Introduction:

In the preface to the second edition of the National Clinical Guidelines for Stroke (Intercollegiate Stroke Working Party, 2004), the experience of stroke is described as “one of the more alarming and devastating things that can happen to a person” (Philp 2004, p.ix), yet despite rapid advances in neuroscience and technology during the past two decades and an increasing emphasis on health promotion, stroke remains the third most common cause of death in the United Kingdom and the single greatest cause of severe disability (Care Quality Commission, 2011; Department of Health, 2007). The effects of a stroke are often complex, affecting not only a person’s physical functioning but also their communication, cognition, mood and social relationships, all of which require input from a multiprofessional stroke care team. The recognition of this complexity has led to the development of standardised, national clinical guidelines for the organisation of services and management of stroke throughout its trajectory (Intercollegiate Working Party for Stroke, 2000; Intercollegiate Stroke Working Party (ISWP), 2004; 2008).

As any serious illness might lead to emotional disturbance, it is not surprising that during the first weeks following a stroke there is an increase in general levels of emotional distress (House, 1996). However, the emotional impact of stroke is arguably one of the most problematic aspects of stroke rehabilitation to assess and within the context of outcome-driven services, it has been largely addressed through the objective measurement of mood disturbance, using standardised screening tools for anxiety and depression (NHS

Improvement, 2011; ISWP, 2008). Moreover, underpinning current approaches to the emotional response to stroke appears to be an implied inevitability that a person will experience mood disturbance, as evidenced by the recommendation of “watchful waiting” for symptoms of distress to develop (ISWP, 2004). Therefore, little attention has been paid to whether any interventions might avert severe emotional distress. In addition, the actual context within which patients and relatives experience their emotional response to stroke also remains largely unexplored, with regard to the specific characteristics of the environment and of the professionals who work within it; except again, in terms of those elements which are accessible to measurable outcomes.

Current recommendations are for all people affected by a stroke to be admitted to a specialised stroke unit (ISWP, 2008) and the stroke unit model is now well-established (Langhorne and Dennis, 1998), together with the range of specific interventions which should be provided there. However, as a nurse with a special interest in and experience of stroke rehabilitation practice, I would argue that there are other factors which contribute to the effectiveness of stroke rehabilitation, such as the quality of the therapeutic relationships developed between patients, relatives and the professionals they engage with during the process of recovery. It is this elusive element of stroke rehabilitation which particularly interests me, as I contend that nurses’ understandings of the emotional effects of stroke on patients and their families inform their interactions with them and are purposefully directed towards supporting their emotional wellbeing in a proactive, as well as in a reactive way. In addition, patients and relatives themselves actively engage in rehabilitation and bring their own knowledge and experiences to bear on the process of recovery. These issues have led me to speculate about how nurses, patients and their families ‘pool’ their resources to achieve emotional wellbeing in stroke rehabilitation and it is their exploration which form the focus for the research study.

The thesis is structured as follows:

Chapter 1 introduces the literature review which informed the research question and also outlines the rationale for the study, its aims and objectives.

Chapter 2 presents the research methodology; the underpinning concepts and theoretical perspectives which inform the research methods.

Chapter 3 focuses upon the development of the research design, how the study was constructed and the methods of sampling, data collection and analysis undertaken.

Chapter 4 introduces the findings, including the proposal of a relationship model to explain the ways in which nurses use their insights into the emotional experience of stroke to inform their interactions with patients. A brief overview of the model is offered before expanding upon each component in the presentation of the findings.

Chapter 5 addresses the ways in which nurses, patients and relatives build the relationships which are the foundation for their therapeutic interactions.

Chapter 6 expands upon the processes whereby relationships are sustained in rehabilitation, to demonstrate how nurses work with patients and relatives to maintain engagement in rehabilitation and enable them to use their own personal attributes of determination and self-efficacy to recover.

Chapter 7 focuses on challenges to recovery and the emotionally supportive strategies used by nurses to enable patients and relatives to manage these.

Chapter 8 focuses on the ways in which relationships between patients, relatives and nurses are reframed in the transfer of care from the stroke unit.

Chapter 9 presents theoretical propositions to explain the culture of nursing on the stroke unit and proposes that recovery and rehabilitation depend upon the quality of relationships forged between nurses, patients and relatives and the achievement of congruence between their core values, personal attributes and approaches. Methodological issues encountered in the conduct of the study are also addressed and the chapter concludes with a restatement of the key messages and offers recommendations for policy, clinical practice, professional education and research.

A note on the presentation of the thesis

Lofland *et al* (2006) contend that it is essential for research studies to be reported in such a way as “to enable the reader to both understand and judge the theoretical and empirical claims made” (p.170). However, Hammersley and Atkinson (2007) explain that it is not an easy task to produce a linear text from the vast and varied data which are constructed during an ethnographic study. Therefore, in order to expose the complexity of the research processes and my role in constructing the data and findings, a reflexive approach has been taken throughout. Reflexivity is defined by Finlay (2002) as “thoughtful, self-conscious self-awareness” (p.532) and in writing reflexively, “the intersubjective dynamics between researcher and researched” are revealed (Finlay and Gough 2003, p.ix), thereby exposing the rationale for decisions made, processes and ideas throughout the course of the research.

There were data constructed during the research study which go beyond the remit of the thesis and, therefore, are not reported here. Because the focus for the exploration is on the interactions between nurses, patients and relatives from the point of entry to the stroke unit until their transfer of care, there are sections of the data which have not been included, notably the detail provided by patients and relatives of the events leading up to admission to the stroke unit, how their strokes occurred and how they were managed in the immediate period. These are important data and will be explored further as part of a programme of post-doctoral study. Additionally, data are also omitted which relate to the point beyond transfer of care and focused on the follow-up interviews occurring in the first two months after discharge from the stroke unit. Again, these findings will be explored at a later date, to gain insights into the experience of learning to live with a stroke.

Finally, a note on the terminology used; although sometimes still described in the research literature as a Cerebrovascular Accident (CVA), the lay term of ‘stroke’ now appears to have been universally adopted by health care professionals, researchers and the public (Pound *et al*, 1997). Therefore, the term ‘stroke’ is used to describe the event which brought the patients and their relatives into contact with the nurses on the stroke unit.

Chapter 1

Exploring the literature on the emotional experience of stroke and its potential for influencing nursing practice

Finlay (2002) argues that the processes of reflection and reflexivity should be recorded from the conception of a research study; therefore, in this opening chapter, the formative influences which guided me towards critically exploring the topic are outlined, together with a summary of the key issues arising from the review of the literature which informed the research question. The research question, aims and objectives are outlined.

Formative influences and developing ideas

The foundations for this study were laid over twenty five years ago, when I was practicing as a staff nurse in a stroke rehabilitation unit. It was there that I first became concerned with the emotional effects of stroke, observable in some of the patients I was caring for (Bennett, 1992) and conversations with colleagues revealed similar concerns and a shared belief that this was a natural and often expected reaction for a person affected by the sudden and catastrophic event of a stroke (Bennett, 1996). Some people appeared to be affected more severely than others, to the extent that their emotional distress overwhelmed them and inhibited their progress in rehabilitation. Our responses were to try to understand what people were experiencing, to comfort and console them. At the time, medical research into the apparent phenomenon of ‘post-stroke depression’ was not well-established (Robinson *et al,* 1990; Starkstein *et al*, 1988; Robinson *et al*, 1983), nevertheless, it strongly influenced my formative beliefs about the nature of emotional distress following a stroke; i.e. that it could be explained as a: “behavioural manifestation of neurophysiological or neurochemical responses to brain injury” (Robinson *et al*, 1983 p.741).

Maintaining an interest in these issues, over time, I began to question whether the explanations offered for the existence of ‘post-stroke depression’ as an observable, measurable and ultimately treatable clinical condition, were altogether convincing. I attributed this change of perspective, at least in part, to my concerns that the methods of experimental research, particularly involving the use of measurement tools, did not fit well with my understanding of the stroke experience gained from working with the people affected. Within the stroke research field, the causal links between brain damage and depressed mood were also being challenged; that depression following stroke appeared “to be far from an homogenous phenomenon” (Kneebone and Dunmore, 2000 p.54). Lincoln *et al* (2003) also acknowledged the uncertainty of the nature of depression after stroke, even suggesting that it might be “an artefact resulting from the use of inappropriate classification criteria” (p.840).

This change in my thinking about the emotional experience of stroke was also influenced by a growth in research studies and autobiographical accounts focusing on the personal experiences of stroke, which appeared to offer powerful insights from the perspective of the persons affected. Too numerous to reference here, they are included in a review of the literature (Appendix 1). Nursing researchers had also started to explore how these insights might influence practice (Easton, 1999; Hafsteindóttir and Grypdonck, 1997; Doolittle, 1991, 1992, 1994); something that increasingly interested me in my transition from the role of practitioner to educator, following a secondment to develop and deliver a post-registration course in rehabilitation nursing practice at a local School of Nursing and Midwifery. I started to explore these alternative, interpretive approaches to understanding the effects of stroke, located within the genre of studies emerging from sociological rather than medical research. I was also influenced by the review of the role of the nurse in rehabilitation undertaken by Nolan *et al* (1997), in which stroke was identified as a paradigm case (Nolan and Nolan, 1998a, 1998b).

The medium of the professional doctorate programme (University of Sheffield, 2003) enabled me to develop these ideas, to interrogate my epistemological and ontological foundations for understanding the emotional experience of stroke (Bennett, 2004) and for challenging current approaches to assessing mood disorders (Bennett, 2005a). Subsequently, a review of the literature was undertaken, which attempted to synthesise the contribution of biomedical and sociological research to understanding the emotional experience of stroke (Bennett, 2005b). Due to the constraints of the wordage allotted for the thesis, as outlined in the course guidelines (University of Sheffield, 2003) and because a substantial part of the literature review has been subsequently published (Bennett, 2008; 2007a; 2007b;), the review itself is appended for reference only (Appendix 1). However, issues which emerged from the review provided the impetus for this research study so they are briefly addressed here.

Reviewing the literature

The literature review aimed to explore what was known about the emotional experience of stroke and how nurses might use this knowledge to inform and enhance their supportive role. It was anticipated that by identifying gaps in the literature, opportunities for research could be exposed (McKevitt *et al*, 2004) and the scarcity of research relating to the nurse’s role in providing emotional support to a person affected by a stroke during the period of hospital-based rehabilitation prompted my further exploration of the subject.

In brief, the review proposed that although the knowledge base and skills required by nurses to fulfil their role in stroke rehabilitation were clearly becoming embedded in practice, the focus was essentially upon either new, specialist roles consistent with service developments or those which were informed by other members of the multiprofessional rehabilitation team; reinforcing the “carry on” role of stroke nursing (Nolan *et al*, 1997). Many of the fundamental aspects of the nurse’s role in relation to stroke had remained poorly developed, attracted little research interest and were identified by Nolan (2003) and Nolan and Nolan (1998a; 1998b) as areas of deficit in stroke rehabilitation. The nurse’s role in providing emotional support to patients and their families was one such neglected area.

Two literature searches were undertaken; the first focusing on the emotional experience of stroke and the second on stroke nursing. The search strategies are explained in Appendix 1, p.4-7. The findings from the first search revealed two distinct epistemological approaches to explaining the emotional experience of stroke, which were used to structure the review. These were firstly, biomedical explanations, which focused on mood disturbance, particularly depression and anxiety and secondly, social science research and personal narratives of the emotional experience of stroke. Both revealed limitations. Biomedical explanations for the emotional experience of stroke were identified as having had limited impact on nursing practice, whilst social science research, although acknowledged as having provided greater insights into the personal experience of stroke, had resulted in such a multitude of theories to explain the experience that they precluded synthesis. However, they informed theoretical frameworks which were proposed as a focus for nursing interventions (Brauer *et* al. 2001; Burton, 2000a; Easton, 1999; Kirkevold, 2002).

The second search focused on identifying the nurse's role in providing emotional support in stroke rehabilitation, which whilst clearly addressed as an element of stroke nursing research (Long *et* al, 2001; O'Conner, 2000a, 2000b; Burton, 2000b; Kirkevold, 1997; Gibbon, 1993; Myco, 1984), had received little specific attention (Jones, 1995; Viinamäki and Koivisto, 1994). Suggestions for nursing interventions for providing emotional support were based on insights into personal experiences, but except in the case of Long *et al* (2001), these experiences were articulated by the nurses themselves;

not the persons affected. It was, therefore, possible that this professional perspective might not accurately reflect the needs for, or effectiveness of emotional support. Indeed, Alaszewski *et al* (2004) and Burton *et al*, (1992) identified significant discrepancies in the perceptions of health care professionals (not exclusively nurses) and the persons affected. The conclusion reached was that congruence needed to be achieved between how nurses perceived their provision of emotional support and how the recipients perceived it, if interventions were to be meaningful.

Updating the literature review

Whilst the body of research exploring the stroke experience had already contributed to an emergent understanding of the effects of stroke on patients' and relatives' emotional wellbeing, Prigatano (2011) emphasised the need for health care professionals to continue learning from patients' subjective experiences to inform their practice. Therefore, further insights into patients' and nurses' perceptions of emotional support needs were sought during the progress of the study and in writing the thesis, by maintaining currency with the related literature. Periodically replicating the original searches also identified a number of papers which previously had been missed; possibly, as Aveyard (2007) asserts, due to the ways in which research and other literature are categorised in the databases and keywords or subject headings organised. In the six years intervening since the original literature review was undertaken, the field had continued to expand, remaining diverse in its scope and methodological orientation. This later body of literature is summarised here, firstly by addressing research into personal experiences of stroke, before moving on to literature focusing on professional perspectives.

The themes identified from the literature on the stroke experience are broadly summarised in Table 1. This later body included nine systematic reviews (Bright *et al* 2011; Kouwenhoven *et al* (2011a); Peoples *et al*, 2011; Rosewilliam *et al*, 2011; Lawrence, 2010; Lamb *et al*, 2008; Pringle *et al*, 2008 and Salter *et al*, 2008; Johnson *et al*, 2006), one of which (Lamb *et al*, 2008) specifically focused on the psychosocial experiences of older adults following stroke. Reviewing 27 studies which met their inclusion criteria, the authors synthesised four themes of the stroke experience as: an unexpected event, a life-altering event, life reconstruction and connectedness with others in the process of recovery. They concluded that the early period following a stroke is a "confusing and terrifying experience" (Lamb *et al*, 2008, p.173) and that recovery involves both considerable physical and psychological 'work' which should be recognised and addressed in health care practice. Kouwenhoven *et al* (2011b) also emphasised the potential depth of emotional distress which nurses need to appreciate in their endeavours to provide emotional support and based on the stages of the patient's journey through recovery, both Kirkevold (2010) and Ellis-Hill *et al* (2008) proposed theoretical models to guide psychosocial interventions.

Gallagher (2011) maintained that the emotional process of recovery following stroke still remained poorly understood and under-researched. Nevertheless, other researchers have attempted to enhance understanding of the process by focusing on different dimensions of the experience. Reviewing the literature in Table 1 which addresses the theme of psychosocial issues, what clearly emerges is a growing recognition of the importance of the personal coping strategies used by patients to maintain their emotional wellbeing during recovery and how these might be supported by health care professionals.

Gillen (2006; 2005) explored individual coping strategies, through structured interviews and standardised measures, whilst Rochette *et al* (2006) identified through in-depth interviews, the need for resources to support coping, including emotional support. Gunn *et al* (2006) also used structured measures to identify the correlation between hopeful thinking and depression, implying that hope mediated against depression. Exploring the influence of hope and its relationship to coping, Popovich *et al* (2007; 2003) suggested that through their interpersonal relationships with patients, nurses can support coping by promoting hope. Focusing on the role of hope in self-healing, Arnaert *et al* (2006) urged nurses to inspire hope by enabling patients to talk about their experiences.

Also focusing on self-healing following stroke, Giaquinto *et al* (2007) explored through semi-structured interviews and mood screening measurements, religious beliefs and the role of faith in protecting against emotional distress following stroke. The researchers suggested that religious beliefs could

Table 1:

Broad thematic focus for the experience of stroke identified through a second, post-study literature review

Theme	Papers
Experience of stroke onset	Faircloth *et al* (2005)
Experience of rehabilitation: participation in decision-making in care planning meetings, goal planning, discharge planning & patient/professional power relationships	Efraimsson *et al* (2003), Gibbon (2004a), Gibbon (2004b), Löfmark and Hammarström (2005), Olofsson *et al* (2005), Slingsby (2006), Morris *et al* (2007), Almborg *et al* (2008), Hedberg *et al* (2008), Mangset *et al* (2008), Andersson and Hansebo (2009), Horton *et al* (2011), Peoples *et al* (2011), Rosewilliam *et al* (2011)
Experience of transition from hospital/rehabilitation unit to home and the early post-discharge period	Lobeck *et al* (2005), Wallenbert and Jonsson (2005), Hjelmblink and Holmstrom (2006), Rittman *et al* (2007), Sigurgeirsdottir and Halldorsdottir (2007), Pringle *et al* (2008), Brunborg (2009), Carlsson *et al* (2009), Ellis-Hill *et al* (2009)
Experience of longer-term recovery, living with stroke and quality of life after stroke	Alaszewski *et al* (2003), Kelley *et al* (2004), Andreassen and Bruun-Wyller (2005), Barker and Brauer (2005), Clarke and Black (2005), Kelley and Betsalel (2005), Stone (2005a), Stone (2005b), Alaszewski (2006), Alaszewski *et al* (2006), Roman (2006), Stone (2007), Vincent (2007), Salter *et al* (2008), Blijlevens *et a*l (2009), Eilertsen *et al* (2010), Lawrence (2010)
Psychosocial experiences and personal coping strategies across the stroke recovery trajectory	Robinson-Smith (2002), Popovich *et al* (2003), Gillen (2005), Williams *et al* (2005), Arnaert *et al* (2006), Johnson *et al* (2006), Gillen (2006), Gunn *et al* (2006), Rochette *et al* (2006), Giaquinto *et al* (2007), Popovich *et al* (2007), Ellis-Hill *et al* (2008), Lamb *et al* (2008), Jones *et al* (2008), Cross and Schneider (2010), Kirkevold (2010), Townend *et al* (2010), Bright *et al* (2011), Gallagher (2011), Kouwenhoven *et al* (2011a, 2011b)

contribute to coping, offering a protective factor against emotional distress, whilst Robinson-Smith (2002) identified the potential of prayer in enhancing coping and argued the need to address the spiritual needs of patients. Spirituality in recovery from stroke was also addressed by Lamb *et al* (2008).

A systematic review conducted by Bright *et al* (2011) which focused on hope after stroke also identified that as a motivating factor and source of strength during recovery, hope was linked to positive outcomes for patients. Through in-depth interviews, Cross and Schneider (2010) explored the perceived influence of hope on stroke recovery, identifying it as an integral factor in fostering optimal recovery. Their findings revealed a complex interplay between positive attitudes and determination, progress in rehabilitation and external sources of support (Cross and Schneider, 2010). Jones *et al* (2008) likewise recognised the interplay between personal, internal resources and external resources accessed through interactions with health care professionals.

Townend *et al* (2010) also identifying that personal beliefs were associated with and predicted emotional adaptation, using structured clinical interviewing and later, open-ended interviews to research the association between acceptance of disability and depression following stroke. Williams *et al* (2005) combined structured measurements and patient narratives to identify how closely subjective experiences correlated with the results of objective measures.

Two of the systematic reviews retrieved through later literature searches specifically focused on the incidence and experience of depression following stroke (Kouwenhoven *et al*, 2011a; Johnson *et al*, 2006). Kouwenhoven *et al* (2011a) reviewed current knowledge of depression occurring within the first month following stroke, whereas Johnson *et al* (2006) focused on the first three months. Both time periods were defined by the reviewers as 'acute', a discrepancy in definition which characterises what they themselves acknowledged as a challenge to achieving meta-synthesis of the literature.

Reaching conclusions from systematic reviews of the stroke experience are problematic, because of the lack of researcher agreement about operational definitions of depression and even of stroke itself; i.e. whether they included both ischaemic and haemorrhagic stroke. Varying methods of diagnosis, the wide range of mood screening instruments used and the timing and frequency of assessments also confound synthesis, as does the differing points beyond the stroke when data were collected. Other factors such as the age, gender, socio-economic status, ethnicity and co-morbidity in study participants further complicate the picture (Kouwenhoven *et al*, 2011a; Johnson *et al*, 2006), leading Kouwenhoven *et al* (2011a) to conclude that knowledge of depression following stroke in the acute phase is still limited.

Understanding and responding to depression, nevertheless, features strongly in the literature representing professional perspectives of the emotional experience of stroke. The small number of research and discussion papers identified in later searches largely focused on raising awareness of and promoting the use of methods for the assessment of mood disorders (anxiety and depression) (Gurr, 2011; Gurr, 2009a; McGinnes, 2009; Pfeil *et al* 2009; Lee *et al*, 2008; Lightbody *et al*, 2007a, 2007b; Chi Leung Fung *et al*, 2006; Dundas, 2006), structured professional education programmes to improve psychosocial care (Ross *et al*, 2009a, 2009b) and recommendations for, or descriptions of potential therapeutic interventions (de Man-van Ginkel, J *et al*, 2010; Gurr, 2009b; Vohora and Ogi, 2008; Welch, 2008); the latter category to which I also contributed (Bennett and Greensmith, 2007; Bennett *et al*, 2007).

One questionnaire survey of a multiprofessional stroke unit team revealed that whilst understanding of and attitudes towards psychosocial care were generally positive (Gurr, 2009a), staff interventions to provide emotional support to patients were inconsistent. In response, an approach which comprised monitoring emotional wellbeing was recommended and implemented by way of a mood screening pathway reflecting the patient's journey and their contact with staff (Gurr, 2011). Interestingly, only 7 of the 33 nurses working in the stroke unit completed the questionnaire, compared to almost total compliance by other team members but the reasons for this are not addressed (Gurr, 2009a).

Nurses themselves have reported a need for improvement in the assessment of mood disorders and urged colleagues to take a more active role in this (McGinnes, 2009; Pfeil *et al*, 2009; Lee *et al*, 2008; Lightbody *et al*, 2007a, 2007b; Chi Leung Fung *et al*, 2006; Dundas, 2006), including healthcare assistants and/ or support workers (Ross *et al,* 2009b; Welch, 2008). Identifying appropriate screening tools, however, is challenging, as there are no specific recommendations made in the National Clinical Guidelines for Stroke (ISWP, 2008; 2004). As an added dimension, in comparing the use of an observational tool, the Signs of Depression Scale (SoDS) (Hammond *et al*, 2000) between family members and nurses, Lightbody *et al* (2007b) revealed that family appeared to be more successful. The researchers speculated as to whether the degree to which the observer knows the patient may be a critical factor in accurate assessment (Lightbody *et al*, 2007b) based upon which premise, Pfeil *et al* (2009) suggested that nurses could consider teaching family members to assess for depression in patients.

In a systematic review of the nurse's role in therapeutic interventions for depression following stroke, de Man-van Ginkel *et al* (2010) identified a variety of approaches to promoting emotional wellbeing which they believed were achievable by nurses; including life review therapy, motivational interviewing and psychosocial support programmes. However, they cautioned that nurses may not be able to actively participate in interventions such as structured programmes or group therapies, because of the routines of daily nursing practice. Vohora and Ogi (2008) also recognised that time constraints and the availability of resources limited the ways in which nurses could respond to disclosures of patient's emotions. In consequence, targeted interventions such as individual or group therapies tended to be facilitated by clinical psychologists (Gurr, 2009; Vohora and Ogi, 2008), or specialist nurses not directly involved in routine patient care (Bennett *et al*, 2007;

Bennett and Greensmith, 2007). Bearing this in mind, in an educational programme aimed at improving patients' and relatives' experiences of rehabilitation and reducing the potentially negative psychosocial consequences of stroke, Ross *et al* (2009a; 2009b) purposely focused on strategies to enable ward-based nurses and healthcare assistants to integrate psychosocial care into their day-to-day practice.

In summary, through briefly reviewing the literature published since commencing this study, there is growing evidence that nurses do attempt to use knowledge and understanding of personal experiences of stroke to inform their interactions with patients but it is unclear whether they have become more effective in meeting emotional support needs. Indeed, there is some suggestion that the organisation of nursing care might limit the extent to which nurses can fully assess and respond to these needs. What is notable is that none of the studies reviewed here explored emotional support from the perspectives of both service users and providers. To repeat the assertions made by Alaszewski *et al* (2004) and Burton *et al* (1992) that for interventions to be meaningful, congruence needs to be achieved between how nurses and patients perceive emotional support, then there clearly remains scope for pursuing an approach to the study of emotional wellbeing following stroke which addresses these multiple perspectives.

Developing the research question, aims and objectives

Although the initial literature review had offered some indication of the main issues which would impinge upon and influence the provision of emotional support by stroke nurses, it stopped short of suggesting a specific research question; which was later refined within the context of developing the formative research proposal submitted for assessment (Bennett, 2005c). The question eventually framed was:

> **“What emotions do persons affected by a stroke experience during hospital-based rehabilitation and how do nurses interact with patients and relatives to promote emotional wellbeing?”**

The aims of the study were to explore the emotional experiences of persons affected by a stroke (patients and relatives), nurses’ interpretations of these experiences and how nurses used these to inform and influence person-to-person interactions during the period of hospital-based rehabilitation. There were several assumptions or pre-understandings inherent in these aims, based on my professional experience and from reading of the literature (Wolfinger, 2002). These were firstly, that patients and their relatives did experience an emotional response to stroke; secondly, that nurses could, or did attempt to interpret these experiences and thirdly, that they used these interpretations to inform their practice.

A further assumption and one which was central to the research endeavour was that these experiences, interpretations and interactions could be articulated and/or observed. Therefore, the objectives for the study focused on how these could be investigated and were expressed as:

1. To explore, through observation, the interactions between nurses and persons affected by a stroke during the course of their day-to-day activities.
2. To explore, through personal accounts, nurses' understanding of the emotional experiences of persons affected by a stroke.
3. To explore, also through observation and personal accounts, the emotional experiences encountered by persons affected by a stroke.
4. To explore the ways in which nurses communicate with colleagues and others during the course of their day-to-day activities, their interpretations of and interactions with the emotional experiences of a person affected by a stroke

Identifying and developing an appropriate research methodology, together with the methods used to achieve the study aims are explained in the following chapter.

Chapter 2

Methodology: Underpinning concepts and theoretical perspectives

This chapter outlines the factors influencing the research approach and explains the conceptual basis for the methodology, in order to justify the approach. An interactionist theory of emotion is argued as the most appropriate perspective for understanding the expressions of emotion created between nurses and patients and central to an understanding of the concept of emotional support; and as a methodology grounded in interactionism, interpretive ethnography is identified as the approach to exploring these nurse-patient interactions.

Identifying an approach

A weakness in my conduct of the literature review was a failure to explicate fully the methodologies utilised to explore the ways in which nurses integrate their interpretations of the experience of stroke into their practice and I simply commented on the diversity of approaches used (Appendix 1). Burton (2000b) and O'Conner (2000a) had focused exclusively on nurses' views of their role in stroke rehabilitation to inform their theoretical frameworks and whilst Doolittle's research study was described as a clinical ethnography, it appears that the observational data related to her own interactions with patients and relatives and not those of the nurses (Doolittle, 1994, 1992, 1991). In contrast, Kirkevold (1997) had observed nurse interactions with patients, relatives and other members of the rehabilitation team but this occurred on only one day a week, over a four week period in relation to individual ‘cases’. During three months’ observation, Kirkevold (1997) constructed 30 paradigm cases to explain what nurses contributed to the recovery of stroke for patients and their families; identifying four key roles of interpreting, consoling, conserving and (social) integration.

Building on Kirkevold’s theoretical framework, O’Conner (2000a, 2000b), argued that whilst this provided a representation of the nurses’ role in stroke rehabilitation in relation to the tasks to be performed, it did not indicate the manner in which these should be undertaken. O’Conner’s (2000a) research proposed a mode of care, identifying facilitative interventions and non-intervention processes to explain how nurses interacted with patients, including a consideration of the differential expectations of patients and nurses in this respect. However, these were based on interview data alone. Only Long *et al* (2001) used multiple methods of data collection, including observation, interviews and a review of healthcare records to explore the contribution of nurses to patient rehabilitation, although they did not focus exclusively on stroke and only three of the seventeen patients in their study who had experienced a stroke received care on a stroke unit. Nevertheless, Kirkevold’s (1997) and Long *et al*’s (2001) studies influenced my choice of research approach; that spending a prolonged period of time in a stroke unit, observing practice, talking to patients, relatives and nurses and reading the records of their interactions would enable a comprehensive exploration of my study’s research aims.

Justifying an interactionist concept of emotion

In sociology, debates have abounded over what precisely emotions are and how they can be studied (Williams and Bendelow, 1998a); and according to Hochschild (1998), until relatively recently, there has been no really well-founded sociological theory of emotion. Nevertheless, because theoretical assumptions will necessarily have implications for the choice of research methodology, Savage (2004, 2003) argues that researchers need to make their theoretical perspective of emotion explicit from the outset; therefore, the following justification is presented for selecting an interactionist concept of emotion.

Within the context of the sociology of health and illness, Williams and Bendelow (1998a, 1996) argue the case for an interactionist approach to the study of emotion, locating it within the debate around the extent to which emotions are considered to be bodily (organismic) or socially constructed phenomena (Savage, 2004, 2003). This can be summarised as follows. In organismic approaches to the study of emotion, originating in early biological sciences, psychoanalysis and psychology, emotional expression is characterised as inherited, genetically inscribed behaviour. Located within the individual, emotion is seen to represent repressed instinct, signals of impending danger (internally or externally) and an impetus for action (Williams and Bendelow, 1998a, 1996); and in this way, emotion functions to separate the individual from a source of danger (Lupton, 1998). The physiological responses produced are generally regarded to be “fixed and universal across cultures and times” (Lupton 1998, p.13).

Savage (2003) argues that this view of emotion as primarily inner, bodily experiences is restrictive, “limiting theoretical understanding of both emotion and social life” (p.12). However, these organismic approaches to the study of the emotion are clearly evident in the neurophysiological and neuropsychological research into the emotional experience of stroke; particularly in relation to mood disorders. For example, screening tools for mood disorders assume a universality of experience and the complexity of human emotion appears to be reduced to essentially psychiatric diagnoses of anxiety and depression (Fineman, 2004; Bowman, 2001; Massé, 2000). This is despite the failure of research to establish any direct causal link between the neurological damage caused by stroke and the affected person’s emotional responses (Cumming *et al*, 2010: Aben *et al*, 2001; Carson *et al*, 2000). Yet the ongoing debate regarding suitable screening instruments (Salter *et al*, 2007; Bennett and Lincoln, 2006) or definitive therapeutic interventions, typically leads to recommendations for further clinical trials (Anderson *et al*, 2004), rather than proposing a challenge to the conceptual basis of emotion upon which these approaches are fixed. Indeed, within this substantial body of research, theoretical assumptions are neither acknowledged nor addressed.

At the other end of the continuum, Williams and Bendelow (1998a; 1996) suggest that social constructionist approaches stress the social rather than biological nature of emotions, wherein the existence of emotions cannot be explained in terms of physiological changes but as social and cultural constructions. Thus, “emotions can neither be reduced to, nor explained by, the organism" (Williams and Bendelow 1996, p.32) but are part of the ways in which a person relates, acts and experiences themselves. From this perspective, there is no such thing as 'an emotion', only ways of feeling and acting emotionally (Williams and Bendelow 1996). However, if emotions are conceptualised as purely contextual and cannot be reified as separate entities (Lupton 1998), they may elude research. Indeed, Williams and Bendelow (1996) argue that such social constructionist approaches are problematic because by ignoring the relevance of the body and perceiving emotions simply as cognitive products, they present a disembodied view of emotions.

Williams and Bendelow (1998a;1996) consider neither the organismic nor social constructionist approaches to be adequate in theorising emotion and instead, propose what they term 'interactionist' approaches, which seek to interlink biological and social factors. From the perspective of interactionist approaches, emotion is "the *interaction* of the biophysical, personal and the social" and provides "a powerful means of intersubjective communication which possesses the capacity to bind individuals into a social entity" (Williams and Bendelow 1996, p.34). Furthermore, Burkitt (1997) argues that emotions only arise within relationships and are essentially communicative expressions occurring between people, with Lupton (1998) concurring that they are "inevitably part of individuals' interactions with others" (p.21).

Thus, interactionist perspectives offer great potential for illuminating both the emotional experiences of the person affected by a stroke and of the nurses who interact with these experiences, within the context of their day-to-day relationships. However, within the context of stroke rehabilitation, such relationships have received little specific attention (Close and Proctor, 1999; Jones *et al*, 1997; Viinamäki and Koivisto, 1994), although interactionist perspectives are evident in broader research which has focused on person-to-person relationships in nursing.

Concepts of emotional labour and emotional support

The ‘interactionist’ approach underpins the work of Hochschild (1979), whose concepts of ‘emotion work’ and ‘emotional labour’ have been clearly influential in the exploration of nurse-patient relationships during the past three decades. Indeed, an area where Hochschild’s (1979) emotional insights have been effectively applied is in relation to the sociology of health and illness; an arguably ‘fertile territory’ within which to explore the role of emotion (Williams and Bendelow, 1998a, 1998b). In brief, Hochschild (1979) defines ‘emotion work’ as an “act of trying to change in degree or quality an emotion or feeling” (p.561); a form of self-management, carried out to ensure that ‘culturally appropriate’ emotions are expressed (Savage, 2004). ‘Emotional labour’ refers to the way in which the feelings of others are responded to and focuses on the relational aspects of work such as nursing (Herdman, 2004). Thus, the purpose of emotional labour is to “promote in others a feeling of being cared for” (McQueen, 2004, p.104).

The term emotional labour is often used to emphasise the important, if undervalued aspects of the nurse’s caring role (Bolton, 2000) and Phillips

(1996) suggests that “the essence of emotional labour lies in its genuine spontaneity, honesty and unaffectedness” (p.142). Perhaps because Aldridge (1994) cautions that ‘talking to patients’ is difficult to defend as ‘work’; this ‘authentic caring behaviour’ more closely fits what Bolton (2000) refers to as a ‘gift’. Integral to the ‘normal routine’ of nursing, emotional labour has identifiable social and psychological components; the ‘social’ element reflected in the caring environment and the ‘psychological’ in building trust and friendship (Smith and Gray, 2001). These aspects signify that “emotional labour is a key component of interpersonal relationships in nurse-patient contact and integral to methods of support in the health services” (Smith and Gray 2001, p.44).

In contrast, as a generic term, ‘emotional support’ is rarely defined in the nursing literature, although Bone (2002) suggests that it serves as an umbrella for “a variety of attitudes, behaviours and understandings” that she calls “ways of being, doing and knowing” (p.141). However, these phenomena are often taken for granted; thus, the skills and knowledge needed to provide emotional support appear to be subjective and elusive (Bone, 2002). Smith (1992, p.1) likewise remarks that these “’gestures of caring’ are difficult to capture and slip by unnoticed in the daily routines and hustle and bustle of ward life”.

Skilbeck and Payne (2003) highlight that whilst the specific aspects of nursing care which focus on emotional support have been largely unexplored, there are also indications that the providers and recipients of ‘emotional support' may not agree on which interactions are emotionally supportive (Williams and Irurita, 2004). As already indicated, within the context of stroke, Alaszewski *et al* (2004) identify a difference between how health care professionals interpret a person's emotional expression and how the person themselves understand their situation; furthermore, Burton *et al* (1992) highlight the dissonance between the amount of time that professionals think they spent on 'dealing with' people's emotional needs and what the recipients themselves think. Further exploration of these issues is clearly indicated and, therefore, the research question was intended both to address the focus for the enquiry and to indicate the underpinning 'interactionist' theoretical perspective.

In short, the broad aims of this study were to explore the emotional experiences of persons affected by a stroke (patients and relatives), nurses' interpretations of these experiences and how they were used to inform and influence person-to-person interactions during the period of hospital-based rehabilitation. Therefore, a methodological approach was required which was consistent with these aims and the underpinning theoretical perspective and the following justification is made for interpretive ethnography as an appropriate approach for this study.

Methodological approach: Interpretive ethnography

In addressing the research aims from an 'interactionist' theoretical perspective, grounded in "the relationships between people in which emotion arises" (Burkitt, 1997, p.52), a methodological approach is implied which facilitates exploration of and, arguably, participation in the relationships between nurses and patients and relatives. Atkinson and Housley (2003) suggest that there is congruence between interactionism and ethnographic research and that, indeed, interactionism has been particularly influential in the development of ethnography. Prus (1996) further argues that interactionist ethnographic accounts "provide invaluable insights into the ways in which "emotional states" are interwoven in the fabric of human lived experience" (p.175).

Different types of ethnographic approach are largely differentiated by their epistemological and ontological perspectives (Savage, 2006). As a methodological approach, Savage (2006) maintains that there is no single, fixed understanding of what ethnography is and Atkinson *et al* (2001) concur that it escapes summary definition but that because contemporary conceptualisations of ethnography reflect "a proliferation of theory, methodology and praxis", it is "too easy to get caught up in methodological and epistemological strife and to lose sight of the abiding commitment to the principled exploration and reconstruction of social worlds" (p.6).

Ethnography is essentially concerned with the study of culture; the knowledge shared within a particular group of people, which is thought to "inform, embed, shape and account for routine and not-so-routine activities of the members of the culture" (Van Maanen 1988, p.3). Originating within the social science of anthropology, traditionally, ethnography had sought to provide 'factual' representations of cultures and patterns of social interaction.

However, a ‘crisis of representation’ arose during the last quarter of the twentieth century, within the context of debates surrounding the nature of qualitative enquiry. This questioned the ways in which the research participants were represented by the researcher and whether such ‘realist’ representations were possible, since ethnographers constructed their own accounts of the world, based on their own interpretations (Atkinson *et al*, 2001). If culture is constituted by the words that people say and the things which they do, then it can only be expressed through the interpretations of the observer (Van Maanen, 1988).

This “interpretative turn” in qualitative research impacted significantly upon the conduct of ethnographic study, (Atkinson *et al*, 2001) and ‘interpretive ethnography’ came to describe an approach which combines the perspectives of both the researcher and the ‘researched’ and draws upon “experiential knowledge gained from physical participation in the field” (Savage, 2000a, p.1400). Savage (2000a) thus identified ethnography as a particularly valuable approach to accessing beliefs and practices within nursing and of being able to view these in the contexts in which they occur. Indeed, she adopted an ethnographic approach in her own study of nurse-patient interactions (Savage 1995); as did Smith (1992), in exploring the emotional labour of nursing. Therefore, in this study, an interactionist concept of emotion has been chosen to underpin an interpretative ethnographic approach to exploring the ways in which nurses interact with the emotional experiences of patients and relatives affected by a stroke. The methods used in this exploration are detailed in the following chapter.

Chapter 3:

The research methods

Alvesson and Sköldberg (2000) describe ethnography as a general research orientation that can assume a variety of forms; the flexibility of which enables the researcher to be creative and use a range of approaches to access the information that they require to answer their research question (Gbrich, 2007). However, Hammersley and Atkinson (2007) caution that because the conduct of ethnography is essentially exploratory in nature, its progress cannot be pre-determined and what might emerge during the course of a study is unpredictable (Hammersley and Atkinson, 1995). As Prus (1996) suggests;

> “When embarking on ethnographic enquiry, researchers enter into complex social worlds and open themselves to interchanges with others in ways that can only be vaguely anticipated at the beginning” (p.187).

Being a neophyte researcher, the prospect of facing such uncertainty was somewhat daunting, yet also exciting and since Spradley (1880, p.176) insists that “The best way to learn to do ethnography is by doing it”, presented in this chapter is an account of how the study was developed and carried out.

This starts with what Finlay (2002) describes as the ‘pre-research’ stage, leading to the development of the research proposal which was submitted for ethical approval. The processes of orientation to the field, participant recruitment and selection, methods of data collection and analysis are also addressed, interwoven with ethical issues and conditions for establishing rigour. In this way, it is intended to demonstrate something of the complexity involved in ethnographic research and this study in particular; and how these issues were addressed, thereby creating an auditable decision trail (Koch and Harrington, 1998).

Designing the study and preparing for ethical approval

In most published reports of research studies, only brief reference is made to the preparations made in leading to ethical approval and often, they simply state that approval was granted by an appropriate research ethics body. However, such a summary statement can belie the lengthy and complex processes which researchers often need to undergo in order to reach this crucial stage in the progress of a research study (Hannigan and Allen, 2003). In the case of this study, over twelve months’ preparation was involved from constructing the formative version of the proposal which comprised the final written assessment in the professional doctorate programme (Bennett, 2005c), to submitting for scientific review within the university and finally achieving formal approval from the Local Research Ethics Committee (LREC) and Trust Research and Development department. Key factors in this developmental process are summarised as follows:

Establishing the acceptability of the study

The formative proposal provided a starting point from which to explore the acceptability and feasibility of the study with those people who potentially would be interested or involved; both service users and stroke unit staff. Earlier discussions with the Ward Manager on the stroke unit and the Stroke Nurse Specialist indicated acceptance in principle of the purpose of the study and I was invited to discuss the proposal with a larger group of ward staff. An opportunity was identified to present an overview of the study, which was received favourably. In addition, the Stroke Nurse Specialist advised speaking to the local stroke support group, as members would be able to offer insights from their own experiences.

This was arranged through the chairperson, who invited me to attend a meeting. The group members were supportive of the intention to explore issues of emotional support, as they perceived it to be a neglected aspect in stroke services and this prompted me to suggest that perhaps they might wish to act in an advisory capacity as the project progressed. Two group members volunteered; a person who had themselves experienced a stroke and another whose husband had been affected. During the progress of the study we were to meet several times, providing valuable opportunities to discuss emerging ideas. All of these expressions of approval were important in affirming the value of undertaking this research.

Developing information booklets and consent forms

With the support of my academic supervisors, the research proposal underwent several revisions in order to achieve the standard required for ethical approval; invaluable preparation which ensured that the proposal was approved without the need for amendments. This was a time-consuming process but most challenging was the development of the supporting documentation; in particular, the research information booklets and consent forms. The provision of clear and unambiguous information is a crucial ethical procedure for enabling potential participants to assess the balance between the benefits and risks of participating in research studies; and in the construction of the information booklets and consent forms, the guidance offered by the former Central Office for Research Ethics Committees (COREC) (Davies, 2005), Consumers for Ethics in Research (CERES) (Williamson and Goodare,2000) and INVOLVE (Hanley *et al*, 2003), was followed. However, in order to achieve maximum inclusivity of potential participants, more specific guidance had to be explored in relation to including people with stroke-related communication difficulties (aphasia).

According to Parr *et al* (1997), around one-third of people who are affected by a stroke will experience some degree of aphasia, defined as: “a defect in the use of language, which may occur in comprehension, expression, reading or writing” but often affecting all of these (Sundin *et al* 2000, p.482). At the time when the study was being designed, there was little published guidance available with regard to processes for providing’ aphasia friendly’ written research information for people affected by a stroke (Kagan and Kimelman,

1995) and additional advice was sought by informal networking with known researchers in the field, organisations specialising in communication disability and from speech and language therapists working in local stroke services. However, examples of both an ‘aphasia-friendly’ information booklet and consent form were eventually located and with the permission of their author (Parr 2004) they were adapted for use in the study (Appendices 2a and 2b).

In addition, because people with aphasia might also be unable to verbally express themselves, potentially, there could be difficulties in obtaining informed consent from them to participate in the research study (Philpin *et al*, 2005; Parr, 2004; Sundin and Janssen, 2003). Although ethical guidance for including people with mental incapacity, such as those with dementia or learning disability was available (Cameron and Murphy, 2006; Bravo *et* al, 2003; Dewing, 2002; Stalker, 1998), this was not the case for obtaining informed consent where participants had physical rather than mental incapacity, as in the case of aphasia resulting from stroke (Philpin *et al*, 2005; Parr, 2004); other than seeking the views of the health care professionals who could assess a person’s competence to participate in research (Brady Wagner, 2003; Braunack-Mayer and Hersch, 2001; Kagan and Kimelman, 1995). Advice from the speech and language therapist on the stroke unit who was also interested in promoting inclusivity was invaluable in this developmental process and in raising my awareness of a ‘total communication’ approach to engaging people with aphasia in conversation.

Identifying research training needs

Kleinman (1992) argues that the trustworthiness of ethnography depends on the skills and training of the researcher, who should be effectively prepared to conduct the study and Morse and Richards (2002) likewise argue that appropriate preparation of the researcher is essential to establishing their trustworthiness and integrity from the design phase of a research project. One particular challenge I anticipated was in conversing with and interviewing people with communication difficulties resulting from a stroke. Researchers often only select for interview people who can articulate their experience in a reflective and meaningful way so those with communication difficulties are rarely invited to participate in the research process (Lloyd *et* al, 2006; Paterson and Scott-Findlay, 2002). However, as Philpin *et al* (2005) argue, not including people with aphasia in research studies can obstruct the transfer of information to health care professionals, impede understanding of a situation from the person's perspective and may ultimately be detrimental to the provision of care. Training programmes for health care professionals are provided by Connect, a London-based communication disability network. One of the programmes was attended in preparation for the study and a place booked on a later course to support the progress of the research.

Hemsley *et al* (2001) and Murphy (2000) highlight the need to devise communication systems in partnership with the person affected and a speech and language therapist; using such strategies as signs, gestures, alphabet boards, picture symbols or electronic communication aids. Indeed, Murphy (2000) suggests that using a visual and interactive format might be more successful than verbal interviewing and one particularly successful strategy developed by speech and language therapist Joan Murphy (1998a), was adopted for this study is Talking Mats™.

Talking Mats™ is a visual framework using picture symbols, designed to provide people with aphasia with a means of expressing their views more easily (Murphy and Cameron, 2002); and has been developed and tested with a variety of people who have communication difficulties, including those resulting from a stroke (Murphy *et al*, 2005; Murphy, 2000, 1998b). For people who have difficulty understanding and following verbal conversation or written language, the visual format is more easily processed and enables them to control what they wish to communicate (Murphy and Cameron, 2005). Again with advice from the speech and language therapist for the stroke unit, an initial set of picture cards was created, using images aimed at facilitating emotional expression. To illustrate, examples used with participants in the study are presented in Appendix 3.

Nevertheless, even with the use of aids such as Talking Mats™, achieving successful communication with a person with aphasia is a skilful process (Sundin *et al*, 2002, 2001, 2000; Sundin and Jansson, 2003) and requires preparation (Paterson and Scott-Findlay, 2002). Again, the limited advice and guidance available was accessed (National Aphasia Association, 2005; Holland and Halper, 1996; Kagan, 1995). On request, other researchers with expertise in the field agreed to offer ongoing advice and support for this aspect of the study (Davies, 2006; Young, 2006) but, opportunistically, only a few months after commencement of the study, Connect published a guide for researchers on including people with communication impairments in stroke research (Swinburn *et al*, 2007). Most of this preparation was undertaken prior to commencing the study but consistent with the exploratory nature of ethnography, further knowledge and skills to inform the conduct of the study were acquired incrementally as it progressed.

Entering the setting and preparing for the study:

The context for the study

The setting chosen for the study was the stroke unit with a local NHS acute Trust hospital. This was a 28 bed unit, combining both acute stroke care and in-patient rehabilitation and in this feature, it was unique within local stroke services and those of the bordering counties. It was anticipated that a single, boundaried setting as such, would allow depth of investigation (Hammersley and Atkinson, 1995) and the unit was selected for study because patients entered at the point of a diagnosis of stroke and remained there until the in-patient phase of their rehabilitation had been completed, thus enabling continuity of nursing contact, potentially over a period of several weeks. A multiprofessional rehabilitation team was based within the ward area, facilitating collaborative professional activity and enabling the person affected by a stroke to participate in therapeutic activities in situ.

