they might have before their input into the study started.

As already mentioned, in the light of findings from this initial part of study, any changes to the main study format could be decided upon once the preliminary study was evaluated by the researcher.

#### **4.9 Diagnostic criteria**

The particular focus of this study was on experiences from the perspective of the participants, rather than in relation to, or focusing on, the severity of stroke symptoms. In this respect the study shares some similarity with Folden (1994) and Pilkington (1999), in that their participants had a range of stroke type and effects. However, unlike Pilkington's study, the focus was not restricted to elements relating to quality of life, and the views of carers were also to be included, rather than just the experiences of stroke survivors.

Hafsteinsdottir and Grypdonck (1997) are critical of Folden (1994), arguing that different types of stroke will lead to different experiences. However, although some stroke studies do include participants with only certain types of stroke (e.g. Hafsteinsdottir and Grypdonck, 1997; Sisson, 1998; Stone, 2007), other authors have found little difference (e.g. de Haan et al, 1995) between survivors of different types of strokes. As Warlow et al (2008) detail, the range of effects following a stroke can be equally broad, regardless of the cause, and other authors agree that even strokes

that may be classified as mild can still have a significant impact on the lives of survivors (Rochette et al, 2007; Greenwood et al, 2009). As Guise et al (2010:76) conclude ‘the observable level of physical impairment is not a reliable indicator of the stroke sufferer’s experience of illness’. Brauer et al (2001:88) also consider stroke to be a life transforming event ‘regardless of the extent and duration of the neurological symptoms’.

In addition to this, the IPA stroke studies of Hunt and Smith (2004) and Murray and Harrison (2004) included people with a variety of abilities and restrictions, and did not focus on any specific stroke type or severity. It was therefore decided not to concentrate on any particular type of stroke. However, the Functional Independence Measure and Functional Assessment Measure (FIM+FAM) classification system (Hall et al, 1993) was utilised as a guide to how the stroke had affected day-to-day functioning.

This system, originally developed in California in the late 1980’s (Cassells et al, 2007), covers a range of thirty everyday activities, ranging from personal care, through to mobility and communication. Within each of these activities, there is a seven level ‘ordinal scale’, which Hawley et al (1999:749) describe as having ‘high level internal consistency and reliability’ for use in clinical or research settings.

In the FIM+FAM rating scales, the higher the score, the greater the level of independence, with a score of seven relating to complete independence, and a score of one indicating that total assistance is required. Any score below five indicates that some level of assistance is needed and, in general, the lower the score the greater the necessity for assistance. The FIM+FAM general descriptor decision tree (Turner-Stokes, 1999) is detailed in Appendix 2.

From the literature review, giving such specific indicators with regard to physical ability is often not detailed in qualitative stroke studies. Greenwood et al (2009) also conclude that greater detail in relation to ability is necessary in stroke studies to help situate a study. Such measures do help to give a good indication of ability over a broad range of activities, and can help in setting the scene of the research better than more vague descriptions such as 'severe' or 'mild' (e.g. Rochette et al, 2006:248).

Although Hobart et al (2001:642) conclude that the FIM+FAM classification is more time consuming than other shorter scales, and that the use of such measures in clinical practice may not improve outcome measurement, they do acknowledge that using FIM+FAM provides 'more comprehensive clinical assessments of disability' than other measures.

Including people with a range of physical and communication ability in research projects is central to the ethos of organisations such as INVOLVE (Hanley et al, 2003) and Connect (2007). INVOLVE is an organisation which promotes public involvement in NHS, public health, and social care research. As previously mentioned, Connect is a charitable organisation which supports people with communication disability. In addition to, or perhaps because of, the influence of these organisations, inclusive strategies are becoming more of a requirement from research ethics committees, particularly within the NHS. In this respect, there certainly seems to have been a change in attitude in more recent years. For example, in Burton's stroke study in 2000, he states that 'ethical approval required that informants were free from dysphasia' (Burton, 2000:303). As has been discussed earlier, similar exclusions were found to be widespread in the literature review



(Pringle et al, 2008); it must be considered that such exclusions could now potentially be challenged under disability discrimination legislation (Dept of Health, 1995b; Dept of Health, 2010b).

It was therefore decided that a general stroke diagnosis (by CT scan and consultant opinion) would be an inclusion criteria, without any further stroke type being specified. That said, people with significant communication difficulties would purposefully be offered the opportunity to be included, to offset the exclusion noted in other stroke studies.

#### **4.10 Homogeneity**

As detailed above, from the perspective of the range of ability of the stroke survivors planned to be included in this study, there might be a distinct amount of diversity between the participants. However, although a certain level of homogeneity between participants is considered appropriate in IPA studies (Smith et al, 2009), if those taking part are too similar or limited in their diversity, then it could be argued that results may not be as useful in their contribution to theory, or their applicability to other areas. As Smith et al (2009:160) discuss, ‘it can be possible to balance some degree of multi-perspectival design against an acceptable level of homogeneity’.

Similarly, if only very able participants are included in studies examining health conditions such as stroke, where some degree of disability is fairly frequent (Harwood et al, 2005), then whether these studies have any claim regarding their representation of stroke experiences could be questioned. Although IPA studies do not set out to be representative or generalizable, contributing to theory is still acknowledged as a beneficial aspect of IPA research studies (Caldwell, 2007).

Clearly a balance must therefore be struck which allows a certain level of commonality of experience to be matched against sufficient diversity to allow some relation and connection to others. As Smith et al (2009:160) discuss, localised studies can still lead to ‘more general critical observations’.

From previous discussions, Rochette et al (2007) argue that even people with what could be considered to be a relatively minor stroke, can still have significant after-effects from their stroke event. It could therefore be concluded that although stroke severity and resulting physical limitations are not necessarily defining features of stroke experience, it is important that people with a range of abilities and disabilities are included. The homogeneity between the participants in this study was to be derived from their common experience of stroke, and their experiences of the early days at home.

#### **4.11 Inclusive strategies**

As has already been identified with regard to participating in interviews, participants with aphasia may be disadvantaged by their communication difficulties. Diary keeping also requires a degree of literacy, physical ability, hand co-ordination, and vision in order to allow participation (Jasper, 1994). Strategies to increase the inclusion of people with such limitations therefore needed to be given further, more detailed, consideration.

Although participants who were unable to write were to be offered a tape recorder/dictaphone to record their diary entries in this study, other studies involving diaries (e.g. Banks and Pearson, 2003; Furness and Garrud, 2010) either did not offer

such an option, or did not mention it in their findings. It was therefore felt that such a strategy needed to be made explicit.

For those who could write, thought was also put into the form of booklet used for the diary, and a spiral notebook was chosen for ease of page turning, given the possibility of reduced manual dexterity that participants might have.

In further relation to participants requiring communication assistance in the form of pictures and diagrams to help with their expression in both their diary and interview, these aids were devised with the help of a local speech and language therapy team, to help allow greater participation and engagement. Forward planning was also considered important to the success of this strategy.

To facilitate the capturing of these picture mat diary entries, a disposable camera and other necessary equipment (e.g. pictures with Velcro™ backing, and fabric mats on which to stick the pictures) were to be given to participants prior to discharge from hospital. The speech and language therapy team also volunteered to help with this element of the research process, since they would be visiting the patients immediately following discharge, as part of their normal practice. Although this could be considered to be more of a ‘prompt’ to complete diary entries than other participants might be getting, the speech therapy team were careful to be led by the participant in the respect of diary entries, and allow them to nominate when, or if, they wanted to either complete a diary page, or receive help in dating and photographing a page that had already been put together. The contribution and support of the speech and language therapy team in this research has been acknowledged in a journal article (Pringle et al, 2009).

In similarity to the work of Murphy et al (2005), pictures were to be placed on mats to allow them to be photographed and preserved for inclusion in the analysis process. For each day of diary keeping, pictures could then be removed and a new mat started. If participants were unable to take the photos themselves, then help was given by family or speech therapy staff. Obviously this meant that these types of diary entries would be viewed by others. However, there was still the opportunity in the individual interviews for further disclosure in private, with just the interviewer and participant present.

Cameras were to be taken to be developed by the researcher, and examples of the type of data produced will be discussed later, with the findings.

Interviews with these participants would also incorporate the placing of pictures selected by the participant on a mat. These mats could then be photographed by the interviewer to preserve the image of what the participant had indicated, for inclusion in the analysis process. Interviews were to be tape-recorded and transcribed, even although in some cases the verbal communication might be largely one-sided.

However, it was felt that for those participants with limited speech, this would allow the accompanying conversation to be related to the pictures on the mats, which would be useful when referring back at a later date.

With further regard to the use of pictures, visual processing ability can also be markedly affected by a stroke (Warlow et al, 2008), and this was another factor which needed to be taken into account. For example, additional time might be needed for participants to be able to consider whether the information portrayed in

the pictures matched what they wanted to 'say'. As Cameron and Murphy (2002) discuss, although participants require sufficient vision to be able to see the pictures, they conclude that the verbal and visual information provided by the researcher can compensate for any restriction in ability to read the actual word relating to the picture. Therefore, if word reading ability has been affected, the verbal and pictorial information may be sufficient for the participant to identify what they want to convey. Similarly, because stroke symptoms generally involve unilateral (one-sided) weakness or paralysis, participants would most likely have sufficient manual dexterity on their unaffected side to pick up or point to the picture they were selecting. It was considered important that all these factors were taken into account before the study commenced.

Although stroke related visual-perceptual disturbances are briefly mentioned by Burton (2000) and Sisson (1998), this does not appear to be an area that has been widely discussed, and therefore would certainly appear to be a topic which would benefit from greater acknowledgement and further research.

With further regard to communication ability, Murphy et al (2005) discuss the fact that picture symbols can also assist in a variety of situations, ranging from hearing loss to comprehension difficulties. In addition, Murphy et al (2005) advocate the use of 'Talking Mats'™ where English is a second language. However, Smith (2004) advises caution with regard to the inclusion of participants in IPA studies who do not speak English, due to the possibility of differing translation interpretations. It was therefore decided that further advice would be needed if such participants came forward.

In further relation to data from differing sources, there had to be consideration regarding interpretation of the data that was produced using pictures and diagrams from participants with communication difficulties. As Prosser (1998:1) states 'images provide researchers with a different order of data and, more importantly, an alternative to the way we have perceived data in the past'. However, as also discussed by Prosser (1998), such images have usually been used as supporting evidence, in particular in anthropological and ethnographic studies.

Borrowing from the thoughts of Prosser (1998), the pictures and images captured in this study were to be accompanied by more detailed field notes, and reflections also kept by the researcher immediately following the interviews. Whilst it needed to be acknowledged that data produced by the use of pictures and diagrams were going to be somewhat different from the verbal and written accounts of the other participants, it was also considered that such accounts were still worthy of being 'heard', and could add to the overall richness of the study, and the analysis. As Dewar et al (2010) argue, pictorial examples of emotions can help people to describe what an experience feels like, in a more detailed way than the use of words alone. Dewar et al (2010) also consider that such pictures can help participants get in touch with their feelings to a greater extent. In this way, experiences may be explored in more detail than if, as in the study by Dickson et al (2008), only an alphabet chart is used for participants with limited speech.

With further regard to field notes, these can contribute greatly to core information about meanings of sentences and body language (Burns, 2000), and notes were planned to be kept by the researcher throughout the research project, not just for participants with communication difficulty. It was also acknowledged that facial

expressions and body language might be more difficult to interpret due to stroke related weaknesses or paralysis, and this would have to be considered, where necessary.

To examine stroke related communication disability in greater depth, such difficulties can fall into a number of categories and severities; a brief summary of common categories is given in Figure 17 below. Apart from these overall categories, there are also issues of memory, intellect, altered body language, and the overall quality of the data that it might be possible to generate. However, as Lloyd et al (2006:1399) conclude, many of these issues can be successfully accommodated in research if there is a ‘willingness to adapt methods appropriately’, as detailed above regarding the use of pictures.

Type of communication difficulty	Details
<ul style="list-style-type: none"> <li>• Aphasia (sometimes referred to as dysphasia)</li> </ul>	Disorder of the production and/or comprehension of spoken and/or written language
<ul style="list-style-type: none"> <li>• Dyspraxia</li> </ul>	Impairment of the planning of movements required for speech sounds
<ul style="list-style-type: none"> <li>• Dysarthria</li> </ul>	Disorder of the articulation of sounds

**Figure 17: Common types of communication difficulty following a stroke**

(summarised from Warlow et al, 2008)

With regard to potential participants, it was felt that people with any, or all, of the above difficulties might be included in the research. As well as people with aphasia having frequently been excluded from stroke research, Dickson et al (2008) consider the same to be true for participants with dysarthria. However, while dysarthria is more likely to spontaneously resolve than stroke related aphasia (Harwood et al, 2005), Dickson et al (2005) argue that the psychosocial impact can still be long term. It is therefore possibly more helpful to define communication difficulties in other ways, to better explain the impact on daily life, and research participation.

In further relation to the severity of communication difficulty, of the twenty eight studies examined in the literature review, only one (Rittman et al, 2004), defined this beyond descriptions such as 'mild' or 'moderate'. Such terms may seem both vague and subjective, and abilities would certainly be more meaningful if they were specified in a more detailed and objective way. Giving greater detail in this regard could also help other researchers gauge what has been possible in terms of inclusion, and enable judgements to be made relating to the strategies used to support such participation. As previously discussed, it is important that researchers and ethics committees promote and facilitate inclusive strategies, especially where participants are willing and able to take part, albeit with assistance. This particular study hoped to expand on previous boundaries in this respect.

As noted above, the FIM+FAM classification system (Turner-Stokes, 1999) was to be used to be more specific with further regard to severity and type of communication problem. The system breaks communication into five different sub-components:



- ❖ Comprehension
- ❖ Expression
- ❖ Reading
- ❖ Writing
- ❖ Speech intelligibility

As has already been identified, within each of these sub-sections there is a rating scale of one to seven, and between these levels there are specific guidelines to gauge the level of assistance required to achieve each score. For example, with regard to expression, at level six the person is able to express complex ideas given extra time or using a communication aid, whereas at level four some interpretation or guess work would be required by the listener, especially out of context. These scores will be related to specific participant ability when the findings are discussed; the classification also gives greater information to people who are unfamiliar with speech pathology terms and restrictions.

#### **4.12 Carers**

Studies have shown that the well-being of stroke patients and their carers can often be inextricably linked (Baker, 1993; Smith et al, 2004; van Exel et al, 2005). It was therefore considered important to include both patients and carers in the study. As Hellgeth (2002:80) stresses, coping with being the carer of a stroke survivor requires a great deal of ‘acceptance and growth’, and the experiences of both carers and patients could be viewed as being two sides of the same coin.

Although phenomenology treats each individual account as a unit of analysis, and IPA in particular emphasises the importance of the ideographic nature of the analysis, comparisons can still be made across individuals, rather than within the accounts, thereby still allowing contrasts to be displayed (Prichard and Trowler, 2003; Smith et al, 1999). However, using the patient/carer dyad does need to be acknowledged as a deviation from the 'pure' IPA ideographic focus. In this respect, although clinical practitioners may have a desire to understand experiences from the dual aspect of both patients and carers, and such knowledge can build a picture which is greater than the sums of the parts, this dyadic approach does require such justification and acknowledgement. Including the accounts of patients and carers can better inform future practice.

Within the research situation there are acknowledged difficulties in interviewing patients and carers together. For example, Bowler (1997) and McLean et al (1991) both discuss the inhibitory effects the presence that one might have on the other. Although some stroke studies have combined both patients and carers in the same interview (Rittman et al, 2004; Alaszewski et al, 2004), and Simon and Kumar (2002) have questioned whether it is ethically correct to discuss stroke patients with their carers in their absence, it was decided that individual interviews would be most appropriate. It was felt that this would allow for freedom of expression and potential disclosure, that might not be possible if both parties were present. For this current study, separate interviews were also recommended by the ethics committee, as a means of accessing more open accounts - a view shared by Smith (2004). Both patients and carers were therefore informed that individual interviews would be

conducted, with the individual self-report diaries being used to potentially capture any further thoughts and feelings that might be inhibited during the interview process, as previously discussed.

A carer is defined by Crossroads (2010:1) as someone who provides ‘unpaid support to family or friends whose health or wellbeing would suffer without this help’. For the purposes of the study, a carer was also taken to be anyone who was nominated by the patient as their carer, and who was willing to be included. More specific definition details, regarding a carer being someone without whom additional statutory help would be required (Proctor, 2001), were not included because the use of a broader definition avoided excluding patients who might not have been (or felt) eligible for statutory support, had their carer not been around. Indeed, Low et al (1999) are critical of studies that do not give consideration to the definition of carers. This is understandable, given the confusion that can exist if definitions are not made more explicit. For example, Wallengren et al (2008) refer to informal caregivers as being family or friends, while healthcare professionals are also referred to as caregivers in the same study. Definitions that are clearer in differentiating between professionals and relatives or friends can help to clarify meanings and findings in such studies.

With further regard to definitions and terminology, the terms ‘stroke survivor’ and ‘patient’ are used interchangeably throughout this current study. It is acknowledged, however, that some people prefer the term ‘person affected by stroke’. However, such a phrase can refer to either a carer or a stroke survivor, and it was felt necessary to use terminology which distinguished between the two.

#### 4.13 Age

In addition to stroke studies that have focused on a particular type of stroke, other studies have chosen to look at survivors in certain age brackets. Stone (2007), Banks and Pearson (2003), Rödning et al (2003), and Bendz (2003) all chose to study younger survivors, arguing, for example, that ‘service provision is often geared towards older individuals, neglecting the particular needs and expectations of younger stroke survivors’ (Banks and Pearson, 2003:4). However, many of the recommendations made by Banks and Pearson (2003) could equally apply to people in other age brackets (for example, the need for home assessments prior to discharge, and improved information provision). Similarly, findings in the study by Stone (2007) into the experiences of young haemorrhagic stroke patients did not identify findings that could be considered specific to a particular age group; likewise with a review of young adults’ stroke experiences by Lawrence (2010).

Rolland (1989) discusses the fact that dealing with a newly diagnosed chronic illness may be viewed as more devastating if it occurs in the child-rearing phase of a person’s life. Rolland (1989:452) considers this to be due to the need to ‘preserve the momentum of a stable period’ following the birth of a child, rather than being thrown back into a ‘transition’ phase, as might happen with a new illness diagnosis. However, it could be argued that much depends on the nature and severity of the effects of the illness, as well as the timing of the event. As Rolland (1989:453) also discusses, chronic illness may well be expected in later adulthood, as one of life’s ‘normally anticipated tasks’. This is certainly evident in the words of the older participants in the study by Faircloth et al (2004:248), whose age created a ‘discourse of normality’ after their stroke. While Banks and Pearson (2003) do argue

the case for improved recognition of the issues facing younger stroke survivors, Almborg et al (2010) report that younger age of survivors was associated with higher health related quality of life, and associated benefits in relation to social activities. However, taking all these points into consideration, and as previously discussed, there are increasing moves away from standard retirement ages, with more people also having children later in life, sometimes in subsequent marriages (Klein, 2007). These trends mean that age related assumptions cannot necessarily be made about financial situations, dependents, or employment status simply because a person is in a certain age bracket. Indeed, a report by the Health Maintenance Organisations (2004:6) makes no distinction between 'non-aged' adults and 'seniors', because the challenges facing both on their transition to home are considered to be similar, regardless of age. With these issues in mind, the only age restriction placed on participants in this study was that they were over the age of 18 years, and therefore able to consent as adults. Whilst it is recognised that there may be stroke patients and carers under the age of 18 years, no potential participants in this study had to be declined on these grounds.

Also in relation to age, Banks and Pearson (2003:19) recommend that young stroke survivors should be visited by a stroke nurse 'within two days of discharge'. However, if this were different to the service offered to older people, such a strategy could potentially be challenged as age discrimination. Whilst it is acknowledged that younger survivors may statistically have longer to live with any disability, older people may be trying to adjust to a new disability in addition to other co-morbidities. As Green and King (2007) conclude, there has been little research into even minor stroke recovery in relation to normal ageing. Can it therefore be said that one group

has a greater need than another? A better strategy would be to encourage needs related assessments for everyone. With current trends and recommendations working to move emphasis away from age related biases (McLafferty et al, 2010), it would therefore seem more important that care is appropriate for the individual, whatever their age.

With further regard to age related issues, Buschenfield et al (2009) point out that the term 'young' can be used in a fairly heterogeneous way, with the studies they examined defining young as anything from under 50 years of age to under 75 years. There therefore seems to be little agreement about age definitions, with a similar situation appearing to exist in relation to older age: for example, Tierney (2006:789) refers to 'old' (over 65 years of age) and 'older old' (over 80 years of age).

It would be helpful if there was greater consensus with regard to such meanings, which could be referred to and used universally. Having said that, chronological and biological age differences can also be markedly different between individuals, and therefore adding additional information with regard to ability or restrictions can give the necessary explanatory detail to inform the reader further.

#### **4.14 Study location**

It was planned that participants would be selected from both a local acute stroke unit and a slower stream rehabilitation unit in the east of Scotland. Because patients with more deficits, including communication difficulties, might have a greater need for slower steam rehabilitation, it was felt necessary to draw the sample from both types of unit.

The geographical location selected comprises a mixture of large towns and more rural village settings. Although the study was not proposing to compare experiences of participants from different locations, there still needed to be an awareness of any geographical considerations that might be of interest or significance.

#### **4.15 Ethical considerations**

Although the proposed qualitative approach would not be putting participants at risk of harm from physical procedures, interviews still need to be regarded as interventions which affect people by laying open thoughts, feelings, and knowledge (Patton, 1990; Brereton and Dawes, 2003). However, it has also been acknowledged that participants can find engaging in such research therapeutic, due to the opportunity to share feelings with an interested but neutral listener (Walker, 2007). It was therefore hoped that those who agreed to contribute would find the experience positive.

Ethical approval was sought and granted by the local research ethics committee, and the local NHS authorities. Participants were to be approached initially by the ward staff, and given an information sheet with details of what the study involved. They would then have at least twenty four hours to read and consider whether they still wanted to take part, before being approached by the researcher. They were to be advised that if they felt upset or uncomfortable by the experience of diary keeping or interview, or indeed if they simply changed their mind, they would be free to withdraw from either or both activities at any time, without the need for any explanation. No rewards or incentives were to be offered to the participants who agreed to take part.

It was also planned that information would be given in written form, and backed up by verbal explanations from the researcher, so that potential participants had ample opportunity to ask questions, and fully consider the study before agreeing to take part. Details of the participant information sheet are given in Appendix 3, including additional information for those with communication or physical difficulties. A copy of the preliminary study ethical approval letter is shown in Appendix 4.

In addition to the above considerations, Behi (1995) argues that care must be taken with vulnerable groups, such as the elderly or those with cognitive deficits, to ensure that relevant information regarding a study is in a form comprehensible to them.

Because of the nature of potential stroke deficits, thought therefore had to be given to providing information in a form suitable for people with aphasia or visual impairments. Advice about font size, wording, and the use of colour was sought from the charity Connect, and the Fife Sensory Impairment Service. The researcher also attended a training course run by the charity Connect specifically relating to the inclusion of people with aphasia in research. Following such advice, font size 14, and type face Times New Roman were used for ease of reading, with even larger font sizes being available, if required. The use of spacing, bold font and underlined headings were also used when planning the layout of information for participants.

With regard to the planned approaches to, and consent from, participants with aphasia, it was felt that this might best be carried out by the speech and language therapist involved in their care. This would mean that there was an additional independent person ensuring they understood what the study involved, before they were introduced to the researcher. The speech and language therapist would also be



able to use pictures or diagrams to inform the participant, if these were considered necessary or beneficial.

Further to this, data protection legislation and local ethical protocols were adhered to, especially with regard to protecting confidentiality and data storage. To achieve this, numerical codes, rather than names or other identifying information, were to be attached to data, whether paper or electronic. All research documentation was to be kept in a secure place when not in use. Each patient's General Practitioner (GP) was also informed of their participation, and the GP letter is detailed in Appendix 5. The participant consent form is detailed in Appendix 6.

As will be discussed further below, there are inherent difficulties in having the inclusive strategies that this study planned, and the vulnerability of each participant needed to be considered before, during, and after the research process. These issues were discussed with the ethics committee, and strategies to deal with contingencies were put in place, such as the availability of support and information services, should these be considered necessary following, or as a result of, the research. However, with regard to other stroke research, not all the studies examined in the literature review gave evidence that such ethical considerations had been made, with some studies even failing to identify whether ethical approval had been granted (Kaufman, 1988; Doolittle, 1992; Thomas and Parry, 1996; Chest, Heart & Stroke Scotland, 2001; Banks and Pearson, 2003).

In further relation to this, there have been previous discussions regarding research studies requiring to have gained ethical approval and informed consent prior to being accepted for publication (Smith, 1997). However, according to Smith (1997) stroke studies have not always sought consent in the past. In addition to this, such rules do

not necessarily apply to privately published accounts, internet resources, or to research carried out in emergency situations (Bateman et al, 2003). However, it would seem vital that adherence to ethical guidelines, and the protection of potentially vulnerable participants, is not only achieved, but made transparent in written reports wherever possible (Finlay and Fernandez, 2008). Indeed, some NHS research guidelines and funding bodies now make this a requirement of support (Wiles et al, 2007).

Where there are concerns about the protection of participants, ethics committees can offer valuable guidance in relation to ensuring consent procedures seek to balance inclusion and opportunity against risk. One of the supervisors for this research project (CH) was able to offer valuable support in this respect, being an active ethics committee member in another geographical area during his time as a supervisor and mentor for the study.

With further regard to the protection of participants, care during interviews also needed to be considered. Although, for example, McNamara (2005:696) advocates ‘interrogating’ participants in phenomenological studies, in order to obtain their more in-depth reflections, such a technique may not be appropriate in research involving sensitive situations or vulnerable people.

If, indeed, the advice of McNamara (2005:698) to seek participants who are ‘hardy creatures’ able to withstand interrogation and challenges is taken, then the inclusion of vulnerable people, with nevertheless valuable narratives, would be prohibited. Perhaps an important distinction to make with regard to the principles of non-maleficence is that rather than the participants being interrogated, it is the transcripts

that can be 'subjected' to rigorous analysis, as advocated by Smith and Osborn (2003:66).

In relation to ability, cognition, and capacity to consent, guidelines and tools relating to the assessment of such ability were sought prior to the research taking place, to anticipate the possibility of their need. However, from this search for suitable tools, one issue that did emerge was that there seem to be few tools in use that relate specifically to assessing capacity to participate in, or consent to, research studies. Assessing such capability is of particular relevance in situations where potential participants have been affected by a neurological condition, with associated potential cognitive deficits. According to the Highland Council (2002:4) although stroke and head injury together are the third most common cause of incapacity, 'the assessment of capacity relating to decision-making is an art still in its infancy'. As Studer (2007) discusses, the highest levels of skill often depend on cognition, which incorporates executive function. However, Studer (2007) also observes that there is no consensus on a definition of what constitutes executive function. Hart et al (cited in Studer, 2007:128) consider executive function to involve 'a set of cognitive control functions used to organize and maintain goal-directed behaviour'.

The Mini Mental State Examination (MMSE: Folstein et al, 1975) is one tool which is referred to in some studies for assessing mental capacity (Nilsson et al, 1997; Rittman et al, 2004; Clare et al, 2008). However, whether this is an appropriate tool is debatable, because it tends to assess memory and cognition, rather than capacity (Highland Council, 2002). Stokholm et al (2005) argue that the MMSE test contains no measurement of executive function, and they explore the Executive Interview (EXIT 25) screening test as an additional measure for use where patients have mild

dementia. As Schillerstrom et al (2007) consider, executive functioning is multi-dimensional, and more specific tools like EXIT 25 may be required for such assessment. When compared with other competency assessment tools, they conclude that the EXIT 25 'was the only instrument to correlate with each decision-making capacity domain: understanding, appreciation, and reasoning' (Schillerstrom et al, 2007:159).

The EXIT 25 was devised by Royall (2002) as a suitable gauge, especially in relation to impaired decision making, the measurement of which, Royall claims, remains fixed in the 1950's. However, while there has been some debate regarding the length and relevance of all twenty five items in the test, Ingram et al (2006) conclude that the EXIT 25 is a valuable addition to the MMSE. Although much of the discussion in this field relates to dementia, Marson et al (2001) argue that similar issues apply in the case of other conditions, including stroke, and for this current study the researcher felt that these issues had to be considered ahead of the study taking place.

As already discussed, stroke survivors in this current study had been assessed using various tools by the hospital multi-disciplinary team as part of their normal care, prior to being suggested as potential participants. This served to ensure that their ability and suitability for involvement was being viewed by people out-with the research project, and tools such as the EXIT 25 were not required. Although this gave the hospital team a potential gate-keeping role (Lee, 2005), barriers in this respect were aimed to be kept to a minimum by advance communication and continuing liaison with the team throughout the project. A guidance sheet relating to the research was also given to the hospital staff prior to the start of the project (see Appendix 7).

With regard to the issue of confidentiality, assurances were to be given to participants throughout the recruitment and data collection stages that their identity would be not be revealed. Smith et al (2009:53) discuss the fact that this should be referred to as ‘anonymity’ rather than ‘confidentiality’, since the verbatim words of the participants are normally used in publications and reports, even although names and other identifying information are changed. The use of the word ‘confidentiality’ is often used to signify this in publications (including earlier work by Smith: e.g. Smith, 2007). However, the distinction made by Smith et al (2009) would seem to be a more accurate use of terminology, and one which perhaps needs to be more widely adopted.

#### **4.16 Rigour**

As previously discussed, there has been much debate about how the quality of qualitative research can, and should, be measured (Barbour, 2001; Koch, 2006). While Rolfe (2006) discusses the fact that the alternative terms used by different authors may have very similar meanings, it is still important that criteria are specified, whichever terms are used. As has already been discussed, terminology can be misunderstood if not made explicit. With regard to quality, for example, Sandelowski (2006:643) argues that the term rigour itself should convey ‘quality in craftsmanship’ rather than the ‘methodological rigidity’ it may be mistakenly taken to mean. What is most important is that the terms used reflect, illustrate, and encourage high quality research practice (Rolfe, 2006).

With further regard to this, Smith et al (2009) suggest the use of criteria advocated by Yardley (2000), namely:

- ❖ Sensitivity to context
- ❖ Commitment and rigour
- ❖ Transparency and coherence
- ❖ Impact and importance

Each of these four broad principles is discussed in further detail below, with brief notes on how each might be achieved in this study.

#### **4.16.1 Sensitivity to context**

Sensitivity to context starts with the rationale for the choice of IPA as an approach which, in itself, encompasses the need for sensitivity to participant narratives, and the context in which they are given.

In the analysis, the co-construction of insightful accounts can give evidence of this and, in particular, can be ‘heard’ in the verbatim extracts used to illustrate themes. Sufficient details about the participants and the location of the study (whilst still preserving anonymity) need to be given.

Sensitivity to context can also be illustrated by the appropriateness and relevance of references to other studies and literature, and the work of other researchers in closely related fields. Yardley (2000:219) refers to this as the ‘context of theory’.

#### **4.16.2 Commitment and rigour**

Commitment and rigour can similarly be illustrated by giving attention to the detail and care with which the study has been carried out. This involves giving sufficient

detail of the data collection methods, and how any challenges within the collection process were met. An honest account of how any deficiencies were dealt with can also help with asserting the rigour of the study. Commitment can also be evidenced in a reflexive account which details the researcher's area of interest, and reasons for conducting the research. Commitment and rigour extend to the writing up stage, which needs to include evidence supporting how interpretations have been made, and linked back to the individual accounts.

#### **4.16.3 Transparency and coherence**

Again, these elements link into the detail of each stage of the research process, which need to provide sufficient clarity of the individual parts within the study as a whole. Coherence should not only be evident throughout the specific sections of the study write-up, but also within an overall sense of how well the findings and arguments hold together in a logical flow, which is credible and also holds true to the principles of IPA.

#### **4.16.4 Impact and importance**

The impact and importance of the study can be displayed through the final discussion and conclusion sections of the write up. It is therefore vital that due attention is paid to this part of the study, which can be used as an opportunity to consider relevance to practice, contribution to theory, and recommendations for practice or further research.

In addition to these four principles, Smith et al (2009) also recommend independent audit, as a means of improving credibility. Whether this is actual or virtual,

nevertheless the availability of a distinct 'paper trail' (Smith et al, 2009:183) should be evident throughout the study report, and any steps taken to include independent evaluation, for example by an external critical commentator, should be detailed.

Considerations regarding how this study has met these requirements will be discussed in the overall conclusion section of the thesis, but are also present for the reader to judge during the write-up of each section.

With further regard to previous arguments relating to whether participant feedback should be used to improve the validity of analysis, Clayton and Thorne (2000) offer a verification tool to check findings with participants. Although the use of this tool was considered during the conceptual stage of the project, heed was also taken of the comments of authors who do not consider verification of findings by participants as appropriate (Sandelowski, 1993; Webb, 2003).

While Bradbury-Jones et al (2010) argue that participant validation can be helpful, it is also worth noting that the particular group of participants Bradbury-Jones et al (2010) refer to is a group of student nurses. Apart from the arguments given by Sandelowski (1993) about the difficulty of incorporating disagreements in relation to findings into the study (if such feedback is sought), it should also be borne in mind that such a strategy may not be as useful or possible with frail, vulnerable people.

Taking these issues into account, and given the potential vulnerability of some of the participants, it was therefore decided not to revisit them to discuss findings, but simply to offer participants the opportunity to check their own transcripts for accuracy, and to send them a short report on the overall findings at the end of the study.



(Post script: During the course of the research process, some of the participants were readmitted to hospital, and three died, which reinforced this decision as an appropriate one, in the circumstances. A further point worth noting is that if the data collection had taken place at a later time, as in the case of some of the other studies mentioned, then the views of these participants would not have had the opportunity to be heard).

#### **4.17 Transcription of data**

Once the data were all gathered, the task of analysis would be able to commence. However, prior to this, thought had to be given to the transcription of data into a form suitable for analysis. It was anticipated that there might be a broad range of ability to contribute amongst the participants, which might be reflected in the data collected. However, all contributions were to be dealt with in a broadly similar way, with diaries and interview tapes being transcribed verbatim either by the interviewer, or by one of the local research and development team. As previously stated, anonymity was to be protected by the removal of any identifying information from the transcripts. Where this needed to be done in the transcripts, square brackets were inserted into the extracts to indicate the type of information that had been removed (e.g. a name or place). Where appropriate, if a participant's name was to be used in a quote, then this would be replaced by their study pseudonym.

Although the same level of detail that might be required for conversational or discourse analysis was not required in the transcripts (Braun and Clark, 2006; Smith et al, 2009), some specific details were to be noted. For example, the transcriptions would include indications of pauses, and notes on any emotions being expressed (e.g. tears, sighs etc) during each interview. As Fleming et al (2006) discuss, because

non-verbal expressions are part of our understanding, they should be considered part of the overall text. In addition, Hayes (1993:24) asserts that ‘fillers’, such as ‘err’ and ‘umm’, can indicate uncertainty about what participants are trying to say.

According to McNamarra (2005), hesitations, re-iterations, and lack of fluency can all be characteristic of extracts from phenomenological studies, where thought and reflection is being put into answers. They may also indicate that the participant is not working from a well-rehearsed script or using pre-planned answers. In addition to these considerations, pauses and hesitation were also expected if people were having stroke related word-finding difficulty.

Such additional information in the transcripts can serve as reminders to the analyst of how the participant was approaching the subject during the interview. Any particular emphases that were placed on words by the participants were therefore to be underlined, and any words that were said loudly or shouted were to be written in capitals, as a reminder. These strategies can help during the analysis process to identify points that may have had particular importance for the participant in question. Having said that, where utterances (either by the interviewer or participant) were considered to be natural and of no particular significance (judging by the surrounding words, topic, or non-verbal body language), although these were to be noted in the transcripts, for ease of reading and flow they would not necessarily be included in the chosen participant quotes (Watson, 2006). As Smith et al (2009:74) discuss, ‘notable’ utterances, or those which give a sense of hesitancy or uncertainty, for example, do need to be included. Full details of the transcription format are given in Appendix 8.

Once complete, all the transcripts were to be re-checked against the original audio recordings. This would help the researcher to 'hear' the participant's voice within subsequent re-readings of the transcripts. For the participants with minimal speech, hearing their limited utterances would also be important in gaining a sense of context and meaning.

The transcription of diary entries was considered necessary for ease of reading and subsequent coding, given that the entries might not always be easily legible in some cases, due to either stroke related weaknesses, or other debility. As Watson (2006:373) discusses, commas and full stops can be inserted where appropriate in transcripts to 'aid understanding and readability'. If there was any doubt with regard to meanings, the original tapes could still be listened to again, and it was envisaged that this would be done at various stages during the analysis process.

Paying such detailed attention to the transcription process can be a good starting point for becoming more familiar with the data. Notes could therefore be made if ideas came to mind even during the early stages of the analysis process.

As noted above, field notes were to be kept throughout, and these could include some initial thoughts, ideas and emotions felt by the interviewer during the actual data collection process. The notes could also include information about the body language observed during the interviews. Such additional information can add significantly to the overall impression gained by the interviewer. As Hayes (1993:25) discusses, if the non-verbal message contradicts the verbal message 'we are five times more likely to believe the non-verbal message'. This is attributed to the fact that non-verbal clues are often unconscious, and therefore may more readily indicate the real attitudes or feelings of the speaker. Field notes can also help to situate the

data, in that they can bring back a sense of the atmosphere and environment in which the data were collected.

Although it was inevitable that some initial impressions would be gained, and notes made during the data collection phase, it would not be until all the transcripts were complete that the process of in-depth analysis would be started in full. The interviewer also had to be mindful of not allowing any initial impressions from one interview to influence her questioning or probing in subsequent interviews, and to approach each participant as having a unique and individual story to tell. In brief, the field notes, and reflective diary kept by the interviewer would all form part of the overall analytical and reflexive process, which will be discussed in greater detail when the research results are summarised in the concluding chapter.

#### **4.18 Analysis**

As discussed in the previous chapter, the process of analysis in qualitative research studies can be a complex and challenging process. IPA offers a flexible structure with which to approach analysis, and the specific guidelines are summarised in Figure 18 below.

### Analytical process

- Read the transcript through several times, making notes and comments
- Identify and label emerging themes and meanings within the text
- Relate back and link themes to quotes in text, using a cyclical process
- Look for potential links between themes that may lead to master/super-ordinate themes
- Repeat the process with subsequent transcripts
- Connect/cluster the themes from the texts into super-ordinate themes, with related sub-themes
- Examine texts more closely for greater detail of meaning and interpretation
- Produce a summary table of themes for the group, and a detailed, interpretative, reflexive written account

**Figure 18: Overview of analytical process** (summarised from Smith et al, 2009)

As has previously been discussed, studies involving in-depth interviews can generate an amount of data that can appear quite overwhelming initially (St John and Johnson, 2000; Barbour, 2008). However, as the analysis process develops, certain connections, themes and sub-themes start to emerge.

Van Manen (1997:87) describes a theme as a form of accurately ‘capturing the phenomenon one tries to understand’. However, he also cautions that a theme is always a ‘reduction of notion’ (van Manen 1997:88) that cannot completely unlock or capture the full meaning. Skill and interpretation are therefore required on behalf of the researcher to produce a persuasive account of how these themes have emerged.

The process of theme production involves putting a label or category to words, phrases or paragraphs to identify specific similar meanings; in this way themes can evolve and may be considered through discussion amongst the research team, to limit the influence of bias or pre-conceptions, and open up different possibilities. During the process of developing emerging themes, connections will also become apparent, with certain themes acting ‘as magnets, pulling other themes towards them’ (Smith et al, 2009:96). Thus clusters of similarity will develop, and additional themes, which fulfil different functions within the transcripts, will become clearer.

According to Braun and Clarke (2006:92) sub-themes can help to give structure to the analysis, and also demonstrate the ‘hierarchy of meaning’ within the data. In addition to this, Braun and Clarke (2006) argue that the relevance of a theme is not necessarily associated with how frequently it is used to explain meanings within transcripts, but rather how well it captures something of importance to the overall topic of investigation.

As Thompson and Ryan (2009) discuss, there may be overlaps and interrelations between themes. However, this is not surprising given the often complex nature of the experiences involved, and the somewhat artificial process of dividing people’s life stories into discrete sections. The challenge for analysts is therefore to use their skill to bring the accounts together to ‘succinctly capture the essence’ of the experiences related to the project (Smith et al, 2009:111).

Caelli (2001:278) describes the complex task of ‘deriving narrative from transcripts’ as not being as straightforward as is often assumed. However, although Caelli (2001) constructs a narrative from each individual account in her study, forming one narrative from multiple accounts is potentially an even more complex task. Having

said that, the initial undertaking is to examine each transcript as an individual account, therefore being analysed 'within case before moving to a cross case analysis' (Smith 2007:8)

Although the examples can be very individual, the aim of the analysis is to reveal certain commonalities across the studies, when they were considered together. It is the commonalities drawn from the accounts of participants that leads to a more powerful understanding of the experience as a whole, and helps the formation of master or super-ordinate themes (Smith et al, 2009).

It was therefore anticipated that common themes (and divergences) would emerge during the analysis process. These convergences and divergences might be between stroke survivors, between carers, or between survivors and carers. As with other such studies, there is a certain tension between maintaining and championing the individual account, against commonality of experience. However, by looking at commonalities, divergences can also become clearer and allowed to surface (Smith et al, 2009).

Alaszewski et al (2004) argue that a focus on the individual is necessary to ensure personalised care, and an understanding of the unique circumstances of each person. Where commonalities exist between participants, these can be understood in a way that enhances the care and understanding of the individual. This link between the group and the individual is a circular process not dissimilar to the double hermeneutic evident in the analysis process.

Oppenheim (1996) considers that free response questions require their own classification scheme, and are therefore rarely able to use a coding frame, or themes derived from another inquiry. However, he also cautions that whilst tentative coding frames may be produced during the pilot stage, they may be unrepresentative of the results of the main study, which may require a different coding frame. It was therefore planned that the data set for each part of the study (preliminary and main studies) would be analysed separately from each other. Greater specific detail of how themes were developed and connected will be given in relation to the main study, where the analysis and interpretative process was engaged in more fully than in the preliminary study, which was used as more of a 'trial run' to explore working with the methods, the participants, and the data.

#### **4.19 Summary**

In conclusion, this chapter has specifically defined the method to be used in the overall study, and the reasoning behind the decisions that were made in relation to method, by the researcher. Greater detail of the transcription and analytical processes has been given, and tensions within the method examined. Considerations in relation to the inclusion of people with various deficits have also been explored

The following chapter will discuss the value and purpose of the preliminary study in setting the scene for the more major and interpretative main study. Findings from the preliminary study will also be given in the next chapter, alongside any recommendations made for revision to method for the main study, as a result of the preliminary study.



## CHAPTER 5

### Preliminary study

#### 5.1 Introduction

This chapter will discuss the preliminary study, detailing the participants and findings from this part of the study. The inclusion of people with communication difficulties will also be explored.

Sarantakos (2005: 255) describes preliminary or pilot studies as ‘trial’ or ‘miniature preparatory studies’ used to ensure that the planning and content of the main study will be appropriate and reliable. Such studies can identify:

- Unclear or misleading questions
- Administrative and organisational problems related to the whole study and its respondents
- Whether any changes or adjustments are needed
- Any ‘fine tuning’ required before the main study begins

The importance of a pilot study is also stressed by Oppenheim (1992). He argues that inadequate pilot work can result in unnecessary work or misguided attempts, and that researchers may find that ‘a great deal of effort has been wasted on unintelligible questions, producing unquantifiable responses and uninterpretable results’ (Oppenheim, 1992: 64). Indeed, Kezar (2000:385) discusses the contribution a pilot

study made in allowing ‘many meaningful revisions’ to the theoretical framework and methodology of her main study.

Taylor (2007) goes further than this, and suggests the ‘pre-pilot’ or feasibility study as a means of clarifying the suitability of the proposal, even before a pilot study is embarked upon. She suggests that research projects can struggle if certain variations are not taken into account, advising that feasibility in relation to several factors will increase the likelihood of a successful study.

Feasibilities that may require consideration include technical, economic, legal, collaborative or operational issues (Taylor, 2007). However, once these issues are addressed, the aims of a pilot study will become clearer, and the probability of fruitful results greater. Sarantakos (2005:256) lists the following as potential goals of pilot studies:

- To estimate the costs and duration of the main study
- To test the effectiveness of the study’s organisation
- To evaluate the suitability of the research methods and instruments
- To ensure that the sample is appropriate
- To gauge the level of response and type of drop-outs
- To ascertain the degree of diversity of the survey population
- To familiarise researchers with the research environment
- To offer an opportunity to practise using the research instruments before the main study begins
- To assess the response of the subjects to the overall research design

- To discover possible weaknesses, inadequacies, ambiguities and problems in all aspects of the research, so that they can be corrected before the main data collection takes place

In addition, Oppenheim (1992) suggests that respondents in pilot studies need to be as similar as possible to those in the main study. However, he also advises that members of special groups, who might not readily appear in the smaller numbers a pilot study generally involves, be sought out to ensure that the questions being asked work for them too.