As the clinical link lecturer for the stroke unit, I had some knowledge of the ward environment and of the nursing staff but only in the context of supporting student learning. Entry to the unit, as the setting for the research study, was informally negotiated with the Ward Manager, the Clinical Management Team and the Director of Nursing and Quality. Formal entry was requested through the processes of local research governance. During the first week spent in the setting, I focused on familiarising myself with the physical environment, the staff and the ward routines. Spradley (1980) notes that an important criterion for selecting a social setting is the frequency of recurrent activities; therefore identifying routine and repeated activity during the twenty four hour period was important. It would also help to identify those activities which were not routine. A floor plan of the stroke unit and typical 'day in the life' of activity is presented in Appendix 4.

Identifying the study participants and developing a case study approach

As the research design developed, it became clear that the approach which would best serve the study was a multiple or collective case study approach; with each 'case' comprising a patient, their closest relative(s) and the nurses who provided their care. A number of cases would be studied together (Stake, 1994), albeit sequentially. Collective case studies are essentially what Stake (1995, 1994) describes as several 'instrumental' case studies, with instrumental cases being those which are closely examined to provide insight into an issue. Here, the case is not of primary interest in itself but facilitates understanding of something else; in that "The phenomenon of interest observable in the case represents the phenomenon generally" (Stake, 1994, p.243).

This approach has been shown to be particularly useful in ethnographic research within health care contexts (Seymour, 2001; Bergen and While, 2000), enabling the researcher to gain in-depth information about each case of interest (de Laine, 1997). One case may be viewed as typical of other cases, or not; but the choice is made because it is expected to advance understanding of the issue of interest. The strength of the case study design is also in its ability to deal with a wide variety of evidence likely to arise form the multiple sources of data collected in ethnographic research (Yin, 2003).

Whilst the stroke unit provided the context, the sampling frame for cases would include all the patients on the unit during the time of the study, their closest relatives and the nurses providing their care. From this sampling frame, participants would be purposively sampled who met the criteria for inclusion and who possessed the characteristics to provide the range required from the sample (Higginbottom, 2005; Schensul *et al*, 1999). In ethnographic studies such as those which focus on health care provision, purposive or judgemental samples are generally used, being based on the researcher's judgement to select the most appropriate participants, in order to answer the research question (Hammersley and Mairs, 2005; Higginbottom, 2005; Fetterman, 1998).

Ethnographic research using a case study design inevitably focuses on small numbers of cases, with the aim of studying them in depth and in detail (Mays and Pope, 1995). In attempting to predict the size of the sample, Schensul *et al* (1999) suggest that this should not only depend upon the objectives of the investigation and how much variability or diversity exists within the study population but also "field realities and capacities", regarding the time and resources available to the researcher (Schensul *et al*, 1999, p.266). With regard to these latter criteria, it was envisaged that I would spend twelve months in the study field, managing episodes of data gathering around my academic workload.

Deciding upon the number of cases to sample was challenging, as little guidance was apparent in the research texts and published reports of the ethnographic studies consulted to justify my choice of methods. Therefore, it was primarily during discussions with the senior academic who supervised the construction of the research proposal that the decision was taken to sample 15 cases. This was informed both by my supervisor's own ethnographic doctoral study (Seymour, 2001) and information I had obtained from the study site that the average length of patient stay on the stroke unit was approximately 30 days. Between twelve and fifteen cases appeared to be an achievable number to provide sufficient diversity within the sample (Lofland *et al*, 2006).

However, Alaszewski *et al* (2003) caution that such a structured approach to sampling may be neither feasible nor appropriate and that an initial sampling strategy might not go to plan for a number of unpredictable reasons. Crang and Cook (2007) and Hammersley and Atkinson (2007) also suggest that sampling strategies developed at the beginning of an investigation may need to change as the study progresses, because of the emergent nature of the research and the likelihood that preliminary analysis of data will direct later sampling. What could not be predicted in this study was that due to fluctuating admissions to the stroke unit, there were periods of several weeks which elapsed when no patients were available who met the selection criteria. In addition, the length of time that half of the participants remained on the ward greatly exceeded the 30 day average and in consequence, just 10 cases were sampled during a period of investigation which extended to 18 months (Table 2).

The selection and recruitment of research participants was planned as follows:

Nurses

During the first month of the study, all of the nurses and care assistants were individually asked to consider participating in the study, provided with an information booklet (Appendix 2c) and offered opportunities to ask questions before deciding whether or not to take part. This process of recruitment proved challenging, as the staff establishment was 16 qualified nurses and 17 care assistants. I wanted to ensure that my visits to the ward coincided with times that enabled all staff to be approached individually so with permission from the Ward Manager, names and rostered shift dates were extracted from the duty rota folder and I developed a checklist to record when I had spoken to an individual and requested signed consent. Nevertheless, this process took over a month to complete. Consent was requested to observe the nurses' interactions with patients and relatives, to participate in interviews, to access care records and to attend shift handovers and team meetings (Appendix 2d).

All potential participants in the study were given at least 48 hours to consider whether they wished to be included in the study. Consistent with ethical principles (Harris and Dyson, 2001), it was clearly indicated in the information booklets that it was their decision alone whether or not to take part and that they would be free to withdraw from the study at any time, without explanation. Two nurses declined to participate in the study and although another care assistant was initially hesitant, on the grounds that she did not like the idea of being interviewed, once a colleague explained to her that this was entirely voluntary, she agreed.

Other health care staff

Concurrent with the recruitment of the nursing staff, other health care professionals were also approached. Although it was not intended to directly involve other members of the multiprofessional team in the study, their presence in the setting could not be excluded, because they worked with patients in such close proximity to the nursing staff. Therefore, all staff who regularly worked on the ward were also provided with information about the study and asked to consent to participate; insofar as they might be present when data were being collected (Appendix 2e). The senior physiotherapist, occupational therapist and speech and language therapist provided the names of their colleagues who had routine contact with patients on the stroke unit and again, I approached them individually. No-one declined to participate but two therapy assistants questioned why the study was focusing only on the nurses, as they felt that they also contributed to the emotional wellbeing of patients. I had anticipated that some of the non-nursing staff might have felt affronted by this exclusive focus and recognised that this would have to be managed sensitively to minimise the risk of causing offence. I tried to assure them to this end, which they appeared to accept.

Patients

Recruitment of staff into the study needed to be achieved in advance of the recruitment of patients and relatives, as without their consent, it would not be possible for me to openly access the study setting where they practiced. However, the process was somewhat different in the case of patients and relatives, as specific criteria for selection had to be considered. With respect to their knowledge and authority, The Ward Manager, Deputy Manager and Stroke Nurse Specialist (SNS), as the senior nurses, were asked to identify a range of patients; with consideration to their age, gender, ethnicity and social networks. Multidisciplinary patient assessments were usually completed within the first seven days following admission to the unit and recruitment of potential participants would only be considered after the assessment had been completed.

Only those patients who had been assessed by the medical staff to be physiologically unstable or too physically frail would be excluded as potential participants, along with those who had been assessed by the speech and language therapist and occupational therapist to have such severe communication or cognitive impairments that their competence to understand and agree to participate would be questionable (Braunack-Meyer and Hersh, 2001; Helm-Estabrooks, 2002). Under such circumstances, it would be inappropriate to engage them in the study. The therapists' advice regarding a patient's competence to process information and give informed consent was respected and guidance was sought, as already indicated, to prepare individual strategies for communication prior to a patient being approached to participate in the study (Harris and Dyson, 2001). However, in excluding patients with severe communication and cognitive impairments, there was a risk that significant data from those patients most severely affected by a stroke would be missing from the study but the grounds for choosing potential participants had to be ethically based. Prior communication with the Trust Research and Development office had identified that the LREC would question any decision to seek assent from nearest relatives or significant others.

To reinforce the criteria for inclusion and exclusion, a written guide to participant selection was posted on the wall behind the staff base and in the Ward Manager's office (Appendix 5). The intention was that once a potential participant had been identified, the nurses would be asked to ascertain whether they would be interested in being given information about the study and if they were, the nurse would then introduce me to the person. However, the senior nurses wanted to apply an additional criterion for recruitment, insisting that the patient's family should be involved in the decision-making process from the outset. They would only introduce me if both the patient and the relative(s) agreed. This was an entirely reasonable proviso, as I appreciated the importance to the nurses of their relationships with relatives and the need to involve them in decisions which might impinge upon the patient's wellbeing.

Having outlined in brief the purpose of the study and the patient's anticipated role, an information booklet (Appendix 2a) was provided. I decided to utilise the aphasia-friendly version of the booklet to aid clarity, explaining to potential participants the purpose of the format. No-one was offended by this; indeed, all the other information booklets were produced in size 16 font for reading ease (Department of Health, 2003a). In most cases, patients immediately agreed to participate and where time allowed, we went through the information booklet and consent form (Appendix 2f) together there and then, otherwise, we arranged to do this as soon as possible.

Relatives

Those patients who expressed an interest in participating in the study were encouraged to discuss their decision with their closest relative, where possible and I then approached the relative directly to ask if they too would like to take part. It was also planned that relatives who were themselves physiologically frail or who lacked the competence to understand and agree to participate would be excluded but this proviso did not need to be implemented. Again, an information booklet (Appendix 2g), supported by verbal explanation was provided and time, as above allocated for decision-making, before requesting formal consent (Appendix 2h). Four of the patients had no close relatives regularly visiting them and in two cases, relatives expressed that they did not wish to participate in the study themselves, although they had no objections to the patient doing so; commenting that it would be nice for them to have someone else for them to talk to. As I did not encounter these relatives very often, their choice not to participate did not create a barrier to observing the patients.

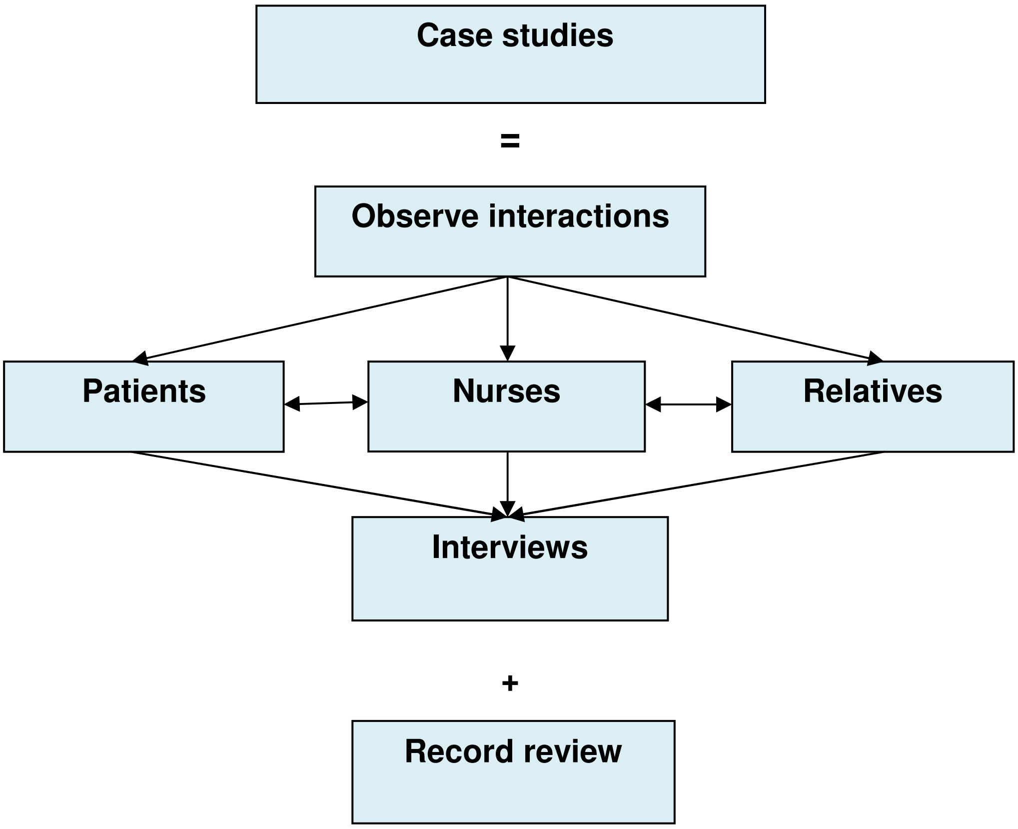
Visitors to the ward

Finally, within practice situations such as an in-patient, multiprofessional stroke rehabilitation unit, there are additional practical problems of informing and obtaining consent, because it is difficult to control who enters and leaves the area, or when a person enters and leaves (Moore and Savage, 2002; Merrell and Williams, 1994). Therefore, an additional strategy for achieving consent included aphasia-friendly, A3 size, printed and laminated notices, positioned at key places within the ward. These provided information for everyone entering the area of the research taking place, my identity, including a photograph and how and from whom further information could be obtained.

Data Collection Strategy:

Ethnography is an essentially pluralistic research approach, in that it usually embraces a number of data collection methods, including participant observation, interviews and other relevant sources of information such as documentary records (Lofland *et al*, 2006; Schensul *et al*, 1999; Hammersley and Atkinson, 1995; Laugharne, 1995). Each of these strategies for data collection was utilised in the study (Figure1), adapted from Long *et al*, (2001 p.19).

Figure 1: Data collection strategy



Participant observation

Participant observation involves long periods of watching people, along with talking to them about what they are doing, thinking and saying (Delamont, 2004). It involves an interweaving of looking, listening and asking (Roper and Shapiro, 2000). Savage (2000b) suggests that there are parallels between participant observation and the practice-based profession of nursing and that examining one might increase understanding of the other. Indeed, within the context of nursing research, participant observation has been widely used as a method of data collection (Barber-Parker, 2002; Davies *et al*, 2000; Gerrish, 1997); although attention is drawn to difficulties with the approach (Mulhall, 2003; Bonner and Tolhurst, 2002; Declercq, 2000; Kite, 1999; Gerrish, 1997). The complexity of participant observation may render it impossible to predict and, therefore, to prescribe for all the difficulties and dilemmas that might be encountered. Nevertheless, I needed to be aware of the issues (Labaree, 2002; Merrell and Williams, 1994) and, as Gerrish (1997) suggests, continuously revisit the literature to 'extract the principles' to apply to the situation encountered.

Mulhall (2003) suggests that participant observation provides insight into interactions, captures context and process, informs about the influence of the whole environment and thereby illustrates 'the whole picture'. Moore and Savage (2002) suggest that this approach can be particularly useful in learning about how people relate to each other and how they make sense of their lives and experiences. The researcher, as observer, is able to explore aspects of practice that might otherwise be difficult to access (Lofland *et al*, 2006; Kennedy, 1999), such as emotional interactions, as observation can reveal much that an individual may be unable to describe or consider “too trivial or extraneous to discuss” (Morse 2003, p.155). In addition, as Lupton (1998) suggests:

> “…language can frequently sadly fail our needs when we try to articulate our feelings to another person. Facial expressions or bodily movements and other physical signs can often be far better indicators of a person’s emotional state than words" (p.32)

Clarifying a role for myself as a researcher was also vitally important and I adopted the position that participation “does not necessarily mean doing what those being observed do, but interacting with them while *they* do it” (Delamont 2004, p.218); *‘they’* being the nurses. Spradley (1980) highlights the need to maintain a balance between participation and observation and Delamont (2004), Coffey and Atkinson (1996) and Morse (1994) all argue that the researcher cannot observe whilst at the same time working, as such competing agendas are distracting and the processes of observing and recording notes interfere with doing work. However, Allen (2004) recognises that because of the pressures on clinical staff, it would be difficult to remain unoccupied whilst others are busy. Therefore, I offered to make beds, serve drinks, run errands and undertake any other tasks which might support the nurses’ work during periods when I was not observing.

My identity as a researcher did have to be considered and Allen (2004), Davis (2001) and Lofland *et al* (2006) raise the importance of ‘dressing for the field' to avoid role ambiguity. Therefore, following consultation with the Ward Manager and in accordance with Trust policy regarding health and safety at work and infection control, I adopted my customary work clothes of plain, dark coloured trousers and top and flat shoes. I created a simple name badge which identified me as 'researcher'. My appearance initially provoked comment from one nurse who said that I looked like a store detective and a physiotherapist jokingly described my behaviour of walking up and down to corridors as 'stalking'. Nevertheless, I did appear to quickly blend into the background; later confirmed by the Ward Manager who said that I had become 'part of the furniture'.

The potential for role conflict when research is undertaken by nurses in health care settings is well-documented (Morse, 2007; Wilkes and Beale, 2005; Casey, 2004; Gerrish, 2003; Hutchinson and Wilson, 1994;); including the risk of experiencing divided loyalty between the code of professional conduct (Nursing and Midwifery Council, 2004) and commitment to the research study. However, as Morse (2007) and Gerrish (2003) remark, professional accountability must take precedence, thus it was made clear from the outset that if I were to observe unsafe practice or negligence, I had a duty to intervene in the patient's interests (Gerrish, 2003). Accordingly, all the information booklets clearly indicated that any unresolved, unsafe practice observed by, or reported to me, would be reported to the appropriate authorities, following discussion with the parties concerned. Several ethical issues did arise during the course of the study and having a clear protocol in place for dealing with them proved invaluable. One such issue is described in Appendix 6 (Research journal extract No.1).

Casey (2004) developed an ethical protocol outlining at what point she would actually intervene in patient care, including: the patient experiencing a life-threatening event, being at risk from other patients or a source of danger and being at risk of sustaining injury in the absence of care personnel. An informal protocol along these lines was agreed in advance of my contact with patients and to ensure that I presented no risk to patients, during the preparation period, I undertook the Trust induction programme which included basic life support and moving and handling training. Care was taken to ensure that no clinical interventions were obstructed or compromised by my presence and it was agreed with the Ward Manager that should a patient or their relative request information about their condition or their care, such requests would be referred to an appropriate member of staff.

Observation was focused around individual ‘cases’ already described and data collection was planned to comprise periods of focused, participant observation of interactions between patients, their relatives and nurses; for 1-2 hours at a time, on 8 to 10 occasions, over a 4 week period. I attempted to position myself in relatively close proximity to the persons concerned, without being obtrusive and made notes in a pocket-size notebook as soon as possible after an episode of observation. I usually returned to the staff base to make these notes, or used the notes trolleys outside each patient bay, as these were the places where most writing occurred. These notes trolleys also afforded good vantage points to observe from outside a bay. I had explained during the recruitment period that I would be making notes and no-one challenged me about this. Occasionally, however, when nurses were conversing at the staff base whilst I was writing, they would jokingly ask me not to write down what they were saying. Informal interviews (conversations), aimed to seek clarification of interactions observed and questions were asked to aid interpretation. In actuality, the number and duration of patient observations greatly exceeded those planned (Table 1) although great care was always taken on every occasion to ensure that participants were agreeable for this to continue.

In maintaining participation in the study, a collaborative, negotiated approach to consent was utilised, supplementing the initial process of written and documented informed consent. This was because there are particular concerns regarding informed consent and participant observation (Moore and Savage, 2002), in that due to the nature of the approach, gaining informed consent cannot be regarded as a single event but as an ongoing process (Jokinen *et al*, 2002). The concept of negotiated consent places the emphasis on the processes of communication (Olsen, 2003), wherein I needed to be sensitive to participants' reactions during data collection and renegotiate consent on a regular basis (Jokinen *et al*, 2002; Ramcharan and Cutcliffe, 2001; Usher and Arthur, 1998). This provides “a documentary strategy for protecting respondents from harm” (Kavanaugh and Ayres, 1998).

Table 2: Research study chronology

No.	Partici-pant	Date of stroke	Intro-duced	Consent given	Interview	Transfer of care	LOS	Length of contact	No. of obs
1	Celia	16.11.06	27.11.06 day 12	28.11.06 day 13	29.11.06 day 14	29.11.06	14 days	3 days	3
2	Gavin	15.10.06 readmitted 16.11.06	29.11.06 day 46	29.11.06 day 46	03.12.06 day 50 13.12.06 day 60	08.11.06 13.12.06	60 days	15 days	7
3	Lily	19.12.06	08.01.07 day 21	11.01.07 day 24	24.01.07 day 37	12.02.07	56 days	36 days	17
4	Fred	21.02.07 readmitted 14.04.07	29.03.07 day 37	30.03.07 day 38	09.04.07 day 48 12.05.07 day 80	11.04.07 18.05.07	87 days	51 days	27
5	Sid	23.03.07	10.04.07 day 19	13.04.07 day 22	30.04.07 day 38	31.05.07	70 days	52 days	21
6	Ingrid	01.07.07 Transfer to Stroke Unit from another hospital 11.07.07	16.07.07 day 16	17.07.07 day 17	29.07.07 day 29	01.08.07	32 days	17 days	10
7	Helen	01.09.07	05.09.07 day 5	08.09.07 day 8	15.09.07 day 15	19.09.07	19 days	15 days	8
8	June	25.09.07	02.10.07 day 8	03.10.07 day 9	07.10.07 day 13	16.10.07	22 days	15 days	9
9	Norman	24.10.07	07.11.07 day 15	26.11.07 day 35	15.12.07 day 53	20.12.07	58 days	44 days	12
10	Iris	02.01.08 Transfer to SU from another ward 10.01.08	12.01.08 day 11	12.01.08 day 11	09.02.08 day 39	17.03.08	76 days	66 days	20

I also attended shift handovers and ward team meetings, when possible, although I felt uncomfortable listening to information about other patients on the ward about whom I had no right of access. Shift handovers on the ward are important occasions for nurses to share knowledge and expertise, in order to inform and promote the continuity of patient care (Kerr, 2002; Sherlock, 1995), although Payne *et al* (2000) have identified that psychological aspects of patient care and psychosocial information are largely invisible from ward handovers. However, Kerr (2002) suggests that this may in part be due to the tension between achieving comprehensiveness and avoiding information overload. Nevertheless, observing the exchange of information about patients and their relatives during handovers provided me with helpful insights into nurses' understanding of the emotional experience of stroke and how they responded to this.

In contrast to nursing handovers, Payne *et al* (2000) maintain that psychological aspects of care have been found to be more apparent in multiprofessional team meetings. Formal, weekly, multiprofessional team meetings are considered key events for the exchange of information about patients and relatives and an opportunity for all team members to share their views (Gibbon, 1999); although Anderson and Dorsay (1998) and Gibbon (1999) have identified that nurses often have difficulty in making a specific contribution to team discussions, which tend to be therapist-led. Nevertheless, it was anticipated that observation of team meetings might yield helpful insights, as above and I tried to attend these whenever possible throughout the study period.

Interviews

Within the context of ethnography, interviews are aimed at describing the person’s cultural knowledge; emphasising interaction and the social context and although they are often conducted as informal, ‘friendly conversations’, the explicit purpose of the interview needs to be reiterated and sensitivity to the emotional focus of questioning requires consideration (Sorrell and Redmond, 1995). Guidance for developing and sequencing ethnographic questions is readily available in the research literature (Lofland *et al*, 2006; Heyl, 2001; Schensul *et al*, 1999; Sorrell and Redmond, 1995; Jorgensen, 1989; Spradley, 1979) and was used to aid the construction of preliminary interview topic guides for all participants (Appendix 7).

In addition to communication difficulties, a stroke can also result in cognitive and perceptual problems which may affect the ability of a person to participate in the interview process and, again, these factors have often resulted in their exclusion from research studies (Paterson and Scott-Findlay, 2002). Poor recall of events, attention and concentration difficulties, fatigue and distraction can severely limit a person’s tolerance of questioning (Michael, 2002; Paterson and Scott-Findlay, 2002; Gregory, 1998). Thus, I planned to undertake careful, pre-interview preparation, in order to assess the best location and timing for the interview, the person’s tolerance of ‘extraneous stimuli’ and their levels of fatigue (Paterson and Scott-Findlay, 2002). Prioritising questions, framing short questions and the use of frequent prompts are suggested (Paterson and Findlay-Scott, 2002).

Jorgensen (1989) suggests that in-depth interviews are particularly valuable when participants who are especially knowledgeable about the matter of interest have been identified during observations. Based on their knowledge, insight and willingness to talk about their situation (Baillie, 1995), all of the patients and some of the relatives and nurses who agreed to participate were subsequently interviewed individually (Table 3). These latter key informants comprised the purposely selected nurses who have been observed during their interactions with patients and their relatives. A digital voice recorder was used and the recordings transcribed verbatim as soon as possible following each interview. One care assistant asked me not to use the voice recorder but only because she was self-conscious of the way that she sounded and another thanked me for the opportunity to share her thoughts about the care she provided to patients. It was also planned that at the point of discharge, a further follow-up interview would be requested of patients and relatives; to take place approximately 4 to 6 weeks later in the person's home, when they would have had time to reflect on their experiences.

Borbasi *et al* (2005) and Kavanaugh and Ayres (1998) highlight the potential for participants to experience emotional distress during interviews, cautioning that assessing distress is complex and challenging. Although the research processes in the study did not involve the risk of physical harm to participants (Olsen, 2003; Murphy, 2000), nevertheless, they could have presented a risk to emotional wellbeing and Wilkes and Beale (2005), recommend that the

Table 3: Research study activity timetable **Key: PI = patient interviews; RI = relative interviews; NI = nurse and HCA interviews**

	2006			2007												2008			
	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr
Month	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
Preparation In the field	▨																		
Observation, Patient & Relative Interviews		PI 1	PI 2 (1)	PI 2 (2) PI 3 RI 1 RI 2	▨	PI 4 (1) PI 5	PI 4 (2)	▨		PI 6		PI 7	PI 8	▨	PI 9	▨	P 10	▨	
Staff interviews						NI 1 NI 2	NI 3								NI 4 NI 5 NI 6	NI 7	NI 8	NI 9	NI10 NI11 NI12

researcher should be prepared for difficult situations. Therefore, care was taken to consider participants' feelings throughout the interviews.

It was anticipated that appropriate preparation as already outlined, in combination with my sensitisation to the needs of persons affected by a stroke during several years of practice experience with neurologically impaired people, would enable any signals of discomfort or distress to be detected and responded to immediately. However, contingency arrangements were made to offer support to any person who might require it, which included, with the person's permission, access to the Stroke Nurse Specialist and the Rotherham Stroke and Disabilities Support Group. Fortunately, such contingencies did not arise. During one interview with a relative, she did start to cry but declined my offer to turn off the recorder and indicated that she did not want to stop talking. Nevertheless, I felt quite guilty for having caused her to become distressed and apologised afterwards.

On occasions, I had to modify or abandon plans to observe or interview participants; patients, relatives and nurses alike, because the timing was not right. If it was evident that the person I was intending to talk with appeared to be distressed, distracted or pre-occupied, then a decision was quickly taken not to proceed. I considered this to be an ethical decision, on the grounds that it was unethical to intrude, or pursue a course of action which may have compromised their wellbeing. Likewise, if a person had visitors, then I did not think that it was appropriate for me to intrude upon this situation and would retreat into the background. However, Hutchinson *et al* (1994) and Murray

(2003) suggest that participants can also experience benefits by talking about their feelings and sharing information with someone who is an attentive listener.

Patient records and other documentary sources

Patient records were also accessed, once consent had been received. Miller and Alvarado (2005) have argued for greater attention to documents as a supplementary source of data in qualitative nursing research, as they can reveal “the competence and often the specialized knowledge of their producers” (p.349). Documenting health care interventions is a routine element of all health care practitioners’ work but as a record of care delivered over a 24 hour period, nursing records are apparently unique. Therefore, nursing records which related to interactions observed provided a further potential source of information.

Permission was requested in line with the Department of Health guidelines (DH, 2005; 2003b) and data protection legislation (Great Britain, 1998), to access, read and make notes from nursing and team meeting records, especially where there was specific reference to emotional expression. However, as Heartfield (1996) argues, in an attempt to meet legal, ethical and institutional guidelines, nursing records may barely represent the care that has actually been delivered and because of the objective language required, there may be difficulties in documenting such subjective aspects of nursing care as emotional support. This proved to be the case, as the nursing records focused almost exclusively on patients’ physical care needs.

However, other documentary sources and cultural artefacts such as 'thank-you' cards provided useful data sources, which will be expanded upon later.

Ensuring participants' privacy and confidentiality

Observation, interviewing and the scrutiny of written records raise important questions in relation to privacy and confidentiality. With respect to privacy, it was decided that should a member of the health care staff or a relative who had not consented to participate in the study come to be in the patient's presence when I was observing interactions, I would withdraw for that period of time. Research participants also have a right to confidentiality and protection from unwarranted revelations of personal information, as outlined in the Data Protection Act 1998 (Great Britain, 1998) and the safeguards embedded in the Department of Health Research Governance Framework (DH, 2005). Therefore, extreme care was taken with the collection, storage and transmission of data, wherein the identification of individuals will be protected by anonymisation, by my acquisition of an honorary contract within the host NHS Trust and by obtaining informed consent from the participants (Souteriou *et al*, 2005; DH, 2003b). All electronic data were stored on a password-protected computer and written field notes and other paper records were stored in a locked filing cabinet, accessible only by me. The participants' information booklets and consent forms clearly stated the right to refuse consent or to withdraw consent at any time. In addition, ongoing, process consent, as already outlined, was utilised to further protect the interests of all participants.

Reflexive research journal

One further source of data was my reflexive research journal. Davies (1999) and Finlay (2003) maintain that reflexive journals or notebooks enable researchers to recount the thoughts and feelings experienced as a result of their interactions with the research so that their experiences belong to the data as well. My interactions with participants and with the research processes, feature prominently within the journal from the outset of the study and as Finlay (2002) asserts that reflexive analysis occurs throughout the research process, keeping a reflexive journal was essential in exposing “how the process and outcomes of data collection depend fundamentally on how the research relationship evolves” (p.58). Entries into the journal extend well beyond the completion of data collection but with the focus shifting more specifically to formal analysis. Several extracts, signposted throughout the thesis are presented in Appendix 6.

Data analysis:

Developing an analytical strategy

De Laine (1997) describes data analysis in ethnography as “The last frontier… that is still cloaked in mystery” (p.211). Approaches to analysing ethnographic data, such as those offered by Crang and Cook (2007), Lofland *et al* (2006), Le Compte and Schensul (1999) and de Laine (1997) offer valuable guidance on processes but because ethnography draws on a broad range of theoretical models, concepts and ideas (de Laine, 1997), there is no single theoretical approach to ethnographic analysis. Nevertheless, in order to ensure rigour, the analytical strategy needed to be carefully and thoroughly planned and executed (Crang and Cook, 2007).

Lofland *et al* (2006) identify 4 key features of data analysis: Firstly, that the process is "*skewed in the direction of induction* rather than deduction", secondly, that because of the inductive nature of analysis, *"researchers are central agents in the analysis process"*; thirdly, it is, therefore, a "*highly interactive process"* between the researcher and the data, which like immersion in the field, requires immersion in the data; and fourthly, it is *"labour-intensive and time-consuming"* and needs to be pursued in a persistent and methodological fashion (p.195-196). With regards to the first of these features, by 'induction', Lofland *et al* (2006) explain that analysis is driven by the data rather than by hypothesis testing; that theoretical or empirical observations which emerge inductively are 'grounded', in that they emerge "from the ground up rather than being called forth by prior theoretical constructs" (p.195). However, they also suggest that this 'grounded' metaphor should be used with caution because of its specific association with the methodological approach of grounded theory; the use of which has been contested within ethnographic research (Lofland *et al*, 2006).

Grounded theory, which has influenced the methods of ethnographic analysis, "…treats data analysis as a form of inductive theory construction, in which every 'explanation' of data is a hypothesis to be rigorously tested by a search for counter examples" (Eraut 2005, p.113). However, this has been criticised because of its apparent failure to address "how theory is inherent in the notion of data in the first place" (de Laine, 1997 p.225); that the researcher's pre-understandings of what they are studying, their ideas and hunches, will necessarily influence how they perceive events and write them up in the data. Hammersley and Atkinson (2007) argue that field notes are always selective, in that it is not possible to capture everything; so researchers have to make informed decisions based on their background knowledge. Therefore, in making any observation, an interpretive process is involved (Wolfinger, 2002).

In other words, the researcher already has some idea of what to look for; that "Theory does not jump out of the data to be 'discovered' but is an orientating force shaping what gets written in the notes as raw data" (de Laine, 1997, p.225). This resonates with the second and third of Lofland *et al*'s (2006) features of ethnographic research, that the researcher is the central agent in the process and is thereby highly interactive with the data from the outset. However, their fourth feature emphasises the need for a careful, thorough and structured approach to analysis and the methods by which I interacted with the data are described in the following sections, starting with the phase of preliminary analysis and moving on to more formal analysis.

Preliminary analysis:

Hammersley and Atkinson (1995) describe the initial task of data analysis as finding some concepts that enable the researcher to make sense of what is going on; "a way of piecing things together, figuring things out, gaining focus and direction as the research unfolds" (Crang and Cook, 2007 p.132). Gbrich (2007) describes preliminary analysis as an ongoing process which occurs whilst the data are being constructed and a means of ‘checking and tracking’ to see what is emerging from them. Engaging with the data (text) in this way enables a deeper understanding of the values and meanings which lie within them and which, Gbrich (2007) argues, is a process that should be undertaken in order to highlight emerging issues and to provide directions for the seeking of further data. This enables the researcher to identify areas which require follow-up and to actively question where these should lead or are leading them (Gbrich, 2007). Thus, theorising starts from the first day of fieldwork, as soon as observations are recorded in the field notes and the emerging theory guides the next phase of the process (de Laine, 1997).

Developing theoretical sensitivity

A researcher’s professional background, their personal experiences and familiarity with the literature all influence the interpretation of the data and not only provide an a priori familiarity with relevant issues but also enhance their ability to make sense of the data (Sword, 1999). Therefore, theoretical sensitivity is important for generating insight. Sensitising concepts are the general points of reference which help to orientate the researcher by “pointing to avenues along which to look” (de Laine, 1997 p.216) and although I was not initially aware of this as a discrete analytical process in my research journal (Appendix 6 – research journal extract 2), it is evident that ideas were starting to form very soon after meeting the first patient participating in the study (Box 1).

Box 1: Example of a sensitising concept

> "Celia told me that her parents had been in the Salvation Army and also that her mother had lived with breast cancer for 18 months. She described her mother as 'a fighter' and that she thinks that a person's state of mind has a great influence on how they deal with an illness. This is where she says her attitude to her stroke comes from; "fight it"…I would really like to speak to her about this, as her approach to recovery appears to be driven by her particular attitude"
>
> **(Research journal – 28.11.06, p.44-45)**

From this point, I started to explore with the nurses and other participants what influence they thought a person's attitude, their personal beliefs or approach to life had on their recovery; together with trying to locate literature which had addressed this aspect of stroke recovery. In these ways, I believed that I was seeking some sort of assurance that I was not completely off-track with this idea and that what I was thinking might resonate with what others thought as well.

However, Sword (1999) cautions that developing theoretical sensitivity can block attempts to think imaginatively and McEvoy (2001) suggests that there is a risk in undertaking research in a familiar practice setting to assume a shared understanding between the researcher and participants. Such cultural assumptions, which are often difficult to recognise, need to be acknowledged as potential barriers to theoretical sensitivity (de Laine, 1997) and It is important to validate the researcher's interpretations with those of the participants during observations by "asking plenty of questions and questioning the obvious" (de Laine, 1997). For example, it is traceable through my research journal that after patients and relatives in the first two cases had described the nurses as “great” or “fantastic”, in response to this, I asked several of the nurses what they thought was meant by this. I included the question in the interview schedule for subsequent interviews; exploring the perspectives of both the caregivers and recipients. This questioning started to reveal insights into what the nurses believed patients and relatives wanted from them, as well as what they in turn valued in the nurses’ approach. Another example is when a patient said that the nurses helped by being encouraging; the nurses were then asked what they thought this meant and how they thought they provided encouragement.

Theoretical sampling

This process of following up on recurrent patterns in participant data and asking key participants to elaborate further, resonates with another strategy derived from grounded theory methodology known as theoretical sampling (Drauker *et al*, 2007). Theoretical sampling involves the modification of data collection, to gain specific information regarding an emerging concept and can also be used to direct researchers to other sources of information such as research papers (Drauker *et al*, 2007). Keeping track of emergent themes can be achieved by a process of memoing; making notes on “personal observations on relationships with people, with novel situations, with thoughts and ideas” (Gardener, 2008 p.76). The use of several coloured highlighter pens and pencil jottings in margins facilitated this process in my research journal and in the case study records.

Constructing the databases

On completion of the data collection, several folders of information had been accumulated, including the research journal, field notes and interview transcripts relating to the ten cases, transcripts of the interviews with nurses and sundry 'artefacts' in the form of blank copies of nursing records and other documents I had considered relevant to the context. Gbrich (2007) suggests that by the time that preliminary analysis has been completed, it is likely that the researcher will have a clear idea of what the database contains and of the issues becoming evident; and that the data will have already been partly analysed, ordered and made sense of. However, translating this "messy process" into a "neat product" still has to be achieved (Crang and Cook, 2007) and this is done through strategies for formal analysis.

Formal analysis

In formal analysis, the data need to be broken down into manageable units, to organise them in a systematic way so that patterns and trends can be identified (Lofland *et al*, 2006). Processes of reducing data into meaningful groups which are easier to manage can involve either a 'block and file' method or 'conceptual mapping'; or a combination of both (Gbrich, 2007). In the first approach, relatively large sections of data can be retained intact but these can become difficult to manage, whereas conceptual mapping can enable a brief and tidy summary of the key issues. However, there are risks with the latter approach, as the use of key words and phrases can oversimplify and decontextualise issues so that it is necessary to keep returning to the database to refocus on the full picture (Gbrich, 2007). I found both approaches helpful; the former for organising the data to facilitate the identification of key issues and the latter for exploring more creatively the inter-relationships between them. However, although it was helpful in the process of sorting, the block and file approach achieved little in terms of data reduction.

Initially, case study files were constructed by integrating all the sources of data relating to the ten individual cases. The means of achieving this evolved from the first case, which was written-up as a chronological narrative, charting the patient's experiences from the stroke event through to their transfer of care from the stroke unit and beyond but also structured around the responses to questions asked in the formal interview (Appendix 7). Analytical memos were written alongside and what appeared to be key issues were colour-coded with highlighter pens; a process consistent with that already described in connection with preliminary analysis. An illustration of the process is provided in the brief extract (Box 2). The sections highlighted in yellow refer to things which the nurses do to help.

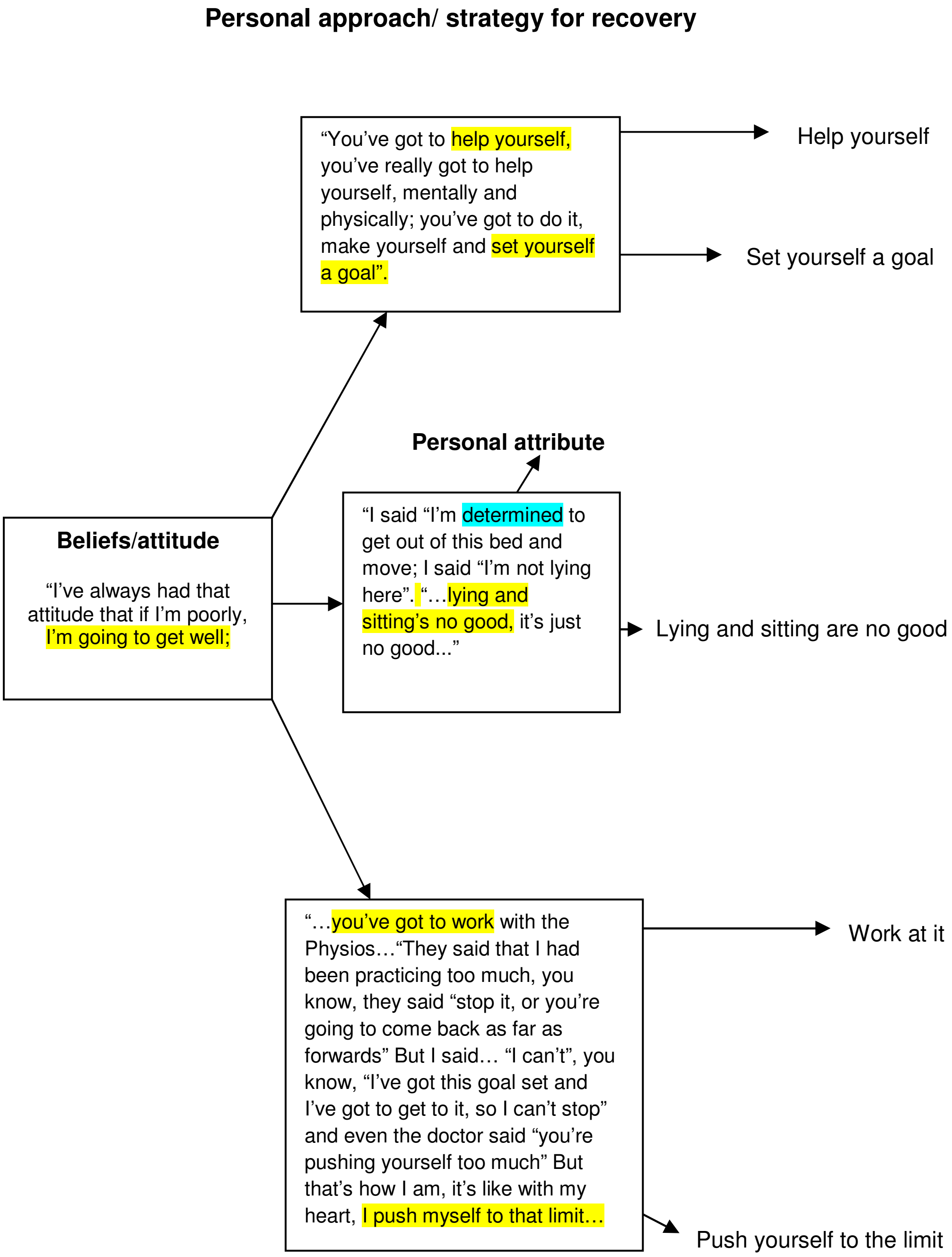
Box 2: Extract from case study 1:

Description of the case	Analytical memos
…during the interview, she had mentioned that the nurses had been really supportive when she had received bad news. "…that night I was upset and the nurses were fantastic, they were absolutely great.	Nurses had been supportive when she received bad news and was upset They were fantastic, great
I asked what they did to help her: "They made me a cup of coffee, one sat at the side of the bed, kept coming to me, you know, the support that they give you, you can't – it's great, fantastic. I mean, one that went off, left me a little note saying to get better and all that and the other one kissed me before she went off. It's little things like that…	Made me a drink Sat with me Attentive The support is great, fantastic Left me a note Kissed me It's the little things that count

This was a useful starting point in order to explore the data reflecting the experiences unique to the individual cases (within-case analysis) before progressing to identify which issues applied across all the cases (across-case analysis) (Ayres *et al*, 2003). A section of within-case analysis is displayed in Figure 2.

Constructing the case studies in this way was useful for displaying the data as a whole but it failed to adequately represent the differing perspectives of the patients and their relatives. Therefore, further blocks of text were constructed, separating these out. The process also assisted with the further identification of key issues and once completed, across-case analysis was possible, enabling a clearer picture to emerge of what it was like to experience a stroke and what key factors either contributed to or created barriers to recovery. These insights were achieved by a process of coding and categorisation; principles again taken from the methodology of grounded

Figure 2: Example of within-case analysis



Personal approach/ strategy for recovery

Beliefs/attitude

"I've always had that attitude that if I'm poorly, I'm going to get well;

"You've got to help yourself, you've really got to help yourself, mentally and physically; you've got to do it, make yourself and set yourself a goal".

"I said "I'm determined to get out of this bed and move; I said "I'm not lying here". "…lying and sitting's no good, it's just no good..."

"…you've got to work with the Physios…"They said that I had been practicing too much, you know, they said "stop it, or you're going to come back as far as forwards" But I said… "I can't", you know, "I've got this goal set and I've got to get to it, so I can't stop" and even the doctor said "you're pushing yourself too much" But that's how I am, it's like with my heart, I push myself to that limit…

theory (Lofland *et al*, 2006). Indeed, Gbrich (2007) refers to this as “quasi” grounded theory; a modification of the approach which involves some form of coding but which is essentially a general hermeneutic approach with variations.

Coding and categorisation

Research texts describe the processes of coding and categorisation differently but essentially, codes are “names or symbols used to stand for a group of similar terms, ideas or phenomena” (Le Compte and Schensul, 1999 p.55). Coding involves fracturing the data and decontextualising them; separating them out and reassembling them in new ways (Lofland *et al* 2006). Patterns in the data become apparent during the coding process, during which it becomes possible to generate statements of relationships between phenomena (Lofland *et al*, 2006). In the initial process of coding, data are taken apart and their discrete components are examined for differences and similarities. This decontextualisation can be achieved by interrogating the data line by line, sentence by sentence or by segment by segment; to identify whether there are specific themes or concepts to which the issues relate (Lofland *et al*, 2006); a process consistent with what is described as the constant comparative method (Priest *et al*, 2002).

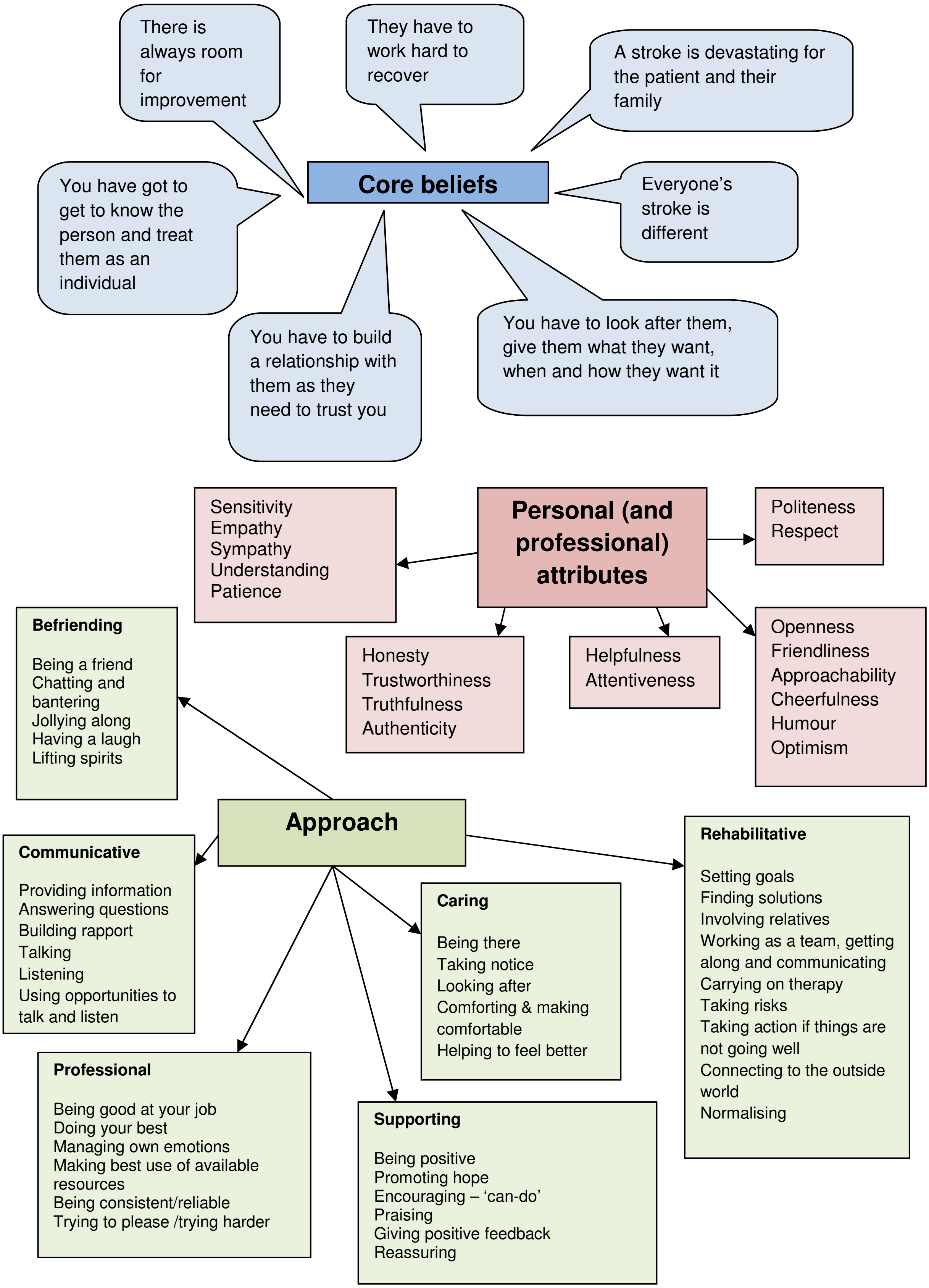
The purpose is to search for a major idea and name it; preferably using the words or phrases which are used by the participants themselves. Concepts which are essentially similar can eventually be labelled with the same name and each concept can then be defined in terms of a set of properties and dimensions that add clarity and understanding (Priest *et al*, 2002). The resulting list can then be sorted into groups of similar or related phenomena, which in turn become categories. Links between categories can be identified by use of diagrams or charts, to facilitate the structuring of evolving analysis (Lofland *et al*, 2006). Recontextualising of the data thus involves identifying relationships between concepts and themes and theory building (de Laine, 1997). Eventually, a small number of core categories are identified, to which all other sub-categories relate and a conceptual framework may be developed. The next stage is to verify whether these statements hold true against the rest of the data but it is also important to look for contradictions and variations in the data.