Taking these issues into consideration, a preliminary study was proposed to answer the research question:

**How do stroke survivors and their carers experience the first weeks at home following discharge from hospital?**

The aim of this part of the study was therefore to trial an investigation into the experiences of stroke survivors and their carers/family during the early post-discharge period, and to examine the type and quality of data that would be possible. By exploring such experiences and identifying key features, the proposed outcome was an improved understanding of such experiences, which may inform and enhance clinical practice. In their study Banks and Pearson (2003:16) state that ‘returning home brought with it a new set of problems as the reality of stroke, impairment, and changes in their day to day living became apparent’. However, this period of time was not the main focus of their study, and the exact time referred to was not

identified, with many of the participants having been home for some time when data were collected.

This chapter discusses the findings of the preliminary study. It will detail the challenges faced by both the researcher and the participants, with particular reference to those with communication problems, and their carers.

Data for this part of the research were collected during 2007-2008, and details of the study have been published in the *British Journal of Community Nursing* (Pringle et al, 2010).

## **5.2 Participants**

As discussed in the previous chapter, it was planned that four patient/carer dyads would participate in this part of the study, by completing a diary and taking part in an in-depth interview. According to Smith et al (2009) numbers of participants in IPA studies can be fairly small, due to the depth of analysis sought. This number of participants for a preliminary study could therefore be considered to be quite large. However, the possibility of including participants with significant communication difficulties needed to be explored further, and the type of data that might be generated identified. The literature review revealed that including such participants had not been widely considered previously, and therefore there was limited evidence on which to base the proposed course of action. As detailed in the previous chapter, many issues in relation to this were considered ahead of the study commencing.

Once the preliminary study had gained ethical approval, the hospital stroke teams were asked to make an initial approach to potential participants, and explain briefly

about the study. This was generally done once a discharge plan had been put in place, with the discharge destination (i.e. home, in the case of potential participants) having been agreed upon, and a predicted date of discharge set. As discussed in chapter 4, the inclusion criteria were used in this process, and the study had been discussed with the hospital teams in advance of this happening. If patients then expressed an interest at this stage, they were then approached by the researcher, and were also given the Participant Information Sheet (Appendix 3) to consider, and discuss with their relatives. Over the following two to three days they were then spoken to by the researcher again, who explained the study in greater detail, and answered any questions. If they agreed to take part, consent forms were then signed (Appendix 6), with a copy being given to each participant; the original was filed in the medical notes, with another copy being held by the researcher. This whole approach was in accordance with the Ethics Committee guidelines, and allowed potential participants adequate opportunity to consider their options, ask questions, and have the choice to decline involvement, both during discussions with the hospital team, and again with the researcher.

The role that the hospital teams might play in acting as ‘gatekeepers’ (Lee, 2005: 36) has already been discussed in the previous chapter. It was considered important that their judgement in selecting participants who would be medically fit to participate was taken, although it needed to be similarly acknowledged that this might not be without bias.

Although four patients were fairly quickly identified, unfortunately one participant’s discharge was delayed due to further medical problems, and another participant had

to be sought. Details of participants who took part are summarised in Figure 19 below.

<b>Participant</b>	<b>Survivor Or carer</b>	<b>Completed Interview</b>	<b>Completed Diary</b>	<b>Communication problems</b>
Andrew	Carer	Yes	Yes	No
Julia	Survivor	Yes	Yes	Minimal
Colin	Survivor	Yes	No	No
Barbara	Carer	Yes	Yes	No
Connie	Survivor	Yes	Yes	Yes
Mary	Carer	Yes	Yes	No
Bert	Survivor	yes – using expression mat	yes – using expression mat	Yes
Rose	Carer	Yes	No	No

**Figure 19: Preliminary study participants** (using pseudonyms)

As the above figure shows, all the participants took part in the interview process. However, although all participants had agreed to keep a diary at the time of consent, following discharge two participants subsequently felt unable complete a diary: one for personal reasons and the other (a carer) due to recent physical difficulties. There is always the possibility in research, especially with potentially vulnerable people, that participants may not all be able to complete every part of the study (Barbour, 2008), but the data that can be contributed is still valuable, and adds to the overall pool of information.

Interviews lasted between forty and seventy minutes. Participants ranged in age from 42-84 years, with all the survivors being over the age of 65 years. As stated in chapter four, participants had been in hospital for a minimum length of one week, and were given adequate time to consider taking part. All participants were of white British cultural and ethnic background, and from a range of educational backgrounds. To help preserve anonymity, further details are not given; as Vickers (2003:88) argues, it is ‘their story, their experience, and their responses’ that are of interest, rather than explicit personal details. Although additional information may become apparent from their quotes, it was considered important to mention only such detail as might add meaning if, and as, required.

As previously discussed, for the two participants with significant communication difficulties (Connie and Bert), this was rated using the FIM+FAM scoring system (Turner-Stokes, 1999), as detailed in the previous chapter. Details are noted in Figure 20 below.

<b>FIM+FAM scores:</b>	<b>Connie</b>	<b>Bert</b>
● Comprehension	6	6
● Expression	5	2
● Reading	5	5
● Writing	5	1
● Speech intelligibility	4	2

**Figure 20: FIM+FAM scores for preliminary study participants** (using pseudonyms)

Connie did not require practical assistance in the form of pictures to express herself, but did need additional time and reassurance; repeating back techniques were also used to ensure the researcher had understood correctly.

Bert had such limited verbal ability that mats with pictures and diagrams were required. For his diary entries, these were completed and photographed with assistance from the speech and language therapist. During the interview, the mats were completed with the assistance of the researcher, who again made frequent efforts to confirm that she had understood what he was trying to convey throughout the interview. Bert was able to confirm by saying 'yes', nodding, or making other affirmative gestures such as giving a 'thumbs up' sign. Similarly, when he disagreed, he was able to say 'no', shake his head, or make a 'thumbs down' sign.

It was considered important that the way in which potential participants with communication difficulties would be able to confirm or deny concordance with the researcher's understanding of their responses was considered ahead of their involvement.

In common with other participants, the interview with Bert was tape-recorded, so that the accompanying conversation could be related to the mats. As previously mentioned, this was particularly useful when referring back at a later date.

Two attempts at the interview with Bert had to be made. During the first attempt, Bert was quite tired, and other people were present. Both of these issues seemed to pose an inhibitory effect on both him, and the interview process. A second attempt carried out at a more suitable time, and with just the researcher and Bert present, proved much more successful. During this second attempt, fewer visual images were



presented at any one time, which also seemed to help Bert identify what he wanted to impart. If visual processing has been affected by a stroke, one of the strategies used to combat this is to limit the amount of information presented at any one time, and advice in this respect was sought from a visual specialist. At the same time, however, researchers still need to be mindful of not leading the direction of the responses, but rather to facilitate the expression of the participant's unique experience, albeit with assistance. As Gordon et al (2009) discuss, it can be difficult for people with aphasia to take the lead in a conversation, or to change to a new topic. A careful balance therefore needed to be struck, and the preliminary study allowed such practical aspects to be considered and trialled, and gave the opportunity for the researcher to gain a feel for the nature, quality, and quantity of data that could be generated from such a strategy. Points worth noting in relation to the inclusion of participants with communication difficulties that were identified from this preliminary study are summarised in Figure 21 below.

### **Considerations for the inclusion of participants with communication problems**

- Try to plan a quiet place and time to conduct the interview
- Be prepared to make more than one attempt and allow plenty of time
- Establish how agreement or disagreement will be indicated (e.g. ‘thumbs up’, making other moves or gestures)
- Enlist the support of a speech and language specialist, at least initially, if this is not the researcher’s area of expertise
- Try to plan the visual images to be relevant to the participant and/or include some blank cards
- Repeat back what has been understood to allow the participant to confirm or disagree
- Be prepared to use some guess work, and get it wrong!
- Be alert to potential participant fatigue
- Be aware of the possible need to limit the amount of visual information presented at any one time
- Record the verbal conversation that accompanies the interview, even if it is one-sided. Indicate in the taped conversation when photos are being taken
- Have a back-up camera for use in the event of main camera failure
- With regard to diaries, if using an expression mat, organise ahead of time who will assist with, and photograph, diary entries, if the participant is unable to do so themselves
- Developing empathy and a good rapport with the participant can allow them to become co-contributors, as their views are explored, even if verbal participation is limited

**Figure 21: Considerations for the inclusion of people with communication difficulties in research**

### **5.3 Analysis and findings**

As discussed in the previous chapter, interviews and diaries were transcribed and analysed, using IPA guidelines. Tapes were listened to carefully, and transcriptions read several times. Notes and codes that might relate to potential themes were made on the transcripts at this stage. This process was repeated with each transcript, until a bigger picture had been built up, and themes started to emerge with greater clarity. Thought was then given to how these themes might be grouped or linked together into master or super-ordinate themes that still related to and reflected a sense of the meanings participants were referring to, either explicitly or implicitly. It was important to find commonalities between the participants, while still preserving the uniqueness of their individual accounts, through the inclusion of their words to illustrate how each theme applied to their own situation.

There was some blind coding done with the transcripts of two participants by a member of the study supervisory team, before a meeting took place to discuss and agree potential themes more fully. Although slightly different names had been used for the potential themes, there was a broad agreement about the types of issues that were identified. Having such team or supervisory members to discuss potential themes with is an important aspect of credibility: if the themes do not resonate with people who are familiar with the research, then they may be even less likely to make sense to an external reader, who is encountering the study for the first time. There may not be full agreement about the themes, or even theme names, but other parties do need to be able to grasp how and why the themes were generated. Because this was a pilot study, it was not considered essential (and neither was there the time) to take the analysis into the degree of depth that would be required in the main study. It

was recognised that a much more thorough and complex process would be necessary for the main study, not only because of greater participant numbers, but also because of the greater depth of interpretative analysis. However, it was planned to use the information from this part of the study as supporting data for the main study; the opportunity to trial the methods, and examine how themes might be derived, and then further developed into main (or super-ordinate) themes, was still considered a very valuable exercise, especially considering the complexity of analysis required in an IPA study. As Murray et al (2003) discuss, due to the shared nature of experiences and problems, findings can be combined in the analysis; however, the approach of IPA allows not only for commonalities, but also divergences to be highlighted, as previously discussed in chapter 4.

Some initial discussion relating to the findings for this part of the study is given here, and summarised in Figure 22 below. Example extracts are also given from the transcripts to illustrate each theme, and these excerpts allowed the researcher to gather an impression of how the circular process of relating themes back to the words of participants could be achieved (Smith et al, 2009). Super-ordinate themes are noted by italics, and sub-themes are underlined, for ease of identification.



As can be seen from the above figure, for these participants returning home involved the processes of *fathoming out* the new situation they found themselves in, and the closely related theme of *adapting to stroke* and the consequences; the *value of support* was also a theme that emerged across participant's narratives. These main, or super-ordinate, themes were present in the accounts of all participants, whether they were survivors or carers. Sub-themes were identified in relation to the super-ordinate themes, and within these sub-themes, some differences emerged between the accounts of carers and patients, and male or female accounts. Super-ordinate themes and sub-themes are further expanded upon below.

One additional point that became clear when the transcripts were being worked on, was the fact that occasionally there was a need to insert explanatory comments or translations of colloquial language in square brackets within the quotes, as will be illustrated below.

### **5.3.1 Fathoming out**

From the diary accounts and the interviews, participants were questioning and trying to work out their new situation, whether they were a survivor or a carer; this involved finding out about physical limitations, making various comparisons, and *fathoming out* new emotional responses.

#### Physical limitations

The impact of physical limitations seemed to become real for the participants now they were home: '*You don't realise how much you use a thumb...even just your thumb*' (Julia, survivor, interview).

*'The first thing I noticed was the door keys..and I couldn't understand'* said survivor Colin, in relation to physically trying to open his front door.

Connie, who had speech and writing difficulty, commented in her diary on specific letters that were causing difficulty: *'F and R are hard to do'*, and in her interview mentioned how she was physically much slower now: *'I want to hurry..but...you can't'* (Connie, survivor).

Physical limitations also had an impact on carers. In her diary, Mary (carer to Connie) commented: *'I had left soup in a pot as Mum felt she wouldn't be able to use a tin-opener (she had managed OK with the tin of soup with a ring-pull on it)'*. This illustrated that thought had to be put into even small physical tasks, and that simple changes could make the difference between managing or not.

Another carer (Andrew) wrote in his diary about feeling the need to intervene when he thought his wife (Julia) was trying to do too much in the way of physical work: *'she wants to do chores around the house and I had to tell her to sit down when she insisted on clearing out the laundry cupboard'* (Andrew, diary).

At this stage, Julia had only been home for about 24 hours, so the impact of physical limitations was presumably still sinking in. Several days later, in her own diary, Julia commented that she was *'not a person who takes things slow. Now I have no choice, but I don't have to like it!'*

### Making comparisons

Comparing their new situation to either their previous ability or to others also seemed to be an important aspect of trying to fathom out where they were now, either as a survivor or a carer.

Survivor Connie commented *'I was always...on the go'*, and her carer (Mary) also said *'she's always been the person who would come over and dust around your house'*. These participants seemed very much at the stage of making comparisons between their previous lives, and the new situation they found themselves in now.

For another survivor (Colin) and his wife (Barbara), the comparisons between a previous stroke and this second stroke were marked. Barbara commented: *'the first stroke I coped quite well. I thought I did anyway....but this time I just haven't been coping at all'*. Colin related this to a reduced ability to do things they had both previously enjoyed, like dancing, even after the first stroke: *'where afore [before] I was actually getting to the stage I loved to put the music on and we were dancing..in here..like..just to try and show that I was okay'*, and now: *'but when the other attack [happened] I couldnae [could not] do that'*. The disappointment for both of them when making these comparisons was evident, with Barbara weeping while she was describing the differences during her interview.

Comparisons with others seemed to give a benchmark measure with regard to their own situation. In her diary survivor Julia wrote *'...realise other people far worse than me'*, and at interview: *'the state those other ladies were in, what am I moaning at?'* and *'I got off very lightly'*. Her carer (husband, Andrew) seemed to be of a similar frame of mind: *'because it's this lesser degree I think, well you can do...work it out, as I say, day to day'*. This was despite the fact that from the researcher's professional standpoint, Julia had quite significant physical deficits.



For another couple, some of the comparisons were to do with changes in the physical set up in their house. When asked about the difference in the house, survivor Bert, who had minimal speech, was very emphatic in his agreement about the difference, when asked by the researcher: 'Aye! [yes]' he stressed. However, he selected a picture to indicate he was still quite content about the situation, when asked about his feelings. His wife (Rose) on the other hand, was slightly less happy at having had to get rid of furniture, and now having a hospital bed in her sitting room: *'the rest are in storage because we hadna [hadn't] room..it's..it's too narrow...however we're managing but it's..it's no nice'*, and although she laughed at this stage, to the researcher it seemed to be with a resigned air. Rose also commented during her interview on the changes brought about by having carers coming in now: *'at first..um..it was everybody coming in, but I've got used to it...so it's no the same..but it's for him getting home...it's for his sake'*.

In common with survivor Julia, the changes in the house seemed to mean more to these two women than to their male partners, who made scant reference to it. As Julia said in her diary: *'No Christmas spring clean this year. Shut eyes – don't look. But driving me mad. Having house like this'*.

### Emotional changes

The difference in emotional responses while participants were *fathoming out* their new situation also highlighted a difference in the way the genders reacted in this small sample. Although both the male and female accounts showed evidence of frustration, this was displayed as outright anger by all three of the male participants, whether they were survivors or carers: Survivor Julia wrote in her diary about how her husband *'gets angry with me ..shouts at me'*, but in her interview she did not

refer to this outburst at all. This gave the researcher the impression that it possibly did not have a lasting impact on her, because of the fondness in her voice when she spoke about her husband during the interview. Another carer (Rose) also appeared to accept the anger as expected: *'he gets angry...of course, but I say "you're doing well" but he hasn't the patience (laughs)'*.

However, Barbara (carer to Colin) appeared to find the anger much more difficult to cope with. In her diary she reported how her husband *'completely lost the head'*, and again in the interview she re-iterated how he *'just went crazy'* and how upset she still was at the time of the interview, a couple of weeks later, crying as she spoke. Her husband (Colin) also admitted in his own interview that *'I've been bad with temper'*.

Apart from these expressions of anger, the mixture of different negative emotions people reported during their adjustment was quite vast, even in this small sample: resentment, frustration, boredom, being fearful, tearful, feeling silly, upset, choked up, experiencing a loss of confidence, temper, being on-edge, feeling friction, being moody, weepy, worried, impatient, guilty, feeling useless, dependent, stupid, alarmed, uncertain, concerned, nervous, tentative, traumatic, panic, dread, and difficult to come to terms with, were all words mentioned by participants at some stage in their diaries or interviews. With the use of pictures, Bert also selected feelings of disappointment, annoyance and embarrassment during his interview. Illustrative mats from the study are shown in Appendix 9.

To give some examples of how these emotions were expressed, carer Andrew wrote in his diary of his feelings on the first day his wife got home: *'she fell asleep*

*immediately after tea, which was a bit alarming*'. Rose also described her worries on the first night her husband got home, because the new hospital bed seemed so narrow: *'I thought "he's going to fall out of the bed" ...so I sat on the chair and thought "oh dear" ...because of that... "what's going to happen?" ..because I couldnae [could not] lift him up anyway...so..er...I just..sort of slept on the chair'*.

The emotions carer Barbara expressed were: *'I've got full of resentment'* (during interview) which appeared to be related to her diary admission that she was *'frightened to leave Colin in case something happens'*. This was re-iterated in her interview: *'when I'm away I'm frightened...it's fear in case he has another stroke...it's really..ach..how can I explain it..it's just terrible fear'*. During her interview, the fear and the restrictions this had on her own life seemed closely linked to the resentment she felt.

Survivors were also fathoming out new emotions: *'When I came home..eh..well the biggest thing I felt was useless..to be honest...absolutely useless'* (Julia, interview).

One of the two survivors with communication difficulties (Connie) alluded to the sadness she sometimes felt: *'I don't like to get sad about my condition'* and *'I'll never get it back, my voice...I don't think'* (sounding pensive and downcast), while Bert, using the expression mat, selected resentment in relation to his lack of speech.

Although such negative emotions far outnumbered the positive emotions that were written or spoken about during these early days, there were still instances when positive emotions surfaced. Carer Mary, for example, described taking her mother

(Connie) on a trip out for lunch in her diary: *'It was obvious how much she enjoyed her meal. It was really reassuring to see how relaxed she looked and happy to chat to me while she ate'*. Humour also emerged in other accounts: for example, survivor Julia joked *'..not that they actually found a brain when they did a scan!'*

Several patients and carers mentioned how good it was to be home: *'lovely to be in my Bed'* (Connie, survivor, diary entry); *'My wife got home at 4 p/m today. Good to be home, getting a decent meal and relaxing in her own home'* (Andrew, carer to Julia, diary).

The two participants with greater communication difficulties (Connie and Bert) particularly expressed their happiness at being home, and this may have been connected to the fact that they had spent the longest time in hospital. Indeed, there was some doubt expressed by their carers about whether they would either get home at all, or manage once home: *'..if he hadna [hadn't] have come home he was going into a...a nursing home'* (Rose, carer to Bert, during her interview).

*'After 8 weeks in hospital, it is great that Mum is finally going home. I have mixed feelings though. I feel so glad for her to be able to get back home to her own familiar things around her, but I also feel anxious about how she is going to manage on her own, particularly communicating with people'* (Mary, carer to Connie, diary).

### 5.3.2 Adapting to stroke

As previously mentioned, the theme of *adapting to stroke* was closely related to the fathoming out process, but was associated more with the progress participants made in their adjustment. As Andrew stated at his interview *'I think the main problem is...learning how to deal with the stroke'*. The sub-themes of managing firsts, balance of caring, back to basics and hope were all aspects which featured in this adaptation process.

#### Managing firsts

How incidences and tasks were approached and dealt with the first time they were encountered after coming home was mentioned quite a number of times:

*'..it was upsetting to her the first time, but getting the "first times" out of the way seems to be the way forward'* (Carer Mary, discussing her mother Connie's attempts to try and communicate with people outside her immediate family).

Julia and Andrew described during their interviews how they struggled to change their duvet cover for the first time: *'..all right it's a king size duvet..and I'm a wee [small] person..but it was an achievement..but you wouldn't think such a simple thing as putting a duvet cover on with one hand and ..well no, just one leg, but I still can't balance right...oh it was awful!'* (survivor, Julia), and as he husband commented *'if there's a way to do a job, the pair of us will work it our between us'* (Andrew, interview).

For survivor Colin it was also the physical tasks that were daunting: '*..approaching the staircase was traumatic*'. Managing these types of first encounters seemed to be an important step in the adaptation process.

### Balance of caring

The balance between giving appropriate care and knowing when to support independence was an adaptation process that was also referred to in several circumstances. As survivor Julia pointed out in her interview '*..he's over protective...he's very very protective of me...and it goes against the grain*'. In a similar vein, Carer Barbara recognised her own protective stance in her diary: '*I am like a mother hen and think I smother Colin, trying to help him, this causes a lot of friction between us*'. The next day her diary entry read: '*to-day I am trying to stop smothering Colin*'. Although she appeared to mean smothering in the sense of being over protective, the researcher wondered if there was a sense of hidden anger in this statement.

Carer Mary, who did not live in the same house as her mother Connie, and who was also working full-time, recognised the need to adapt the level of caring needed in both her interview and diary: '*I mean I'm less nervous than I was at the beginning because I was obviously checking up on her all the time, you know, when she first got home..phoning her*' and '*..it was good to hear she had the confidence to go out by herself, no matter how short a trip it was*'.

Rose did not initially see herself as a carer at all, because there were paid, formal carers coming in, saying *'I couldn't do what they're doing'*, although as the interview progressed it became obvious to the researcher that she did far more than she gave herself credit for, giving her husband Bert drinks, encouragement and even sleeping in a chair beside his bed on his first night at home, as mentioned above.

Carers also reported the need to stay positive for the sake of the survivor:

*'I try to keep upbeat and say that things are gonnae [going to] be okay, but obviously inside I've got my own doubts and stuff like that, but as long as I don't show it and stay positive, then I think it helps my wife to keep positive herself as well'* (Andrew, carer, interview).

In her diary carer Mary wrote *'It can be difficult sometimes to be continually positive and up-beat – I feel like I have to try and keep Mum's spirits up. I might not have done a very good job of that today'*. This was one example where the diary gave a more day-to-day insight into the process and progress as it was happening, and that was not mentioned later during the interview.

### Back to basics

Although small things often seemed to cause significant worry during these early days, simple occurrences also brought great pleasure. In this way, there was a sense that the situation participants found themselves in brought with it an acknowledgement that it was the simple basics of everyday life that were important.

Survivor Julia described in her diary how just walking to the steps in her back garden made her *'feel good'*, and the following day *'Got up steps!! Shattered!!'*. For Julia a simple short trip out was also a great achievement, just one week after getting home: *'Out in car for ½ hour - fantastic!'*. For survivor Bert the simple pleasures of being able to watch football and snooker on the television at home were highlighted on his expression mat as bringing happiness, and as his wife pointed out *'he wasn't interested in television in hospital, or papers'*, but now *'..since he's come home ..he's took an interest in television..and that's..that's something...good..for him'* (Rose, carer, interview).

### Hope

Throughout the adaptation process, with all its mixed emotions, there was also a message of hope for the future which pervaded the diaries and interviews. Uncertainty gave way to anticipation that the future would be better. Progress over the time of diary keeping was evident, and when people reflected back on the few weeks since the return home at the time of their interviews, there was also a sense that things were moving forward. For example, carer Andrew in his interview said he saw *'a curve of things getting better and better'* and Julia, his wife, appeared to agree in her interview: *'I have improved and I will improve more'*. Even carer Barbara, who was weepy and emotional during most of her interview, had reported in her diary some progress after a day out: *'..really enjoyed it, this is the first day we have got on for a whole day in weeks'*.



Survivor Connie, in addition to her communication difficulties, also seemed to have struggled with the physical act of writing her diary. She often used a ‘telegramatic’ style of writing (brief, and missing out of adjoining words), or the use of capitals when writing in script form appeared to become too tiring or difficult to attempt, as can sometimes be the case post-stroke (Van der Zalm and Bergum, 2000). This was verified by her therapists, although the use of capitals could also be a way of emphasising particular words. However, despite these difficulties, she still recorded an entry every day, and reflected back with a sense of hope at the end: *‘LAST DAY of my diary – Month to-day to came home – My feel a made PROgress’*. The mixing up of words in the diary related to her associated language dyspraxia (Warlow et al, 2008), but the sense of what she is trying to impart still comes through.

Hope was also mingled with a sense of real determination. As one carer (Mary) said in her interview *‘she’s showing so much determination at getting back to as close as she can be..to what she would like..’*. Survivor Colin , who wanted to return to driving eventually, said at interview *‘..see I believe that if I get stronger and that..I maybe can’* even although his current restrictions made this seem a difficult challenge.

### **5.3.3 Value of support**

The importance of support was a theme that again repeated itself throughout the diaries and interviews of all participants. This was not only to do with support being present and available, but also to do with the impact that not feeling supported had on the situation.

### It's good to talk

The value of talking, and being listened to, was emphasised by most participants. In both her diary and interview, survivor Julia stated how beneficial talking with the therapists had been, for example: *'just talking to them helped as much as my exercising'*, with her husband (Andrew) making similar comments in his interview. Carer Barbara also commented on how helpful this had been: *'I was really upset you know...and she sat and talked to me about it'*.

The participants with aphasia valued the opportunity to talk, even although their ability was difficult or very limited. For example, although Bert had expressed resentment about this using his expression mats, he also felt happy and content to see and hear from friends who visited. Formal carers also provided an opportunity for him to practise his limited vocabulary in a light-hearted way. As his wife said in her interview *'they're getting a laugh at this...so he's enjoying this...he's getting attention (laughs)'* (Rose, carer).

Progress was also evident, with carer Mary stating towards the end of her diary keeping: *'After all my worrying about us talking on the phone, it's great to have a good chat with Mum – no problems understanding what she is saying'*.

### Importance of understanding

Having their situation understood seemed to play an important role for participants.

When that understanding was not forthcoming, however, this could cause distress.

As carer Andrew stated in his diary, he felt a family member had *'no regard for our*

*feelings or needs*'. However, in his interview this was not mentioned, and the researcher gained the impression that other support had made up for this lack of understanding from within the family, with him stating of the professional help: *'we've had complete great support'*.

Carer Barbara also stressed the value of such support from professionals when difficult situations arose, writing that one of the therapists *'was so understanding'* in her diary, and then talking during her interview about how this person had explained the situation to her: *'she said it's just frustration'*.

For another survivor (Colin), not having the contact and understanding from family and friends caused a great deal of pain: *'..it's sore...it's really sore'* and *'they used to come about, but they never come now'*.

Survivor Connie talked about her need for more time in which to speak: *'I've got a pace I'm able to go, and let everyone...and understand me'*, and how family members had an understanding of this need for additional time: *'[names] are very good and patient with me...(laughs)'*.

In further relation to understanding, carer Andrew also emphasised during his interview his limited knowledge of stroke as a condition, even although his wife (Julia) reported feeling well informed: *'I'm in the dark'* and *'it's the sort of lack of information'*. However, he was also ambivalent about how much he wanted to know and understand: *'maybe the more you know..it can be frightening...but if you know enough it can help'*.

## Reliance on others

Part of valuing support involved having a reliance on others. This appeared to be accepted in some circumstances. As survivor Julia said: *'I have to depend very very very much on my husband'*, but also *'he's been fantastic'*. For Connie just the simple act of having her daughter (Mary) present seemed to the researcher to be reassuring: *'I had a bath...she was there'*.

Carers were also reliant on, and grateful for, other help: *'..of course if it wasn't for the carers he couldnae [couldn't] get home'* (Rose, interview) and *'I was really pleased she was getting so much input'* (Mary, diary). However, for carer Rose and her husband Bert, this reliance on others also involved having to pass many responsibilities over to their son: *'the financial affairs..he's in charge of them all now'* (Rose, interview).

Survivor Julia reported that it was *'very difficult to watch someone else do my work'*, and Bert also mirrored these sorts of comments on his expression mat. In her diary, Julia connected support and reliance on others to *'not being a good patient'* now she was in the changed role of being more dependent, and also repeated this theme in her interview, stating that it was difficult to *'do as I'm told...let my body mend itself'*.

So having a reliance on others seemed to be viewed with mixed feelings, being seen as a benefit, a necessity and a frustration.

## 5.4 Discussion

The above accounts have illustrated how the major themes of *fathoming out*, *adapting to stroke* and the *value of support* are all interwoven in the early days after getting home from hospital. The diaries proved valuable in adding additional information which was not necessarily mentioned in the interviews. Progress and hope could also be identified when comparing the diary and interview accounts, given that the diaries were kept for up to a month, and the interviews took place shortly after that. As Brocki and Wearden (2006:90) state: ‘illnesses occur over time and it is over time that the processes in which IPA is interested unfold’.

From the accounts, physical limitations seemed to take on greater meaning when they related to the participant’s specific and individual home situation. Comparing with others or previous abilities appeared to be part of the greater fathoming out process. As Pashley and Henry (1990:87) state, as humans we ‘define the self by comparing it to other’. However, Rochette et al (2006) argue that comparing with others is a more helpful strategy than comparing with the previous self which, they assert, can lead to increased frustration.

Following the stroke, new strategies had to be made in the light and aftermath of the illness. Survivors and carers reported ways of managing situations for the first time in these accounts, which could be regarded as a positive approach. Being open to trying new situations may not always happen: Davidson and Young (1985:127) reported that even some time after returning home survivors could still regard new situations as ‘too traumatic and risky’ to attempt.

In contrast to other neurological conditions such as multiple sclerosis or Parkinson's disease, functional and sensory loss almost always happens suddenly with a stroke (Warlow et al, 2008). There is therefore not the opportunity for the gradual adaptation that might happen in a slowly progressing illness. Perhaps in similarity to traumatic brain injuries, awareness of the new situation that stroke survivors find themselves in therefore significantly increases after discharge home (Fleming et al, 2006) rather than developing more gradually over time.

However, whether sudden or gradual, Finlay (2006) argues that the full impact of such losses is not always understood by professionals. Similarly, comparison between stroke and other long term conditions such as heart and pulmonary diseases, or diabetes, reveals other differences (Jones, 2006), with sustained improvements being more likely with stroke than progressive conditions. As Folden (1994:84) describes, stroke can have a 'very different illness trajectory' to other disease processes.

However, the tendency is for none of these long term conditions to resolve completely or be 'cured' in the medical sense. In addition to this, the medical approach, whilst useful for symptom control in other chronic conditions, becomes perhaps less relevant in stroke. Indeed, O'Connell et al (2001) argue that although stroke patients are discharged into the care of their GPs, the nature of the on-going support that is required is such that GPs may not be the most appropriate professional group to provide it. Having said that, Smith et al (2004: 238) report that survivors may continue to feel 'medically vulnerable' for up to one year after discharge. Community healthcare workers such as nurses and therapists, with their understanding and involvement in long term conditions, would seem well placed to

offer some of the necessary support and follow-up, and participants in this study certainly placed value on the support they did receive.

Changes in the home environment seemed to have specific implications, particularly for the female participants. Even without the physical limitations that can be imposed by a stroke, Ogletree et al (2006) discuss the greater guilt and resentment that women may generally feel towards housework and cleanliness, compared to men. Tamm (1999) and Visser-Meily et al (2006) both agree that surroundings can have a big impact on functioning and health in general. Tamm (1999) identifies home, at least in Western culture, as a place of sanctuary, privacy and control for its inhabitants, and questions the impact and intrusion rehabilitation equipment and services have, not only on the patient, but on the family and the whole concept of what home means to these individuals. It is clear from the accounts that even although acknowledging change as somewhat inevitable, the participants, both male and female, were not entirely happy. What is not clear, however, is how much these changes were discussed with the participants either prior to, or following, discharge.

Tamm's study (1999) did not involve stroke patients specifically, but examined home as a rehabilitation setting in general, and discussed the fact that a prevailing theme for many patients centres around the concept of everything being 'all right' once they are home, even if this is in conflict with what professionals are telling them. Wiles et al (2002) suggest that this concept is due to a psychological need to be optimistic, and is part of the coping mechanism for stroke patients. Certainly, hope came through in many of the accounts, and is recognised as an important aspect of recovery (Pilkington 1999; Burton, 2000). Indeed, fostering hope is seen as an

important part of encouraging rehabilitation and promoting adaptation to change, if ability is altered (Raleigh, 1992; Bluvol and Ford-Gilboe, 2004). O'Connell et al (2001) suggest that initial hope and optimism about stroke rehabilitation may diminish over time, making the on-going encouragement of positive emotions seem even more relevant. Indeed, Bluvol and Ford-Gilboe (2004) urge clinicians to foster hope by focusing on strengths and achievements, rather than deficits and challenges, and consider that such an approach may also inspire a more realistic form of hope. The importance of this is recognised by Wiles et al (2008). Ostir et al (2008) go so far as to claim that positive emotions can increase actual functional ability post-stroke, not just general well-being, which further strengthens arguments about the role professionals can play in encouraging hope.

Emotional changes and reactions featured markedly in all the accounts, in keeping with other stroke studies (Burton, 2000; O'Connell, 2001; Banks and Pearson, 2003; Smith et al, 2004; Bäckström and Sundin, 2007). What surfaced in this study, however, was some difference in the emotional response between the male and female participants. This appears to relate to the increased likelihood of men to display anger more overtly or directly than women (Lowenstein, 2004). As has been mentioned, where there may have been anger present in the account of one female carer, this was not explicitly evident, and expressed more in terms of tears and sadness. Eatough et al (2008) discuss the fact that whereas male anger may serve to ensure the continuation of power, female anger can result from powerlessness and subsequent frustration. This illustrates the differing relationships that anger may have for each gender.



Lowenstein (2004) asserts that there can be a value to anger, due to it sometimes resulting in positive action, and feelings of greater control over situations. However, Stoney and Engebretson (2000) report associated rises in blood pressure, resulting in an increased risk of heart disease and stroke. Anger may therefore result in increased risk in terms of both primary and secondary prevention.

Steffen (2000) reports on the benefits of an anger intervention programme for the carers of dementia patients, which positively influenced their ability to remain in their caring role. It could therefore be suggested that understanding the anger that may exist after a stroke could be important in supporting both patients and carers to cope in their new situations.

From the analysis, the accounts of survivors and their carers in this study seemed interwoven, whether this was by displaying their support for one another, or the tensions that existed between partners, and the ensuing struggle they had to hold their relationship together. As Visser-Meily et al (2006:1559) consider, 'the usual balanced and reciprocal relationship between partners is disturbed' in such situations.

The account of one carer in the study also displayed that the role of being a carer may have different meanings for different people. Procter et al (2001) caution practitioners to take into account such differing role definitions when planning discharges from hospital, and although their study covered a broad range of diagnoses, it is also relevant to a variety of discharge situations.

From previous definitions of the role of a carer, the participant who did not consider herself to be a carer in this study, certainly fulfilled the criteria of being a carer in the researcher's eyes, and according to the definition of Proctor et al (2001).

For another carer (Mary) who did not live with the survivor (her mother, Connie), the worries of the adaptation process for her mother surfaced in both diary and interview accounts, especially as her 'balance of caring' also involved being at work full-time.

The findings suggest that from many perspectives, for these participants the value and impact of support and understanding from others was important. If this was not forthcoming, however, there was an effect on the adaptation process. As others suggest, the well-being of patients and carers are closely interlinked (Baker, 1993; Smith et al, 2004; van Exel et al, 2005), and it is debatable whether accounts from one perspective are as useful and meaningful, if the account of the other is not also heard. This view is supported by Procter et al (2001).

Although carer strain can affect ability to care (Bugge et al, 1999), thereby impacting on patients, Baker (1993) argues that patients with spouses fare better than those without. Providing support and understanding for carers can therefore be seen as vital role for professionals, and all of the carer accounts in this part of the study acknowledged the value of this.

Draper and Brocklehurst (2007) and Visser-Meily et al, 2006) also comment on the detrimental impact aphasia can have on the spouse or family as a whole, thus

potentially adding to an already difficult adaptation process. However, whilst these two studies focused on the carers or family of stroke survivors, Lloyd et al (2006) argue that it is the voice of the person with expressive difficulties which should be heard by researchers, whether the difficulties have arisen from stroke, traumatic brain injury, or dementia. As has already been discussed, this preliminary study actively sought to include participants with reduced communication ability and ‘hear’ their accounts.

This study has also examined the impact of stroke on both parties in the patient-carer dyad, rather than people without a carer, which must be an acknowledged limitation. However, people without informal carers may be in receipt of greater formal care, and it is out-with the scope of this study to examine how informal care might compare with formal care in terms of experiences. What is suggested by Visser-Meily et al (2006) is that family-centred approaches are becoming increasingly important with the greater emphasis on care in the community, and the ensuing reliance on informal carers.

Also, with regard to reliance, is the reported dependence survivors had on their carers in these findings. According to O’Connell et al (2001) such reliance can have a detrimental effect on quality of life for carers. However, Haun et al (2008) suggest that support does not only come from carers, but also through other social interactions, and it is a more general sense of ‘connectedness’ which can improve the adjustment to returning home. Haun et al (2008) consider that feeling understood is an important aspect of feeling connected to others, and certainly for most of the participants in this study, the importance of understanding from others was

highlighted. O'Connell et al (2001) argue that this need for understanding is why public education campaigns and stroke support groups are of such importance.

Closely related to being understood by others was the need to gain enough information to meet needs. One carer specifically talked about lack of information, which agrees with the findings of Wiles et al (1998) and Almborg et al (2010), who found that carers felt particularly let down in relation to post-discharge stroke information. However, as Pashley and Henry (1990) discuss, processing capacity in relation to new information declines with age, as does the ability to adapt to new situations. Both of these are very relevant concepts for professionals to bear in mind when trying to prepare older patients and carers for their return home.

Certainly, in some situations, written information booklets have been shown to be of benefit during the early days at home for other conditions (Fagermoen and Hamilton, 2006), a view supported by O'Connell et al (2001) for stroke survivors. Coleman et al (2006) also reported fewer readmissions amongst better informed older patients and carers. In spite of the lack of information mentioned in this study, none of the survivors were readmitted during their first month at home.

As has already been stated, all but one of the participants in this study were over 65 years of age, and even without stroke related communication difficulties, expressive vocabulary has been shown to decline with age (Au et al, 1995). Additionally, for stroke patients, there may be concentration or cognitive deficits which may reduce this ability even further. These factors need to be borne in mind by practitioners

involved in stroke care or research, particularly when either giving information to such people, or listening to their accounts.

### **5.5 Researcher reflections**

In keeping with the ‘double hermeneutic’ (Smith, 2004:40), discussed in chapter 3, the researcher tried to make sense of the participants sense-making process.

Wherever possible, direct quotes have been used to illustrate the themes, with the investigator’s interpretations or considerations adding to the overall story.

To the researcher, although themes were identified, in some ways it felt artificial separating these out, because they seemed to be so interlinked. It appeared that participants were on a journey of discovery into their new world post-stroke – a world that during their first month at home they were still trying to fathom out and adjust to; a journey with an associated roller-coaster of emotions, for both survivors and their travelling companions. As mentioned in the previous chapter, where strong emotions were expressed, the researcher was able to suggest further support for participants once the interviews had ended.

Although the researcher had worked closely with stroke patients and carers over a number of years, she was surprised at how frequently the use of comparisons emerged when analysing a relatively small number of transcripts. Through the analysis process the researcher came to have a greater understanding of the role and purpose of such comparison, and ‘heard’ this better through the research process than she had done previously in her day-to-day clinical work. She became more aware of how comparisons were part of fathoming out, and adjusting to, the new self

and new situation. The researcher also became more open to the role that comparisons played in allowing hope to be fostered: things could have been worse; support and small pleasures were valued more.

As discussed in chapter 3, Finlay (2008:21) regards the ability to be open to hearing experiences in a new way, as enabling new understandings to emerge. However, Finlay (2008) also suggests that such understandings are founded in the previous knowledge of professionals, which cannot be fully bracketed out, and needs to be acknowledged and exploited as a source of insight.

At the end of this part of the study participants were given a written summary of the research findings, which outlined the super-ordinate and sub-themes that had come out of the analytical process. The summary is detailed in Appendix 10. In two cases the researcher also gave verbal feedback to participants, and at that time these participants voluntarily reflected back on how they had been feeling at the time of discharge (six to eight months previously). These reflections seemed to be in agreement with the findings, and although this was not formal participant validation, the researcher felt that the reflections made by the participants did give additional credibility to the analysis.

There was a sense, however, that this preliminary study was still just touching the tip of these experiences. As Smith (2007:5) discusses, it is possible to be ‘constantly digging deeper with ones interpretation’ and there comes a stage at which one has to decide to stop. There are acknowledged differing depths of analysis that can be achieved using IPA (Smith, 2004), and the researcher felt that the more in-depth

main study that was planned would give the opportunity for these initial findings to be explored further and revisited in the light of the main study analysis.

## 5.6 Summary

This preliminary study has examined the early discharge experiences of a small sample of stroke survivors and their carers in east Scotland. The way in which participants were fathoming out and adjusting to their new situation has been explored, as well as the meaning and value of support. Suggestions regarding how the inclusion of participants with aphasia may be facilitated in other research have been made, and will assist the main study. Problems relating to the use of expression aids also had the opportunity to be addressed at an early stage, thereby allowing for greater inclusion strategies in the main part of the study.

The study has given the opportunity for the effectiveness of the study format to be assessed by the researcher, ahead of a more in-depth study; a deeper and more involved analysis of the discharge experiences of stroke patients and their carers may help to further enlighten professionals and others engaged in supporting those affected, either prior to discharge or during the early post-discharge period. As Tierney states ‘it is *solutions* to discharge planning and post-discharge support that we desperately need to find rather than accumulating even more evidence of the *problems*’ (Tierney, 2006:789; emphases in original). It could be argued that part of any solutions package needs to include an experiential understanding of returning home.

The following chapter will detail the main study which proceeded on from this preliminary study, as well as discussing any changes to method that were considered necessary by the researcher, once the preliminary study had been fully evaluated and appraised.



## **CHAPTER 6**

### **Main study**

#### **6.1 Introduction**

The following three chapters will detail the recruitment, analysis, findings, and discussion relating to the main study. In common with the preliminary study, the approach of interpretative phenomenological analysis (IPA) was used to guide the analytical process in the main study, with the focus remaining on the experiential accounts of stroke survivors and their carers during the first month at home. As Kaufman (1988:340) states, phenomenology ‘attends to the reality of experience’, and by continuing such an approach for the main study it was hoped to further increase understanding of the emotions, thoughts and feelings being experienced at this time.

From the on-going literature review, and as discussed previously, other studies which have examined the first month at home have all considered it as a challenging time. Although studies have taken place in many countries, only one of the UK studies identified so far (Ellis-Hill et al, 2009) specifically researched the first month at home. However, the focus of the study by Ellis-Hill et al (2009) predominantly concerned mobility and functional recovery, as well as views about therapy services. This is not surprising, given that the lead researcher stems from a physiotherapy background.

The proposed research format being discussed here follows on from the preliminary study, and adds to the pool of knowledge about the transition period, by including analysis and interpretation of further experiential accounts which, in contrast to the study by Ellis-Hill et al (2009), remain very much participant-led, with no particular therapy focus. Changes in relation to method, in the light of the preliminary study, will be discussed where appropriate. As Barbour (2008) concludes, even carefully thought-out research plans may need to be modified once in the real world of the research setting.

## **6.2 Main study method**

In keeping with other IPA studies (Smith et al, 2009), the interview format continued to be kept as open and unstructured as possible, in order to facilitate the free expression of participants' experiences. Twelve patient/carer dyads contributed to this part of the study. Although this is a comparatively small number in relation to some other research methods (Barbour, 2008), as discussed in chapter 3, it is a fairly high number for an IPA study (Smith et al, 2009). However, as previously discussed, the views gained are generated from people with a diverse range of stroke related restrictions, some of whom were not able to participate in the same way, or as fully, as others. Given the varying degrees of ability to contribute, therefore, this number of participants allowed for a range of depth of account to be included. In similarity to the preliminary study, participants with communication difficulties were purposefully recruited, and communication aids again used to facilitate their inclusion. These aspects of the study will be discussed further below.

Diaries and in-depth interviews were again used as the methods of data collection. The diaries in this part of study also allowed the views of one participant who was

readmitted just prior to her interview to be included, even although the interview was not able to be carried out.

In common with the preliminary study, for a few participants in this current cohort, even additional prompting and support did not yield the depth of data normally associated with a phenomenological study (McNamara, 2005; McNamara, 2007; Smith et al, 2009). This added a certain amount of tension to the research and analysis process. However, the input that these participants were able to give was done with such apparent willingness and enthusiasm that the researcher felt a duty to ensure that their views were understood and included to the greatest extent possible. This was achieved by paying particular attention to the non-verbal language used, and notes in relation to this were made by the researcher either during, or immediately after, their interview. For those participants with little verbal ability, the pictures that were selected to illustrate what they wanted to convey were also accompanied by more detailed field notes because of the reduced verbal information available. As Prosser and Schwartz (1998:115) discuss, such ‘full contextual detail’ allows and enables the trustworthiness and limitations of studies using visual images to be assessed. Although Smith et al (2009:46) discuss the necessity of obtaining a ‘reasonably rich and reflective’ account in an IPA study, they also acknowledge that analysing thinner data is possible, although more challenging.