Negative, atypical, or deviant case analysis is both a way of establishing trustworthiness and a process for testing tentative propositions, where patterns and trends in the data have been identified (de Laine, 1997). Understanding of these patterns and trends is increased by considering instances and cases which do not fit with the pattern (de Laine, 1997), as they provide a different perspective or exception to the emergent rule. In the dataset, one atypical case was clearly identified, with a second deviating to a lesser extent from the others and these proved particularly insightful with respect to testing the emergent theory.

The main challenge that I experienced was that having undertaken a within-case and across-case analysis of the case study data and developed an appreciation of the atypical case, I achieved a perspective of recovery from stroke mainly from the patients' and relatives' perspectives. I had not really captured how nurses interacted with their experiences from the perspective of the nurses themselves. This required a further analysis of the interview transcripts, together with records of conversations (informal interviews) and observations as a separate dataset. It was this process which stimulated the development of a conceptual framework and enabled a tentative explanation of the relationship between patients, relatives and nurses and the ways in which, when synchronised, their emotional wellbeing during the process of recovery from stroke was supported (Figure 3).

Figure 3 displays how through their statement of **core beliefs**, the nurses indicated that they perceived the experience of stroke to be a catastrophic event for both the patient and their family. Every stroke was an experience unique to the individual. The nurses also believed that there was always potential for improvement but this involved hard work. Therefore, building a relationship with the patient and their relatives, getting to know them and caring for their individual needs was essential. Achieving this involved the purposeful application of their **personal and professional attributes** to an **approach** which focused on enabling the patient and their family to engage in the process of recovery. Their emotional wellbeing was supported through the medium of the relationship.

Figure 3: Concept map of the nurses’ perceptions of their contribution to stroke recovery

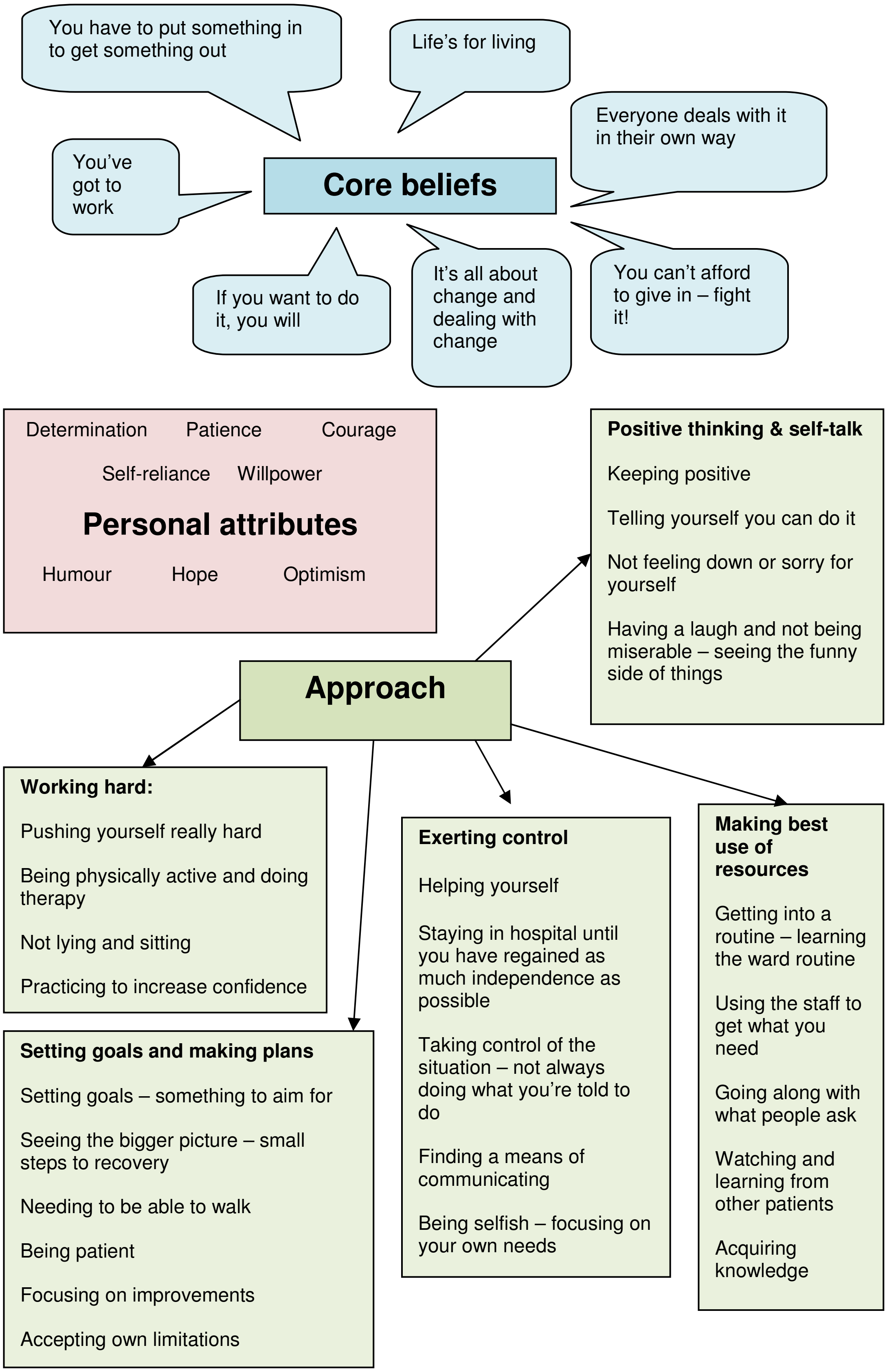


For the nurses, working with people affected by a stroke was the focus for their everyday working experience and over time, they had developed and embedded into their practice, the knowledge and skills which informed their approach to care. They believed that their interactions with patients and their families would necessarily impact upon the experience of recovery, through the medium of a therapeutic relationship built and sustained between them.

For patients and their relatives, stroke rehabilitation was a new experience, even when this had not been the first stroke (see Table 4 in the next chapter). None of them had previously been admitted to the stroke unit so would have no prior experiences to draw upon. However, many of the patients in the study had concurrent long-term conditions, which when questioned about, appeared to have influenced their **core beliefs** with regard to recovery from the stroke. These beliefs emphasised their active role in the recovery process, which was necessary to deal with change and get on with life (Figure 4). Patients harnessed their **personal attributes** or strengths to drive themselves forward through an **approach** which focused on keeping positive, exerting control, working hard, setting goals and making the best use of available resources.

Figure 4:

Concept map of patients' perceptions of recovery from stroke



Core beliefs

You have to put something in to get something out

Life's for living

Everyone deals with it in their own way

You've got to work

If you want to do it, you will

It's all about change and dealing with change

You can't afford to give in – fight it!

Personal attributes

Determination, Patience, Courage, Self-reliance, Willpower, Humour, Hope, Optimism

Approach

Positive thinking & self-talk

Keeping positive

Telling yourself you can do it

Not feeling down or sorry for yourself

Having a laugh and not being miserable – seeing the funny side of things

Working hard:

Pushing yourself really hard

Being physically active and doing therapy

Not lying and sitting

Practicing to increase confidence

Setting goals and making plans

Setting goals – something to aim for

Seeing the bigger picture – small steps to recovery

Needing to be able to walk

Being patient

Focusing on improvements

Accepting own limitations

Exerting control

Helping yourself

Staying in hospital until you have regained as much independence as possible

Taking control of the situation – not always doing what you're told to do

Finding a means of communicating

Being selfish – focusing on your own needs

Making best use of resources

Getting into a routine – learning the ward routine

Using the staff to get what you need

Going along with what people ask

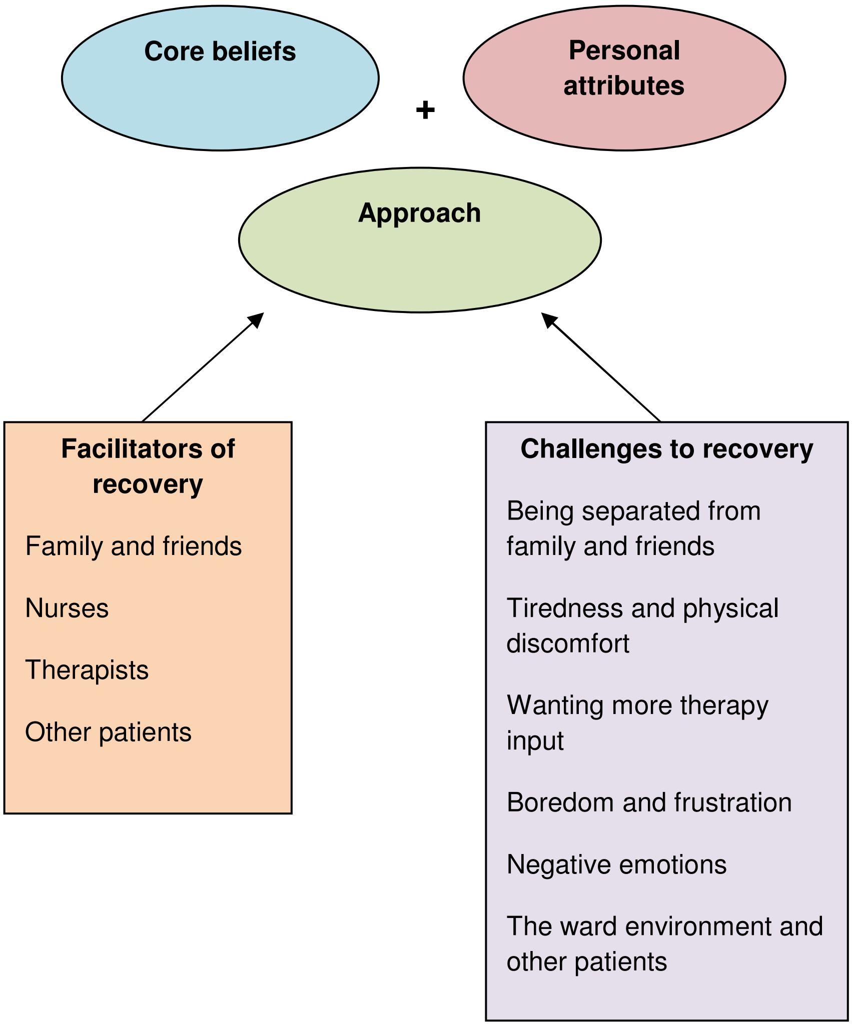
Watching and learning from other patients

Acquiring knowledge

The patients also clearly identified a number of facilitators and challenges to recovery (Figure 5).

Figure 5:

Patients' perceptions of facilitators and challenges

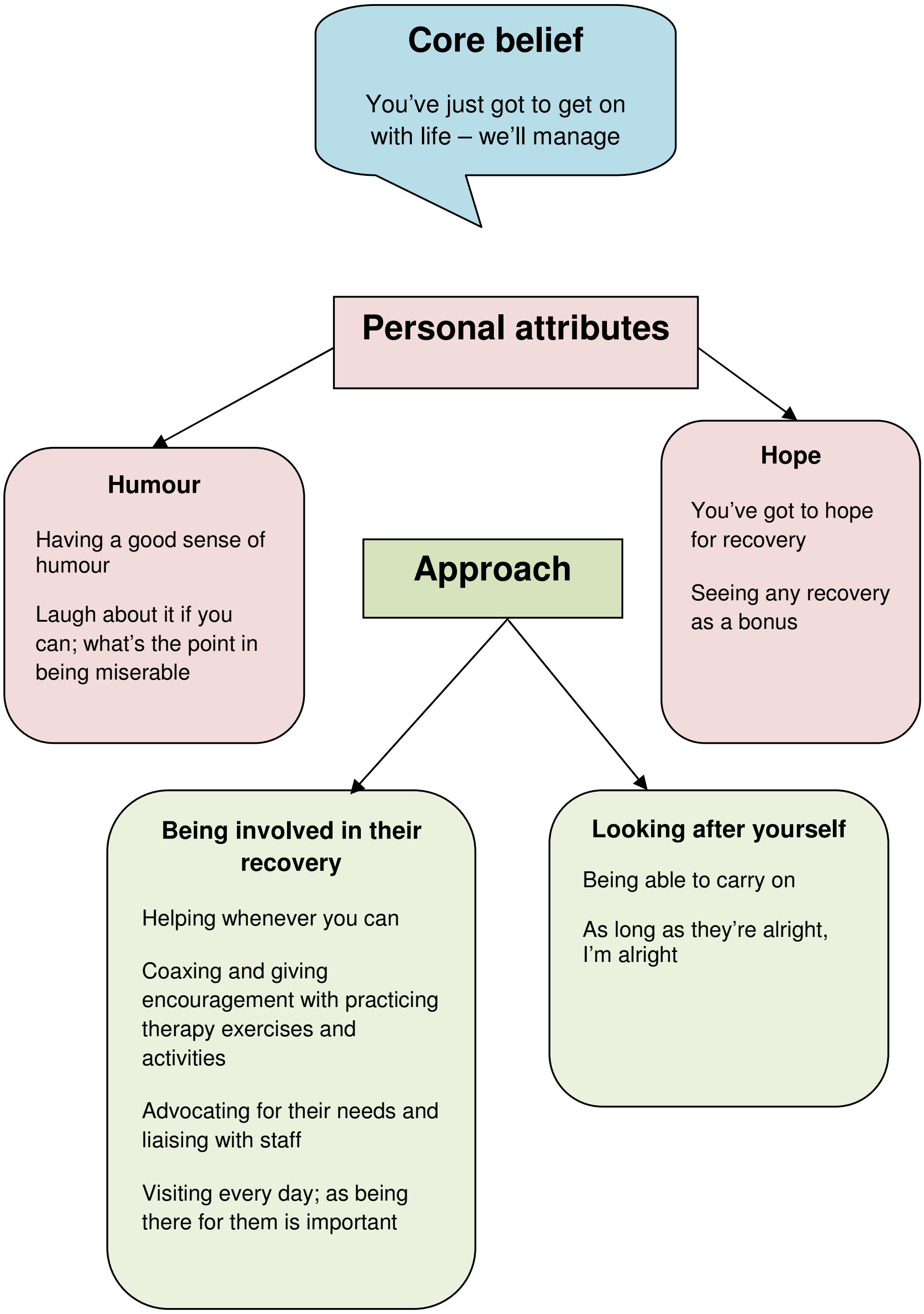


Challenges arose both from within themselves and the ward environment, the latter of which they had little control over, such as wanting more therapy input, being bored and wanting to be at home. However, despite these challenges, their continued engagement in rehabilitation was sustained and facilitated by several sources of support. Family and friends were identified as being the most important sources of emotional and social support, whilst other patients offered peer support. The therapists enabled them to assess their functional progress in rehabilitation, whilst the nurses, in whose company they spent their days, facilitated their recovery by being there for them, by paying them individual attention and through their positive and friendly approach. A more detailed display of these factors is presented in Appendices 8a and 8b but what is clearly apparent is the congruence between what patients identified as the core contribution of the nurses and what the nurses themselves perceived as their contribution to patient recovery.

Achieving a sense of how relatives managed the experience of stroke was limited by the small number of relative participants with whom I was able to spend time. Nevertheless, it is possible to identify a **core belief** that whatever the outcome of the stroke; they had to try to get on with life and they would manage. This was achieved by **attributes** of keeping positive, hoping for the best and an **approach** which focused on the interests of the patient; all of which required that they also looked after themselves (Figure 6). Relatives were also able to articulate a number of challenges to and facilitators of recovery (Appendices 8c and 8d). The challenges identified reflect relatives’

Figure 6:

Concept map of relatives' perceptions of their contribution to patient recovery



Core belief

You've just got to get on with life – we'll manage

Personal attributes

Humour

Having a good sense of humour

Laugh about it if you can; what's the point in being miserable

Hope

You've got to hope for recovery

Seeing any recovery as a bonus

Approach

Being involved in their recovery

Helping whenever you can

Coaxing and giving encouragement with practicing therapy exercises and activities

Advocating for their needs and liaising with staff

Visiting every day; as being there for them is important

Looking after yourself

Being able to carry on

As long as they're alright, I'm alright

overarching worries and concerns about the wellbeing of the patient, whilst also trying to manage the effects on their own wellbeing of frequent episodes of visiting over a prolonged period of time. The sources of support and facilitators to recovery are essentially the same as those identified by patient participants, although naturally reflecting a different focus.

This complex network of interconnecting concepts can be most coherently explained by focusing on the interpersonal relationships created between the nurses, patients and relatives. Revisiting Figure 3, it appears that the nurses had assimilated into the core beliefs which informed their practice the knowledge gained through experiences of working with persons affected by a stroke. Their personal and professional attributes were purposefully applied to facilitating recovery, focusing on enabling patients and relatives to combine their own personal resources with those of the stroke unit, to achieve the best possible outcomes; both in terms of functional recovery and emotional wellbeing.

To reiterate, the focus for this research study was the emotional experience of stroke and how nurses interpreted these experiences to inform their interactions with patients and relatives. Analysis of the datasets indicated a complex interplay between the participants' core beliefs and values, their personal attributes and their approaches to recovery. This interplay has been visualised through the medium of concept maps which demonstrate how the categories or concepts fit together (Alvesson and Sköldberg, 2010). The findings represent the patient's journey, from admission to the stroke unit to transfer of care and illuminate how relationships are initially developed, sustained and finally reframed as the journey progresses.

Demonstrating rigour in the conduct of the study

Presenting the study's methodology and methods in detail is intended to contribute to an evaluation of its rigour; the means by which the overall quality of the conduct of the study can be judged. In ethnographic studies, de Laine (1997) identifies that the main criteria for establishing rigour are prolonged engagement in the field, persistent observation, triangulation of sources, methods and theories, member checks and audit trails. All of these criteria have been considered in the design, implementation and evaluation of the study.

With regards to prolonged engagement, the study was undertaken during an 18 month period, during which I spent approximately 600 hours in the setting, often for short periods of only one or two hours but sometimes, whole days in succession. This enabled me to achieve the immersion in the field that is consistent with ethnographic research (Hammersley and Atkinson, 2007; 1995). Not all of this time was spent observing interactions between participants in the cases but observation remained persistent. However, it was evident that by the time the final case was completed, there would be little gained from extending the study period further, as a sense of data saturation had been achieved (Drauker *et al*, 2007). I was not observing any new issues or actions.

Triangulation enhances rigour by contributing to the search for ‘completeness’ of data, in as much that “each method adds a different piece to the jigsaw” (McDonnell et al, 2000). This involves using more than one approach or data source to examine a phenomenon from different angles (Rebar *et al*, 2004) and triangulation of data sources, methods and theories has been demonstrated. The study's academic supervisors contributed to this process through their critical commentary on the case studies, data analysis and engagement with the researcher's theorising throughout the study.

Member checking, or respondent validation was not undertaken. Member checking proposes that exploring the extent to which participants “recognise or give assent to the judgements of the researcher” (p.228), establishes correspondence between the researcher’s and the participant’s views. However, Hammersley and Atkinson (1995) note that the notion of respondent validation is sometimes contested in ethnographic research, arguing that as “much social action occurs at a subconscious level, leaving no memory traces” (p.229), it cannot be assumed that participants will remember the things that they have said or done or even recognise them when someone else documents them. Furthermore, participants are likely to interpret data "in the light of different concerns to, and sometimes by criteria at odds with, those of the ethnographer” (p.229). Therefore, their reactions "cannot be taken as direct validation or refutation of the observer’s inferences” (p.230).

McDonnell *et al* (2000) also argue that member checking can imply a false sense of openness which is not defensible, that it offers dubious benefits and serves only to make the researcher feel 'good'. In addition, because multiple data sources are used in constructing cases, for confidentiality reasons, as McDonnell *et al* (2000) indicate, these could not be returned to individuals for comment. Presenting just an interview transcript, as one item of data relating to a case, could be misleading with regards to its place within the whole dataset. Eraut (2005) also contends that interview transcripts might have a negative effect on participant morale because they can be difficult to read if transcribed verbatim and cause embarrassment in revealing in text, the way that the person speaks. Participants might also feel unable to challenge a transcript if it has been tape-recorded, because it is viewed as a 'true' account of what was said (Eraut, 2005).

Although member checking was not undertaken in this study, a process of informal validation was pursued through engagement of the participants in questioning about ideas and theories as they were emerging and by seeking clarification to enhance understanding of the data. Meetings with the project advisors from the local support group also provided a forum to further discuss ideas and meanings. Finally, as the process of decision-making has been exposed through writing reflexively, an audit trail has been created, supported by reference to sections of the research journal and thus providing a "demonstration of the degree to which the researcher has remained true to the data and to the boundaries of the sample" (Long and Johnson, 2000 p.35). Further evidence is demonstrated in the findings chapters. In the introduction to the findings, the structure for the presentation of the findings is explained, before proceeding to illuminate the findings themselves.

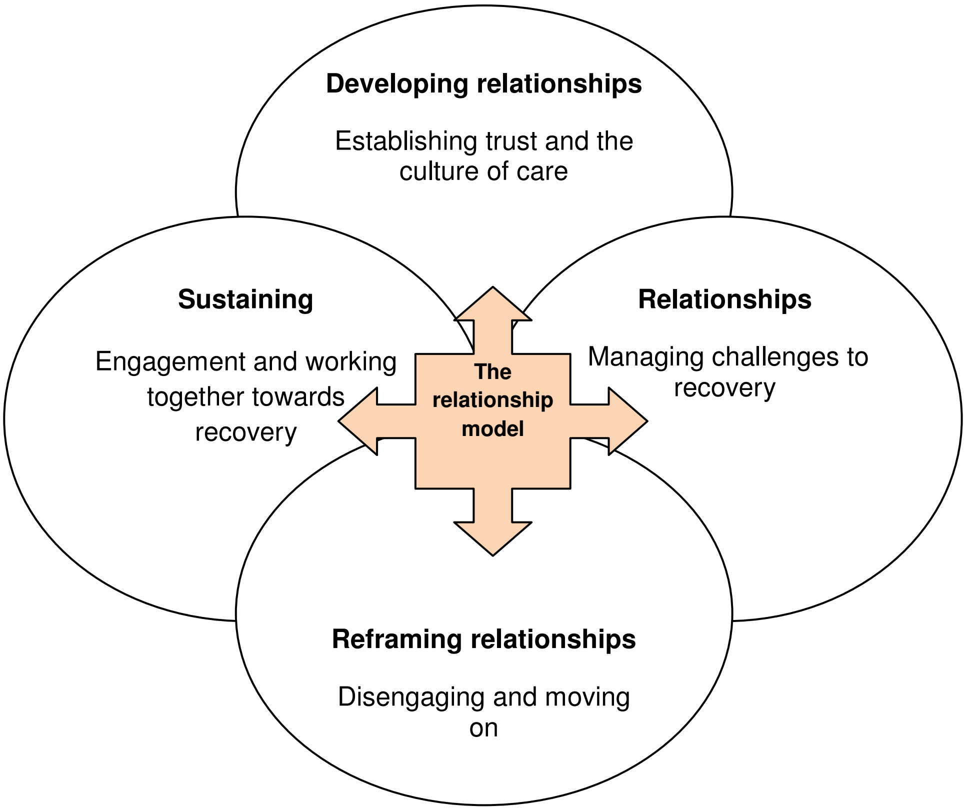
Chapter 4:

Introduction to the findings

In this introduction, a brief overview is provided of the findings chapters detailing the components of an emerging relationship model of promoting emotional wellbeing and recovery (Figure 7). Two tables of information relating to the study participants introduce the key informants, together with an explanation regarding the representation of the participants' voices in the findings.

Figure 7:

The emergent relationship model of promoting emotional wellbeing and recovery



The chapters are structured as follows:

Developing relationships: establishing trust and the culture of care

In order to support patients and their families through the traumatic, early stage of recovery following a stroke and in addition to attending to patients' physical wellbeing, the priority for the nurses was building a relationship with patients and their relatives; getting to know them, gaining their trust and establishing a basis for the work ahead. This required the use of their knowledge, skills and experience, particularly their interpersonal skills; and how these were utilised during day-to-day caring activities to provide comfort and reassurance and to inspire trust. For relatives, it was about how they perceived the care that the patient was receiving and how accessible the nurses were to them when they needed them. The congruence between these different perspectives is explored. This first of the findings chapters also addresses the immediate response to the stroke event – the nurses' understandings of how this could affect patients and their families; illustrated through their descriptions based on multiple experiences and how these concurred with the descriptions offered by patients and their families.

Sustaining relationships 1: Engagement and working together towards recovery

By engaging patients in their recovery, this chapter focuses on the nurses' approach to supporting patients through rehabilitation, based on mutually shared values and beliefs; again comparing their perspectives with those of patients and relatives. The therapy team features prominently here too. Key themes focus upon how supporting and maintaining a positive approach can be achieved by the interplay between patients' and relatives' positive emotion, motivation, determination and self-efficacy through praise and encouragement, humour and repartee (banter). However, through exploring one particular, atypical case, it is apparent that this latter approach was not always successful.

Sustaining relationships 2: Managing challenges to recovery

The third chapter focuses on particular challenges experienced by patients and relatives over which neither they nor the nurses appeared to have much control and which exerted a negative impact on wellbeing. These challenges included the stroke unit environment itself, the patient mix, boredom and inactivity. The ways in which the relationships between the nurses, patients and relatives were sustained against these challenges through supportive interventions are addressed.

Reframing relationships: disengaging and moving on

The final chapter addresses how the nurses worked with patients and families in the lead up to their transfer of care. It includes consideration of the potential threats to the nurse-patient/relative relationship, especially at a point when anxiety and apprehension about the future were brought into focus. The mutual reward of caring and the ways in which the nurse-patient relationship was maintained in the longer term also feature here.

The study participants

The following tables provide brief biographical information about the study participants and introduce their pseudonyms. Terms used to differentiate between patients, relatives and nurse participants are also indicated. Only those relatives whose voices are directly quoted or paraphrased in the findings are indicated by codes. Due to the unpredictable nature of recovery from stroke and the suitability of potential participants, the number of cases studied was 10, achieved by extending the study period from 12 to 18 months. There were occasions when several weeks elapsed between recruiting participants but I was assured by the senior staff that this was because there was no-one suitable for inclusion at my times of asking.

Table 4: Patient and relative participants' brief biographical information

Name &Age	Personal circumstances	Health history	Type of stroke and its effects
Celia **Pt.1** 62	Lives with husband Trevor Son and daughter live in the area Returned home following stoke	History of Coronary Heart Disease and previous heart attacks. Previous stroke 14 years ago. Secondary prevention medication.	Evolving left-sided cerebral infarct Slurring of speech – quickly resolved Weakness in right hand Numbness in right leg – initially unable to walk
Gavin **Pt.2** 39	Working in local steel industry Lives with wife Paula and two children Some tensions between wife and Gavin's mother Returned home following stroke	No previous health-related problems Father died following a cerebral haemorrhage two years previously – was admitted to and died on the same stroke unit	Sudden left-sided cerebral haemorrhage Expressive and receptive dysphasia and dyspraxia – difficulty making the sounds of the words. Right sided-paralysis – cannot walk or use his right arm and hand.

Lily **Pt.3** 75	Widow Lives with daughter Kath **(rel.2)** in adapted 'Granny flat' at back of daughter's home. Other daughter Mel **(rel.1)** lives close by and is a nurse Returned home following stroke	Diagnosed with MS at 22 years but no specific impairments until later in life, when she developed a left-sided weakness. Also has IBS. Treated for depression after husband's death and still taking SSRI medication	Evolving left-sided cerebral haemorrhage Expressive dysphasia – word finding difficulties. Can read but not write (right handed) Weakness in right arm, hand and leg
Fred **Pt.4** 49	Unemployed prior to stroke Lives with wife Thelma **(rel.3)** Some family living locally Returned home following stroke	History of Coronary Heart Disease and surgery (angioplasty and stenting) Previous TIA and severe carotid stenosis. Secondary prevention medication. Both parents died in mid life from heart attacks.	Evolving left-sided cerebral infarct Right sided weakness Severe expressive and receptive dysphasia
Sid **Pt.5** 48	Working as a chef in a care home prior to stroke Lives with wife Mandy **(rel.4)**, adult daughter Sally **(rel.5)** and young son Johnnie Large, local extended family network Returned home following stroke	No previous health-related problems, although experiencing headaches around the time of the stroke. Evidence of previous left-sided stroke identified on CT scan. No cardiovascular problems, no carotid stenosis.	Evolving right-sided cerebral haemorrhage Left-sided paralysis, including facial weakness, visual deficit and left-sided inattention Cognitive impairments, including memory, initiation, attention and concentration. Diagnosed as depressed within two weeks of admission
Ingrid **Pt.6** 73	Retired company secretary. Widow Lives on houseboat Son, daughter-in-law and two grandchildren live locally Transferred to intermediate care – plan to temporarily live with family Decided not to return to the a houseboat following the stroke	No previous health-related problems; although an episode of 'tingling in left hand' was reported 3-4 years ago (Trapped nerve or TIA?) CT on admission revealed evidence of previous multifocal ischaemic changes. Untreated diabetes found on admission. Both parents had experienced strokes	Evolving left-sided frontal and parietal haemorrhage within an infarct Right-sided weakness, facial weakness Slight speech slurring Newly diagnosed with diabetes

Helen **Pt.7** 71	Widow Lives alone – wide social network of friends and close family Transferred to intermediate care – then returned home.	Numerous long-term conditions, including cardiovascular disease and diabetes. Secondary prevention medication. Previous history of anxiety-related mental health problems – still taking SSRI medication.	Sudden right-sided Cerebellar infarct Left-sided weakness and loss of co-ordination in left arm, with intention tremor
June **Pt.8** 82	Retired school secretary. Widowed for over 40 years. Lives alone – wide social network of friends Son and his family not close to her – rarely visit. Transferred to intermediate care - then returned home	No known long standing health problems but had recently experienced a number of 'blackouts' of unknown cause. Possible head injury on one occasion? Described on previous admission to A&E as 'dazed'	Sudden - no definite diagnosis – small vessel ischaemia? right side Initial left-sided weakness Cognitive changes?
Norman **Pt.9** 80	Retired miner Lives with wife Elsie who herself is rather frail Daughter Shirley and son Martin visit regularly, both work Now needing input from home care services 4 X day Respite care arranged for regular intervals after discharge Returned home following stroke	Longstanding respiratory disease, benign prostatic hypertrophy and arthritis. Two previous strokes from which good recovery was made. Diagnosed with depression following last stroke (2004) but refused antidepressant medication. Secondary prevention medication.	Evolving right-sided cerebral infarct Left sided paralysis
Iris **Pt.10** 77	Widow Already lives in sheltered housing complex but home care now required to meet care needs. Daughter Ruby visits daily, other daughter Pearl occasionally Brother lives in same complex. Returned home following stroke	Previous surgical operations, atrial fibrillation/ SVT? Vertebrobasilar Insufficiency. Ongoing cardiac investigations and secondary prevention medication. History of anxiety-related mental health problems – accessed counselling.	Sudden right-sided Cerebral infarct/haematoma? Left-sided paralysis

There were a further five potential participants with whom I spent time in anticipation of recruitment but two declined; one immediately and the second after several days. Summarised in my research journal (Appendix 6 – research journal extract 3), this description does not reflect the time and effort that was involved in the process of unsuccessfully recruiting participants and the feelings of failure that they generated in me as a researcher; that it was somehow my ineptitude which had contributed to their decisions. A third person did not meet the criteria for selection due to a communication impairment which appeared to be more severe than indicated and I abandoned the process feeling rather distressed by the experience and frustrated with the nurse who had suggested her to me. I withdrew from the process of recruitment with the other two patients when their physical condition deteriorated.

Particular difficulties were presented with regards to interviewing the nurses, as their busy working schedule offered little ‘free’ time to engage in the process. Inevitably, most interviews occurred at weekends, usually mid-afternoon, towards the end of the morning shift, or during break times. In consequence, the interviews were relatively short in duration.

Table 5:

Nurse participants - demographic information, code names and numbers

Code name	Code in text	Age	Stroke care experience	Post	Previous nursing Experience
Angie	**Nur.1**	45	2yr 7m	RN	ADNS - first post
Barbara	**Ca.1**	43	2yr 8m	HCA	HCA - Residential care home
Christine	**Nur.2**	60	12 yr 5m	RN	RN - Older adult care - NHS
Donna	**Nur.3**	48	3yr 4m	RN	RN - Older adult care - NHS
Emily	**Nur.4**	43	13 yr 3m	RN	RN - Older adult care - NHS
Felicity	**Nur.5**	28	2yr 3m	RN	ADNS - first post
Gary	**Nur.6**	49	13 yr 4m	RN	RN - Older adult care - NHS
Hilary	**Ca.2**	27	3yr 10m	HCA	None – first post
Isabel	**Nur.7**	45	2yr 10m	RN	ADNS - first post
Julie	**Nur.8**	44	11yr	RN	RN - Medical & older adult care- NHS
Karen	**Nur.9**	48	6 yr	RN	RN - Older adult care - NHS
Lloyd	**Ca.3**	46	3yr 6m	HCA	HCA - Older adult care - NHS

Key:

RN = Registered Nurse

HCA = Health Care Assistant

ADNS = Advanced Diploma in Nursing Studies
(local pre-registration nursing education programme)

The names are listed in the sequence in which they were interviewed.

A brief explanation is necessary regarding the representation of the participants' voices in the findings. Some patients' voices are heard more clearly than others for a number of reasons: Gavin **(pt.2)** and Fred **(pt.4)** had severe aphasia, which limited the content of our conversations and interviews, even with the use of communication aids. In Fred's case, his wife Thelma provided the main channel of communication between us. Sid **(pt.5)** was not easy to engage in conversation, possibly through his difficulties with information processing and as a result of her cognitive impairments, June **(pt.8)** talked a great deal but rarely answered the questions I asked her and digressed to unrelated topics. Iris (**pt.10)** was reluctant to talk about her stroke, although conversed more freely about other matters. Therefore, the voices which are heard the loudest are those of the more vocal Celia **(pt.1),** Lily **(pt.3)**, Ingrid **(pt.6)** Helen **(pt.7)** and Norman **(pt.9)**. Difficulties engaging relatives in the study mean that only Lily's daughters Mel **(rel.1)** and Kath **(rel.2)** and Fred's wife Thelma **(rel.3)** are consistently evident, together with lesser contributions from Sid's wife Mandy **(rel.4)**.

Reflections on issues relating to the selection and recruitment of participants and their representation within the findings are presented in Appendix 6, Research journal extract 4.

Chapter 5

Developing relationships: establishing trust and the culture of care

The focus for this first chapter is on how from the point of first contact, the stroke unit nurses set out to develop relationships with patients and relatives. It seeks to demonstrate how combining their knowledge and understanding of the stroke experience with their beliefs, values and personal attributes, the nurses were able to establish essential trust with patients and relatives, as a foundation for rehabilitation. First, the nurses' insights into the experience of stroke are summarised and compared with those of patients and relatives; following which, how the nurses used their knowledge and understanding to inform interactions is discussed. Finally, the culture of caring on the stroke unit is presented as an essential prerequisite for the successful development of relationships with patients and carers.

Initial reactions to the experience of stroke

For all but two of the patients, transfer to the stroke unit occurred quickly, often within a few hours of admission to hospital and on arrival, the nurses described that their immediate priority was to stabilise the patient's physical condition and reduce the risk of potential complications. This included frequent monitoring of vital signs, regular repositioning to promote comfort, prevent muscle spasticity and soft tissue damage and attending to essential equipment such as intravenous infusions, nasogastric feeding tubes and urinary drainage catheters. For the first few days or, in some cases, weeks, patients could be quite ill, minimally conscious or drowsy, confused and disorientated. They might be in a state of shock or bewilderment and, as such, would have difficulty in comprehending their situation or communicating their needs. By observing and interpreting patients' body language and facial expressions, the nurses could tell whether or not they were anxious and frightened so at this time, their interactions focused on responding to signs of distress and providing reassurance. Understanding something of what patients and relatives were experiencing informed their approach and enabled them to anticipate their needs.

To gain insight into the nurses' perceptions of the initial effects of a stroke on patients and relatives, they were asked during their interviews what they thought it might be like to have a stroke. Many said that they could not possibly imagine how it must feel, yet perceived it to be devastating to experience something so sudden and catastrophic. The nurses' perceptions were reflected in patients' and relatives' own descriptions of their reactions to the stroke event and subsequent diagnosis; that it would be invariably shocking and difficult to accept.

Patients such as Gavin, Fred and Sid who had severe communication and cognitive impairments, had difficulty articulating their initial reactions to their experiences but Paula, Gavin's wife described how the diagnosis had devastated their family and the period immediately following his collapse was a “frightening time”. This was not least because two years earlier, Gavin's father had experienced a similar collapse and died on the stroke unit, without regaining consciousness. Although Gavin himself could not voice his response to the event, the Speech and Language Therapist (SLT) who first assessed him five days after admission, described how he appeared to be “really frightened”. Indeed, she had said to him; “You look frightened” and he nodded to her that he was.

Fred's wife Thelma described how the revelation of the extent of Fred’s stroke had “knocked us for six” and Fred later described it himself as “terrifying”. Celia was also shocked by her diagnosis: “…it just hit me in the face…I didn’t expect that” **Celia (pt.1)**. Lily described being "gob smacked" and Helen was similarly “dumbfounded”. Helen further described her disbelief when the doctor gave her the diagnosis of a stroke, responding: “Who has?” and “Are you sure?” Iris also exclaimed that she could not take it in, when asked for her first reactions to being told that she had had a stroke.

The metaphors used by Thelma, Celia, Lily and Helen to describe their responses to the stroke all suggest that it came as an unexpected blow. In addition to her shock, Ingrid also explained that although she was aware of everything that was going on at the time, she did not think that it related to her. She did not want to believe that it was happening; a description which reflects something of the disembodiment reported by participants in other studies of the stroke experience explored in the literature review (Appendix 1). During the first two weeks, she believed she would wake up and discover that it had not occurred and it was only over time that she accepted the reality of her situation. June also described being shocked, yet puzzled because she had not been given a definite diagnosis of stroke. However, she was aware that something was wrong because, as she described it: "…the computer's on the blink" **June (pt.8)**. Norman had previously experienced mild strokes from which he had made a speedy recovery but this time, he felt that it was different; an altogether more dramatic experience. In summary, for patients and relatives, experiencing a stroke was a shocking and frightening event which they struggled to understand. Therefore, as the first step to reducing their fear and engaging them in their rehabilitation, the nurses' aim was to help them to make sense of what had happened to them and the ways in which they had been affected.

Responding to the experience of stroke

Once the nurses observed that a patient was more alert and they were beginning to ask questions, they could start to offer information and explanations. Taking cues from patients about when they were ready to receive information and telling them what they wanted to know, helped to build trust and it was during this early period, when the nurses needed to spend lengthy periods of time with the patient and their family that the process of developing a close and supportive relationship really began. As Lloyd, one of the care assistants stated:

> "…you've got to have some foundation there. When you're going to be working with somebody for a long period, it's important to get off on the right foot" **Lloyd (ca.3)**.

Lloyd asserted that consistency and continuity, the “familiarity of the same faces” was important too, particularly as patients could be on the stroke unit for several weeks. Indeed, the closeness that developed between the patients and nurses was likened to: " moving in with somebody for a couple of months” **Lloyd (ca.3)**.

For many patients, being in hospital was in itself reassuring, being attended to by nurses and doctors but building a relationship with a patient could be challenging if they did not want to be there, when, as Hilary stated “...they don’t like the ward, they don’t like the hospital, they don’t like the staff; they don’t like anything” **Hilary (ca.2)**. They might even be scared of the nurses, literally pushing them away and resisting assistance. In such circumstances, extra time would be devoted to listening to them and trying to explore why they felt that way. They might have a relative or friend who had been in the hospital and complained of their experience, in which case, they would need to be convinced that this ward was different. However, the nurses were confident that once such patients had got to know them, they would feel more comfortable and become more accepting of being on the stroke unit. Indeed, they prided themselves in working to create a friendly and welcoming atmosphere which put people at their ease.

Calling patients by the first names, as Gary explained, saying things like "I'll be seeing you in the morning Fred, or Jim or Sheila or whatever", helped to make them feel secure:

> “…you often find that if you shake their hand and have that little bit of physical contact with them, they feel reassured…a personal, friendly approach and they know the name of somebody and they actually feel as though they’ve got someone…they need that sort of relationship to feel secure with the people who are looking after them" **Gary (nur.6)**.

Assuring patients that they were in good hands was also a way of helping them to feel secure, particularly at a time when they were heavily dependent upon the nurses for their physical wellbeing. This could be achieved by nurses explaining how long they had worked on the stroke unit and that they were experienced in stroke care: "because they seem to like that reassurance of knowing that you know what you’re doing” **Gary (nur.6)**. Essential caring activities thus provided opportunities to talk and contributed to the rapport which was perceived as essential to building trust between the patient and the nurses who were going to be working with them over the coming weeks.

When asked to describe what they recalled about the first days following admission to the stroke unit, patients generally had little memory of this time and the nurses caring for them. Their relationships with the nurses were described more fully within the context of their ongoing recovery and rehabilitation. In contrast, for many relatives, the admission of the patient to the stroke unit triggered a period of heightened vigilance, marked by anxiety, fear and distress. Here, the nurses drew on their experience to show that they understood how relatives would be feeling at this time, believing that:

"It's as bad for them as it is for the person that's had the stroke" **Angie (nur.1)**.

Initially, relatives wanted as much information as possible and constantly asked the nurses for test results and scan reports, or repeatedly asked to speak to a doctor. As Gary explained:

> "…they always ask the same sorts of things about 'how long are they going to be here?', 'how soon are they going to get better?' and all you can tell them is that we often don't know, because it's one of those illnesses which is very unpredictable" **Gary (nur.6)**.

The first few days could be very challenging for the nurses to manage, as uncertainty about recovery and not always being able to give relatives the answers they wanted to hear, required careful handling. It was important to ensure that relatives did not think that information was being withheld or that they were being misinformed, because if this occurred, the opportunity to develop trust in the nurses could be lost. The nurses expressed their belief that it was difficult for relatives, not knowing whether there was going to be any improvement in the patient's condition and yet at the same time, as Angie asserted: "…they're the ones who have got to be seen to be coping…so they've got to take that on board as well" **Angie (nur.1)**.

Having to entrust a close family member to the care of others, as Kath described, could be "heart wrenching", like "leaving your baby" **Kath (rel.2)**. Something had occurred which was completely outside their control and this could generate feelings of helplessness and of being useless. They wanted to make things better, yet could not and the nurses needed to help them understand that the patient would start to recover in their own time. Some relatives found it difficult to leave the ward and go home and even felt guilty about doing so. It helped to be assured that the nurses would ring them if there was anything wrong, as did being told that they could phone the ward at any time, even late at night and especially if they could not sleep through worrying. Relatives were also reassured by the nurses when they rang the ward first thing in the morning and were told that the patient had spent a comfortable night. Thus, recognising and responding to relatives' emotional distress enabled the nurses to help them feel more at ease when visiting the stroke unit and raised confidence in their commitment to looking after the patient.

After these first few days and having become familiar with the nurses and the ward routines, the nurses perceived that relatives became more relaxed:

> “They're not always at the desk. They're not always ringing you up and asking and they seem to settle down a little bit” **Gary (nur.6)**.

Once they had been reassured that the patient was no longer critically ill, relatives would start to talk more openly to the nurses, call them by their first names and begin to develop a relationship with them. For the nurses, building this relationship with relatives required the use of every available opportunity but making this effort also enabled them to gain a greater understanding of the patient and their background. This would involve stopping other activities on the ward to talk to relatives, to ask them probing questions and find out about family relationships. Patient records provided a limited insight into the circumstances surrounding the stroke and it was thought that much more could be learned by talking to those who had first-hand knowledge of the patient. In this way, a more complete picture could be developed of their life before the stroke. The nurses wanted to know more about the person behind the patient; the person before their illness, as they believed that this would enable them to develop rapport and build a relationship of trust.

Relationships with relatives were also influenced by the ways in which nurses communicated with them. Talking to relatives in the same way as the nurses talked to each other was thought to be important and helped to create, as Angie **(nur. 1)** described, a “natural atmosphere”. This was also perceived by the nurses to help break down barriers and put relatives at ease. Nevertheless, at this early stage, relatives could still be emotionally fragile and the nurses were aware that they needed to be cautious in their approaches to them. Insensitive remarks or inappropriate banter could undermine trust. Indeed, Fred's wife Thelma recounted an early episode when a care assistant had upset her. She had been telling them about how her husband had been under a great deal of stress at work and that she thought this had contributed to his stroke. Apparently, the care assistant had said “sarcastically” (in Thelma's view), something like: “I’m right glad you told me that!” Thelma found this inappropriate response hurtful and thought that the care assistant should not have said what she did. From then on, she avoided contact with her; a situation that the nurses would have been keen to prevent. As already indicated, their aim was to create a friendly and welcoming atmosphere, which reflected the culture of nursing care on the stroke unit.

Creating a culture of care

Being friendly and approachable and showing that they understood and cared about what patients and relatives were experiencing, were believed by the nurses to be essential foundations for building long-term, trusting relationships. As Gary explained:

> "It's very important to become almost a friend to the family…They must feel that they can trust you and they must feel that they can talk to you about any issues they've got; because if they bottle those issues up, then that's when problems arise" **Gary (nur.6)**.

For the nurses, becoming "a friend to family" was also enjoyable and getting to know patients and their families, gaining their trust and confidence was mutually rewarding. It required time and effort but this emphasis on close working relationships also appeared both to attract and retain nurses who shared similar characteristics and who enjoyed working together to create a mutually supportive and therapeutic atmosphere. The general feeling expressed by the nurses was that they valued a sense of belonging to the stroke unit team. There were established role models in senior nurses such as Gary and Emily, whose influences could clearly be detected in the beliefs and values expressed by other nurses and care assistants in the interviews.

In her interview, Barbara **(ca.1)** described watching and learning from experienced staff on the ward and how much she respected their knowledge and expertise.

Working as a team was described by the nurses as crucial. In Angie's view, the nurses all worked well together, because they were, as she described, "strong people who are good for patients" **Angie (nur.1)**. By this, she explained that the nurses put the patients' interests first and were prepared to defend this position in multiprofessional team decisions about rehabilitation needs and interventions. The nurses were willing to express their views and everyone's view was respected, as Hilary summarised:

> "It's about pulling together and understanding each other as well. It's not holding people back, it's listening to people, it's giving each other ideas without offending people and I think we do well on here for that". **Hilary (ca.2)**

The importance of this team approach was further illustrated in Barbara's description of how difficult she found it to understand a particular colleague who had refused to work with a patient because they did not like them. She thought this was unacceptable and unprofessional behaviour, as in her view, every patient deserved the same attention. Barbara also identified that the same colleague sometimes spoke to patients in a less than respectful way and that this concerned her, not just for the patient's sake but because it reflected poorly on the team as a whole. Her approach to the colleague's behaviour was to try to explain the necessity for all the nurses to be consistent in their approach to patients, reinforcing the culture of nursing care on the stroke unit.