### **6.3 Sample**

Morse (2000) discusses the fact that small sample sizes are not considered unusual in phenomenological studies, and as has already been mentioned, smaller numbers of

participants in IPA studies are advocated by Smith et al (2009), to allow for greater depth of analysis. The sample size of twelve patient/carer dyads in this part of the study was therefore considered sufficient to generate a range of accounts, whilst allowing for more limited accounts due to stroke related restrictions to be off-set by those participants who were able to produce more lengthy and detailed data. That is not to say that the more limited accounts are necessarily less rich – as Smith (2007) considers, essential meanings can be conveyed in as little as one phrase in an account.

In similarity to the preliminary study, the participants were approached in connection with the study without any prior assumptions or criteria relating to their social, cultural, ethnic or economic status. In a review of IPA studies, Reid et al (2005) conclude that participants may be drawn from a broad sociocultural spectrum, but should have a shared willingness to engage in the research process. One gentleman of Asian origin was approached as a potential participant, and one lady of Chinese origin, but although both were able to communicate well in English, each later declined after reading the participant information sheet. In the event, therefore, all participants in this part of the study were again of white British origin, with a variety of educational and occupational backgrounds, ranging from a skilled tradesman to a retired medical practitioner. Again, to preserve anonymity, greater detail is not made explicit, although occasionally such information does surface in individual quotes. As Morse (2008) argues, researchers need to be careful to only divulge such detail as is necessary and relevant to the study findings.

#### **6.4 Geographical location**

The participants again lived in a variety of geographical locations in the east of Scotland, both rural and urban, and were discharged from either an acute stroke unit or from a stroke rehabilitation unit.

#### **6.5 Inclusion criteria**

Inclusion criteria for this main study remained the same as for the preliminary study, with the exception of the length of time in hospital. Due to the arguments relating to the possibility of people who suffer minor strokes still having significant adjustments to make (Rochette et al, 2007), it was decided to lift the earlier preliminary study restriction of a minimum hospital stay of one week. Having said that, in this part of the study all the participants were actually in hospital for at least a week, and as discussed previously, this allowed sufficient time for information, consideration, and consent to be given.

Age range and further details of study participants, and their contribution, are detailed in Figure 23 below. As considered above, and advised by Morse (2008), detail is only such that anonymity is still preserved, and pseudonyms are used throughout.

<b>Pseudonym and role (p=patient, c=carer)</b>	<b>Relationship</b>	<b>Age</b>	<b>Participation in interview</b>	<b>Diary contribution</b>	<b>Comments</b>
Bett (p) Carol (c)	Bett is Carol's mother	47 25	X  X	√  X	Neither Bett or Carol were contactable after Bett submitted her diary
Dennis (p) Daphne (c)	Dennis is Daphne's husband	77 70	√ √	X √	Dennis was offered a dictaphone to record diary entries, but later declined
Callum (p) Fiona (c)	Callum is Fiona's husband	66 60	√ √	√ X	Fiona did not feel able to complete a diary due to her own health issues
John (p) Angela (c)	John is Angela's husband	82 81	√ √	√ X	Carer strain affected Angela's ability to complete the diary
Hugh (p) Elizabeth (c)	Hugh is Elizabeth's husband	69 67	√ √	X √	Hugh did not feel able to complete a diary
Bernadette (p) Janis (c)	Bernadette and Janis are friends. (Janis has a carer's role in relation to helping Bernadette)	82 60	X √	√ √	Bernadette was readmitted prior to the interview date
Rachel (p) Bill (c) Maureen (c)	Rachel and Bill are partners. Maureen is a friend (who also takes on a carer's role)	57 59 58	√ √ √	√ √ X	Maureen was not recruited to the study in time to be offered a diary

<b>Pseudonym and role</b>	<b>Relationship</b>	<b>Age</b>	<b>Participation in interview</b>	<b>Diary contribution</b>	<b>Comments</b>
Norman (p) Jill (c)	Norman is Jill's husband	70 65	√ √	√ √	Norman and Jill contributed to all parts of the study
Sam (p) Ann (c)	Sam is Ann's Husband	82 78	√ √	X X	Both Sam and Ann were frail and subsequently felt unable to keep their diaries
Dorothy (p) Douglas (c)	Dorothy and Douglas are husband and wife	78 80	√ √	√ √	Dorothy used pictures and diagrams to express her views
Judith (p) Sheila (c)	Judith is Sheila's mother	74 49	√ √	√ √	Sheila chose not to have her interview tape recorded, so written notes were made instead by the interviewer
Morris (p) Audrey (c)	Morris is Audrey's husband	66 64	√ √	√ √	Morris used pictures and diagrams to express his views

**Figure 23: Details of main study participants**

As can be seen from Figure 23 above, not all the participants felt able to participate in all parts of the study format. Even although all were keen and agreeable whilst in hospital, circumstances sometimes changed after the stroke survivor returned home. As previously discussed, it was felt that this was all part of the challenge of conducting research at what could potentially be an uncertain and vulnerable time.

Rather than excluding participants who later felt unable to fully participate in all parts of the study, it was decided that the data they were able to contribute would be included. For example, one survivor (Dennis) had initially been keen to use a dictaphone to record diary entries (because his stroke related arm weakness had left him unable to write), but later felt unable to use the machine.

Sheila (Judith's carer/daughter) also changed her mind about her interview being tape recorded at the last minute, so written, short-hand notes were made by the interviewer to allow her to participate. As discussed by Smith and Osborn (2003), this eventuality can happen, although not an ideal situation; it is therefore acknowledged that some detail may have been lost.

In this respect, however, the contribution process was still kept as open as possible, allowing a wide range of views to be heard. The broad overall approach was to facilitate the inclusion of people to the greatest extent, where practicable.

Murray and Harrison (2004), in their stroke study, similarly allowed participants to take part either by interview or by email, to facilitate the inclusion of a broad range of people. However, they do acknowledge the limitation that email contribution places on gaining non-verbal signals. Participants in their study were also an average of nine years post-stroke, and the time and opportunity to adjust to physical restrictions may have allowed them to be more open to trying this form of communication, in a way that participants who are still in the early period of adjustment may not be. The use of email contribution was therefore not considered for this current study.



Patients were able to nominate more than one carer, if they wished. In the event, only one person asked for the account of a further carer to be included. The fact that only two of the carers were men reflects the fact that carers are more commonly adult females, and that the risk of having a stroke remains higher in men (Proctor et al, 2001; Green and King, 2007).

## **6.6 Effects of stroke**

In similarity to the preliminary study, it was decided not to focus on any particular type of stroke, or severity of symptoms. However, the Functional Independence Measure and Functional Assessment Measure (FIM+FAM: Turner-Stokes, 1999) classification system was again used to give a guide to how the stroke had affected day-to-day functioning, and to give additional information to this part of the study.

Individual FIM+FAM scores were added together for each stroke survivor to create a total score, giving an indication of overall difference in ability between participants. From the on-going literature review, giving such specific indicators with regard to physical ability is not often detailed in qualitative stroke studies. However, such measures do help to give a good indication of functioning over a broad range of activities, and can help with setting the scene of the research better than more vague descriptions, such as 'severe' or 'mild' (e.g. Rochette et al, 2006:248). Although there are thirty areas that can potentially be assessed using the FIM+FAM classification system, certain activities were chosen by the researcher to give a brief illustration of the type of stroke effect. Such scores can give much greater information than, for example, Modified Rankin scores (Scottish Intercollegiate Guidelines Network (SIGN), 2008), which only differentiate between rough degrees of disability.

Details of the FIM+FAM scores can be seen in Figure 24 below.

<b>Participant</b>	<b>Locomotion: walking/wheelchair</b>	<b>Stairs</b>	<b>community mobility</b>	<b>Dressing upper body</b>	<b>Dressing lower body</b>	<b>Toileting</b>	<b>Total</b>
<b>Bett</b>	7	7	7	7	7	7	42
<b>Dennis</b>	1	1	1	1	1	1	6
<b>Callum</b>	7	7	6	7	7	7	41
<b>John</b>	6	6	5	6	6	7	36
<b>Hugh</b>	6	7	4	7	7	7	38
<b>Bernadette</b>	3	4	1	4	4	6	22
<b>Rachel</b>	7	7	6	7	7	7	41
<b>Norman</b>	3	3	1	2	1	3	13
<b>Sam</b>	3	4	2	4	3	5	21
<b>Dorothy</b>	1	1	1	1	1	1	6
<b>Judith</b>	6	6	5	6	6	6	35
<b>Morris</b>	2	2	1	1	1	2	9

**Figure 24: Physical ability: FIM+FAM rating: main study, stroke survivors**

As stated earlier, within the FIM+FAM classification, a score of seven equates to total independence, and a score of one indicates total dependence. It can be seen from the total scores above that there was a variety of ability amongst the participants, and this has been discussed in relation to homogeneity in Chapter 4.

Again, the homogeneity for these participants stems from their common experience of stroke, and their experience of having recently returned home from hospital.

Although none of the participants in the main study had suffered a previous stroke, it might have been beneficial to have specified this in the inclusion criteria, in order to exclude the influence of comparing one stroke with another, as identified in the preliminary study. That said, the comparisons that were made in the first part of the study did help to clarify how associations were used by participants to make sense of their current situation. However, with the larger number of participants planned for the main study, such an additional focus might have over-complicated the narratives and analysis.

In further relation to the findings from the preliminary study, the analyst had to be aware of approaching the main study accounts on their own content and merit, whilst acknowledging any influence from prior findings. This tension will be discussed later in the thesis.

## **6.7 Diaries**

With further regard to ability, Alaszewski (2006) discusses the fact that participation in diary keeping can vary considerably, which is in keeping with the data collected here: out of the twenty four participants, seventeen contributed diary accounts; within these accounts there was a distinct variety in the amount written, ranging from a few lines in total, to entries being made several times throughout the course of each day for which the diary was kept.

As discussed in chapter 4, there was one example of a diary being 'back-filled', with Norman summarising the first few days at home in one entry, before moving on to make daily entries thereafter.

As before, participants were given the option of not parting with their diary at the end of the month, although none took up this option. Judith found the diary-keeping so beneficial, she asked to keep the blank pages to continue her writing, and this will be discussed in greater detail later. The contribution of Bernadette, who was registered blind, will also be discussed further below.

In the light of the preliminary study, it was decided to collect diaries prior to the interviews taking place in this part of the study. This enabled the researcher to read the entries, and also allowed for clarification and probing about diary entries at the time of the interviews. During the analysis of the preliminary study diary transcripts, it was identified that this might add to richer interview data, and any uncertainty with regard to meaning in the diary entries could also potentially be clarified.

Additionally, it was noted in the preliminary study that there were some things mentioned in the diaries which were subsequently not mentioned during the interviews, and this revised strategy again allowed for further probing in relation to this. As Collins (1998) discusses, the full significance of diary entries can become clearer during interview conversations, especially if there is the opportunity to discuss various entries further. Flowers (2008) considers that depth of understanding can be maximised by such possibilities. Although Flowers (2008) refers to this strategy in relation to subsequent interviews, diary data can also provide the occasion to do this, if the entries can be read before the interviews take place. The interview format and diary guidelines remained similar to the preliminary study, as detailed in

chapter 4, and Appendix 2. However, one additional final question was added to the interview format, where participants were asked if there was any information they would offer to another person in a similar situation. It was felt that adding this question towards the end of the interview might help participants to reflect more fully on their experience.

### **6.8 Interview format and considerations**

Due to the largely unstructured nature of the interview format, there was therefore no set pattern with regard to how the interviews flowed, and participants varied considerably, not only in the amount of prompting or probing required, but also in the level of detail and information they provided. Interview lengths varied from twenty five to ninety minutes. Because the study included people with a variety of ability, such variation was somewhat expected, and also accepted as an inevitable part of having a broader inclusive approach. According to Jarrett et al (1999) symptoms such as pain, fatigue and weakness may significantly limit the contribution of more vulnerable research participants, with some interview lengths lasting as little as five minutes in their IPA study involving cancer patients.

As with the preliminary study, all the interviews took place in the homes of the participants, at a time that was mutually agreed upon. Interviews were planned to be conducted with only the individual participant and the interviewer present. However, there was one exception to this, when one carer (Douglas) did not feel able to ask his wife (Dorothy) to leave the room. Dorothy had very limited mobility and speech, and sat quietly in the same room while the interview took place. It is difficult to know how

different her husband's account would have been had she not been there. Although this was only the case for one interview, it does require to be acknowledged. Further data collection limitations will be discussed later.

### **6.9 Ethical issues**

Due to the changes made to the main study method, even although fairly minor, ethical approval for the study was again sought and granted by the local ethics committee (see Appendix 11), and all patients gave written, informed consent.

### **6.10 Communication ability**

As already mentioned, both this part of the research, and the earlier preliminary study, facilitated the inclusion of participants with a broad range of communication ability. Again, participants who were unable to speak used pictures and diagrams to express their views. In similarity to the preliminary study, for both diaries and interviews, the participant was able to select a topic, followed by accompanying pictures displaying emotions or feelings which related to the issue or topic being discussed.

FIM+FAM scores relating to the communication ability of the stroke survivors are detailed in Figure 25 below. (None of the carers in the study had any communication difficulties, but if they had, similar strategies to assist participation would have been used).

<b>Participant (pseudonym)</b>	<b>Comprehension</b>	<b>Expression</b>	<b>reading</b>	<b>writing</b>	<b>Speech intelligibility</b>	<b>Total score</b>
<b>Bett</b>	6	7	7	7	7	34
<b>Dennis</b>	5	4	5	2	6	22
<b>Callum</b>	7	7	7	7	7	35
<b>John</b>	7	6	7	7	6	33
<b>Hugh</b>	5	4	5	6	4	24
<b>Bernadette</b>	7	6	6	6	6	31
<b>Rachel</b>	7	6	7	6	7	33
<b>Norman</b>	7	7	7	7	6	34
<b>Sam</b>	6	3	5	4	4	22
<b>Dorothy</b>	5	2	4	1	1	13
<b>Judith</b>	7	6	7	7	6	33
<b>Morris</b>	6	2	5	2	2	17

**Figure 25: FIM+FAM scores in relation to communication: main study participants**

Out of a possible maximum score of thirty five across all five components, scores ranged from thirteen to thirty four. There was therefore quite a wide range of communication ability.

In more specific detail, with regard to the comprehension scores in the above figure, the participants were all rated at five or above. This is stated in the FIM+FAM system as meaning that the individual ‘understands questions about basic daily needs more than 90% of the time. Requires prompting (slowed speech, repetition, visual or gestural cues) less than 10% of the time’ (Cassells et al, 2007:41). However, this

related to comprehension, not expression, for which the scores for some participants were much lower, and aids required to a much greater extent (i.e. with the use of expression mats, as discussed in chapter 4).

With further regard to this, comprehension or cognition in relation to ability to participate was assessed by the hospital team, rather than the researcher, prior to potential participants being approached. Such assessments were part of the overall hospital evaluation process and, as a result, before recruitment participants had recently been assessed in-depth by the hospital therapists using a range of screening tools specific to each individual. This was a component of their normal treatment; however, in other situations where potential research participants had not had such screening, and researchers sought to be as inclusive as possible, some thought about the use of suitable tools to assess ability would have to be given, as detailed in chapter 4.

In the event, therefore, the overall ability to participate was guided by the stroke specialist team involved in the care of each participant, while they were in hospital. In relation to this, the therapy team considered one participant (Dorothy) as potentially having the lowest level of ability to participate, in terms of overall physical, communication and cognitive functioning. This was based on both hospital screening and the professional opinion of the hospital specialists associated with her care. Whilst it is sometimes the case that stroke survivors can make significant progress after discharge home (Warlow et al, 2008), it seemed prudent to accept the opinion of the ward staff in relation to ability to participate in the study.



With regard to reading ability, Dorothy also had difficulty due to stroke related visual problems. At times during her interview she held the pictures very close to her eyes, moving the images backwards and forwards, in order to make out the illustrations. However, she was able to confirm when she had selected the image that matched what she wanted to say by nodding and saying 'uh-huh'. She was also able to say 'no' or shake her head, and used facial gestures, arm movements and other verbal noises to get across what she was trying to impart. It should be noted that Dorothy was very keen to participate, and during her interview remained enthusiastic throughout.

Proxy consent, as discussed by Nelson and Merz (2002), did not apply for any of the participants, who were all able to give consent themselves. With further regard to proxy, all participants were able to contribute accounts for themselves, albeit with researcher assistance. As Palmer and Glass (2003) argue, if family members act as proxies, they may not represent the survivor's experience accurately.

As already mentioned, Bernadette was registered blind, but still preferred to write, rather than use a dictaphone for her diary entries. In this case, after a discussion about her preferences, diary pages with a few, broadly spaced, very dark lines were devised by the occupational therapist who was supporting her, and used to help guide her writing. In this respect, her inclusion in the study was also facilitated.

## 6.11 Analysis

The process of linking the findings from this comparatively large sample (in IPA terms) was quite a challenging process, and one which required the analyst to ‘reduce the volume of detail’ whilst at the same time ‘maintaining complexity’ (Smith et al, 2009: 91). Although coding for potential themes can be assisted by computer software, there has been much discussion about whether the use of computerised packages such as NVivo or NUD\*IST can assist with the process (St John and Johnson, 2000; Dixon-Woods et al, 2004). Smith et al (2009:100) state that they ‘would not necessarily recommend this to the novice researcher’, while Mauthner and Doucet (2003:415) also consider that the positivistic model ‘is reinforced by computer aided programs for qualitative data analysis’. Thorne (2000) similarly cautions that no computer package is capable of the intellectual and conceptual processes required to transform data into findings that are meaningful. Given these views, it was decided not to use a computer software package, and this decision will be considered further in the reflexive discussion in the final chapter.

Manual coding, using a pen and paper, was therefore used to help organise the potential themes and connections, firstly within individual accounts, and latterly between accounts. Patterns of meaning from within one transcript are referred to as ‘cumulative’ coding, whereas patterns across several transcripts are referred to as ‘integrative’ (Larkin et al, 2006:116). Sundin et al (2002:97) also discuss ‘meaning units’ as being sentences or paragraphs which have related meanings, which can be ‘condensed, abstracted and organised’ into sub-themes. However, as Braun and

Clarke (2006) argue, it is important that themes are not too complex or diverse, and that they adequately identify the essence of the narratives.

At this stage, many variations in terms of potential related themes were looked at, as well as reviewing transcripts to ensure each potential theme was linked back sufficiently to examples within the transcripts. This process not only added to the rigour of the analysis, but also facilitated identification of examples for the written account. As Braun and Clarke (2006) discuss, during this stage of analysis, some potential themes may be discarded as having insufficient examples to support the classification. Alternatively, other potential themes may be joined to form one larger theme that encompasses the joint elements of smaller themes, or equally, bigger themes may be split.

Following on from this, the drawing up of a concept (or mind) map was found to be particularly useful to the researcher in making sense of, and illustrating, the findings. Although concept maps are not specifically mentioned, they are consistent with advice given by Smith et al (2009).

The use of 'Mind Maps' (a form of concept map, developed by Buzan and Buzan, 1993) in relation to research analysis is advocated by Tattersall et al (2007:33) as a means of 'awakening possibilities' in analytical interpretation. This would certainly be congruent with the 'imaginative variation' Giorgi (2000:13) considered necessary and important in phenomenological approaches. As Murphy-Black (1994:545) states, the combination of patterns and drawings can help the analyst 'to remember and to connect one part with another'. This, in turn, utilises the creative and

imaginative right side of the brain (Smith and Morris, 2002), which may assist in opening up a more interpretative account. As Finlay (2009) stresses, both the scientific rigour and the creative, artistic elements of the analysis are important.

Certainly the use of pictures, diagrams and colours, as suggested by Buzan and Buzan (1993) can add to this creative process, whereas some concept mapping processes only rearrange words in an alternative format (Novak and Cañas, 2006; Braun and Clarke, 2006); this could be viewed as not having the same impact on either the reader or the creative analytical process.

The use of such maps to assist with the analysis is not mentioned specifically in the other stroke or phenomenological articles examined during this research process, although Brereton and Nolan (2002:27) do refer to the fact that ‘memos and diagrams were used to assist the development of axial codes’ linking categories and sub-categories together. It was felt that there was scope to take the ideas of Tattershall et al (2007) further, and indeed, as a result of these thoughts, the researcher was able to give input into a further research study (Tattersall et al, 2011). The mind map produced during the analysis process can be seen in Appendix 12.

As indicated above, the analytical process is complex and time consuming, especially where larger data sets are involved, and increased depth of analysis sought. In this respect, although the preliminary study gave a general feel for the quantity and quality of data that might be generated from individual accounts, a more simplistic and descriptive analysis was employed at that stage. The full complexity

of analysis and theme production was not fully engaged in until this main stage of the study.

As already mentioned, alongside looking at the variety of possibilities within the data, the analyst does need to be moving from the descriptive to a more interpretative view. Giorgi and Giorgi (2003) argue that the same data can be the basis for several different disciplinary analyses, and meanings can be generated that are applicable to a variety of different healthcare settings. From this point of view, although IPA has its roots in psychology, a research account can be written that is 'psychologically sensitive' rather than necessarily being labelled in terms of 'psychological jargon' (Giorgi and Giorgi, 2003:34). The former approach would certainly seem more beneficial in terms of writing an account of findings from (and for) a nursing perspective, where such 'jargon' may not be as readily meaningful. Producing an account of study findings that is useful and relevant to the disciplinary background of the analyst would therefore seem to make greater sense.

Although Smith et al (2009:106) discuss differing levels of interpretation, they also conclude that 'almost inevitably the analysis of each case cannot be so detailed' with larger sample sizes (e.g. more than 6 participants). Their advice with larger numbers of participants is to delay looking for connections and patterns until such time as the cases can be examined together. This advice was followed for this main part of the study, with the analysis process not being started in full until all the data were gathered. The mind map also certainly helped to link the accounts of the individuals to the super-ordinate themes, and vice versa, within the context of having a large amount of data. Being able to track the flow of research findings is very much at the

heart of the concept of leaving a ‘decision trail’ (Koch, 2006:91), to enhance the rigour or credibility of the study.

## **6.12 Overview of findings**

In this section the themes will be discussed further, with super-ordinate themes being noted in italics, and related sub-themes being underlined.

Once the complex process of analysing the data was complete, it was possible to draw together three major (or super-ordinate) themes, which not only related to the findings of this main part of the study, but which could also be viewed as having relevance to the themes identified in the preliminary study. However, initially the super-ordinate and sub-themes were derived from the main study, with all the participant quotes and excerpts that will follow in the next chapter being taken from the main study data.

In brief, stroke survivors and their carers seemed to be describing the first month at home as a very dynamic time, both externally and internally. Participants seemed to be recounting a process that involved *revisoning*, *reconnecting* and *revisiting* the past, present and the future. These three activities seemed to help participants make (and find) sense in their new situation. Each of the three super-ordinate themes also connected to several sub-themes. Details of super-ordinate themes and sub-themes are given in Figure 26 below, before being discussed in further detail.

<b>Super-ordinate themes</b>	<b>Sub-themes</b>	<b>Details</b>
<i>Revisioning</i>	<ul style="list-style-type: none"> <li>• <u>Image and identity</u></li> <li>• <u>Alternating focus and a new reality</u></li> <li>• <u>The mortal future</u></li> </ul>	<p>Sense of self; new or changed roles</p> <p>sharper relief or lack of clarity; new reality/new horizons</p> <p>loss and grief</p>
<i>Reconnecting</i>	<ul style="list-style-type: none"> <li>• <u>With important relationships</u></li> <li>• <u>With the past/past self</u></li> <li>• <u>With choice and control</u></li> </ul>	<p>Making connections again with family/friends</p> <p>Connecting with previous self and social roles</p> <p>Regaining control and exiting the sick role</p>
<i>Revisiting</i>	<ul style="list-style-type: none"> <li>• <u>The stroke event</u></li> <li>• <u>Previous life</u></li> </ul>	<p>Recounting the shock of the event and hospitalisation</p> <p>Looking back and reflecting on previous life/experiences/roles</p>

**Figure 26: Super-ordinate and sub-themes: main study**

To consider the findings further, *revisioning* involved participants looking again at their image and identity, either in relation to new disabilities, or in relation to new or

changed roles. It also involved an alternating focus between those things which had been brought into sharper relief: for example, the things that really mattered to them, or the things that had become less clear, like having a less certain future, or not having enough information. This alternating focus also seemed to involve looking at others as a means of comparing and contrasting to their own situation. Therapeutic distractions, like TV and music, seemed to help to distract, and take the focus away from things that were difficult to deal with. Also closely related to the alternating focus, were the changing visions participants had of a new reality.

During this first month there seemed to be a turning towards and a turning against acceptance of this new reality, for both survivors and carers. Participants were working on 'placing' themselves within this new reality, and also working towards adjusting to it. However, the accounts were not without hope, and new horizons were looked towards. For some participants who had greater physical needs, their new reality meant accepting care and equipment as a means of returning to their home.

*Revisioning* also seemed to involve looking to a mortal future where death had to be faced, whether this was explicitly or implicitly referred to. Participants seemed to be more aware of their age, feel more vulnerable, and be seeking reassurance about the prevention of another stroke happening. With regard to losses, whether these were to do with ability, future plans, or losses within a relationship, there seemed to be a grief that was a 'living loss' rather than a loss associated with a death.



In relation to *reconnecting*, this involved making connections again with important relationships, whether these were with partners, family members or colleagues.

These reconnections were also highlighted by those participants with communication difficulties, who had lost some (or in two cases, almost all) of their former means of reconnecting verbally.

Stroke survivors were reconnecting with their home and their 'belongings', both in terms of possessions, and in terms of a personal sense of belonging. Carers were reconnecting with the person who was home again after their hospital stay.

Reconnections were also being made with the past, whether this was with previously enjoyed activities, or with the past self. Participants seemed especially keen to take forward as much of their past lives as possible, and to regain a sense of 'normal' from this. Familiar things became more valued, as did past activities. After a period of life dominated by hospital visits, carers also felt able to restart previous pursuits.

For both stroke survivors and their carers the time of coming home seemed to signify a taking back, or reconnecting with choice and control. However, it was also recognised that tiredness limited, and to a certain extent overcame, choice and control.

In spite of this, participants still wanted to move beyond the passive, and exit the sick role. They voiced opinions about services, privacy, freedom (or lack of it) and whether they wanted support or not. With regard to having more choice and freedom, getting out of their home seemed to equate to 'getting on' for both patients and carers. Getting out and about also seemed to be closely linked with the theme of

revising, in that it helped to alter the focus away from being purely stroke and illness related.

At the same time as moving forward with this new life, participants were also *revisiting* and reflecting on their previous life, and revisiting the stroke event, including the period of hospitalisation. Although the interviewer did not ask about the time in hospital, this was something that participants seemed keen to talk about, and make sense of. *Revisiting* the past, and the stroke event, seemed to help in the sense-making process relating to their present situation.

### **6.13 Data collection limitations**

An important aspect of situating the data and findings, is an awareness of limitations relating to any element of the data collection process (Barbour, 2008). Difficulties encountered during the research also need to be acknowledged, and any strategies used to overcome these challenges should be noted. As Furman (2004:163) concludes, researchers need to resist the temptation of trying to ‘look good’ by indulging in ‘impression management’. It was therefore felt that limitations needed to be detailed and discussed in order to appreciate the findings more fully.

As has been already identified, Yow (2005) discusses the inhibiting effect that other people can have on disclosure during interviews. Banks and Pearson (2003) also acknowledge that carers may sometimes be uncomfortable discussing difficulties in

the presence of the person they are caring for. Interviewing participants separately was again encouraged by the ethics committee for this part of the study, with a view to facilitating a more open disclosure. However, not all studies can achieve this, and Smith et al (2004) acknowledge the fact that this did not happen in their stroke study as a potential limiting factor in their research.

As has already been mentioned, the fact that this also happened in one of the interview situations in this part of the study, may have affected the depth of data given in that case. However, being a guest in the houses of participants, the interviewer often has to accept the situation that is offered on the day of the visit. As discussed in the preliminary study, interviews also sometimes have to be attempted twice, if the first interview fails for some reason. In the case of the preliminary study, this was partly due to the presence of other people, and partly due to participant fatigue. However, it is not always feasible to carry out more than one interview, and any possible or potential differences in data collected as a result needs to be acknowledged in the research write-up.

In the main study, one interview had to be re-scheduled due to equipment failure, and another interview also yielded a more limited account due to a damaged tape. In addition to this, as mentioned earlier, one carer changed her mind at the last moment about being tape-recorded during her interview. Her views were respected with regard to this, and hand written notes were kept by the interviewer instead. This may have affected the accuracy and detail captured in this situation, although every attempt was made by the interviewer to ensure that the account was as precise as possible.

In this situation, more attention also had to be paid to detailed field notes, to avoid losing the account altogether, especially since a diary account had already been completed.

These issues will be discussed further in the overall study limitations section, but it is considered important that the reality and complexity of gathering data from participants at such a potentially vulnerable and sensitive time is acknowledged. As Morse (2010:3) discusses, if a research account appears ‘too neat and tidy’, this can raise questions about the quality of the study. Morse (2010:3) also considers that ‘missing perspectives’ (for example, divergences within data) may indicate that there has been either inadequate analysis, or sparse data collection. This further emphasises the need to acknowledge any inconsistencies within the research.

Although Morse’s plea for increased sample sizes to avoid such limitations (Morse, 2010) cannot generally be met by the number of participants in many IPA studies, the depth and inclusiveness of the study being discussed here can hopefully compensate for other elements that may be lacking in terms of numbers and breadth. An inclusive strategy also avoids merely involving participants who are easy to reach and verbally eloquent, and who may, in turn, only give limited perspectives - an equally flawed approach. However, in certain cases, data sometimes has to be rejected as inadequate, and whilst the input of the first participant is acknowledged, the contribution to the overall study was minimal in her case, due to the paucity of data provided.

As has already been discussed, not all participants completed a diary, which may have affected the detail of their recall during the interview; there was also no diary data for the interviewer to refer to, or probe from. As previously stated, this raises

the issue of whether only participants who are able to complete all aspects of a study should be included. Where there might be logic for exclusion on these grounds in a quantitative or comparative study, such a strategy does not seem as relevant in an experiential study, where there is generally quite a natural variation in the amount of input given by different participants.

As has been stated previously, this study sought to be as inclusive as possible, and thereby still hear potentially more limited, but no less important, experiences. As Brocki and Wearden (2006) conclude, in any qualitative research, one participant may summarise a point succinctly, that other participants have struggled to convey in a less precise way. At such times, the selection of quotes that are more articulate may have to be made. Although Smith et al (2009) discuss the fact that attempts should be made to draw quotes proportionately from all the participants in a study, the range of communication and physical ability of participants in this study meant that there was some disparity in their ability to give as rich or reflective accounts as other participants. However, in order to avoid the possible need to ‘overdraw from a small number of participants’ (Smith et al, 2009:116) who may be the most articulate, some quotes from less able participants have also been included, and this should be borne in mind during the reading of the quotes. As Braun and Clarke (2006:98) consider, producing a good analysis from poorer quality data can be far more demanding, but ‘can potentially be performed by a skilled and experienced analyst’. In this respect, the preliminary study provided valuable initial experience of working with such participants and data.

With further regard to limitations, it is acknowledged that the experiences of people without a carer, and those who were discharged to places other than their own home are not included. Limitations will be further summarised in the concluding chapter.

#### **6.14 Summary**

This chapter has given details of the main study method, and how this differed from the preliminary study. Participants to this part of the study have been specified, and their ability to contribute explored. The possibility of including further participants with communication and other physical restrictions has been examined, and an overview of findings from this part of the study has been given. The means by which the super-ordinate and sub-themes were developed has been explained, with the main themes of *revisiting*, *reconnecting* and *revisiting* being discussed. Challenges in data collection have been considered, and limitations have also been acknowledged.

The following chapter will discuss the super-ordinate and sub-themes in greater detail, giving specific examples and quotes from the participants, for all the identified themes. The links that were made between the super-ordinate and sub-themes, and the participants' words, will be explored and explained. Some initial interpretation and reference to other literature will be made in chapter 7, with a more in-depth and interpretative analysis being discussed in chapter 8.

## CHAPTER 7

### Main study findings

#### 7.1 Introduction

This chapter will explore the main study findings in greater detail, giving specific examples from the words of the participants to explain and explore how each super-ordinate and sub-theme was derived from, and connected to, the narratives. The super-ordinate themes of *revisiting*, *reconnecting* and *revisiting* will therefore be examined in turn, with each sub-theme being linked to examples from the transcripts. In this way it should become clear how the analyst formed a broader understanding of the emerging themes, and related or grouped these into more major super-ordinate themes. A ‘worked’ example from the interview transcript of one participant (Angela, carer) is given in Appendix 13, to further explain how themes were derived. This transcript was chosen because it is relatively short, but still quite succinctly allows the emerging themes to be displayed. Some initial discussion in relation to these themes is made in this chapter, with the following chapter allowing for engagement in a more involved and broader discussion.

In common with the preliminary study, pseudonyms are used throughout, and ‘I’ is used to indicate that the words are those of the interviewer. Dialogue is again noted in italics, with the pseudonyms used within quotes being indicated by normal font. The transcript format is similar to the preliminary study, as detailed in Appendix 8.

## 7.2 Revisioning

*Revisioning* involved a process of looking again at roles, image, a new reality, and future mortality. The focus of participants alternated between various aspects of current and past lives.

### 7.2.1 Image and Identity

Both patients and carers seemed to be revisioning their image of themselves, in relation to new or lost roles, and ability versus disability. For example, one survivor with aphasia (Dorothy) was particularly keen to maintain her image as a smartly dressed person, feeling unable to go out for a meal because of her clothing. In the mind map, (Appendix 12) this has been noted as ‘keeping up appearances’. In the following interview extract, the patient had selected a picture of a nice meal, and the interviewer is asking about it:

I: *Was that in the house, or was that outside, somewhere? ..Where was that?*

Dorothy: (indicates her own clothes, and crosses/moves hands in a ‘no’ gesture, and grimaces)

I: *You were not dressed for it!*

Dorothy: (nods head vigorously)

I: *Ah, right! So you wanted to go..you didn’t feel dressed for it..for a..for a nice meal out – so, was this just in the house then?*

Dorothy: (nods, smiles)

I: *But it was good in the house, was it?*



Dorothy: (nods several times and smiles)

Her husband (Douglas) re-inforced this point by describing the struggle he experienced trying to select clothes for her to wear not long after she returned home:

*She's talking about a top, and you don't know if it's a blouse or a jersey or a jacket...er...you're..I mean..eh..when she first came home, I had the whole..very near the whole wardrobe out on the bed, trying to get what she was after, you know...but er... now it's.....(laughing) because you know what you women are like! (laughter) you've certain things to wear...and ..an it's not like ..the man - just goes in.. and any old shirt and any old pair of trousers 'il do him – but, you women are different!*

*So....I mean, er..if it had been me in her place, I'd have been no problem, she would have just went and given me a pair of trousers and a shirt – “wear these”.. but, you can't say that to a woman! (laughter).....aye..you can't...it's just...they're different! .... (more laughter) (Douglas, carer, interview)*

In this conversation, Douglas still refers to his wife 'talking', even although she has virtually no speech. Differences between the gender approaches to clothes, and his new role as almost 'wardrobe mistress' for his wife are also mentioned – something which exasperates and mystifies him. They eventually find support through the use of colour charts and diagrams from the speech and language therapist, but this problem had obviously not been anticipated in hospital.

Douglas is also comparing how the situation would have been if the roles had been reversed, and he had been the one who had suffered the stroke. He also moves from discussing his wife individually to making a statement about all women: *'they're different!'*.

For a further participant (Judith), the physical difference in her facial appearance had a marked impact on her image of herself:

*I felt I was ugly. I mean I was ugly because I actually.. I went for a passport photo for my .. to apply for a parking, disabled parking meantime, temporary one, and my first photo, I don't know how it is today, I never look at myself, but my face was right down.*

*And I didn't want my grandchildren or my great grandchildren to see me like that.*

(Judith, survivor, interview)

There are several different aspects to her identity mentioned here. Firstly seeing herself as physically changed and *'ugly'*, with the photo being offered as *'proof'*. Initially she says she felt ugly, then she uses the more certain *'I was ugly'*. She also refers to her image as a grandmother, and later confesses:

*I don't think it would've make any difference but I just, I don't know, I don't know whether I always want them to see me as being perfect I don't know (laughs).*

(Judith, interview)

Even although she doesn't think it would make a difference to her family, her own desire to be seen as perfect has been affected, and although she laughs, there is a sense that this is very important to her. Judith also talks about putting on make-up, or as she calls it, '*war paint*' because she did not want to '*look ill*'. However, she says in the earlier extract that she doesn't look in the mirror, and one wonders if this is because she wants to avoid seeing her changed image. Although, as discussed earlier, awareness may increase on returning home, as Studer (2007) observes, awareness can also increase emotional distress, and thereby may not improve outcome.

Interestingly, Judith does not seem to accept being disabled as a permanent situation, using the words '*meantime*' and '*temporary*' together to emphasise this fact, and indicating an unwillingness to accept being disabled as part of her identity. However, the repeated use of '*I don't think*' and '*I don't know*' does indicate that she is by no means certain. In a later passage she also twice denies (in quick succession) that this is to do with being '*ashamed*'. Such 'language of negation' (Rogers et al, 1999:93) will be discussed further below, but may in fact indicate that it is exactly the issue that is being denied, that is in fact felt. These aspects of identity are illustrated quite expressively in a poem that was created solely from this participant's interview by the analyst (see Appendix 14). This poem will be discussed further in the following chapter, but the purpose of composing it was to illustrate findings in another form, that might add some additional interpretation and insight into the experiences being described.

In further relation to image, other survivors similarly talked about this, as well as not wanting to *'be a burden to anybody else, things like that'* (Rachel, interview), or regaining their previous identity: *'If I was there [at college] I may get my old self back. Need to be more confident, happier'* (Rachel, diary).

In the above extract, it is almost as if Rachel is seeking something that she has lost in her *'old self'*, but may be able to find again by going back to previous places and activities. For both Judith and Rachel, as with many of the others, the desire not to be a burden, or be seen as disabled, seemed to place greater importance on rehabilitation exercises, with the diaries giving day-to-day accounts of what was being achieved, either with the therapists, or on their own. For these participants, their image of themselves was closely linked to their incentive to engage in rehabilitation.

However, not all the participants were as able to be so proactive. One of the survivors with minimal speech (Morris) indicated his feelings of being helpless, disappointed, embarrassed, and angry in pictures, as his identity had changed from being able and capable, to now being unable to speak, and largely confined to a wheelchair. He matched pictures of these emotions to having to watch his wife do most of the practical tasks around the house. Morris had little choice in the matter, but where there were options within the rehabilitation process for other survivors, certain help was deemed acceptable, but other aspects were considered more fundamental to a person's image of themselves, and assistance was therefore less bearable:

*I think that's helped me to get better so quickly, because I was determined that people wouldn't dress me or feed me. The nurse helped me with my walking – well, I didn't mind my walking so much - but em, no, not personal things. (Judith, survivor, interview)*

This echoes the participant with aphasia in the preliminary study (Bert), who indicated through pictures that certain help (in his case, shaving) was too personal to be welcome, presumably having too big an impact on self-image for him, individually, to be comfortable with.

The desire to be as independent as possible, expressed by many of the participants, is in contrast to the IPA stroke study of Murray and Harrison (2004), who reported that participants felt that having a visible disability allowed acknowledgement of problems, thereby potentially eliciting a compassionate or caring response from others.

In further relation to identity, carers were also revisioning their image of the person they were caring for, as Daphne illustrates below:

*I feel I've got a different man home than he was before he had the stroke, because before he was a very well educated man, and although we tended to make decisions together, I always took his lead because I felt, you know, he knew what he was doing and now he's not – he's not even interested in anything (Daphne, carer to husband Dennis, interview)*

And:

*He became an old man practically overnight, you know, from being quite a young – a spry retired person – pensioner – we thought we were quite active pensioners*  
(Daphne, interview)

It is interesting that Daphne viewed her husband's previous status and identity as an educated man as now having been lost or negated by the stroke. Her words convey a sense that part of his identity has been taken away, and suddenly she sees an old man instead. Her final comment about them both being 'active pensioners' is in the past tense, and it may be that she is seeing herself in a different light, as older, now too.

In further relation to body image issues, toileting and continence were mentioned by several participants. For example:

*Didn't make it in time to the loo again. I only get a couple of seconds warning which means I have to rush and today I didn't rush enough. I suppose that makes me a bit incontinent, what a horrible word.* (Judith, survivor, diary)

*I think one of the biggest ties is the toilet, because when he was in the hospital they were very keen that he would be independent with that, but in fact I mean it's awful to be talking about it really, but just wiping himself afterwards, he can't turn, he can't twist round without falling over so I do that, but he's very good – he only goes twice a day, so we get it over with in the morning and then there's about mid-*

*afternoon and that's it. But the afternoon one does sort of cut into your day a bit, when you're leaving him with somebody else, because I think he would just hold on till I got back – so that's a bit of a tie isn't it?* (Daphne, carer to husband Dennis, interview)

As can be seen from the example above, carers were not only having to take over very personal tasks, but they also no longer had their previous freedom. Many were also struggling with maintaining their own identity in a selfish-selfless dilemma:

*I think everybody tackles their problems differently you know – em it depends whether you're going at it from a point of view that you're prepared to be selfless about it, or if you think "I'm entitled to my life" and you want to be a bit more selfish about it.* (Daphne, interview)

Also:

*Because I was so free to come and go when I wanted*

*Oh, yes! Yeh..I mean, Morris had his golf, and he had his gardening, and he liked to..to go to the town centre and wander round the shops..*

*I had my bingo..I could see my friends..you know..*

*That, suddenly that all stops, so..I take every opportunity [to get out] of course I do!*

(laughs) (Audrey, carer to husband Morris, interview)

Identity changes also related to carers who were husbands/wives/partners, having to take on a more parental role, and in that respect, also much greater responsibility:

*I feel when I'm away..I'm.. I mean I'm trusting him to do..to sort of behave.. (Ann, carer to husband Sam, interview)*

*I couldn't sleep for listening..like when you've got a new baby, you're not totally sleeping, you're constantly listening for any wee..you know..em..noises and whatever..but he slept fine! (laughs)...ah, dear..but oh.. no, no that was just not like proper sleep.. a lot of folk are like that, you know.. you know what I mean...just suddenly you're responsible..when there was a whole team of people in the hospital looking after him for 6 months, you know what I mean? ..And then suddenly the door shuts and it's just me...and I thought "oh god I canna cope, canna cope" you know but - I have (Audrey, carer to husband Morris, interview)*

Here, Audrey initially doubted her ability to rise to the demands of the new caring role, but her identity has now changed to that of someone who can cope. Her repeated use of the words 'you know' in this excerpt appears to be playing the part of checking that the interviewer is gaining an understanding of what the situation was like for her.

Other carers mirrored this transition from fear of not coping to starting to manage, even in the few short weeks since discharge:



*I was pleased to have him home but I did feel the responsibility, but that's fading a bit now even though I'm still responsible. I'm not so terrified of the responsibility, possibly because obviously we've lasted for four weeks, so that's better, but I know it's still my responsibility to do things for him, and he still won't make phone calls - I've always got to do that. You see, he did everything* (Jill, carer to husband Norman, interview)

The use of the word 'lasted' somehow seems to indicate a sense of survival, where perhaps there was some doubt about managing initially. Changes in the roles they now play within the relationship are also mentioned by Jill in the above quote.

Role changes may have had an impact on the more personal aspects of relationships between partners, but this was more implicit rather than explicit in the accounts.

Even when the interviewer probed, details were not always forthcoming:

Douglas: *If she's to go to the toilet, I've to go with her, and...*

*and everything...*

I: *So that's.. been a bit different then...?*

Douglas: *Oh aye...oh aye..it's em...you get used to it...I laugh about it an...*

*...aye..but er..when she says we go, well, we just go..*

I: *So has that had any effect on your relationship?*

Douglas: *Not at all* (quick, emphatic)...*not at all, no...* (laughs) *..not at all* (softer)...

(Douglas, carer to wife Dorothy, interview)

His repeated denials became less emphatic, and there was a sense that in the pauses he may have actually been reflecting on the fact that perhaps there had been an impact on their relationship after all. This seemed especially evident during a moment of quiet sadness after his final denial.

Further aspects of relationship changes related to *reconnecting*, and these will be discussed further below.

In other aspects, participants had to change their image of themselves to help them rise to the challenges they were facing. One carer described how she had to deal with a problem relating to a therapist being absent, and no replacement being available:

*If someone is away on the day they're supposed to work, the other one doesn't do anything extra, so you just don't get seen. And then I did complain a bit, which was hard because I'm not really a complainer, but obviously I've to sort of up my game a bit, and they found someone* (Jill, carer to husband Norman, interview)

Her husband similarly struggled with his image of himself as a *'fighter'*, and as a golfer, he uses the game as an analogy to describe how it feels:

*I'm starting one down at every hole, which I'm not very good at - I'm quite a fighter, always have been with everything I've done in my life, but I just can't seem to have the guts to face some of these things, so I feel a bit down about it, my fighting spirit's not there. It is, but I can't use it* (Norman, survivor, interview)

Here Norman seems to be struggling to find his previous spirit, and he and his wife have had some role reversal in this respect. Again, this raises questions about the impact on their relationship. The change in his self image is brought into stark relief in the following quote, where the word ‘*nothing*’ takes on two completely different meanings:

*So really I’m vegetating here, I’m achieving nothing and my wife will do everything, and if I say to her “is there anything I can do to help”, she says “the only thing you can do to help is get better” and I say “right, that’s all I can do to help”. I put a couple of plates in the dishwasher and that’s it – all I’ve done. She does everything.*

*From being somebody who can do everything, I’ve turned into somebody who can do nothing. There was nothing I couldn’t do before – nothing* (Norman, survivor, interview)

Rogers et al (1999:79) discuss the significance of examining and identifying not only the explicit in narratives, but also ‘the presence and importance of what is unsaid, and perhaps unsayable’. Examples of things being unsaid may be indicated through hesitation, denial, silence or evasion (Rogers et al, 1999).