In their everyday conversations with me, patients and relatives would often talk about the nurses, commenting upon their personal attributes, particularly their friendliness and approachability. Relaying these observations (anonymised) to the nurses for comment, it was evident that they were fully aware of the ways in which they presented themselves and that this is what helped them to secure relationships with patients and relatives. Angie explained:

> "I'm just a really natural person and I'm no different at work than I am outside work and I hope it comes over in my job that I'm just who I am; I'm a friendly, outgoing person who sees everybody as equal and does my best; I do my best for everybody and hope that's OK" **Angie (nur.1)**.

In Angie's view, the nurses were all there for the same reason and that was to care for the patient.

Barbara **(ca.1)** agreed that personality was important and that being able to chat helped everyone to get along together. Christine **(nur.2)** believed that the nurses needed to be cheerful and friendly and be prepared to listen, whilst Donna **(nur.3)** maintained that all the nurses aimed to please. Again, being approachable was viewed as particularly important, because they believed that it would be frightening for patients and relatives to feel that they could not ask questions, or that the nurses dismissed their concerns. Felicity **(nur.5)** perceived that during the process of getting to know one another, patients, relatives and nurses became familiar with ways of communicating and would find opportunities to strengthen their relationships through talking to each other.

Both Hilary **(ca.2)** and Lloyd **(ca.3)** recognised, however, that this approach to communicating with patients and relatives was not easy for everyone to achieve, because of differing personalities; but these differences could actually work to advantage. Although Lloyd described most of the nurses as outgoing, he thought that quieter and more reserved colleagues were able to bond more effectively with patients and relatives who shared these characteristics. Therefore, being a staff group comprising a range of personalities ensured that there was always someone to get along with and share understandings.

In summary, the combination of personal and professional attributes, together with shared knowledge, understanding and core values, created the approach to patient care on the stroke unit which the nurses believed would enable patients and relatives to achieve the maximum benefit from their time spent there. These were perceived as the essential foundations for recovery and having established them, the nurses would work to sustain them throughout the patient’s rehabilitation journey. The means by which they achieved this are explored in the following chapters.

Chapter 6

Sustaining relationships 1: Engagement and working together towards recovery

This second findings chapter focuses on the nurses' approaches to the engagement and support of patients and relatives during rehabilitation. A key finding is the central importance of the interplay between patients' and relatives' personal resources (beliefs, attitudes and approaches to recovery) and those of the nurses; which in combination, work to facilitate the rehabilitation process. The chapter begins by exploring the importance of attending to the patients' personal care needs, which enabled the nurses to achieve closeness and provide opportunities to talk. Next, the engagement of patients in rehabilitation therapies, as the primary purpose of the stroke unit, is addressed and the identification of strategies to enable patients to gain maximum benefit from therapy activities. Sustaining engagement is demonstrated through encouragement and focusing on achievement and by promoting a positive attitude and hope for recovery. As a way of interacting with patients and relatives, the use of humour and repartee (banter) is identified as an effective strategy for further sustaining engagement.

Caring for the individual and attending to needs: Giving them what they want, when they want it

Believing a stroke to affect everyone differently, the nurses identified that the most successful way of supporting patients and relatives was to do so on their own terms; to develop an awareness of their individual preferences and modes of relating and use this knowledge to inform their interactions with them. For example, Sid described how the nurses showed their concern for him as an individual by asking how he was feeling, whether he was he warm enough or if he wanted anything, such as a drink or a pillow to support his affected arm. Ingrid described how the nurses used her own teabags when they made her a drink, which to her, was a measure of their willingness to do something just for her. Such actions signified to patients that the nurses cared for them.

The nurses would spend as much time as they could in attending to individual patients' needs but because of competing demands, opportunities within the busy working day were limited. From Gary's perspective, there always had to be a compromise reached between the ideal of providing individualised care and the reality of the finite nursing resources available, although Lloyd suggested that because patients spent so much time observing the nurses, they did not need to have it drawn to their attention how busy they were. The patients reinforced this perception. As Celia commented:

> "…I know they're busy, they've a lot on the
> ward but they do come, they do come
> when they can get to you and see to you"
> **(Celia (pt.1)**.

Lily also described how: "…you've only got to go like "come here, come here" (*whispering*) and they'll come to you" **Lily (pt.3)**; so even though the nurses were busy, they would always respond to patients when requested. Helen related how she felt that nothing was too much trouble for the nurses and that even before she asked for help they seemed to know what she wanted.

For the nurses, demonstrating that they were caring for patients signified to them that they were doing their job properly. Emily expressed her belief that:

> "Being a nurse…means that you should be looking after them and giving them what they want, when they want it and how they want it; answering the buzzers when they buzz, taking them to the toilet when they want, instead of saying "You'll have to wait" **Emily (nur.4)**

Isabel **(nur.7)** commented that on the stroke unit, priority was always given to patients in most need. Nursing care was not routinised and inflexible. She also thought that many of the nurses tried to empathise with the patient's situation and expressed their empathy through planning individual approaches to care.

The nurses tried to appreciate the distress that patients would experience as a result of the effects of the stroke. The loss of independence and the reliance on help with even the most essential of bodily functions was believed to be the most difficult thing for patients to bear. Many patients would lose the ability to control their bladder and bowel functions immediately after the stroke, requiring the temporary use of urinary drainage catheters or incontinence pads. The nurses perceived that it could be profoundly embarrassing to be incontinent and humiliating to have to ask to use a disposal urinal or a bedpan, even to be assisted to transfer on and off a toilet and be cleaned down afterwards. For patients, having to ask for help could also reinforce feelings of dependency and the nurses expressed their awareness that these very personal and intimate caring activities had to be undertaken with sensitivity and understanding.

Asking for help could be difficult. Helen, who described herself as easily embarrassed, recounted when she first needed to use the toilet after arriving on the ward and how hard she found it to ask for assistance. She resisted as long as possible before it was a matter of necessity, although once she had overcome this initial embarrassment, she felt more comfortable with asking. However, the readiness of the nurses to respond to her need also enabled her to feel that she was not being a nuisance:

> "…you're thinking, 'Oh, I wonder what they'll think now because it's only an hour or so since I've been to the toilet'… but they say 'Oh, don't worry, it doesn't matter if it's five times in an hour. We don't count it. If you want it, we're there' " **Helen (pt.7)**.

It was whilst attending to patients' personal care that the nurses felt that they really got to know them. Washing and bathing, another intimate aspect of patient care served a function other than just meeting personal hygiene needs. It provided an opportunity to talk in private so that patients might feel more comfortable in discussing their concerns or sharing information. As Emily described:

> "…that's usually when they tell you the little things that they forgot to tell you before…or when they tell you they're upset about such-and-such a thing" **Emily (nur.4)**.

Lily also reinforced that most opportunities to have a conversation with the nurses occurred when they were helping her to wash. Attending to personal care could also provide comfort and a general sense of wellbeing for patients, as just having a bath could help them to feel better in themselves.

Occasionally, opportunities did arise to pay the greater attention to detail than was usually possible and Emily described one such occasion:

> “…with the ladies yesterday; it was a lovely, lovely shift and we managed to wash all the bed patient ladies’ hair. Simple but we managed to get all those ladies’ hair washed and you don’t get time to do it”. **Emily (nur.4)**

Styling hair was a skill that few of the nurses said they felt competent undertaking, nevertheless, they tried to oblige because patients enjoyed it. This was perceived as a mutually rewarding experience and also signified to relatives that the nurses were doing their best for the patient; that they were being cared for.

Talking to patients, answering questions and providing information was generally achieved whilst undertaking caregiving activities throughout the working day. However, this multitasking, although largely taken for granted by most of the nurses, did require skill, particularly for staff not used to this way of working. Donna **(nur.3)** described how staff new to the stroke unit sometimes felt out of their depth because patients distracted them with questions, whilst Hilary **(ca.2)** explained how she actually had to learn to talk to patients at the same time as working with them. She described how when she first came to the stroke unit, she had to stop whatever she was doing in order to concentrate on talking to a patient and it was only with experience that she could actually achieve both things at once.

Providing personal care also enabled nurses to prepare patients for rehabilitation. Initially, patients and relatives might not be able to see a way forward because of the perceived enormity of the stroke effects and talking to them about what rehabilitation was likely to involve was an important first step. This enabled patients and relatives to understand what would be expected of them and also how it might affect them; that the physical work of recovery and rehabilitation was tiring and sometimes painful and frustrating. As Gary **(nur.6)** explained, most people's previous experiences of health care had been fairly brief and predictable but recovering from a stroke was a lengthy and unpredictable process. Therefore, the better patients and relatives could be prepared for what was involved, the more effectively they could be helped to engage with the nurses and therapists in working towards their recovery.

Engaging in rehabilitation: working hard to recover

Once a patient was assessed as physiologically stable, the expectation of the stroke unit team was that they would actively engage in rehabilitation therapies. Patients were keen to gain full advantage of their time spent with the therapists and said that they did as they were asked to do, because it was clearly crucial to their recovery. This approach was affirmed by Lily:

> “I’ve got to try everything that people ask me to. Yes, you know, all the physios and I like to think I’m doing alright…They say I am but, I’d like to think I am, you know" **Lily (pt.3)**

However, in their keenness to recover and with increasing confidence in their ability, some patients were observed to become pro-active, seeking to influence their therapy. For example, Ingrid explained that she had informed the physiotherapists how she was determined not to leave the stroke unit until she felt able to manage independently; a purpose also voiced by Helen, who insisted that she would not be discharged until she was fully mobile. In another instance, Helen had been practising walking with a frame but said that she intended to ask the physiotherapist for a walking stick, as she could not see how the frame would be much use to her went she went home. Helen had also devised her own exercises to improve her balance and coordination:

> "… I keep rolling some of these (socks) up and putting them on the bed and going and getting them and bringing them back and throwing them again; it’s like a bit of therapy that I’m doing myself” **Helen (pt.7)**

During the process of transcribing the interview with Helen, I had been struck by the similarities between her explanation for her approach to recovery and that of Ingrid. In our conversations, they had both emphasised the imperative to recover from the stroke; that they had to do it in order to continue living the lives that they had made for themselves. Both were independent women and far from treating the stroke as a problem, they focused instead on solutions. Something sudden and unexpected had happened to them and they had to find a way of dealing with it. Consequently, Ingrid and Helen had developed coping strategies which they utilised to deal with their current situation. They were determined to remain in control. Neither of them was particularly daunted by the prospect of change, so long as they could continue to live as they chose. They just had to make the necessary adjustments.

Celia's determination to recover was also influenced by her life experiences of dealing both with family illness and the management of her own health. She had experienced a previous stroke and two heart attacks and had ongoing cardiac problems. Her mother and several family members had died from cancer and her husband had also been seriously ill with cancer. As a consequence of these experiences, Celia maintained that she had become "hardened" in her current response to the stroke, asserting that:

> "…you've got to think: 'I'm going to be alright'… You've got to live for today and get on with what you're going to do" **Celia (pt.1)**

This was evident in her approach to rehabilitation therapy, as she related that once she felt confident, she had been mobilising without assistance, even though she was not supposed to. She knew that the therapists would be concerned but she was determined to do everything she could to get better.

On the stroke unit, it was accepted, if not expected practice that the nurses would carry on therapy activities with patients whilst attending to their personal care needs. Barbara **(ca.1)** indicated that she had gained a great deal from the physiotherapy staff, who taught the nurses moving and handling skills specific to individual patients. In turn, the nurses could then report on a patient's progress to the therapists, to inform their ongoing treatment decisions. However, contrary to the therapists' recommendations, the nurses described how they also sometimes took risks with patients, if they believed it to be in their best interests. On one occasion, I observed Helen walking to the toilet with Barbara who was supervising her using her walking frame. Barbara related how the therapists had removed the walking frame from Helen's use, because they believed that she was developing abnormally increased muscle tone in her affected side. Barbara had retrieved it from the therapy department, commenting that although she was unsure as to whether she was supposed to do this, she was nevertheless prepared to "get into trouble" because she thought it was important for Helen to practice walking. Helen had been distressed by being immobilised and as the nurses had not been specifically instructed to act otherwise, Barbara used her discretion to assist her to walk.

This episode illustrates the perception expressed by the nurses that there were differences in the ways that they and the therapists approached patient recovery; that therapists were exclusively concerned with patient safety and risk assessment. The physiotherapists were believed to have strict criteria regarding whether or not a patient could transfer or mobilise in a specific way, whereas although also mindful of patient safety and accepting the rationale for specific approaches, the nurses viewed rehabilitation less prescriptively.

The ward manager related how when she first took up her post on the stroke unit, she was horrified to think that the nurses would act contrary to therapists' advice but soon realised that their knowledge of the patient enabled them to assess their ability to achieve something and the risk involved.

When nurses were asked what they perceived to be the contribution of therapists to overall patient wellbeing, they said it was their ability to spend their time with them individually, in focused one-to-one sessions. This was in contrast to the multitasking context of many nurse-patient interactions. The therapists' central role in helping patients to recover physically was acknowledged. However, there was a general feeling expressed by the nurses that patients still developed much stronger bonds with them on a personal level. The therapists' remit was mobility and physical functioning, not emotional support and this was reflected in the type of relationships developed between therapists, patients and relatives, which were different to those with the nurses. Angie summarised:

> "They have a more 'professional' stance, a more standoffish stance…Distant. We have…almost a personal relationship with patients and relatives; it's not like that with the therapists… I think the patients do think that the nurses are totally different from the therapists." **Angie (nur.1)**

Nevertheless, the therapists' and nurses' differing relationships with patients and relatives could work to everyone's advantage; complementing rather than competing with one another to enable rehabilitation goals to be met. Whilst the therapists focused on improving physical ability and functioning, the therapeutic strategies of encouragement and focusing on achievement implemented by the nurses, facilitated and sustained patient engagement in rehabilitation.

There is always room for improvement: Motivation, encouragement and focusing on achievement

One of the beliefs expressed by the nurses was that there was always room for improvement. Encouraging and sustaining patient and relative engagement in their rehabilitation required a specific and focused nursing approach, which comprised offering encouragement, reinforcing achievements with praise and positive feedback. Achieving recovery also depended upon the patients' and relatives' own approaches and the nurses believed that personal attributes such as a positive attitude and determination were essential. Recovery was most likely when everyone shared these same core values. Although some patients might need little encouragement because of their personal motivation, others would require more concerted input and the nurses would just have to work harder to engage them.

In a conversation with the ward manager, I asked her what she thought patients meant when they said that the nurses were encouraging. Her explanation was that the nurses used the words “you can do that”, with the emphasis on “can”, as in having the ability to do something. She elaborated by saying that the nurses were generally very positive about patients and their condition and did not focus on disability. The focus was on achievement, the things that patients could do, rather than what they could not. Setting

“Well, I'll do this for you now but just for a specific goals helped. For example, Barbara described how she might say to a patient:

> "Well, I'll do this for you now but just for a week and after a week; you can do it for yourself" **Barbara (ca.1)**

This would be because she had observed that the patient could wash their own face and taking her cue from them, recognised that perhaps within a week or so they would be able to start washing their upper body so she set goals with them, motivating and encouraging them to do things for themselves.

Routine, daily repetition of such activities provided patients with opportunities to practice new skills and over time, tasks became easier to achieve. As Sid **(pt.5)** explained, at first, he found it really difficult to dress himself using only one arm but with repetition, he worked out how to do it and it became much easier. Reminding patients of what they had achieved was also a way of enabling them to see how far they had improved since admission and reinforcing these improvements in their ability, emphasising the likelihood that they would continue was thought to be a motivating strategy. Gary provided an example of this approach to a patient who had regained some movement in his affected leg. He had responded encouragingly, saying that the chances were he would be walking soon and he believed that patients generally appreciated this approach:

> "…you can see their reaction… they like what you're saying to them…they like a positive attitude; they definitely like people to be positive about their condition" **Gary (nur.6)**.

Emily maintained that for patients who required more encouragement than others, praise should be given for every small achievement: "You just have to say one word; 'fantastic' and encourage them to do more" **Emily (nur.4)**. That praise and encouragement from the nurses helped patients to feel more positive about themselves was illustrated by Helen:

> "Oh, they'll *(the nurses)* say 'You're coming on, you're doing better today' or 'You're coming on lovely', 'That was good, you're standing better' and when you're thinking that you're not doing good or you're not doing as such; you don't think that they're noticing but they are. They're noticing what you're doing and how you're going and it's really good". **Helen (pt.7)**

Being encouraged to celebrate their achievements in rehabilitation was also motivating for patients and relatives, particularly in relation to the recovery of physical abilities. Helen's primary goal was to be able to walk safely. She was initially rather unsteady using a walking frame but soon regained her balance and progressed to a walking stick. She described the elation she felt on walking with a stick from her bed to the toilet and that how, when she got there, she felt like waving the stick in the air and cheering. Celia likewise related her delight in being able to walk again. She had only been able to drag her right leg when first admitted but despite some lasting numbness, it was, nevertheless an achievement. Ingrid described how "chuffed" she felt when she started to walk again and felt the sensation returning to her right hand.

The patient's own interpretations of their recovery were important. Lily described in detail how the first sign of movement in her right hand was twitching in her thumb and then, as each day progressed, she was able to move her fingers until finally, the sensation in her hand returned. This had really pleased her and she expressed how although it was just a start, she was hopeful it would continue to improve. Although June experienced painful sensations in her legs, she still thought that this was positive; evidence, as she described it, that "blood was flowing back and the dead areas were coming alive" **June (pt.8)**. When Fred succeeded in walking between two physiotherapists, he felt "fantastic".

Recovery of speech was also a major achievement. Lily celebrated the fact that her speech had returned quite quickly. Helen also quickly regained her speech, although she was aware that it was slower than before; like Ingrid, who felt conscious of the change in the way her voice sounded. In contrast, although Gavin's speech remained severely affected several weeks after the stroke, because he had been unable to speak at all for the first two weeks, this was still perceived by him as an improvement. Fred's speech also remained severely affected, though improvement for him was to be able to understand more clearly what people were saying.

For Sid, whose memory remained poor, an achievement was just being assured that he had remembered something correctly. I asked Sid what helped him to feel positive and he replied that it was support and encouragement, which made him realise that the little steps he was taking towards recovery were part of the bigger picture. He believed that one day he would achieve more. When recovery was slow, as in Fred's case, it was still important to focus on the progress made and on any areas of potential for further improvement.

It was not only the nurses who provided encouragement and relatives were also advised to adopt an encouraging approach, often following advice from the therapists or nurses as to what would be most helpful. For example, Thelma explained how she encouraged Fred to repeat words, such as the names of items of clothing, colours and the names of people in the photographs that she had placed in the scrap book. Fred also practiced copying letters and words with his left hand and Thelma encouraged him to do these 'exercises'. According to Lily, her daughters provided her with constant encouragement: "Come on mam, get going!" **Lily (pt.3)**

Lloyd also explained how the nurses would work with relatives to enable them to appreciate the need not to intervene when the patient could do something for themselves, that:

> "…you need a pro-active kind of family…who says "Yes, you can do that mum/dad", you know "You can; I'm not doing it" **Lloyd (ca.3)**

However, this was not always easy to achieve, as relatives often wanted to show their caring by assisting patients with tasks that they found difficult. For example, when visiting around the time of the evening meal, they might want to feed the patient because they had difficulty eating with one hand but as feeding themselves might be the only activity they could perform without help, relatives would be dissuaded from assisting, often against their desire to do so. It was important for them not to undermine the patient's independence by being overly protective.

Other patients could also be a source of motivation and encouragement. As Lily indicated: "…everybody was in the same boat" and she thought "…well, if they can do it, I can do it… if they can get that far, I can get that far" **Lily (pt.3)**. She enjoyed listening to other patients talk about their recovery although she did not think that it helped to compare herself to others and she did not envy them, recognising that everyone was at their own stage of recovery.

Having a positive attitude to recovery was one of the sensitising concepts which emerged from my brief encounter with Celia, the first patient participating in the study; that a person's outlook on life and their personality has a bearing on their approach to recovery from stroke. In conversations, Celia repeatedly described herself as a very positive person, believing that a person's state of mind had a great influence on how they dealt with an illness. In her words: "…if you want to do it, you'll do it won't you; at the end of the day. It's all up here" (*pointing to her head*) **Celia (pt.1)**. In subsequent conversations and interviews with other patients, they were specifically asked to comment on their personal approach to recovery from the stroke, although Lily, Ingrid and Helen all described themselves as very positive people without prompting.

In exploring this with Gavin, although he understood what was said to him, because of his severe speech difficulty and inability to write since his stroke, he could only express himself through the words or concepts depicted on the emotion picture cards. However, on our first interview, when asked about how he was feeling at the time, he chose the card for 'optimistic' and with further questioning clarified that he was optimistic about his recovery. Similarly, when Fred was asked about his feelings at the time of his first interview, he selected the emotion cards labelled 'cheerful', 'confident' and 'optimistic'. He was confident about the future but also confident in his own ability to recover. I asked whether this was his usual personality, whether he was generally a cheerful, confident and optimistic person and he said that he was. Further conversation clarified that the emotion cards he had chosen were really about him as a person and his attitude and outlook on life. Throughout the conversation, Fred repeated the word "positive" and when asked if he meant that he had a positive attitude, he said emphatically "Yes".

A feature of this positive attitude was determination to recover. In keeping with the nurses' focus on ability and achievement, patients focused on activity and the need to overcome obstacles. Lily described the stroke as a hurdle to get over. Celia had been determined to get out of bed and move, stating that “…lying and sitting’s no good, it’s just no good...” **Celia (pt.1)**, beliefs echoed by Ingrid. Self-talk was also a strategy employed by Ingrid and Helen who described how they willed their affected limbs to move. Ingrid spoke of encouraging movement in her right arm, whilst Helen talked to her left arm and instructed it to move. Sat in a toilet cubicle one day, a nurse had asked her who she was talking to. She thought she could hear Helen talking to someone and Helen had to explain that she was talking to her arm, telling it that it was “no good just dangling there!” **Helen (pt.7)**.

Determination also involved working hard and both Celia and Lily described how they pushed themselves to the limit in their efforts to achieve their goal to go home. Celia had actually been cautioned by a doctor and physiotherapist about pushing herself too hard and practicing her exercises too frequently but as she explained, she had a goal which she had to achieve so she could not stop. “You’ve got to help yourself, mentally and physically; you’ve got to do it, make yourself” **Celia (pt.1)**.

Some patients, however, were more difficult to engage than others and, occasionally, nurses and therapists would express their view that patients could achieve more if they tried harder. Sometimes, comments such as “not motivated” would be recorded in patients’ notes. Hilary admitted that whenever she felt that a patient was not trying, she wanted to cajole them with “…come on…you could probably do better than this” **Hilary (ca.2)**. However, she would never say as much to the patient themselves and instead, discussed her concerns about their progress in the shift handover or at a multiprofessional team meeting.

Norman and Iris were two patients in the study whose motivation was an issue of concern for the stroke team. In contrast to Celia, Ingrid and Helen, whose drive towards recovery was clearly derived from strong self-belief in their ability to overcome the effects of the stroke, Norman and Iris appeared to feel powerless to influence their recovery. Observing their progress and in conversations with them, neither demonstrated the self-belief that appeared to enable other patients to thrive on the stroke unit and instead, they viewed recovery as something outside of their control. Therapy was not something they engaged in so much as it was done to them. They did not refuse therapy and went along with what was asked of them but they did not actively participate. This was clearly illustrated in Norman's comment once about the physiotherapists "knocking him about" and in the following description of a dressing practice session with an occupational therapist:

> "…she tries to teach me to do it myself and quite frankly, I can't. I just can't do it so she says 'Well, I'll help you' and by the time we've done, she might as well have done it herself; from what I've done towards it, you know. 'Try and get this arm out of this sleeve', it's practically impossible for me without someone doing it for me" **Norman (pt.9)**

Even when Norman had achieved minor improvements, his own evaluation remained negative. "They say I'm doing really well but I can't see it" **Norman (pt.9)**.

Iris likewise commented that contrary to the general opinion of the staff that she was improving, she could not see this herself. In her view, there was nothing that she could do except sit and wait for things to happen. Both Norman and Iris appeared to find it difficult to understand why they were not recovering in comparison to other patients and they described their situation as hopeless. However, there might have been factors relating to their age, increasing dependency and psychological wellbeing before the stroke which contributed to their current negative outlook and hopelessness. Both were older adults, aged 80 and 77 years respectively, Norman already had restricted mobility and Iris lived in sheltered accommodation and they both had a history of mental health problems. To them, the effects of the stroke appeared to represent a further threat to their wellbeing, which was just too great for them to overcome.

Focusing on progress and potential for improvement could, therefore, sometimes be difficult. Patients often sought definite answers to questions and it required careful management by the nurses to promote hope whilst remaining honest and truthful about their situation. Although the nurses emphasised the need to promote and sustain hope for recovery, they also believed that it was their responsibility to be honest with patients and relatives. Balancing these two obligations could be challenging and required tact and sensitivity and Barbara **(ca.1)** further emphasised that it was important that patients were able to trust the nurses so it was not acceptable to tell lies or deceive them. It was also a matter of demonstrating respect for the patient and their relatives, that they had a right to accurate information.

Hope for continued recovery was tempered with caution. As Lily summarised, "…I think I will walk but if I don't, I don't; but if I do, I do" **Lily (pt.3)**. This was a perspective shared by Lily's daughters, who exclaimed that anything beyond what she had already recovered was a bonus. During one conversation with Fred, he indicated that he was uncertain whether his right arm would regain function; communicating this by running his hand along the length of his arm and saying: "don't know", with a shrug. Regarding the movement in his right leg, he pushed himself away from the table in front of him and demonstrated that he had regained some movement, lifting his leg off the ground. He remained hopeful that he would walk again. There was no time limit imposed on coming to terms with the affects of a stroke and it was accepted that each individual would deal with this in their own time. However, the nurses believed that hope could be maintained, encouragement enhanced and engagement sustained by what they described as "jollying along"; the therapeutic use of 'banter' (repartee) and humour in their interactions with patients.

Sustaining engagement through repartee and humour

A perception frequently expressed by the nurses was how much patients appeared to enjoy hearing about their lives outside work; that they welcomed opportunities to become better acquainted with the people caring for them, just as the nurses attempted to discover as much as possible about the people in their care. Consequently, the nurses were happy to share personal information with patients.

As an example, Hilary described that she had recently returned from a holiday abroad and all the patients in the bay she was working in wanted to know about it; where she went and what the food was like. Initially, she said that she felt uncomfortable talking about it because the patients were confined to the ward but they pressed her for information and appeared genuinely happy to hear that she had enjoyed a good time. More importantly, Hilary recognised that it: "…sparks off a conversation, just completely away from any stroke-related conversation. It takes their mind off it" **Hilary (ca.2)**. It was a welcome distraction; normal conversation about an everyday situation. Even talking about the weather and what it was like outside was welcomed. Not being able themselves to get outside, patients could nevertheless still imagine a frosty morning, when a complaining nurse described having to scrape the ice from her car windscreen. Isabel summarised "…you have to give a little bit of yourself don't you…let them know that you're human" **Isabel (nur.7)**

Although the nurses appreciated that it might be considered by some to be unprofessional; patients often took great delight in teasing them about their occasional lapses in good behaviour. Emily recalled how patients responded when she was feeling hung-over following a night out:

> "They go 'What's the matter' and I'll say 'Oh, I went out last night and I need to go to bed' and 'Oh, I can remember when I used to do that; in at twelve, up at six'. I know its ridiculous behaviour" **Emily (nur.4)**

Emily and Felicity **(nur.5)** both recounted how when they had been out the night before a shift, patients always wanted to know where they had been and what they had done. Sometimes they would know the venue, as it might have been a place they socialised themselves and within minutes, a whole bay of patients would be chatting to each other. It acted as a catalyst to conversation and again, it distracted them from their current situation. From observation, many patients appeared to frequently engage in conversations amongst themselves, learning each other's names and exchanging information about their lives. They shared problems and concerns, after all, as Lily had stated, they had something in common.

The nurses expressed their beliefs that a particularly effective way of sustaining a positive outlook was by using humour. Light hearted interactions between nurses, patients and relatives were observed to be commonplace and the nurses recognised their therapeutic value. They believed that making a joke of things could help patients to feel relaxed and this approach was also valued by relatives, who thought that the nurses' laughter and repartee with patients kept their spirits up and made them feel better. Emily asserted that patients and relatives could still enjoy themselves on the stroke unit, even though they were generally not having a good time. Some even expressed that there was no point in being miserable, as exemplified in Lily's statement that "You've got to have a laugh haven't you? You've got to have joy in your life; even though you're in hospital" **Lily (pt.3)**.

Humour could occur unexpectedly in everyday caregiving situations. For example, Lily recounted an incident, when the Standaid used to transfer her on to the toilet malfunctioned and she was trapped in the toilet cubicle. Although it took quite some time and five staff to rescue her, Lily found the whole situation highly amusing and laughed whilst recounting it. Likewise, Helen found pleasure in describing another incident which occurred one morning:

> "…I said: 'I'd love a bath'. No problem, straight in. Then what happened? The bath leaked! (*Laughs*) She (*the nurse)* said it wasn't leaking before but I said: 'Well, I've lost some weight so it shouldn't be me!'" **Helen (pt.6)**

In Lily's case and that of her family, humour was a coping mechanism, because laughing and joking made light of difficult situations. This was reinforced by Lily's daughters, Mel and Kath. Their mother was ill, it was a serious situation but it could either make them miserable or they could get on with it and have a laugh about it. Mel **(rel.1)** went on to explain further that within their family, they tended to laugh about things rather than "get uptight" and Lily's sense of humour was a positive attribute which helped her to take things in her stride. Indeed, both her daughters perceived that the 'return' of Lily's sense of humour following her initial illness was a sign of recovery in itself.

Relatives also gained positive benefits from humour and nurses took this approach to building their relationships with them as well as patients. As Hilary described, they would first "test the ground" to see how far they might go with an individual but estimated that most relatives were “pretty light hearted” and did not: “…want to come on the ward to visit their mum, or dad, or whoever and see that there’s just no fun…because it’s not encouraging” **Hilary (ca.2)**. Regular visitors like Lily’s daughters recognised the nurses’ humour as important to their own wellbeing, particularly as their mother had been in hospital for several weeks. Humour also enhanced the nurses’ own sense of wellbeing: “…it lifts you both really. You get on with your job better, you’re happier at work” **Isabel (nur.7)**.

Humour could still be appreciated by patients who were identified by the nurses as low in mood, even though they might not have so easily shown it. This was certainly the case with Iris, who although describing herself as always having been “a bit negative”, nevertheless appeared to enjoy humourous exchanges with the nurses. On one occasion, Iris joked about a bruise that one of the nurses had found on her bottom. The nurse had said to her that it looked like an old one and Iris had joked back that it was; her bottom that is. She also thought that having a sense of humour was important because it helped to keep her spirits up and Iris clearly responded positively to humourous interactions with the nurses, even though her general outlook remained negative.

Sid, who was being treated for depression, albeit in the absence of any formal assessment, also responded positively to humourous repartee. During one lunchtime handover, Gary, a nurse who regularly joked with Sid, commented on liking his very dry sense of humour. Christine, one of the other nurses attending, expressed surprise at this; replying: “I must have missed that”. Hoping to explore this further, I joined in the discussion, suggesting that because of Sid’s ‘flat’ facial expression, his slowness of information processing and slow speech, perhaps his sense of humour was only really obvious during the more lengthy periods of time spent with him. I knew from my observations that Gary was not a nurse who rushed around hurriedly, unlike Christine. Gary spent time talking to patients, including Sid, who was a captive audience for his jokes.

However, not all patients appreciated the nurses’ attempts to engage them in humourous exchanges. Indeed, June commented that: “Some of the jokiness was a bit heavy-handed” **June (pt.8)**, which suggests that the nurses’ humour could be perceived as teasing. Norman found attempts at “jokiness” even more hurtful. In contrast to finding humour in caregiving situations, such as those related above by Lily and Helen, Norman’s perception was very different. To illustrate, on the occasion when I was pushing him in his wheelchair to the therapy room, where we were going to hold his interview, we passed by the staff base. Several of the nurses were writing up notes and chatting. Norman spoke to Joan, one of the care assistants and said “You’re not going to torment me are you, like you did that other man?” **Norman (pt.9)**. Joan asked what he meant and he explained that she had been rather “skittish” with the patient concerned and that he (Norman) did not like it. Joan explained that she had been sharing a joke with the patient and that he enjoyed the banter. Norman said that he did not and he would not want her to talk to him like that, as it would upset him. Joan assured him that she would do as he asked.

Maintaining a cheerful and positive approach could be challenging for the nurses themselves, especially when they were tired or not feeling well. As Hilary commented, at seven o’clock in the morning it was not always easy to be smiling and cheerful but the patients needed to see somebody who could “make them feel a bit happier than they probably are generally”. Their patients’ needs had to be prioritised. I asked Hilary whether this was something she had learnt from observing other nurses but she recounted how she had previously worked in a hotel, serving paying guests and had developed strategies for managing her emotions there. However, she believed that same principles applied in patient care.

Barbara also reinforced the importance of keeping personal emotions such as unhappiness in check, because of the potential effect that this could have on patients’ emotional wellbeing. Miserable nurses were thought to have a demotivating effect on patients because, as Barbara believed:

> “…it’s really important that the patients know that they can rely upon the staff to keep them going, to encourage them and to motivate them” **Barbara (ca.1)**.

Lloyd agreed that the nurses had to adapt themselves to the patients they were working with, that they had to be able to adjust how they presented themselves according to whatever the situation required. He emphasised the importance of assessing the most appropriate means of communicating for each patient interaction. For example, he might have been working with the patients in a bay, bantering with them and sharing a joke, immediately following which, he could be caring for a dying patient in a side room:

> " ...the minute you enter through them doors (you) change the way you are…I think every situation; you have to stand back and look at it and think 'what does it need?' 'It doesn't need that now. That's not the time for that'" **Lloyd (ca.3)**.

I suggested to Lloyd that this ability to assess a situation and respond with the most appropriate communication style was quite skilful and I also asked other nurses whether this was something that they were conscious of. However, Angie thought not, remarking that the approach came naturally because the nurses were, as she put it, "tuned into what they do" **Angie (nur.1)**. Nevertheless, it was evident from observing and discussing their interactions with patients, that the nurses were sensitive to and made positive attempts to support patients' emotional wellbeing.

In summary, aligning patients', relatives and nurses' positive emotion enabled a therapeutic relationship to be sustained. However, stroke rehabilitation could be both physically and emotionally demanding and, inevitably, there would be times when determination and a positive outlook might waver in the face of new and difficult challenges. How the nurses recognised and responded to potential challenges to recovery is addressed in the next chapter.

Chapter 7

Sustaining relationships 2: Managing challenges to recovery

Emerging from the data thus far is that interactions between nurses, patients and relatives helped to facilitate coping with the effects of the stroke and sustain engagement in the work of rehabilitation. Through caring, encouragement and support and by promoting a positive attitude, patients' determination to recover could be nurtured and enhanced. Maintaining a sense of purpose was achieved by working towards the ultimate goal of returning home to the life which patients and their families shared before the stroke. Recovery did not always progress smoothly, yet it appears that whilst patients remained engaged in meaningful activities, they were able to tolerate the less positive elements of the rehabilitation experience. These included the ward environment and boredom, over which they had little control and which, therefore, could generate negative emotions of impatience and frustration.

Supporting patients and relatives through the more challenging aspects of their stroke rehabilitation journey forms the basis for this chapter. First to be addressed is the actuality that although the stroke unit environment was generally believed to contribute positively to patient recovery and rehabilitation, reported factors such as noisiness and the patient mix within the six-bedded bays, could exert a potentially negative impact on individuals' emotional wellbeing. Considered next is the effects of the lengthy periods of time which patients spent unoccupied during the day and the feelings of boredom and frustration which they generated, compounded by the limited availability of rehabilitation therapies and opportunities to practice. The focus then shifts to the supportive interventions utilised by the nurses to enable patients and relatives to deal with these perceived challenges to recovery.

The negative impact of the ward environment and its occupants

The nature of activity on any hospital ward necessitates the use of audible communication devises such as nurse call buzzers and alarms from enteral feeding pumps and intravenous fluid monitors. When combined with multiple, concurrent conversations and the general clatter of equipment, a cacophony of background noise ensues, over which patients have little control. This was apparent on the stroke unit. In general, patients appeared to tolerate these noises, although visiting times could exacerbate the situation and were reported to cause distress and agitation. Indeed, in conversation with June **(pt.8)**, she described the “bloody hell” of afternoon visiting time, or “the family hour”, as she called it. June found it difficult to tolerate children running about and making a noise and also commented on numerous occasions about the volume of the television in the bay, which remained switched on even when visitors were present. However, she had not wanted to complain to the nurses, concerned not to cause offence to anyone.

Not just visitors but patients themselves could be a source of noisy disturbance at times. Celia was occupying a single room at the far end of the ward when I met her and although commenting that she did not particularly enjoy being on her own because it was so quiet; nevertheless, she preferred it to being in a six-bedded bay. Celia described having been admitted into the female bay closest to the staff base but asked to be moved because of the disturbing behaviour of a fellow patient with dementia who was screaming and shouting and trying to climb out of bed. She found this difficult to endure so on her request, the nurses moved her into to the next bay. However, on this occasion, it was Celia who caused a disturbance, as she liked to have the television on all the time. The other patients in that bay objected and the only solution was to move her into a single room on her own.

In contrast to Celia, Ingrid enjoyed the solitude that a single room afforded, as she did not wish to mix with other patients. Unfortunately, when her room was required for another patient, she had to move into a bay where she also found the behaviour of one of the other patients disturbing:

> "… this old biddy, she's nearly driven me daft this morning (*a confused and wandering lady in the next bed)* and I'm thinking, 'God, I shall be like her soon', you know. I know I shouldn't; I know it's not nice but what else do you do, you know?" **Ingrid (pt.6)**

However, Celia and Ingrid's responses to these patients were not shared by Lily, who remarked that she enjoyed their company and found them entertaining.

Confused and noisy patients could also deprive others of sleep at night and the nurses sometimes had to remove a particularly disruptive patient to the staff base, or the therapy room; not ideal but a manageable, temporary solution. Lack of sleep then affected patients' wellbeing during the day and complaints of increased tiredness were common, particularly for patients like Fred and Sid, who also experienced intense daytime fatigue as a consequence of their stroke. Most participants commented at some point on sleep disturbance caused by disruptive fellow patients.

Conversely, being with a group of very ill and quiet patients could also be unsettling. Having been moved into a six-bedded bay, Ingrid occupied the middle bed on the left hand side and was observed to deliberately pull the bed curtain round, to obscure from her view the woman in the bed to her right. She told me that she did not enjoy the company of the other patients and described the atmosphere in the bay as “morbid”. Ingrid explained that she was trying to keep herself motivated and this was not easy when she was faced with a group of patients who did not speak much and spent much of their time asleep. On glancing around, it did appear that the other women in the bay were older than Ingrid and had been more severely affected by their strokes. This observation reinforced beliefs expressed by the nurses that sometimes, patients needed to be moved from one bay to another, where they might benefit from a greater level of stimulation or interaction. Indeed, limited stimulation on the stroke unit presented a particular challenge in itself.

Having nothing to do and doing nothing: The effects of boredom

All of the patients participating in the study occasionally complained of being bored; missing home and their usual routines. From my observations of day-to-day activity on the stroke unit, it appeared that apart from periods of essential nursing care, mealtimes and episodes of therapy input, patients spent several hours of each day unoccupied at their bedsides. During the first weeks following their stroke, patients did not necessarily perceive this to be problematic, as many experienced low energy levels and required frequent rests between episodes of care or therapy. However, once they had started to recover and were actively engaging in rehabilitation, lengthier periods of time would be spent awake and alert.

There were few recreational activities available, except for the games organised within the context of therapy sessions and patients were largely dependent upon family or friends to bring in reading or other diversional materials. The hospital library provided a mobile service once a week and a trolley service for newspapers and magazines was available daily. However, only the more able patients could access these services unassisted and the trolley often appeared on the ward at a time in the morning when many were washing and dressing. Participants who were not cognitively impaired and could concentrate did appear to find diversions; such as Ingrid and June, who were both observed reading books and watching television. Lily passed her time reading magazines, conversing with other patients or, as she described, “observing the ward goings-on”. Gavin had portable DVD and CD players and occupied his non-therapy time watching films or listening to music. Helen had arranged for her craft materials to be brought in by a friend so that she could continue making embossed greetings cards; commenting that it stopped her from feeling bored.

To illustrate how much time patients might spend unoccupied, I once asked Sid what he had planned for the day, to which he replied that he would probably be sat in his wheelchair for twelve hours, before going back to bed. He also commented that he never knew what day it was, because every day seemed the same and when I asked him how he passed the time, he joked that he counted the holes in the polystyrene ceiling tiles. As Sid was already low in mood, this did not appear to be a particularly helpful situation.

Norman said that he had tried to pass the time by reading a newspaper but could not concentrate. Even talking to other patients did not distract him, as he questioned “What is there to talk about?” **Norman (pt.9)**. Norman further described that whilst sat doing nothing, he was in “turmoil”, because of the long hours he spent thinking. He said that psychologically (his word), it was really hard for him because the days were “blank” and his mind wandered away from his objectives. Iris’s experience was similarly expressed: “…they're very boring days…you think, ‘Oh, what am I going to do?’ You get right down in the dumps” **Iris (pt.10)**.

Norman and Iris also both expressed their physical discomfort from being sat in a chair for lengthy periods. Neither could adjust their own position in the chair, in response to which, Iris complained that “everything aches” and that although she took analgesia, she could not comfortably relax.

Boredom caused by inactivity and lack of stimulation appeared to be largely outside the control of the nurses and interventions to avert or remedy boredom were limited. Christine **(nur.2)** recalled in her interview how a previous ward manager had attempted to identify an hour every afternoon, where nurses and patients could engage in recreational activities together but due to competing clinical priorities, the idea had been quickly abandoned. Nevertheless, the nurses expressed their awareness of the effects of boredom on patients, recognising that spending long periods of unoccupied time could have a negative impact on their emotional wellbeing:

> “…they’ve been poorly and we’ve got them to a stage where they’re well…and then we have them for another week or so and you can see them going back down; you can see their mood going back down and their motivation deteriorating and I think that’s a big factor, because they’re sat for long periods… I’ve heard a lot of patients say ‘I’m just fed up. I just want to go home now’” **Isabel (nur.7)**

Although not specifically articulated by the nurses, arising from my observations of participant activity on the ward, there appeared to be a gradual reduction in the number and duration of therapy sessions offered to patients over time, which was also remarked upon by participants. I asked the ward manager on one occasion what criteria the therapists used to assess the intensity of interventions offered to patients but she admitted that she was unaware of any. In response to a similar question, a senior physiotherapist affirmed that such decisions were based on individual need. However, this did not appear to be how patients and relatives always perceived the situation.

Limited availability of therapy and opportunities to practice

One of the most common causes of frustration voiced by participants was not only the length of time they were unoccupied but that this time should have been spent engaging in rehabilitation therapies. Many commented that they thought they did not receive sufficient physiotherapy, occupational therapy or speech and language therapy for their needs. Gavin complained that he only received physiotherapy three times a week and speech and language therapy twice. This was reinforced by his mother, who asserted that she did not think Gavin was improving because of the lack of physiotherapy and that his speech had actually deteriorated because he was not getting sufficient speech and language therapy.

Although none of the patients in the study expressed any expectations of exactly how much rehabilitation therapy they thought should be offered, the nurses acknowledged that patients often expected daily sessions and could become particularly anxious during weekends and Bank Holidays, when the therapists did not work. Norman bemoaned the absence of therapy at weekends, exclaiming:

> "That's why it's so boring. There's nothing happening on the ward; nothing. Even if it's happening to somebody else, it takes your mind off things"
> **Norman (pt.9)**

There were also no arrangements for staff cover when therapists were sick or on holiday. An example of such a situation occurred shortly after I met Helen, when she described how unhappy she was about having been on the stroke unit for over a week without receiving any physiotherapy. She argued that unless she was able to practice walking, she would not improve her mobility and had even threatened to discharge herself until her son dissuaded her from doing so.

Some patients would be provided with therapy exercises to carry on by their bedsides but opportunities to practice walking or other self-care skills were few, because although the nurses generally attempted to integrate techniques recommended by the therapists into patient care, they had limited time available to achieve this. A nurse herself, Lily's daughter Mel expressed her view that the reliance on mobility aids such as Standaids delayed patient recovery and denied them opportunities to further practice standing and transferring. Mel was convinced that Lily would have progressed much more quickly if:

> "…she had been standing on her own rather than the machines lifting her up and down and would probably not have been in as long" **Mel (rel.1)**.

The frustration expressed by Mel represents just one of the emotional demands made upon patients and relatives during the process of recovering from a stroke and many experienced situations when their usual coping strategies of determination, a positive outlook and good humour were challenged.

Helping patients through difficult times: coping with emotional distress

The nurses believed that the time when patients most appeared to suffer emotionally was when they realised the full extent of the stroke effects. As Felicity surmised, “I think it’s when that kind of reality hits them, you know; they’ll say like ‘Oh, this arm’s useless or ‘I’m useless’” **Felicity (nur.5)**. The nurses described that recognising that they might not be able to walk again, drive again or do other things they did before the stroke was an extremely distressing experience for patients and their emotional distress appeared to negatively impact upon their continued recovery and rehabilitation. Sometimes, they would disengage by withdrawing and refusing to participate in their rehabilitation and such changes in the patient’s behaviour would be noticed during their interactions with the nurses and other members of the rehabilitation team.

Sensitivity to a patient’s emotional wellbeing enabled nurses to identify when patients were not feeling too good. Asking them how they felt, if anything was the matter or reflecting back to them that they seemed low in mood were described as everyday communication strategies. By empathising with how they might be feeling about their situation, it was possible to appreciate something of what they might be experiencing and it was important to understand what might be worrying or upsetting them, in order to respond in the most appropriate way.

Many of the nurses expressed their belief that emotional support was given to patients as part of their day-to-day nursing practice, that it was not singled out as a specific activity. As Angie summarised:

> "…you don't even think about it; you just do it…it's incorporated into your working day, without you being able to pinpoint the times… every time you have a conversation, every time you do an intervention, you look at that patient and you know that they're upset about something, you just do it naturally…. I don't think any of us think: 'I've got to give this patient emotional support'; we just do it"
> **Angie (nur.1)**

Indeed, such emotional care was rarely documented in the patients' records because, as Angie further explained: "…we give it without even realising that we're doing it so it's difficult to put that into words at times" **Angie (nur.1)**. The nursing documentation focused almost exclusively on physical care needs so there was no specific trigger to writing about the patient's emotional wellbeing.

In addition to the approach described by Angie, there were occasions when it was important to devote specific time to respond to emotional distress; to listen without interruption. Just taking ten or fifteen minutes to sit with each patient and talk with them was in Donna's view "better than all the medicine that you can give them" **Donna (nur.3)**. Sometimes patients might feel that they were being a nuisance, taking up the nurses' time but it was important to explain that they were not; that the nurses cared about them and wanted to help talk through any problems they might have. When considered appropriate, expressions of physical comfort sometimes helped; holding someone's hand whilst talking to them, or giving them a hug or a kiss. However, finding such time was something of a luxury in the nurses' busy working day and not having time to talk with patients was said to be a source of frustration for the nurses.

At night, there could be more time to talk, although this was obviously a time when patients would generally be asleep. However, it was also a time when they could be laid awake worrying, without the distraction of daytime activities. Karen, a nurse who regularly worked nights, described the example of a man who had difficulty sleeping and was prescribed night sedation. However, when she went to him in the early hours of one morning and asked why he was not sleeping, he burst into tears; explaining that he was worried about not being able to drive any more and of becoming socially isolated. In response, Karen encouraged him to think about other ways of getting about, even the positive benefits of using public transport, thus enabling him to focus on solutions to the problem. He later thanked her for helping him to feel better.

Lily voiced her belief that everyone had their own way of coping. Indeed, Ingrid was determined not to let the stroke experience get her down, stating resolutely: “No, I’m not allowing myself ...I think once you start giving in, ugh, no (laughs)…I personally feel that I cannot afford to do it” **Ingrid (pt.6)**. She appeared to be stoically determined to remain in control of her emotions and such an effort to retain emotional control was also observable in the case of Iris. It appeared to me both in our everyday conversations and particularly during her interview, that talking about her stroke and its effects was difficult, if not distressing for her, as she did not respond to such questions and avoided eye contact. Instead, Iris appeared to use distraction as a means of diverting the emotion, as evidenced in the sudden changes of topic which often followed lengthy silences. This was her way of coping and having recognised this, I was careful not to pursue this line of questioning.