For instance, the following participant, even although expressing what seemed like very clear worry to the interviewer, when questioned about it, explained:

*Callum: It’s not worry as much as being... just wondering “will it happen again?” you know? It’s not worry. I don’t think I worry about that, I just think about that, you know*

I: *Right, so you would call it more apprehension than a worry?*

Callum: *Oh yes, yes, it's more of the... that is it going to happen again, you know?*

*But I don't worry about it too much...*

*Don't worry about it, it's not, not because, it's not like the thought's at the top of my mind all the time you know, it's just eh every now and again I'll say "Will it?"*

(laughs) (Callum, survivor, interview)

Such examples form a 'language of negation' which Rogers et al (1999:93) argue can reveal the unsayable, and (in this case) the possible significant fear being felt by the participant. He shrugs it off with a laugh at this stage in the interview, perhaps in an attempt to preserve his image, both to himself and to the interviewer, even although earlier he had used the specific word '*frightened*' on two occasions. When the interviewer suggests another word (although in hindsight it would have been better to ask him to suggest an alternative word himself), Callum seems to grasp at this as a more acceptable word.

As Rogers et al (1999) consider, such denials and contradictions may leave the reader confused, but they may also reveal more than they conceal.

Elliot (1997:11) also considers that researchers should be alert to the possibility of 'external voices' being present in participants' accounts. Such 'voices' may reflect the views of others, whom the participant does not necessarily agree with. For example, there may be commonly held views that the participant feels they must subscribe to, or things they may have been advised about by professionals. Speaking to a known professional person (the interviewer), participants may feel they have to

uphold a view that within themselves they do not necessarily agree with, or feel. The need to project a certain image, as already discussed, is one incidence of this.

A further participant (Dennis) who had some cognitive impairment relating to his executive functioning, and higher order abstract thinking ability (see Warlow et al, 2008) expresses explicit anger when asked to consider how his life had changed since the stroke:

*Well I'm sick to death of people asking me questions – how do you feel it has changed your life – for God's sake, how do you think I would feel? End of story.*

(Dennis, survivor, interview)

There are several aspects to consider in relation to his outburst – was he finding such abstract questions too difficult to answer? Was his anger masking other emotions that he wanted to conceal, or which were just too painful to admit? As Rogers et al (1999:88) consider, such 'language of smokescreens and evasions' may indicate just that. His 'shut down' comment at the end made further pursuance by the interviewer difficult, which was presumably his aim at that time.

Rogers et al (1999:88) describe silence as 'the most elusive language of the unsayable' and advise caution in relation to the projection of meaning into silence. However, they also stress the importance of being able to 'hear' silence when it occurs.

When the interviewer ventured back to the topic later in the same interview, Dennis did at least admit that the subject was just *'too personal'* to discuss, so some further information about how he was feeling was accessed, and did indeed seem to indicate a reluctance to reveal, or admit to, very personal and possibly intense emotions. As Parkes (1971) considers, while people may be preoccupied by fear and loss, at the same time they may try to avoid reminders, with anger being a frequent consequence.

In common with participants in the preliminary study, expression of the emotions that may lie behind anger did seem to be more difficult for some of the male participants, with one man stating how he had felt when he saw another man crying in hospital:

*He was a man who cried – a lot – and I thought that was disgusting, you know, a grown man crying - but that's what I was doing* (Norman, survivor, interview)

The fact that Norman was then driven to tears himself seemed to be challenging and making him revise not only his image of himself, but also his values of men in general, with tears previously not being acceptable beyond boyhood. He later rationalises that the tears had been explained as *'normal'* to him by the psychologist, which seemed to then make them more acceptable to him. Certainly, according to Fox (2004), crying has only become more acceptable for men in the last 20 years, with the current trend now being viewed as healthier. It may be that Norman's initial views are based on previously accepted 'norms', that are now being challenged and

changed. As Eatough et al (2008:1791) discuss, crying is a 'hugely potent form of emotional expression', but one that has received little attention from psychologists.

Looking again at evasions, many (but not all) examples of silence and the unsayable related to the male participants. One of the female carers (Angela) also had difficulty talking about her situation, but alluded to the fact that her previous identity as someone who was strong was being challenged by the situation she now found herself in. There was a point where she too avoided discussing this further, as can be seen from these various excerpts:

*I: How did that make you feel then?*

*Angela: Exhausted – physically and mentally exhausted - I still am actually, but eh.. that's just something I have to cope with.*

*Mentally I'm strong. I'm determined to fight this and get over it. I think when you get over seventy-five - you know, I'm knocking on eighty-two, so it's not easy – it's not really easy, but, you know, because you know people think you're strong, they don't realise that you're not as strong.*

*I feel this isn't helping anything, me moaning on about how I feel!*

*I: No, it's very important*

*Angela: Is it?*

When asked to expand further, several 'shut down' statements were made:

Angela: *I would rather not discuss it*

and:

Angela: *I think I'll cope...*

I: *You think so, do you?*

Angela: *Yes – it's just that things are getting on top of me at times, you know*

I: *Are they?*

Angela: *Yes*

I: *Do you feel that quite a bit?*

Angela: *Yeah... But he's really very considerate and very thoughtful, you know, so I just don't want to worry him at all, so that's.. I mean I don't like talking about myself... We're having a house full of visitors at the weekend, and that's why I'm so keen to get rid of you really, because I've got so much to do I don't know where to begin, you know (Angela, carer to husband John, interview)*

The interviewer had a strong sense that if Angela had let her guard down, and disclosed her true feelings, her image of being a 'coper' might have dissolved in a flow of tears.

From these extracts, the impact of the stroke on participant's image and identity, and the *revisioning* process that was taking place, can be seen to be quite complex and



multi-faceted. Both patients and carers were adjusting their image of themselves, and of each other. Such ‘identity work’ (Watson, 2006: 379) will be examined further in the overall discussion.

### 7.2.2 Alternating focus and a new reality

Whilst *revisoning* various aspects of their lives, identity, and future, there was an alternating focus between things that fell into sharper focus, and others that became less clear or certain. Issues that fell into sharper focus included an emphasis on the things or people that really mattered. For example:

*This is such a beautiful hot, sunny day, I’m counting my blessings that I’m able to enjoy it. It doesn’t bear thinking of how it could have been!!* (Judith, carer, diary)

And:

*I’m going to make the most of what I’ve got now. And that’s what I have been doing - I’ve been doing my long walks along the beach, getting on with things* (Rachel, survivor, interview)

Also:

*Well, with our life it’s been all go all the time, and all of a sudden it’s a complete change, we’re just relaxing and seeing what’s going on with the countryside, whereas before it was all go, go, go, with work* (Elizabeth, carer to husband Hugh, interview)

The repeated use of the words ‘*all*’ and ‘*go*’ in this last example gives some indication of the extent of the change in their lives, almost going from one extreme to the other.

Another participant’s focus seemed to become more insular, as her diary entries indicate:

*I was a little afraid, but just kept myself busy in the house tidying up – feel very tired all the time but trying to keep myself in gear.*

*Started reading more books – good excuse as I do have a habit of buying them a lot.*

*Remaining very positive and hopeful.*

*Sun is shining on me as I sit in my front room, big white fluffy clouds on their way across the sea.*

*So will make my list and tick it off as I go and also obey my body when I start to feel tired or weak* (Rachel, survivor, diary)

This last part is almost poetic in its description, and seems to evoke a sense of her stillness, as she sits and watches the clouds move by. This is in contrast to her talk about tidying up, and getting ‘*in gear*’, even although she is obviously very tired. Further ambiguities exist in the fact that she is fearful, but also hopeful and positive. Watson (2006) discusses the fact that such seeming contradictions are not uncommon, and are part of narrative construction. Certainly, over time, Watson (2006:371) discusses the fact that ‘events may be altered, marginalized or forgotten if they do not fit the overall plot’, so such early detail of experiences, as expressed

here, might not be possible or accessible at later stages in the recovery process, if narratives and the way things are viewed change over time.

Other situations described by participants became less focused and clear, with some participants feeling they did not have all the information and advice they felt they needed. One of the participants with virtually no speech (Dorothy) was able to indicate her confusion and worry through pictures:

I: *So, a bit confused – anything in particular you've been feeling confused about?*

... (Dorothy shrugs)...*no?.. just in general?* (Dorothy nods) ...*right.* (Dorothy points to another picture)

I: *Have you?..have you been worried?*

Dorothy: *I have...I have* (very faint and slurred)

I: *You have been a bit worried, have you?*

Dorothy: *Uh-huh* (selects another picture)

I: *You have felt a bit weepy?* (Dorothy nods, looks sad)...*I'll put those over there together* (Dorothy, survivor, interview)

Although Dorothy could not go on to be very specific about what was causing these emotions, the pictures did allow her to disclose how she had been feeling in general.

For her husband, the focus alternated between trying to differentiate between things that were important and those which weren't:

*If she's trying to tell me something and I can't make it out, I'll say "is it important?"*

*If it's not important, just forget about it at the moment and try some other time"*

(Douglas, carer, interview)

Yet again, for other participants there were gaps in knowledge that seemed to create an uncertain focus about more specific issues:

*I need to see the Doctor every fortnight and you come out the doctor's "Oh I should have asked about that" you know, so eh.. that's a couple of questions to ask him you know - "What's the tablets for?" Eh, and "What sort of exercise can I do now?"*

(Callum, survivor, interview)

*Obviously we're hoping that it will never happen again. It's maybe just a one-off, I don't know. And I don't think anyone can tell that, you wouldn't be able to tell that, and the doctor wouldn't either, you know* (Fiona, carer to husband Callum, interview)

Such fear of recurrence echoes that noted in the preliminary study. As Parkes (1971:108) identifies, fear of further losses can be associated with 'loss of confidence in the world as a secure, reliable place', with subsequent effects on future visions.

The gentleman with higher order dysfunction (Dennis), as mentioned above, also only seemed able to deal with very focused, rather than abstract questions, as this quote indicates:

*They drove me daft with questions which had no apparent direct approach and there was no obvious answers to them* (Dennis, survivor, interview)

As with the preliminary study participants, there was some ambivalence about how much information people wanted to have:

*I haven't spoken to anybody else about whether it affects them, maybe it does. I don't know whether I want to know in case it doesn't* (laughs). *Because I'm really hoping it clears up itself, if I do start doing these exercises* (Judith, survivor, interview)

Here Judith is talking about post-stroke incontinence, and although she laughed, there was still a sense that this was a real worry for her.

From this aspect, participants appeared to be engaging with what Brereton and Nolan (2002:22) describe as 'seeking' knowledge about their condition, diagnosis and future. In Brereton and Nolan's (2002) study the focus was on carer's information needs, while the patient was still in hospital. However, both patients and carers in this current study were still seeking answers after discharge, even although they were not entirely sure that they would like what they heard in response.

Also with regard to alternating focus, were the different perspectives patient and carers viewed situations from. As this carer describes, while her husband was focusing on regaining his independence, her own focus differed in that she was more concerned for his safety:

*He'll ring the bell some days, other days you just hear the bathroom door open – and there he's stood..now, right opposite the stairs – if he was to..to trip his self up, which he could, because he's..he's not very..you know, his leg doesn't move that well..he could be down the stair (faint sigh) so... you feel you're nagging (laughs) cos you're saying "Morris – why didn't you ring the bell!" but he's fair pleased that he's done this (Audrey, carer, interview)*

It is important that such contrasting perspectives are identified because, as Palmer and Glass (2003) observe, there may be negative impacts associated with an over-protective approach. However, as will be discussed later, the balance of matching safety against opportunities to be independent can be a challenging one.

Other aspects of an alternating focus involved participants comparing their situation with others - a theme which was also found in the preliminary study. By moving the focus from themselves to others, participants seemed to be judging their own progress:

*I was in hospital with people that were really bad, that couldn't walk properly, couldn't dress, couldn't feed themselves, couldn't go to the toilet, had to wear liners all the time. Em... I could have been so much worse. And each day when I see a*

*slight improvement, and I do every day, I'm so thankful* (Judith, survivor, interview)

By looking at others, participants also seemed to gain inspiration to carry on, as this participant, who had marked speech hesitation and dysarthria managed to impart:

*I think of that other boy - he used ..he had this thing on the back ..of his leg -*

*you pull it..it fixes on there, and you pull er.. the strapping...but em...that helped me...seeing him (emphasised quite clearly)... got me cranking up* (Sam, survivor, interview)

A further element in alternating focus seemed to relate to moving the focus away from ill health, to looking at 'therapeutic distractions' for some respite and escape from current difficulties:

*I haven't had many days when I've been happy. My happiness is playing music on my television. I've got music DVDs which I play a lot of. I love those, and American comedy videos - I've got, you know, things that make me laugh – something has to make me laugh to make me feel happy. I can't be happy about circumstances. I don't want to be a burden to my wife, and I am, so everything's a bit..... But I can laugh at my comedy, and I can enjoy my music...*

*Just sit around, play some music, and it made a huge difference – a huge difference.*

(Norman, carer, interview)

The participants with aphasia, both in this part of the study and the preliminary study, all indicated that such distractions were enjoyable and helpful. Carers also seemed to find some comfort from this, and the fact that appropriate laughter had greater meaning to them, in the context of little other communication:

*To see him sitting laughing at..at television programmes – just absolutely killing himself laughing, which means, you know, that he’s taking everything in, you see. Although he can’t..voluntary speak to us, he knows everything that’s going on, you know* (Audrey, carer, interview)

In addition to these aspects, there was also the *revisioning* of a new reality, and the long, winding road to possible recovery:

*As I say, it just takes a lot of adjusting..it’s er not the retirement we planned! (sighs).. you know, we’d hoped to be going...doing a lot more than...we’re doing, obviously ....life goes on..and just totally different from what we expected it to be... but em...we’ll just have to adjust to it, and get on with it...*(Audrey, carer, interview)

*I think he thought that this was going to be a big new beginning, once he was home. It was as if there would be a magic wand waved and home was it, but while in fact coming home was the beginning of yet another long road for him, and for me in a way, I suppose, even though – you know - I’m not the one who’s infirm* (Jill, carer interview)



For Douglas, it was another situation which brought the new reality into sharper relief, as he spoke about his wife going to an out-patient appointment:

*Wheelchair right into the taxi and the same at the other end, an ..so she left the house in a wheelchair and never rose out of it until she... came back home...*

(sounding quite despondent) *so, everything was..went swimmingly.....but as I say..our life.. our life has changed..* (Douglas, carer to wife Dorothy, interview)

This last quote was spoken with a sadness that was in marked contrast to his description of everything going ‘*swimmingly*’. The fact that his wife was now more or less wheelchair-bound seemed to be hitting home, as the new life that they were both facing seemed to be starting to dawn on him.

However, although the stroke survivors did allude to the way circumstances had changed in their lives, as can be seen from the above quotes, it was the carers who were more expressive and explicit about the magnitude of the changes to their future. To a certain extent, there was a sense that the survivors still had to take on board the full reality of the situation they were facing. They expressed hope that things might improve, even although there was sometimes uncertainty about this:

*That surprised me because I thought by the time – I thought I’d be going up and down them stairs on purpose with nobody here, once an hour, you know, just up and*

*down as an exercise. I haven't got the energy to do that... I don't know if it would do me any good, or if it'd finish me off* (Norman, survivor, interview)

*Went to college. Bill drove me – that bit is frustrating, as I do like driving.*

*I hate seeing my car outside when all I want to do is go for a wee drive.*

*Oh well, soon be driving again* (Rachel, survivor, diary)

And:

*I'm really feeling good today, I actually think I could drive the car, my arm is nearly like it was before. I scratched an itch on my back without any effort at all. Yes, I'm getting there* (Judith, survivor, diary)

The dilemma here, as discussed in the preliminary study, is the balance between maintaining hope, versus facing reality. This may be very difficult, as can be seen from the next excerpt, when Norman was told that his recovery might be quite limited:

Norman: *I felt like I could cut my throat*

I: *When they told you that piece of news?*

Norman: *Poleaxed....I felt.... I felt like topping myself* (Norman, survivor, interview)

However, later Norman denies still feeling like that:

*I'm not in despair. It must sound as if I'm suicidal, I'm not that .... it's just that I think to achieve something you've got to be in a good frame of mind and you've got to be em, ready for battle. All these other things sort of put me back on my heels*  
(Norman, interview)

Throughout the interview, Norman struggled between despair and trying to see hope. He fantasises about being back at his golf club, and when he hears about a one-armed golfer, feels that he might be able to achieve this too:

*Probably sounds like I'm feeling a bit sorry for myself. I'm not feeling sorry for myself at all, I'm very enthusiastic about the next few weeks because within the next couple of weeks I'll be on the driving range hitting balls properly and once I'm doing that, and I can do it without falling over, I'll be away - going to the golf club and seeing my friends. If I do that, they'll be talking to me, and I'll be getting worn out, and they'll be putting pints in front of me, and I can't drink with these pills, so I'll be talking to them. And I know that I can't drive, I can't go anywhere - I've got no - someone's taken my car away, I can't drive, I can't get to the supermarket, I can't get to the golf club, can't walk around the golf course you know, because the most I can walk is about two hundred yards at the moment, so my life hasn't got back to normal at all. In a way it's more frustrating because I'm so near to it, but I can't do it - nobody will stop me now. If I want to go out on a Saturday morning and walk with my friends around the golf course, I know my wife has said "don't do it", but I'll say "no, I'm doing it" and then I'll probably go round, and it's too far.*

*So I'm liberated up to a point, but I'm still like in a prison, you know, I'm not - I haven't got the ability to do the things I want to do...* (Norman, survivor, interview)

There is a sense that holding on to these fantasies is keeping his hope alive, but at the same time, he deviates to an awareness of the reality of his situation. There is a conflict between his hopes and visions, and his feelings of being trapped. Perhaps it is only these dreams which stand between him and his thoughts of suicide.

Further talk relating to mortality seemed to come into sharper relief for a number of participants, as can be seen in the next sub-theme.

### 7.2.3 A mortal future

With further regard to changing viewpoints, some of the emphasis seemed to link into a *revisoning* of mortality. As Rolland (1989:451) states, transitions 'involve the basic processes of termination and initiation' and, as such, these changes can lead to a preoccupation with death and finiteness, as seen in the *revisoning* sub-theme of a mortal future. This was sometimes evident fairly explicitly in the words of the participants:

*I know it sounds like a daft thing to say, I'm just more grateful now. Every day I wake up I just feel kind of grateful I'm still here* (Rachel, survivor, interview)

*You just don't know. I mean strokes can go on for years or they can – something can happen, and that's it. So it's – you're on a bit of a volcano because you don't know if it's just going to slumber away, or if there's going to be drama, or what. You've got*

*to be more or less prepared for anything really, at this stage* (Daphne, carer, interview)

When Daphne compares the situation to a volcano that is going to ‘*slumber away*’ there seems to be an ambiguity in what she actually means by this – is she referring to the fact that nothing much might happen, and her husband may go on as he is for some time, or does she mean that he might just ‘*slumber*’ (or pass away) in his sleep, as opposed there being a more dramatic ending?

Interestingly, Daphne talked in very impersonal terms at this stage, with the distance that this presumably allowed, appearing to be a possible protection from the emotion she really felt. Later in the interview, when she talked more personally about herself and her husband, she started to weep:

*It just makes you wonder how long you’re going to have him, you know.*

*I don’t know – sometimes I wonder what would happen to him if something happened to me?* (Daphne, carer, interview)

Here she seems to be realising not only her husband’s mortality, but also her own.

Later she talks about the feeling of being morally blackmailed by the situation, anticipating the future, and the control that knowledge has over her:

*The fact that he could go at any point – I think everybody likes to have as few regrets as possible. I think that’s the sort of moral blackmail that they have over you, you know – I can get quite emotional about it because, well, I don’t like to think of*

*anything being terminal, but I'm having to be realistic about it, you know, because he is quite weak physically* (Daphne, carer, interview)

As Rolland (1989:439) discusses, losses resulting from illness, even if death is not involved, can affect the whole family, with a need to 'grieve for the loss of the preillness family identity'. Buschenfeld et al (2009:1648) also acknowledge that caring for a stroke survivor affects the whole family, and that this impact is 'an identified gap in knowledge', suggesting that the effect on the family identity as a whole might benefit from further study.

Depending on the situation, there may also be anticipation of further loss, and possibly death, as noted above. Again this relates to the *revisioning* process, as described in the following quotes:

*I'm just grateful that she's still here...it brings it back to you how fragile everything is. Mum's not as independent as she was...she used to drive everywhere.*

*As a result I'm more involved in her life now* (Sheila, carer, interview)

*According to my family and various other people, I was in quite a bad way presumably after the stroke, and I think they were all a bit fearful that I was coming to the end of my natural life. And they seemed to be aware of that, and according to the people on the staff of the hospital, it's a miracle that I've recovered as well as I have. I don't know – I really don't know how bad I was* (John, survivor, interview)

At other times, the meanings were less explicit, for example:

*Give me a chance to get my house a little bit into order – more so my mind, with this awful divorce situation. Worrying about money does not help* (Rachel, survivor, diary)

References to ‘putting one’s house in order’ are very often the sort of comments heard when the end of life is approaching. However, this participant was only in her late 40’s, and was perhaps for the first time recognising her own mortality.

Andersson and Fridlund (2002) consider that such losses, in particular where the loss of speech has occurred, may precipitate a grief reaction. For example, as Douglas (carer to Dorothy, who has virtually no speech) stated:

*I’ve had my day.....em...I’m..I’m resigned to the fact that there’s certain things that I just can’t do now....and..er....I’ve pushed them aside, and that’s it...(sounding very low in mood) (Douglas, interview).*

Loss and grief will be discussed at further length in the following chapter, but as Hjelmblink and Holmstrom (2006) conclude, following a stroke, survivors may develop a greater understanding of their vulnerability and mortality. These findings indicate that the same may also be the case for carers.

### 7.3 Reconnecting

The process of *reconnecting* was multifaceted for both patients and their carers, and involved reaffirming connections with significant others, regaining control, and reconnecting with important aspects of their past lives.

When referring to psychosocial transitions, Parkes (1971:104) defines bonds with people, places, and roles as ‘affectional bonds’, and stresses the importance that maintaining such bonds has on people. As Parkes (1971:103) argues, these bonds are an integral part of an individual’s ‘assumptive’ or known world.

The bonds and reconnections participants were making in terms of relationships, control, and the past, will be discussed next.

#### 7.3.1 Important relationships

With regard to reconnecting with important relationships, for most participants the initial experience was of increased connectedness, and in many cases this seemed to come as a surprise – noted as ‘I didn’t know you cared’ on the mind map.

*There’s always somebody asking if they can get anything for me or do anything, you know, even further afield! (laughs). I mean I could even go and ask any other neighbour – the ones I know personally, er and they would just do, ken [you know], if I was really needing anything, so ..I have had a good lot of support*

*...even from Hugh’s nieces ..and his cousins and everything..they’ve all been coming down to see if there’s...if they could do anything for us (laughs).. Aye... it’s nice...aye...so.. you don’t know your friends..you don’t really know all your friends until something happens like this (Ann, carer to husband Hugh, interview)*



*When I got back to college, it was great to get back with everybody there. We've got a good group, we're very close and have become really good friends in the class, and I realised how much it had affected them as much as me. It's like with all my friends - I didn't realise how much it had affected them all. And it was how everybody welcomed me back... I felt like a film star! (Rachel survivor, interview)*

*I think that he thought that nobody worried about him, but whenever he came home we ended up with a house full of visitors! His brother had never been in..well, not very often in my house, eh..and he came in on the Sunday, and then his wife came in, and the grandchildren, and then my daughter was here as well, you see, and so..and then ..em.. everyone's been here, and even the cards – we're still getting cards yet from..caring about him (Elizabeth, carer to husband Hugh, interview)*

These quotes show the impact that the stroke had on friends and family, with connections being reaffirmed in ways that were very significant for both survivors and carers. The day of home-coming was also quite an emotional reconnection:

*This was a great day for Dennis. It was a beautiful, sunny, winter's day and he enjoyed looking at the familiar countryside on the journey home.*

*All the family had come to welcome him home and his delight brought a lump to everyone's throat (Daphne, carer, diary)*

Perhaps because participants with carers were sought for participation in both parts of the study (even if they did not necessarily live together) there were few reports of participants feeling isolated, as has been reported in the study by Haun et al (2008). However, on the occasions that survivors were on their own, even for a few hours, some fear and apprehension was evident:

*When I first came home it was nerve-wracking being alone in the house because I was frightened at first em , I felt kind of, as you say, vulnerable being on my own.*

*I knew that this is a weakness that's there [referring to stroke incidence in her family] and I remember what my mum had, because she had lots of mini-strokes, and I think the fear at the back of that is the dementia that my mum got at the end*  
(Rachel, survivor, interview)

Carers also expressed worry about periods of not being closely connected during the first days at home. For example:

*I am..I'm a..I'm a born worrier, you know, and I was just (gasps).. what if he needed me in the night and I didn't hear him?.. and just, you know..cos he's in the room next to me now* (Audrey, carer, interview)

Haun et al (2008:56) describe connectedness as a 'mutually occurring process between the stroke survivor and others'. For the participants in the study by Haun et al (2008) the 'others' seemed to be considered as family, friends, or social contacts, rather than 'professional' support. However, as noted in the preliminary study,

professional support can also be greatly valued. Indeed, Saha et al (2010:i45) report that patients in their study who had support from community rehabilitation services had ‘significantly less emotional difficulties in coping with their stroke’ than the cohort who did not. Given that Haun et al (2008:55) consider that inadequate emotional support diminishes recovery ability, and is a ‘health modifier’, it would seem important to assess whether further support from professionals is required, especially for more socially isolated patients.

Although Sit et al (2004) report that social networks cannot substitute for a lack of care and love from a close family member, as Glass et al (2000) discuss, many studies have associated better social networks with lower mortality risk, making the encouragement of *reconnecting* to be of importance.

The study sample of Haun et al (2008), mentioned above, were all American war veterans, which may give rise to issues surrounding the payment for such services, which may differ in other countries. The fact that only males were included may also have had significance, although gender issues have not been expanded upon to any great extent by Haun et al (2008), or other authors.

Further aspects of *reconnecting* with important relationships related to intimacy between partners. One carer (Bill) alluded to his uncertainty about resuming sexual activity, especially since his partner (Rachel) had been discharged with a 24 hour blood pressure monitor in place:

*It was good to have her back in our bed despite the incessant snoring, and had to behave myself because of the monitor (didn't want to set the alarm off). But risked it anyway (Bill, carer, diary)*

For another carer, the opportunity for any initial intimacy was taken away by the constant flow of care staff and therapists from the discharge support team:

*(Sighs) we just used to look at each other and think "God, it's like Piccadilly Circus here!". It would have been nice to have had a few hours to enjoy Morris being home, if you know what I mean. That was my ..you know, I thought...we never got any time to ourselves his first day home..til'..you know...(sighs). I thought.. I know it was all for our benefit and they were all there to see things were going to be ok, and that..but just.. from the minute he set foot in the house, for the next 48 hours it was just constant ...comings and goings, and comings and...you know...*

*I know it has to be done... but er..it would have been nice to have relaxed together for a... a couple of hours even..just to, you know..*

*but er....hang on a wee minute... I want to check on him...(Audrey, carer, interview)*

At this stage Audrey left the room on the pretext of checking on her husband, but to the interviewer it seemed as if there were elements being referred to that were too intimate and private to discuss explicitly. Again, her repeated use of 'you know' may indicate that she is hoping that the implicit meaning is being understood. When she re-entered the room the tone and emphasis of the interview altered; she quickly

resumed talking, but about a different aspect of the situation. There was a sense, however, that she felt that their opportunity to reconnect as a couple had been inhibited.

Another carer (Daphne) also made veiled reference to the loss of sexual intimacy, even although she still felt very close to her husband:

*I sleep in another room from him so that we both don't keep interrupting each other, but there's no – there's not much of an evening really, it's all adjusting to each other and Dennis's needs really – that's what we're doing now. I think if we were young it would be a problem, but I mean we've been fifty years married next summer and, well, there's just nothing I wouldn't do for him, you know* (Daphne, carer, interview)

Audrey also referred to herself and her husband as sitting together *'like Darby and Joan'*. According to the internet resource *The Phrase Finder* (2010), this reference is thought to date back to a poem by Woodfall (1735) and generally refers to a devoted older couple.

For a further lady, having her husband home in time to celebrate their diamond wedding was a significant event, allowing them to be seen *'together'*, reconnected and reunited as a couple:

*When he came home at first he was elated because he was home, you know, because ..we celebrated our diamond wedding three days after it..and er.. it was quite nice to*

*have him home, and friends coming to see us, both together* (Ann, carer to husband Sam, interview)

As these quotes illustrate, the disconnection that hospitalisation causes may be felt quite strongly by patients and carers, a fact that may not be fully understood or appreciated by hospital staff or community follow-up teams. These excerpts do help to literally bring home a sense of the importance that *reconnecting* has had for these participants.

Although the carers quoted above seem to have security in the strength of their relationship due to the length of their partnerships, another younger participant several times expressed her uncertainty and need for reassurance that her new relationship would not be affected by her stroke:

*Bill was my backbone – he talked to me and showed me I had no worries that this would affect our relationship. He has kept my spirits flying high and feel even closer in our relationship. He is very patient and understanding.*

*At night time we made love. I did not know what to expect in feelings, but we were both ok* (Rachel, survivor, diary)

Although these details were given in Rachel's diary, during the interviews such intimacies were not discussed so explicitly, even when the opportunity to discuss the

effect on relationships was offered to participants at appropriate stages in the interviews. Perhaps the diary provided a safer place to disclose such private detail.

Where aphasia was present, both patients and carers mentioned the fact that this made reconnecting a bit more difficult, but still possible, and appreciated:

*It can be a bit mentally tiring with Morris as well – not being able to have a ... a normal conversation..you know, and er, sometimes..well it takes a wee while sometimes to get out of him what he’s trying to tell you, but we do it in good humour, that’s the main thing – we have a laugh (laughs) you know (Audrey, carer, interview)*

*It’s a two-way thing, because.. er.....I keep saying to her to try and be more explicit in what she’s trying to tell me..and then I’ve to try and be a little more patient and try to find out what it is, you know. Many’s the time she’s been pointing at something, and telling me something and I’ve given up.. and I..I maybe walk out the room and go to the toilet or something..and..and then I say “cor, I know what it is!” (Douglas, carer, interview)*

Reconnections were therefore all the more challenging when aphasia was present. As Nystöm (2009:2509) stresses, additional support may be required by carers in this respect, because it is important that they ‘dare’ to communicate.

In similarity to the preliminary study findings, for many participants in the main study, reconnections were not only with friends and family, but also with their GP and other professionals, who were able to offer help and support that was valued. However, also mentioned were quite a few examples of role confusion with regard to the way participants described the professionals who visited, which may indicate that further clarification on behalf of the professionals might have been beneficial.

The interviewer was able to pick up on these role confusions due to her professional knowledge, rather than any confusion being explicitly mentioned in the narratives.

As with the preliminary study, the value of just talking with professionals was also discussed by participants in this part of the study, but not in as much detail as in the previous participants' accounts.

### 7.3.2 Choice and control

With regard to choice and control, getting out and about seemed to relate to making progress, as well as reconnecting with the outside world. For some of the participants with reduced physical ability, accessibility seemed to be less of an issue than has been reported in other studies (for example, Davidson and Young, 1985; Murray and Harrison, 2004):

*Today I took Morris out in the car to town. It was the first time I had got him from house into car, and out again, with wheelchair etc. and I managed pretty well.*

*[Son's name] was there in case I needed help, which I didn't – it was good to do something ordinary like a trip to town with Morris! (Audrey, carer, diary)*



*Sheila came and took me away in the car. I thought we were going locally for lunch, but she drove on through the countryside and coast till we got to [town]. We got a parking space at the front and she took me to a seat then went and got fish suppers and juice for us both. My, I enjoyed it.*

*I was tired when I got in, so went for a sleep, but it was a magical day. I thoroughly enjoyed it. Pure happiness (Judith, survivor, diary)*

The pleasure that managing these trips brought is evident from these excerpts, and gives a sense of the participants regaining some freedom and choice again after the restrictions of being in hospital.

However, not all participants found getting out quite so enjoyable.

For Norman, who was one of the more physically restricted of the participants, although he was getting out, it was not to the places he wanted to visit. The fact that he hadn't '*even reached the shops, even accompanied!*' was doubly accentuated by the repeated use of the word 'even' and the verbal stress placed on the word. This seemed to emphasise the impact such restrictions were having on him, and his ability to reconnect with things he previously had possibly not given much thought to. For Norman, such achievements had now become major goals, and steps on the route to independence. However, he had not given up hope, and shortly afterwards was talking about his wish to drive again.

Emphasis on particular words in narratives is something Smith et al (2009) encourage researchers using IPA to be aware of, as potentially giving clues to participants' underlying thoughts about their situation. The '*even accompanied*' words Norman uses could also be looked at in relation to way his identity has changed, and his revisioning of himself. However, at this stage he seems to use the words more in relation to his physical restrictions and frustrations, than a changed identity and concept of himself. Perhaps in these early days he was yet to form a new identity impression, or engage more fully in 'identity work'.

Getting out and getting on was also an important part of the life of carers, whose opportunities may have been restricted by their new responsibilities:

*It is a bit hard, at..at the beginning, not to be just ..totally free to come and go as you want..as normal..that you've got a husband to think of, you know..he.. he has to come first..you have to see that everything's all right for Morris..and then...em...*

*luckily I've got good family who'll come and say "right Mum, we'll stay with Dad, and off you go" - so I am off, like a shot! (interviewer and participant both laugh loudly) – you'd better believe it! (Audrey, carer, interview)*

*It's just..you know...I'm..I'm confined*

*I'm confined, to the house more or less*

*Er..I mean I go away maybe for an hour to ..if there's nobody in, I have to go, to get messages and essentials, and I'm only away to Tesco's or up to Sainsbury's – about an hour, about the longest I'm out [out of] the house*

*I make sure she's at the toilet and everything before I go (Douglas, carer, interview)*

*She's worse off with me not being in hospital. She used to lose maybe three or four hours a day, now she loses twenty-four hours a day. I mean that's a big problem, you know, it seems a bit unfair to me. I've got what I want - I've got home - I'm free from the things I wanted to get away from, but it's at a cost to her (Norman, survivor, interview)*

This balance between freedom and responsibility seemed to impact quite heavily on many of the participants, and, as may also be being implied in the last extract, might generate a sense of guilt in the survivors.

In addition to this, lack of knowledge and understanding by staff may also lead to needs not being understood. For example, one carer (Daphne) discussed a situation where she used the time when care staff were working with her husband to get out for a short time:

*I was told that it would give me time to do some other jobs. As we don't get our newspapers delivered where we live, I chose to go to the local shop and get these, and any groceries we needed. Most of the nurses were happy with this, as Dennis*

*was confident to sit alone for a short time, if they needed go before I got back. This time gap was always kept to the minimum.*

*We both felt that one or two of the nurses were resenting this situation as the weeks passed. We felt these ones were expecting to be coming, but not to be needed to do anything* (Daphne, carer, diary)

Living in a rural location, this situation impinged on her own reconnecting needs, and is consistent with the lack of carer freedom mentioned by Banks and Pearson (2003). It also displays the lack of partnership working needed by carers, as advocated by Brereton and Nolan (2002), especially in their early days as carers.

Being able to feel in control and having choice, either as a patient or a carer was therefore an important part of the reconnection process for these participants.

Greenwood et al (2009) report that lack of freedom, and needing time to themselves, was more evident for carers later in the recovery process. In contrast, these current findings show that such needs can surface early in the caring role.

In some cases, it was equipment that facilitated greater freedom and control. For example:

*I had a bath. I bless the person who invented the bath seat, it was wonderful. You don't think about things like that when you don't need them, but it is so lovely not to be worrying all the time about how you will get out, and will you manage without help, which I would hate to have to do* (Judith, survivor, diary)

With regard to the participants with aphasia, reconnecting also involved trying to find alternative ways of communicating need, and thereby feeling in greater control:

*You know, I know exactly when she wants me [to help her] to go to the toilet, and I know exactly when she's heading for her pill, because she makes a sign for her pills* (Douglas, carer to wife Daphne, interview)

Support from family and friends was especially highlighted through the pictures all the participants with aphasia chose to illustrate this. As Bergquist et al (1994) conclude, such support can have a positive impact on progress and well-being, where aphasia is present.

On other occasions, reconnecting with choice and control meant feeling able to make choices about not accepting care and input, as these further excerpts illustrate:

*She will stay for a few days. I won't let her do anything for me, I want to be able to look after myself* (Judith, survivor, diary)

*His tolerance level has gone, and when he's fed up with something...*

*This speech therapist came yesterday, and he was trying to get rid of her – em, he – she just thought oh, it's the illness, I'll pay no attention to what he's saying. She was just carrying on with what she wanted to do, and he said "I'm drawing this interview to a close now" and she sort of looked – "oh" she said "what does that mean?" and he said "it means you're to clear off"* (Daphne, carer to husband Dennis, interview)

Examples of unwanted or inappropriate support were evident in both parts of the study and, as Sit et al (2004) discuss, can infringe on autonomy and self-esteem. Taking control in these situations, by expressing views about rejecting support, could therefore be seen as a positive stance.

Regaining control was not always an easy process, however, and often tiredness would overcome desire and ability to exercise control:

*Just want to fall asleep*

*Decided to do Make a List each day to help myself remember to do things. Stop for a moment. As my eyesight bad today with being tired – giving me nodding dog syndrome*

*Give up just now and going to rest*

*Tired out* (Rachel, survivor, diary)

*Had a walk round town centre with my wife – about 1hr, but was very breathless. Ok after short rest and had a quiet day after that* (Callum, survivor, diary)

*My friends came up this week, and I'd been dying to see them, and when they'd gone –phhhh was I tuckered! Oh dear! I was happy when they were here, but there was a price to pay – being shattered* (Norman, survivor, interview)

Other excerpts illustrated how being home gave a sense of freedom, and a chance to exit the sick role:

*I've done alright, I .. I enjoyed coming home*

*well...I was home and able to do what I liked ...and all that*

*ah...it's the kind of freedom I like*

*Er...er... I canna explain it very well..... Ahh.....it's braw [good] coming home, that's it... (Sam, survivor, interview)*

*Enjoyed her birthday with several visitors. Seems to be coping quite well with meals.*

*Has been making sandwiches and preparing tins of soup for herself. Again talking about family and subjects other than her health problems (Janis, carer to friend Bernadette, diary)*

*I: Thinking back to the day that you came home from hospital what was that day like?*

*Dennis: It was a great relief...yes ... to get the first inkling of freedom – okay? Liberation, yes. (Dennis, survivor, interview)*

However, being at home did not always signify freedom for other participants:

*I'm liberated up to a point, but I'm still like in a prison, you know, I'm not - I haven't got the ability to do the things I want to do. Really this is just like another ward in the hospital in here, it's not like being at home at all for me. Apart from being more comfortable and I've got a bit more control, but from a medical point of view I don't feel better off at home than I did in hospital. The timetable that we stick to is for my own good, I know that, but it's a bit suffocating at times* (Norman, survivor, interview)

And:

*I mean, one minute I'm living on my own.. for six and a half months, and the next minute my house is full of people coming and going, and you know, just – it was a bigger thing having Morris home and, as I say, quite a daunting thing, knowing that you're going to be responsible for (slight laugh) er.. for him now, and then to have all the different faces coming and going. But, as I say, I know it had to be done* (Audrey, carer, interview)

From these extracts it seems evident that the concept of home had changed significantly for these participants. As has been discussed in the preliminary study, the impact of having unfamiliar equipment and staff in the home may not be fully appreciated by professionals. However, reconnecting with the familiarity of home and belongings could give a sense of security and protection, as the following quotes illustrate:

*It was good to go to sleep in my own bed and be cuddled up safe and secure*  
(Rachel, survivor, dairy)



*Good to see my home and all things familiar. Feeling very tired and rather fragile*  
(Bernadette, survivor, diary)

*I knew once I was in my own home, with family and friends round me, I would start to improve – and I did* (Judith, survivor, diary)

For another participant, it was felt that being at home might help his psychological well-being, even although getting home had posed difficulties:

*He was so low mentally that I think they thought that he should come home, and he might be better off at home mentally. So, well, he came home obviously, and that was traumatic you know – even getting him up the stairs* (Jill, carer to husband Norman, interview)

Coming home and reconnecting with things that were part of home, was also quite an emotional experience for some participants, and brought to the fore the impression that perhaps they had thought they might never see these things again:

*When he came back again, and he sat in that chair and looked out at the view from these windows, and I don't think he'd had a view for eleven weeks, and then I got the binoculars out and he was studying things in the garden – birds and plants – and, you know, he just got a bit choked* (Daphne, carer to husband Dennis, interview)

Although this participant was house-bound initially, he was able to reconnect with his garden through the lens of the binoculars.

### 7.3.3 Past self and activities

In addition to reconnecting with close family and friends, both patients and carers were also starting to make connections again with activities that had been part of their life previously, and there was a desire to return to as many past pursuits as possible. Using a quote from one carer, this was referred to on the mind map as reconnecting with '*some form of normal*' (Audrey, interview). Other examples included:

*Really pleased I managed to take Morris out for our tea to Brewsters. We always ate out once a week and I intend to continue this. Morris was really pleased* (Audrey, carer, diary)

*I've not seen any of my friends. I usually have quite a good day-time social life. I have quite a lot of friends and I've just dropped them completely at the moment. They're very understanding, and I'm trying to – I thought next week, after my visitors go this weekend, I would try and get back to normal* (Angela, carer to husband John, interview)

*To me these things felt normal, I don't want to put that in brackets, but eh.. today I made soup now, which wasn't a big deal at all because it was an easy soup, but I haven't, that's the first time I've made soup* (Judith, survivor, interview)

It is interesting that Judith talks about not putting these activities *'in brackets'* or not set apart, but instead wants to have them fully integrated into her life again.

However, where this was not fully possible for other participants, bargains were struck in relation to what might be acceptable, as in the case of one-armed golfing, as discussed above, or, for others, limiting the amount attempted:

*I hope to play golf sometime in the fairly near future, but it's not a necessity – I haven't – I'll take a swing of the golf club if I can.... I think the main problem we'll have is I'll have to limit myself to just playing a few holes because I don't think I'll be strong enough to play a round yet* (John, survivor, interview)

The importance of re-establishing *'some form of normal'* is consistent with other studies (Burton, 2000; Faircloth et al, 2004), and displays how the participants still wanted to retain and reconnect with parts of their former life through their activities. This was seen as contributing to the new meanings that were being formed, in which *reconnecting* and *revisoning* played a large part; limited activity in certain areas compensated for, and replaced, a total loss.

#### **7.4 Revisiting**

Closely associated with the processes of reconnecting and revisoning, there seemed to be a need to revisit and replay past circumstances. Revisiting involved thinking again about the stroke event and hospital experience, as well as the process of discharge from hospital. In reflective moments, participants also revisited their previous life, past experiences and former roles.

#### 7.4.1 The stroke event

With regard to being hospitalised, this time was obviously very difficult for some patients and carers, especially when they looked back on the experience:

*He just went out to his work in the morning and the next thing I knew he was up in the [city] hospital, you know. So I got the shock of my life. So the phone rings [on the day of the stroke] and you think “oh what is it now?”* (Fiona, carer to husband Callum, interview)

*I couldn't go back, and when I think about it now, now I'm out of hospital, I'm now happy I'm home. I've not been like that – I've not been as bad here as I was sometimes there, so it's been worthwhile talking to you. It now comes back, I'd forgotten how bad it was in the hospital, especially the first one* (Norman, survivor, interview)

*That little corner in the hospital for 6 and a half months!* (sounding angry).

*That was just....that was hard! Just seeing your husband there..you know what I mean* (sounding a bit bitter) *still, for all it was over six months, it was still... seemed unreal, you know..just...the whole thing still seems unreal to me...* (Audrey, carer, interview)

With further regard to the distress of the situation, some of the ways the participants spoke about this seemed akin to post traumatic stress disorder (PTSD), in that the

narratives involved talk of their shock, as well as nightmares, flashbacks and a sense of the unreal (Bruggimann et al, 2006):

*This is all part of my horrible dream. A nightmare. I really wish I could wake up from and everything would be normal* (Judith, survivor, diary)

*I mean, it's not unreal, I know it's not unreal (laughs).. but it's just...it's just...you know..... (sounding sad and pensive) ...hard to accept it...*

*This is it, from now on...you know* (Audrey, carer, interview)

*When I wakened in my own bed I was upset that I hadn't had a bad dream, and was a bit depressed to find I was still unable to do some things. But I am feeling better, and don't mean to let things get me down* (Judith, survivor, diary)

There was also a real 'groundhog day' (Rubin and Ramis, 1993) feeling in Norman's description of each day being a flashback to the previous day:

*Every day is exactly the same from morning till bedtime, just like a photograph of the same day – repeating, repeating, repeating. I wake up in the morning and think "what time is the nurse coming?". I've got to get into the shower, I've got to be washed, shaved, cleaned up, in the shower and half-dressed before she gets here. I don't want her coming here to dress me, I can dress myself.*

*Every day. Even on Sundays it's the same. Every day is an identical day, emotionally and physically, just repeats, repeats, repeats, repeats* (Norman, survivor, interview)

This reiteration of the word '*repeating*' almost gives a sense of the 'repeat' of gunfire, and his other talk also gives a strong impression of the battle that he seems to be confronting in his desire to recover, describing himself as a '*fighter*' whose days are '*regimented*' by other people.

Although Bruggimann et al (2006) discuss stroke recovery in relation to PTSD, the WHO definition (1992), and the National Clinical Practice Guideline (The Royal College of Psychiatrists and The British Psychological Society, 2005:5), would seem to define such experiences more as 'adjustment disorders' than PTSD. As the National Clinical Practice Guideline (The Royal College of Psychiatrists and The British Psychological Society, 2005:5) states, adjustment disorders may be related to 'less severe stressors', whilst still having a significant psychological impact on the individual. However, Sembi et al (1998:316) consider that there is a 'growing body of evidence' to suggest that PTSD can occur after much smaller events or stressors, arguing that there are 'close similarities' between post-stroke PTSD and classic PTSD (Sembi et al, 1998:315). Certainly the shock of the stroke event itself came across very strongly in the accounts of both survivors and carers. In one case there was also real distress involved in the discharge process, for both the patient and her carer, as will be discussed next.

Although participants in this study were not asked about their hospital stay or the discharge process, many of them wanted to talk about it, both in their diaries and their interviews. Occasionally this was identifying the timing of the discharge as appropriate but, in common with Stone (2007), more frequently this was about their unhappiness with their hospital care:

*I was VERY angry at the hospital staff today. I had got washed and dressed and had my breakfast. My clothes etc were packed all ready, as I had thought I was getting home yesterday. The sister came to tell me that my daughter Sheila had phoned to say she would collect me around 2.30pm, but they might have to put me in the collection lounge, which I thought was reasonable. Then she came back with my supply of pills and asked where my things were to take me away. At the same time my daughter came with the sweets and cards I had asked her to buy. So I had to rush to write the cards and then say goodbye to other patients and actually deliver the gifts on the way out when the nurse was taking me away in the wheelchair. I was down in the lounge just after 10am. Talk about rush. I couldn't believe it. I am still angry at the speed and the way it was done (Judith, survivor, diary)*

Her unhappiness was shared by her daughter:

*She felt "flung out" and we were not involved in the discharge, and when I did say something, I felt I was not being listened to...*

*As a result we were not as organised as we might have been -*

*it didn't seem as if the family were involved, home first, then equipment – not the right way round - it seemed a back to front way of doing things to me (Sheila, carer, interview)*

This unhappiness with hospital care is in contrast to the findings of Banks and Pearson (2003), where the majority of comments about hospital staff were very

positive. However, as has already been discussed, participants in the study by Banks and Pearson (2003) may have adjusted to a more positive frame of mind in the period since discharge, having been at home for a number of months at the time of the interviews. Although impressions may change fairly quickly, collecting data closer to the time of the event may still give access to the process of views altering with the passage of time, and in the light of further experience, as can be seen especially in the words of this survivor:

*I had the stroke and they saved me, and kept me five weeks, and that was the worst period of my life. They were terrible in there – the nurses were awful, absolutely. I've never told anybody the whole story, but they were dreadful, and it was a relief to get to the second hospital... and at first I thought they weren't much better, but once I got to know them I was okay, and they were really good and I was very, very fond of some of them, and they sort of calmed me down a bit (Norman, interview)*

Later he adds:

*I started liking the nurses. I started respecting the nurses because I could see they weren't all – you know, I might have made a mistake at the other hospital (Norman, survivor, interview)*

Although he had initially been going to make a formal complaint about his treatment in the first hospital, Norman later relented due to some more favourable experiences. However, his use of the words 'incompetent' 'unkind' and 'evil' to describe the nursing care gives a very strong impression of how initially unhappy he was, and it



is difficult to read his account without wondering how often similar distress does go unreported.

Although happier in the second hospital, he was still very angry about some aspects of the care there. As can be noted from this following quote, his initial use of the present tense, using the word '*current*' when referring to the hospital, even although he has been home for a month, perhaps indicates how immediate this experience still feels for him when he revisits it in his thoughts:

*I'll tell you the terrible thing about the current – the last hospital I was in – the bathroom. The bathroom and the shower combined, one door - so if somebody's in the toilet, you can't go to the bathroom, and if somebody's in the shower you can't go to the bathroom, which is evil – that's inhuman and ... .. when you're using the bathroom, for people to walk in and open the door, I just don't think that that's – there's no dignity in that at all. If I could've stood up I would've hit some people, but I wasn't fit* (Norman, survivor, interview)

Norman and another patient (John) also discussed their concerns about safety, either of themselves, or of others in the hospital setting:

*In the other hospital I saw a patient who couldn't speak, didn't know what was going on, being served hot soup, and left to feed themselves. Burning, you know, boiling soup and left to feed themselves. I mean I couldn't eat it, it was too hot. I had to blow on it, but he couldn't speak - he'd lost his speech - plonked it by him, and walked away and left him* (Norman, survivor, interview)

*I was in a situation where I wasn't conscious of everything, but I managed to fall out of bed and bang my head, which is exactly the wrong thing to happen to me. There was no one there, unfortunately, to look after me, and I wasn't conscious enough to make a decision myself, so I feel somebody should have been there for most of the time, to sit beside me* (John, survivor, interview)

*I saw a man who couldn't stand up without falling over, stand up, fall over and cut his eyes open - bruising, bruises all over his body, falling over... ..getting out of bed and falling over and hitting his head on the sodding floor, and in the end I was left to watch this man, then call the nurses, and the nurse would come rushing through to save him from falling, if they got there in time, and then put him back in bed. So I was left to save him from falling over because they wouldn't put somebody near there to look, and he was in such a bad state he could have killed himself. They didn't bother to have somebody on the ward to look after him, and that got me going* (Norman, survivor, interview)

Safety of patients was an issue highlighted by the Chest, Heart & Stroke Scotland (CHSS) stroke study (CHSS and Scottish Association of Health Councils, 2001).

From these accounts it would seem that issues around safety still exist, despite recommendations made by CHSS in 2001. These issues will be discussed further in the following chapter.

Having focused on negative aspects of hospital care, as mentioned initially, there were some more positive comments, with some participants almost wishing they were back in the protective and supportive environment of the ward:

*A long day ahead and missing my companions on ward [number]!*

*Another restless night. Dreamt I was back on ward [number]!* (Bernadette, survivor, diary)

*They were very helpful cheerful and kept my spirits high. Now I am home – feel very much alone* (Rachel, survivor, diary)

Although Bernadette lived alone, Rachel lived with her partner (Bill), but still similarly missed the ward environment.

In addition to reflecting on their time in hospital, participants also gave consideration to how their lives had been before the stroke, as will be illustrated next.

#### 7.4.2 Previous life

Revisiting also involved some examination of participant's previous life, as well as past experiences and former roles, in the light of changes brought about by the stroke:

*When I was at work I never came home - I worked like a dog - so I retired when I was fifty four to spend some time with her [his wife] you know, to make up for it, and*

*in the end she's doing everything for me. It's not right* (Norman, survivor, interview)

*I think it's the nature of the job I've done all my life. Everything's... the day before to get it done. See what I mean, you're self-employed - you're trying to keep everyone happy* (Hugh, survivor, interview)

*I had a background when I was younger where I played football, so I was able to do exercises, from what I remembered of things from that. I think up until the middle of December I played two games of golf a week* (John, survivor, interview)

Also revisited in the light of this stroke were previous experiences in relation to other strokes:

*It's an awful thing to say, but they had to have her [participant's mother] sectioned so she could get into a nursing home. Yeah, which I felt was a bit unfair because she was very vulnerable to having strokes and very quiet, and not a pest or anything like that* (Rachel, survivor, interview)

*I was just thinking back eh.. how it was with my mother ken [you know] and how it was the fact that when I went in she was sleeping, so she didn't ken [know] I was there, ken what I mean, cos the only time I ever actually seen my mother awake was*

*the morning that she took the stroke. So that was the only time I sat with her*

(Maureen, carer to friend Rachel, interview)

This part of the revisiting and reflection process seemed tinged with regret with regard to things that had not been done previously, or with an unspoken wish that things had happened differently in the past. The revisiting process may be part of the 'life review' Hilton (2002:24) discusses as resulting from, or precipitated by, a transforming illness. As the excerpts display, this reviewing or revisiting process was evident in both patient and carer accounts. Hilton (2002) suggests that supporting people through this process can promote adaptation and, ultimately, survival.

As mentioned before, participants wanted to discuss their hospital stay, even although it was the experience of coming home that was the focus of the study. This need to talk about hospitalisation is also highlighted by Stone (2007), who found that this was the most common topic of discussion between patients, even years after the event. However, as this section has also highlighted, narratives alter and get rewritten with subsequent retelling, and whilst some events may remain vivid in the memory, the potential for changing stories must be borne in mind, as time elapses.

The revisiting of events may be part of what Rolland (1989:439) refers to as the need to 'create a meaning for the illness event that maximises a preservation of a sense of mastery and competency'. Such issues will be discussed in further detail in the following chapter.

## 7.5 Giving advice to others

The final part of the interviews, which was an addition to the interview format of the preliminary study, involved asking participants if they had any advice they might offer others in a similar situation to themselves. It was felt this might add some further information about how the participants viewed their own experience. Most of the comments re-iterated issues that had already been talked about earlier in the interviews, and gave ‘added value’ to the things that were important to each participant, thereby giving further pointers to the analyst. Various comments stressed the importance of hope, and accepting help. The following excerpt sums up many of the views, and will be expanded upon below in relation to the super-ordinate themes:

*There isn't really any advice I could give anybody except to be hopeful, I suppose, and just keep breathing! And laugh whenever you can, that's – laughter, and any help that's offered, take it!* (Jill, carer to husband Norman, interview)

Although Brazil et al (2000) asked carers about advice they would give to others, this type of question does not seem to have been widely asked of patients themselves. Asking such questions, however, can give additional insight into the things people have found problematic, or their attitude to a situation. Many of the comments given in response were congruent with the super-ordinate themes:

### 7.5.1 reconnecting:

*Try and keep a small routine going for yourself, and lots of people have said “you've still got to look after yourself, don't let yourself go”, you know, so even at my age –*

*well, I'm going to the hairdressers tomorrow!* (Jill, wife and carer to Norman, interview)

*The fear of what has happened shouldn't overtake your everyday life.*

*And em the more that you do for yourself, you know, gradually, obey your body and your mind. You do feel tired sometimes, yes. Spoil yourself, go and do things, don't hold back, just get on with it and keep positive* (Rachel, survivor, interview)

#### 7.5.2 revisioning:

*You just have to adjust...*

*Life will not be the same again, but you just get into another routine..you know, you just.. you just have to adapt..that's it..you know* (Audrey, wife and carer to Morris, interview)

*I always thought that I would accept all the help I could get so that I could have a bit of independence, but when it actually came to the crunch and he didn't want other people, I felt myself... I found myself caving in and saying "right, well just so long as he's happy" sort of thing* (Daphne, wife and carer to Dennis, interview)

#### 7.5.3 revisiting:

*I think we should have asked a lot more questions, likes of when Dr [name] gave me the tablets, I should have asked if these tablets will give me a headache, things like*

*that. I never asked you know, I just said “well I’ve been told to take them, I’ll take them” you know... and I think it’s ask, because if you don’t ask you’re not informed*  
(Callum, survivor, interview)

*Be very vigilant, you know, em, but if the person takes unwell again, make sure that you do know what to look for... and also if it was a heart attack – no, I wouldn’t know that - but I wouldn’t be long in getting another stroke* (Fiona, wife and carer to Callum, interview)

These quotes, as well as the previous participant accounts, can help to give an additional sense of the three super-ordinate themes present throughout the narratives.

## **7.6 Summary**

To summarise, this chapter has detailed many participant quotes to illustrate the super-ordinate themes and sub-themes identified by the researcher during the analysis process. In relation to the double hermeneutic discussed by Smith et al (2009), the analyst has tried to make sense of the participant’s sense-making process, and to capture the ‘content and complexity’ in their accounts (Hunt and Smith, 2004:1009). Evidence to support this has been given in the cyclical process of relating themes directly back to the words of the participants, and vice versa. The following chapter will explore these themes in greater detail, and in relation to certain models, theories, and the findings of other studies. As Braun and Clarke (2006:94) argue, analysts need to demonstrate their dual position as ‘both cultural *members* and cultural *commentators*’ (emphases in the original). This again relates to



the process of alternating between harnessing existing knowledge in the interpretation process, and taking a more detached view as a neutral bystander.

It is important that findings are placed in the wider context, in order to ‘frame’ their contribution adequately (Smith et al, 2009:113). The following chapter will aim to do this.

As previously discussed, to aid the discussion in chapters 8 and 9, the mind map of the super-ordinate and sub-themes is reproduced on the following page, as well as being illustrated in Appendix 12.

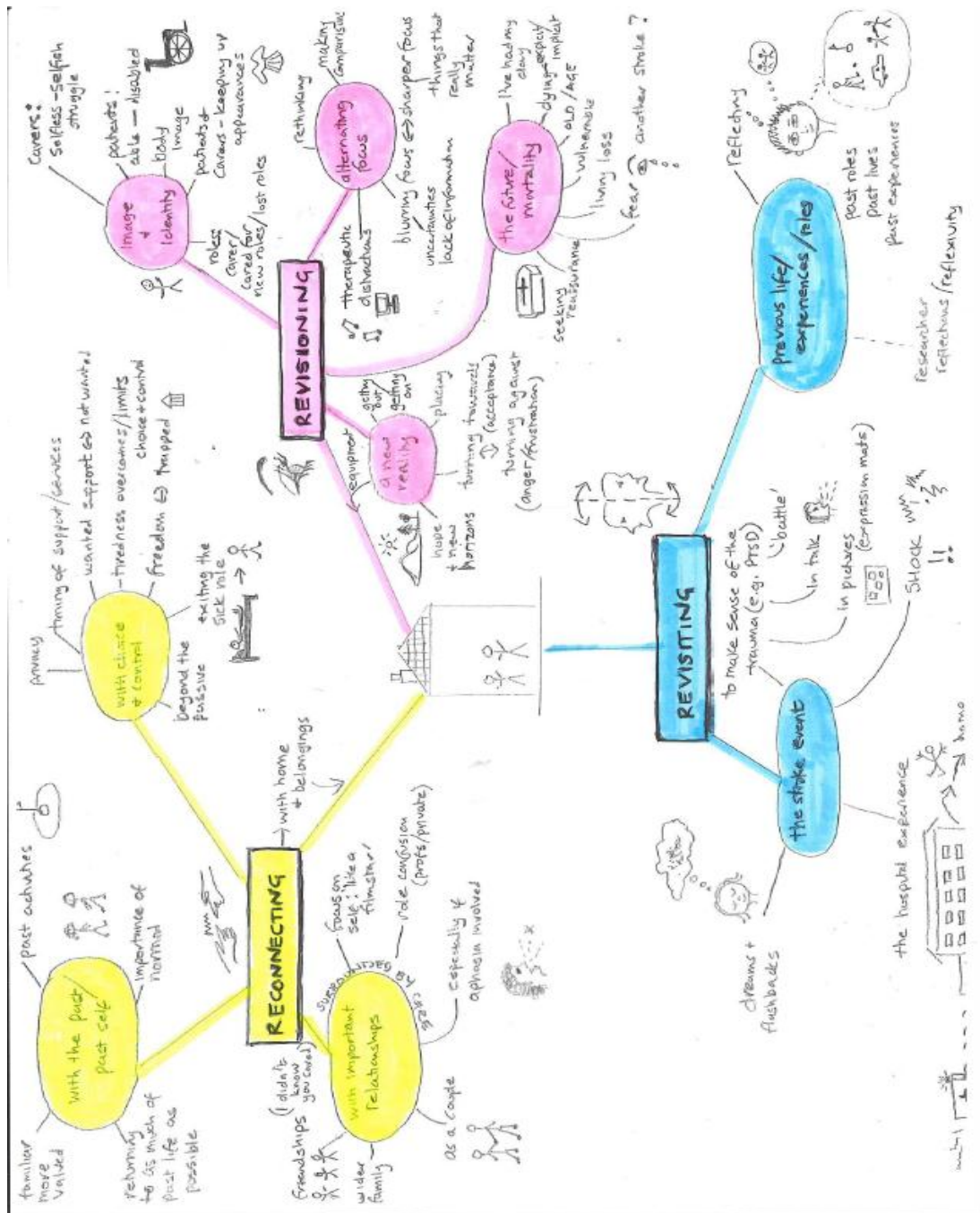


Figure 27: Mind map of main study findings

## CHAPTER 8

### Discussion and interpretation

#### 8.1 Introduction

This chapter will further explore the issues identified in the initial analysis, and discuss the themes and findings in relation to certain models and theories. Firstly, the super-ordinate themes will be considered together, then each will be discussed individually, with the related sub-themes. The data will also be situated with regard to other research and literature. Descriptive findings from the preliminary study will be taken further, and used to support the more interpretative analysis of the main findings. Finally, particular reference will be given to the discharge experience, post-discharge support, and timing of data collection. An overall summary, conclusions and implications for research and service provision will be made from these considerations in the final chapter, which will also include a reflexive account.

#### 8.2 Revisioning, reconnecting and revisiting

The concepts and themes explored in this chapter are situated within the context of an overall *revisioning, reconnecting* and *revisiting* process. As has been discussed, this process gives the impression of a very dynamic time, both internally (within reflections on the past, identity work, and thoughts about loss and mortality), and externally (regarding physical progress, tiredness, and reconnection efforts).

Although uncertainty is a concept previously noted as applying to stroke experiences, here it will be discussed as being inherent in the super-ordinate themes,

thereby giving a more comprehensive view of how uncertainty can be understood in relation to early stroke recovery. A detailed sense of how uncertainty and biographical disruption can be understood in relation to the revisioning, reconnecting and revisiting process will therefore be given below, before contextualising the main theme findings in relation to the concept of transition.

### **8.2.1 Uncertain progress and biographical disruption**

Uncertainty in relation to stroke recovery and rehabilitation is widely accepted and discussed in other stroke studies, as a major component within the experiences of both stroke survivors (Nilsson et al, 1997; Burton, 2000; Rittman et al, 2007) and carers (Brereton and Nolan 2002; Hunt and Smith, 2004; King and Semik, 2006).

In a descriptive study, Greenwood et al (2009) identified uncertainty as the central theme for carers within the first three months following discharge from hospital. However, although Greenwood et al (2009) acknowledge stroke as a shared experience between carers and stroke survivors, only carers are included in their study. Analysis is also described as ‘ending with themes’ (Greenwood et al, 2009:1122) rather than attempting to explore and interpret further, particularly in relation to other theorists, or a particular philosophical backdrop. This would seem to be a limitation with regard to the depth of analysis. The current study aims to expand on the findings of Greenwood et al (2009), by not only including both stroke survivors and carers, but also by taking analysis beyond the descriptive level, exploring and interpreting findings further.

With regard to making progress, participants in this study seemed to be describing a process that moved backwards and forwards on a continuum, on a frequent, if not daily, basis. Progress was felt to be good on some days, but at other times the participants felt any headway had been lost, or even reversed.

This is in contrast to other studies which seem to suggest that progress following a stroke is more linear (Doolittle, 1992), or discussed as ‘opposite poles’ in progress or situation. For example, Haun et al (2008:61) describe their stroke survivors as being either ‘socially isolated’ or ‘socially connected’ which, they argue, may impact on recovery progress. However, although the attributes of social isolation or connection are discussed as being part of a continuum, there is little acknowledgement that participants in the study by Haun et al (2008) might have the ability to move between these two poles, either frequently, or in the early days post-stroke.

Data in the study by Haun et al (2008) were also collected at specific set points in time, six months apart. As has already been discussed, this may pose problems if participants feel a particular way at the specific point of inquiry. In turn, this could also make any conclusions regarding situations or progress over time less relevant. Whilst it would seem to make sense to present progress on a continuum, there also needs to be acknowledgement of individual frequent variation within that continuum. If such an image of variable progress is given to stroke survivors and their carers by professionals, then it might help with the coping and adjustment process if they have a greater understanding of the fact that frequent fluctuations are an expected part of recovery, and have been experienced by others. As Vickers (2003:86) argues, difficulties may be intensified if ‘inappropriate expectations of consistency exist’.

Frequent moving backwards and forwards in relation to progress may seem more congruent with the 'biographical flow' Faircloth et al (2004:242) suggest as an alternative to 'biographical disruption' (Bury, 1982). However, even the term 'flow' does still imply a somewhat one-way process. Perhaps the term 'alternation' as briefly referred to by Bäckstöm and Sundin (2007:253) comes closer to the process being described by participants, and 'ebb and flow' might be even more appropriate. Certainly references to a more fluid type of progress, that encompasses the uncertainty of being '*all at sea*' and the feeling that '*you need to have anchorage points*' (Dennis, survivor, interview) would seem more in keeping with participants' own descriptions of trying to find some solid reference points to hold onto, in an acknowledged sea of uncertainty. As Kralik and Visentin (2006:326) suggest, the process of transition is altogether 'more intricate and convoluted' than may have been previously acknowledged.

With further regard to biographical disruption (Bury,1982), there may be benefit in challenging this as a universal concept beyond the arguments of Faircloth et al (2004). In the economic climate that exists today, there might be more uncertainty in life now than in earlier decades, especially in relation to employment and relationships. As a result, there may be wider acceptance that life might have to change (Klein, 2007; Brown et al, 2009), even before the impact of a disabling illness enters the picture. 'Jobs for life' are no longer an accepted norm (Schulz J, 2000; Carey, 2007), and the publication of individual illness stories appears to be more common and accessible (Frank, 2006); divorce rates are also higher than in previous generations (Cohen, 2009). All these factors make it perhaps more

accepted, and less shocking, when life is disrupted by illness or other changes.

Biographical disruption, therefore, possibly becomes less of a phenomenon when life already follows an acknowledged less certain path.

That said, there were nevertheless examples where participants' life story projections had been markedly altered, as discussed by survivor Norman, in relation to his life plan following early retirement.

However, in comparison, another participant (Hugh) who had struggled all his life with a severe hearing impairment, and related dysarthria, found his post-stroke life to be not very different - his previous coping techniques possibly helping him to adapt to his additional difficulties. Therefore, whilst biographical disruption may indeed be present in some cases, as Faircloth et al (2004) argue, it should not be assumed as inevitable.

In contrast to the findings of Faircloth et al (2004), there is also evidence to suggest that simplistic correlations with other variables such as age, degree of impairment following the stroke, or previous illness, may be open for questioning. For example, as has already been discussed, age in itself is not necessarily a predictor of how people will react or cope following a stroke. With regard to the participants noted above, Norman and Hugh are aged 70 and 69 years respectively, yet their adaptation stories are very different. Similarly, less obvious disabilities may be just as difficult to cope with as more overt physical disablement (Röding et al, 2003; Vickers, 2003; Rochette et al, 2007). Comparisons may therefore be more complex than might otherwise be suggested.

As will be argued later in relation to loss and grief, accepting existing concepts and theories, such as biographical disruption, without further critical examination of both the wider and individual issues involved, may not be the most beneficial way to view the impact and experience of stroke.

With further regard to variations in progress following a stroke, these differences also raise questions about the appropriateness of measures such as Likert scales, or other standardised outcome measures, to quantify progress (Carpita and Manisera, 2011). Such measures would seem inadequate when progress is described by participants in such a regularly variant way. This is where qualitative studies can excel over quantitative methods in really leading to fuller understandings of what is actually happening for individuals (Munhall, 1994).

With regard to progress, therefore, rather than experiencing a biographical disruption and starting a new life story, participants seemed instead to be ‘revisiting’ their past, ‘reconnecting’ with past activities and relationships, and ‘revisoning’ their future, with as much of their past life and identity intact as they can manage. In that respect, although life is acknowledged as not being the same, attempts are being made to normalise and redefine their situation to the greatest extent possible (Larner, 2005).

The desire to return to ‘*some form of normal*’, as vocalised by carer Audrey, and shared by many participants in this current study (either explicitly or implicitly) is mentioned in several other studies (Murray and Harrison, 2004; Bäckström and Sundin, 2007; Ellis-Hill et al, 2009). In the current findings it is related to the super-ordinate theme of ‘reconnecting’ with normality, and thereby, as Parkes (1971:103) suggests, helping to realign ‘assumptive’ worlds.



Awareness of the circumstances in which data are collected can also help in making sense of research findings. For example, Guise et al (2010:87) consider that stroke survivors may not discuss their 'disrupted self' in a possible attempt to play down the 'stigma surrounding stroke'. However, it is worth noting that the survivors in the study by Guise et al (2010) were interviewed with their carers present; considerations in relation to dependency (on carers) and the self-esteem of survivors were not explored by the authors, but could have a potential bearing on their findings.

### **8.2.2 Psychosocial transitions**

With further regard to the super-ordinate themes of revisioning, reconnecting and revisiting, were the transitions that people were making in relation to their altered situation. Revisioning, reconnecting and revisiting were evident as a means of engaging with the process of transition.

As previously referred to, 'psychosocial transitions' (Parkes, 1971:103) involve changes to a person's 'assumptive world'. Previous assumptions about the way life will be spent in the future may be challenged and changed by many different types of sudden, unexpected situation. According to Kralik and Visentin (2006:320) transition involves 'people's responses during a passage of change'; however, not all changes involve transitions, and transition is not just another word for change. Rather, transition involves psychological adaptation to disruption (Kralik and Visentin, 2006).

Helping people to successfully cope with transition, and avoid getting 'stuck', according to Kralik and Visentin (2006:324), requires good information and support

services, as well as a heightened awareness of self. This latter part could be viewed as meaning not only the self-awareness of patients, but also that of practitioners. Such self-awareness on behalf of the researcher in this study will be discussed more fully in the following chapter.

With regard to the ‘affectional bonds’ that Parkes (1971:104) discusses, the unforeseen changes brought about by a stroke may have a distinct effect on such connections. Whether these bonds relate to people, places, or previous roles, the reconnecting efforts participants are making in the findings of this study can be viewed as efforts to maintain ties, and stabilise assumptive worlds.

However, as Parkes (1971:105) also asserts, ‘each man’s assumptive world is unique to himself and no outsider can be sure of its extent’. Approaches such as IPA can be seen as attempting to enter these assumptive worlds, and to explore how participants make sense of, and respond to, such changes.

As Parkes (1971) concludes, the process of examining what is happening can be painful, because of the threats to the person’s established world. This pain has been evidenced in the tears and sadness expressed by many of the participants in this study. Similarly, as Parkes (1971) also discusses, there may be considerable anger in some cases, and expressions of anger and depression will be considered later. Each super-ordinate theme will now be discussed individually, with the related sub-themes, as illustrated in the mind map at the end of the previous chapter.

## **8.3 Revisioning**

Sub-themes relating to revisioning included a new reality, alternating focus, future mortality, and image and identity. The way in which these sub-themes related and connected to the revisioning that was taking place, will now be examined in greater detail.

Firstly, to consider the theme of a new reality further, whilst participants in this study were adapting to their new situation, with all the inherent difficulties, there was also a strong sense of hope for the future, and this will be examined next in relation to the concept of revisioning.

### **8.3.1 Hope as a feature of the revisioning of a new reality**

Hope is characterised by ‘a confident, yet uncertain, expectation of achieving a future goal that is realistically possible and personally significant’ (Bluvol and Ford-Gilboe, 2004:323). In common with the preliminary study, hope was also widely present in the accounts of participants in the main study. This was largely incorporated in the process of *revisioning* a new reality.

During the early days at home there seemed to be tentative steps towards trying to locate some form of hope for the future, and ‘placing’ oneself and their future life in relation to this. Duggleby et al (2010) recognise that this change in focus from an uncertain and difficult present, to a more positive future, can be evident even in the presence of a chronic illness. The accounts given by participants in the current study appear to show the start of a revisioning process, which allows hope to begin to

form. Although not stroke specific, and only examining caregivers experiences, the findings of Duggleby et al (2010) therefore do resonate with the process that is starting for participants here.

Wiles et al (2008) consider that destroying or reducing hope, because it seems unrealistic in professional terms, may damage adaptation and coping mechanisms; as Anderson and Marlett (2004:442) state, 'negative discourses' can create hopelessness. Telford et al (2006) also discuss unrealistic positive beliefs as actually being of greater adaptive help than a more realistic approach, which may reduce feelings of hope. Telford et al (2006) recognise that people feel and react more positively when they feel hopeful, and indulge in fewer health compromising activities (such as smoking or substance use). In contrast, a sense of hopelessness can lead to attitudes that lend themselves to unhealthy choices, largely because there no longer seems to be a purpose in trying to be healthy, if hope is not present. Equally, as Boazman (2003) argues, the reality of a situation, even when explained by professionals, may not register in the early days. This concurs with some of the experiences being examined here. For example, survivor Norman talks about being hit by 'a sledgehammer' when he was told that he would never be able to use his affected hand again.

In his words, the sense of disbelief, and the need to ask the same question several times, and of different people, illustrates the difficulty that Norman is having accepting the information he is being given. Hope is removed to such an extent that he describes feeling suicidal. His tears and the use of both past and present tenses in his dialogue may indicate that he still feels like this at times.

Later, the relief and hope relating to the unexpected discovery of a one-armed golfer was '*like winning the lottery to me!*' (Norman, interview).

It is also worth noting the mixed metaphors Norman uses in his speech. Instead of the usual analogy of being knocked over by a feather (i.e. very easily), he uses the word '*sledgehammer*' to define not only the flooring effect of the realisation, but also how hard the knowledge has hit him. In the face of such distressing knowledge, being able to latch onto something positive, like the one-armed golfer, allows him to cope by offering hope and meaning for the future, even if it is not realistic in professional terms. This also further displays Norman's variation on a continuum between having hope, and the utter despair of feeling hopeless and suicidal.

Although Yardley (2000:220) asserts that many qualitative approaches 'take speech not as a revelation of internal feelings, beliefs or opinions, but as an act of communication intended to have specific meanings for and effects on particular listeners', it would seem that in this honest and open account of very specific emotions, Norman is reflecting and exploring his internal feelings, rather than having an intentional focus on the listener. However, a later denial: '*it must sound like I'm suicidal. I'm not that...*' does indicate that he is subsequently thinking more specifically about the impact of his words on the listener.

As can be seen, the possibility of engaging with activities in an altered or even partial way, brought joy and a sense of hope to Norman, giving him the will and strength to carry on, even following some suicidal thoughts. This gives an impression of how motivating hope can be in certain circumstances.

Although ‘the risk of hope’ is disappointment, hope is also seen as ‘an intrinsic element necessary to human life’ (Turner and Stokes, 2006:364). As Arnaert et al (2006:137) conclude, the encouragement of an ‘active type of hope’ may impact positively on progress.

To the analyst, the hope expressed by participants here appeared to be similar to that referred to by Wiles et al (2008: 565) as ‘hope-as-expectation’ (for example, an outcome that is likely to occur) rather than ‘hope as want’ (a less certain desire). As Wiles et al (2008) discuss, it can be useful in terms of understanding to differentiate between types of hope. However, as they also conclude, such distinctions may only be a starting point, and further research into exploring hope trajectories over time are necessary.

Wiles et al (2008) also refer to the strong links between the body of literature on hope, and that relating to biographical disruption. However, there may be challenges to definitions of hope, just as there have been to the concept of biographical disruption.

Lorenz (2010) argues that too much research following brain injury focuses on problems and deficits, rather than the strengths and hope people require for optimum recovery. Lorenz (2010) considers this negative focus to be representative of a medical model of care which is not particularly relevant, or helpful in offering inspiration or hope. Barker and Brauer (2005) conclude that stroke survivors can maintain hope over a prolonged period, particularly if they have active participation

in their own recovery. However, when recovery is unpredictable, especially in the early days, hope may be more difficult to identify and connect with for patients, carers and professionals. The important issue is to be able to maintain hope by encouragement, without being dishonest or unrealistic. As can be seen from the example above, this can be a very difficult balance to strike.

Also relating to the emotional responses associated with the revisioning of a new reality were issues regarding anger and depression. These emotions were in contrast to the feelings of hope in the revisioning process, and this paradox helps in the understanding of the complexity and potentially conflicting emotions that may be present, as will be illustrated below. Although anger did not surface as overtly in the main study findings as it had done in the preliminary findings, it is still worthy of consideration in connection with the new reality with which participants were grappling.

### **8.3.2 Anger and depression in relation to a new reality**

The preliminary study found that the male participants displayed anger more overtly than the female participants, and this was also evident for some of the men in the main part of the study. Aldridge (2000) agrees that men are more likely to display anger and violence, whereas women have a greater tendency to direct rage inwards, resulting in potential depression. However, such generalisations are possibly too simplistic – depression can incorporate an angry element (Aldridge, 2000), with anger and depression being experienced by both sexes in the post-stroke period

(Warlow et al, 2008). As Broomfield et al (2011) discuss, there may be many factors behind the development of emotional responses such as post-stroke depression.

Ytterberg et al (2000) suggest that depression may contribute to the failure of some patients to improve after discharge. In contrast, Nyström (2009:2506) considers anger to indicate a 'fighting spirit', the expression of which may help to maintain integrity and identity. Accepting the outlet of such emotions may therefore aid recovery. However, as Elton (1992) argues, the justifiable rage that might exist after someone becomes disabled may have to be managed and contained, to allow people to function. However, this may in turn lead to a greater likelihood of developing depression, as Aldridge (2000) discusses.

With further regard to depression, this can affect up to one-third of all stroke survivors (Almborg et al, 2010), more especially during the first few months.

Millward et al (2005: 565) considers the fact that health care systems can reinforce the sick role, consequently allowing depression to become 'inextricably part of someone's identity, with important implications for functional recovery'.

Encouraging the reconnection process, and thereby the process of exiting the sick role, can therefore be seen as an important aspect of recovery, and one in which participants in this part of the study seemed keen to engage in.

Kim et al (2002:1106) argue that inability to control anger after a stroke is associated more with 'emotional incontinence' due to the physical damage to the brain (affecting Serotonin levels), rather than anger being reactive, and thereby possibly associated with depression. However, Aldridge (2000) considers anger and



depression to be two sides of the same coin, with emotional rather than biochemical links. Both physiological and psychological reactions may therefore play a part in the emotional experiences described by participants in this study, particularly because the damage to the brain may have been fairly recent. It is worth noting that the study by Kim et al (2002) had a fairly large exclusion list that would have precluded three-quarters of the participants in the present study from taking part (e.g. people with severe communication problems; those over 80 years of age; those living alone). The findings from Kim's study might therefore not have broad relevance to all stroke survivors.

Although both anger and depression are identified in much of the stroke literature (Santos et al, 2006; Brazil et al, 2000; Sisson, 1998), depression in particular may be under-recognised, according to Pfeil et al (2009). Suggestions about how nurses can assist in dealing with anger and depression are not widely expanded upon in the literature. Indeed, some of the accounts already described by participants in relation to their anger do tend to indicate that the nurses involved may have had difficulty in understanding that anger might be justified. This leads to questions about how well such emotions are recognised by nurses.

In Banks and Pearson's study (2003) two-thirds of the participants who were experiencing depressive symptoms at six months post-discharge were not receiving any support or treatment. However, if anger and depression are to be adequately dealt with, there may be a greater need to acknowledge the benefits of being allowed to express these emotions. Such strategies may help in reducing depression in ways other than by the use of medication. As Banks and Pearson (2003:27) report, even

with the use of antidepressants, some stroke survivors still felt 'significantly worse' on medication. Other support methods therefore clearly need to be considered, and although understanding and dealing with feelings such as anger can be a very complex process (Eatough and Smith, 2006), strategies that may help to at least start the process of addressing difficult emotions are suggested by Aldridge (2000). Aldridge (2000) also argues that specialist training and knowledge are not always necessary to provide some initial support, prior to referral for more complex interventions (Broomfield et al, 2011).

Such support may include:

- Music, film and theatre as possible beneficial recreational activities
- Journal or diary writing as a means of expressing and clarifying thoughts and emotions
- Helping people to acknowledge and face their challenges
- Talking through coping mechanisms, abilities and previous coping strategies
- Encouraging problem solving approaches
- Offering respect, regard and praise

Indeed, many of these suggestions mirror the strategies that participants in the current study are reporting themselves as beneficial. Certainly the value of talking was highlighted by participants in both parts of this current study, and concurs with findings relating to other groups of patients (Hogg et al, 2007). However, Buschenfeld et al (2009) describe how some participants, even several years post-stroke, avoid thinking about the early days after the event, because they do not wish to revisit the raw emotions felt at that time. This may indicate that these emotions

could have been more adequately acknowledged and dealt with at that earlier stage. As has been mentioned several times by participants in this study, and others (Lowenstein, 2004), the benefit of talking, or expressing thoughts and strong emotions in other ways, has a value in its own right. In this part of the study, for example, one participant reflected on how talking about his situation during the interview helped him to realise how important being at home was for him, as well as helping with revisiting the trauma of the hospital experience. For another lady, it was the process of writing her diary that proved therapeutic.

Buschenfeld et al (2009) conclude that re-appraising a situation may occur years after the stroke, and that this is potentially when positive psychological adjustment may occur. The quotes above show that this process of revisiting and reassessing can occur much earlier, and may potentially be assisted by the chance to reflect, either through talk, or through writing. As Vickers (2003:89) argues, research respondents 'may have been reflexively using narratives to reconstruct a sense of self'. Having the opportunity to divulge emotions either to a confidant, or in a journal, in the early days post-stroke may therefore assist earlier adjustment, and thereby longer term outcomes.

That said, Shadden and Hagström (2007) suggest that people with aphasia may have fewer opportunities to do this, making the role for professionals seem even more important in facilitating this process for them. Certainly, community nurses may be in a good position to offer such support (Pringle et al, 2010).

As mentioned above, there were certain ambiguities present in the emotions and reactions felt during the recovery process. These sometimes oscillating views were brought together further in the sub-theme of alternating focus, and can be seen as evident in participants' accounts of the revisioning process.

### **8.3.3 Alternating focus as part of revisioning**

A part of alternating focus, as illustrated in the extracts already given, involved participants talking about the benefits of therapeutic distractions, such as music and television. There may have also been an element of 'filling the void' in other accounts, whether this was possibly the void of silence created by the aphasia, or allowing the carer some respite from caring.

Rittman et al (2004:265) identified television as an important resource in 'passing time' and taking the focus away, temporarily, from health issues. As Jordan (2006:169) discusses, media such as television have become 'an important backdrop to much of family life', which is not always fully appreciated by professionals or researchers. In the current study, this was seen as part of the 'alternating focus' whereby participants were able to change their view away from their immediate problems and, in common with Rittman et al (2004), this was understood as a helpful coping strategy.

The use of resources such as music and television are not discussed in any detail in other studies examined in the literature review, but may provide a valuable means of escapism. Participants in Pilkington's (1999) study recognised such diversions as improving quality of life, and being distracted from difficult situations can help by

allowing a temporary break from ‘the painful reminders of loss’ (Marris, 1993:vii). The value of music therapy in recovery is also an area of increasing interest in stroke research (Sarkamo et al, 2008), which may benefit from further exploration.

In the revisioning sub-theme of future mortality, grief and loss were identified as important issues that surfaced as part of the increased awareness that participants appeared to be developing during the revisioning of their future. These issues will be examined further below.

#### **8.3.4 Grief and loss in relation to the revisioning of a mortal future**

In common with biographical disruption, issues relating to grief and loss form another area where accepted models may be questioned: Boazman (2003:40) argues that feelings of having confidence and control are all important in life-changing illnesses, but are aspects that may be overlooked in the ‘accepted approach to grief’ that may be applied to stroke related losses.

Alaszewski et al (2004) discuss the use by professionals of the traditional bereavement model to describe and explain patient and carer behaviours and emotions post-stroke. However, in the very telling words of one of the participants in the study by Alaszewski et al (2004: 1076), such a model may be ‘convenient’ for professionals and, in that respect, may be denying the very individual and personal emotions being experienced by those affected by stroke.

Boazman (2003:40) similarly criticizes the use of standard grief models, and the fact that an absence of anger in patients may be dismissed as ‘denial’ by professionals.

Boazman (2003:40) argues that the term ‘denial’ is over-used and too simplistic, stating that the use of the term may be ‘more to do with the limited imagination of an “expert” than any real understanding of an individual’s internal reality’. Telford et al (2006) similarly caution against such standardised use of frameworks or terminology.

The risks associated with the use of such models or words are that perhaps what is really being said may not be heard, and emotional experiences almost dismissed by explaining them as just a manifestation of a particular model, theory, or state of mind. Again reflexivity can assist throughout the research process to identify and internally challenge assumptions and biases that may be made by the analyst.

A further concern in relation to grief models is whether a living loss, such as that experienced by those affected by stroke (losses which can affect both patients and carers) can be compared to the loss experienced after a death. The dismissive quote by the patient in the study by Alaszewski et al (2004), as mentioned above, and Boazman’s (2003) arguments, suggest that it is worth considering that the losses in each situation may have quite different meanings for those affected. Boss (1999:4), for example, talks about ‘ambiguous loss’ or ‘frozen grief’ being present in situations where the losses felt are less certain and, indeed, in situations where the person may still be alive. Although not specifically referring to stroke, there are similarities discussed by Boss (1999) which may prove beneficial to those trying to understand the feelings that are being dealt with by people affected by stroke. For

instance, the uncertainty in relation to roles and identity mentioned by Boss (1999), when a living loss is being dealt with, also resonates with the narratives being examined in this current study.

Similarly, Gilliland and Fleming (1998:541), although again not referring specifically to stroke, acknowledge that anticipatory grief may be associated with greater levels of anger, and other losses of emotional control, when compared to 'conventional' grief. Kelly (2008:335) also describes living loss as helping to define how people live 'not with loss but "in" loss'. Kelly (2008) is discussing experiences relating to AIDS rather than stroke, but nevertheless there are still parallels that can be drawn in relation to the emotional experiences of the participants being described here.

Boss (1999) suggests that giving a different label to the particular type of loss involved, and exploring the nature of feelings across the whole family, may help to prevent unresolved grief from having pathological effects. As Boss (1999:5) concludes, the family group may then reach 'some measure of consensus about how to mourn what they have irretrievably lost and how to enjoy what remains'. There seems to be evidence in some of the participants' words in this current study that such grief work is taking place, but there may also be further support and understanding that might be of additional benefit.

With further regard to psycho-social transitions and assumptive worlds, Parkes (1971) contends that it is the lost future that is grieved for and, as displayed in the previous chapter, such grief can affect both survivors and carers.

The final sub-theme within revisioning related to image and identity issues, and the sense-making process that was taking place in connection with the participants altered reality, as will be illustrated further next.

### **8.3.5 The revisioning of image and identity**

Image and identity considerations featured widely in participants' accounts. As mentioned above, this could be in quite an explicit way, with regard to hiding a physical disability. However, it could also be in less obvious ways: the lady who had the least speech (Dorothy) and her husband (Douglas) both made reference to issues relating to her choice of clothes. Douglas describes how he was suddenly thrown into the role of having to select clothes for his wife, which created tensions between them. However, with the use of charts from the speech and language therapists, this task eventually got easier. By the use of gestures and facial expression, Dorothy was able to convey to the interviewer how she had felt unable to go out for a meal at one stage because she did not feel she was dressed appropriately. This seemed to relate to her past identity, and her desire to retain her previous image in relation to how she dressed. However, when she gestured this to the researcher, she made a sweeping movement with her arms moving down her whole body, which seemed to encompass not just her clothes, but perhaps her whole altered self. As Kvinge et al (2002:64) argue 'the body is fundamental in constituting a person's life-world' and therefore any changes in bodily function or appearance will similarly have an impact on the existence and essence of that individual.

Rittman et al (2007:24) consider that 'the way people experience and talk about their body is one of many resources used in construction of sense of self'. Although



Rittman et al (2007) also studied participants' first month at home, the participants in their study were all American war veterans (98% male) who may have had a very different experience in comparison to the participants being studied here. For example, war injuries, although not specifically mentioned, may have impacted on their accounts. In addition, Rittman et al (2007) did not report on the views of carers.

A further image issue was apparent in one participant's account of having continence problems following her stroke. Although many continence issues will improve with time, up to 79% of survivors will experience such problems in their early recovery period, according to Matthews and Mitchell (2010). From the literature review, although continence receives little acknowledgement in the other studies that examined the early days at home, it can have a significant impact on self-image.

For example, although the effect on survivor Judith was quite marked, the impact on self-image of being incontinent does not appear to be widely recognised in the literature. One of the few articles specifically discussing body image after stroke (Keppel and Crowe, 2000) makes no mention of continence issues. Similarly, Han and Haley (1999) consider that the effects of caring for someone who has continence problems do not seem to have been well researched. However, as Hägglund and Ahlström (2007) argue, if such topics are not acknowledged and addressed, they can leave a longer term sense of vulnerability and powerlessness. Whilst Elstad et al (2010) discuss the stigma attached to urinary frequency, and the desire to be in control of bodily functions, the impact on self-image of incontinence appears to be an area which may benefit from further study. Equally, more positive attitudes, and

further education for nursing staff, can positively influence patient outcomes in relation to improving continence (Dingwall and McLafferty, 2006).