Celia admitted that although she was generally very positive in outlook, there were times when she became tearful, usually when thinking about her family and home which she was missing. On such occasions, she explained that she would talk herself out of it. Nevertheless, when she received distressing news one evening about a neighbour’s death, Celia appreciated the emotional support provided by the nurses who spent time with her during the night, sitting with her and listening. At the end of the night shift, she recalled:

> “…one that went off left me a little note saying to get better and all that and the other one kissed me before she went off. It’s little things like that” **Celia (pt.1)**.

In Gary’s view, patients needed someone to talk to about their feelings. Indeed, the nurses believed that they were able to deal with emotional issues most of the time but if they considered that a patient needed emotional support beyond what they could offer, they would discuss the matter within the multiprofessional team. In these circumstances a referral for further assessment and alternative interventions such as antidepressant medication might be considered. This was not perceived as a failing on their behalf and certainly not in the patients themselves; just an appropriate response to the severity of the situation.

However, Norman presented the nurses with particular challenges. It appeared from his medical records that he had initially become depressed following his first stroke several years previously and although he had been prescribed antidepressant medication, he had been reluctant to take it and resisted all subsequent suggestions that he might benefit from it. In consequence, he appeared to be in a constant state of emotional distress and often asked whether other “stroke victims” felt as low as he did.

The nurses recognised Norman’s emotional distress but because of his persistently negative responses to any of their attempts to influence his outlook, they were unsure about what they could do to improve the situation, other than refer him for specialist assessment. Patients who were believed to be depressed would be referred to a clinical psychologist, even though there might be a lengthy wait for an appointment. However, identifying patients for referral to psychology services was not straight forward, as no formal mood assessment tools were in use on the stroke unit, even though they were available. However, the value of these forms of measurement was questioned. As Gary argued:

> "…assessing depression and assessing mental health can be quite specialised and can be difficult, because it's not very measurable…you can't put a cuff on somebody's arm and measure their depression can you, like you can their blood pressure…it's a more difficult thing to measure" **Gary (n.6)**

None of the nurses suggested that formal mood assessments should be undertaken, which resonates with suggestions that nurses believe presenting patients with negatively worded statements such as: "I can no longer do the things I used to" could further contribute to existing emotional distress. In preference, the nurses focused on the positive aspects of the patient's recovery.

Sometimes, unexpected and unpleasant events occurred on the ward, such as the sudden death of a patient, which would upset other patients; especially those in the same bay. Gary commented that this would be perceived as a frightening experience, because if someone could suddenly die, then this could happen to them too. Under such circumstances it was also difficult for the nurses not to feel emotionally involved. As Angie admitted:

> "…you know, I've cried with relatives and felt gutted and we're only human at the end of the day so sometimes that's really difficult to deal with" **Angie (nur.1)**

Nevertheless, Angie thought that relatives really appreciated it when the nurses shared their grief: “I think that it shows that you’ve got a human side to you, yeah. Definitely; I’ve never had any relatives that’s objected to it” **Angie (nur.1)** It was a way of demonstrating their understanding of relatives’ needs and of offering them support. Indeed, the nurses often expressed their belief that when a stroke was experienced by a family member, it affected everyone in the family.

Buffering the effects of stroke on relatives’ emotional wellbeing

For a person like Gavin, who had two young children, his stroke would necessarily impact upon them and Paula, his wife, who would be caring for the children and managing the household alone whilst Gavin was in hospital. For Thelma, who, like Paula, was dependent upon her husband’s income, managing finances was particularly difficult, as because of Fred’s severe speech disorder, his capacity to provide consent for Thelma to assume temporary control of his bank accounts had to be formally assessed. Delays in processing the necessary documentation by both the solicitor and Fred’s bank left Thelma without financial support for several weeks, causing her additional anxiety and requiring the intervention of the stroke unit social worker. In Sid’s case, he had an infant son, Johnnie, who was awaiting hospital treatment. The stress that this caused Sid’s wife Mandy was evident in a comment she made one evening when Sid was bidding goodnight to Johnnie. Sid said: “I’ll see you tomorrow”, to which Mandy replied: “No you won’t; it kills me bringing him here every day” **Mandy (rel.4)**. Sid later told me that he understood how tired Mandy must be, because he always helped out as much as possible at home, especially with Johnnie’s care.

Most patients relied upon their relatives to visit every day and particularly at the weekends, when, as already described, there was little else happening on the ward to occupy their time. Because there would be no timetabled therapy sessions or other appointments at the weekend, there was also an added expectation that visitors would spend lengthier periods with them than usual, or that other family members who were working during the week, or who lived at some distance, would visit as well. Thelma spent around six hours a day on the ward every day, in addition to which, the bus journey to and from the hospital took nearly an hour in each direction. This left her little time for anything else but as she was Fred’s only regular visitor, she felt compelled to spend this time with him. Besides, as she said herself, she would not know what else to do, because as a couple, they always did everything together. Nevertheless, Thelma expressed her disappointment than none of Fred’s family had been to see him since his stroke, nor had they offered her any help or support whilst Fred had been in hospital. She felt very alone in dealing with Fred’s stroke; his wellbeing was her priority but she needed support as well.

There were two occasions during my time spent with Fred and Thelma that Thelma was unable to visit due to exhaustion. She always looked tired, as did Paula, Gavin’s wife. Lily’s daughter Mel summarised the demands of daily visiting:

> "…It's tiring and there's times when you can think, 'Oh God, I can do without this tonight'. I work seven while three and I'm actually only spending about four hours a day in my house, awake. But it's just something you do – it's just life isn't it? You know, I mean, you just get on with it" **Mel (rel.1)**

Lily was aware of how tired her daughters were and told me that she wished they would take it in turns to visit. However, she knew that she would miss them if they did not come in and that they would also miss visiting her. Concern for their relative's wellbeing was also expressed by other participants, who deterred family members from visiting frequently because of the disruption this caused to their busy lives.

Although the hospital stipulated specific visiting hours, these were only loosely applied on the stroke unit and visitors were welcomed at any time of the day, particularly if the prescribed hours were difficult for them to manage. As Gary asserted: "…some patents just live for their visitors coming; and they just count the hours round until they come" **Gary (nur.5)** so it was important for their wellbeing that visiting was restricted as little as possible. It was also important to tell patients when their relatives had telephoned the ward and the availability to patients of a cordless phone enabled them to talk to family and friends at any time of day.

In general, patients expressed their appreciation of the efforts made by their relatives to visit, although in Norman's case, he bemoaned the fact that his wife and daughter did not visit him enough and even described how he felt abandoned by them. This was despite the fact that they both visited every afternoon and his wife was herself unwell and very frail. His son also visited briefly every evening. Nevertheless, Norman believed that they should prioritise his needs above their own and, therefore, spend more time with him. He said that he needed his wife to be with him, for company and for comfort and believed that this must be what all patients wanted. However, he also felt sorry for his wife being on her own at home and thought that she too must be feeling lonely.

Relatives sometimes had to deal with patients' expressions of frustration. Thelma described how Fred had started to swear, which was out of character for him and that she also had to work hard to keep his spirits up, because of his increasing impatience and frustration. He often "kicked off", as Thelma explained, when they were away from the ward, in the cafeteria or elsewhere in the hospital. Thelma believed that Fred's frustration was largely due to his communication problems, echoed by Paula, Gavin's wife, who also reported that Gavin's inability to express himself resulted in bad tempered outbursts directed at her.

Christine **(nur.2)** expressed her view that the stroke unit was purposely family-friendly and that this was achieved by creating a relaxed informality. By this, she meant that there were no rigid rules or routines which had to be observed and that the nurses tried to involve relatives as much as possible in the patient's recovery. Indeed, despite the demands of regular visiting, Lily's daughters described enjoying the friendly and supportive atmosphere on the stroke unit and Mel explained that one of the ways in which the nurses particularly supported her was by allowing her to become involved in her mother's care. Initially and because she was herself a nurse, she was hesitant to do anything, concerned that the nurses might not approve and think that she was being intrusive. However, her concerns proved to be unfounded, as once aware that Mel was a nurse, they expressed their confidence in her ability by stepping back and letting her do what she felt capable of for her mother.

The nurses expressed their awareness of how challenging it could be for relatives to visit every day and that they were concerned about their wellbeing as well as that of the patients. Therefore, when visiting for lengthy periods, they would suggest to relatives that they should take a break, perhaps just go for a drink or a walk. Alternatively, they might make them a drink on the ward and show them where the quiet room was. The nurses also respected that relatives would be experiencing a difficult time and believed that they needed emotional support. However, when I asked Lily's daughter Kath whether the nurses enquired how she was feeling, her response was:

> "To be honest with you, I'm not too bothered about them asking how I am, as long as they're making sure that my mum's alright" **Kath (rel.2)**.

So long as Lily was being well cared for, Kath was happy and this was consistent with the nurses' perceptions that what relatives most wanted from them was for the patient to be well cared for.

Felicity **(nur.5)** summarised the nurses' view that for relatives, adjusting to the effects of a stroke both on the patient and on themselves was a steep learning curve, in addition to which, as Donna **(nur.3)** explained, because of the unpredictable nature of stroke recovery, a patient's condition could vary from day to day. One day the patient might appear to be quite bright and alert but the next, she/he could be drowsy and tired and this could be particularly stressful to deal with. For example, Fred's wife Thelma found the intense fatigue that he initially experienced difficult to understand and interpreted this as deterioration in his condition. She described how Fred had "lost consciousness" several times during one day and did not understand why the nurses appeared to be unconcerned. It was not easy to reassure her that this was a normal feature of recovery from stroke.

Unfortunately, relatives' expectations for the patient's recovery were not often fully realised. Asking herself how she might feel in this situation, Donna surmised: "…you want answers, you want miracles and they're not going to happen. The answers will come but the miracles won't" **Donna (nur.3)**. Occasionally, relatives' grief or disappointment would be expressed as dissatisfaction with the patient's care, which could be upsetting for the nurses. It challenged their ethos of caring on the stroke unit, as they spoke in their interviews of the shared aim of creating a positive and supportive environment for patients and their relatives alike. Maintaining this depended upon a mutual understanding that the nurses were doing their best for patients and could be easily threatened if a relative expressed dissatisfaction with the care that their relative was receiving.

Although concerns were occasionally raised by relatives about aspects of nursing care they were not entirely happy with, overall, the nurses were not openly criticised by either relatives or patients in the study. The nurses' focus was clearly upon easing the journey through rehabilitation, even in the presence of potential challenges to recovery such as those addressed here. Patients and relatives commented upon these factors but generally did not complain; appearing to accept that they were, to some extent, unavoidable. The nurses where not blamed, as it was recognised that preventing them was largely beyond their control. These less positive experiences did not appear to undermine patients' and relatives' relationships with the nurses; indeed, it was the strength of these relationships which enabled the nurses to provide support and offset the inevitable frustrations generated by being in hospital. It was important that patients and relatives continued to trust them, as progress towards discharge from the stroke unit often brought additional emotional challenges such as fear, apprehension and uncertainty about the future. The ways in which the nurses anticipated and responded to these challenges; enabling patients and relatives to successfully move on, is addressed in the next and final chapter of the findings.

Chapter 8

Reframing relationships: disengaging and moving on

Sustaining engagement required a collaborative effort to combine personal resources with practical strategies for recovery. From the data, it appears that one factor which positively contributed to this was early planning for discharge. Preparing to return home would evoke emotions of excitement and apprehension but for some patients and relatives, additional feelings of impatience, anger and frustration could be generated; if their personal priorities and perceptions of readiness for discharge differed from those of the rehabilitation team. At such times, their relationships with the nurses were central to supporting the transfer of care and it is the challenges inherent in achieving a successful discharge from the stroke unit which provide the focus for this final chapter of the findings.

First to be addressed is goal planning; the personal goals expressed by patients and their relatives and how these both informed and were shaped by the formal processes of multiprofessional team meetings and family meetings. Service-induced delays to discharge are revealed to negatively impact upon experiences for patients and relatives on the stroke unit during the days leading to discharge and occasions where the criteria for discharge imposed by the rehabilitation therapists differed from those of the patient and their relatives are raised to highlight conflicting priorities. The ways in which the nurses attempted to mediate in such situations are demonstrated. Finally, the emotions associated with leaving the stroke unit are focused upon to emphasise the closeness of the relationships forged between patients, relatives and the nurses, the perceived reward of caring and the ways in which relationships might be maintained in the longer term.

Planning ahead and preparing for life after stroke

Observations of ward activity identified that weekly goal planning meetings were routinely convened within the multiprofessional stroke team, to discuss patients' progress and to focus on short and longer-term rehabilitation goals. In addition, depending on individual circumstances and progress being made in rehabilitation, patients and their relatives would also be invited to participate in family meetings; to share information and decision-making. They provided a formal channel for communication and the main forum for the co-ordination of post-discharge services and equipment. Attended by the nurses and therapists involved in the care of the patient concerned, it was usual for two or three of such meetings to take place during the course of a patient's stay on the stroke unit; although the level of active participation in this process differed considerably between patients.

In day-to-day conversations and during interviews, all the patients in the study talked about their plans for the future and of the adjustments they thought they might need to make in their lives. Such plans were also observed to be frequently discussed during everyday interactions between nurses, therapists, patients and relatives. Patients such as Norman and Iris who chose not to actively participate in planning for their future through the medium of the family meeting, nevertheless, still expressed their general goals in conversation. Norman explained that he had wanted to attend the family meeting but he was unsure of what to say. He thought that if he was asked what he wanted, he could only state that his goal was to go home. Iris stated that she was happy for her family to make decisions on her behalf about her future care; although ideally, she wanted to return to the sheltered housing where she lived.

Some patients started to make plans quite early on in their rehabilitation and even before the full extent of their potential recovery was known. For example, not much more than a week after her stroke, Helen had already planned what changes she thought she could make to her home and daily routines, to ensure that she could carry on looking after herself. Focusing on practical issues, she described in detail the ways in which she could accommodate the physical limitations which she thought might result from her stroke. When I enquired whether the way in which she was thinking about her future was influenced by the fact that she had been ill in the past (with heart failure) and already had experience of reorganising her life, she confirmed that this was the case. To continue managing on her own, she was prepared to make whatever adjustments might be necessary, remarking that:

> "I'm hoping to be still be able to carry on doing like I've been doing but I'll have to probably just slow down the jobs I've been doing each day" **Helen (pt.7)**

Such planning enabled her to visualise a long-term future for herself.

Like Helen, Celia described her long-term goal as to “get back to proper, normal life” **Celia (pt.1)** but she also recognised that in the short-term, her ability to achieve this could be restricted by the effects of the stroke and that she might not be fit enough to do everything she wanted to straight away. Sid’s goals also focused on his overall wellbeing and ability to resume his role within the family. He described wanting:

> “…to get my head clear so that I can think for myself and a little bit more stable on my feet…And build my strength up so I’ve got the energy to help Mandy in the house and play with Johnnie and keep him occupied...you know” **Sid (pt.5)**

Even though he recognised that what he could achieve might be limited, he did not think that it was fair for his family to have to manage without his contribution.

Ingrid also conceded that she would probably "have to slow down" as a result of her stroke and that it would take her longer to do things. However, her situation was unique in that she was living on a houseboat at the time of her stroke and she described that although she had already considered selling it and moving into a recently acquired holiday home, the stroke had hastened this decision. Having re-evaluated her situation, she recognised that continued life alone on the boat would no longer be feasible:

> "…there's just no way that I would be able to get the engine cover off to service the engine, because I couldn't lift it. It's very awkward and not a lot of room" **Ingrid (pt.6)**

In the short term, Ingrid had agreed to stay with her son and his family.

Sharing personal goals with the nurses and therapists enabled the detailed planning necessary to ensure individually-tailored discharge strategies. These conversations offered frequent opportunities to discuss possible options, to resolve problems and help to sustain motivation. They would also inform the more formal processes of discharge planning and following patients through the course of their rehabilitation on the stroke unit, there appeared to be a point when more definite plans for discharge were instigated; commencing with an assessment of the patient's home circumstances. This was often referred to by the nurses and therapists as an "access visit". Arrangements would be made with relatives for the OTs to assess the accessibility and layout of a person's home, to identify the need for any equipment, practical aids or adaptations required to meet their changed ability following the stroke.

Discussions with the patients and relatives would identify what could be provided by health or social services and what patients and relatives themselves might be expected to provide. It was also usually at this point that the Stroke Nurse Specialist or a social worker would become involved, particularly if sources of financial support needed to be explored. The Stroke

Nurse Specialist summarised that her role was central to ensuring a well-co-ordinated discharge plan:

> "I think because everybody knows I'm here…any issue that comes up…they'll send them to me… I see what problems they've got; they just come to me… you're finding out things for them to make it less stressful" **Julie (nur.8)**

Although intended as a positive step towards discharge from the stroke unit, access visits had to be managed carefully so as not to raise undue expectations in patients. The purpose of the visit would be clarified to ensure that patients fully realised that they would not be staying at home following the visit and needed to return to hospital. For some, like Gavin, this prospect was not always easy to bear and the OT reported that he had been crying because he did not want to come back to hospital. Access visits could, therefore, provoke or exacerbate feelings of impatience or frustration, which could be further intensified by subsequent delays to finalising the arrangements for discharge.

Delays to discharge: Just waiting to go home

Gary expressed his belief that plans could sometimes be discussed too soon after admission and raise expectations for an early discharge, although what all patients needed was a definite date for discharge. This gave them something to work towards and sustain motivation and also made bearable the length of time it often required to organise aids and equipment, home care and continuing rehabilitation packages:

> "…they like to have goals and dates and times and they hate this endless 'oh, another few weeks', 'another couple of weeks', they like to have definite goals, definite dates; the 23rd of this month, or the 18th of that month, you'll be going" **Gary (nur.6)**

Sid confirmed this view, as following his second family meeting he complained about not having been given a date for discharge and wanted to be told when he was going home: "Being told something like 2 to 3 weeks is no good; it's a bit like, how long is a piece of string?" **Sid (pt.5)**. Fred had similarly expressed his frustration when I once asked him if he knew when he would be going home. Holding up the fingers on his left hand, he counted: "one, two three, four, five, ooh" and shrugged his shoulders.

It appeared that once the therapists had assessed what aids and equipment would be required for patients, they would be speedily requested. The OTs took the lead role with respect to this activity; liaising with patients and relatives to arrange delivery dates. Mobility aids including hoists and wheelchairs, beds and commodes, could be provided through a central supplies service but there were often waiting lists. One way of avoiding delays was for patients or relatives to purchase their own equipment; although only in Lily's case was this observed to be done. Her daughters agreed to buy a new bed and armchair which were delivered to her home within 48 hours; however Lily's discharge was still held up awaiting the availability of the hoist and wheelchair. Sid's discharge was also delayed pending an adjustable-height bed.

Norman’s home equipment needs had been met quite quickly, although his family needed to make alterations to the layout of the ground floor of the house and he perceived this to be slowing things down. He became increasingly impatient and annoyed with them, saying that he failed to see why they could not take him home once the equipment had been delivered, questioning “Who is more important, the house or me?” **Norman (pt.9)**. However, it was because of Norman’s high level of physical dependency that he also needed home carers to attend on him four times a day and arranging his home care package was another course for delay in his case. Having been given a definite date for discharge, he described being devastated to hear that it would be a further three days before the carers could begin visiting; that both he and his wife had broken down and cried in response to the news:

> “…I know at the end of the day, they’re all going to say exactly the same thing; ‘It’s not long to Thursday, just be patient’. I haven’t got any patience left though…I had got my heart set on it. The time was getting near; I was getting so close, I’d battled it so hard, pushed myself to get to that point. Even all the nurses knew I was going on Monday. Now its Thursday, this is a long, long way distant” **Norman (pt.9)**

It was planned for Norman to receive continuing therapy in his home, via the Early Discharge Scheme (EDS), which offered home-based physiotherapy and occupational therapy, five days a week for four to six weeks and was provided as an outreach activity by the stroke unit team. However, access to this service was limited and as the outreach team could only accommodate three patients at any one time, there was often a waiting list, which could prolong delays to discharge. Indeed, Julie, the Stroke Nurse Specialist jokingly commented that the term EDS was rather a misnomer, as it did not necessarily speed-up the discharge process. In Fred's case, although he would have been a candidate for the EDS, it could not be provided when he required it and so referral to the rehabilitation centre could only be offered as an alternative.

On discharge from the stroke unit, all patients would be offered some form of continuing rehabilitation, depending on their needs. There was a range of options available, including, as already mentioned, the EDS, which Gavin, Lily, Sid, Norman and Iris were offered. For Celia, whose continuing rehabilitation needs were minimal, attendance one day a week at a local rehabilitation centre was offered, whilst Ingrid, Helen and June were transferred to a local intermediate care unit for further in-patient rehabilitation before going home. The Stroke Nurse Specialist explained that she would try to ensure that all patients and families understood the arrangements for their future care and rehabilitation; her priority, as already outlined, being to ensure a well-co-ordinated discharge. However, there were occasions observed when disagreements between patients, relatives and therapists presented challenges to this process.

Listening to discussions to at the staff base and during shift handovers, it appeared that the nurses perceived there to be significant differences in approaches to rehabilitation between themselves and the therapists. The latter were viewed as more prescriptive in their interventions and less holistic in their approach; i.e. that they focused exclusively on their own aspects of professional practice rather than considering the patient's situation as a whole. As Angie explained:

> "I think they've got their own backs to protect and I think if they send somebody home too early, I think that's got a lot to do with it and that patient has an accident, or whatever, they've got to cover themselves but I also think that they don't see patients like we see patients because they're only with them a small amount of time and they don't get involved" **Angie (nur.1)**.

This perception was echoed in the case of Fred, whose discharge from the stroke unit was preceded by intense disagreement with the therapists.

Fred's circumstances were unusual in that he had already been discharged from the stroke unit to another neurorehabilitation unit adjacent to the main hospital, which could provide him with an extended period of in-patient rehabilitation, focusing more on the needs of younger rather than older adults. However, Fred's time on the neurorehabilitation unit lasted only three days, as he immediately took a dislike to both the environment and the patient group; mainly young adults with severe traumatic brain injuries. He and Thelma had expressed initial enthusiasm about his transfer there, believing it to be a step nearer to returning home but during the short time spent on the neurorehabilitation unit, Thelma claimed that Fred had lost his confidence and become so emotionally distressed that the only option now was for him to go home. She had been persuaded at the neurorehabilitation unit not to discharge Fred herself but to return to the stroke unit instead. Thelma had agreed but it was evident from our conversations that she was now set on arguing for his discharge as soon as possible.

On Fred and Thelma's behalf, Gary later related that he had tried to speak with the OT and the physiotherapist about the need to set a firm discharge date for Fred but neither had been receptive and insisted that he was not ready to go home because he could not master a safe step transfer technique. It was Gary's opinion that they were not looking at his situation holistically; purely from a functional, safety perspective. In short, they wanted him to remain on the ward. However, after a further three weeks, Thelma had decided that Fred was going home.

A final family meeting was arranged, where a strong case was presented by the physiotherapist as to why Fred should continue rehabilitation on the ward; on the basis that he was still unsafe. Thelma was not convinced by this argument, insisting that "There's more to life than a perfect turn off a bed" **Thelma (rel.3)**. It did not matter that Fred could not transfer safely, as they would just “muddle through”. Reluctantly, the physiotherapist agreed that Fred could be discharged at the end of week, although Thelma later related that the OT had actually agreed with her that it was time Fred went home. Fred and Thelma's experiences appeared to be unique amongst those in the study, although Gary commented that the build-up towards discharge was always an understandably emotive time.

Excitement and apprehension: dealing with an uncertain future

The day before Fred’s discharge, I asked Thelma if she was ready for his homecoming. She told me that she had been busy with housework and arranging furniture but also that she had spent a long time thinking about what it would be like when Fred came home. She said that it had only just struck her how different things would be, because even though Fred had been really ill on the day of his stroke, he had walked out of the house but three months later, he would be returning in a wheelchair. She was very anxious about the arrangements for Fred’s care and how they would manage. Sid’s wife Mandy and Norman’s wife Elsie both expressed similar concerns; that they were worried whether they would be able to cope but had to hope that things would be alright.

I interviewed Gavin on the morning of his discharge, placing the ‘feelings now I’m going home’ card in front of him and laying out a pile of emotion pictures for him to choose from. He did not select any of them. I asked him, “Is it something else?” to which he nodded and said “yes”. I asked him if he could think of the words to describe what his feelings were but he could not verbalise these or write them down. I then suggested that I could say a few words and see if they were appropriate. I also asked if he could indicate on the ‘feelings scale’ chart how he was feeling. He pointed to spot beyond the top of the scale and I asked him if this meant it was much better than just feeling good, to which he responded with a “yes”. I suggested "overjoyed" and Gavin said “yes”. I also said "fantastic" and again he said “yes”; but he also tried to indicate, by moving his left hand from side to side, that he had mixed feelings. He was pleased to be going home but apprehensive about the future. I checked my interpretation with him and he agreed that it was accurate.

Iris was also anxious about how she was going to manage at home and when I asked her how she was feeling about going home, she too was “apprehensive”. On asking whether this related to anything in particular, she said that it was being on her own at night. The carers would come in to put her to bed at night and get her up in the morning but she would be on her own throughout the night and she did not know what that would be like. As Iris’s stroke had occurred at night time, her fear was understandable.

The only worry that Ingrid expressed was the possibility of having another stroke. She wanted more information because she did not really understand why it had happened:

> “ I mean the only thing I’ve got to think about…is the likelihood of it happening again…What can you do to, perhaps it won’t ensure that it won’t happen again but take precautions… you don’t want to feel ‘I wonder what’s going to happen today?’, you know. I don’t want to have that on my mind” **Ingrid (pt.6)**

The Stroke Nurse Specialist later informed me that she spent time explaining this to Ingrid before her discharge and also recommended that she register with a local General Practitioner who could monitor her health. Helen had also expressed her concerns about the prospect of having a further stroke and said that she intended to speak to her GP about this as soon as she got home. For the same purpose, June said that she intended to read the leaflets she had been given. In their own ways, all the participating patients appeared to be preparing for finally leaving the stroke unit.

Leaving the stroke unit:

The nurses maintained that they would always try to be present when patients they had been working with left the ward, as it was perceived to be an important occasion. One of the care assistants expressed how upset she had been when she had forgotten to say “goodbye” to a patient who was being discharged. A patient’s departure from the stroke unit could be an emotionally charged experience for all concerned. To illustrate, on the morning that Gavin left the ward, I noticed he had lipstick kisses all over his face and forehead and two more of the nurses kissed him before he left. He had been laughing with the nurses but I observed that shortly afterwards, as his wheelchair was being pushed along the corridor away from the ward, he looked rather sad, almost close to tears, in contrast to the previous joviality.

As a tangible measure of patients’ and relatives’ satisfaction with the care they have received in hospital, a ‘Thank-you’ card and gift of chocolates or other treats were often presented to the nurses for sharing with the team. Even despite their negative experiences, Fred and Thelma still left these customary tokens of appreciation. On the day before Sid was discharged from the stroke unit, his wife Mandy brought two greetings cards, a box of fruit and tin of sweets to the staff base. Later, I observed that as she was passing the base, she asked the nurses if they had opened the cards yet. Hilary, one of the care assistants immediately did so. One card was from Sid and Mandy and the other from their daughter Sally, on behalf of herself and baby Johnnie. After the preliminary thanks for looking after their dad, Sally's card read: "You guys are the reason he's still with us and for that we are eternally grateful" **(Sally, rel.5)**. Hilary thought this rather touching and Gary remarked how important it was for the nurses to receive such words of appreciation, as it acknowledged that what they were doing was worthwhile. Hilary agreed that patients' and relatives' gratitude affirmed that they were seen to be doing their best for them.

All the 'Thank-you' cards were displayed on top of the wall-mounted cupboards at the staff base and I had observed that they were often taken down by the nurses and commented upon. Care assistant Barbara remarked that she always read these cards and that the nurses made a special point of reading the messages of thanks from both patients and relatives. Words frequently observed to be written were: "kindness", "consideration", "devotion", "patience", "comfort" and "support". One card which appeared to particularly reflect the supportive ethos of nursing care on the stroke unit simply stated: "Thank-you for all the love, care, jokes and banter".

Christine explained that before patients were discharged, they were always told that they could ring the ward if they wanted to talk or if they had a problem, even if they had only been at home a short while. In addition, they were asked to come back and visit the ward when they attended for their follow-up appointment in the stroke clinic, just to let the nurses know how they're getting on. She said that he nurses always enjoyed seeing patients again and hearing about their continued recovery and patients likewise enjoyed seeing the nurses again. Sometimes, the Stroke Nurse Specialist or one of the therapists attending the out-patient clinic would convey greetings and messages from patients and relatives and I overheard numerous conversations concerning chance encounters with ex-patients and their families when out and about locally, which stimulated great interest from the nurses listening.

For all the patients and their families in the study, discharge from the stroke unit marked the end of the first stage in their journey towards recovery. The length of time patients had spent on the stroke unit varied from two to twelve weeks, depending on the severity of the stroke and progress in rehabilitation; all of which time they spent in the company of nurses. Throughout the stroke journey, the nurses responded to the changing needs of patients and relatives as they progressed towards recovery and enabling them to move on was their ultimate goal. During this time, the nurses had attended to their needs, befriended them, encouraged and supported them and their families and the relationships built and sustained had enabled their recovery and rehabilitation. The nurses' reward was seeing patients leave the stroke unit as well prepared as possible for the life that lay ahead of them.

Chapter 9

Discussion, conclusion and recommendations

What the findings in this study demonstrate is that the relationships built and sustained between nurses, patients and relatives during their encounters with each other on a stroke rehabilitation unit were central to promoting emotional wellbeing. The detailed description of interactions reveals a multilayered approach to promoting wellbeing and enabling recovery from stroke. However, in order to give the findings broader significance beyond the local setting, they require further explanation, which can be achieved by drawing comparisons with other experiences and situations (Le Compte and Schensul, 1999; Coffey and Atkinson, 1996). Therefore, the purpose of this chapter is to compare the key concepts emerging from the findings with related research, to more fully explain what they contribute to understanding how nurses promote emotional wellbeing in patients and relatives following a stroke.

It is proposed that promoting and sustaining emotional wellbeing involves a far more complex process than is implied in the term ‘emotional support’ and that although there are specific interactions or interventions which can be more clearly identified as emotionally supportive, often in the presence of emotional distress, these represent only one element of a much more pervasive relationship-focused approach which is central to every interaction. The challenges in undertaking the study and the limitations of the methodology are also considered, before the concluding with recommendations for policy, practice, education and research.

The multiplicity of factors contributing to emotional wellbeing

The nurses in this study clearly appreciated how crucial it was to use every opportunity to build trusting relationships with patients and relatives and Manderson and Warren (2010) suggest that trust is central to any therapeutic relationship. Furthermore, Close and Procter (1999) remark that patients and carers are able to identify members of staff who they regard as trustworthy and supportive and proactively build relationships with them, in order to gain the knowledge and information they need to deal with their uncertainty following stroke. Löfmark and Hammarström (2005) likewise describe how building alliances with staff enables patients to ask for help and information and that trusting relationships positively influence a person's emotional wellbeing, helping them feel more supported and less isolated. Nurses in rehabilitation practice have been identified as enjoying considerable trust from patients because in addition to attending to bodily care, they also provide emotional support and routine social interaction (Manderson and Warren, 2010).

Hupcey and Miller (2006) remark that patients may have difficulty in defining trust, nevertheless, the patients in their study were able to describe trustworthy attributes of health care professionals as: being personable, truthful, honest, respectful, professional, sincere; compassionate, being a good listener and, most importantly, caring. In nurses, caring was the most important attribute (Hupcey and Miller, 2006), resonating with this study's findings, as although patients and relatives did not use the term ‘trust’, caring attributes of the nurses were clearly recognised and articulated.

The nurses on the stroke unit demonstrated caring through paying attention to patients’ and relatives’ needs, at a time when they were struggling to make sense of what was happening to them. Caring for patients involves “subtle, unobtrusive processes” (Arnaert *et al*, 2006 p.144) and Mangset *et al* (2008) maintain that often it is the ‘trivial’ daily care activities which matter. Nursing attentiveness and presence; a sense of ‘being there’ are important to patients and relatives (Long *et al*, 2001; Macduff, 1998) and they value being treated well and receiving help when they need it (Andersson and Hansebo, 2009). These demonstrations of caring all resonate with those expressed by the nurses, patients and relatives in the study.

The nurses sought information from patients and relatives to create a picture of who the person was and the things that were important to them. They spent time getting to know patients and relatives, listening to the stories of their stroke experience and empathising with them. Talking with stroke survivors about their experiences is thought to be an important aspect of their recovery process, as telling the story of the stroke can evoke feelings and memories, providing a means for patients and relatives to articulate their hopes, fears and aspirations (Arnaert *et al*, 2006). It can enable patients to retain their sense of individual identity (Bays, 2001; Kautz, 2008). In addition, Banja (2011) argues that listening to patients' discourses can alert rehabilitation professionals to coping mechanisms, resources (or lack of them), beliefs and attitudes which might influence their engagement in rehabilitation. The nurses in this study also articulated their belief that this was an essential foundation for building the alliance with patients and relatives that enabled them to start preparing them for engagement in rehabilitation.

A concept which has potential for explaining progress in rehabilitation (or not) is that of therapeutic engagement, defined as:

> "…deliberate effort and commitment to working toward the goals of rehabilitation interventions, typically demonstrated through active, effortful participation in therapies and cooperation with treatment providers" (Lequerica and Kortte, 2010 p.416).

The quality of the interactions with nurses in rehabilitation appears to play an important role in determining patient engagement and Kralik *et al* (1997) list a number of characteristics of engagement which are consistent with those described by patients about the nurses in the study. According to Kralik *et al* (1997), these include: nothing being too much trouble, asking the patient/consulting them, being cheerful and using humour, being compassionate and kind, knowing what the patient wanted without asking, always being available, having a gentle touch and being friendly and warm. In order to engage patients and relatives in working towards recovery, the nurses on the stroke unit utilised their personal and professional attributes to enable patients and relatives to use their own and thereby maximise their resources.

Jones *el al* (2008) offer insights into the specific personal resources that individuals use to support their recovery from stroke. Exploring individual beliefs about what contributed to their recovery, albeit at a time largely beyond their hospital-based rehabilitation, Jones *et al* (2008) identified three categories of personal influences which were seen as particularly important; personal strength and control on recovery, generalised optimism and hope and their perceived dependence following stroke. Their research participants also described the external influences which supported their recovery, focusing on their therapeutic interactions with rehabilitation staff, including nurses. In care providers, a characteristic of optimism was thought to induce feelings of hope and confidence and helped when facing stressful situations over which there was little control (Jones *et al*, 2008). The researchers surmised that "Progress achieved in the first few weeks may be vital in reinforcing an optimistic notion that further change may be likely" (Jones *et al*, 2008 p.514).

The nurses on the stroke unit believed that thinking positively about stroke recovery was essential. Indeed, keeping positive was identified by most of the study participants as making a major contribution to recovery following stroke. Ramanthan *et al* (2011) contend that although the influence of personality traits or attributes on health outcomes has not been well-researched, a personality trait of dispositional optimism acts as a buffer against the detrimental psychological consequences of illness. Dispositional optimism refers to “a generic, cross-situational pattern of optimistic beliefs which has most often been linked to positive emotional outcomes” (Bedi and Brown, 2005 p.59); a general expectancy that good rather than bad will happen (Peleg *et al*, 2009). It is associated with emotional wellbeing in people with both acute and chronic health problems, because they are likely to implement problem-focused coping (Lyon, 2002).

Contending that this is a previously unexplored area of research within the context of stroke, Ostir *et al* (2008a) argue that recovery and resilience can be enhanced by focusing on positive emotion, engendering a fighting spirit. Ostir *et al* (2008b) suggest that a person with a positive outlook would view a stroke as more of a challenge than a threat, believing that a favourable outcome is possible. Reporting on the same study, Seale *et al* (2010) further suggest that the relationship between change in positive emotion and recovery of functional status may represent a positive feedback loop, whereby increases in positive emotion provide motivation to the person affected by a stroke to engage in activities which result in improved functional status. Therefore, having a positive outlook can enable a person to recognise even small gains in function as evidence of improvement, providing hope for further improvement and motivation to maintain their engagement in rehabilitation (Ostir *et al*, 2008b).

Patients in this study clearly celebrated positive signs of recovery as evidence that they were improving and expressed hope for continued improvement. Investigating the relationship between hope and recovery in stroke, Popovich *et al* (2003, 2007) conclude that fostering hope is an important nursing intervention. Cross and Schneider (2010) and Western (2007) further suggest that understanding the influence of hope is important because of its role in long-term recovery and enabling individuals to achieve quality of life after a stroke. Bays (2001) also maintains that hope is a concept which positively effects stroke survival and that inspiring hope in individuals is an emerging philosophy of stroke care.

A positive appraisal of a situation, therefore, is thought to influence positive coping; an important process for managing stress (Lyon, 2002). Relevant positive coping processes are those which provide comfort and give a continued sense of meaning and purpose to the life. Positive emotion can broaden the individual's attentional focus and behavioural repertoire, promoting creativity and flexibility in problem-solving (Folkman and Moskowitz, 2000) and it is an important element of psychological resilience. Referring to what they describe as a 'broaden and build' theory, Tugade and Fredrickson (2004) suggest that positive emotions "broaden an individual's thought-action repertoire, which in turn helps to build that individual's personal resources" (p.330).This is arguably a useful framework for understanding the construct of psychological resilience, which is characterised by an ability to bounce back from negative emotional experiences by flexible adaptation to the changing demands of stressful experiences (Tugade and Fredrickson, 2004). Building on previous life experiences of illness and loss, patient participants such as Celia, Ingrid and

Helen clearly demonstrated the use of their resilience in dealing with the effects of the stroke.

Voicing positive feelings is intended to infect a person with enthusiasm (Garberding, 2009) and positive emotions can be elicited through the use of humour (Tugade and Fredrickson, 2004). Having “a laugh and a joke” was a strategy routinely utilised by the nurses on the stroke unit to support patients and relatives. Increasing interest in the therapeutic uses of humour in nursing care is evident from recent literature reviews on the subject (Moore, 2008; Chinery, 2007; McCreaddie and Wiggins, 2007). The benefits of humour to physiological and psychological health and wellbeing are now fairly well-established and researchers have explored how humour can assist with coping and maintaining positive emotion for patients, families and health care providers (Greenberg, 2003; Kinsman and Major, 2008; Scholl and Ragan, 2003; Olsson *et al*, 2002). The findings from this study resonate with these assertions.

The use of humour in stroke rehabilitation has received some specific attention, but mainly with respect to the effects of stroke on humour appreciation and emotional response to humour. For example, the ability to laugh and smile can be affected by damage to the non-dominant (usually the right) hemisphere of the brain (Cheang and Pell, 2006; Health and Blonder, 2005, 2003; Shammi and Stuss, 1999; LaPointe *et al*, 1985), although of the study participants who had experienced right sided strokes (Sid, Helen, June, Norman and Iris), it was unclear whether any of them had been specifically affected in this way. However, studies of patients with right hemisphere strokes also identify that they may have difficulties in the comprehension and expression of emotional language and humour and that depression exacerbates this; having a marked effect on interpersonal interactions (Turner and Andrew, 2010; Blake, 2003). This might explain why Norman evaluated the nurses' attempts to cheer him up as 'tormenting' rather than caring.

Humour facilitates co-operation and goal achievement and playful banter is used in therapeutic encounters as a skilfully managed means of engagement (Walsh *et al*, 2009). Banter is described as an exchange back and forth; an equitable interaction which occurs when people are in a playful mood or share good humour (Walsh *et al*, 2009) and was clearly valued by patients, relatives and nurses in the study. A light-hearted environment enables patients to feel "valued, looked after, included, cheerful and safe"(Geanellos, 2005 p.243) and Geanellos (2002) further suggests that whilst technical care, professional knowledge and skills are important so are involvement and attachment and patients and relatives value the ways in which nurses use "personal sharing, humour and friendliness" (p.237).

The nurses in this study recognised the positive effects of friendliness, which were likewise valued by patients and relatives. Friendliness relates to nurses' use of interpersonal skills such as smiling, joking, touch, a warm tone of voice and showing interest; and it reflects a positive person-to-person interaction which has therapeutic outcomes (Geanellos, 2002). Friendly nurses relate to and respect patients as individuals and friendliness results in a therapeutic relationship and a therapeutic milieu which sustain wellbeing and enable recovery (Geanellos, 2005). Hunt (1991) describes how being 'friendly and informal' is an often unquestioned, taken-for-granted aspect of practice. This 'friendly-informal' role is symbolised by use of first names, self-disclosure and use of social talk, smiling and tone of voice; and is a type of relationship motivated by a desire to break down traditional, authoritarian nurse-patient barriers.

Griffiths *et al* (2010) explored the concept of therapeutic chatting and the ways that nurses freely and openly exchange personal information; which patients and their relatives valued. Just taking a few minutes to chat, smiling and showing that they care could have a positive impact on a person, when they know that their thoughts an feelings are important to the nurse (Goble, 2008). What Burnard (2003) refers to as 'ordinary chat' or 'small talk'; is used to acknowledge a person's presence or indicate that they matter and he further suggests that it might be as important as therapeutic conversation. Jarrett and Payne (2000) argue that criticisms of nurses' apparently superficial, positive and chatty interactions as indicators of poor communication skills training are misplaced, because both patients and the nurses are active in the construction of these conversations. Furthermore, Cox *et al* (2002) suggest that 'good' nurses are distinguished by the efforts they make to chat to patients; the everyday talk and smiling which patients feel like a person. It is characteristic of the culture of a caring environment (Cox *et al*, 2002). Again, there are clear resonances with the ways in which the nurses, patients and relatives in the study positively evaluated the importance of these characteristics.

Promoting and sustaining a positive attitude or affect and enabling patients and relatives to feel that they are cared about through everyday interactions were strategies employed by the nurses on the stroke unit. They are also key features in motivation and self-efficacy and primary requirements in rehabilitation. Maclean *et al* (2000a) emphasise the importance of understanding the concept of motivation and its use in rehabilitation practice, because a subjective assessment of a patient as either being well motivated or poorly motivated is unhelpful. Resnick *et al* (1998), Guthrie and Harvey (1994) and King and Barrowclough (1989) describe motivation as an inner urge, which moves or prompts a person to action but Maclean and Pound (2000) also caution that seeing motivation as a purely internal quality of the individual patient can lead to moralising on behalf of health care staff, who may judge the patient as somehow lacking. Indeed, Geelen and Soons (1996) suggest that motivation is more to do with “the way in which a patient experiences or interprets their own efforts … the subjective perception and evaluation of one’s own chances of successful rehabilitation” (p.70) and is affected by all sorts of social or external factors. Resnick (2002, 1994) suggests that motivation can be facilitated by rehabilitation nurses through qualities of competence, caring, humour, kindness and encouragement; again resonating with the approaches taken by the stroke unit nurses.

Robinson-Smith and Pizzi (2003) explored self-efficacy as a concept in rehabilitation, explaining that it influences patients' expectations of their competence to perform a task. The degree of a person's belief in their capabilities affects the manner in which challenging activities are approached so that patients with strong self-efficacy beliefs have confidence. Self-efficacy influences motivation by determining the goals that patients set, how much effort they are prepared to invest in achieving them and their resilience when faced with difficulties (Dixon *et al*, 2007). In this study, both Norman and Iris appeared to demonstrate low levels of self-efficacy, judging themselves to be incapable of achievement. Norman remained passive in his therapy sessions, subjecting himself to being "knocked about" and bemoaning that he could do nothing to help himself. He evaluated himself as a "poorly man" and did not think that anyone realised how ill he was. Mclean *et al* (2000b) identify that patients like Norman do not appear to understand the purpose or importance of rehabilitation, or why they cannot have things done for them.

Patients and relatives will have expectations for recovery and express these as goals to achieve, although Almborg *et al* (2008), Holiday *et al* (2007) and Playford *et al* (2000) identify barriers which limit patients' abilities to participate in decision-making, such as preparedness and understanding of their condition. Ellis-Hill *et* al (2009) argue that rehabilitation professionals need to understand and explore individual perspectives of recovery, to enable them to achieve a successful transfer of care from hospital to home. However, Playford *et al* (2000) suggest that most people are not used to 'formal' processes of goal setting and so goals set in hospital do not always easily transfer to the community. In their experience, goals tended to be formulated and agreed by the team rather than by the patient (Playford *et al,* 2000). Cott (2004) also notes that many patients do not feel prepared enough to participate in decision-making, particularly in the early stages of rehabilitation, when they may not yet have accepted the long-term consequences of their condition.

Comparing patients' and professionals perspectives (nurses and OTs) of participation in rehabilitation planning, Lund *et al* (2001) categorised patients as participants, occasional participants and relinquishers. Relinquishers were generally older and did not wish to participate in the process of decision-making (like Iris in this study), whereas participants used shared decision-making and were proactive; Celia, Ingrid and Helen being obvious examples here. Occasional participants believed that they had insufficient information and/or not enough time to make decisions (Lund *et al*, 2001). Hedberg *et al* (2008) conclude that strengthening participation is important and health care professionals need to know how to do this, as meetings tend to be dominated by professionals. Therefore, patients need allies to help them express their goals.

The consequences of failing to fully consider the goals of the patient and their relatives are clearly illustrated in Fred and Thelma's case; where the insistence of prioritising the therapists' goals for Fred's safety over his and Thelma's goal to go home, resulted in conflict, only following which a compromise acceptable to all parties was reached. Fred and Thelma had allies amongst the nurses who advocated on their behalf but the nurses did not feel able to challenge the therapists' decisions; conceding to their authority in planning discharge. Like Fred and Thlema, Lily's daughters also rejected the therapists' recommendations, choosing instead to take risks in order to achieve their own goals for discharge.

Horton *et al* (2011) suggest that patient risk-taking appears not to be uncommon in rehabilitation and represents a balance between institutional control and self-governance. Patients may understand the risks involved but they choose to take them anyway, yet they are aware of the need for a gradual approach to the development of autonomy, facilitated by staff support (Horton *et al*, 2011). The nurses on the stroke unit were prepared to enable patients to take risks, despite the potential censure of the therapists. Providing positive feedback on accomplishments, using encouragement and affirmation of capability, as utilised by the nurses in this study, are positive interventions to promote self-efficacy (Korpershoek *et al*, 2011; Robinson-Smith and Pizzi, 2003). However, sustaining motivation and maintaining a positive outlook sometimes involved great effort for patients and relatives, which was when the nurses' support for their emotional wellbeing was most valued.

Glass and Maddox (1992) identified a high level of emotional support as the intervention which most positively impacted on recovery in the first few weeks following stroke. Cott (2004) perceives emotional support as offering advice, encouragement and direction and that emotional needs are met by respecting patient’s wishes and decisions and treating them with respect and dignity. Emotional support thus conveys a genuine sense of caring and concern and resonates with suggestions that it does not necessarily involve talking about emotional issues directly (Ellis-Hill *et al* 2008). Mel, one of Lily's daughters exemplified this conceptualisation when she said that she did not expect the nurses to offer her emotional support, as they demonstrated this just by looking after her mother. It was their 'being there' that was important, which suggests that patients and families do not necessarily want or need nurses to discuss their emotional wellbeing with them directly but just to demonstrate through their approach and actions, that they care about them and value their opinions. This is also demonstrable in the claims of the nurse participants in the study, that providing emotional support was something that they achieved through their everyday interventions, because they were ‘tuned-in’ to the patents and relatives they had established relationships with.

Summarising thus far, the relationship-focused, pro-active approach used by the nurses to engage with patients and relatives in rehabilitation on the stroke unit is supported by evidence drawn from research in the context of stroke and rehabilitation more generally. Strategies for managing challenges to recovery, largely presented by the physical environment of the stroke unit and the organisation the stroke service, also depended upon the nurses’ ability to react supportively and are likewise supported by the research.