In the excerpt given above, Judith also refers to her continence product as being 'like a nappy'. Certainly Keppel and Crowe (2000:17) consider the fact that the stroke survivor may be viewed as 'more childlike' by their carers following a stroke, as already mentioned in the previous chapter. Becoming unable to control elimination may compound this image for both patients and carers.

Watson (2006: 379) considers that fact that 'identity work' may be taking place for a participant even during the context of an interview. She concludes that rather than being something that is fixed, identity is relational and 'an ongoing process that is never finally and fully accomplished' (Watson 2006:372). This view would seem to have particular resonance in the case of stroke, where identity may have been threatened and altered by sudden new disabilities, or changes in appearance. The extracts that relate to the identity of either the carer, or the person they are caring for, in the previous chapter give good examples of this. Such relational aspects can also be seen in the way that comparisons are being made with others in both parts of the study.

Parkes (1971:112) discusses the fact that seeing another person in a similar situation making progress and coping well, can positively influence peoples' views of the future. Parkes (1971:112) argues that it is for this reason that survivors of a major life event are well suited to support others 'still caught up in the process of realization'.

With regard to revisioning, Vickers (2003:89) considers that participants may have to step ‘outside themselves’ as part of image adjustment, with memories and fantasies being a necessary part of this process. Similarly, as Watson (2008:336) explores, although narratives enable us to make sense of our lives, such accounts just represent another version, with meanings never being truly ‘fixed’ (Watson, 2008:335). Watson (2008:334) argues that this creates an ‘aporia’ or ‘insoluble contradiction’ that must be acknowledged.

As further participant accounts show, maintaining or projecting a certain image does not always reveal the reality of the situation as others might see it. Those closest to the survivors, in particular, may be very aware of this, as this next quote displays:

*So the last few days there’s been more going on which makes him tired, but underlying all that sort of froth I still can’t see him much different.*

*[Names] came up from down south yesterday so there’s been something going on, and to me that’s like window dressing. I just don’t know if he’s really much better under all that, or what will he be like when they’ve gone on Wednesday? Will I see that he’s improved? (Jill, wife and carer to Norman, interview)*

The use of the word ‘*froth*’ by this carer gives a sense of an airy, insubstantial covering that hides what lies beneath. Jill is not entirely sure herself what the real situation is, or what she will be left to cope with, after the visitors have gone. The image her husband (Norman) is trying to project for their guests may not be one he feels in reality himself and, as has been detailed in the previous chapter, he is full of

uncertainty himself. This may be an example of how identities can become ‘fractured’ by ambiguous or conflicting parts (Vickers, 2003:96). However, being able to at least project a more desired image, even for a short time, may help Norman to preserve an important sense of self.

Similar image projection issues can also be read in the lines of the poem from the words of Judith, and give a sense of the shift in image that has occurred, and the work that is still being done in trying to create a new image that is acceptable to the self. In the first line of the poem, Judith declares that she would rather not be alive than to have to live with an image she would find unacceptable. As Andersson and Hansebo (2009) discuss, women may feel more vulnerable with regard to post-stroke disability because their bodies are linked to a greater extent to their female identity. Gender issues therefore formed part of the revisioning sub-theme of image and identity, and are worthy of further consideration:

### **8.3.6 Gender and the revisioning of image and identity**

With regard to gender, issues relating to role changes were also identified, with participants taking on tasks that they had previously regarded as belonging to the opposite sex. Such accounts are congruent with those in Rittman et al (2004:265), and are important in defining ‘one’s sense of self’. In this current analysis, these accounts are related to the revisioning process.

According to Lobeck et al (2005) and Greenwood et al (2009), few stroke studies have discussed gender roles, or made comparisons between male and female accounts in their findings. However, Andersson and Hansebo (2009) do discuss roles in relation to gender and age, with older participants being suggested as possibly

having more defined and separate roles prior to the stroke. As Andersson and Hansebo (2009) further consider, male and female descriptors are formed through social interaction, varying over time and between different generations. Role changes between the genders may also impact on post-stroke adjustment: as possibly indicated by the different tenses used in extracts, the new situation may not yet be fully accepted, and further adjustment may be taking place during these early days at home.

Although some stroke studies (Kvigne and Kirkevold, 2003; Kvigne et al, 2005; Stone, 2007; Green and King, 2007) concentrate specifically on the experiences of different genders, other studies have gender limitations due to the type of participants being sought. It is recognised, for example, that women are more frequently providers of care (Fraser and Patterson, 2010), and in similarity to this current study, greater numbers of female carers may be reflected likewise in the gender of caregiver participants in other research. However, in the study by Bakas et al (2002:244) the input of one male carer was excluded because his 'needs and concerns were very different' from the remaining all-female participants. Whether such exclusion is appropriate (or indeed ethical) is debatable, and the findings of that study might have been very different if his views had been included.

Rittman et al (2004) and Haun et al (2008) only had male participants, with their samples being taken from American war veterans. Although a later study by Rittman et al (2007) did include two female war veterans (out of an overall sample of one hundred and twenty five) gender implications are not discussed in any of these studies.

As previously discussed, the preliminary study did identify gender differences in terms of the expression of anger (Pringle et al, 2010); Röding et al (2003) also discuss the differences in women's gender roles in their study. However, whilst Stone (2007) found few gender differences, gender is still an issue that may benefit from greater awareness when analysing research data. As Kvigne et al (2002:67) argue, 'being in the world as a woman leads to different experiences from being in the world as a man'.

Andersson and Hansebo (2009) also point out that acceptance of personal care may be more difficult for men because it may threaten their identity as a man. This would certainly concur with the account from the preliminary study of the man who found being shaved by a female carer embarrassing, and just too personal for him to be comfortable with (Pringle et al, 2010). Similarly, in the main study, one of the male survivors (Norman) also seemed determined not to be dressed by his female nurse, once he was at home.

The use of the words '*she*' and '*her*' in his quotes seemed to indicate to the analyst that the gender of the helper was of significance to Norman. With regard to such issues, it was difficult for the female analyst to fully understand the male perspective on, for example, the daily facial shaving ritual. This does not appear to have been a widely researched area. As Andersson and Hansebo (2009:2044) conclude 'further research is needed to improve our knowledge of the importance of gender-sensitive nursing care'. These points will be further explored in the reflexive discussion in the following chapter.

Another consideration with regard to gender is the conclusion by Andersson and Hansebo (2009) that married men are more likely to hide their sadness from family

and professionals, in order to protect their wives, with both sexes tending to hide their sorrow from their nurses. As discussed previously, being able to disclose emotions is an important part of adjustment, and if nurses are aware of the inhibitions that patients may feel, they can act towards giving greater opportunity for discussions to take place. The discussion will now move on to discuss the second super-ordinate theme of reconnecting, and the sub-themes of important relationships, choice and control, and past/past self.

## **8.4 Reconnecting**

Reconnecting with important relationships, was an important sub-theme, and influences on the family unit in particular:

### **8.4.1 Impact of stroke on the family unit**

The need to move initially to a more centripetal (inward focusing) family structure was evident in the current study participants' descriptions of the closeness of family and friends in the reconnecting process. Reconnecting can be especially significant in relation to wider health issues: as Brummett et al (2001) discuss, smaller social networks may be associated with increased morbidity and mortality. However, during these early days at home, participants were only making tentative steps to reconnect out-with their immediate physical environment, or beyond close family and friends. More expansive social networks, including stroke support groups, may be something for consideration at a later stage. As Ussher et al (2006:2571) discuss, although some support groups may provide an opportunity to focus on and discuss

the illness with people who have a similar diagnosis, family and friends can offer a ‘normalizing’ influence, away from a more immediate sickness orientation.

According to Rolland (1989:435) sudden onset illnesses (such as stroke) require ‘rapid mobilisation of crisis management skills’ by the family unit, compared with conditions that involve a more gradual onset or slower deterioration. However, the fact that some stroke patients can make progress, even some time after the event itself, does tend to mean that stroke as a condition does not fall neatly into the general forms of chronic illness mentioned by Rolland (1989), namely: progressive, constant, or relapsing/episodic. However, that is not to say that some of the features relating to family adjustment discussed by Rolland (1989) are not relevant. Indeed, the adjustments needed by the family to deal with dependency and disability issues, where they exist, may be very important for health care workers to understand, if they are to offer appropriate advice.

For example, Rolland (1989: 448) discusses the illness as exerting ‘a centripetal pull on the family system’, with this inward focus possibly being contrary to the needs of some family members. As has been identified in a number of the participant quotes, roles may change, with partners or children having to take on a more parental role, which may be unwanted, unexpected and unwelcome. Associated with role changes and increasing dependence, is the incumbent risk that the stroke survivor may become infantilised. Accordingly, survivors may then become blocked in their development and progress by complying, conforming or colluding with such an imposed identity change. Professionals who are offering support in such cases can help by working towards a more realistic balance within the individual situation.



In further relation to this, Rolland (1989: 452) considers that chronic illness, especially where the effects are more severe, may 'like the addition of a newborn, require a period of socialisation'. This requires the centripetal focus to be in place initially, but also requires that after the immediate crisis is over, centrifugal forces are re-established, in order to avoid the need for family members to 'sacrifice their own or the family's development' (Rolland, 1989:452). This process can be evidenced in the participants' accounts of their desire to return to more normal activities, and relates to the reconnecting of both survivors and carers with past activities, relationships and, indeed, choice and control.

With regard to voicing opinions about services, for example, this can be viewed as taking steps towards reasserting autonomy. In the case of Dennis, who declined further input from his therapist (and the interviewer), these actions should not necessarily be viewed as negative. Rather than indicating denial, Telford et al (2006:461) assert that such reactions may alternatively be understood as 'a way of asserting self-agency through realizing personal needs and wishes in the life context'.

However, in contrast, with situations where there are indicators that dependency and passivity are present (rather than self-assertion) these signs may help professionals to identify areas where further support and encouragement may be beneficial, in order to improve and increase independence and control.

Further exploration by health professionals may also reveal more complex forces at play. For example, 'system induced setbacks' relating to the way services are

organised and delivered, can underestimate, undermine and restrict attempts by survivors and families to manage their illness. Mold et al (2006) argue that this is because service users are often required to fit in with the system that is currently in place, rather than services adapting to their needs. However, as Mayo et al (2000:1016) discuss, where interventions serve to empower people, there may not only be a 'significantly beneficial impact', but also a reduction in the services that are required. As Coleman et al (2009) assert, patients and their caregivers are often the only common factor across sites of care, and encouraging them to take a more active role, especially during transitions such as discharge from hospital, can reduce readmission rates.

Such strategies are in keeping with initiatives to deliver better outcomes to those with long term conditions (The Scottish Government, 2009b), where independence and self-management by patients is being encouraged as a means to improve illness experience, and reduce unnecessary hospital admission. Whilst self-management initiatives have much in common with self-actualization, or the 'capacity to maximise use of one's abilities and resources' (Couture et al, 2007:111), Jones (2006) advises caution in relation to stroke survivors. As Jones (2006:846) argues, there is a particular need where cognitive impairment may be present to be 'mindful of making assumptions about an individual's readiness for self-responsibility and insight into their problems'. Indeed Couture et al (2007:111) suggest that many stroke survivors are not only 'poorly actualized' but that 'self-actualization levels do not improve during rehabilitation'. These considerations therefore require to be acknowledged to a greater extent in policies advocating self-management, with

healthcare professionals possibly needing to take on a greater advocacy role where self-management is inappropriate.

Related to the impact on the family unit, were issues surrounding reconnecting with close relationships:

#### **8.4.2 Close relationships**

With regard to close relationships, sexual issues are frequently not mentioned in stroke research studies, and can also be poorly addressed by healthcare professionals in clinical situations (Thompson and Ryan, 2009). Haun et al (2008) report that socially isolated individuals, even if married, seldom spoke about sex in their study. However, it is difficult to draw firm conclusions from a reluctance to discuss very personal information. Factors such as unfamiliarity with the researcher, embarrassment, timing, or cultural norms may all have an impact on the disclosure of such information. Participants in the study by Thompson and Ryan (2009), for example, were not only an average of eighteen months post-stroke, but were also already known to the researcher. Both of these factors may have impacted on their experiences, and desire to discuss such detail.

It is interesting that the only participants who did mention sex explicitly in this current part of the study were the two youngest. For older people, there may not have been the same social acceptance related to such disclosures in their past, and therefore it may not be something they are in the habit of revealing. Although studies by Thompson and Ryan (2009), Bäckström and Sundin (2007) and Murray and Harrison (2004) do discuss sexual relations more explicitly, in all cases the mean age of participants was under sixty five years of age.

As has already been discussed, it was the diaries rather than the interviews that included any detail about intimate relations between couples, even with sensitive probing by the researcher during the interviews. This was considered to be one of the added benefits of the use of diaries: participants seemed to feel more able to write things down than to discuss them face to face, perhaps because the interview was conducted by a relative stranger. In this respect, therefore, the diaries were a useful tool in facilitating a certain amount of additional disclosure.

Aside from discussing intimate relations, the general confessional and cathartic use of the diary was especially alluded to by one participant. Such was the benefit of the diary that this participant asked to keep the unused pages of the diary to continue with it personally, beyond the scope of the research project.

Although these reflections were not addressed to anybody in particular, the value of disclosure is evident from her words. The benefit of divulging details about feelings and emotions, whether vocally or in writing, is a common theme between the main part of the study and the preliminary study. In both parts of the study, the participants who were unable to speak also appeared very enthusiastic about using pictures and diagrams to express themselves. This brings into question how often such opportunities are afforded to patients, and whether the beneficial aspects of such disclosure are fully appreciated. Talking therapy is well recognised in psychology and mental health (Bennett and Greensmith, 2007), but with the continued emphasis on physical rehabilitation and functional recovery in stroke, such

opportunities may be overlooked or not available. Certainly, Broomfield et al (2011) emphasise the benefits of more complex approaches, such as cognitive behavioural therapy, where mood disorders such as depression are more problematic.

With regard to keeping a diary, Smith (2006:2) considers the word 'journal' to more accurately capture the purpose of the 'conscious reflection and commentary' that this current research was hoping to achieve via diaries. Whichever term is used, Klug (2002:1) asserts that such recordings may also be 'a tool for self-discovery', and a 'safety valve for the emotions'. Perhaps there is therefore scope for the keeping of a diary or journal to be further investigated as a helpful support strategy for stroke survivors and carers, other than just for research purposes.

With regard to the reconnecting sub-theme of choice and control, the chronic illness model also required consideration, due to the connections that are made to stroke diagnosis by other authors:

#### **8.4.3 The chronic illness model**

With regard to the use of models in general, Nilsson et al (1997:958) report that their analysis is directed by a 'developmental crises model'. However, they also suggest that some of the elements of the model are 'entirely absent' in some cases. This might indicate a tendency to try and fit the data to the model. An alternative, as explored here, is to discuss findings in relation to several different models, each having some relevance to differing aspects of the data.

As Ellis-Hill et al (2009) conclude, healthcare workers need to develop a shared language and understanding with their patients, and this is also true of research participants. Patients in the Ellis-Hill et al (2009) study felt this shared understanding was sometimes missing, and as Ellis-Hill et al (2009) further discuss, patients may often be working on their own model of recovery. This was also evident in the participants' accounts in this current study.

As Ellis-Hill et al (2009) argue, shared models can lead to patients having greater feelings of control, which would be congruent with current thinking in relation to long term conditions management (Scottish Executive, 2006). Certainly using models that are 'convenient' to professionals does not seem the way forward in this respect, as will be explored further next, in relation to the chronic illness model.

Although stroke is regarded as a long term condition, and discussed in relation to chronic illness (Guise et al, 2010), within the time scale being researched here (i.e. the first month after discharge from hospital) it is questionable whether participants would define themselves as having a chronic or long term condition at this stage, at least in relation to their stroke. In the participant accounts there were varying references to lack of ability, and question marks over how much recovery could be expected, but there were no references to chronic illness, or having a long-term condition.

Whilst Kaufman (1988) discusses the first year post-stroke in relation to the experience of chronic illness, in the two case studies explored in Kaufman's account, the participants were either still in hospital, or had only been home for a few weeks when the interviews took place; improvements were still expected by the

participants, and it is not clear if the definition of being chronically ill would be one that they would have applied to themselves.

In similarity to Kaufman (1988), Folden (1994) also refers to the chronic illness model, but again data for Folden's study were gathered while participants were still in hospital, and again 3-4 weeks post-discharge.

Indeed, although the terms chronic illness and long term condition are sometimes used interchangeably, there seems to be no agreed definition of either term (National Health Service (NHS), 2008). The World Health Organisation (WHO, 2010:1) includes stroke in a definition which encompasses 'long duration and generally slow progression'. This definition in itself does not acknowledge the variable nature of stroke effects and recovery. Other definitions may seem equally inadequate, with MedicineNet (2010:1) referring to chronic as lasting '3 months or more', and the NHS (2008:1) stating that a long term condition 'requires on-going care, limits what one can do and is likely to last longer than a year'. This latter definition again fails to acknowledge that many people manage to live independently, without care, after a stroke. Perhaps the time has come for clearer definitions to be adopted, which encompass the real experience of stroke and other long term conditions.

With regard to both research and clinical practice, there would therefore seem to be a need for researchers and nurses to be clearer in their own minds about the definitions they apply, and to consider whether these are the same as those that might be used by their patients. If having more common understandings does not happen, then there is the possibility of making assumptions based on a chronic illness model that might not be applicable in the circumstances. In research projects, the analyst may then be

making interpretations that do not relate to the participant's perceptions, if indeed this is not a model or definition they would assign to themselves.

Zola (1993) also concludes that applying labels or definitions may have the effect of altering people's image of themselves in a detrimental way, and as Telford et al (2006:457) discuss, people may 'internalize these labels as reflections of the self' which may, in turn, impact on adjustment and recovery. Names or labels may therefore have connections and associations, in addition to having the potential to allow inappropriate generalizations. In this respect, by referring to participants as chronically ill, the tone or expectation relating to a particular study may already be set in the minds of readers, with associated connotations.

Similar arguments may apply to the use of the word 'patient'. In this current study, although the word is used as an alternative to 'stroke survivor', there are still associations with dependency and illness linked to the term 'patient'. Whereas the term 'person affected by stroke' may help with viewing the person more as an individual, rather than the focus of generalised assumptions (Zola, 1993), there is still a need for some short-hand terminology that differentiates between the stroke survivor and their carer, which 'person affected by stroke' does not do. Whatever terminology is used, however, there may still be a risk of stigma (Rochette et al, 2007), and of not seeing the person as an individual. Although the idiographic approach of IPA aims to promote the focus on individual experience, as researchers we do need to acknowledge the limitations of the terms used to describe participants.



Equally, it could also be argued that the term ‘carer’ implies an emotionally caring attachment (in relation to informal carers) that may not always exist. In the study by Wallengren et al (2008:48), a relative is also described as a person who is ‘tied by emotional bonds’. Again, such definitions can make assumptions that do not hold true in reality. For example, although nominated by Bernadette as her carer, Janis seemed rather distanced in her description of the help that was being ‘requested’ of her, rather than more voluntarily offering assistance and support:

*I was happy that Bernadette seemed very positive about going home. She seemed very bright on arrival and was not requesting any more help from me. Seemed quite content to get on with things* (Janis, friend and carer to Bernadette, diary)

Her final point here could be interpreted as a self-justification of her intention to leave Bernadette to ‘get on’ by herself. Field notes written by the interviewer also noted a certain detachment in her attitude, which was somewhat unexpected. Again, this may be an example of researcher preconception that, as her nominated carer, there might be a bond or attachment that did not actually exist.

As discussed in the preliminary study, the use of the term ‘carer’ may benefit from further exploration, both in individual studies, and more generally in research, to explore understandings into the differing meanings people may ascribe to the term.

It may also be beneficial if the terms used in studies are explained and expanded upon, as above, to allow the researcher to be more open about their own potential beliefs and values.

Issues surrounding the making of assumptions and bringing biases to the research analysis are discussed more fully in the reflexivity considerations in the following chapter.

The final sub-theme in relation to reconnecting, was that relating to past self and past activities. This brought to the fore issues concerned with disability and accessibility, which will be considered next.

#### **8.4.4 Disability and accessibility**

Hare et al (2005:133) conclude that ‘stigma and isolation’ may be common amongst stroke survivors, and relate this to the nature of the geographical environment and lack of knowledge about stroke amongst the general public. Although the participants in the study by Hare et al (2005) were also living in the UK, and were further on in their recovery, their experiences appear to be different from the participants in this current study, who reported few such difficulties.

As Almborg et al (2010) consider, pursuing social and leisure activities is an important aspect of maintaining higher health-related quality of life. The fact that participants in this current study were actively seeking such activities, may therefore be seen as a positive aspect of overall recovery, and one which needs to be encouraged and facilitated beyond the early days at home.

In addition to the issues discussed earlier in relation to understanding patients’ experiences of service provision, Thomas and Parry (1996) argue that patient and

carer views are needed to help to shape services, especially with regard to disability and accessibility. As Parkes (1971:104) argues, people still need to feel a 'degree of mastery' over their environment, regardless of the extent of their altered situation. In common with the study by Hare et al (2005), in many of the studies examined in the literature review, participants reported difficulties or disinclination with regard to engaging in social activities out-with the home.

For example, Davidson and Young (1985) discuss environmental restrictions, whilst Thompson and Ryan (2009) report a reluctance to leave the comfort and safety of home, even many months after discharge from hospital. Ellis-Hill et al (2000) also reported that participants in their study were less active outside the house, and urged practitioners to 'move beyond treating the physical body out of context', in order to encourage greater meaningful involvement. Certainly, participants in this current study appear to have moved beyond the '1 day thinking as a coping strategy' that Wallengren et al (2008:54) describe as being used by carers whilst stroke survivors are still in hospital.

For participants in this current study, therapists often appeared to be working closely with stroke survivors in their own environment, and in ways that seemed to be meaningful to them. However, for one participant (survivor, Julia), her improvement seemed to connect to her spiritual beliefs, rather than being considered in relation to the skill and input of healthcare staff. There was a sense of almost comparing improvements with biblical accounts of disabled people being healed, and certainly spiritual beliefs can assist recovery by inspiring hope and helping people to look beyond the immediate situation (Popovich et al, 2007). Lamb et al (2008:173) also discuss the role that spiritual beliefs can play in feelings of 'connectedness'.

However, Nasser et al (2005) argue that such aspects can often be overlooked in studies of social support systems. Although Vance (2001) found that barriers to acknowledging and supporting patient's spiritual beliefs amongst nurses included lack of time, knowledge, confidence, and training, Hilton (2002) argues that a diminished ability to engage in previous spiritual activities has not been well researched. Given the benefits that can be felt by patients, it would seem appropriate for these aspects to be acknowledged to a greater extent in both research and clinical nursing practice. As Vance (2001) argues, there is no sense in healing the body, if we ignore the soul.

With regard to accessibility, and as has been discussed in the previous chapter, for many of the participants 'getting out' was equated to 'getting on', and came under the super-ordinate theme of reconnecting. It may be that both therapists' awareness and disability legislation are proving successful in making progress in this respect. Such participant accounts relating to getting out and about can be signified as 'a marker of recovery' (Smith et al, 2009:2), and may also indicate that environments are moving towards being more disability friendly. However, this is another area where the dates of data collection are important – if such information isn't given, it is more difficult to evaluate progress in relation to disability regulations and initiatives, and the impact that these may have on patient experiences. As has been seen in the findings, the lives of carers can also either be improved or diminished by their ability to get out with the stroke survivor, and how easily this can be achieved. Rather than Hilton's (2002:24) view of nurses facilitating a 'transformation into disability', an enabling and engaging attitude would seem more appropriate.

## **8.5 Revisiting**

In relation to the super-ordinate theme of revisiting, the stroke event and previous life sub-themes included issues concerned with the hospital experience and the discharge process. Post-discharge support was also an area that emerged as important, and this related to healthcare provision, as will be discussed further below.

### **8.5.1 The discharge process**

In relation to the time of discharge from hospital, Ellis-Hill et al (2009:1) deliver an excellent account of what their participants felt constituted a ‘good’ or ‘poor’ experience of the transition from hospital to home. However, although Ellis-Hill et al (2009) acknowledge that this area has been very limited in terms of previous research, their focus is predominantly concerned with mobility and functional recovery, as well as views about therapy services. The findings from the current study add to the pool of knowledge about the transition period by including analysis from experiential accounts which are very much participant led.

There is acknowledgement in the study by Ellis-Hill et al (2009) that standardised outcome measures are not always able to capture the views of patients and carers about therapy and services. However, in their account they do not indicate when data from their study were collected. In fact, of the twenty eight studies examined during

the review of literature to inform this current study, only five indicated dates relating to data collection.

With the inevitable delays between acceptance and publication of research papers (let alone data collection and writing up) it may often have been several years since the study participants actually gave their input. It could be argued that the time of data collection is not as relevant to qualitative studies – an experience is an experience, after all. However, if service improvements are recommended as, for example, in SIGN guidelines, or by organisations such as The Stroke Association, it is important that experiential accounts can be related to service provision at that time.

Participant accounts can also be useful for future comparisons, if the relevant dates are made explicit. As Doolittle (1992) asserts, we must provide frequent opportunities for patients to describe their experiences in order to facilitate a good understanding.

It may therefore be helpful to listen to experiences in parallel with, or in relation to, any changes in service provision, to give some indication of whether experiences are also changing.

For example, changes in stroke services, and increased public and professional awareness of stroke issues, would hopefully lead to improved experiences. However, we cannot assume that because we know what experiences were like at one point in time, we continue to know. If views and experiences remain the same after supposed service improvements, we have to ask questions about those changes, and not make assumptions. Therefore, to be meaningful to service providers and funders, dates of

data collection will help to identify what services were in place at that time, and may assist in answering questions about whether services could still be operating in better ways.

Discussions relating to the cost of services or equipment (e.g. Grant et al, 2004) especially need to be related to the time of data collection to be meaningful. As Ellis-Hill et al (2009:9) state ‘if we want to provide services that are more supportive of people following stroke, understanding of their perspectives are necessary and action to address these perspectives may well promote better processes’. If we do not know the dates when these perspectives were gathered, we cannot judge them against services, cultures and climate at that time.

In further relation to this, in the study area in which the current data were collected, new stroke posts and services had been in place for a number of years prior to data collection – sufficient time to have become established and embedded. However, if patients and carers are still reporting similar issues compared to earlier studies, albeit in different geographical locations, then it might be helpful to ask questions about what is being achieved, and if the situation could be further improved upon.

The important factor is that professionals listen to, and take account of, the experiences that are being reported by participants. For example, in 1991 McLean et al identified information gaps that they felt might be improved by the provision of literature, such as that provided by Chest, Heart & Stroke Scotland. However, even although such literature is now provided routinely in the geographical area of this study, participants in both the preliminary and main parts of the study were still reporting a lack of information.

Providing information is a complex and multi-faceted field, but there does seem to be consensus that provision needs to be tailored to individual need to a greater extent. For example, looking at other research findings, whilst participants in the study by Brazil et al (2000) nominated hospital as their preferred site for receiving information, Luker et al (2009) suggest that needs cannot always be predicted whilst patients are in hospital, making follow-up in the community all the more important. Information requirements also change over time and, as Pringle et al (2010) conclude, community nurses can fulfil many information needs as they arise after discharge home. Indeed, Mauk and Boss (2006) suggest that patients may be most ready to learn during this time, when there is a blending of their former life, with their current abilities. However, although stroke survivors may need more information on their return home, Wallengren et al (2008) argue that carers might have greater need at an earlier stage than this.

A further factor is the differing needs that information may fulfil: for example, Wiles et al (1998) conclude that information may fall into clinical, practical, or resource categories. It would therefore seem necessary that these differing types of information need are met, and acknowledgement given to the fact that the timing of provision may require to be varied. As Simon and Kumar (2002:159) discuss, there is a need to move away from providing information in an initial 'glut' whilst patients are still in hospital.

In relation to discharge home, Young and Forster (2007:89) also urge clinicians to think more in terms of 'transfer of care' rather than treating different settings as separate and distinct entities. As previously discussed, community follow-up has



been open to much debate. For example, Langhorne et al (2010) argue that although early supported discharge schemes can offer benefits to patients, carer outcomes do not necessarily improve. In concurrence with the issues stated above, Almborg et al (2010) conclude that relatives of stroke survivors continue to require greater information and knowledge than they are currently getting.

In the case of stroke, it should also not be forgotten that memory and cognitive deficits, especially in the early days, may make repetition and the use of differing information formats more necessary for patients. According to Sit et al (2004), information may not be taken on board if it is too complicated, or not sufficiently related to the person's individual situation; retention may also be poor due to the stress of the situation. As discussed earlier, participants in both the preliminary study, and this main study, indicated that they still had unmet information needs. Although these participants are only small in number, their experiences add to suggestions that there is still little room for complacency regarding patient and carer support. Staff in both hospital and community settings therefore need to be frequently checking for unmet information and support needs with both patients and carers.

As has already been discussed, caution is needed with regard to claims that are extrapolated from small, idiographic studies. However, as Yardley (2000) concludes, the impact and importance of such studies in relation wider issues does still need to be evaluated. According to Smith et al (2009:183) the 'real validity [of a study] lies in whether it tells the reader something interesting, important or useful'. A careful balance therefore needs to be struck between the findings from the participants in an

individual study, and any wider thoughts or implications that are made in relation to (for example) health service provision as a whole. In this respect, and as previously discussed, relating findings to other research can help to build up a bigger picture, that is both informative and potentially useful for clinical practice.

### **8.5.2 Discharge support**

Support following discharge was discussed by participants in relation to their overall hospital experience, while they were looking back and revisiting that time.

Participants in the main part of this study were supported by a short-term discharge team in seven out of twelve cases, and their input was mainly highly praised.

The support from the team seemed to be almost physically felt (*I've got them round about me*), even when the team were not actually present. The second quote about missing their input when it came to an end (typically after two to three weeks, therefore before the interviews took place) was repeated by several participants.

In contrast, however, were experiences when input was not forthcoming, and a couple of participants expressed a strong sense of not being supported.

Support from the service therefore seemed to impact on the reconnecting process, and because such input is only short-term in the geographical study area, independence rather than dependency is encouraged by the team. In relation to this, although there were expressions of missing the service, there was also an acceptance that this was a natural occurrence, and part of the process of exiting the sick role.

Looking at the broader picture, where such teams have expert knowledge, co-ordinated care can be given in a way which may be lacking if less experienced staff are involved (Brereton and Nolan, 2002). Certainly, not all stroke follow-up care has been positively evaluated in the past (Dennis et al, 1997; Salter et al 2010).

However, it should be borne in mind that such care is not always given by specialist or expert staff. In the case of Mant et al (2000:811), for example, the follow-up service was given by a 'family support organiser' with unspecified training, who was 'gaining experience' during the course of the study. It may also be that such positivistic trials are not identifying a true picture of actual experiences.

The accounts of the participants in this current study, although few in number, add to the body of evidence that indicates that such initial expert support can help with the reconnection process, thereby lessening the feelings of abandonment that have been reported in other studies (e.g. McLean et al, 1991; Thomas and Parry, 1996; Bäckström and Sundin, 2007), and mentioned by the participants here who did not receive the expected level of care. As Salter et al (2010) conclude, it is early initiation and intensity of input that may be more likely to improve outcomes.

Whilst individualised support appeared to be very valued by the participants at this stage of the recovery process, group support and networks are discussed by a number of other studies (e.g. O'Connell et al, 2001; Stone, 2007), which report on findings from later in the re-integration process. However, as previously discussed, group support was not mentioned as a means of reconnecting by the current participants during their early days at home. The main body of support at this stage seemed to be

experienced as coming from people (family, friends and professionals) who were closer to home.

As considered in relation to the preliminary study findings, being able to compare oneself with others can help in the definition of self, and the task of redefining a new identity. This may also help with adjustment to the changes that have taken place, both for survivors and carers. Group support can help with such comparisons, and although not necessarily accessed during these early stages, may also help to lessen feelings of being abandoned, especially when therapy services stop. In addition, if such groups are run by a trained expert, they may fulfil some of the information needs that have been identified as missing. However, Hare et al (2005:133) found awareness of such support groups to be 'surprisingly low'. This may also explain their lack of mention, and suggest a need to raise the profile of these organisations.

## **8.6 Further discussion**

This discussion will consider the overall findings in relation to the involvement of participants in the research and rehabilitation process. Financial issues that may arise in relation stroke recovery will also be debated. Following on from this, established nursing theory will be examined in the context of the research finding. Finally, the presentation of findings in the alternative form of poetry will be considered, before a summary is given.

### **8.6.1 Involvement of participants in the research and rehabilitation process**

As has already been stated, findings were not discussed with participants during the analysis of the main study data. However, whether this happens or not, Smith et al (2009) still stress the value of participants as co-constructors in the research process. This bears similarity to the emphasis placed on regarding survivors and carers as co-partners in the recovery and rehabilitation process (Glass et al, 2000; Ellis-Hill et al, 2009). In further relation to regarding survivors as partners, it was noted that many of the participants in this current study displayed evidence of confusion about the roles of the professionals who were helping them during their early days at home.

It was possible for the researcher to identify this role confusion because of her close knowledge of services in the area. A less familiar researcher may not have picked up on such confusion, which was also reported by Doolittle (1992). Identification of such issues may add to the earlier arguments about whether being familiar with the research environment is a bonus or a drawback. However, having insight into issues such as role confusion also gives rise to questions about how people can be true co-partners in the recovery process if they don't understand the roles and goals of the professionals who are looking after them.

Sometimes there was doubt about survivors' desire to engage with therapy, and this also gives an example of how 'tiredness overcomes' ability to participate in activities. It would therefore seem appropriate for professionals to make their identity and purpose clearer, and for some common agreement to be made, which takes into account desire and ability to engage in therapy; as Doolittle (1992) and

Olofsson et al (2005) also discuss, frequent reassessment and reinforcement of such information may be necessary to ensure common understandings continue to exist.

In addition to this, Andesson and Hanesbo (2009) found that patients may not always share their own hopes and goals with healthcare professionals, fearing that their views might not be listened to, or accepted. It would therefore be helpful if professionals also made their position with regard to being open to hearing the views of service users more explicit, at the same time as working towards being flexible and adaptable, according to patients' abilities.

With further regard to information giving, according to Ellis-Hill et al (2009) there is a need to move away from the passive recipient model. They argue that it is insufficient to merely give out information, but rather to assess current understandings and take account of the timing of information needs. As Anderson and Marlett (2004:440) also conclude, communication following a stroke can often be 'the overlooked rehabilitation tool'. The findings from the current study therefore concur with other studies in this respect, and indicate that further progress with regard to engagement in therapy, and meeting information needs, would benefit patients and carers.

In additional relation to the passive recipient role, and has already been discussed, participant accounts in this current study indicate that during the first month patients were moving away from the sick role and regaining, or reconnecting with, choice and control. Carers also indicated a need to become more assertive. Participants were voicing opinions about the timing of services, and about what they did or didn't

want. This 'moving beyond the passive', although a healthy stage in the rehabilitation process, is also something which may challenge professionals (Olofsson et al, 2005). For example, in Burton's study (2000:307) input by professionals was considered somewhat 'artificial' by patients, rather than being truly related to the individual's environment or circumstances. Brazil et al (2000) also found that service providers underestimated the difficulties that might be faced on discharge home, whilst Bendz (2003) identified a lack of shared perceptions between healthcare workers and stroke survivors. A greater understanding of experiences may go some way to help bridge this gap. Professionals also need to lessen their tenure on control, and allow carers greater access to their 'territory', according to Brereton and Nolan (2002:30).

Although the need to individualise care has been stressed earlier in the thesis, McBride et al ((2004) argue that there is a need to more clearly articulate the contribution that nursing interventions can make in the recovery process, concluding that a standardised classification of nursing care could make this more explicit. However, while nursing care interventions may be standardised for such classification purposes, the need to adjust these to the individual also needs to be stressed.

With regard to discharge from hospital, Tamm (1999) discusses the impact that equipment and services may have in the home environment, an issue which seems to receive scant acknowledgement in other stroke studies. As has been heard in the words of one carer in this study (Audrey), the sheer number of people entering the house following the discharge of her husband from hospital, had the effect of

disrupting the intimacy of being able to reconnect with her husband as part of a couple. In common with another carer (Daphne), this was said with a sense of great sadness, which perhaps alluded to the loss of a closeness that might never be fully regained.

The fact that the intrusions caused by healthcare staff and equipment are given little consideration, and no solutions suggested, even when mentioned by participants in other studies (e.g. Banks and Pearson, 2003; Grant et al, 2004; Bäckström and Sundin, 2007), would certainly seem to indicate a need for professionals to engage in greater understanding and sensitivity in this respect. This would appear to be not only an under-acknowledged area in practice, but also an under-researched topic. As has been discussed, the reconnection process is an important psychological activity in the readjustment and adaptation period. Healthcare professionals need to develop insight into actions which may enhance or detract from this process, in order to more fully support families.

Von Koch et al (1998) also emphasise the importance that the context of rehabilitation can have on the attitudes adopted by survivors, which may, in turn, influence their desire to engage more fully with professionals. The context and setting of care interventions may therefore benefit from greater consideration.

### **8.6.2 Financial issues**

With regard to financial resources, many USA studies discuss the implications of finance in relation to healthcare provision and health insurance (Eaves, 2002; Weil, 2003; Catalino, 2010). Although the situation looks set to change in coming years in



America, caution needs to be taken when comparing healthcare provision between countries with differing care systems. It should also not be assumed that the financing of services and equipment are not issues in the UK. For example Chest, Heart & Stroke Scotland and Scottish Association of Health Councils (2001) report that some families affected by stroke choose to pay for equipment themselves, due to time delays, or a lack of choice and availability within NHS supplies. Although equipment was mentioned by participants in the preliminary study, such issues did not seem to feature to any great extent in the accounts of participants in the main study, even although some of the participants had very restricted ability. In fact, those participants who did receive equipment seemed generally pleased with it.

During the on-going literature review that informed this current study, a few studies were found that advocated the use of internet resources, either as a means of data collection from on-line discussions (Hunt and Smith, 2004; Stone, 2007), or as a means of information provision (Smith et al, 2004; Pierce et al, 2006; Ellis-Hill et al, 2009). However, little regard has been given to cost or accessibility issues in these studies. Stone (2007) does briefly acknowledge internet accessibility as a limitation, but does not consider the fact that computer hardware is expensive to buy and maintain; internet access also has on-going costs attached to its use. Even if such resources are provided free of charge at centres out-with the home, there are still issues relating to travel and timing, which may make accessibility difficult.

Quite apart from these issues, are those of manual dexterity, age related technological knowledge, and training requirements. Although there are developing initiatives to address such considerations (Communication Matters, 2001), these

issues are given very little consideration in the articles referenced above. It is worth noting, for example, that of the participants in both parts of this current study, only two had a computer at home and could be considered to be ‘computer literate’. While studies such as Smith et al (2004) recommend that more use of internet resources is made, the wider picture still needs to be addressed to make these resources truly accessible and affordable.

In relation to models and theories, as has already been discussed, certain of these may resonate with research findings in particular studies. Levine’s adaptation and conservation theory (Levine, 1996) is a set of principles which appeared to have relevance to the current study findings, and this will be discussed next, with regard to the super-ordinate themes of revisioning, reconnecting and revisiting. Comparing findings with a well-established theory can further help to explore their relevance in terms of nursing practice.

### **8.6.3 Levine’s Conservation Principles**

Taking the earlier arguments relating to caution with regard to the use of models into consideration, according to Hickman (2003:17) models or nursing theories do nevertheless provide ‘the critical-thinking structures to direct the clinical decision-making process’ of nursing practice. Hickman (2003) also discusses the fact that research can help to validate models, and that models and theories can similarly be used in relation to research conclusions, to assist in explaining, situating and expanding on the meaning within findings. In this respect, the accounts of the

participants in the current study were felt to have resonance with Levine’s Conservation Principles (Levine, 1996).

According to George (2003), Levine did not set out to create a theory or model, but rather to move towards a more individualised, holistic type of care. Levine considered that as humans, we adapt to conserve unity, whether this involves the conservation of energy, or the preservation of structural, personal or social integrity (see Figure 28, below).

<b>Conservation Principle</b>	<b>Details</b>
Conservation of energy	Balance and renewal of energy to maintain life activities
Conservation of structural integrity	Defence of wholeness, and preservation of structural and functional integrity
Conservation of social integrity	Preservation of life meaning through social connections and social dimensions of health
Conservation of personal integrity	Recognition of individuality, self-worth and identity

**Figure 28: Levine’s Conservation Principles** (summarised from Schaefer, 2006)

These concepts will be discussed in relation to the current findings. Each principle is underlined in the following discussion:

With regard to the conservation of energy, every participant in both parts of the current study (preliminary and main study findings) described some form of tiredness, exhaustion or lack of energy, whether they were a patient or a carer. Austin (1996) relates such tiredness to the additional vigilance required by stroke survivors to overcome their stroke related problems, but does not consider tiredness in connection with carers.

Tiredness is also widely reported in other stroke studies, but not in great detail in relation to the limit it places on choice and control, and the ability to start reconnecting. Within the themes in the current study findings, this was described as 'tiredness overcomes' in the mind map.

The tiredness felt was quite overwhelming for these participants, and can overcome other desires and goals. In this respect, it overpowers choice and control by possibly acting as a biological preservation mechanism to allow the internal healing process to take place (Tyrrell, 2008).

Levine's second conservation principle relates to structural integrity, and more specifically to physical ability in this current study. As has been discussed previously, there was a wide variety of physical ability and disability within the sample of stroke survivors in the study. Some of those most physically affected described the struggle to maintain some form of structural integrity through the use of aids, or sheer physical effort. In this respect there was a significant amount of revisioning in relation to ability.

However, even those not requiring aids, and with little visual evidence of disability, still found maintaining physical integrity challenging, and were also revisioning their image and identity.

Carers were also affected by the physical deficits of those they were caring for. As described in the previous chapter, some of the carer accounts seemed to the researcher to be said with such sadness and finality that, even while relating the account, the true extent of the losses and physical restrictions seemed to be hitting home. These narratives appeared to relate not only to the revisioning of a future encompassing those losses, but also seemed to bring issues of mortality into sharper focus.

With regard to social integrity, this very much related to the efforts both patients and carers were making with regard to reconnecting with family, friends and previous social activities. Putnam (2000:17) refers to the importance of ‘social capital’, or the connections people make, as positively influencing the uptake and recall of health information. This further strengthens the value of supporting the reconnection efforts that people are striving to make.

The conservation of personal integrity connected with the image and identity issues mentioned by both carers and patients. As described above, the desire of one participant not to be seen as disabled was very powerful. In this respect the account of the participant spoke so clearly to the researcher, that it was interpreted into a poetic form (Appendix 14) by the analyst, in an attempt to crystalize and convey the power of the narrative. The poem was created solely from excerpts from this one participant’s interview, but in a rearranged form.

Although all the super-ordinate and sub-themes are displayed in the poem, it is perhaps issues of personal integrity that come across most strongly. Further issues in relation to poetry will be discussed next.

#### **8.6.4 Poetic interpretations**

Flowers (2010) encourages IPA researchers to bring something of themselves to their analysis, especially in relation to interpretation. Such inclusion of the self in the analysis process is not common to all forms of phenomenology, but is one of the distinctive features of IPA studies (Smith et al, 2009).

With regard to the poem discussed above, placing such an emphasis on only one participant's narrative could be criticised as overdrawing disproportionately from within the sample (Smith et al, 2009). However, as Smith (2010) also considers, with a larger sample, it may be that some narratives are examined in greater depth, and others used more as supporting evidence.

Poetic forms, and their inclusion in academic journals, have been the subject of recent debate and discussion (Morse et al, 2009). However, as has already been considered, using such an approach would seem congruent with the imaginative variation encouraged by Giorgi (2000), and Finlay's (2003) advice to look creatively at data in order to open up possibilities within the interpretive process.

Poetry may also speak to readers in different ways: as Carr (2003:1330) discusses, poetry can be 'an effective way to reconstruct and confirm the lived experience of

others' which may 'evoke the reader's emotional response and produce a shared experience'. It could therefore be argued that poetic forms of data representation have a part to play in the dissemination of research that may enable findings to reach and strike a chord with audiences who might otherwise not access more academic writings. Indeed Raingruber (2009) asserts that poetry has a valuable role to play in nurse education, and although Morse et al (2009) may no longer accept poetic forms for publication, there is a good argument for such representations of data to be available elsewhere.

## **8.7 Summary**

To summarise, this chapter has sought to examine the findings from both parts of the study in a more interpretative sense. In the words of McNamara (2005:700) the study has endeavoured to provide the 'intuitive integration of the apparent and the hidden' necessary in a phenomenological study. In addition to this, findings have been discussed in relation to a range of models and theories. A broader sense of how the findings relate to other research has also been given, and consideration of how these issues relate to, and impact on, clinical practice has been explored.

The impact that more rapid transitions to the home environment, and the subsequent effects this may have on the family, have also been considered. According to Clarke (2009) individuals cannot be understood in isolation from their environment or sociocultural context.

Although Young and Forster (2007) discuss stroke recovery in relation to re-enablement, resettlement, and the functional aspects of recovery, these current

findings aim to make sense of the aftershock of stroke in a broader way that encapsulates the wider situation, beyond just physical recovery. Being able to understand such experiences more fully can enable health professionals to better support survivors and their carers in their transition and transfer to the home environment.

The following chapter will detail conclusions from all parts of the study, and give a reflexive account of the research process from the researcher's perspective. The thesis will conclude by outlining recommendations for future research and clinical practice, which have been drawn from relating the findings of this study to the broader body of existing knowledge.



## CHAPTER 9

### Overview and conclusions

#### 9.1 Introduction

This research project has sought to explore stroke experiences further, and although only examining data from a small group of participants in one area of Scotland, the findings from the study can still add to the overall picture of stroke experiences for both patients and carers, particularly during the early days at home. At the time of writing, no other Scottish studies appear to have had such a focus. With healthcare provision in Scotland having been devolved to The Scottish Parliament, it is important that the voices of patients and carers are heard and acted upon, not only by the healthcare professionals who are looking after them, but also by people who are involved in service planning and provision. Looking in depth at individual experiences can be enlightening to all those concerned, at whatever level.

Elliot (1997) argues that particularly within primary care, many episodes of illness may not come to the attention of health professionals. This study has sought to access patient experiences that might otherwise have been invisible and unheard. Sit et al (2004:816) also stress the importance of understanding the experiences of carers in order to better support them, and prevent them becoming ‘the second patient in the family’.

By taking an interpretative phenomenological approach, experiences have been highlighted in a way that may not have been achieved by using a different method.

As Ellis-Hill et al (2000) argue, participants in research can sometimes find it hard to explain their experiences to themselves, let alone others. Having the opportunity to be listened to during this research project has facilitated participants to explore their experiences, and allowed a detailed analysis that has sought to expand on, and make sense of, participants' own attempts to understand their situation. Through an iterative, inductive process, data were decontextualized and re-contextualised in a manner that distilled and crystallised meanings into super-ordinate and sub-themes. The overall aim has been to produce an account that allows the reader to feel they have 'vicariously experienced' the phenomenon (Starks and Trinidad, 2007:1376). Studying chronic illness stories can allow others to be more aware of the 'fractured, multidimensional, ambiguous, and shifting existence' (Vickers, 2003:47) that may be present. Although, as already discussed, stroke survivors and their carers may not yet regard their situation as one involving a chronic illness, these accounts do nevertheless portray their start on a journey that is only just beginning during these early days at home.

The accounts bring to life and personalise what is really happening on a daily basis, and although very individual, may also be indicative of what is occurring elsewhere in a broader sense. Adding these narratives to the wider known data helps to construct a picture of how people's lives are affected, not only by conditions such as stroke, but also regarding how encounters with healthcare providers are experienced on a personal basis. From such knowledge, areas that have more to aspire to in the way of training, co-ordination or information provision can potentially be identified. Recognition of possible knowledge and skills gaps can stem from individual accounts, and may help to inform training programmes, and ensure that professional

development strategies are being related back to evidence that comes directly from patients and carers. Hearing such individual accounts, especially those which are rich in direct participant quotes, can help to situate their position in reality.

All this may seem challenging for such small idiographic studies to achieve.

However, as Smith et al (2009: 202) conclude, although interpretative phenomenological analysis (IPA) is concerned primarily with analysis at the micro level, such analyses can be complimentary to, and enrich, ‘the development of more macro accounts’.

Findings from this study have concurred with a range of stroke studies, but have also highlighted differences with others. Because the study focus has been on the early days at home, the transition and adaptation phase has been examined as it is happening, rather than some time after the event, which may involve associated memory or re-interpretation issues. Unmet needs, and factors that might impact on later adjustment, have been identified from the participants, and further related to other study findings.

An additional unique feature of this study has been the commitment to include participants with virtually no speech. The issues and challenges of doing so have been explored, and suggestions made that may encourage and facilitate other researchers to do likewise. As Shadden and Hagström (2007:333) argue, it is important that encounters with people who have communication difficulties are used to accomplish more than ‘simply improving word-finding skills or enhancing auditory comprehension’. According to Cameron and Murphy (2002), greater opportunities for the expression of thoughts and feelings can reveal views and

emotions previously unknown even to close family. Reflections on the dilemmas that the inclusion of these participants posed for the researcher will be given later.

As has been discussed, the overall aim of an IPA study is not to generate theory, but rather to add to the body of knowledge already known. However, one of the main issues stemming from the current research findings, and from the other studies examined as part of the overall discussion process, is that messages relating to the individual nature of stroke recovery (regardless of age, stroke type or degree of disability) are not always getting across.

This chapter will summarise the study findings, and give a reflexive account from the researcher, followed by a discussion of the study limitations. In addition to this, issues relating to service provision will be considered, and suggestions for further research made.

## **9.2 Reflexive account**

Reflective practice is often talked about in terms of improving nursing practice (Johns, 2009). However, according to Clinton (1998:200), reflexivity involves a potentially more complex 'higher order' activity. Finlay & Gough (2003: ix) differentiate between the two processes thus:

‘reflection can be defined as “thinking about” something after the event.

Reflexivity, in contrast, involves a more immediate, dynamic and continuing self awareness’

This definition of reflection gives a more simplistic idea of the process than that encouraged by Schön (1983), who discusses the difference between a more proactive reflection in the midst of action, against later reflection after the event. However, Clinton (1998:201) argues that reflection 'in action' is more difficult and complex than might be immediately understood. Kinsella (2010:4) also concludes that there is a lack of conceptual clarity surrounding reflective practice, arguing that the term is 'in danger of becoming an empty, meaningless phrase, that at once means everything and nothing'.

It is therefore important to distinguish between the different types of reflective activity that are taking place, and to detail how these are being achieved, for any account of reflective practice or reflexivity to be meaningful. According to Mauthner and Doucet(2003:414), although the interpretation of data is considered to be a reflexive exercise, there is a lack of guidance about how to 'operationalize' reflexivity.

Finlay & Gough (2003) suggest a reflection-reflexivity continuum to distinguish between the differing levels that may be engaged in. Similarly, Smith et al (2009:189) discuss 'layers of reflection' as ranging from an everyday 'awareness', through to the type of 'deliberate controlled reflection' required of a phenomenological study. In this latter type (which can involve both the researcher and participants) the researcher may initially ask the participant to focus and reflect on a particular experience, or sequence of events, to a greater extent than they would do naturally in everyday life. Probing or questioning may then divulge greater meaning and detail through further reflection. The focus of fully attending to the process, and the participant, also helps to ensure that researcher preconceptions are

kept in the background (Smith et al, 2009). As well as entering into a dialogue with participants as part of the interpretative process, the analyst enters a dialogue with the works of other authors in order to situate the findings in relation to other research. In this respect, during the discussion of the current study findings, a number of quotes have been used from the words of other authors, to signify this research 'conversation'. Making such connections between the individual participant accounts and the wider known evidence (the parts and the whole) is an example of how the hermeneutic circle extends to many aspects of the research process, as discussed in chapter 3.

In addition to this, however, the researcher must be carrying out his or her own reflexive activity, to challenge and identify any preconceived ideas or influences which may be shaping and directing the interview or analytical process, with a view to exposing 'tacit', or hidden, subjectivities (Kinsella, 2010:12). As Lowes and Prowse (2001) assert, we can only interpret something in relation to our own background of beliefs, understandings or prior knowledge.

With regard to reflexivity in research, Byrne (2004) considers this to involve a critical self-awareness on behalf of the researcher, vital in acknowledging the roles and influences being brought to the research process by the individual researcher or research team. Seale (2004) also considers reflexive accounts to be part of the process of enhancing research quality. However, as McKay et al (2003) discuss, the process of questioning oneself, and the data, during the reflexive journey requires time, space and engagement.

Holmes (2010:149) concludes that recognising emotions felt both in ourselves, and in our research participants, forms an important part of reflexivity, and that 'interpreting one's own and others' emotions' is necessary to better understand and make sense of how and why people adapt, or 'feel their way', when changes occur (Holmes, 2010:150). As Brauer et al (2001) argue, emotional support and understanding can have a greater impact on health than instrumental help.

In the research situation being examined here, the researcher had been working closely with stroke patients and carers on a daily basis at the time of the research. This could have potentially led to some preconceptions, which needed to be taken into account and acknowledged, throughout the research process. As Finlay & Gough (2003:ix) argue, reflexivity 'demands acknowledgement of how researchers (co-) construct their research findings'. One way of doing this is by keeping a reflective diary, as recommended by Smith et al (2009). However, as Kinsella (2010) discusses, original guidance on reflective practice concentrated on an internal dialogue, with journal accounts being a more recent suggestion. Writing reflective notes can help to record and clarify meanings during the research process, and also help the researcher 'hear' their participants better than may be possible in everyday clinical work. A personal notebook or diary can also provide an on-going account of thought processes, initial impressions, and ideas for inclusion in the analysis; as Bradbury-Jones et al (2009b:2485) conclude, it can also help to identify the 'subjective I'.

As previously discussed, Finlay (2008:4) relates the ability to be open to hearing experiences in a new way to Husserl's stages of reduction, where prior knowledge or

preconceptions are set aside, and ‘objectivity is constituted out of subjectivity’, thereby allowing alternative understandings to develop.

However, Finlay (2008) also suggests that new understandings cannot be totally detached from the previous knowledge of professionals, which rather needs to be harnessed, managed, acknowledged, exploited and explored, as a source of insight. Clinton (1998) agrees that this process is similar to Ricoeur’s description of the double hermeneutic, with the first level describing the experience, and the second level interpreting the experience beyond that which is immediately apparent. Finlay (2008:3) expands on this by likening the process to a dance between having ‘naïve openness and sophisticated criticality’.

It would therefore seem that by seeking to be reflexive, it is possible for researchers to combine the ostensibly opposing phenomenological concepts of bracketing preconceptions, and allowing prior knowledge to assist interpretation. However, Giorgi & Giorgi (2003:28) caution that while phenomenology allows a better understanding than one would have ‘spontaneously in everyday life’, the process itself should not ‘transform the original situation beyond recognition’. This highlights the importance of relating findings back to the original transcripts, as advocated by Smith et al (2009), and engaging in a ‘double hermeneutic’ (Smith et al, 2009:35).

The ‘double hermeneutic’ process involves the analyst attempting to make sense of the participants’ sense-making activities (Giddens, 1987; Smith et al, 2009). This process can be viewed as overlapping with the hermeneutic circle, where the parts and the whole are interconnected: participants’ sense-making activities cannot be disconnected from, and are influenced by, wider society and social processes



(Giddens, 1987). In this way, by making sense of participants' sense-making, the researcher is also acknowledging social influences that may become apparent in the analysis (for example, the gender roles and generational differences discussed in the previous chapter).

In further relation to reflection, Finlay (2003:8) discusses five 'variants' of reflexivity, as detailed in Figure 29 below:

<b>Variant</b>	<b>Detail</b>
Introspection	Knowledge of self as a springboard for interpretations
Inter-subjective reflection	Looking inward for personal meaning, and outward for shared meaning
Mutual collaboration	Recognising participants as having the capacity to be reflexive
Reflexivity as social critique	Examining tensions of power, culture, class, gender, or race within the research
Ironic deconstruction	Attention is paid to the ambiguity or multiple meanings within language used by participants

**Figure 29: Variants of reflexivity** (Summarised from Finlay, 2003)

Looking critically at these different types of reflexivity, elements from each of the five components were engaged in during the research process. For example, the

reflective journal allowed personal thoughts to be noted, whilst more complex social and language considerations have been identified in the analytical discussion. It would therefore seem possible to combine multiple ways of achieving reflexivity within the analysis of one data set.

However, as Finlay (2003) cautions, reflexivity should not be used to imply greater authority of the findings, or to shift attention away from the phenomenon being studied; reflexive strategies as a whole merely give evidence of the thought processes of the researcher, and other background information. As such, reflexivity does form part of the audit trail, and in this respect the process can be seen as enhancing the rigour of the research. As Hammond (2010) argues, self-reflection and self-critique can help to contextualise a study using IPA. With these thoughts being kept in mind, some of the reflexive considerations of this research project are noted below; italics are used to indicate the personal thoughts of the researcher:

### **9.2.1 Background to the study**

*During my years as a community nurse, I became aware that on discharge home some people did not always cope very well. Often the first indication of this would be a note of their readmission to hospital. I felt that if I understood their experiences, then I might be better placed to support people during the early days at home. Stroke patients seemed a particularly important group of potential participants in this respect, due to the sudden and potentially life-altering nature of stroke as a condition, for both survivors and carers. However, even during my time offering community stroke follow-up support, my contact would sometimes not happen until*

*people had been home for a number of weeks, and therefore the opportunity to engage with people during the early days at home was not possible. The opportunity to engage with participants during this initial period, through research, was an area of great personal and professional interest.*

### **9.2.2 Selection of participants**

*In order to minimise any researcher bias in the selection process, participants in the study were initially chosen by my colleagues at ward level, according to the inclusion criteria. I only approached people on the ward once they had already been given some information about the project, and had tentatively agreed to consider taking part. The ward staff had already assessed for their ability to engage in the process, and if potential participants declined at that stage, I was none the wiser. Indeed, I did not ask how many people were approached and refused.*

*Participants were therefore taken on a 'first come' basis, rather than the researcher having any influence on the selection process. This had both positive and negative effects: on the one hand, part of the work of obtaining potential candidates had been done for me, and I was introduced to patients who were already 'primed' and agreeable to hearing more about the study. On the other hand, I had limited control over how many people (or who) would be approached in any one week, which could potentially have led to difficulties in relation to the timing. However, in the event, this did not cause any problems.*

*After making contact with potential participants, not everyone then went on to be included in the study – three patients later declined after hearing a bit more about the research. Others agreed to take part, but following discharge then felt unable to*

*fulfil certain parts of the study – completion of the diary was the main obstacle for a few people. This was a challenge that raised several questions: should I discard their input because it was not ‘complete’, or should I accept what they felt able to offer? In the event, I decided that I would have to view the data set as a whole, with some participants being able to offer more than others. Indeed, this was already going to be the case for the participants with speech difficulties. My desire to be inclusive, and to incorporate the views of people who would have been left out of many other studies, overcame my misgivings about the data not being exactly the same. However, I had to make sure I clarified this throughout the research process, and acknowledge the limitations that were inherent in following this course.*

### **9.2.3 Data generation**

*With regard to the diary and interview structure, these were both kept as unstructured as possible, to allow some kind of ‘free reign’ to the participants. However, this was also a risky strategy because, as I soon discovered, some of the preliminary diary accounts were very descriptive. This was a disappointment, which may have been partly due to a misunderstanding on behalf of the participants in question, or perhaps a reluctance to disclose their more private thoughts. In these cases, at least the interview gave the opportunity to probe a little further, and for the main study I was able to be a bit more detailed in my description of the diary-keeping when I met any potential participants.*

*Again, probing during interviews can sometimes also be problematic. In hindsight, there can be few qualitative researchers who, on listening to the tapes of their interviews, cannot identify times when they wished they had probed further, or asked questions at a particular point in the interview. I was no exception.*

*In addition to this, I was also aware of the need to be alert for points of significance during each interview, and to truly attend to what was being said. I felt I achieved this better with the main study participants than with in the preliminary study, largely due to the fact that I was gaining more experience and confidence. I certainly felt more at ease during the main study interviews, and hopefully this acted to make my participants more comfortable too, and therefore more willing to engage.*

*However, some of the participants, even although initially enthusiastic, were not as forthcoming on the day of the actual interview as I would have liked. Fortunately these people were offset by some very intuitive and reflective accounts. This is presumably always a risk with qualitative interviewing, but one that does not seem to be widely acknowledged in research reports. I found myself wondering what happens to those participants who don't produce very detailed accounts and stories – are they quietly discarded, with only those very eloquent participant accounts being included? It is difficult to know. This study sought to be inclusive, although obviously there are more example quotes from those people who were able to give more detailed accounts. However, where possible, the views of all the participants are represented.*

*Having said that, I also had to be aware of my own subjectivity in relation to which excerpts I chose to represent the themes, and in this respect, acknowledge the impact of individual choice in this process. For another researcher, different quotes may have stood out as having greater impact.*

#### **9.2.4 The impact of self and prior knowledge**

*One initial consideration was the issue of my prior knowledge of stroke, and the potential impact this might have. Whilst this could mean that I had preconceived ideas about what I might hear or read in participant accounts during the analytical process, I also viewed it as a bonus. I knew I was sufficiently engaged and interested in the topic that I would do my best to ensure that it was the words of my participants that would hopefully be heard above my own thoughts. Two other considerations also helped here: firstly I was confident that I had good links with academic colleagues, who would both encourage and challenge me, to ensure I was producing an account that was true to the data; secondly, in my choice of IPA, I was aware that my interpretation would be acknowledged as just that – one of a number of possible versions, not the only valid account. Participant's words would be included to such an extent as 'evidence', that readers would be able to either agree, or form their own different interpretation from the extracts.*

*With regard to the interview process itself, I was very aware of the need not to lead the participants to any great extent, or make suggestions that might influence the direction of the interview. I found my previous counselling training helped here. Having said that, I did find myself trying to draw participants back to discussing their early days at home when they veered away from the topic. Initially, I found myself feeling quite frustrated when they talked about their stay in hospital; however, I then started to realise that this was very much something they wanted and needed to tell me about - for them, it did have relevance to coming home, and was very much related to their understanding of their new and altered situation. This was something I had not anticipated, and it made me realise that I was seeing the*

*process very much from a professional point of view (where the two environments are quite separate) rather than seeing the whole process as being part of someone's overall life story. If I had done as Caelli (2001) discusses, and deleted or ignored this information as irrelevant, I would have missed an important aspect of the process of meaning-making for my participants.*

*Further to this was my status, especially in the eyes of my participants, as a nurse. Patients who were approached by the ward staff were told I was a nurse. This may have given me some credibility and acceptability, which I was happy to have: perhaps I would be seen as more trustworthy, and possibly people would agree to take part based on this. However, the other side of the coin was that I may have been viewed as part of the 'establishment', and thereby I might not be as open to hearing criticisms within their narratives. In addition to this, they might also not have felt as able to disclose activities that they thought I might consider unhealthy, or that went against health advice they had been given. I dealt with these issues by making sure that I re-iterated statements about confidentiality and anonymity, both when I first met them, and later before the interviews started. I also talked to them about how I was there as a researcher primarily, rather than a nurse.*

*A further question, and one which the NHS ethics committee was keen for me to acknowledge and consider, was the issue of health concerns or emotional upset that might arise during the interviews. It was expected that the topic and timing were sufficiently sensitive that such issues were likely to arise in some cases, and indeed dealing with such considerations was already part of my clinical role. However, how would I deal with such issues in the context of the research interview process? In the event, it felt quite natural to let the interview proceed, with questions and*

*expressions of emotion being an integral part of the interaction, and not unexpected. Having said that, even with my previous counselling training and knowledge, I was not always able to remain neutral and unemotional at all times myself: the tears and pain expressed by some of the participants had me close to tears myself occasionally, and it is difficult to know whether this was noticed by my participants, or what impact it might have had on the data. However, once the interview was over, I did feel able to offer advice and information about further support. One or two simple questions I answered myself at that time, such as fairly straightforward questions about medication that had arisen during the interview. Indeed, as a nurse, albeit in a research capacity, I felt unable to totally ignore these information deficits, but at least I waited until the interview had been completed before doing so. In this respect, I was aware of the 'duality' that Borbasi et al (2005:493) discuss in relation to nurse researchers. I was also aware that in many cases support services were already in place, and I encouraged participants to discuss any on-going issues with these people.*

*In a few cases, I knew that I would be seeing the participants myself as part of my clinical role, and again it fell in place quite comfortably to offer them the support and advice they required after the interview. In these cases, I did explain both before and after the interview that I was seeing them in two distinct roles. This did not seem to cause any concern to the participants, but whether it had any effect on the interview process itself is difficult to know. Certainly I was reassured to read positive accounts from nurses who had conducted research in similar situations, before I conducted my own study.*



*With regard to expressions of anger, either during the actual interviews, or references to earlier angry outbursts made by participants, although these had not been necessarily anticipated, they did seem understandable and acceptable within the context in which they were given. During this same period, I was also reading the novel 'Gridlock' by the comedian and author, Ben Elton (1992). In one part of this book, an account is given that relates to the understandable nature of anger following disability; this had a marked influence on my ability to understand such emotion. [The passage from this novel is given in Appendix 15, to further explain this timely influence].*

*With regard to the poor hospital experiences that a few of the participants reported, although I could not alter the experiences that had already happened, I was unsure how much I could, or should, do to try and prevent such experiences happening again, whilst still preserving participant anonymity. I also had to bear in mind that participants were not asking me to take any action, and Norman's own decision had been not to report or complain about the treatment he had received. As Caelli (2001:280) discusses, nurse researchers may be unprepared for such ethical dilemmas, and may feel a 'conflict of loyalties' when such situations arise. In the event, I hoped that further publications from the research might help to highlight such deficiencies in care.*

*Further issues relating to my individual impact on the research process included my gender, and possibly my age. During the process of analysis in particular, it*

*occurred to me that people might have related differently to me because of my gender. For example, as a female, could I fully understand the meaning of the daily shaving ritual for a man, and how not being able to do this oneself might affect someone? Other studies, either research based or informal, appeared elusive on the subject, but at least I was able to highlight that such issues might benefit from further research. However, it seemed impossible to know the impact of these factors on the nature of the data generated, and the best I could do was to acknowledge their existence.*

*Other gender issues seemed more positive: I felt sure that the lady with continence problems might not have been so open and honest with a male interviewer, and I also felt I could understand the issues discussed in relation to clothes and image for Dorothy in the main study.*

*With regard to age, this may have had an impact on other disclosures. Being at about the same life stage as the youngest participants may have signified a common bond that perhaps might have been missing with the oldest participants. Similarly, being of white British origin myself, there were no cultural or ethnic differences in understanding that I was aware of. However, these are issues that cannot be known for sure, and it is necessary to acknowledge that a different researcher may have been offered different accounts, or made different interpretations.*

### **9.2.5 The analytical process**

*Having spent a considerable period considering the complexities of phenomenological approaches, I had been advised by one of the university professors (who witnessed my struggle and confusion) to look at the work of the*

*psychologist Professor Jonathan Smith. This led me to the approach of interpretative phenomenological analysis (IPA). At this stage (2007), although the approach of IPA was gaining in use and popularity, the first dedicated handbook was still to be produced. However, there were some useful chapters in other books, which I located and studied. I also made contact with the Scottish IPA group based at Glasgow Caledonian University (GCU), which was being run under the leadership of Professor Paul Flowers.*

*Through readings and discussions at GCU, my understanding of IPA increased, and I found myself particularly drawn to the way the approach stayed very close to participant accounts. I also found myself more comfortable with the interpretative element of the approach, rather than the more descriptive phenomenological approaches, which advocate trying to 'bracket out' researcher pre-knowledge or preconceptions.*

*Once the IPA handbook was published, my understanding developed further. However, by this stage much of my data were gathered, so decisions had already been made, and actions taken which I couldn't reverse. I questioned whether I had too many participants, whether the participants were homogenous enough, whether I had probed enough in the interviews (an inevitable question, especially when one listens to the interview tapes again), and whether I was foolish to even consider including people who had communication difficulties, and possibly couldn't therefore give the same depth of reflective account (but how could I have excluded them?).*

*I knew I had to be able to address and answer these questions, and be able to discuss how I had attempted to rise to the challenges of the research. (Hopefully, the answers to many of these dilemmas are evident in the text of this thesis).*

*Initially, thinking about the data from a theoretical/methodological perspective, the idea of using a computer package to assist with data analysis seemed very appealing at the start of the project. That was very much the way I intended to go – to get a computer to do some of the organisational work seemed like an ideal solution.*

*I also imagined that perhaps it would lead to greater credibility for the study – after all, computer packages may be considered to be objective rather than subjective. I started looking into which computer software was being used by other researchers, and talked about my plan with my supervisors. They didn't give me any guidance one way or the other, but like all good supervisors, suggested I looked at the pros and cons before making a decision. I therefore searched for articles on the matter, and quickly became aware of a body of researchers who were questioning and challenging the benefits of computer packages, for qualitative data analysis in particular.*

*Once I actually had my first patient and carer transcripts, I noticed a subtle change in my attitude. Due to the nature of the data generation process, which involved personal diaries and in-depth interviews, I was becoming quite involved in my participants' experiential stories. The idea of working on a computer to analyse these stories seemed to be losing its appeal. I felt that it would take me one step further away from the participants, who had given up their time to keep a diary and*

*talk to me during a personal interview session. Using a computer package seemed as if it would somehow depersonalise their stories, when I very much wanted to keep their experiences to the forefront. I was also aware that keeping the accounts of my participants very much to the fore would help to avoid any pre-conceived ideas taking over from what was actually in the text. However, I also knew I had to be able to justify and defend every decision I was making in the research process. I also had to engage in an empathetic but questioning manner, asking myself “what’s going on here” when listening to participants, or reading their transcripts.*

*Throughout the analysis, I felt that the decision not to use a computer package in the analysis process was the correct one. I acknowledge that decisions may be different for other research analysts, and feel the choice will often be a personal one. As discussed in the main text, Smith et al (2009) make no definite suggestion, but do advise that computer software would not necessarily be recommended for all researchers, unless this is very close to their usual way of working, or they are very experienced.*

### **9.2.6 Inclusion strategies**

*With regard to the participants with communication difficulties, I felt my speech and language colleagues were keen to give me a robust challenge! Not content with suggesting participants with mild communication problems, they encouraged me to include people with virtually no speech. However, having done so, they were then available to offer me advice with regard to how such inclusion could be facilitated, and supported me during initial periods of uncertainty; before long we were working with pictures and diagrams that could be tailored to the individual concerned. Here, the preliminary study at least allowed a trial of strategies, and for the practical*

*considerations to be worked on. For example, in my desire not to lead the 'conversation' during interviews, I found that supplying too open a forum proved a bit more difficult than anticipated. In the event, grouping topics together, and limiting the number of visual images presented at any one time, helped in this respect. I was then able to present broad topics and ask if the participant had anything they wanted to say about, for instance, how it felt to be home. I was also able to use their diary pictures to expand on things they had already identified themselves as being important. In this way, although not identical, their input was still able to be added to the other accounts, and build up a richer picture than might have been achieved if they had been excluded.*

*With further regard to the selection of participants, this proved more complex than I had initially envisaged. For example, the impact of gender, and whether or not to specify the type or severity of stroke, were not considered during the planning stage. However, the inclusion of a broader range of participants did seem to add to the overall richness of the discussion once the data had been gathered. In this respect, I became increasingly aware of the importance of building leeway and adaptability into any future research proposals: there are definitely issues that only become clear after a project has started, and too prescriptive an approach could bind a researcher in ways that might restrict innovation.*

These deliberations form only a small sample of the overall reflexive process engaged in throughout the research project, but do give examples of some of the

ideas being considered. Towards the end of the writing up phase, I also looked back on the study as a whole and made observations about what I would do differently, if I were repeating the research with the benefit of hindsight.

The points I noted were:

- *It would be interesting to have the opportunity to work with a smaller sample, to allow engagement with the data to an even greater extent. For example, to be able to look more closely at the individual choice of words used, and the way they are said, in relation to the meaning and sense-making process*
- *I would have considered homogeneity issues further with a smaller number of participants, with the awareness that there has to be a careful balance between homogeneity and achieving findings that are meaningful in a broader sense*
- *This study has enabled me to have a greater awareness of areas where further probing may be of benefit in any future interview situations*
- *Where participants are veering away from the area of immediate interest, I feel I would be better able to 'go with the flow' initially, and assess whether the direction was important to the experience, or a distraction away from the main topic*
- *With regard to participants with very limited speech, I would include pictures or diagrams that expressed an even wider selection of more complex or specific emotions for participants to choose from, and to allow further probing (e.g. turmoil, chaos, panic, delight, hope)*

- *Due to past exclusion of many participants with significant communication deficits, the opportunity and funding to carry out a study involving a greater number of such participants would not only be very valuable, but it would also seek to redress the balance*

### **9.3 Findings in relation to the wider context**

During the research process, many different studies were identified as a result of the on-going literature review. Towards the end of the analysis, the findings from these other studies were critically examined, and used for comparison with the experiences of the current study participants. As Dewar et al (2010:34) consider, to be meaningful, participant stories need to be linked to the other evidence of research, or theories, so that ‘learning and action can be facilitated’ from such information. From these considerations, a number of different ideas and gaps in potential knowledge emerged. Suggestions therefore arose for further research, and improvements in service provision, which might be beneficial. According to van Manen (1997:62) ‘we gather other people’s experiences because they allow us to become more experienced ourselves’. As already discussed, the aim of the current study was to gain further understanding, and through that, suggestions for improving practice might emerge. With regard to knowledge generated using the approach of IPA, Warwick et al (2004) conclude that IPA studies can yield information that is more useful in terms of clinical implications than, for example, a standard thematic analysis.



### **9.3.1 Linking findings to service provision**

Issues that are pertinent to service provision that arose from considering the findings in relation to other research are discussed further below, and linked back to the themes from this study, under the super-ordinate theme headings.

#### **Revisioning**

The findings demonstrated that stroke recovery can result in strong emotions being expressed (e.g. anger, sadness, frustration), especially when the participants were revisioning their new reality. Dewar et al (2010:34) acknowledge that hearing how others feel, especially if intense emotions are involved, ‘takes courage and can be a humbling experience’; however, they also consider that dialogue that ‘engages emotionally is a vital part of compassionate caring’ (Dewar et al, 2010:39). It is therefore important to be able to think creatively about encouraging positive changes in practice, and indeed research, as a result of what has been learnt in terms of the emotions that may be felt in the early days post-stroke. Understanding of anger, and opportunities to express difficult emotions, may benefit from being given greater prominence, and may help in later adjustment.

However, as noted in the findings, not all emotions expressed by the participants were negative. As noted in previous chapters, hope was displayed as evident, even in quite difficult circumstances. The complex nature of hope, and the role it plays in recovery, might benefit from greater prominence in both training programmes, and from further research.

With regard to service provision, McKeivitt et al (2004:1502) discuss the 'limited contribution' that community nurses may feel they can make to caring for patients following a stroke. Similar findings were reported by Gibbon (1994) ten years earlier, indicating that there may have been limited progress in this respect.

However, as identified earlier in the thesis, there are important contributions that community nurses can make that they may not be fully aware of themselves. Perhaps recent initiatives towards a case management approach in the community (Dept of Health, 2008; The Scottish Government, 2009b) will lead to greater community nurse involvement with stroke patients. As Hafsteinsdottir and Grydonck (1997) consider, the earlier signs of dysfunction are recognised, the earlier appropriate support can be initiated. Jopp and Schmitt (2010) also conclude that earlier support and resources can lead to fewer negative outcomes.

During both parts of the study, lack of information was identified as an aspect of the alternating focus that was part of the revisioning process. For example, the focus became less clear for participants if there was uncertainty and a lack of the necessary facts. Information provision for patients and carers therefore seems to be an on-going challenge that is mentioned throughout the literature studied; such needs require to be continually kept to the forefront, and may be of particular relevance to discharge planning. The need for re-iteration of information, especially where there may be cognitive or memory problems, might also benefit from greater consideration.

As a further part of information provision, several studies were identified that used on-line forums, either as part of the research process, or for post-discharge support and information provision. However, the accessibility, usability, and cost of IT

equipment needs to be acknowledged in areas where such use is recommended, a fact that appears to have been overlooked by the studies that mention such usage.

The losses that were experienced by participants, as part of the revisioning of their future mortality, also need further consideration. With regard to the use of models or theories (e.g. grief/loss) to explain individual experiences or reactions, caution needs to be taken to avoid the possibility of not acknowledging the individual nature of such experiences.

Future mortality was also associated with a greater awareness of age for many of the participants. This highlighted the fact that care needs to be taken not to make age related assumptions in either service provision or research; offering different services solely on the basis of age needs to be challenged as not necessarily appropriate or good practice.

Also as part of the revisioning process, the impact of conditions such as stroke on the family unit and family identity might benefit from greater acknowledgement, and may lead to the needs of carers and other family members being better understood. For example, awareness that carers may require time to themselves, even during the early days post-discharge, could improve longer term outcomes for both survivors and carers. By being able to support people during their *revisioning*, *reconnecting* and *revisiting* efforts, nurses can promote survival in its broadest sense, as advocated by Hilton (2002).

## **Reconnecting**

As identified during the discussions relating to reconnecting, role confusion can exist for patients and carers, and assumptions should not be made regarding knowledge about roles and responsibilities. The issue of differing therapy roles may become greater with the recent introduction of a common uniform for all therapists across NHS Scotland, regardless of discipline. Equally, as discussed in the previous chapter, definitions used to describe roles or conditions need to be clarified and shared (e.g. the use of the term ‘carer’; the use of terms such as ‘chronic’ or ‘long term’ condition).

With further regard to reconnecting, the capacity, desire and willingness to engage or connect with rehabilitation programmes needs to be continually evaluated, especially if self-management of long term conditions, and the achievement of greater self-actualisation are to be encouraged.

## **Revisiting**

In relation to revisiting their hospital experience, the narratives explored issues relating to the safety of patients while they were under the care of healthcare staff. Deficits in relation to safety appear to be in need of on-going emphasis in order to ensure that the protection of patients is of top priority.

The beneficial aspects of journal writing, or other forms of supported, confidential disclosure and reflection could be developed further; likewise, the value of therapeutic distractions and spiritual beliefs, in relation to the impact these can have on recovery.

## **9.4 Findings in relation to further research**

In addition to recommendations for clinical practice, the study findings and related literature highlighted further research opportunities from areas that were identified as having limited previous research. Other research considerations were also observed as a result of this current study, and the points that came to the fore will now be discussed.

### **9.4.1 Research considerations**

- The literature review detailed in chapter 2 emphasised the fact that stroke survivors with aphasia have been frequently excluded from participation in research. The need to continue to include participants with communication difficulties in research has therefore been highlighted throughout the study. The facilitation of such involvement has been considered, practical issues discussed, and suggestions have been made  
In addition to more inclusive strategies, as mentioned in chapter 4, there appears to have been a dearth of research into visual-perceptual disturbances following stroke, and the impact these may have on a range of activities (including rehabilitation and research); further studies in this area would be very beneficial.
- When the support given to stroke survivors and their carers is the subject of research and evaluation, the discussion has identified that the skills, training and expertise of people in such roles need to be detailed if studies that are assessing the impact of post-discharge support services are to be compared meaningfully; similarly, whilst examining studies from a range of countries,

the literature review concluded that the financing of healthcare provision needs to be borne in mind when comparing studies across different countries. In further relation to this is the need for research papers to give an indication of when the data for the study were collected, if the findings are to be useful in terms of service provision and assessing improvements.

- While considering the research findings in relation to the revisioning sub-theme of image and identity, it became apparent that gender difference in relation to stroke recovery is an area that has received little previous recognition. Whilst the topic has been briefly acknowledged in a few studies, further research in this area would be beneficial to inform healthcare practice.
- As recognised in the ethical discussions in chapter 4, capacity to consent in research is an area which would benefit from greater consideration, with boundaries regarding inclusion being potentially expanded to incorporate groups of people who have been previously largely excluded. With further regard to ethics, the term ‘anonymity’ rather than ‘confidentiality’ may be more appropriate in relation to what is offered to study participants, especially where quotes are used verbatim, and such terminology should be encouraged as a more accurate means of explaining what is being offered to research participants.
- In the findings from both parts of the study, the impact of services or equipment on the home environment, families, and in relation to privacy, was highlighted by participants. This is an area where greater understanding might be achieved through further research.
- The poem created by the analyst from the words of one study participant, and detailed in Appendix 14, displays that poetic forms of data representation can

have an impact value that other forms of research writing may not achieve, and such compositions may reach different audiences. However, whilst such alternative forms of depicting data may not be acceptable to all journals, they still have a role to play in dissemination.

- From the findings of this study, and the broader literature, knowledge regarding the impact of incontinence on self or body-image could be expanded upon through additional research.
- The analysis has shown that the use of mind maps as tools to explain and explore interpretations during, and from, research findings may benefit from further evaluation and study; certainly in this current study, mind mapping enabled the findings to be drawn together in a visual format that promotes an additional understanding of how the findings are linked and connected. Likewise using several different models in relation to research findings can help to expand on possibilities within the analysis and demonstrate how the findings compare or contrast with existing disciplinary ideas and reasoning.

In addition to the above observations and suggestions for further research and improvements in clinical practice that resulted from the study, thought was continually given to how awareness of the findings might become more widely recognised. The importance of dissemination will be considered next.

## **9.5 Dissemination**

By using the phenomenological approach of IPA, this study has sought to make previously unheard and possibly poorly understood experiences clearer and more accessible. It has brought together a perception of how stroke survivors and their carers experience and make sense of the aftermath and aftershock of stroke, particularly in the early days following discharge from hospital. When situated in relation to other research, models, and theories, this has enabled areas where health care professionals can support and assist to become more distinct. However, if thought is not given to how such findings can be more widely known, then research efforts may be wasted (Robson, 2002; Barbour, 2008). Throughout the research process, dissemination was therefore achieved through oral and poster presentations at both local and national level. Details of these presentations are given in Appendix 16. Publication in a variety of journals has already been accomplished, and future submissions are planned. Publications already in print are detailed in Appendix 17.

The opportunity to expand on the study findings through further research is currently being investigated, and it is hoped that this thesis will be accessed by other researchers who wish to carry out associated studies. Shorter reports are currently being written in a variety of different formats, using both research and lay terminology, to allow the findings to be read by as wide an audience as possible, and to give feedback to main study participants. Additional opportunities to disseminate findings are also being sought.



## **9.6 Limitations of the study**

Although some issues relating to limitations have already been discussed, as with other studies, it is necessary to give an overview of limitations in order to fully situate the contribution that the findings make in relation to the wider body of research knowledge. For example, it is acknowledged that the experiences of those too ill or frail to be included in either part of the study have not been heard. In particular, those with marked cognitive deficits were not included. The guidance and assessment of the hospital team with regard to ability to take part was appreciated and accepted in this respect. Suggestions with regard to assessing cognitive ability and capacity to both consent and engage in research have been discussed in chapter 4, however.

As has been mentioned previously, the small idiographic nature of both parts of the study could be viewed as a limitation and, indeed, although findings are discussed in relation to a wide range of other research, broad generalisations stemming from the particular findings have been avoided. Equally, however, there are issues with potential loss of more subtle analysis if sample sizes are too large (Brocki and Wearden, 2006). As Greenwood et al (2009) argue, larger studies may also be more likely to have researcher-led agendas. A balance was therefore struck within this study that allowed for a range of participation, both in terms of ability to contribute, and richness of account from within the participant numbers.

That said, as discussed in chapters 4 and 5, within the study sample participants with a broad range of ability and disability were included, thereby making the findings potentially relevant to an equally diverse number of other situations. In addition to this, the inclusion of people with very limited verbal ability should be viewed as a

strength of the study. Rather than limiting participation in terms of the effects of their stroke, therefore, the study has sought to be more inclusive than previous stroke research.

The diverse nature of the physical effects of the stroke on the survivors has been acknowledged earlier in the thesis as a potential factor for consideration with regard to homogeneity. However, the shared issues of timing, and the impact of the stroke diagnosis, are acknowledged as being common to all participants; as has been discussed, severity of impairment is not necessarily related to experiences following a stroke, and therefore the range of disability within the participant group should not necessarily be viewed as a limitation, but rather as a strength in relation to their shared meaning-making, and how such sense-making is accomplished.

Likewise, a range of ability within the stroke survivors also dictated that their length of hospital stay might differ considerably. However, whilst this is an acknowledged variable, it was the transition to home that was the focus of the study, rather than the hospital stay.

With regard to gender, although Grewal and Ritchie (2006) consider it important that the interviewer and participants are matched in terms of such issues as gender, age and ethnicity, how often this is achievable is debatable; such a view has also not been supported by other research (e.g. Graham et al, 2007). Although issues of gender, age and ethnicity have been discussed within the current research, as has also been considered, rapport and empathy are vital components of successful research, which may overcome any disparity with regard to these other differences between participants and researcher.

Issues relating to geographical situation were referred to in the preliminary study, and in the main study one participant in a more remote and rural location was included. However, it was not the role of this study to compare and contrast experiences in relation to geographical location. Although there was an incident mentioned by one participant that did relate to living in a more isolated place, the issue that emerged from this was more to do with feeling supported, than to do with location. Similarly, it has been out-with the scope of the study to examine the experiences of people that may have been discharged to other locations, such as care homes.

With further regard to the limitations imposed by language and culture, this may be viewed as a restriction. In the literature review, for example, research studies not written in the English language were excluded. The difficulty of comparing results across geographical areas and countries has also been acknowledged. As Van der Zalm and Bergum (2000:216) conclude, if language and cultural practices are not shared, nurses 'may not fully grasp the meaning of the lived experience of others'. In this respect, it is important that these issues are highlighted, so that any potential differences can be examined, rather than being ignored.

As discussed in the findings with regard to the participants' ethnic and cultural backgrounds, all the study participants came from similar white British backgrounds, which reflected the predominant geographical population. People from a range of economic and occupation backgrounds were included, however, and there were occasional incidences within the accounts where this was referred to; it needs to be

acknowledged that findings from a different group of participants might have yielded different narratives, and thereby different findings.

As previously noted, patients and carers were not contacted again by the researcher to discuss the findings; it was considered that participants may have moved forward, both in terms of recovery, and in relation their memory of past events. These factors may have had an effect on any subsequent input, and could potentially have altered the analysis in way that was not true to their original experience. It is recognised that not going back to participants does lessen their impact as co-constructors of the research. However, the fact that three participants died during the course of the analytical process, and others were admitted to hospital, does make the decision not to go back to participants seem a reasonable decision in the circumstances. All participants (or their family) will receive a brief study report and a note of appreciation for their input.

## **9.7 Summary**

This study has added to the pool of stroke recovery knowledge in several important areas. Firstly, the immediate discharge experiences of stroke survivors and their carers have been accessed through the use of diaries and interviews, adding a depth of information not previously available. Inclusive strategies in terms of supporting people with a broad range of disability, including those with severe aphasia, have been achieved. Suggestions to support other studies adopt these methods have also

been made. As noted above, such additional knowledge is valuable in assisting and directing clinical practice, as well as identifying further research opportunities

From the findings, the first month at home was found to be a very dynamic time for both the patients and carers who took part in the project. In the preliminary study analysis, participants were detailing a process of *fathoming out* their new situation, including how to manage new physical limitations and emotional reactions. Making comparisons with others helped in this process. While participants were working on *adapting to stroke*, they were also trying to manage new situations for the first time, including getting the balance of caring right. Maintaining hope and an appreciation of the small things in life became more important at this time. Throughout this process, *the value of support* and being listened to (and understood) by those around them was very much appreciated, especially where a new reliance existed.

In the main study, findings from the preliminary study were used to inform and support a more interpretative analysis. Here, the super-ordinate themes of *revisoning*, *reconnecting* and *revisiting* expanded on the meanings developed in the initial study. Participants were in the process of revisoning their identity, either as a stroke survivor or a carer. They were looking at a new and different reality, which brought certain things into sharper focus, and made others less certain. Included in this was a clearer knowledge of their own mortality, although hope was again evident and important in this process too.

Reconnecting with important relationships, and with as much of their past lives as possible, was an integral aspect of the adjustment process; both patients and carers were keen to regain a sense of choice and control, and for stroke survivors this included moving away from the sick role and regaining a sense of independence.

During this time, participants were also revisiting the past, and in particular the stroke event and hospital experience. This seemed to help situate the whole narrative, and to help make sense of the place they were in at the time of the interview.

Knowledge of these themes can be used to offer support in terms of the revisioning of an acceptable future life, to encourage the reconnections that may enhance this, and to facilitate opportunities for revisiting the past, and the stroke event, in order to make progress and move forward.

In addition to the interviews, participant diaries also helped to provide a more immediate account of experiences during that first month. In the main study, information in the diaries helped to act as a prompt for the interviews, and to provide some detail that might not have been accessible otherwise.

Issues of rigour were met by providing sufficient detail of the methodological decision making process; participant quotes have been used liberally to illustrate themes, and a reflexive account also given to expand upon the detail of the decision trail.

The inclusion of several participants with significant communication problems proved both a challenge and a valuable experience. As well as participants with various degrees of dysarthria or word-finding difficulty, three stroke survivors who had virtually no speech had the opportunity to take part, assisted by pictures and gestures. Their enthusiasm and willingness to co-construct a narrative with the support of the interviewer was particularly appreciated, and undoubtedly added to the richness of the study. As has been noted, opportunities to include participants with such restrictions have not been offered in other stroke research.

With a final consideration regarding the current emphasis on community care, the transitions that Parkes (1971) discusses are now taking place to a greater extent in the home setting. Parkes (1971) argues that such psychosocial transitions have the possibility of being transformed from major events to more minor, and easier to cope with changes, with advance planning and preparatory training. It is evident from the narratives given here, that there is much that health professionals can do to assist with this transformation.

In this study, the approach of interpretative phenomenological analysis has facilitated an exploration of the experiences of stroke survivors and their carers during their personal psychosocial transition, in a way that has been rewarding and illuminating. The study findings are offered as a means to increase understanding and support for those in similar situations in the future.

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# Appendix 1

## Diary guidance notes

### **A study to investigate the experience of returning home for stroke survivors and their carers**

#### **Participant Diaries**

#### **Instructions for use:**

The purpose of this study is to find out about your thoughts, feelings and emotions as you (your relative/friend) return home, and over the 3-4 weeks afterwards.

Please write as much or as little as you feel able to.

Please date every entry you make.

You may stop keeping the diary at any time. Your usual care will not be changed if you stop.

Your entries into the diary will be treated as confidential, and any information that might identify you will be removed or altered when the study is written up.

You may change your mind about giving the diary back to the researcher, or a copy could be taken and you could keep the original.

Thank you very much for considering taking part.