Organisational challenges to emotional wellbeing

Pryor (2000) contends that the context within which rehabilitation takes place has received little specific consideration and that it is necessary to look beyond the multiprofessional team to where it is that rehabilitation takes place. The importance of the ward atmosphere, as a component of a ‘healing environment’ has received some attention and in exploring the processes which lead contexts of care to be experienced as supportive, Edvardsson *et al* (2003) identified a ‘sense of atmosphere’ which was characterised by being welcoming and a place where patients could feel safe, cared about and where they could create and maintain social relations. Pryor (2000) maintains that nurses are in an ideal position to purposefully create such a therapeutic milieu and the nurses on the stroke unit reported that they tried to achieve this, through their welcoming and flexible approach.

In contrast to such welcoming environments, Edvardsson *et al* (2005) also identify those which are chaotic and discomforting, recognising important considerations to creating a therapeutic environment. These include organisational aspects of care such as visiting times and when activities take place (Mion, 2009) and the proximity to others of patients with cognitive and behavioural impairments (Oh, 2006). Challenges for patients and relatives on the stoke unit which were not easy to resolve were observed and reported in the study, such as the patient mix within the bays and achieving a balance between encouraging families to visit and the noise and chaos that large numbers of visitors created. There was a reluctance expressed by the nurses to limit visiting because of its perceived importance to both patients’ and relatives' wellbeing so achieving equanimity without resort to prohibitive measures relied upon them resolving these issues on a day-to-day basis; illustrating their desire to remain flexible in their approach.

Other organisational aspects of the stroke unit which were perceived by patients, relatives and nurses in this study to exert a negative influence on recovery and emotional wellbeing, were boredom and the length of time that patients spent unoccupied. Although the physiotherapists and OTs were perceived by the nurses to spend more time than they did on an individual, one-to-one basis with patients, the overall amount of time that patients spent with the therapists was very limited. This caused concerns for the patients, as they clearly related their functional progress and recovery to therapist input; i.e. that more therapy would lead to a more rapid improvement (Mangset *et al*, 2008)

Although comparisons are difficult to make between widely varying stroke units, a small number of studies have specifically explored time use in stroke rehabilitation. Esmonde *et al* (1997) observed that when they were not receiving therapy interventions, patients spent most of their time between 09.00 and 17.00 physically inactive. Bernhardt *et al* (2004) found that only 13% of patients' time was engaged in activities which had the potential to prevent complications and improve recovery of mobility. Furthermore, Huijben-Schoenmakers *et al* (2009) also identified that patients spent 60% of their time alone; i.e. unattended by any member of the health care team. Cowdell and Garrett (2003) identified that boredom was 'soul destroying' and contributed to a sense of loss of control, whilst inactivity and boredom were identified by Löfmark and Hammarström (2005) as contributing to a sense of helplessness in patients. The perceived withdrawal of therapy, as patients in this study moved towards discharge from the stroke unit could exacerbate this situation and the nurses clearly identified the detrimental effects that inactivity and therapy withdrawal could have on patients. Maintaining momentum in the direction of recovery is considered important (Ellis-Hill *et* al 2009).

The nurses on the stroke unit had little influence on the intensity or duration of the therapy patients received and focused on supporting them and their relatives when such demotivating situations occurred, by attempting to enable them to maintain the gains they have already made in rehabilitation. As Kearney and Lever (2010) argue, rehabilitation practice maximises all opportunities for patients to enhance self-determination and increased function so time spent with nurses should also be seen as "added value". Some patients might not perceive nursing interventions as intrinsically therapeutic (Pryor and O'Connell, 2008; Secrest, 2002) but Gibbon (2004b) maintains that nurses are, nevertheless, highly valued by patients and their contribution to rehabilitation is seen as helping them to recover in a different dimension to that of the therapists. Within the context of this study, this different dimension was the therapeutic relationship.

Refining the relationship model

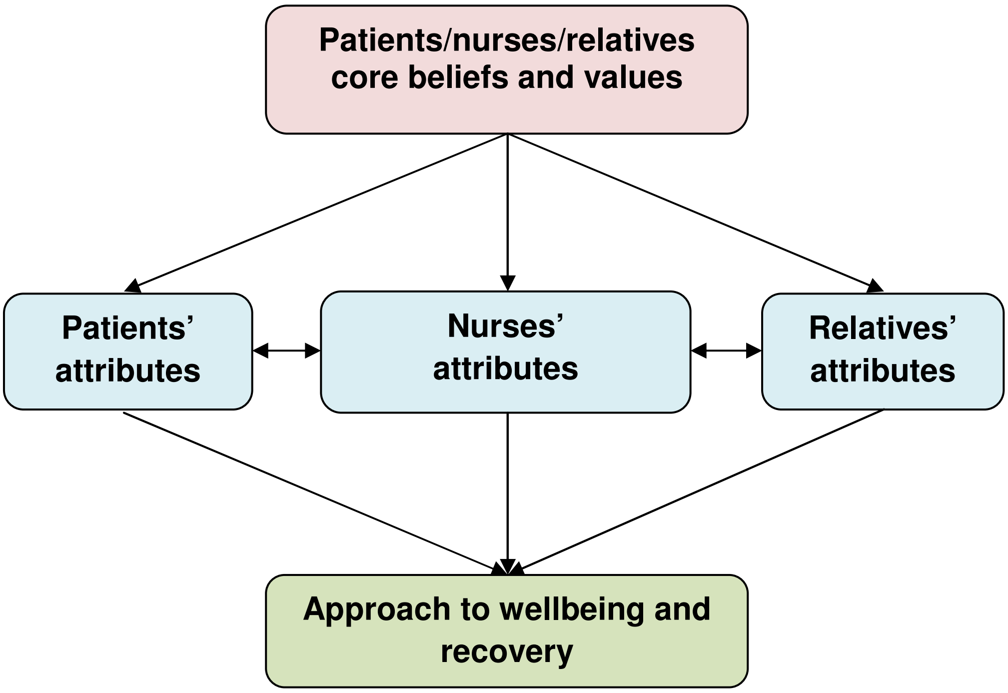
Having discussed the findings in the context of other substantive research in the field, the relationship model of promoting emotional wellbeing and recovery from stroke can be further explained as follows: The nurses on the stroke unit espoused and expressed a set of core values and beliefs based on knowledge of the emotional experience of stroke acquired through multiple episodes of working with patients and relatives. They used their personal and professional attributes and interpersonal skills to build and sustain trusting relationships with patients and relatives and allied them to these core values. These relationships enabled patients and relatives to access and utilise their own personal attributes in order to recover, supported by and engaging with the nurses' approaches and interventions. This created and enforced a positive culture of caring which promoted emotional wellbeing and aided recovery (Figure 8).

There are both familiar and novel dimensions to the findings, consistent with Le Compte and Schensul's (1999) remark that although researchers often seek to discover something that no-one else knows, much of what they achieve is to:

> "…illuminate the obvious…to attribute meaning and importance to patterns and regularities that people otherwise take for granted in everyday life – until the researcher points them out" (p.214).

Figure 8:

The relationship model for promoting emotional wellbeing and aiding recovery following stroke



Similarities can be identified between this model and elements of others which have explored the role of the stroke rehabilitation nurse more generally (Kirkevold, 2010, 1997; Long *et al*, 2001; Burton, 2000; O'Connor, 2000a, 2000b). In their own ways, all these studies seek to explain the processes by which nurses interact with patients and their relatives to enhance recovery following stroke. However, it was not the purpose of this study to achieve a comprehensive description of the components or constituents of the nurse's role in stroke rehabilitation but to focus specifically on the ways in which nurses promote emotional wellbeing. Whilst Kirkevold (2010, 1997), Long *et al* (2001) and O'Connor (2000a, 2000b) all addressed promoting emotional wellbeing as an essential element of stroke recovery and how nurses can contribute to this, it was not central to their enquiries.

The main point of divergence for this study is that rather than confining the promotion of emotional wellbeing to a single or discrete element of the nurse's role in stroke rehabilitation, the findings indicate that all nursing interactions with patients and relatives have the potential to promote emotional wellbeing, through the relationships formed between them. Furthermore, these relationships are constructed by a skilful and deliberate process of achieving congruence between the core beliefs of nurses, patients and relatives, with the purpose of enabling the combination of personal and professional resources to strengthen coping strategies and sustain engagement in rehabilitation. The focus for this approach is essentially proactive, with the aim of generating positive emotion.

The role of positive emotion in enhancing coping resources in the face of illness, has received some research attention in recent years, particularly in relation to cardiovascular disease (Bedi and Brown, 2005; Fredrickson and Levenson, 1998). However, the contribution of positive emotion to recovery following stroke has only more recently been explored and in a single, measurement-based study which was referred to earlier in this chapter (Ostir *el al*, 2008a, 2008b; Seale *et al*, 2010). Nevertheless it offers promising indictors for exploring how rehabilitation professionals might develop strategies to enhance emotional wellbeing and recovery, to which the findings from this study can contribute.

In contrast to focusing on the negative emotional experience of stroke, more specifically depression, this research has illuminated how by recognising and supporting patients’ personal strengths and coping strategies, recovery from stroke can be enhanced. It appears reasonable to suggest that if 30% of people affected by a stroke are estimated to experience depression (NHS Improvement, 2011), then 70% do not. Therefore, there may be significant factors which enable stroke survivors to transcend this potentially damaging mood state and maintain their emotional wellbeing. The findings from this study suggest that the nurses on the stroke unit had embedded strategies into their interventions which enhanced positive emotion with patients and relatives, even though they might not have conceptualised them as such.

However, before proceeding further, a note of caution should be sounded regarding the promotion of positive emotion in rehabilitation, because there may be other service or profession-driven factors informing and influencing this approach which need to be acknowledged. Warren and Manderson (2008) offer useful insights into the situation from their research on the rehabilitation following lower limb amputation of older adults with long-term vascular disorders. They note that with regards to many long-term conditions, patients are often faced with an incomplete and unattainable recovery, yet rehabilitation professionals attempt to work with them towards achieving meaningful outcomes, by providing what they perceive as attainable goals. However, in order to succeed, patients have to play by the rules set by the professionals and are expected to adopt the goals of the rehabilitation team as their own (Warren and Manderson, 2008). Patients who engage in rehabilitation activities are praised for complying with the professionals' core values of "effort, co-operation and productivity" and to reinforce their goals, the professionals engage in the "deflection of negativity"; i.e. they deliberately seek to enhance a sense of emotional wellbeing by focusing on positive emotions.

There appears to be nothing intrinsically wrong with this approach, except that the patients in Warren and Manderson's (2008) study who, like Norman in this study, expressed pessimism or hopelessness, were judged as "pathological" and their resistance to rehabilitation was attributed to "individual illness or personality failings rather than processes or objectives" (Warren and Manderson, 2008 p.197). In other words, their failure to engage in rehabilitation was blamed on having a negative personality, rather than on the professionals who had failed to understand their needs, which were the "competing but contestable value" of "the right of the elderly to be cared for" (Warren and Manderson, 2008 p.197).

Norman presented the nurses in this study with a challenge because he did not respond to their usual therapeutic approach and they had no alternative strategies to draw upon. The nurses were unable to promote in Norman a sense of emotional wellbeing both because of his long-standing depressed mood and because the success of their approach depended upon patients playing by the ‘rules’ of rehabilitation and he could not (see Appendix 8e). Although outside the scope of this study, this important observation is clearly worthy of further exploration.

Not having been addressed thus far, it should be acknowledged that the relationship-focused approach to promoting emotional wellbeing also extended to the nurses themselves. Their personal and professional attributes and interpersonal skills influenced their relationships with one another, as well as with patients, relatives and other members of the multiprofessional team. They were also exposed to sources of stress both in the personal and professional lives, which would necessarily impact upon these relationships and there were times when I became aware of individuals experiencing personal and family illness, relationship difficulties and other stressors in their lives; yet they continued to fulfil their duty of care to patients, relatives and their colleagues.

Work-related stressors were largely attributed by the nurses to changes in service provision, resulting in increased patient throughput and reduced lengths of stay on the stroke unit, increased demands for documentation to support discharge planning and onward patient referrals and an erosion of ‘down time’ through persistent in-service professional development requirements. All of these resulted in a reduced length of time available to spend with patients, resulting in frustration. As indicated by some of the nurse participants in the study, managing their own emotions in order to enable them to continue to care in the face of such competing demands was essential and collegial relationships were important as their primary sources of emotional support.

Seneviratne *et al* (2009), Barreca and Wilkins (2008) and Burton *et al* (2008) all raise questions regarding the effects on the nurses themselves of competing demands of meeting patient’s needs. This important issue of the nurses’ wellbeing, the enjoyment they experience in stroke care and frustration they encounter in not being able to fulfil their potential for aiding recovery reinforces Nolan’s (2002) observations and more recently Teasell (2011), that stroke services exemplify many of the tensions within current healthcare systems.

Methodological challenges and limitations of the study

The nurses’ approach to promoting emotional wellbeing was also evident in my role as researcher. From the theoretical premise that emotions are experienced and expressed during interactions between people, then it is likely that my interactions with participants will have also contributed, either positively or negatively to their emotional wellbeing. Therefore, the findings might have been influenced, particularly with respect to the patients with whom I spent most time on an individual basis. Two issues relating to my role as researcher are that firstly, I was someone else for them to talk to and secondly, my practice background as a neurorehabilitation nurse meant that the relationship was constructed in a way that prevented me from being a neutral observer.

In the selection of patient participants, the view repeatedly expressed by nurses, relatives and patients themselves was that it would be good for them to have someone else to talk to and I did spend lengthy periods sitting and talking with patient participants, engaging in social conversation. This additional attention, irrespective of its content could have contributed to a sense of being cared about, offering opportunities to talk about their lives and the things they valued. I also provided an additional channel of communication with the nurses in their absence, by relaying questions and gathering information requested by patients. However, the added dimension to this relationship was that as a nurse, I found myself undertaking small tasks which perhaps would otherwise not have been performed by other non-family visitors, such as cleaning dentures and spectacles and fetching items from locker drawers. Norman once commented: “You haven’t forgotten your nursing skills have you?”

As a rehabilitation nurse, I was conscious of reinforcing positive messages about recovery and promoting hope for the future. I praised achievements and listened to patients’ plans, exploring how they might achieve their goals and shared my knowledge and experience of practicing in the field. I listened to worries, empathised and offered reassurance. I spent time with them when they might have otherwise been alone. This is not an unusual situation to encounter for nurses and other health care practitioners undertaking research in familiar settings but it does raise issues around the risk of confusing research practice and therapeutic interventions (Easter *et al*, 2006) and I had to remain aware of the boundaries. I also had to ensure that my activities as the link lecturer for the stroke unit remained separate, although it is not possible to say how the nurses' perceptions of me in that role influenced our relationships within the context of the research study.

Lofland *et al* (2006) and Declercq (2000) caution that undertaking ethnographic research can be physically and emotionally exhausting and stressful in a multitude of ways. Indeed, a number of researchers have specifically addressed the potential hazards of engaging in ethnographic fieldwork (Davis, 2001; Coffey, 1999; LeCompte, 1999; Kleinman and Copp, 1993). Spending time with participants impacted upon my emotional wellbeing, particularly because of the efforts required to manage my own emotions in certain interactions. As experienced by Darra (2008), I did not expect to feel guilty about involving participants for my own research ends and tried to offset this by identifying ways of reciprocating, such as trying to make myself useful to them and offering support, as already indicated.

I was also not prepared for the negative feelings that spending time with Norman evoked (Moyle, 2002). As recommended by Davis (2001) and Rager (2005), this necessitated developing a protective strategy, which in this case, involved limiting the periods of time spent in his company to no more than 15 minutes and taking a break before returning to him. I was not alone in this, as one of the therapists described how she too experienced time in Norman's company as emotionally draining. His case illustrates the necessity for developing strategies which nurses and therapists can employ to protect themselves from the effects of negative emotion whilst simultaneously seeking to promote positive emotion in others.

In addition to these challenges, there are limitations to the study which need to be acknowledged. The first is that the study focused on nurses and their interactions with patients and relatives, to the exclusion of the therapy staff with whom they also related. The culture of care on the stroke rehabilitation unit cannot be fully represented without consideration of all the members of that culture and the contribution by therapy staff and others to the emotional wellbeing of patients and relatives has not been explored. In consequence, the nurses' contribution may have been overemphasised. However, based on the nurses' expressed perceptions of the differences between the therapists' priorities for care and their own, the findings have illuminated potential tensions in their differing approaches. The impact of these on the emotional wellbeing of patients and relatives could benefit from further exploration, to which Burton *et al* (2009) and Pryor (2008) have already contributed.

Finally, as this study focused on a small number of cases and within a unique context, there are obvious limitations to any claims for extending the findings beyond these boundaries. Within the context of health care, ethnography offers the potential to explore complex issues relating to the contexts of care and the nature of care provided (Savage, 2006), yet its purpose, like other qualitative research approaches, is not to produce generalisable findings so much as offer insights into the phenomenon studied. However, it may be possible to identify whether these findings are transferable to other similar contexts through processes of dissemination.

Conclusion and recommendations

In summary, I can confidently assert that the aims and objectives of this study have been achieved and the findings have revealed new insights into the relationships between patients, relatives and nurses which have not been previously reported. In developing the research question and designing the study, I had speculated that it would be possible to observe interactions between nurses, patients and relatives that would somehow demonstrate an overt expression of emotional support and that this is what I would be focusing upon. Of course, there were occasions when such interactions were observed and described to me by the participants, as revealed through the findings but, as advised by Hammersley and Atkinson (2007) it was probably not until after several months of data collection and analysis that I began to gain insight into the culture of nursing on the stroke unit and the complexity of interactions which enabled supportive relationships to be developed and sustained between the nurses, patients and relatives. McLeod and McPherson (2007) suggest that although there are few research studies which have examined the explicit nature of caring in rehabilitation, care and compassion are factors which are clearly important to promoting wellbeing. The findings from this study contribute to this understanding.

It remains to consider how policy, practice, research and education might be informed by the findings from the study. With regards to health care policy, it is suggested that in view of the experience of patients like Norman, greater consideration should be given to the competing needs of older adults with complex health conditions who may not comfortably ‘fit’ into the current model for stroke service provision. The National Stroke Strategy (DH, 2007), National Clinical Guidelines (Intercollegiate Stroke Working Party, 2008) and impending National Institute for Health and Clinical Excellence (NICE) (2011) guidelines for stroke rehabilitation direct all persons affected by a stroke to a care pathway which may not fully embrace the needs of frail older adults. Co-ordination with older adult services might more effectively serve those who cannot participate in a physically and emotionally demanding rehabilitation programme.

This also has implications for practice and a recommendation is made for the exploration of assumed philosophies of care which underpin rehabilitation. It is not suggested that current approaches to engaging persons affected by a stroke in rehabilitation are misguided but that there might be scope for considering a broader range of approaches. Within a context of rapidly changing service organisation and delivery which emphasises measurable outcomes and cost containment, there is a significant risk that the contribution of nurses to stroke rehabilitation will become increasingly focused on technical care and remain otherwise therapeutically non-specific. Therefore, the importance to promoting emotional wellbeing and recovery of the relationships nurses forge with patients and their relatives needs to be more fully acknowledged; both within the profession itself and within the wider multiprofessional rehabilitation team.

There are clear implications for professional education, which should capitalise on the recent impetus for focusing on compassionate care, which is central to therapeutic nurse-patient relationships (Ellis-Hill, 2011; Parliamentary and Health Service Ombudsman, 2011; Dewar *et al*, 2009; MacLeod and McPherson, 2007). Educational curricula underpinned by a framework of relationship-centred care could offer a positive contribution in this direction (Smith *et al*, 2010; Nolan *et al*, 2004); both from a uniprofessional and interprofessional perspective. It is disappointing that the Stroke-Specific Education Framework (Department of Health, 2010) focuses on knowledge and skills required for specific interventions without due consideration to the mode or context in which they are delivered.

Finally, with regards to research, there may be potential to enhance rehabilitation practice by generating further insights into the relationship between positive emotion and recovery from stroke and how this can be enhanced through nursing interventions and those of the multiprofessional rehabilitation team. There are also potentially important gains to be made for promoting the emotional wellbeing of persons affected by a stroke by broadening the focus from the assessment and management of mood disorders to strategies which potentially avert enduring emotional distress and prevent the more damaging consequences of the experience of stroke.

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Appendix 1:

Literature review submitted for assessment for the degree of Doctor of Medical Science, University of Sheffield, June 21st, 2005

Title:

What is known of the emotional experience of stroke and how can nurses use this knowledge to inform and enhance their supportive role in stroke rehabilitation? A review of the literature

Introduction: Identifying the issues

Stroke is the third most common cause of death in the United Kingdom and the single greatest cause of severe disability (Department of Health (DoH), 2001). It also fits the definition for a long-term health condition, insofar that it is likely to affect a person and their family for the rest of their lives (DoH, 2005). A stroke can affect not only a person's physical functioning but also their communication, cognition, mood and social relationships (DH, 2001). Accordingly, experiencing a stroke has been described as "one of the more alarming and devastating things that can happen to a person" (Philp 2004, p.ix). The inclusion of stroke in the National Service Framework (NSF) for Older People (DoH, 2001) and the neurological emphasis of the NSF for Long-term Conditions (DoH, 2005), has highlighted stroke services as a national priority. Furthermore, National Clinical Guidelines for Stroke (Intercollegiate Working Party for Stroke (IWPS), 2000, 2002; Intercollegiate Stroke Working Party (ISWP), 2004), have established standards for best practice in the delivery of stroke services, across the health care continuum.

Nurses play a key role in stroke care and the identification of appropriate knowledge and skills for stroke nursing is attracting research attention (McMahon *et al*, 2003; Petty, 2000). The increasingly specialised nature of stroke nursing has been recognised in the foundation of the National Stroke Nursing Forum (NSNF) and, since 2001, the Stroke Association has sponsored an annual National Stroke Nursing Conference (McMahon *et al*, 2003; Perry *et al*, 2004). Although a proliferation in new nursing roles has been evident since the early 1990's (Levenson and Vaughan, 1999) policy and professional developments in stroke care have added impetus to the growth in specialist stroke nursing roles. These include stroke nurse consultants (Ayers *et al*, 2002; Bryan, 2002), stroke nurse practitioners (Minchin and Wensley, 2003; Hoban, 2005), stroke nurse clinicians (Whyte, 2004) and stroke co-ordinators (Burton, 1999; McDonald *et al* 2002).

Whilst the nurse practitioner and nurse clinician roles tend to focus more specifically on acute stroke services, the consultant and co-ordinator roles are more diffuse, often working across the stroke care continuum; from primary prevention to long-term care. To date, most research into specialist stroke nursing roles has focused on roles in community liaison and family support (Dowswell *et al*, 1999a, 2000a; Forster and Young, 1996; Lawler *et al*, 1999), however, the number of nurses occupying specialist roles in stroke care is arguably small compared with those working in hospital-based stroke rehabilitation units. It is within this broader context of stroke care that the role of the nurse has eluded definition (Burton, 2000a; Gibbon, 1993, 1999, 2000, Gibbon *et al*, 2002; O'Connor, 1993, 1996, 2000a, 2000b).

Although it has been argued that a key attribute of stroke rehabilitation nursing is its holistic approach (Gibbon, 1994; Gibbon *et al*, 2002; Mitchell and Moore, 2004; Scott, 2000), attention has tended to focus on those nursing activities which are informed by other members of the multiprofessional rehabilitation team, such as physiotherapists, occupational therapists and speech and language therapists. Thus, the aspects of stroke rehabilitation nursing which have received most attention are nurses' positioning, handling and mobilising skills (Booth *et al*, 2001, 2005; Davidson *et al*, 2005; Dowswell *et al*, 1999b, 2000b; Forster *et al*, 1999a, 1999b; Jones *et al*, 2005; Mitchell *et al*, 2005; Rowat, 2001); and assessment of swallowing (Davies, 1999, 2002; Perry 2001a, 2001b, 2001c, Perry and McLaren, 2001, 2003). These are undoubtedly crucial elements of stroke management that require a skilled, consistent approach across the multiprofessional team but it could be argued that they essentially reinforce the nurse's 'carry-on' role in stroke rehabilitation (Nolan *et al*, 1997), rather than enhancing what is unique to nursing.

Furthermore, there is little in the UK nursing literature which focuses on fundamental issues of continence management (Brittain, 2001; Eldar *et al*, 2001; Nazarko, 2003; Olsen-Vetland, 2003); communication (Hemsley *et al*, 2001; Sundin *et al*, 2000) and pain management (Wilson, 2002). An awareness of perceptual and cognitive difficulties is indicated but nursing interventions in response to these have hardly been addressed (Sander, 1998) and there are no nursing papers specifically relating to issues of the sexuality following stroke. Education (Edwards, 2003; Vanetzian, 1997, Wiles *et al*, 1998; Warner, 2000) and emotional support (Braithwaite and McGown, 1993) mainly feature within the context of family care giving, which has itself started to feature as an area of concern (Brereton, 1997; Brereton and Nolan, 2000, 2002). The palliative care needs of the person who is unlikely to recover form the effects of a stroke have yet to be explored. All of these elements have been highlighted by Nolan and Nolan (1998a, 1998b), as areas of deficit in stroke rehabilitation and many have been indicated as potential areas for nursing research (Perry *et al*, 2004).

As greater insight is gained into the experience of stroke from the perspective of the person affected (McKevitt *et* al, 2004), what is becoming apparent is their need to make sense of what has happened to them and to face the fear and uncertainty that follow (Kirkevold, 1997). Emotional support features highly in nursing interventions within the context of community-based stroke services (Dowswell *et al*, 1999a, 2000a; Lawler *et al*, 1999; Webster, 2001a, 2001b) and although it is often cited as an important aspect of holistic rehabilitative care (Nolan *et al*, 1997; Long *et al*, 2001), it has rarely been specifically addressed as a nursing issue in stroke rehabilitation (Bennett, 1996; Jones, 1995).

Thus, as an aspect of the nurse’s role in stroke rehabilitation where evidence is clearly lacking (Perry *et al*, 2004) and one which is arguably crucial to the well-being of any person affected by a stroke, it is my intention to explore here, through a review of the literature, what is known about the emotional experience of stroke and how nurses might use this knowledge to inform and enhance their supportive role. As Grant and Davis (1995) argue; one of the goals of nursing is to identify and implement meaningful interventions that will positively impact on the health and well-being of service users and their families.

Locating the literature

Although the full complement of any body of literature is probably unknown, in undertaking a systematic search of the literature, the aim is to compile as comprehensive a list as possible (Hek *et al*, 2000). Carnwell and Daly (2001) emphasise the importance of having a well-planned search and selection strategy and it is, therefore, extremely helpful when researchers describe in detail their own search strategies and share their experiences with the reader: for example, Hek *et al* (2000), Lloyd Jones (2004) and McKevitt *et al* (2004). Identifying gaps in the literature highlights opportunities for research (Doolittle, 1988; McKevitt *et al*, 2004) and it is the scarcity of literature relating to the nurse's role in providing emotional support to a person affected by a stroke during the period of hospital-based rehabilitation, which has prompted my exploration of this subject.

I was already familiar with much of the literature published before 1992, as a result of the search conducted in preparation for a small, practice-based study of depression following stroke (Bennett, 1992); part of which was subsequently published (Bennett, 1996). As my interest in the subject of emotional support following stroke has been maintained, I have continued to acquire published papers on the subject and this personal collection has proved to be a useful starting point from which to identify appropriate journals, databases and search terms. However, at the time when my initial study was undertaken, all the literature had to be hand-searched through the local hospital library and, therefore, it is likely that large areas of literature were missed; particularly as I had restricted my search to nursing and medical journals, believing them to be the only sources of relevant information.

The current literature search was conducted systematically, in that I made a list of search terms, selected databases and methodically entered each term into each database, with appropriate combinations and truncations. The questions I was asking of the literature were: ‘what is known of the emotional experience of stroke?’ and ‘how can nurses use this knowledge to inform and enhance their supportive role in hospital-based stroke rehabilitation?’ Therefore, I decided to conduct two separate, albeit partially overlapping searches, using different sets of key terms: the first focusing on the stroke experience and the second on nursing.

Criteria for the database searches suggested by Evans and Pearson (2001) include a timeframe, language, focus of the paper and methodology. I did not select a particular timeframe, as I had a vague idea that much of the literature would span no more than two decades and although Lloyd Jones (2004) does recommend searching in all languages, from a practical perspective, it was unlikely that I would be able to translate many of the international papers, particularly those from Scandinavia. Nevertheless, the search has alerted me to those areas where the most extensive research around the subjective experience of stroke has taken place and, thankfully, much of the Scandinavian research is published in English.

For the first search, the terms were simply constructed by adding key words to ‘stroke AND’, although this involved a certain amount of creative guesswork and experimentation. Using the words ‘cerebrovascular accident’ instead of ‘stroke’ generated a largely inappropriate body of neuromedical and neurosurgical papers, which were rejected on the basis of their title or abstract. The lay word ‘stroke’ appears to have been universally adopted by health care professionals (Pound *et al*, 1997), by social science researchers and by those recounting personal experiences. The search terms were chosen from previous reading and were added to, as I became more familiar with the field. They included the words: ‘emotion’, ‘mood’, ‘grief’, ‘loss’, ‘distress’, ‘depression’, ‘disruption’, ‘biography’, ‘experience’, ‘subjective’, ‘narrative’, ‘meaning’, ‘survivor’, ‘crisis’, ‘chaos’, ‘qualitative’, ‘phenomenology’, ‘ethnography’ and ‘anthropology’.

McKevitt *et al* (2004) had been successful in locating a substantial body of literature of literature by using only three search terms but although some of the terms in my list were unsuccessful when applied to certain databases, I believe the strategy has enabled me to locate the greatest majority of the literature available. The electronic databases selected include MEDLINE, CINAHL and the Cochrane Library; as the most obvious source of health care literature; followed by AMED (Allied and Complementary Medicine); PsycINFO (psychology); the social sciences databases ASSIA and Social Sciences Citation Index; BIDS and Index to Theses. The Arts and Humanities Index was not a useful resource in this instance. The range is similar but not identical to that chosen by McKevitt *et al* (2004).

Papers were immediately excluded if the title was obviously unrelated to the topic, although this only commonly occurred with the search term ‘stroke and chaos’. All but one of these papers (Puskar and Lucke, 1999) related to chaos theory, mathematics and physical science. Most papers were actually selected on the strength of their title, despite the caution advised by McKevitt *et al* (2004). Abstracts were read only if there was any doubt regarding the relevance of the paper and few were excluded on this basis. Every paper selected was obtained, either electronically, photocopied from Sheffield University’s library collections, or through the interlibrary loan service. Each reference list was checked for additional papers and these were also located electronically or, more often, by hand searching. A search for conference abstracts and proceedings had not proved particularly fruitful but I am fortunate to have attended a number of stroke-related conferences myself and was able to scan those abstracts for additional information. Finally, websites for support organisations such as the Stroke Association and Different Strokes were also searched for personal accounts of the stroke experience.

A similar strategy was utilised in the search for literature relating to stroke nursing, although a greater number of combined search terms were used and the focus was more on context and patterns of service delivery. The words ‘stroke and nurse’ were appended with ‘emotion’, ‘depression’, ‘hospital’, ‘rehabilitation’, ‘recovery’ and ‘role’. As I already possessed a sizable personal collection of papers relating to stroke rehabilitation nursing, it was unsurprising that few additional papers were retrieved and most of these had been identified in the first search. Finally, all the papers were read and summarised within a framework similar to the matrices suggested by Davies (1998). This proved to be a very time-consuming and laborious process but was essential in enabling the identification of key issues and theoretical perspectives. What emerged were two quite distinct epistemological approaches to explaining the emotional experience of stroke and these, along with their implications for stroke nursing practice will be used to structure the review.

Biomedical explanations for the emotional experience of stroke: “Mood disturbance, depression, emotionalism and anxiety”

Medicine and medical research have a long and well-established foundation in the positivist philosophy of science, characterised by empirical research using a hypothetico-deductive model (Dean, 2004). Since the second half of the 20th century, large scale clinical trials, particularly those involving the randomisation of study populations and the use of control groups, have become accepted as the ‘gold standard’ in medical research and as the primary source of evidence to guide clinical practice (Dean, 2004). Therefore, literature located within the fields of biomedical science, including psychology, largely concerns the results of clinical trials; the development and testing of measurement scales and diagnostic tools; trials of physical treatments and comparisons of the efficacies of different stroke care services.

Actually, clinical research in the field of stroke is a relatively recent phenomenon, as it is really only in the past thirty years that rehabilitation following stroke has been considered a worthwhile use of health care resources. Prior to this, the prevailing attitude towards people affected by a stroke was that nothing could be done (Hoffman, 1974) and as a problem essentially of old age, stroke rehabilitation attracted little interest and attention (Becker, 1994; Kaufman and Becker, 1986). However, the emergence of specialised stroke rehabilitation units created a new context for developing clinical research.

Because stroke rehabilitation was, and largely still is, focused on the recovery of physical function, the emotional experience of stroke rarely featured in early stroke research. An exception to this is an early paper by Adams and Hurwitz (1963), who described what they had observed as ‘mental barriers to recovery from stroke’. Although reports of “depression of mood” started to emerge in the 1970’s, they were commonly explained as “an expected psychological reaction of the patient to his disability or restrictions in activity …the inevitable consequences of an unhappy circumstance” (Folstein *et al* 1977, p.1018). However, Folstein *et al* (1977) began to doubt the adequacy of this explanation and questioned whether something other than this natural, ‘expected’ reaction to stroke could be identified.

To test their hypothesis, Folstein *et al* (1977), conducted a clinical trial, comparing the emotional ‘symptoms’ observable in a group of patients who had experienced a stroke, with those of another group who had ‘disabling’, non-neurological conditions. Although not a rigorous trial by today’s standards, nevertheless, the researchers were confident their results demonstrated that “mood disorder is a common and specific symptom of patients recovering from a stroke” (Folstein *et al*, 1977, p.1019). This often cited, early research study is significant, in that it first hypothesised mood disorder as a specific complication of stroke and because it subsequently inspired over two decades’ research into its incidence, prevalence, causation, diagnosis and treatment. The term ‘post-stroke depression’ appears consistently in the literature from the early 1980’s onwards. Other no less distressing emotional ‘consequences’ of stroke such as emotionalism (uncontrollable crying or, less frequently, laughing), have received far less attention (Allman and House, 1990; House, 1987a; House *et al*, 1989).

Throughout the 1980’s, a team of researchers based at Johns Hopkins University School of Medicine in Baltimore, USA, conducted numerous clinical trials, testing their hypothesis that depressed mood following stroke was “a behavioural manifestation of neurophysiological or neurochemical responses to brain injury” (Robinson *et al*, 1983, p.741). In other words, “stroke may damage cerebral regions or pathways involved in the regulation of emotions” (Aben *et al* 2001 p.672) and was thus implicated in depressive disorders (Robinson *et al*, 1990; Starkstein *et al* 1988). In isolating such a specific cause, treatment, generally in the form of antidepressant medication should, in theory, resolve the problem (Robinson *et al*, 1990).

Estimates of depression, as the primary mood disorder following stroke have varied quite radically; ranging from 23% to 60% of people affected (O’Rourke *et al*, 1998), or even higher at 25% to 79% (Lincoln *et al*, 2003) and as depression has been implicated in increased morbidity, delayed rehabilitation, longer periods of hospitalisation and overall poorer outcomes (Turner-Stokes and Hassan, 2002a); identifying appropriate assessment tools, diagnostic criteria and effective interventions for the prevention and treatment of depression following stroke have received considerable research investment (Turner-Stokes and Hassan, 2002a, 2000b; Anderson *et al*, 2004). However, after two decades of research, there is still poor agreement on recommended practice in all these areas.

Two major systematic reviews of the literature relating to depression following stroke have identified no conclusive evidence that depression is affected by damage to any specific structures within the brain (Aben *et al*, 2001; Carson *et al*, 2000) and another systematic review exploring the evidence on which to base an Integrated Care Pathway for the management of 'post-stroke depression', concluded that the diversity of diagnostic and assessment criteria "confound assimilation of the available literature" (Turner Stokes and Hassan 2002a, p.231). The Cochrane Stroke Group (Anderson *et al*, 2004) was unable to identify either pharmacological or psychological therapies for the prevention of depression following stroke, although they identified some effect on the improvement of depressed mood using psychotherapy.

Furthermore, reviewing the evidence for the effectiveness of psychological therapies in the management of depression following stroke, Kneebone and Dunmore (2000) suggest that this form of mood disturbance following stroke is "far from an homogenous phenomenon (p.54) and Lincoln *et al* (2003) even suggest that it might be "an artefact resulting from the use of inappropriate classification criteria" (p.840). House *et al* (1991) reached the conclusion some years earlier that depression following stroke was no different to depression following any illness and that the term 'post-stroke depression', as a descriptive term for a specific clinical syndrome, should be discontinued.

House (1987a, 1987b) was intensely critical of the Johns Hopkins researchers, questioning the numerous methodological inconsistencies in their work but the overwhelming attraction of their theories stifled the development of alternative explanations. Elsewhere, Jarman (1978) and Kotila *et al* (1984), sought to explain mood disturbance following stroke as an emotional crisis of grief and a result of the struggle to adjust to the experience of stroke. Holland and Whalley (1981) suggested that experiencing a stroke challenged a person's assumptions about themselves and their life world. However, psychological therapies and counselling within the context of stroke rehabilitation had been barely researched and their influence on the occurrence of mood disorder was uncertain (House, 1987b). More recently, Kneebone and Dunmore (2000) have concluded that there is still insufficient evidence to support the use of any particular psychological therapy in the treatment of depression following stroke.

This failure of biomedical and neuropsychological research to provide a conclusive explanation for the emotional experience of stroke has been attributed, in part to methodological difficulties, as already indicated (Aben *et al*, 2001; Kneebone and Dunmore, 2000). Nevertheless, it has heavily influenced therapeutic interventions and, as Turner-Stokes and Hassan (2002a) suggest, there is a general consensus that early recognition and management of depression following stroke is desirable, despite the lack of 'hard' evidence. Indeed, the authors of the National Clinical Guidelines for Stroke (IWPS, 2000, 2002; ISWP, 2004) acknowledge that there are many important areas of clinical practice which do not have evidence to guide them and the levels of evidence, as used by the National Institute for Clinical Effectiveness (NICE), are not well suited to the development of such guidelines.

Within the clinical guidelines, the emotional experience of stroke is addressed in the rehabilitation section, under the heading of "Mood disturbance: depression, emotionalism and anxiety" (ISWP 2004, p.53). In addition to depression and emotionalism; anxiety and post-traumatic stress disorder, as identifiable sequelae of stroke are also briefly alluded to in the preamble to the recommendations (ISWP, 2004). Assessment of psychological need and screening for anxiety and depression are highlighted, together with the recommendation that a person who has been diagnosed with one mood disorder should be screened for others (ISWP, 2004).

Psychological therapy “given by an appropriately trained and supervised practitioner” (ISWP 2004, p.54) is recommended for anxiety and depression but antidepressant medication features highly in the recommended interventions for all of the ‘mood disturbances’ identified.

Thus, in accordance with the National Clinical Guidelines for Stroke (ISWP, 2004), it appears that people who enter stroke rehabilitation services should have their emotional state assessed in much the same way as their functional ability is assessed; with a standardised screening tool, even though there is no agreement as to which measurement tools to use (Bennett and Lincoln, 2004). If they are identified as requiring some form of intervention, they may be referred to a psychologist, yet many stroke rehabilitation services still have no access to this professional service (Bowen, A *et al*, 2005). In all likelihood, they will be prescribed antidepressant medication, although, in the light of the systematic review on interventions for preventing depression following stroke (Anderson *et al*, 2004), the guidelines now specifically recommend that this should not be used to prevent depression (ISWP, 2004). There had been instances reported of antidepressants being prescribed for anyone entering stroke services, irrespective of whether or not mood disturbance had been observed (Lockwood, 2002).

In summary, the emotional experience of stroke as revealed through the biomedical literature is conceptualised as a cluster of mood disorders, particularly depression, which may or may not be a result of damage to the brain. As such, emotional ‘disturbance’ can be construed as a consequence of stroke in much the same way as hemiplegia or dysphagia and has consequently been treated as just another element of functional recovery to be addressed. Although these views are now being challenged through the process of systematic review (Aben *et al*, 2001; Anderson *et al*, 2004; Carson *et al* , 2000), they have become deeply embedded in stroke medicine.

However, there is only very limited evidence that this explanation for a person's emotional response to stroke has been assimilated into the practice of stroke rehabilitation nurses. Bruckbauer (1991) and Hinkle (1998) have alluded to the biomedical theory in relation to nursing interventions and there are other vague references in descriptive papers addressing depression following stroke (Hayn and Fisher, 1997; Murphy, 1995; Vogel, 1995). Whitney *et al* (1994) have articulated the growing scepticism regarding the research linking laterality of stroke to the incidence of depression and nurse researchers such as Doolittle (1988, 1991, 1992, 1994); Folden (1994) and Mumma, (1986) have responded to the inadequacy of biomedical theory by looking elsewhere for knowledge to inform their interventions; focusing their attention on the personal experiences of the people they encountered in their everyday stroke nursing practice.

Social science research and personal narratives of the emotional experience of stroke:

A second body of literature retrieved for review comprises reports of qualitative research studies conducted by health care researchers, psychologists, sociologists and anthropologists. As a counter position to the positivist theories of mood disorder following stroke, these researchers have addressed the emotional experience of stroke from a largely interpretivist perspective. Although it is acknowledged that the experience of stroke is unique to each individual, nevertheless, through interpretive processes, researchers have sought to reveal possible commonalities and similarities within these experiences and have developed theory to explain them Murphy *et al*, 1998). The intrinsic value of this research in relation to health care practice is that, as Doolittle (1988) suggests; descriptions of the 'practical knowledge' of the person affected by a stroke, "including an account of sensations and responses to the stroke experience will allow identification of potential passages in the recovery process" (p.170).

In addition to research reports, there are also numerous autobiographical accounts of the experience of stroke published in professional and academic journals, including Buscherhof (1998), Cant (1997), Clark (1983), Francis (1983), McCrum (1998a), Norton (1993) and O'Kelly (2002). More lengthy autobiographical accounts published as books include Bauby (1997), McCrum (1998b) and Sarton (1988). Numerous short 'stories' of stroke experiences are available on the websites of stroke support organisations such as the Stroke Association (www.stroke.org.uk), Different Strokes (www.differentstrokes.co.uk) and Stroke Survivor (www.strokesurvivor.org).

In contrast to the research reports, autobiographical accounts of the stroke experience are intensely personal narratives and although Pound *et al* (1998) suggest that such first-hand accounts are usually written by "articulate, relatively young, professional people" (p.489) and may thus represent a perspective that differs significantly from that of the predominately older adults who constitute the majority of people affected; their contribution may be no less valuable in providing insights into the experience of stroke. For example, Easton (1999) undertook a concept synthesis of four autobiographies of the stroke experience to build a theory of "the post-stroke journey", which she then used to underpin her own research (Easton, 2001). However, true to the caution advised by Pound *et al* (1998), the authors of the books selected by Easton (1999) were, indeed, all less than 60 years of age, of above average educational level, had successful careers and had strong social support systems. Nevertheless, such accounts may be particularly valuable in revealing the specific and allegedly neglected service needs of younger people affected by a stroke (Kersten *et al*, 2002). In addition, autobiographies may also be valuable for "fellow-sufferers", who might derive useful information and support by comparing themselves "with others whose situation resembles their own", (Wachters-Kaufmann 2000, p.296).

Several papers have attempted to synthesise the research relating to the stroke experience through the medium of a literature review. In the earliest of these, Doolittle (1988) highlighted “the paucity of literature on the stress of the stroke experience” (p.169) at that time and the small body of literature which she did identify was essentially biomedical in nature. Indeed, Doolittle’s own research was one of the first ethnographic studies of the stroke experience conducted within the context of hospital care (Doolittle, 1991, 1992, 1994).

Nearly a decade later, Hafsteindóttir and Grypdonck (1997) were able to locate a more substantial body of research literature, although still maintaining that little attention had been paid to “research on the experience of stroke from the patient’s point of view” (p.581). Focusing on Doolittle’s (1991,1992,1994) research, along with three further studies by Folden (1994), Häggström *et al* (1994) and Mumma (1986), they synthesised the findings by organising them into sections addressing the experience of being a stroke patient; physical changes that occurred following stroke; psychological changes and social changes.

Actually, there had been other studies of the stroke experience published but as Hafsteindóttir and Grypdonck (1997) did not describe their search or selection criteria, it is not possible to say why these studies were missed; in particular the longitudinal research of Becker and Kaufman (Becker, 1993, 1994; Becker and Kaufman, 1995; Kaufman, 1998a, 1998b; Kaufman and Becker, 1986). However, as these latter researchers were anthropologists, the publication of their reports in predominantly sociological journals may have eluded the reviewers; if they had focused on the biomedical literature alone. Nevertheless, the review by Hafsteindóttir and Grypdonck (1997) does reveal a growing recognition of the importance of appreciating the individual’s perspective in the planning, delivery and evaluation of stroke care.

The third and most recently published review by McKevitt *et al* (2004), aimed to identify the scope of qualitative research in general, within the context of stroke care and to consider what contribution it could make to service development and delivery. The framework for structuring the review is based on a care pathway, tracking stroke care from the acute stage, through rehabilitation into community care, whilst also addressing the experience of service users and their carers (McKevitt *et al*, 2004). The potential contribution of this qualitative research includes an emphasis on “the human experience of stroke”, an identification of needs as perceived by patients and carers; differences in priorities between health care professionals and patients and the barriers to providing best quality of care (McKevitt *et al,* 2004). However, McKevitt *et al* (2004) suggest that there are limitations to this body of research, in so far that much of it is small-scale in nature and comprises mainly ‘one-off’ interviews; although these features are generally inherent in the aims of qualitative research (Murphy *et al* 1998).

Thorn (2000) also highlights the prevalence of ‘one-off’ studies within the field, resulting in what she perceived to be a lack of overall depth and direction in the research. However, if most research studies focusing on the experience of stroke are small-scale in terms of number of subjects involved, this is arguably not an issue when the primary purpose of the research is to achieve an in-depth description and interpretation of the subjects’ lived experiences. (Murphy *et al*, 1998) Indeed, some of the studies involving greater numbers of participants tend towards the use of response rating scales and structured interview schedules, supplemented by smaller numbers of in-depth interviews (Clark, 2000; Johnston *et al*, 1999).

Incorporating the perspectives of people affected by a stroke is now considered as essential in developing practice standards (DoH, 2001; IWPS, 2000; ISWP, 2004) but isolating the research to inform the different components of that practice is not an easy task. The differing research aims and diverse theoretical perspectives of the researchers have resulted in an impressive range of theory to explain the stroke experience. These include crisis theory (Backe *et al* 1996, Nilsson *et al* 1997, 1999); adjustment (attribution) theory (Thompson, 1991) and social theory (impression management) (Gold, 1983). Several researchers have conceptualised the experience of stroke as biographical disruption/discontinuity (Becker, 1993; Doolittle, 1991, 1992, 1994; Dowswell *et al*, 2000c; Folden, 1994; Fleming and Russell, 2004; Kaufman, 1988; Mumma, 1986; Secrest and Thomas, 1999; Secrest and Zeller, 2000); challenged by Faircloth *et al* (2004a, 2004b) and Pound *et al* (1998), who suggest that the experience of stroke can be more adequately explained within a theoretical framework of biographical continuity, rather than one of discontinuity and disruption.

Doolittle (1991, 1992, 1994); Ellis-Hill *et al* (2000); Ellis and Horn (2000); Faircloth *et al* (2004c); Kvigne (2002); Kvigne and Kirkevold (2002, 2003); Kvigne *et* al (2004), have focused on the embodied experience of stroke, within the philosophical frameworks of existential and feminist phenomenology (Merleau-Ponty, 1962; de Beauvoir, 1974). Finally, Buscherof (1998), Easton (1999, 2001) and Eaves (2000) have described the experience of stroke as a staged journey, whilst Burton (2000b), Becker and Kaufman (1995) and Kirkevold (2001, 2002) have interpreted this experience within the Illness Trajectory Framework of Corbin and Strauss (1991).