(Font size 14 used in original)



## Appendix 2

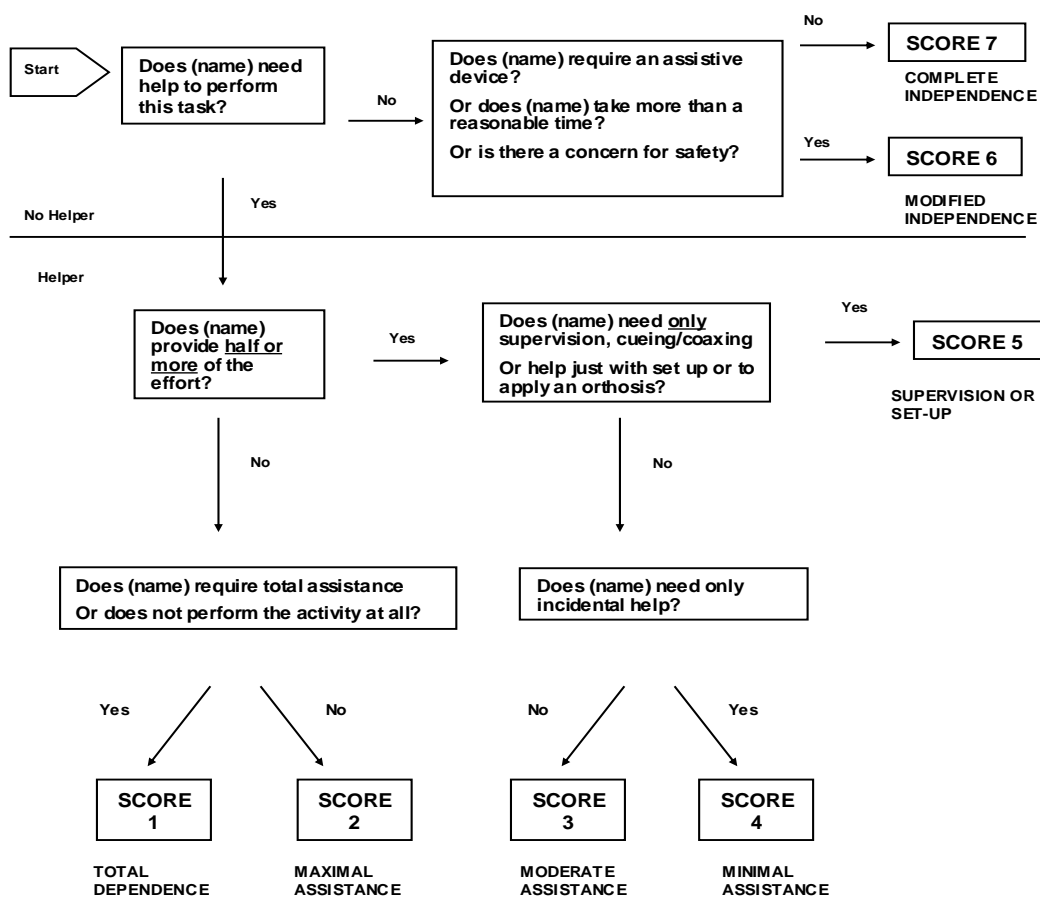
# Functional Independence Measure/ Functional Assessment Measure (FIM+FAM) general descriptor decision tree

### 1. GENERAL DESCRIPTION OF ITEMS

4

Item includes: Various components included in the task	At level 7, the subject : Description of complete independence
---	---

**Start at the top left hand corner  
Follow the tree down**



<b>NOTES</b>	
Level 7 : Complete independence: Performs independently and safely	
Level 6 : Modified independence: Requires an assistive device, or there is consideration for time / safety	
Level 5 : Supervision or set-up: Requires only curing or coaxing but no physical contact - or help just with set-up	
Level 4 : Minimal assistance: Requires incidental help but performs more than 75% of the task themselves	
Level 3 : Requires moderate assistance: but still performs more than half the task themselves	
Level 2 : Maximal assistance: provides less than half of the effort to complete the task	
Level 1 : Requires total assistance - contributes less than 25% of the effort. Or does not perform the activity at all.	

(Turner-Stokes, 1999)

## Appendix 3

### Participant Information Sheet

(Printed on headed notepaper)

#### **A study to investigate the experience of returning home for stroke survivors and their carers**

You are invited to take part in a research project that I am undertaking as part of my PhD studies at the University of Dundee. The study will investigate the experiences of stroke survivors (and their carers) after their return home from hospital.

Before you decide whether you wish to take part, I need to be sure that you understand why I am doing the project, and what would be involved if you agree to take part.

I am therefore providing you with the following information. Please read it carefully and ask any questions you might have. You may also want to discuss it with your family and friends. I will do my best to explain the project to you and provide you with any information you may ask, now or later.

#### **Background to the project**

The project is about finding out more about stroke survivors' and their carers' experiences in the first few weeks after they return home. If more is known about these experiences, then staff may feel better able to support people during the time of their return home.

The study will involve 8-12 stroke survivors and their carers. The ward consultant has agreed that you can be approached about taking part. If you agree to take part, and with your permission, your GP will also be informed that you are doing so.

(continued)

### **Why have I been chosen?**

You have been chosen because you have had a stroke and are now going home. This study is interested in finding out about your experience of returning home.

### **What does the project involve?**

Everyone who agrees to take part in the study will be interviewed at home within 3-4 weeks of returning home. To help the researcher keep a record of what you say, this interview will be tape recorded. The researcher may also take notes during the interview. You and your carer will be interviewed separately. The interview will take approximately 1-2 hours.

People who take part in the study will also be asked to keep a diary of their experiences. This diary will be given to you before you leave hospital, and you will be free to write as much or as little as you feel able.

For either the interview or the diary, help will be available if you have difficulty talking or writing. If either of these situations applies to you, an extra information sheet on what help is available will be given to you.

### **What are the discomforts or risks?**

It is unlikely that taking part in the study would cause you any discomfort or harm, however you may find that writing or talking about your experience makes you feel upset. If this happens, you will be free to stop at any time.

Some people find that having the chance to talk about their experience and be listened to is helpful.

If you have a concern about any aspect of this study, you should ask to speak to the researcher, who will do her best to answer your questions (see contact details below). If you remain unhappy and wish to complain formally, you can do this through the NHS Complaints Procedure. Details can be obtained from the hospital.

(continued)

### **What will happen to the information you collect about me?**

The information you give to me will be treated in the strictest confidence. The diary you keep and the interview tape will be given a number and will not refer to you by name. The number will be stored securely on my computer in a file protected by a password. When the research is written up, any information that may connect you with quotes will be changed or removed.

You may be contacted by me after the interview to check that I have understood correctly what you have told me.

You will also be sent a copy of the study report once it is completed.

At the end of the research, all audio tapes will be destroyed. All other paperwork will be stored securely and destroyed after 5 years. The Tayside Committee on Medical Research Ethics, which has responsibility for overseeing all proposals for medical research on humans, has examined this study and raised no objections from the point of view of medical ethics.

### **What are my rights?**

You do not have to take part in this study, and even if you do, you are free to stop at any time without having to give me an explanation.

If you decide not to take part, or to stop, this will have no effect on the treatment you receive now or in the future, or your relationship with the staff who look after you.

If you have any questions or you wish to obtain further information about this study, you may contact [name and contact details of ward consultant].

Jan Pringle

Beehive Room, Cameron Hospital

Windygates, Fife KY8 5RR Tel: 01592 719 292

**Thank you for reading this Information Sheet and considering taking part**

(original in font size 14 – additional information sheet overleaf)

## **A study to investigate the experience of returning home for stroke survivors and their carers**

### Additional information

#### **Information Sheet for participants with writing or talking difficulties**

If you have difficulty talking or writing, we are still keen to understand your experiences.

If you have difficulty writing, and you still wish to take part, you will be offered a tape recorder instead of a diary to record your experiences.

If you have difficulty talking, and you still wish to take part, at the interview stage you will be offered the help of visual aids by the researcher. If necessary, your responses using the visual aids will be photographed by the researcher.

If you have difficulty with both talking and writing, you will be offered visual aids for both the diary keeping and the interview.

If any photographs are taken, they will not include you, or identify you. They will be destroyed at the end of the research.

(original in font size 14)

## Appendix 4

### Ethical approval letter (preliminary study)



Fife



Forth Valley



Tayside

#### *Fife, Forth Valley & Tayside Research Ethics Service*

Tayside Committee on Medical Research Ethics B  
Research Ethics Office  
Level 9  
Ninewells Hospital & Medical School  
DUNDEE  
DD1 9SY

Mrs Jan Pringle  
Lead Stroke Nurse  
CHSS/NHS Fife  
Beehive Room  
Cameron Hospital  
Fife  
KY8 5RR

Date: 6 August 2007  
Your Ref:  
Our Ref: LR/07/S1402/53  
Enquiries to: Mrs Lorraine Reilly  
Extension: Ninewells extension 40099  
Direct Line: 01382 740099  
Email: Lorraine.reilly@nhs.net

Dear Mrs Pringle

**Full title of study:** A study to explore the experiences of stroke survivors and their carers as they make their transition back home  
**REC reference number:** 07/S1402/53

Thank you for your letter of 25 July 2007, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Medical/Scientific Adviser and Co-ordinator.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

#### **Conditions of approval**

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Application		29 June 2007
Investigator CV		20 June 2007
Investigator CV		27 June 2007
Protocol	1.1	20 June 2007
Covering Letter		28 June 2007
Letter from Sponsor		28 June 2007



## Appendix5

### Letter to participant's GP

**A study to investigate the experience of returning home for stroke survivors and their carers**

Dr [name and address of participant's GP]

Dear Dr [name of GP]

Your patient [name of participant] has agreed to take part in our research study investigating the experiences of stroke survivors and their carers after they return home from hospital.

The study involves taking part in an interview at home 3-4 weeks after discharge from hospital. The interview will last approximately 1-2 hrs. Participants will also be asked to complete a self-report diary of their experiences for up to 28 days.

If you have any concerns about this patient participating in this research, could you please contact me to let me know.

Yours sincerely

Jan Pringle

The Beehive Room

Cameron Hospital

Windygates, Fife KY8 5RR

01592 719292    J.Pringle@dundee.ac.uk

**Appendix 6**  
**Participant consent form**

Centre Number:    Study Number:    Patient Identification Number for this trial:

**Title of Project: The experience of returning home for stroke survivors and their carers**

Name of Researcher: Jan Pringle

Please initial box

1 I confirm that I have read and understood the information sheet dated [date and version number] for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without any medical care or legal rights being affected.

3 I understand that relevant sections of my medical notes and data collected during the study may be looked at by co-researchers from the University of Dundee, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

4 I agree to being tape-recorded during the interview stage of this study. Audio tapes will be destroyed after use in this research.

(continued)



4 I agree to my GP being informed of my participation in the study.

6 I agree that if I complete a picture expression mat [for people with communication difficulties] it may be photographed.

7 I agree to take part in the above study.

\_\_\_\_\_  
\_\_\_\_\_

Name of participant

\_\_\_\_\_

Date

Signature

\_\_\_\_\_  
\_\_\_\_\_

Name of person taking consent

\_\_\_\_\_

Date

Signature

When complete, 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes

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## Appendix 7

### Guidance sheet: hospital staff

#### **A study to investigate the experience of returning home for stroke survivors and their carers**

Recruitment of study participants:

Information sheet for clinical staff

This study will investigate the experiences of stroke survivors and their carers during the first 4 weeks after their return home.

Participants will be asked to take part in a tape-recorded depth interview lasting approximately 1-2 hours, 3-4 weeks after getting home.

Participants will also be asked to complete a self-report diary, which will be given to them prior to them leaving the ward.

Participants with speech or writing difficulties will be included, and be given additional help, if they wish to participate in the study.

Inclusion criteria:

Over 18

Confirmed diagnosis of stroke

Discharge to home environment planned

Willing to take part in tape recorded interview at home

Medically fit to participate

(continued)

Your assistance in identifying suitable participants would be appreciated. If any of your patients fit the above criteria and are interested in learning more about the study with a view to taking part, please let me know.

If you have any further questions, please do not hesitate to contact me.

Jan Pringle, Beehive Room, Cameron Hospital. Fife KY8 5RR

Tel 01592 719 292. [J.Pringle@dundee.ac.uk](mailto:J.Pringle@dundee.ac.uk)

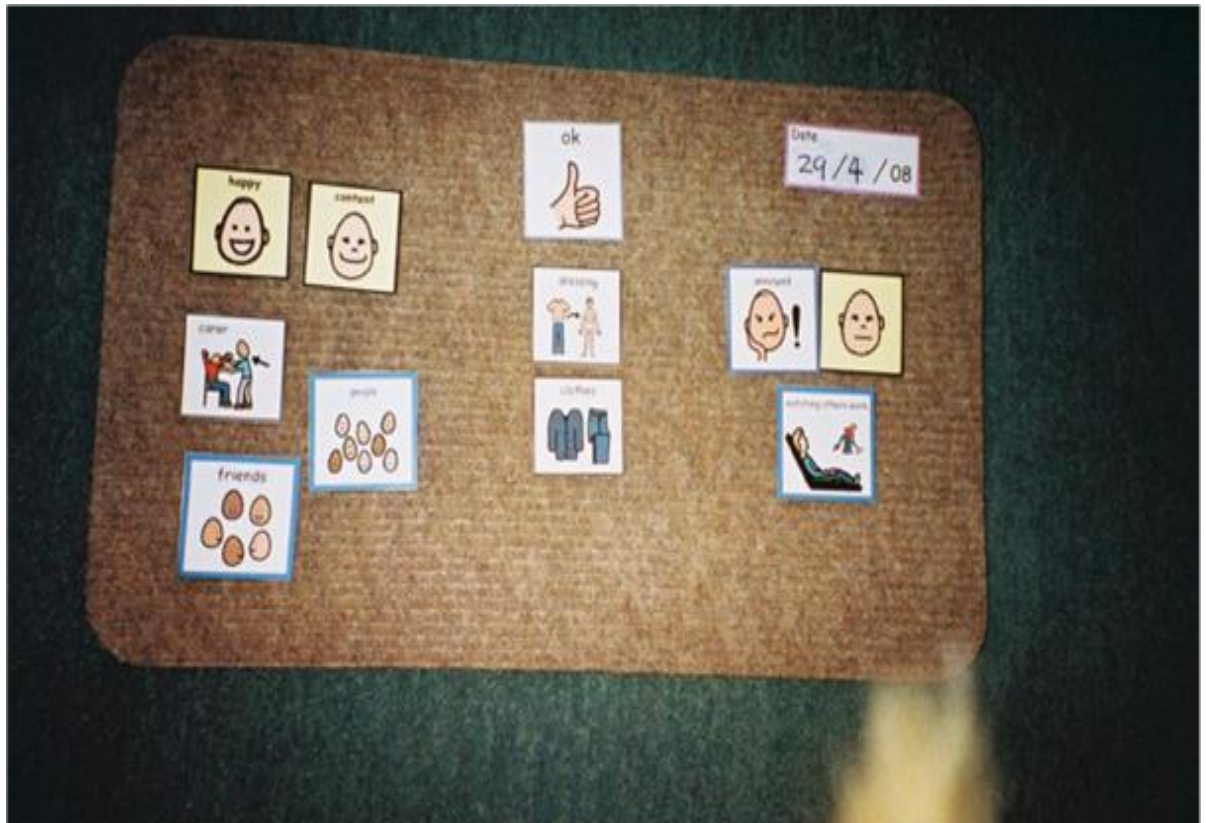
## Appendix 8

### Transcription format

- Anonymity has been protected by the removal of any identifying information from the transcripts
- Square brackets have been inserted into the extracts to indicate the type of information that had been removed: [e.g. a name or place]. Any explanatory notes that were necessary have also been put in square brackets
- Where appropriate, if a participant's name is used in a quote, then this has been replaced by their study pseudonym
- Dialogue is noted in italics, with pseudonyms used within quotes, or explanatory notes, being indicated by normal font
- Dots are used to indicate thoughtful pauses or hesitation: '...', with a greater number of dots being related to a longer pause (although this was not measured precisely)
- Natural gaps between words are indicated by commas or, for slightly more deliberate gaps, dashes: ' - '
- Notes on any emotions being expressed (e.g. tears, sighs etc) during each interview are placed in brackets
- 'Fillers', such as 'err' and 'umm', which can indicate uncertainty about what participants are trying to say, have been included, if considered relevant
- Any particular emphases that were placed on words by the participants are underlined
- Any words that were said loudly or shouted are written in CAPITALS
  - 'I' has been used to indicate that the words are those of the interviewer

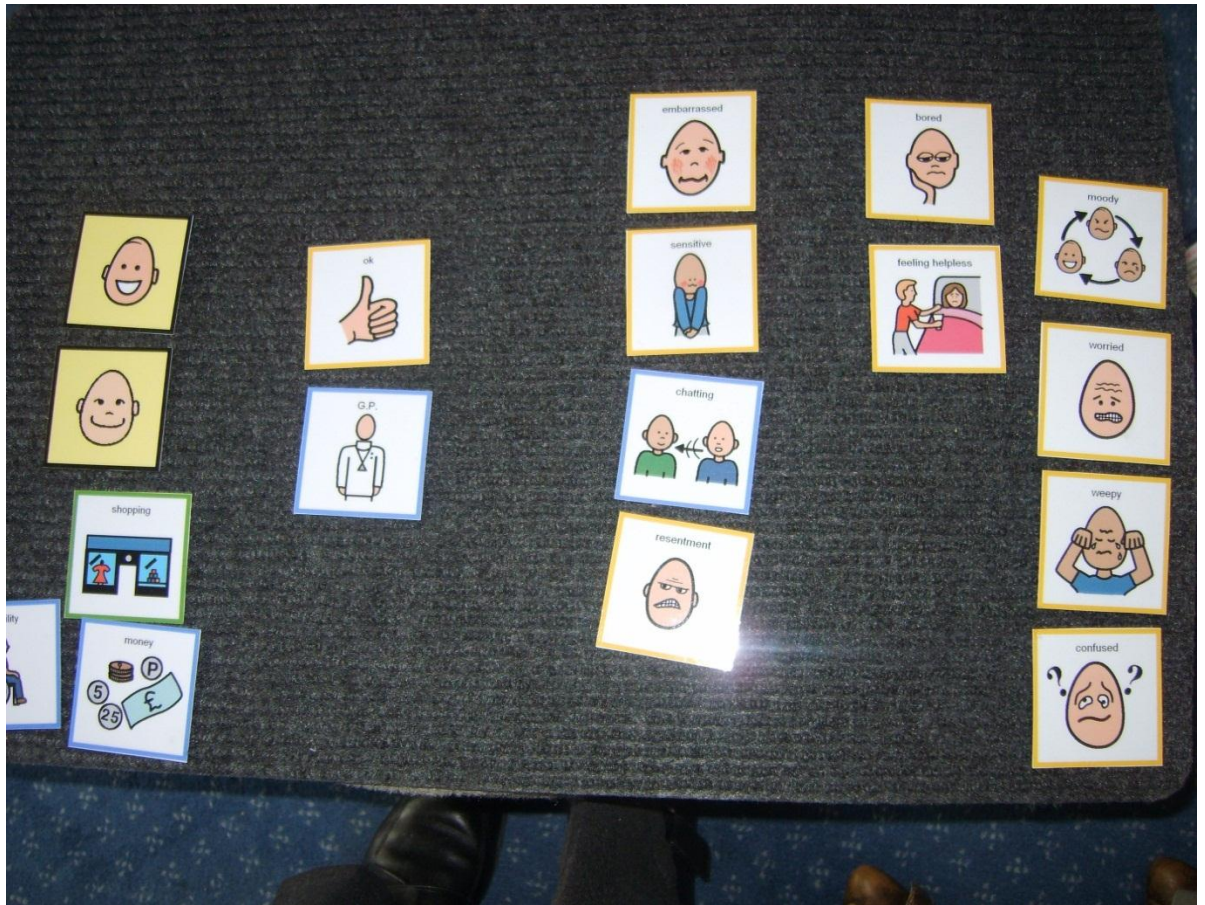
## Appendix 9

### Examples of expression mats



In this mat, Bert (preliminary study participant) is expressing his pleasure at being home, receiving care from his wife, and seeing his family and friends. Getting help with dressing is noted as 'ok', but he is annoyed to have to watch others working, when he is restricted himself

(continued)



In this example, the participant (Morris, main study) is conveying his pleasure at being able to get out to the shops, and having greater control of his finances again; he is pleased that his GP has made contact and visited him at home. He also conveys his emotions about his speech, and that he often feels bored and helpless now, having previously been a very active man. He signifies his mood swings, with the worries, confusions, and weepiness also mentioned

## Appendix 10

### Summary report: preliminary study

#### A study to investigate the experience of returning home for stroke survivors and their carers

##### Short report

**Aim:** The aim of this study was to explore and gain a greater understanding of the experience of returning home for stroke survivors and their carers.

**Timing:** Data collection for this preliminary study took place between October 2007 and April 2008.

**Participants:** A purposeful sample of 4 stroke survivors and their carers took part in the study (8 participants in total). Two of the stroke survivors had communication difficulties (aphasia), one of whom required the assistance of picture expression mats to participate in the study. These mats were photographed for the purpose of analysis.

All participants, apart from one carer, were retired and over 65yrs of age.

**Location:** East Scotland; 2 of the survivors were discharged from an acute stroke unit, and 2 from a slower stream stroke rehabilitation unit.

(continued)

**Ethics:** Approval for the study was granted by the area Research and Ethics committee, and

the relevant NHS Research and Development Department. Survivors were given an information sheet and signed a consent form prior to participating. They were informed of their right to withdraw from the study at any stage without it affecting their usual care.

**Method:** Participants agreed to take part in a tape recorded in-depth interview approximately 4 weeks after discharge from hospital, and were also asked to complete a self-report diary of their experience from the day of discharge.

Participants were asked to describe the experience of returning home; both interviews and diaries were unstructured, allowing for maximum freedom of expression. Interviews and diaries were transcribed 'verbatim' (word for word), and analysed using interpretative phenomenological analysis (IPA), which is a research approach that identifies common themes from participant's accounts.

All 8 participants took part in the interview (one with the assistance of expression mats, where pictures representing what the participant wanted to say were selected by the participant and placed on a mat). Interviews lasted approximately 35-75 minutes, and were conducted in participant's homes. 6 participants completed a diary (one using expression mats).

**Analysis and findings:** Transcripts of interviews and diaries were studied to identify common themes, according to the approach of IPA.

Three master themes and ten sub-themes were identified, as detailed in the figure below:

(continued)



Master themes	Sub-themes	Summary of details
<ul style="list-style-type: none"> <li>Fathoming out</li> </ul>	<ul style="list-style-type: none"> <li>Physical limitations</li> <li>Making comparisons</li> <li>Emotional changes</li> </ul>	<ul style="list-style-type: none"> <li>Discovering the things that could no longer be done, or done in the same way</li> <li>With old self, previous stroke, others, physical environment</li> <li>Fathoming out emotions &amp; reactions to the new situation</li> </ul>
<ul style="list-style-type: none"> <li>Adapting to stroke</li> </ul>	<ul style="list-style-type: none"> <li>Managing firsts</li> <li>Balance of caring</li> <li>Back to basics</li> <li>Hope</li> </ul>	<ul style="list-style-type: none"> <li>Coping strategies, settling back</li> <li>Giving the 'right' help, changing roles</li> <li>Small things having a big impact</li> <li>Making progress; determination to improve</li> </ul>
<ul style="list-style-type: none"> <li>Value of support</li> </ul>	<ul style="list-style-type: none"> <li>It's good to talk</li> <li>Importance of understanding</li> <li>Reliance on others</li> </ul>	<ul style="list-style-type: none"> <li>Value of talking and being listened to</li> <li>Gaining information to meet needs, feeling others understand</li> <li>Accepting help; being a 'good' patient</li> </ul>

Figure 1: Summary of findings

As can be seen from the above figure, for these participants returning home involved the processes of **'fathoming out'** and questioning the new situation they found themselves in, whether they were a survivor or a carer. The impact of physical limitations seemed to become real for the participants now they were home. Comparing their new situation to either their previous ability/situation, or with others, also seemed to be an important aspect of trying to fathom out where they were now, either as a survivor or carer. This process also involved a wide variety of emotional responses.

(continued)

The second theme of ‘**adapting to stroke**’ and its consequences related to the progress participants made in their adjustment to their new situation. Participants talked about how they approached tasks for the first time and how they adapted to either being a carer, or being cared for by others. Small things could cause greater difficulties, but small things also resulted in pleasure and hope.

The ‘**value of support**’ was also a theme that emerged across participant’s stories. Talking and being listened to and understood came across as important to participants. Reliance on the support of other was also viewed as a benefit, a necessity, and sometimes with frustration.

Due to the inclusion of participants with communication problems, some suggestions about facilitating such participation were able to be made.

**Conclusions:** This preliminary study has allowed analysis of information about how participants experienced returning home following either their own stroke or that of the person they were caring for. Although only involving a small number of participants, it has increased understanding into such experiences. It has allowed the research processes and approach to be tested and considered ahead of a similar, more in-depth main study.

This report contains brief details of the study and findings. For further information, please feel free to contact Jan Pringle, the Beehive Room, Cameron Hospital, Fife, KY8 5RR; tel 01592 719 292; email [J.Pringle@dundee.ac.uk](mailto:J.Pringle@dundee.ac.uk).

**Research Team:** Jan Pringle, PhD student, University of Dundee; Dr Charles Hendry, Senior Lecturer, University of Dundee; Dr Ella McLafferty, Senior Lecturer, University of Dundee

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## Appendix 11

### Ethical approval letter (main study)



Fife



Forth Valley



Tayside

#### *Fife, Forth Valley & Tayside Research Ethics Service*

Tayside Committee on Medical Research Ethics B  
Research Ethics Office  
Level 9  
Ninewells Hospital & Medical School  
DUNDEE  
DD1 9SY

Mrs Jan Pringle  
Lead Stroke Nurse  
CHSS/NHS Fife  
Beehive Room  
Cameron Hospital  
Fife  
KY8 5RR

Date: 21 October 2008  
Your Ref:  
Our Ref: LR/08/S1402/50  
Enquiries to: Mrs Lorraine Reilly  
Extension: Ninewells extension 40099  
Direct Line: 01382 740099  
Email: Lorraine.reilly@nhs.net

Dear Mrs Pringle

**Full title of study:** A study to explore the experiences of stroke survivors and their carers as they make their transition back home  
**REC reference number:** 08/S1402/50

Thank you for your letter of 04 October 2008, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Scientific Officer and Co-ordinator.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

A copy of the sponsor letter and insurance/indemnity policy being received.

**Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.**

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

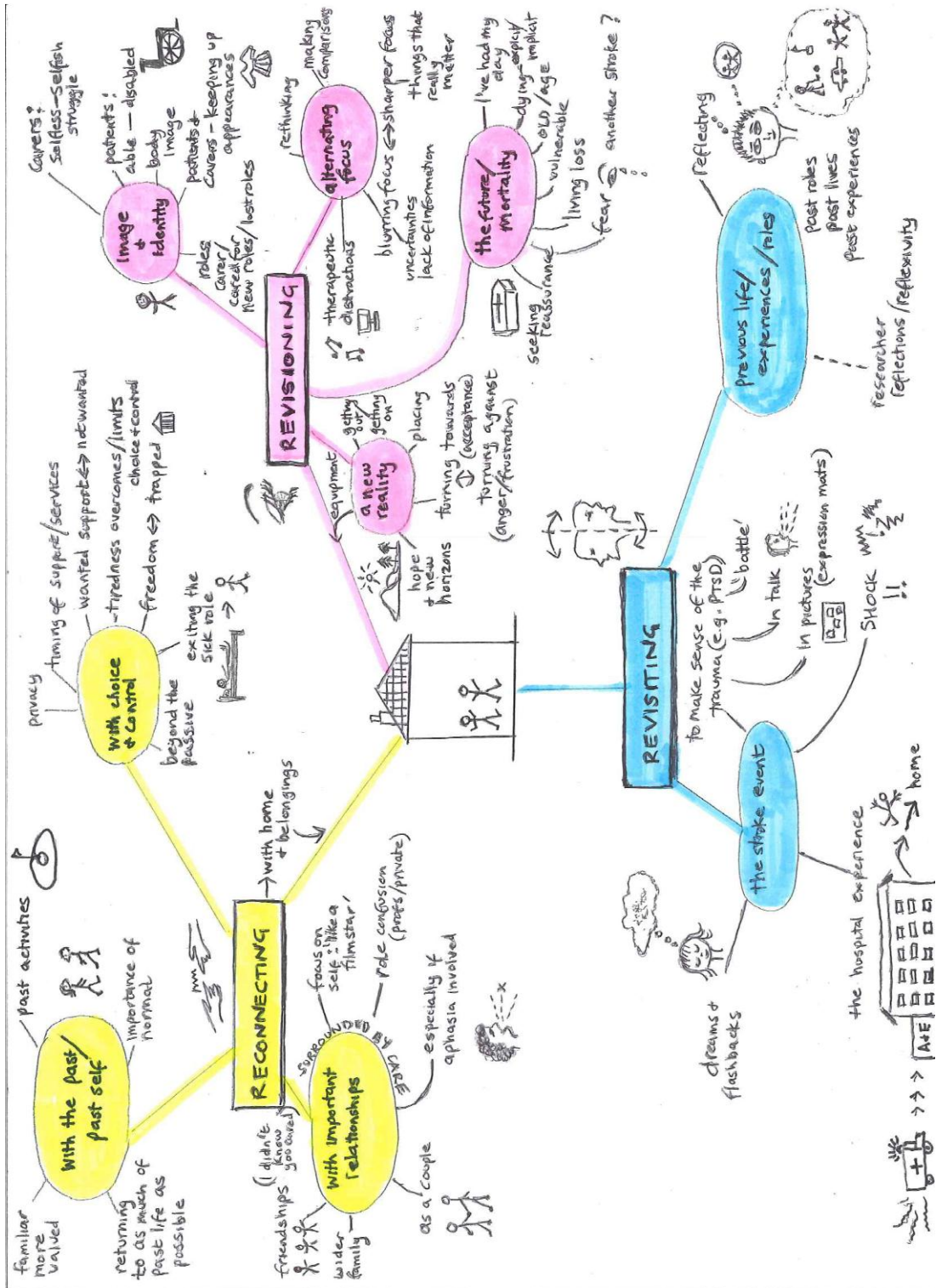
#### **Ethical review of research sites**

The favourable opinion applies to the research sites listed on the attached form.



# Appendix 12

## Mind map: main study analysis



## Appendix 13

### Worked example of transcript analysis

Initial comments	Interview transcript	Potential theme ideas
<p>Sounding quite guarded – is she worried about admitting exactly how she feels?</p> <p>Strongly emphasising by repeated use of word ‘very’</p> <p>Still guarded Doubting own ability</p> <p>Reluctance to open up?</p>	<p><i>I: As I said, thank you very much for agreeing to take part – this is a study that I’m doing at the university and it’s just to hear a bit more about your experiences as your husband came home following his stroke</i></p> <p><i>Angela: After his stroke..</i></p> <p><i>I: Yes, so from after he came home - if you could just talk to me a little bit about how you found that experience that would be good</i></p> <p><i>Angela: Exactly how I felt? What do you mean, the extra work I had to do or how I coped with it?</i></p> <p><i>I: Yes anything, anything like that</i></p> <p><i>Angela: It was very, very, very busy – a very busy time – mainly because we got lots of visitors and eh.. I just didn’t seem to have time to do anything in the house, I could – I found it difficult to find time to shop, it was a lot of extra work and I’m not so young either so it was very difficult. It still is because we’re having a house full of visitors at the weekend and that’s why I’m so keen to get rid of you, really, because I’ve got so much to do I don’t know where to begin, you know, with having people to stay – relatives to stay at the weekend</i></p> <p><i>I: Yes</i></p> <p><i>Angela: So apart from – I mean I don’t know what else you want to know. Is it all about me at the moment, aha?</i></p> <p><i>I: It is, yes, and just how you’ve been feeling</i></p>	<p style="text-align: center;">Burden of New role/new responsibilities</p>

Time apart	<p>Angela: <i>Well, I was very happy to have him home in the first place, you know, it was a long time he was in hospital – four and a half weeks and I was very pleased to have him home, but he’s able to do more for himself now which is a great help, but that’s almost three weeks</i></p>	Re-establishing links with husband and friends
Making progress	<p><i>I: Right, yes</i></p> <p>Angela: <i>I think it’s three weeks, or is it four, come Thursday? I’m not sure, but he’s able to do a little more for himself and he’s able to go out walking on his own now aha just – he has a short walk every day, so that’s a help too</i></p>	Re-establishing independence
Support and contact with friends versus burden of extra work	<p><i>I: So it was very busy, you’ve said, for you</i></p> <p>Angela: <i>Oh yes, terrible – all the phone calls, you know - I couldn’t get anything done for people phoning or people popping in to see him – it’s lovely to have such a concern, you know – we’ve got a lot of friends and a lot of relatives so it was lovely that we have them, and we always made them very welcome, but at the same time I was pushed for time</i></p>	Getting out/getting on
Tiredness – overwhelming	<p><i>I: Right, and how did that make you feel then?</i></p> <p>Angela: <i>Exhausted – physically and mentally exhausted. I still am actually, but.. eh.. that’s just something I have to cope with. I did phone to enquire about getting a carer in, you know a carer to help you know, but we don’t – we don’t – because we’re reasonably well off we don’t, we’re not allowed anyone you know. Any help I would get in the house we would have to pay for ourselves, but that’s okay, I’ve decided to just struggle on for a few months and see how I get on, because I don’t really</i></p>	Alternating view of situation
Intrusion?	<p><i>I: No, no... so you feel you’re struggling on</i></p>	Tiredness overcomes
		Choices Taking control
		Independence versus help

<p>Image of self as someone who copes?</p> <p>house/personal standards</p>	<p>Angela: (Laughs) <i>yes! But I'm managing fine – I just get up an hour earlier in the morning and things like that, but ..eh.. it's only when we're having extra – I'm quite happy to live in filth, you know, but when you're having visitors you like your house nice and people to stay, so once this weekend's over it might quieten down this weekend ...although I've got others booked to come and stay (laughs) – it's just because we have quite a lot of relatives, I suppose</i></p> <p><i>I: So you were saying you've...</i></p> <p><i>Angela: So I didn't have time to do any of – I just – when I had the time I was too exhausted physically and mentally, so I didn't bother doing the diary, I just couldn't</i></p> <p><i>I: So you were saying you found it physically and mentally..</i></p> <p><i>Angela: Oh, terrible</i></p> <p><i>I: Mentally – could you talk a bit more about the mental exhaustion</i></p>	<p>Image</p> <p>Connections with family/friends</p> <p>Tiredness overcomes desire/ability</p>
<p>Self image – independent, copes</p>	<p><i>Angela: Well, I would rather not - actually I think I'm coping with it on my own, and I don't want John to worry about me so I would rather not discuss it</i></p> <p><i>I: Right, no, that's fine</i></p> <p><i>Angela: I think I'll cope</i></p> <p><i>I: You think so, do you?</i></p> <p><i>Angela: Yes – it's just that things are getting on top of me at times, you know</i></p>	<p>Image and identity</p>
<p>Doubts about ability</p> <p>Rethinking ability/image</p>	<p><i>I: Are they?</i></p> <p><i>Angela: Yes</i></p> <p><i>I: Do you feel that quite a bit?</i></p> <p><i>Angela: Yeah. But he's really very considerate and very thoughtful you know so I just don't want to worry him at all, so that's... I mean I</i></p>	<p>Changing image/identity</p>

<p>Maintaining image – is she wondering whether to be more open/disclose how she is really feeling?</p>	<p><i>don't like talking about myself, so I hope this isn't going to be – who is going to listen to this - you use it, do you?</i></p> <p><i>I: In the studies, yes, it's just to help</i></p> <p><i>Angela: But there's no names, of course?</i></p> <p><i>I: Absolutely not, no, and this is to remind me of what you've said – of what we've talked about</i></p> <p><i>Angela: Uhuh..</i></p> <p><i>I: So could you just say just a little bit more – I'll try not to keep you too long, but just a little bit more about your life now, since your husband was in hospital</i></p>	
<p>Comparing with the past Changes due to caring role Losses</p>	<p><i>Angela: Well, I've not seen any of my friends. I usually have quite good day time social life - I have quite a lot of friends, and I've just dropped them completely at the moment</i></p> <p><i>I: Have you?</i></p> <p><i>Angela: Oh, yes – they're very understanding and I'm trying to – I thought next week, after my visitors go this weekend, I would try and get back to normal</i></p>	<p>Revisiting past/ comparing with present</p>
<p>normality</p>	<p><i>I: And by normal, what do you mean by that?</i></p> <p><i>Angela: Well, seeing my friends for coffee and things, because now I don't do anything else, I don't socialise, you know, the way I did when I was younger. You know, I played golf and, you know, I had a good social life, but I don't at the moment, but I do have quite a lot of friends, actually, so they've been to see him and things, but I'm not meeting up with anyone at the moment - so it's very difficult. Not that I mind, I don't mind doing that at all...</i></p>	<p>Importance of normal</p>
<p>Connecting with friends again and previous social life</p> <p>Does she really not mind?</p>	<p><i>I: So that's a change for you?</i></p> <p><i>Angela: Oh, a big change, aha, but I'm hoping</i></p>	<p>Revisiting past</p> <p>Image as carer: selfish-selfless struggle</p>



<p>Rethinking self image?</p>	<p><i>to get back soon to my normal visits</i></p> <p><i>I: Yes to the things that you used to do, yes. And another thing I would like to ask about is just.. what advice would you give to somebody else in your situation?</i></p> <p><i>Angela: Well, I'm really very strong mentally and physically – well, I'm not strong physically now – I had major surgery three and a half years ago so I'm not able to – it was my – a spinal operation, and it was really quite major which has left me with a lot of problems, but mentally I'm strong - I'm determined to fight this and get over it, this awful feeling of frustration, you know, and the fact that John's improving is a big help, so...</i></p>	<p>Self image</p>
<p>Determination/fight</p>	<p><i>I: You mentioned the word frustration, so has it been quite frustrating for you then, as you say?</i></p> <p><i>Angela: Yes, yeah... I'm pleased for him that he's had so many people interested in him, but.. eh.. I think I will, you know, probably get stronger.. I'm bound to</i></p>	<p>Future vision</p>
<p>Frustrations but some hope too</p>	<p><i>I: Yes, so just a couple of things..</i></p> <p><i>Angela: I feel this isn't helping anything, me moaning on about how I feel!</i></p>	<p>Future vision</p>
<p>Uncomfortable about disclosing?</p>	<p><i>I: No, it's very important</i></p> <p><i>Angela: Is it?</i></p>	<p>Future vision</p>
<p>Doubts about caring role – who is important here?</p>	<p><i>I: Yes, it is...just..so just to go back to – would there be anything..any advice that you could offer another person</i></p> <p><i>Angela: No – no, I think every individual is different. People will cope with this in different ways</i></p> <p><i>I: Yes..</i></p> <p><i>Angela: I've done really extremely well, you know, because John doesn't cook at all, so</i></p>	<p>Future vision</p>

Assessing own ability – contradicting with her previous thoughts?	<i>there's a lot – you know - there's a lot of work involved in looking after someone who's not able to - but he does help a little, you know, with the vegetables and things.. but, no I feel that every person is different, so what I'm saying doesn't mean that other people would be affected this way, and it depends on your age group - I think when you get over seventy-five, you know, I'm knocking on eighty-two, so it's not easy – it's not really easy, but, you know, because.. you know, people think you're strong, they don't realise that you're not as strong...</i>	Roles
Gender roles		
Impact of age on situation		
Reassessing self – more vulnerable	<i>I: Right.. so anything else – you've mentioned the frustration there – anything else you've been feeling as well, or apart from, the frustration</i>	identity
Is she wondering if people really understand?	<i>Angela: In what way? – is that not bad enough (laughs)!</i>	
Overwhelming tiredness	<i>I: Well, yes! I just wondered if there was anything else as well as that, or anything else apart from that?</i>	Tiredness overcomes
	<i>Angela: No, no</i>	Roles and ability
	<i>I: So that's been the main thing...</i>	
	<i>Angela: Yes – it's just physically and mentally exhausting – I just can't even take my clothes off at night some nights, I'm so exhausted.. but it's bound to happen, you know.. you really – at my age you can't look after an invalid and look after a house, and cook and shop, and do all the washing and ironing, and that kind of thing, you know, there's a lot of extra work..</i>	
	<i>I: Yes.. a lot..</i>	
	<i>Angela: I should really have help in, but I'm loathe to do it yet</i>	

<p>Loathe to 'give in' and admit changed ability/vulnerability?</p>	<p><i>I: Are you?</i> <i>Angela: Yes... so I think that's it.....</i></p>	<p>Choices/control</p>
<p>Tailing off, looking tired After all her admissions of exhaustion, it didn't seem appropriate to push her further</p>	<p><i>I: Okay.. well, thank you very much indeed - I do appreciate you taking the time.. thank you</i></p>	

## Appendix 14

### Poem

Think how it could have been

I'd rather do away with myself

Although I love them and they love me

Have people look after me

All the time

That to me is hell

That's not a life

Just count my blessings

Think how it could have been

Didn't want my family to know

Didn't want them to see me the way I was

Want them to see me as being perfect

I don't know why

Because they would understand

I would think

Tell me not to be so silly

Think how it could have been

(continued)

Could feel the support all the time

I really could

Didn't realise there was so much

I can laugh about it

She laughs about it too

Which isn't bad

Just count my blessings

Think how it could have been

I was always sitting down

When they came

Didn't want them to see me

Dragging my foot

With my face squint

Not that I was ashamed

No I wasn't ashamed

Think how it could have been

It would be lovely

If it were all a bad dream

It really would

I think about that often

If I could just wish it all away

And waken up

Yet by the same as me wishing that

Think how it could have been

(continued)

I've improved so much  
That's something else  
I wouldn't have believed  
Knew I had to stay positive  
If I could wake up one morning  
This all be normal  
I still hope for that  
Think how it could have been

(This poem was composed by the researcher solely using words from one participant, as part of the interpretative process)

## Appendix 15

### Extract from *Gridlock* (Elton, 1992)

*She was to vow a thousand times a week for the rest of her life, not to consume her precious energy on anger and frustration. She could not allow herself the luxury that most people indulge in, of letting off steam by having a raving good whinge. Who can honestly say that they have never been consumed by that intense annoyance, never felt that burning but wrenching tension and anger at life's petty frustrations. A barman repeatedly ignoring you; a screw head that has for some reason been made out of soft putty instead of steel; a traffic light which has a thing about red – such tiny irritations make one ready to kill. What then, would be the inner fury felt by a person who has lost the use of certain limbs? How terrible would be the endless turmoil to the stomach that simple inanimate objects and petty bureaucracy will engender? If that fury were to be given expression, the person in question would die of exhaustion within a week. (Elton, 1992: 148)*

## **Appendix 16**

### **Details of presentations**

March 2007 University of Dundee, Post Graduate Research Forum – oral presentation

February 2008 Royal College of Nursing (RCN) International Rehabilitation and Intermediate Care Conference, London – oral presentation

February 2008 Fife Stroke Managed Clinical Network (MCN), Research and Audit Group – oral presentation

February 08 Fife Stroke MCN Learning and Sharing Event – poster presentation

June 2008 University of Dundee Annual Post Graduate Symposium – poster presentation

February 2009 Connect (The Communication Disability Network) Headquarters, London – oral presentation

February 2009 Fife Stroke MCN Learning and Sharing Event – poster presentation

February 2009 University of Dundee, Post Graduate Research Forum – oral presentation

March 2009 RCN International Research Conference, Cardiff – poster presentation

June 2009 NHS Fife Stroke Case Presentation Event – oral presentation

(continued)



January 2010 University of Dundee, College of Medicine, Dentistry and Nursing  
Research Symposium – poster presentation

February 2010 University of Dundee, Post Graduate Research Forum – oral  
presentation

June 2010 University of Dundee, Academic Professional Development Conference –  
poster presentation

September 2010 Glasgow Caledonian University, IPA Annual Conference – oral  
presentation

January 2011 University of Dundee, College of Medicine, Dentistry and Nursing  
Research Symposium – poster presentation

March 2011 University of Dundee, Post Graduate Research Forum – oral  
presentation

May 2011 International Conference on Rehabilitation and Participation in Long-  
Term Conditions: Building Bridges between Researchers, Practitioners and Service  
Users, Dundee – poster and oral presentations

## Appendix 17

### Details of publications

Pringle J, Hendry C, McLafferty E 2008 A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing* 17 (18) 2384-2397

Pringle J, Hendry C, McLafferty E, Nicholson L 2009 Including people with aphasia in stroke research. *Bulletin: Royal College of Speech and Language Therapists* Dec 09 (692) 12-13

Pringle J, Hendry C, McLafferty E, Drummond J 2010 Stroke survivors with aphasia: personal experiences of coming home. *British Journal of Community Nursing* 15 (5) 241- 247

Pringle J, Hendry C, McLafferty E 2011 Phenomenological approaches: challenges and choices. *Nurse Researcher* 18 (2) 7-18

Pringle J, Drummond J, McLafferty E, Hendry C 2011 Interpretative phenomenological analysis: a discussion and critique. *Nurse Researcher* 18 (3) 20-24

Tattersall C, Powell J, Stroud J, Pringle J 2011 Mind mapping in qualitative research. *Nursing Times* 107 (18) 20-22