It is perhaps not surprising that so many different theoretical perspectives have emerged from the research, in consideration of the extreme diversity in the methodologies employed by researchers in this field. For example, there are wide differences in the number of participants selected; the criteria for inclusion (particularly in relation to the exclusion from study of people with impaired communication and cognition); the time elapsed between the occurrence of stroke and the period of data collection; the duration of the period of data collection and the frequency of interviews; all of which makes comparison of findings extremely difficult. Issues of culture and ethnicity have received little attention and the influence of gender in the way that stroke is experienced is only recently emerging (Fleming and Russell, 2004; Hilton, 2002; Kvigne, 2002; Kvigne and Kirkevold, 2002, 2003; Kvigne *et al,* 2004). As, according to Sisson's (1998) research, women expressed their mood state, whilst men elaborated on physical problems; this issue may have considerable implications for the interpretation of experiential accounts of stroke.

Furthermore, as much of the research is concerned with the experience of life after stroke, descriptions of the experience of stroke focus on a point well beyond the person's contact with in-patient rehabilitation services, if indeed they came into contact with them at all. Descriptions of the early stages of recovery are, as identified by Hafsteindóttir and Grypdonck (1997), retrospective in nature and this could be problematic; as there is likely to be a difference between how a person describes their experience when interviewed shortly after the stroke event and when, after a period of time has elapsed, they have reflected upon the event.

However, there also appear to be particular methodological difficulties in researching the experience of stroke in the early period of hospitalisation. Kvigne *et al* (2002) suggest that as a stroke often occurs suddenly and dramatically, it will take time before the person realises what is going on. They proffer this as an explanation for "why informants at an initial interview give short and perhaps superficial descriptions" (Kvigne *et al* 2002, p.67). Kirkevold (2002) likewise suggests that a person may only dimly remember the first few days following stroke and that in describing it, there is little emotional involvement: "As an evolving experiential event, it does not seem to match the recounted objective drama" (Kirkevold 2002, p.892). Furthermore, Morse (2000) highlights that in the state of bewilderment that follows any sudden illness or injury, a person is neither able to comprehend their situation nor "have the words to describe their responses or experiences" and "have difficulty expressing their feelings and communicating their distress" (p.541).

Only one study specifically focuses upon the experience of stroke within the first week of hospital care. Backe *et al* (1996) interviewed six people within three weeks of their stroke, with the aim of discovering how they “conceived their life situation” within the first week of care. They used a phenomenographic approach, which deals with people’s conceptions of experience; those which are tacitly understood and have not been the subject of reflection (Backe *et al*, 1996). This approach is not concerned with factual happening but “with how something is experienced by a person, how it is conceived to be” (Backe *et al* 1996, p.287).

Emergent themes from the data analysis included feelings of unreality; not knowing what is happening to their bodies, not understanding, or even denying what is going on. However, once people had begun to realise what had happened, they were able to start dealing with their situations, emotionally and intellectually (Backe *et al*, 1996), although it does need to be borne in mind that this was a small group of relatively young people (aged 50-66 years), with no communication difficulties. Nonetheless, they articulated their conceptions of loss, anxiety for the future and an awareness of a change in their life situation and the importance of the interest, encouragement and support of those around them (Backe *et al*, 1996). These early conceptions of stroke are interpreted by Backe *et al* (1996) within a framework of crisis theory, which they suggest should underpin all nursing interventions. During this period of crisis, communication, as a primary form of help and support, should be frequent, brief and responsive to the individual person’s needs (Backe *et al*, 1996).

Doolittle (1991, 1992, 1994) also interviewed people from one week post-stroke and then at frequent, weekly intervals thereafter during their stay in hospital and beyond. They described the experience of stroke as a bodily event and that they were shocked and stunned by the suddenness of the stroke. However, she asserts that “because the clinical priority is objective assessment of neurological changes, the distressing experience for the person is frequently overlooked" (Doolittle 1991, p.237). People expressed a need to understand their experience of stroke and for frequent opportunities to describe their experiences, particularly during the first one to three weeks (Doolittle, 1991).

During the process of conducting a larger, biomedically-oriented research study, Sisson (1998) noticed recurrent themes when she interviewed participants. In addition to answering the structured questions she asked, Sisson (1998) noted that participants also described what the stroke meant to them. At the first interview, one week after their stroke, all of the people she interviewed said that they were sad or depressed and that they all had memory problems (Sisson, 1998).It was also noted that they displayed lack of insight into the extent of their impairments and had unrealistic expectations regarding their recovery; at least according to her professional opinion. However, these interviews were structured around a neurobehavioural rating scale and the questions specifically focused on changes in mental status (Sisson, 1998).

Becker and Kaufman (1995) identified, through the narratives of the people they interviewed, that they experienced a three phase process in their recovery. The first phase was initial, acute care; the second, in-patient and continuing rehabilitation at home and the third; progress to independent living and getting on with life (Becker and Kaufman, 1995). The first phase was characterised by disruption and uncertainty for the future, hope for recovery and a dependence upon the knowledge and skills of the health care personnel. During the second, rehabilitative phase, an 'illusion of certainty' prevailed, whereby the person affected by a stroke believed that working hard at therapeutic activities equated with recovery: "Rehabilitation lent structure and meaning to their daily lives" (Becker and Kaufman 1995, p.176). The third phase occurred when formal rehabilitation finished and was marked by feelings of frustration and depression, in response to the realisation that further recovery was unlikely (Becker and Kaufman, 1995).

Summarising thus far, in the early weeks following a stroke, there is an expressed need for interactions, opportunities to talk, seek explanations; deal with uncertainty, loss and change and to receive comfort and reassurance. Clearly there are implications for the nurse's role in providing emotional support within these contexts of personal meaning and indeed, attempts have been made to incorporate knowledge of the experience of stroke into rehabilitation nursing practice.

Snape and Burton (2002) used a review of literature relating to the stroke experience to explore the potential for developing nursing practice in stroke care but focusing on interventions to promote long-term recovery. This was thought only to be achievable through a strategic agenda for the development of stroke nursing, exploiting new roles and ways of working, across the stroke care continuum (Snape and Burton, 2002). Brauer *et al*, (2001) also attempted to use the stroke experience literature to inform practice; constructing a framework for nursing interventions, based on a synthesis of the literature and an existing theoretical model.

They rejected the Illness Trajectory Framework (Corbin and Strauss, 1991), on the basis that the focus on symptoms over time does not make a holistic understanding of the stroke experience possible (Brauer *et al*, 2001). They also contended that the model had not been applied to people experiencing illness for the first time, as is often the case of stroke; although it has since been used as a theoretical framework to explain the experience of stroke, as indicated earlier (Burton, 2000b; Kirkevold, 2001, 2002). Instead, Brauer *et al* (2001) selected the Illness Constellation Model (Morse and Johnson, 1991), because of its basis in grounded theory studies of both acute and chronic illness and from the perspectives of both the person affected and their family.

Following their own review of the literature relating to the experience of stroke, Brauer *et al* (2001) developed a three-phase model to provide "a generic understanding of the stroke experience and a basis for selecting interventions" (p.90). The initial phase of the model is marked by deterioration; from the time when the person affected first notices the 'symptoms' of stroke. Physiological integrity starts to break down and the person becomes aware that something is wrong (Brauer *et al*, 2001). The intensity of health care interventions during this initial stage adds to the person's emotional strain and their interpersonal relationships change as they become dependent on others for physical and psychological support (Brauer *et al*, 2001).

Discovery marks the second phase of Brauer *et al*'s (2001) model of the stroke experience, when deterioration slows down and the person begins to realise the impact of the stroke. Attempts are made at understanding what has happened; representing a striving for recovery but because the self cannot be 'recovered', they "must strive to construct a new self through the process of exploration and discovery" (Brauer *et* al 2001, p.90). Physical and psychological effort is focused on personal goals and all activities represent "attempts to investigate and learn new ways of being and becoming" (Brauer *et al* 2001, p.91). The third phase of the model is described as resynthesis; as the impact of stroke becomes apparent and issues have to be confronted. This phase may be prolonged but resynthesis occurs only when a sense of well-being has been achieved (Brauer *et al*, 2001).

Within the context of their model: "The nature of each phase suggests the focus of care needed and the appropriate types of health-promoting interventions" (Brauer *et al* 2001, p.91). Nursing care is viewed as actions which facilitate growth and from this perspective, "nursing care in the stroke experience … is distinguished from the care of other professionals by its nature" (Brauer *et al* 2001, p.92). In summary, Brauer *et* al (2001) are suggesting that it is possible, if not desirable, to develop therapeutic nursing interventions based on insights gained from accounts of the experience of stroke and the following section of the literature review will address whether this is evident in descriptions of the nurse’s role in providing emotional support in stroke rehabilitation.

Identifying the nurse’s role in providing emotional support in stroke rehabilitation:

At the time when I was searching the literature for my study into the nurse’s role in providing emotional support for people who were thought to have become depressed following a stroke (Bennett, 1992), I could find little in the way of nursing commentary and no nursing research in this area. The weekly nursing magazines had occasionally published care studies and short clinical features relating to stroke care and which demonstrated awareness of the emotional experience of stroke (Bannister, 1984; Barron, 1992; Batehup, 1986; Brandrick, 1980; Chesterman, 1984) but there was little that specifically addressed the issue.

All the literature I could obtain to inform the study was hand-searched in the local hospital library. A few nursing papers were located but these were largely descriptive studies of the emergent role of the stroke rehabilitation nurse in the USA (Bukowski, 1986; Dudas, 1986; Goetter, 1986; Myco, 1984; Tellis-Nayak, 1986). Bronstein (1991) and Bruckbauer (1991) first alerted me to the biomedical research that was being conducted into ‘post-stroke depression’ and the implications for nursing were suggested. However, Bronstein (1991) noted that although nurses are ideally placed to facilitate psychosocial adaptation to stroke, there was “no evidence that any intervention can improve emotional and social wellbeing” (p.1015).

Myco (1983) had published a nursing textbook addressing the care of a person affected by a stroke, wherein emotional needs are addressed in a chapter titled ‘Nursing Management of Spiritual Comfort’. Here Myco (1983) describes the needs of a stroke affected person to “express their innermost feelings, and needing to share their distress with another human being" … "looking for an explanation for a situation which they do not understand" (Myco 1983, p.210-211). She continues: "Those suffering or sharing a catastrophe often unwittingly look for support" (Myco, 1983, p.211). Myco (1984) was one of the first nurse researchers to focus on the role of the nurse in stroke rehabilitation, although she argued that based on the evidence available at the time, this was really just an extension of the nursing care offered to any client group. Indeed, the textbook essentially applied nursing skills to the context of stroke care; nevertheless, Myco (1984) challenged nurses to acquire the knowledge and skills to structure a specific role in stroke rehabilitation.

Taking Myco's (1984) literature review as a starting point, an updated and more extensive review of the literature relating to nursing in stroke rehabilitation was undertaken by O'Connor (1993). This revealed that although there was indeed evidence of an emerging role, it was "therapeutically non-specific" (p.30) and was generally described in terms of care management or as an understudy to other health care professionals. Even when specific aspects of care were isolated, these were areas that were the primary concern of other professionals (O'Connor, 1993).

O'Connor (1993) questioned whether there was a specific role for nurses in stroke rehabilitation, even in the absence of other professionals but identified that the round the clock presence of nurses enhanced the nurse-patient relationship and could lead to a supportive and counselling role. Gibbon (1993) also suggested that "therapy, caring and counselling" (p.137) were the three principle ways in which a person affected by a stroke can be helped, however, as it is difficult to measure these three elements, evaluations of the effectiveness of stroke rehabilitation had added little to an understanding of the nurse's role (Gibbon, 1993).

Jones (1995) suggested that a nursing theory which guides the nurse to focus on how a person affected by a stroke interprets their experience is paramount. By utilising a psychodynamic theory based on reciprocal nurse-patient interactions, Jones (1995) described a four-phase model which could be used to underpin nursing interventions. Within this relationship-centred model, the nurse might adopt the role of counsellor, enabling the person to explore their thoughts and feelings (Jones, 1995).

There is also a clear focus on the therapeutic nature of nursing interactions in Kirkevold's (1997) theoretical model for stroke nursing. Characterised by four therapeutic nursing functions, the interpretive function focuses on assisting the person affected by a stroke and their relatives to understand their experience and to reinterpret their life situation. Exercising this function, the nurse responds to their questions, their fears and 'agonising thoughts', during the course of nursing interactions in different situations (Kirkevold, 1997). A closely related consoling function focuses on the provision of emotional support, wherein the nurse can facilitate grieving, promote hope and prevent depression; by establishing a trusting relationship. The conserving and integrative functions of the nurse focus primarily on the physical elements of nursing care and the integration of newly learned skills into meaningful activities, although all the functions intersect.

Kirkevold's (1997) Unified Theoretical Perspective of stroke rehabilitation emerged from the analysis of data collected during an intensive period of observation on a stroke rehabilitation unit and thus reflects the nursing activities and interventions undertaken. Building on O'Connor's (1993) literature review, Kirkevold (1997) noted that the literature now included phenomenological studies of the lived experience of stroke. Although few of these focused on how nursing care could be designed to improve a person's psychological functioning and emotional well-being, nevertheless, they were thought to offer valuable insights which might provide an important base from which to enhance the nurse’s performance of the interpretive and consoling functions.

O’Connor (2000a) sought to determine the nature of nursing interventions in stroke rehabilitation, through the analysis of nurses’ views, beliefs and experiences. Whilst Kirkevold’s research (1990, 1992, 1997) had been carried out within one specialist stroke unit, O’Connor (2000a) sought responses from nurses working in 21 stroke units. He identified six categories for nursing interventions: focus of care, outcomes of care, direct care, continuity of care, mode of care and context of care; all of which were interdependent (O’Connor, 2000a). Psychological care was identified within the category of ‘direct care’ and one respondent was reported to have claimed that emotional and psychological care was always seen as the responsibility of the nurses (O’Connor, 2000a). Although O’Connor (2000a) identified that his findings were similar to those of Kirkevold (1997), there were also important differences and he claimed that his findings went beyond hers in highlighting “the manner in which functions are defined and delivered” (O’Connor 2000b, p.180).

In another study of the role of the nurse in stroke rehabilitation, focusing on a single rehabilitation ward; Burton (2000a), identified three categories to describe the nursing role, each with sub-categories described in terms of the interventions. The category of ‘facilitator of recovery’ shares similarities with Kirkevold’s (1997) four therapeutic nursing functions. Communication and the recognition of the psychological effects of a stroke were viewed by the nurses as important and high priority was given to the activities which they perceived to alleviate stress and anxiety and to promote effective coping (Burton, 2000a). Also, as highlighted by Kirkevold (1997), these activities were both specific and indirect, carried out whilst undertaking other activities. This latter observation is important and may in part explain why the emotional support provided by nurses evades clear description.

In reporting their research into the role of the nurse in rehabilitation, Long *et al* (2001) noted that the continuous presence of nurses in stroke rehabilitation provides them with important insights into a person's mood, their fears, anxieties and family relationships. Indeed, other members of the multiprofessional rehabilitation team believed that nurses were better equipped than others to take on this role. (Long *et al*, 2001). The elements of psychological and emotional care were described as 'layered and interconnected' and included relationship building, individualised care, offering encouragement and reassurance and, when necessary, referring to a specialist (Long *et al*, 2001). A meaningful relationship with a nurse could make all the difference and nurses "had a greater sense of responsibility to the emotional care of clients and their families than any other health care professionals" (Long *et al* 2002, p.97).

Providing individualised care was closely linked to, or integral to, the emotional caring role of the nurse; as the way in which physical care was delivered expressed their psychological and emotional caring (Long *et al*, 2001). Encouragement and giving positive feedback were viewed as very important and although referral to a specialist such as a psychologist was made when thought appropriate, this was not seen as a "complete and effective response" (Long *et al* 2001, p.100). In summary, the provision of emotional support was seen by many practitioners as a special and unique nursing contribution, although it is often regarded as an 'informal activity' and was rarely documented (Long *et al*, 2001).

Viinamäki and Koivisto (1994) identified that nursing staff were able to accurately recognise depression in a person affected by a stroke in the majority of those who had been diagnosed as such. It was assumed that the nurses noticed characteristic signs in the people they worked closely with, based on their daily interactions and in response to a person's verbal and non-verbal communications; nurses were able to evoke “direct emotional reactions and impetus for action” (Viinamäki and Koivisto 1994, p.243). These “Empathic responses are the results of transient identification with the other person’s subjective way of experiencing himself and his situation” Viinamäki and Koivisto 1994, p.244).

One published study which specifically focuses on nursing interventions for providing emotional support within the context of a stroke rehabilitation unit was undertaken by myself (Bennett, 1992) and underpinning the study was the assumption that emotional support played a specific role in stroke rehabilitation nursing. The structured interview schedule which was constructed to guide the participants’ interviews in the study implied that the nurses understood something of the concept of depression, as a form of emotional distress and its association with the experience of stroke (Bennett 1996, appendix 1, p.321). Further implied was that the nurses might try to assess a person’s mood state and respond in some meaningful way but it was also acknowledged that there may be constraints to achieving this (Bennett 1992, 1996). Furthermore, the enquiry had been prompted by a perceived collective belief that there must be more that could be done to improve the situation for the person affected (Bennett, 1996).

The study was niave and simplistic in its design but the findings indicated that my colleagues were able to recognise a change in mood in a person; explained in terms of loss and grief. They also recognised that depressed mood might affect a person’s ability to engage in active rehabilitation and that they needed time to accept their situation (Bennett, 1992, 1996). Although no formal assessment of mood was undertaken, the nurses clearly used their observational skills to alert themselves and each other to a change in a person’s emotional state. Their interventions in response to this involved “spending as much time with them as possible, talking and listening” (Bennett 1996, p.317). Despite the constraints they experienced in not having sufficient time or opportunities to sit with people, not having specific knowledge or skills for providing emotional support and with no access to ‘expert help’; the nurses still wanted to take on psychological care for themselves, as part of their role (Bennett, 1992). These findings resonate with another small study, more recently undertaken by Barnston (2004), which reflects not only similar views of the nurse‘s role in providing emotional support to a person affected by a stroke but also the persistent constraints nurses face in lack of time and inadequate skills preparation.

It does appear from these descriptions of the nurse’s role in providing emotional support that they are indeed based on insights into personal experiences of stroke. However, as most of the findings summarised here are self-reported by nurses themselves or, very occasionally, by other members of the multiprofessional rehabilitation team; it is possible that their perceptions of their actions may not correspond with those of the people with whom they interact. For example, Alaszewski *et al* (2004) identified a difference between how health care professionals interpreted a person’s emotional expression and how the person themselves understood their situation. Professionals used a bereavement model; a process of loss and adjustment to explain the behaviour they observed in the people they interacted with but there was no evidence that the people themselves saw their situation in this way and instead; sought to manage their recovery by setting goals(Alaszewski *et al*, 2004).

Burton *et al* (1992) noted that “there is little evidence concerning the perceptions of stroke patients themselves about the way in which the emotional and personal worries are handled by professional carers and whether they feel they would benefit from more specialised forms of therapy for dealing with such problems” (p.305). Accordingly, they conducted interviews with health care professionals and with people affected by a stroke to explore the possible role of counselling in alleviating ‘psychological difficulties’ (Burton et al, 1992). Counselling was conceptualised as providing emotional support, reassurance and empathy.

The staff felt that their professional role involved listening to patients' emotional needs and agreed that their interactions with the people in their care involved an element of counselling. Indeed, they thought that they spent 25% or more of their time dealing with people's emotional needs, often diverting them from their primary professional role (Burton *et al*, 1992). However, amongst the people affected by a stroke who were interviewed, there was a general feeling that the staff had insufficient time and therefore, they did not feel comfortable discussing their worries with them (Burton *et al*, 1992). Therefore, the researchers concluded that there was little evidence that the need for support was being met (Burton *et al*, 1992).

In an often quoted statement, Anderson (1992) suggests that “It is likely that more comforting, counselling and communication are provided to stroke patients by nursing staff than by any other group in the hospital” (p.61). However, elsewhere, one person who had experienced a stroke complained that the nurses she encountered ‘didn't have a clue’ about emotional and psychological support and, indeed, they received more empathy from one of the domestic staff (Sheppard, 2002). Furthermore, Pound *et al* (1999) observed, in their comparison of processes of care on a general medical ward, an older adult ward and a stroke unit, that “Stroke unit patients were given eye contact less frequently, ignored more frequently, treated in a dehumanizing manner more frequently, and more frequently had an overall negative quality of interaction” (p.437).

Only two of the eight people interviewed by Macduff (1998) in her study of stroke patients' perceptions of nursing, described nurses' attentiveness to their psychological needs and one of the participants in Secrest's (2002) study of the experience of nursing in stroke rehabilitation, even thought that nurses were not supposed to provide emotional support. Furthermore, Secrest and Thomas (1999) were alarmed that, considering the amount of time nurses spend with individuals in rehabilitation, they were never mentioned in people's accounts of their ‘meaningful experiences’ since the stroke. Such differences in the perception of health care experiences between professionals and service users have been noted elsewhere within the context of stroke rehabilitation (Becker and Kaufman, 1995; Bendz, 2000; Bendz, 2003), explained by the “different frameworks of understanding …different interpretations of the condition” and how these affect expectations (Becker and Kaufman 1995, p.180).

Congruence between how nurses perceive their provision of emotional support and how the recipients perceive it needs to be achieved; if interventions are to be meaningful to the individual. This may only be possible by grounding each interaction in what is known to be unique to the person and not by the application of collective professional knowledge generalised from numerous individual cases (Alaszewski *et al* 2004). In other words, providing emotional support for a person affected by a stroke may only be possible by taking the time to learn about the individual and giving them time to talk; as highlighted in numerous personal accounts of the stroke experience. However, within the current biomedical model of hospital-based stroke rehabilitation, this may be difficult to achieve.

A clash of cultures: barriers to providing emotional support within the context of hospital-based stroke rehabilitation nursing.

Reynolds (1999) contends that the way in which health care services are funded limits the time available to nurses to communicate in depth with the people they care for. Current models of hospital-based stroke rehabilitation are based on a biomedical perspective, which emphasises technical care (Reynolds, 1999). Indeed, Gibbon (2000b) noted that in his research on the career aspirations of staff working on a stroke unit, there was a prevailing “concept of science and in particular neuroscience rather than of ‘caring’” (p.44). Rehabilitation was “a problem solving intervention process more than a humanistic endeavour” (Gibbon 2000b, p.44).

The biomedical view of rehabilitation prioritises functional independence as the optimal outcome for a person affected by a stroke, although for the person themselves, “recovery is not lived as a completion of functional tasks prescribed by others” (Doolittle 1994, p.216). Indeed, there is some indication that stroke service users appreciate the non-technical aspects of nursing such as “caring, compassion and communication” and that better functional outcomes are being achieved at the expense of the person’s emotional well-being (Pound and Ebrahim, 2000) As Close and Proctor (1999) observed, in their study of ‘Coping strategies used by hospitalised stroke patients’, emotional support was more important in helping a person deal with their situation than searching for information about prognosis and outcomes.

Relating back to the biomedical explanation for the emotional experience of stroke as being caused by neurological damage; if this is believed to be the case, then spending time on providing emotional support may not be seen as relevant (Reynolds, 1999) and referral to a psychologist or psychiatrist working within the medical model may be viewed as more useful (White and Johnstone, 2000). Such a referral would be supported by information about a person’s mood state, obtained by administering a standardised screening tool. This approach is promoted in The Nursing Concise Guide for Stroke (ISWP, 2004), which summarises those elements of the clinical guidelines that are thought to be particularly relevant to nurses.

The only reference to emotional or psychological support is in the reiteration that screening for anxiety and depression should take place within the first month and the person’s mood kept under review. Minor depression should be treated by ‘watchful waiting’, with treatment only starting if it becomes severe or persistent (ISWP, 2004). The Nursing Concise Guide for Stroke (ISWP, 2004) suggests enhancing the nurse’s role in psychological assessment, and Kneebone (1999) promotes the involvement of nurses in assessment of mood; through the use of screening instruments and by “providing descriptions of relevant behaviour in case notes and during ward rounds and case conferences” (p.478). However, as argued elsewhere, the usefulness of ‘screening’ for mood ‘disorders’ by these means has doubtful therapeutic benefits for either the person being assessed and those caring for them (Bennett, 2005).

In addition to the recommendations above, Kneebone (1999) suggests that nurses can also provide emotional support to a person affected by a stroke by offering ‘an empathic, listening ear. However, achieving this might require a considerable shift in work culture; as it would necessitate the allocation of time specifically for that purpose (Kneebone, 1999). Long *et al* (2001) likewise report that one of the psychologists they interviewed wanted stroke nurses “to work towards creating a ‘psychologically-minded’ unit with a much greater role in counselling” (p.114). Only then would this role receive the same level of commitment as that given to physical care.

The implication is that within the current context of hospital-based stroke rehabilitation services, nurses may be seriously constrained from developing their role in providing emotional support; both from the perspective of the people they care for and of themselves as professionals. This resonates with wider concerns about the problems of providing emotional work in nursing generally (Bone, 2002; Rinard, 1996; Wiggins, 1997) and there is a risk that the conflict created for nurses practicing in such a culture, may result in not only a failure to provide emotional support (Pound and Ebrahim, 2000) but to frustration and burnout for the nurses themselves (Billeter-Koponen and Fréden, 2005).

Conclusion

It remains to conclude whether the questions that were asked of the literature reviewed here have been answered. In addressing the questions; ‘what is known of the emotional experience of stroke?', and 'how can nurses use this knowledge to enhance and inform their supportive role?' the literature clearly identifies two very different perspectives, grounded in differing epistemological assumptions. This is not necessarily unexpected, given that one body of literature was located within the biomedical sciences and the other within social sciences; nevertheless, the implications for stroke nursing practice are important.

The biomedical literature quite clearly locates a person's emotional response to stroke in the physical changes which occur in the brain as a result of a stroke. This position indicates a theory of emotion based in materialism and positivism (Savage, 2004). The response to this is to physically treat the damaged brain with antidepressants or treat with psychological therapies that are based in the biomedical model. It is no surprise that most of the research conducted into the use of different therapeutic approaches to treating mood disorder following stroke have focused on Cognitive Behavioural Therapy (CBT) (Khan-Bourne and Brown, 2003; Lincoln and Flannaghan, 2003).

The nurse's role within this model centres on structured assessment of mood and referral for pharmacological treatment or psychological therapy (ISWP, 2004). Stroke rehabilitation services based on this biomedical model may prevent nurses from developing and practicing their role in providing emotional support, because of the priority for providing 'physical' care and the lack of time available to sit and talk with people. They will also arguably prevent the users of the services from receiving the support they may need to help them deal with their emotional experiences of stroke.

On the other hand, the sociological literature locates the person's emotional response to stroke within the theoretical constructs of interpretivism and relativism (Savage, 2002), which focus on the person's struggle to make sense of what has happened to them and their efforts to deal with the challenges they face as a result of a stroke. Within his framework, the nurse can respond therapeutically by spending time with the person and offering emotional support. This support can also be integrated into their everyday caring activities. Descriptions of the nurse’s role as provider of emotional support following a stroke clearly incorporate this perspective; although the providers’ and recipients’ views of emotional support might not always correspond.

Nolan (2003) suggests that “stroke represents a paradigm case that encapsulates and exemplifies most of the tensions within modern-day healthcare systems” and that such tensions “reflect the paradox faced by a system oriented primarily towards cure” (p.212). This is clearly evident in the difficulties faced by nurses in attempting to provide emotional support to a person affected by a stroke. Ayers *et al* (2001) have argued that the emotional expertise employed by nurses determines whether a person feels ‘cared for’. They continue that this is why it is an area of stroke nursing that is currently undervalued and that it should, therefore, be made a priority for research (Ayers *et al*, 2001). What this review of the literature has provided is some indication of the key issues which influence and impinge upon emotional support in stroke rehabilitation nursing; a refinement of which could inform future research inquiry into the topic.

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Appendix 2a: aphasia-friendly patient information booklet

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Patient Information Booklet

The emotional experience of stroke: nurse-patient interactions

My name is **Bev Bennett.**

I am a research student in the **School of Nursing and Midwifery**, at Sheffield University.

I would like to **invite you to take part** in a research study**.**

The study aims to **find out** what it is like to **have a stroke** and how **nurses** might be able to **help**.

Please could you take the time to **read** this **information booklet**?

Discuss it with others, if you wish.

Please **ask questions** before you decide

What is the purpose of the study?

Everybody reacts differently to **having a stroke** so the care they receive will depend on **how the stroke has affected them.**

Learning about these different needs is **important for nurses** so they can give the best possible care.

This study aims to find out **what it is like** to have a stroke and **what nurses may do to help** someone.

Why have I been chosen to take part?

You are being asked to **take part** in the research study because you are on the ward **here and now**.

To find out **what nurses do to help** someone who has had a stroke, I would like to **spend some time** with them and with the patients they care for.

I would like to find out **what having a stroke is like for you**.

I can give you more **information** if you want it.

You can **ask me questions** about the study.

Who else is involved in the study?

Your **relative**

Other **patients**

The **nurses**

Do I have to take part?

No.

Taking part is **voluntary** and your care will not be affected in any way.

You will be asked to sign a **consent form**.

You are **free to pull-out** of the study at any time and without giving a reason

What will I have to do?

If you **agree** to take part in the study, this will include:

- Allowing me to **spend time** with **you** and **the nurses** during your usual **daily activities** and sometimes when your **relatives** visit:

1 to 2 hours at a time

on **8 to 10** occasions

over a period of up to **4** weeks

- **Talking** with me and letting me **write** down some **notes** about you

- Being i**nterviewed** in a private room on the ward, for **1 hour**, if you are able

- Being **tape recorded**

- Allowing me to **read** what the nurses write in your **care records**

Allowing me to **ask the nurses** about the care they give you

- Agreeing for me to attend **staff handovers** and ward **team meetings**, where you might be discussed

- Being **interviewed at home**, on **1** occasion, **4 to 6 weeks** after you leave hospital

- If you choose not to take part in the study, **I will not observe you** but you may see me around the ward, working with other people

What are the benefits of taking part?

There will be **no** direct **benefit to you** in taking part in the study

However, the study may **help nurses** to understand the best ways of **helping people to cope** with their stroke.

What are the disadvantages of taking part?

Sometimes you might **not want me** to be with you

You may **not want to talk** to me.

I will always **ask you first**.

Talking about your stroke **may upset you**

If this happens, I will make sure there is **someone to support you**.

Will my taking part in the study be kept confidential?

Yes. Anything I see or hear will be treated as **confidential**

It will only be shared with **my supervisor**.

The notes I make and the interview transcripts **will not contain any information which could identify you**, your relative or the staff on the ward.

Pseudonyms will be used where appropriate

Short extracts from my notes and the interview transcripts may be used in the study report and in publications but **these will remain anonymous**

What if unsafe practice is observed or raised during verbal reports or interviews?

If I observe or I am told about any **unsafe practice** which concerns you and which has not been dealt with, I have to report it.

This is because **I am a nurse** and I have to abide by the Nursing and Midwifery Council code of **professional conduct**.

What will happen to the information I give?

My **notes** of what I see and hear and the tape-recorded interviews will be **stored safely on a computer**.

These will be looked at to try and **explain the emotional experience of stroke** and what nurses do to help.

All **records will be destroyed** after 5 years

What will happen at the end of the study?

The findings will be written up in a **report**.

You will be given **a summary the report** to keep.

The findings may be:

- **Published**
- Presented at **conferences**
- Used in **teaching**

Who is paying for the research study?

Expenses will be met by the School of Nursing and Midwifery at the **University of Sheffield**, where I am studying.

Who has reviewed the study?

The research study has been reviewed by the School of Nursing and Midwifery **Ethics Review Panel**

It has also been reviewed by the **Rotherham Local Research Ethics Committee**.

Where can I get further information about the study?

You can **ask** me – Bev Bennett.

I can be contacted on **0114 222 9906**

Email: **b.bennett@sheffield.ac.uk**

What can I do if I have a complaint about the study ?

You can **talk to someone** from the hospital Patient Advisory and Liaison Service (PALS).

They can be contacted on **01709 307646**

You can also talk to my research supervisor,

Lorraine Ellis on: **0114 222 6398**

Email : l.b.ellis@sheffield.ac.uk

You can **contact** Miss D Patel, Lead for Research & Development, Rotherham NHS Foundation Trust, on **01709 304355**

Thank-you for taking the time to read this.

Appendix 2b: aphasia-friendly patient consent form

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

The emotional experience of stroke: nurse-patient interactions

Patient Consent Form

Please mark the correct box

- I have seen the **information booklet** about this research study, dated 25.05.06 (version 1)

Yes No

☐ 👍 ☐ 👎

- **I have talked** with Bev Bennett about the study

Yes No

☐ 👍 ☐ 👎

- We have **looked at the information** together

Yes ☐ 👍

No ☐ 👎

- **My questions have been answered**.

Yes ☐ 👍

No ☐ 👎

- I **understand** what is involved in the study and my part in it.

Yes	No
☐ 👍	☐ 👎

- I understand that if I choose to take part, it is **my free choice**.

Yes	No
☐ 👍	☐ 👎

- I understand that **I can stop** at any time and my care and treatment will not be affected.

Yes	No
☐ 👍	☐ 👎

- **I agree** to take part in the study

Yes	No
☐ 👍	☐ 👎

- **I agree** that the information I provide may be used for **research** and **teaching**.

  I will not be named or identified.

Yes ☐ 👍

No ☐ 👎

Name of person agreeing to take part

……………………………………………………………

Date …………… Signature ………………………..

Name of person taking/witnessing consent

…………………………………………………………..

Date …………... Signature …………………………

Appendix 2c: Information booklet for nursing staff

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Information Booklet for Nurses

The emotional experience of stroke: nurse-patient interactions

My name is Bev Bennett and I am a lecturer in the School of Nursing and Midwifery at Sheffield University. I am also studying for a Doctor of Medical Science degree and in connection with this, I would like to invite you to take part in a research study. However, before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study, if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Everyone reacts to having a stroke in different ways and the care offered to them will depend on how the stroke has affected them. Learning about this is important for nurses so that they can give the best possible care. The study aims to explore the emotional experience of having a stroke, how nurses interpret this experience and how they use this knowledge to influence their interactions with patients during the period of hospital-based rehabilitation.

Why have I been chosen?

You are being asked to take part in the study because you are a nurse working here on the ward, caring for patients who will be approached to participate in the study. A number of other staff, patients and relatives will also be asked to take part.

Do I have to take part?

No. It is up to you to decide whether or not to take part in the study. If you do, you will be given this information booklet to keep and you will be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason.

What will happen to me if I take part?

If you agree to take part in the study, this will include:

- Spending time observing you, together with patients you care for, their relatives and other staff you liaise with, during your usual daily activities on the ward. This will be for no more than 1 to 2 hours at a time, on 8 to 10 occasions over a 4 week period. This will also involve talking with you about what I observe.
- Interviewing you on your own for 1 hour, in private and, with your permission, tape-recording what you say.
- Looking at the patient records that you write in.
- Attending staff handovers and multiprofessional team meetings.
- If you choose not to participate, I will not observe you in relation to the study interests. Nevertheless, you may see me around in my work with other nurses on the ward, in shift handovers and team meetings.

What are the benefits of taking part in the study?

There are no intended direct benefits to yourself but the information gained from patients, their relatives and staff taking part in the study may help nurses to understand the best ways of helping people to cope with their stroke. This will lead to recommendations for an improved service.

What are the disadvantages of taking part in the study?

I will always try to ensure that normal ward routines are not disrupted by my presence but there may be times when you do not want me to be with you or do not want to talk to me. I will always check with you first and respect your wishes. You can stop at any time and should you become upset whilst participating in the study, I will ensure that there is someone available to support you.

Will my taking part in the study be kept confidential?

Yes. Anything that I see or hear in connection with the study will be treated as confidential and will be disclosed only to my research supervisor. My observation notes and the interview transcripts will not contain any information which could identify you, your colleagues or the organisation in which you work. Pseudonyms will be used where appropriate. Some short extracts from my notes and the transcripts may be used in the report and in publications but these will remain anonymous.

What if unsafe practice is observed or raised during verbal reports or interviews?

It is possible that cases of unsafe practice which have not been resolved may be observed by or reported to me. As a registered nurse bound by the Nursing & Midwifery Council code of professional conduct and in accordance with my honorary contract with the Trust, any concerns I have regarding patient safety or well-being must be reported to the appropriate authorities. Should this situation arise, it will be discussed with you before any action is taken.

What will happen to the information I provide?

The notes made of my observations and conversations, along with transcripts of the tape-recorded interviews, will be stored on a password protected computer. This data will be analysed using a computer software package, in order to identify themes and patterns to explain the emotional experience of stroke and how nurses interpret and respond to this. All records will be destroyed after 5 years.

What will happen to the findings of the study?

At the end of the study, the findings will be written up in a report which will form part of the thesis I submit for my doctoral degree. In addition, a summary of the findings will be distributed to all participants in the study and the Rotherham Stroke and Disability Support Group. The findings may also be published in journals and presented at conferences so that other people can learn from the research.

Who is funding the research study?

As the study is being undertaken for a higher education degree, the University of Sheffield will act as sponsor for the research. Expenses incurred during the study will be met by the School of Nursing and Midwifery.

Who has reviewed the study?

The proposal for the research study has been reviewed by the School of Nursing and Midwifery Ethics Review Panel and by the Rotherham Local Research Ethics Committee.

Where can I get further information about the study?

You can obtain further information by asking me, Bev Bennett. You can speak to me on the ward or I can be contacted by telephone on: 0114 222 9906 and email at:

bev.bennett@sheffield.ac.uk

What can I do if I have a complaint about the study?

Any complaint about the way that you have been dealt with during the study will be addressed. You can talk to my research supervisor, Lorraine Ellis on 0114 222 9776 or by email at l.b.ellis@sheffield.ac.uk Alternatively, you can contact Miss D Patel, Lead for Research & Development, Rotherham NHS Foundation Trust, on 01709 03355.

Thank-you for taking the time to read this.

Appendix 2d: Health care consent form

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Consent Form

Health Care Staff

Title of study: The emotional experience of stroke: nurse-patient interactions

Name of Researcher: Beverley Bennett

Please initial box

1. I confirm that I have read and understand the information booklet dated 25.05.06 (version 1) for the above study and I have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time. Without giving any reason and without my legal rights being affected. ☐
3. I agree to take part in the above study. ☐

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Name of participant	Date	Signature
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Researcher	Date	Signature

Appendix 2e: Information booklet for other health care staff

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,

Golden Smithies Lane,

Manvers,

Rotherham,

S63.7ER

Telephone: 0114 222 9906

Email: b.bennett@sheffield.ac.uk

Information Booklet for the multiprofessional team

The emotional experience of stroke:

nurse-patient interactions

My name is Bev Bennett and I am a lecturer in the School of Nursing and Midwifery at Sheffield University. I am also studying for a Doctor of Medical Science degree and in connection with this, I would like to invite you to take part in a research study. However, before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study, if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Everyone reacts to having a stroke in different ways and the care offered to them will depend on how the stroke has affected them. Learning about this is important for nurses so that they can give the best possible care. The study aims to explore the emotional experience of having a stroke, how nurses interpret this experience and how they use this knowledge to influence their interactions with patients during the period of hospital-based rehabilitation.

This will include:

- Spending time observing nurses, together with patients they care for, their relatives and other staff they liaise with, during their usual daily activities on the ward. This will be for 1 to 2 hours, on 8 to 10 occasions over a 4 week period. This will also involve talking with them and writing down some notes.
- Interviewing nurses, patients and relatives on their own, in private for 1 hour and tape-recording what they say.
- Looking at the patient records that nurses write in.
- Attending staff handovers and multiprofessional team meetings.
- Interviewing patients and their relatives at home, on one occasion, after the patient leaves hospital.
- If you choose not to participate, I will not observe you in relation to the study interests. Nevertheless, you may see me around in my work with the nurses on the ward, in shift handovers and team meetings.

Why have I been chosen?

You are being asked to take part in the study because you are a member of the multiprofessional rehabilitation team working here on the ward. To find out what nurses do to help a person who has had a stroke, I would like to spend time with them, together with the patients that they care for and with the patients' relatives. A number of other staff, patients and relatives will also be asked to take part in the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part in the study. If you do, you will be given this information booklet to keep and you will be asked to sign a consent form. You are free to withdraw from the study at any time and without giving a reason.

What will happen to me if I take part?

During periods when I am observing patients and their relatives interacting with nurses, it is possible that you might also need to be present. Likewise, you may be present at staff handovers and multiprofessional team meetings where I am observing the nurses.

If this occurs, I would like to continue observing with you present. I may also wish to read what the nurses have written in patient records where you might also write.

What are the benefits of taking part in the study?

There are no intended direct benefits to yourself but information gained from patients, their relatives and staff taking part in the study may help nurses to understand the best ways of helping people to cope with their stroke. This will lead to recommendations for an improved service.

What are the disadvantages of taking part in the study?

I will always try to ensure that normal ward routines are not disrupted by my presence but there may be times when you do not want me to be with you or do not want to talk to me. I will always check with you first and respect your wishes. Should you become upset whilst participating in the study, I will ensure that there is someone available to support you.

Will my taking part in the study be kept confidential?

Yes. Anything that I see or hear in connection with the study will be treated as confidential and will be disclosed only to my research supervisor. My observation notes and the interview transcripts will not contain any information which could identify you, your colleagues or the organisation in which you work. Pseudonyms will be used where appropriate. Some short extracts from my notes and the transcripts may be used in the report and in publications but these will remain anonymous.

What if unsafe practice is observed or raised during verbal reports or interviews?

It is possible that cases of unsafe practice which have not been resolved, may be observed by or reported to me. As a registered nurse bound by the Nursing & Midwifery Council code of professional conduct and in accordance with my honorary contract with the Trust, any concerns I have regarding patient safety or well-being must be reported to the appropriate authorities. Should this situation arise, it will be discussed with you before any action is taken.

What will happen to the information I provide?

The notes made of my observations and conversations, along with transcripts of the tape-recorded interviews, will be stored on a password protected computer. This data will be analysed using a computer software package, in order to identify themes and patterns to explain the emotional experience of stroke and how nurses interpret and respond to this. All records will be destroyed after 5 years.

What will happen to the findings of the study?

At the end of the study, the findings will be written up in a report which will form part of the thesis I submit for my doctoral degree. In addition, a summary of the findings will be distributed to all participants in the study and the Rotherham Stroke and Disability Support Group. The findings may also be published in journals and presented at conferences so that other people can learn from the research.

Who is funding the research study?

As the study is being undertaken for a higher education degree, the University of Sheffield will act as sponsor for the research. Expenses incurred during the study will be met by the School of Nursing and Midwifery.

Who has reviewed the study?

The proposal for the research study has been reviewed by the School of Nursing and Midwifery Ethics Review Panel and by the Rotherham Local Research Ethics Committee.

Where can I get further information about the study?

You can obtain further information by asking me, Bev Bennett. You can speak to me on the ward or I can be contacted by telephone on: 0114 222 9906 and email at:

bev.bennett@sheffield.ac.uk

What can I do if I have a complaint about the study?

Any complaint about the way that you have been dealt with during the study will be addressed. You can talk to my research supervisor, Lorraine Ellis, on 0114 222 9776 or by email at l.b.ellis@sheffield.ac.uk Alternatively, you can contact Miss D Patel, Lead for Research & Development, Rotherham NHS Foundation Trust, on 01709 304355.

Thank-you for taking the time to read this.

Appendix 2f: Patient consent form

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Consent Form

Patient consent form

Title of study: The emotional experience of stroke: nurse-patient interactions

Name of Researcher: Beverley Bennett

Please initial box

1. I confirm that I have read and understand the information booklet dated 25.05.06 (version 1) for the above study and I have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time. Without giving any reason and without my legal rights being affected. ☐
3. I agree to take part in the above study. ☐

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Name of participant	Date	Signature
--	-----------------------	------------------
Researcher	Date	Signature

Appendix 2g: Relative information booklet

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Information Booklet for Relatives

The emotional experience of stroke:
nurse-patient interactions

My name is Bev Bennett and I am a lecturer in the School of Nursing and Midwifery at Sheffield University. I am also studying for a Doctor of Medical Science degree and in connection with this, I would like to invite you to take part in a research study. However, before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and talk to others about the study, if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

Everyone reacts to having a stroke in different ways and the care offered them will depend on how the stroke has affected them. Learning about this is important for nurses so that they can give the best possible care. The study aims to explore the emotional experience of having a stroke, what nurses understand this experience and how they use this knowledge to influence the care they give to patients, during the period of hospital-based rehabilitation.

Why have I been chosen?

You are being asked to take part in the study because your relative is a patient here on the ward. To find out what nurses do to help them, I would like to spend time with your relative, with the nurses caring for them and with yourself. A number of other relatives, patients and staff will also be asked to take part in the study.

Do I have to take part?

No. It is up to you to decide whether or not to take part in the study. If you do, you will be given this information booklet to keep and you will be asked to sign a consent form. You are also free to withdraw from the study at any time and without giving a reason. A decision not to take part or to withdraw will not affect the care given to your relative or the consideration given to you as a relative.

What will happen to me if I take part?

If you agree to take part in the study, this will include:

- Spending time observing you, together with your relative and the nurses caring for them, at times when you visit the ward. This may be for 1 to 2 hours at a time, on 8 to 10 occasions over a 4 week period; if your relative is in hospital that long. It will also involve talking with you and writing down some notes.

- Interviewing you on your own, in private, for 1 hour and tape-recording what you say, with your permission.

- Interviewing you and your relative at home, on one occasion, 4 to 6 weeks after they have left hospital.

- Looking at your relative's care records.

- Attending staff handovers and ward team meetings, where you and your relative may be discussed

- If you choose not to participate, I will not observe you in relation to the study interests. Nevertheless, you may see me around in my work with the nurses on the ward.

What are the benefits of taking part in the study?

There are no intended direct benefits to yourself but the information gained from all the patients taking part in the study, their relatives and the staff, may help nurses to understand the best ways of helping people to cope with their stroke. This will lead to recommendations for an improved service.

What are the disadvantages of taking part in the study?

I will always try to ensure that your visits to the ward are not disrupted by my presence but there may be times when you do not want me to be with you or do not want to talk to me. I will always check with you first and respect your wishes. You can stop at any time and should you become upset by talking about the stroke, I will ensure that there will be someone to support you.

Will my taking part in the study be kept confidential?

Yes. Anything that I see or hear in connection with the study will be treated as confidential and will be disclosed only to my research supervisor. My observation notes and the interview transcripts will not contain any information which could identify you, your relative or the staff working on the ward. Pseudonyms will be used where appropriate. Some short extracts from my notes and the transcripts may be used in the report and in publications but these will remain anonymous.

What if unsafe practice is observed or raised during verbal reports or interviews?

It is possible that cases of unsafe practice concerning your relative, which have not been resolved, may be observed by or reported to me. As a registered nurse bound by the Nursing & Midwifery Council code of professional conduct and in accordance with my honorary contract with the Trust, any concerns I have regarding patient safety or well-being must be reported to the appropriate authorities. Should this situation arise, it will be discussed with you before any action is taken.

What will happen to the information I provide?

The notes made of my observations and conversations, along with the tape-recorded interviews, will be stored on a password-protected computer. This information will be examined using a computer programme, in order to identify themes and patterns which may explain the emotional experience of stroke and how nurses interpret and respond to this. All records will be destroyed after 5 years.

What will happen to the findings of the study?

At the end of the study, the findings will be written up in a report which will form part of the thesis I submit for my doctoral degree. In the report, your name will be kept secret and you will be given a summary of the report to keep. The findings may be published, presented at conferences or used in teaching.

Who is paying for the research study?

As the study is being undertaken for a higher education degree, the University of Sheffield will act as sponsor for the research. Expenses incurred during the study will be met by the School of Nursing and Midwifery.

Who has reviewed the study?

The proposal for the research study has been reviewed by the School of Nursing and Midwifery Ethics Review Panel and by the Rotherham Local Research Ethics Committee.

Where can I get further information about the study?

You can obtain further information by asking me, Bev Bennett. You can speak to me on the ward or I can be contacted by telephone on: 0114 222 9906 and email at:

bev.bennett@sheffield.ac.uk

What can I do if I have a complaint about the study?

Any complaint about the way that you have been dealt with during the study will be addressed.

You can contact Miss D Patel, Lead for Research & Development, Rotherham NHS Foundation Trust, on 01709 304355, or talk to someone from the hospital Patient Advisory and Liaison Service (PALS). They can be contacted on 01709 07646.

Alternatively, you can talk to my research supervisor, Lorraine Ellis, on 0114 222 9776 or by email at l.b.ellis@sheffield.ac.uk

Thank-you for taking the time to read this.

Appendix 2h: Relative consent form

The University of Sheffield

Dean: Anne M Peat

Humphry Davy House,
Golden Smithies Lane,
Manvers,
Rotherham,
S63.7ER
Telephone: 0114 222 9906
Email: b.bennett@sheffield.ac.uk

Consent Form

Relatives

Title of study: The emotional experience of stroke: nurse-patient interactions

Name of Researcher: Beverley Bennett

Please initial box

1. I confirm that I have read and understand the information booklet dated 25.05.06 (version 1) for the above study and I have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time. Without giving any reason and without my legal rights being affected. ☐
3. I agree to take part in the above study. ☐

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Name of participant	Date	Signature
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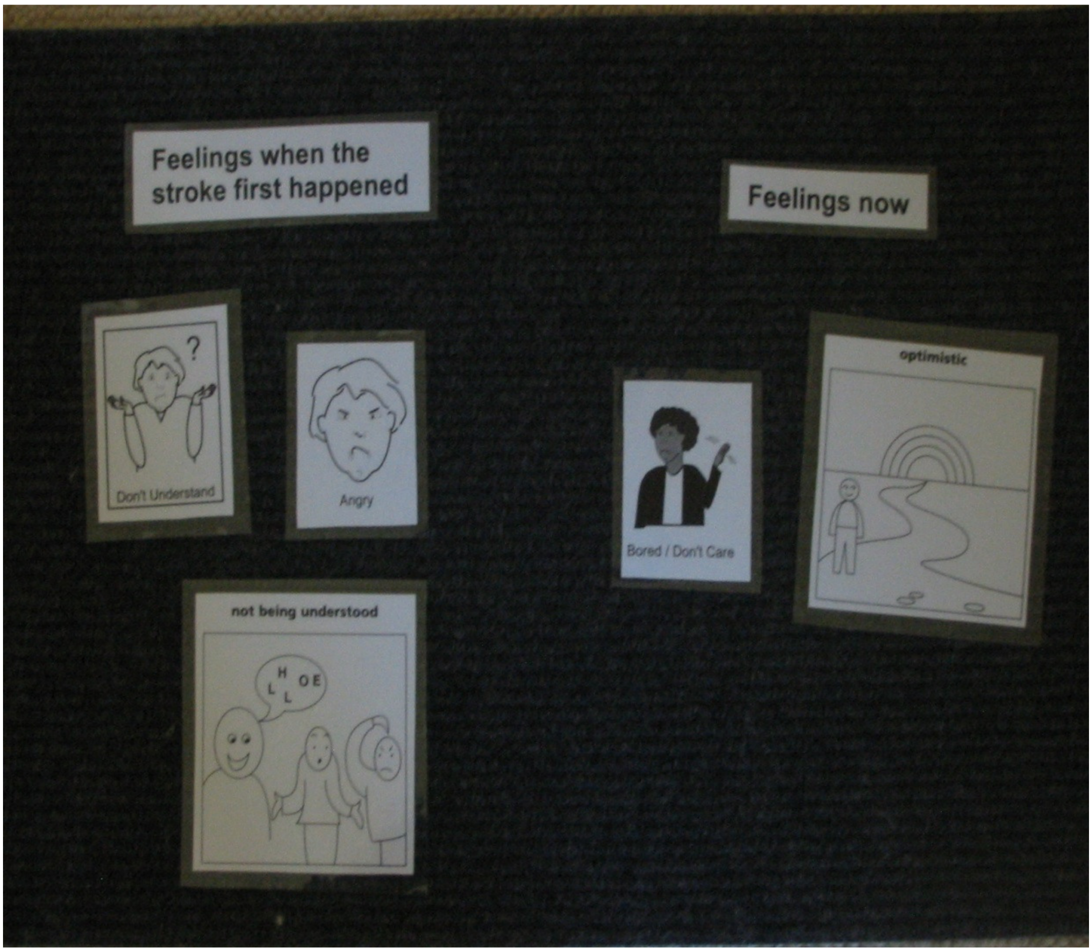
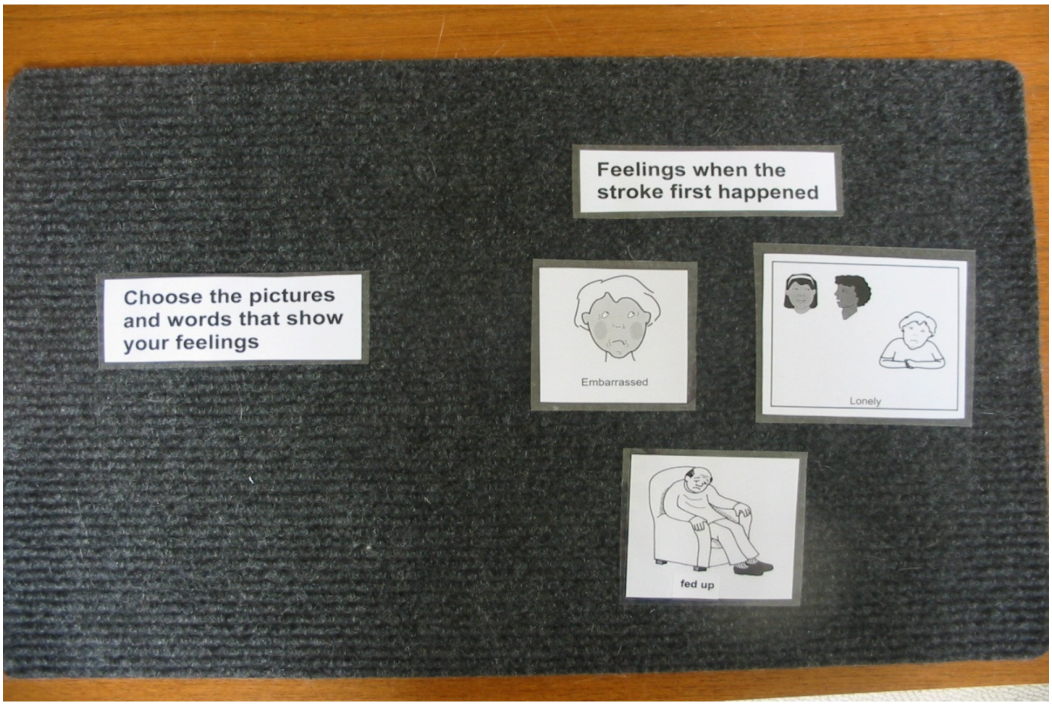
Researcher	Date	Signature

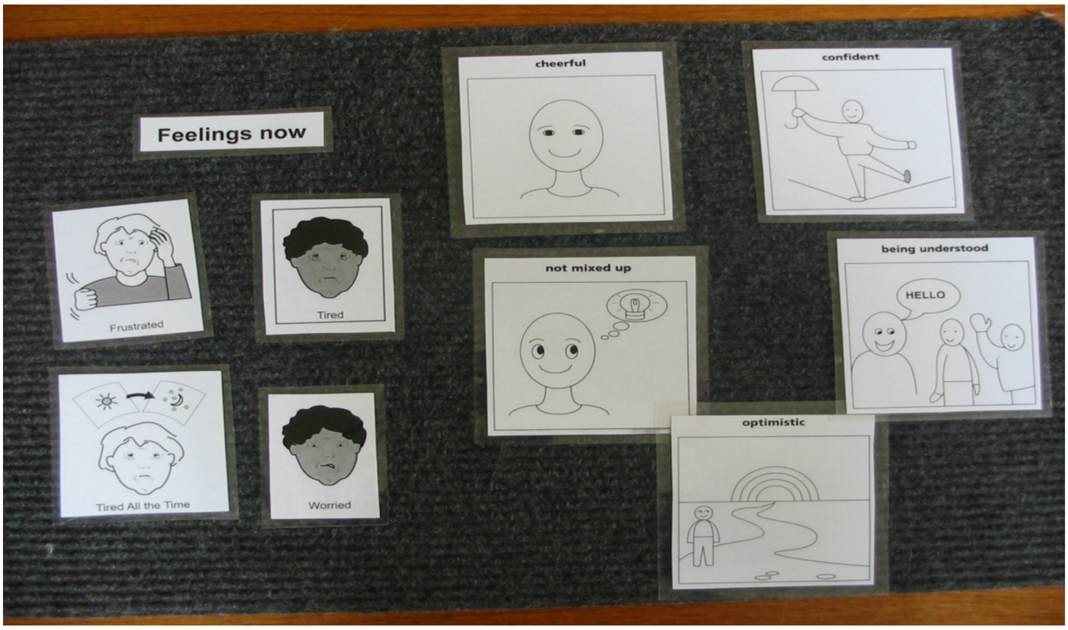
Appendix 3: Talking Mats – photographic record of interviews with aphasic patient particpants

Gavin (pt.2)

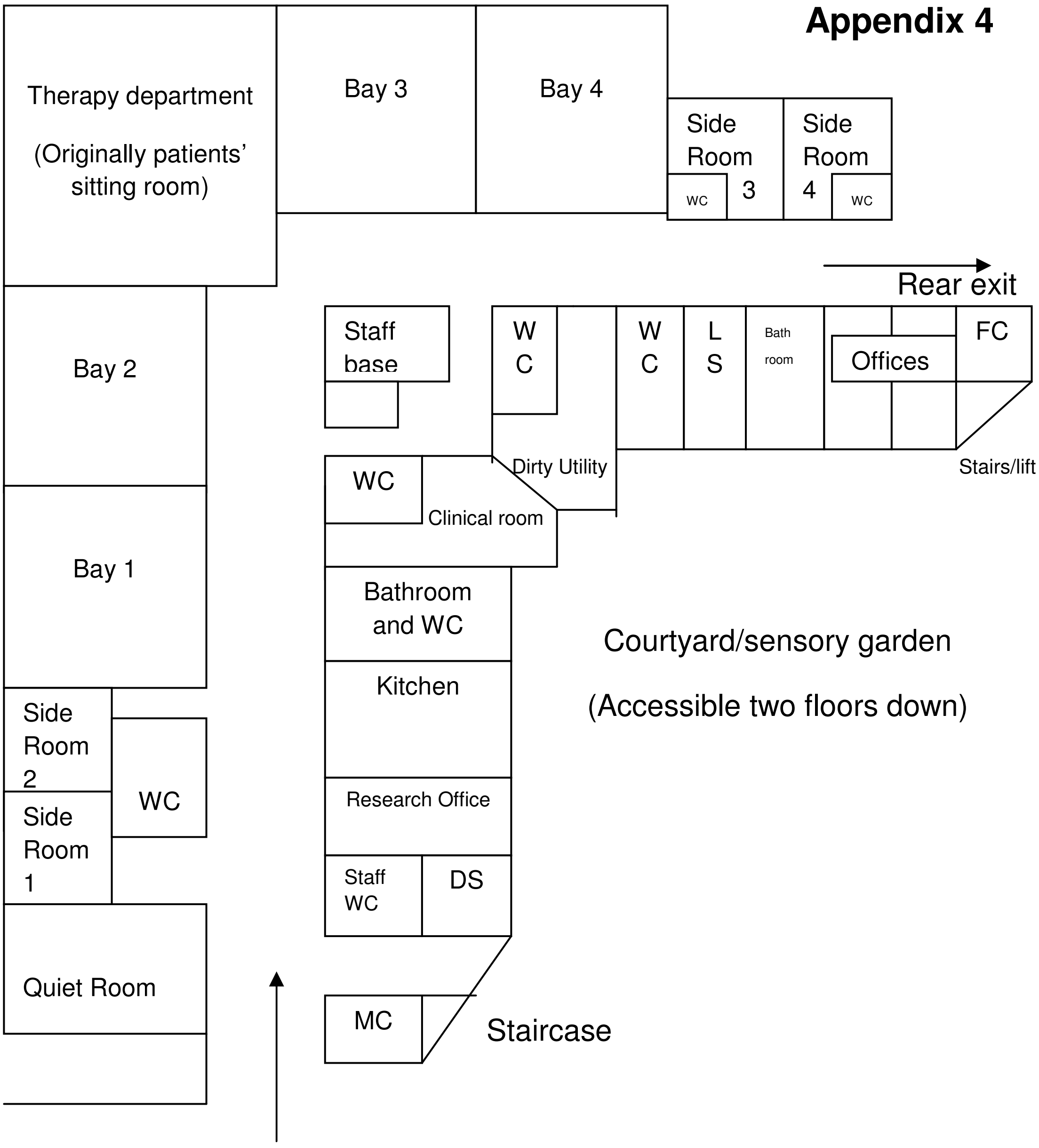


Fred (pt.4)


Feelings when the stroke first happened
Choose the pictures and words that show your feelings
Embarrassed
Lonely
fed up


Feelings now
cheerful
confident
Frustrated
Tired
not mixed up
being understood
HELLO
Tired All the Time
Worried
optimistic

Appendix 4



Ward entrance via main hospital

Floor plan of the stroke unit (not to scale)

Key: WC = toilet LS = linen store DS = domestic store

FC = female staff changing room

MC = male changing room

A day in the life of the stroke unit:

This description of the stroke unit has been complied from a number of episodes of observation to provide a general picture of activity over a 24 hour period.

The ward layout and occupancy

The stroke unit is located within the Medicine for the Elderly Unit, which was annexed to the main hospital building in 1998. It is, therefore, a relatively new addition to the main hospital building, which was opened in the mid-1970s. In contrast to the layout of the older wards, which comprise essentially a long corridor with various rooms positioned on either side along its length, the stroke unit is ‘L-shaped’. (See floor plan). The entrance to the ward from the main hospital building is figuratively, at the base of the ‘L’ and along the left side of this main corridor and the quiet room, two single rooms and the two male patient bays (1 and 2).On the right are the research office, ward kitchen, a bathroom, clinical room and toilet. The staff base or nurses’ station is set into the crook of the ‘L’, with the therapy department located directly opposite. Originally, this was designed as a patients’ sitting room but was almost immediately converted for its current purpose, as the ward has a dedicated team of therapists.

The two women’s bays are located along the other axis of the ‘L’ in a corridor leading to the back doors to the ward, which lead to the external entrance to the Medicine for the Elderly Unit, two floors below. The entrance to the ward from the main hospital is on the same level as the ground floor of the hospital building but to exit via the back doors, there are two flights of stairs down or a lift to navigate. Opposite the two women’s bays are a toilet, dirty utility room, linen store, bathroom and, at the Ward Manager’s and Stroke Nurse Specialist’s office. In general, this area at the far end of the ward is the least busy, as few staff have cause to visit the offices. The location of two of the single rooms also ensures that their occupants would be relatively undisturbed, if this is an objective.

Each of the four bays accommodates 6 patients, which together with the four single rooms makes a total of 28 beds. Although there is generally an equal mix of male and female patients, depending on patient demand, this arrangement can change; and indeed, it needs to in order to ensure that the minimum number of beds remain unoccupied. The four single rooms are particularly helpful in this respect, although their occupancy is always respected if a patient is nearing the end of their life. There is always movement between the bays, as the aim is to admit patients into the bays closest to the staff base, for observation purposes. These are bays 2 and 3. As new patients arrive, those who are assessed as needing less intensive supervision will be transferred into bays 1 and 4.

The ward staff

The multiprofessional nature of stroke rehabilitation requires a team comprising several professions and their composition is:

33 nurses: 1 X Band 7 (ward manager)

7 X Band 6 (senior nurses + Stroke Nurse Specialist)

9 X Band 5 (junior nurses)

16 X Band 2 (health care assistants)

Physiotherapists (physios):

4 X qualified

2 X assistants

Occupational Therapists (OTs):

4 X qualified

3 X assistants

Speech and Language Therapists (SLTs):

2 X qualified

1 X assistant

Doctors:

1 X Consultant

2 X junior grade

Many of the staff work part-time hours. The nurses work every day and across the 24 hour period, in three shifts of 07.00 – 15.00, 13.00- 21.00 and 20.30 – 07.15. All other staff work between Monday to Friday, at varying hours between 08.00 and 17.00, as do the ward housekeeper, domestic assistants and ward clerk. There is always access to an on-call doctor and physiotherapist outside office hours. Other dedicated core team members (i.e. it is the same person who usually attends) include a social worker, pharmacist and dietitian. They visit the ward daily, also within these office hours; in addition to which, there are numerous other professional and ancillary staff that complement the activities of the ward-based team.

The daily routine

From my observations, at 07.00 and the beginning of the nursing morning shift, it is very quiet, except for patients snoring. The qualified nurses hand over to the morning staff in the therapy department, for confidentiality reasons and so as not to disturb sleeping patients. The night shift health care assistants stay at the staff base or attend to any patients who might buzz for assistance. After the handover, the night nurses go home and the nurses divide into two teams; one for the male patients and the other for the women. There are four qualified nurses and three care assistants. The nurse in charge for the morning checks the ward diary to see who has dressing practice or investigations booked, which might require priority attention.

The nurses greet the patients with cheery ‘Good mornings’ and everyone gets to work straight away, assisting with washing, dressing and toileting patients. As they do so, the noise levels start to escalate. The ward housekeeper also starts work at 07.00 and helps out with patient care activities. One or two of the nurses talk quite loudly to one another and there are other noises as well, such as the mechanical sounds of the hoisting equipment and a tap in bay 3 which makes a gurgling noise; possibly due to air in the pipes. The ward clerk arrives at 07.30 and by 07.40, someone has turned on the radio in bay 3 and pop music is playing.

The domestic assistant arrives at 08.00, as does the breakfast trolley and attention is immediately directed to giving out breakfasts and morning drinks; assisting patients who require help with feeding. The qualified nurses who are leading the teams for the men’s and women’s sides collect the medicines trolleys from the clinical room and start to administer medicines. The phone starts to ring at around 08.00; a relative asking how a patient has slept. The nurse in charge assures them that they are fine. Other team members start to arrive from 08.30 and the Stroke Nurse Specialist arrives at 09.00. She goes straight to her office. Likewise, therapy staff go into the therapy department. An OT assistant emerges again shortly afterwards with a tea trolley and proceeds to the ward kitchen to make drinks, as the therapists meet together at the beginning of the shift to plan their work for the day. The trolley is greeting with a comment from a health care assistant about how nice it must be to have time to sit down, as there is no opportunity for the nurses to do this. They might have a drink whilst taking the morning handover but will not get another until their break time.

By now, the television in bay 2 has been switched on and although no-one appears to be watching it, it doesn't seem to bother anyone either; just background noise really. However, by 09.30, the ward has quietened down a bit. The Speech and Language Therapist has turned off the television, in order to assess a patient. The nurses administering medicines are finishing off but they also have intravenous infusion pumps and enteral feeding pumps to check, as well as recording patient observations. Electronic equipment is used for this purpose.

The bathrooms are constantly in use, as are the toilets; and hoists, Standaids and other moving and handling equipments add to the traffic in the corridors. Linen trolleys are being manoeuvred around, curtains open and close, beds are made, breakfast trays collected. A porter arrives to take a patient for an X-Ray and the junior doctor who has just arrived and the ward clerk spends time talking to them about results from investigations which need to be looked at before filing.

The physios and OTs are also busy on the ward by 09.00, collecting patients to take into the department or to the main department in the hospital which is, conveniently, adjacent to the ward. The OTs look in the ward diary to see who needs dressing practice and move to those patients. The nurses continue with their patient care activities. The doctor starts her round and moves between patients with the notes trolley, talking to the nurses who are to hand. The nurses do not accompany the doctors as this activity will take the rest of the morning and they do not have the time to spare. Morning breaks do not usually start until around 10.00 and the nurses then organise between themselves in their teams, the order in which to take them. They have 20 minutes and this is their only meal break, as they will work through until leaving at 15.00; possibly grabbing a quick drink when the afternoon staff arrive at 13.00.

There does not seem to be much interaction between the patients themselves whilst all this activity is going on but when things quieten down and the curtains between heir beds are all pulled back, then they can talk. There is no communal area for patients to sit so they stay by their bedsides until taken elsewhere by the staff or visiting relatives. Most of them are unable to walk unassisted and only one male patient is walking about the ward using a walking stick. There appears to a wide range of ages amongst the male patients but all of the women appear quite frail and poorly. A newspaper trolley appears around 11.00 and patients are offered papers, magazines, sweets and drinks. Very few of them buy anything. There appears to be a quiet efficiency in the way that the nurses and therapists work with and around each other and everyone smiles as they pass.

This goes on until around 12.00, when the lunch trolley arrives and again, all other activity is suspended, where possible, until these are distributed. The therapists leave the ward to take their lunch break in the staff room located near the day hospital on the ground floor of the Medicine for the Elderly unit. One of the health care assistants is having a rather heated discussion with a colleague about prioritising patient ‘turns’ before lunches are given out; that the patients who were attended to early on in the morning need their position changing. The patients’ positioning is prioritised but this means that lunches are delayed some minutes and this interrupts the tight mealtime schedule. The housekeeper takes the drinks trolley round whilst lunches are being eaten.

The afternoon nursing staff start to drift in whilst lunches are still in progress. One of the staff nurses explains that she likes to come in a little earlier after her days off to catch up with what’s being going on, before the afternoon handover. Others walk through on their way to the female changing room which is at the far end of the corridor. By 13.00, everyone has arrived and they all go into the quiet room for the handover. This afternoon, there are five nurses on duty, three qualified and two care assistants. At this time of day, one of the therapy staff joins them and makes notes, contributing information about how patients are progressing with their therapy and collecting information to feed back to the therapy team. Dates for family meetings are discussed along with issues to be taken forward to multidisciplinary team meetings which occur twice a week.

In the afternoon, there are fewer nurses on duty so they work across the ward and not in teams. By now, it is nearing 14.00. The qualified nurses start to give out medicines again and record patient observations and the morning staff gather around the staff base to write up the patient notes from the morning. There are four notes trolleys, one for each bay and a side room but they are constantly interrupted by other staff needing to look at patient records. Many of the patients are resting on their beds now. If they were sat out for the morning, they are put back to bed for a rest, unless the therapists have arranged to see them. Visitors start to arrive at 15.00, some on whom have been waiting outside the ward for several minutes already. Visiting time is 15.00 – 20.00 and it is during this period that family meetings take place in the quiet room. Visitors come to the staff base wanting to talk to the nurses and the ward becomes increasingly busy with human traffic. The stacks of visitor's chairs are soon depleted and the chairs from the staff base are taken so that the nurses have to write their notes standing up.

At 15.00, the nurses from the morning shift leave and promptly. They have worked flat out since arriving. Now the afternoon staff is left to carry on with patient activities but they also stop to talk to relatives in the bays where they are working. Therapy activity appears to cease around 16.00 and the therapists sit down in their room to write up the notes before leaving. The department is not used once they leave late afternoon, although it is left unlocked and the lights are left on. The evening domestic assistant arrives at 17.00 and changes the patients' water jugs before the evening meals arrive at 17.30. Meal time activity starts again and the domestic assistant takes round hot drinks. Relatives are not asked to leave and some offer to assist if a patient needs feeding, others take the opportunity to leave or take a break in the snack bar or restaurant. Tea-time medicines are administered. There is little respite for the nurses and they carry on once the meal trays are cleared away, helping patients to prepare for bed if they are tired, or if they need toileting. The television sets in bays have been switched on and off during much of the day, although it isn't obvious whether or not anyone is really watching them, apart from visitors.

The last visitors leave at 20.00 and the qualified nurses update the patient notes. Messages for the next day's morning staff are written in the ward diary or the doctor's book and the health care assistants carry on helping patients to bed. The night nurses arrive around 20.30 and a tray of drinks is brought to the staff base for all the nurses. The handover takes place in the therapy room and the afternoon nurses leave at 21.00. At night, there are two qualified nurses and two assistants. The qualified nurses start to give out medicines, whilst the assistants continue to help patients to bed and attend to toileting. A drinks trolley had been taken round by one of the afternoon care assistants at 20.00 and this is now cleared away.

The nurses do not lower their voices when speaking to one another. It is quiet except for a loud, continuous bleep coming from one of the electronic beds in bay 2 and this persists throughout the night. A care assistant jokes that when there is more than one of these beds in use at a time, the bleeps can be very annoying. The TVs in the two male patients' bays were turned off around 22.30 and the lights dimmed. The other care assistants is heard to say "peace at last", although the TV is still on in bay 4 and one female patient is sat out of bed, watching it. Another lady in the bed next to her is also watching it and the ladies are talking to each other. However, because the ward is much quieter now, their conversation sounds rather loud and can clearly be overheard. Nevertheless, a nurse comments that it is good for the lady in bed to have someone to talk to, as she has been rather low in mood and "the company would do her good". One of the care assistants comments to the ladies that it is only 10.30 and they should not feel that they have to go to sleep yet if they don’t want to. However, this is the only bay where patients are still out of bed. By 23.00, all but the one female patient are in bed and most of the lights have been dimmed – apart from at the staff base, where they remain full on for the rest of the night. The last patient goes to bed around midnight.

I asked whether patients tended to sleep well and was told that there are good and bad nights. Sometimes, the ward is very peaceful but on occasions, when there are noisy or confused patients, this can be very disruptive. There is one point in the night, at around 02.30, when patients are all attended to and their positions changed, if needed; and several patients are assisted to the toilet or given bedpans. During the night, patients are still assisted to the toilet if indicated on their moving and handling assessment that they can walk. However, if they are taking night sedation, it could be unsafe for them to do so, especially when the lights had been dimmed. The night nurses base their decisions on the patient’s level of alertness or tiredness. One said that it was a difficult balance to achieve between promoting independence and responding to their need for rest.

Otherwise, apart from the one or two patients who request to go to the toilet, there is little disturbance, in fact, the patients are left pretty much undisturbed altogether. The only visitors to the ward are a security guard, to check that everything is OK and the on-call doctor, who drops in to see if there is anything that they need to do. There is not. The qualified nurses update the care plans for the following shift, to save the morning staff time but other than answering buzzers, the night is quiet and uneventful. The morning shift nurses start to arrive around 06.45 and the day starts again.

Appendix 5: Nursing guidelines for patient recruitment

Bev's research study

Recruitment criteria

A range of patients is required; with consideration to their age, gender, ethnicity and social networks.

Which patients should be included?

Any patient on the ward can be potentially included in the study; once they have been assessed. This includes patients with speech difficulties.

Which patients should be excluded from the study?

- Patients who have been assessed by the medical staff to be **physiologically unstable or unwell**.

- Patients who have been assessed by the speech and language therapist and the occupational therapist to have such **severe communication or cognitive impairments** that their competence to understand and agree to participate would be questionable.

Initially, a patient should be asked if they are interested in being given information about the study, indicating that I am interested in finding out how the stroke has affected them and those close to them.

If the patient agrees to this, a nurse could then introduce me to the patient and I will then arrange to go through the information booklet with the patient and ask them to consider consenting to participate in the study. I will also ask the patient's nearest relative if they would like to take part.

If there are any concerns about this process, please feel free to voice them.

Thank-you

Appendix 6: Extracts from the research journal

Extract 1:

Example of an ethical issue encountered

15.01.07

A rather interesting situation occurred on Thursday last, when I was looking through Lily's medical records. I noticed that she had a DNAR form in the front of the notes, dated December 24th, 2006. The document indicated that the patient was not aware of the order, due to her being 'too poorly' but it also indicated that her family had not been consulted either, on the grounds that they were 'unavailable'. This lady's family visit every day, often in the afternoon and stay until the evening. The order also stated that it was to be reviewed in one week's time and this had not been done.

Granted, at the time that the order was completed, Lily was seriously ill and there were probably good grounds for suggesting that a resuscitation attempts should not be made. However, it appeared that her family had remained unaware of this and during the two weeks or so that had passed, Lily had significantly recovered and was now sitting out of bed, eating and drinking and was engaging in conversation. There was a family meeting booked for that afternoon.

I asked the nurse in charge a general question about DNAR policy and he stated that it was unusual for patients on that ward to have DNAR status. He was obviously unaware of Lily's DNAR status. I asked him about reviewing the orders and he said that it was usually done at each admission/readmission! Following the family meeting, the physiotherapist who had attended was writing a summary of decisions made in Lily's notes. She was also discussing this with a colleague. It was noted that the plan was for Lily to go home, to the care of her daughter, with whom she currently lived. There was a general feeling of optimism about her progress. At this point I felt that I had to ask the physio whether she was aware of the DNAR notice in Lily's notes. She was not and quite alarmed by this, she immediately went to see the doctor on the ward and asked if she would review/rescind the order; but the doctor was reluctant to do so, saying that Lily had been very ill. The physio argued that this was no longer the case and in view of the doctor's reluctance to change the order, she took it out of the file and ripped it up.

I visited the ward briefly on Friday afternoon (11th) to see Lily and then had a quick chat with the ward manager, Penny, just to let her know my plans for the coming week. I felt that she should also be told about the 'incident' and she too was quite alarmed. The staff nurse who was with her at the time seemed to think that there was another patient who was in a similar position and she was going to check her notes. Penny said that this was an issue that was easily missed, because the nurses don't look in the medical notes very often. I did explain that the reason why I had taken particular notice of the DNAR sheet was firstly, my lack of familiarity with the document and my curiosity in reading it. Secondly, I mentioned that it was an issue that often came up on my rehab course, on the study day addressing ethico-legal issues. It will be interesting to see if there are any further repercussions.

Extract 2:

Reflections on preliminary data analysis

06.08.08

I had been aware, throughout the data collection phase and beyond that I constantly thought about what was happening; about what people had said and the things I had observed. Many of these reflections were recorded in my field notes, then research journal and had triggered further observations, questioning; even theory testing. For example, early on in the study, a theme of **humour** started to emerge; often described as 'having a laugh' or 'banter' between the nurses, patients and relatives. This was of particular interest, as the study focused on nurse-patient relationships (interactions) and the ways in which nurses responded to the emotional impact of the stroke on the person. In response to these early musings, I started to search the literature on humour in nursing and collect together a body of papers. I also started to ask questions about the importance of humour – sometimes directly but often indirectly; e.g. "What sorts of things help patients to get through their time on the ward?" Each time someone mentioned humour, it reinforced my belief of the importance of this. In addition, my general observations regarding the ward atmosphere and the ways in which the staff related to one another (and me (collegial emotional labour?), as well as the patients and relatives also reinforced this. There were also similarities emerging with issues identified in the existing literature.

However, I was also very conscious that accepting and pursuing this ‘theme’ might have blinded me or distracted me from pursing other alternative explanations. Was I just seeing what I wanted to see? Was I ignoring observations and descriptions which did not conform to this emerging theme? The case of Norman is important in this respect because humour was of absolutely no therapeutic benefit to him; indeed, he considered attempts at light hearted banter and jokes on behalf of the staff as ‘tormenting’.

Nevertheless, this approach was not used indiscriminately and staff interviews revealed that care was exercised with the approach taken with different patients (sometimes); based on an assessment of each situation. This further led me to think about the use of emotional intelligence by the nursing staff and how they used this skill to judge the emotional tenor of a situation before deciding on the most appropriate approach to take with the patient or relative. Again, a body of literature relating to emotional intelligence was collected. Furthermore, another theme which appeared to be closely connected is the personal characteristics of the staff – how important was personality? Several staff had explained their approach to patients as being: “that’s just the way I am”.

In addition, another theme which was emerging was patients’ descriptions of the nurses. They would describe the nurses as ‘brilliant’ and ‘wonderful’. I started to explore this from the outset – after the first interview and asked nurses what they thought it meant and asked the patients to explain if they used such phrases. I started to make connections with artefacts such as ‘thank-you’ cards and look at the words used by ‘grateful’ relatives. Some of these resonated with descriptions provided in interviews and conversations; e.g. ‘Thank-you for all the love, care, jokes and banter’. Even more literature was accumulated around the theme of caring – how this was demonstrated and interpreted by nurses patients and relatives.

Suddenly – as I was writing this and thinking about all the different avenues my reflections had been taking me, I burst out laughing. Behind me (I’m writing this at home in the attic which serves as my work space) are rows of magazine files filled with papers. They are all labelled with the theme of the literature they contain. Most relate to methodological issues but some are clearly themes relating to the preliminary analysis described above; i.e. caring, nurse-patient relationships, humour, ward atmosphere/therapeutic environment, emotional labour/emotional intelligence. I must have been doing this preliminary analysis all along but had just not recognised it as a discrete research activity!!! This is evidence of the clearly iterative process involved in data analysis per se; the constant movement within the data, emersion in them to find clues, connections and understanding.

Extract 3:

Examples of unsuccessful attempts at recruitment

06.07.07

I had decided not to try and recruit anyone else into the study during June, since the last two participants left hospital. Anyway, last week, I went up to the ward on Monday June 25th, to alert staff that I was now looking for another participant. There was no-one who immediately sprung to mind at that point so I decided to leave it a few days and call back at the end of the week. There were some admissions due. On Friday, the 29th, I returned to the ward and it was suggested that a Mrs B might be a suitable candidate. I asked one of the staff nurses who was working over the weekend, if she could have a word with the patient and ask whether she would be interested in participating. I went back on Sunday afternoon (July 1st) but the staff nurse had forgotten all about it. The ward manager was on duty so I asked her if she could ask the patient; as she was on duty for the coming week. She said that she would and wrote a note to herself in the ward diary. Once again I returned, on Tuesday pm (3rd). The ward manager was in a meeting so I left her a note in the diary, asking her to speak with the patient and said that I would be returning to the ward on Wednesday afternoon (4th).

When I returned, it transpired that another staff nurse had actually been to speak to the patient concerned and she had been agreeable. The patient was in a therapy group at the time of my visiting so I waited until she came out. When she was settled at her bedside, I introduced myself. She knew what it was I had come to speak to her about but I could see that she was tired so I arranged to return tomorrow afternoon, when her husband was visiting. All I knew about the lady at this point was that she had originally been taken to another hospital for assessment for thrombolysis but for some reason, it had not been administered and she was transferred to the stroke unit. In the short space of time I spoke with Mrs B, she informed me that she had been offered thrombolysis but the family had decided against it when they had been informed that there was a chance that she might have a bleed. It was a difficult decision but that's the one they made. Mrs B had subsequently spent 4 weeks on a ward at the other hospital, before being transferred to this one.

When I arrived at the ward yesterday afternoon (Thursday, the 5th), Mrs B was sitting at her bedside so I approached her, armed with the patient information booklet. She said that she was very tired, as a gentleman in the next bay had been shouting all night and keeping her awake. She had also had a short therapy session. I asked if she was alright to go through the information and she agreed. I sat down next to her and placed the booklet in front of her, again informing her that it was laid out in a format that should be easy to understand and read – she has a left visual field deficit, affecting the outer quadrant of her left eye. We had just started to look at the booklet when her husband arrived.

When I explained who I was, Mr B pulled out some papers and asked if I was anything to do with another research study that his wife had been approached to participate in. The study turned out to be the palliative care study which I know about I explained that it was not. I also explained that I had just started to go through the information booklet with Mrs B. He agreed to listen, although I told him that I would give him a booklet of his own. I had just completed the first page when Mrs B said that she couldn't read it now. She was too tired and could not concentrate. I stopped the explanation there and then and said that I appreciated that she was tired and I would arrange to come back again. I asked when a good time would be for her and she said the morning. I asked if I could come back this morning (Friday, 6th) at 10.00am. She tentatively agreed. I left the booklet with her but said that I did not expect her to look at it until I returned. I went to get Mr B's booklet but when I returned to Mrs B's bedside, she was crying. I asked if she wanted to lie down but she said not. I took my leave and informed one of the health care assistants that Mrs B was very tired and tearful but had not wanted to lie down. I thought that I should draw the staff's attention to Mrs B's tiredness, as she had said that when she gets really tired, it makes her feel sick. I am going in to see her this morning but if she is unable or unwilling to talk, then I will not return until next week. I was told by the staff nurse who first approached her on my behalf, that Mrs B liked to talk but I have not been given this impression by the patient herself. She did say that she was happy to do anything to help other people and that this appeared to be her primary reason for agreeing to take part in the study.

Well, I'm not having much luck! I arrived on the ward at around 10.00am and when I entered the bay where Mrs B is, I could see that she was yawning. I greeted her and asked how she was feeling. She had slept better during the night but was still very tired. She said that she had not been able to look at the booklet I brought in and that she was missing words when she tried to read. I did not attempt to engage her further and said that I could see that this was not a good time to talk about the study. Mrs B said that she had asked her husband to read the booklet and explain it to her and that this might be the best way. In respect of this, I suggested that I should call back at the week-end, when her husband is visiting. I checked whether other family would be visiting and she said that her daughter was coming today and possibly tomorrow. She has two young children so cannot visit very often. We agreed that I would return on Sunday afternoon.

After my brief encounter with Mrs B, I decided to leave the ward, as there was really nothing else I could do. Walking home, I started to think about the problem of Mrs B's fatigue and reflected that I had encountered fatigue in other study participant. It is not surprising but should be addressed as a significant factor when recounting the experience of recruiting and involving participants.

08.07.07

I returned to the stroke unit at 4.00pm this afternoon, as agreed. When I walked into Mrs B's bay, she had a female visitor who was standing in front of her. She looked as though she was just leaving (had a coat on and carrying a bag) so I did not intrude. When I returned about ten minutes later, the visitor was still standing and talking with Mrs B so I decided to approach anyway. I greeted Mrs B and straight away, she told me that she was still very tired and that her husband had gone through the booklet and explained it to her, following which, she decided that it would be too much for her – too many hours (the periods of observation). Besides, she thinks that she will be going home very soon. Her visitor (daughter?) reinforced Mrs B's decision and I told her that it was OK. I thanked her for considering participating in the study and wished her all the best with her recovery. I mentioned Mrs B's decision to Claire, one of the staff nurses (and research nurse) and she asked if it was the first time I had been turned down. I said that it was and in consequence of Mrs B’s decision, I was on the look out for another suitable participant. Claire said that a new gentleman has just transferred on to the ward. He had a communication impairment but she thought that he had good comprehension. I asked her if she would approach him for me and that I would return on Tuesday, after a meeting I had in the hospital.

On the way home, I felt really deflated. I felt that I had invested a lot of time and effort in trying to recruit this new participant but had been delayed by staff ‘forgetting’ to speak to the patient and then by the patient herself, through her fatigue. Whilst I was walking up to the hospital, I did speculate whether this was not going to be successful. I did not have a very positive feeling about it and Mrs B had been evasive. Still, she is obviously very tired and is having to deal with a great deal of change at present. I fully understand her explanation that involvement in the study might be too much for her. Nevertheless, Claire had suggested another patient and I have this to consider now. I need to print off and bind two more information booklets, as I left the others with Mr and Mrs B. I did not feel that it was appropriate to ask for them back, when she had made her decision.

29.08.07

Julie asked about who I was looking to recruit and when I told her about Mrs K she did not think that this was a particularly good idea, because of all the lady’s problems. She suggested someone else; a gentleman, Mr N. I said that I would come back tomorrow and sit in on the afternoon handover.

I did just that and entered the handover shortly after it had started. I sat through the information about the female patients, including Mrs K. Following this, I listened to the report relating to the gentleman. There was a suggestion that Mr N denied that there was anything wrong with him and that he was very impulsive. When the handover finished, I asked to speak to the OT who was there and asked whether Mr N had been assessed regarding his cognitive and perceptual status. She said that he had no obvious executive problems and that his ‘denial’ and impetuosity were probably just related to his personality. I decided that I would try to speak to him.

Julie said that she would ask him if he was interested in talking to me and she did. He said that it would be OK so I approached him. He is a tall and well-built gentleman, who, because of the warm weather, is walking around in shorts and nothing else. He has a very hairy chest and a bushy beard and wondered whether his appearance might be distracting when I spoke to him. Anyway, I approached him and introduced myself. Straight away, he said that he was not emotional about his stroke. I tried to explain that the study was really concerned with his feelings following the stroke but he insisted that the only thing wrong was that his leg was affected. I tried to explain further, saying that 'feelings' included his feelings about being in hospital and having had the stroke. He explained that his mother had had a stroke, which she 'never got over' and that he was, therefore, expecting it. His feelings about being in hospital were quite clear; he did not want to be here and expected to go home soon. When I also tried to explain that the study was interested in finding out the relationship between the nurses and the patient's experience of stroke, he said that he did not have a relationship with the nurses: They just got on with their work and he did not relate to them. He did not have or make friends and had always been a loner. He said that he did not 'care' about his stroke but then amended this to say that he didn't actually mean 'care'. I suggested that he might mean that he was not concerned about the stroke and he agreed that this is what he meant. I reiterated that he did not have to make a decision now about whether or not to participate but he said that he did not see what further there was to say. I thanked him for his time and wished him well; explaining that he would see me around the ward but that I would not bother him.

02.01.08

My latest participant was discharged home on Thursday, December 20th. On the day before this, I visited him on the ward and asked the staff if there were any other patients they could recommend. A couple of the nurses suggested a Mrs D, who has a speech and language difficulty. I went to introduce myself to her and recognised immediately that her communication problem was quite severe but she did appear to be able to understand what I was saying. I arranged to visit her again after the weekend. On this occasion, I took along a copy of the patient information booklet and asked if I could go through it with her. However, after only a short time, it became evident that she could not read the information and that she also did not really follow what I was trying to tell her. Her speech is limited but we did manage to agree that this was perhaps not going to work. I tried to explain that it would not be right for me to continue, if it was unclear whether she understood what was being asked of her and she agreed. I said that I would come back and speak with her whenever I visited the ward and that as time went on, we would look again at her participation.

Much of this conversation was carried out with simple sentences and one word answers from Mrs D. She did understand when I came to the part of the information booklet that stated that I wanted to know what it was like to have had a stroke. She used the words ‘terrible’ and ‘awful’ and she shook her head slowly. She also appeared to be sad and her eyes became moist. I decided that I was causing her distress talking about this and realised that it was unfair of me to continue in this way. I found it particularly difficult to talk to her about possibly revisiting her participation in the future because I did not want to promote false hope by saying that her speech would improve; whilst not wanting to undermine her hope that it would. The phrase’ we’ll wait and see’ sprang to mind – stated with a smile to convey optimism.

I was actually quite upset by this encounter and found myself feeling annoyed with the staff nurses who had suggested that Mrs D might be a good candidate. One of the nurses had said that her speech was not bad and that although she sometimes used the wrong words, she could understand what was being said to her. This was evidently not the case and I had risked causing Mrs D additional distress by drawing attention to her difficulties and even ‘rejecting’ her as a participant because her speech an verbal comprehension were too poor. I won’t abandon her though and perhaps I will ask the SLT for advice before proceeding. In the meantime, I will seek to recruit someone else.

Extract 4:

Reflections on the recruitment, selection and engagement of participants

30.08.11

“They’ll be a good one for you”:

I had anticipated that there would be no difficulty in identifying potential participants for the study but I was apprehensive about leaving the selection to the senior nurses and did wonder how they would decide who to recommend. Indeed, they did all appear to apply different criteria. The first three were selected by the Ward Manager and In recommending Celia as the first participant, she actually said that she had deliberately chosen her because she was “articulate and agreeable” and would be easy to talk to; and it was certainly helpful in building my confidence to start with her. Then, because I had reiterated that I was happy to involve people with aphasia, when Gavin was suggested, as a person with a severe communication difficulty, I was keen to involve him; but did question myself as to whether this was because I had spent so much time developing the emotion cards and other Talking Mats™ materials. Lily was so easy to get along with and her daughters were equally enthusiastic to engage with the study

However, the next two participants were selected by a nurse who appeared to put a different slant on things; they were both relatively young, in their 40’s and Fred was recommended because of his very close relationship with his wife, who was experiencing difficulties managing in Fred’s absence. Sid on the other hand was identified as “a good one” for me because at 47 years of age, it was reported that he thought he had nothing to live for.

Ingrid was new to the ward and described as "a good participant for the study because she used to be very independent and is rather bored at present", Helen had been admitted only two days before I met her and June had also been on the ward for just a few days. However, there was some question as to whether or not June had cognitive problems and it was suggested that I talk to the OT first. The nurse described her as rather eccentric. Norman was suggested as being “another good one” for me because he had experienced has “a devastating stroke but is all there”. He was also depressed. Iris had only recently been transferred from another ward.

Intrigued by some of the comments about the rationale for patient section, I asked this question in the interview with the Stroke Nurse Specialist, who had recommended some of the participants. She said that she had tended to look for people that she thought would have:

> “issues and problems; not someone that's just sailing through, recovering nicely, or dealing with things…someone that I can see is really struggling”

The way she looked at it was:

> “…you would probably get more from that because of the things they were going through, they would give you more insight”.

In addition:

> “…you're just listening. Well, I just assumed that obviously, you were just talking, listening and they would, if you like, offload all their baggage, problems to you”.

She continued that if a patient said that they were alright:

> “then there wouldn't be anything juicy, if you like, for you to get your teeth into”….”If I've met someone that I know is going to be very private and not want to share anything and I'm struggling to get things out of them, then I wouldn't bother referring them to you, because they're probably going to say 'No, I'm not bothered thanks'…Because to me, there wouldn't be any benefit for you to do all this because we're really looking, aren't we, to get any answers…to give us a better insight into 'can we do this better, what have we done, was that right?'”
> **Julie (nur.8)**

Based on this information, it is difficult to assess whether the participants were representative of the patient population as a whole and it can only be surmised that if at one end of the spectrum are those who feel that they are “just sailing through” and at the other, those who did not meet criteria for inclusion because of the severity of their strokes; then the participants represented something of a middle range.

Timing of interviews with patient participants:

The interviews with all patient participants did not take place until some time after the stroke, when plans for his discharge home were already underway. The point at which I joined the participants in their stroke journey varied between 4 and 45 days post-stroke. Although not an issue often acknowledged as significant by researchers of the stroke experience, this contextual element should be considered, as it could have a bearing on the nature of the information shared and on the participant-researcher relationship. As all the interviews took place some time after the participant’s strokes had occurred, their narratives and recall of events, thoughts and feelings might have been influenced by subsequent conversations with others involved in their journey; filling in gaps and framing explanations. It is likely that reflecting upon what happened, to try and make sense of it, would also inform the narratives.

The focus for the interviews with the aphasic participants:

Gavin and Fred both had severe communication impairments and although in my interactions with them on a day-to-day basis was similar to those with other participants; i.e. general conversations about their lives, interests, families etc., the formal interviews with them were very structured, restricted in scope and focused specifically on their emotional response to the stroke rather than their broader experiences of the stroke event and their rehabilitation. This latter information was provided by their partners. The use of the emotion cards was helpful, if not an essential strategy, given the degree of their communication impairments and although these had been developed in keeping with recommended principles, I was unsure of whether the range of emotions depicted were truly representative of the those which the participants might have experienced. I did ask both Gavin and Fred for feedback on the use of the cards and they affirmed that they were useful; and Gavin actually assisted me in naming a couple of the new cards which I had added to the collection, when I was uncertain as to whether our interpretations of their meaning would concur. Fortunately, they did.

Interestingly, Dewar *et al* (2009) suggest that people generally do not have a rich emotional vocabulary and that providing them with emotion words/cards can enable them to describe more accurately feelings relating to their experiences. In retrospect, I wondered whether it might have been helpful to have offered to use the cards to other participants as well.

Dewar, B *et al* (2009) Use of emotional touchpoints as a method of tapping into the experience of receiving compassionate care in a hospital setting. Journal of Research in Nursing, 15(1), 29-41.

Difficulties with engaging relatives in the study

During the course of the study, there were only two patient participants whose relatives I managed to spend time with; Lily's daughters, who both agreed to be interviewed and Thelma, Fred's wife. However, my interview with Thlema did not take place. She spent a great deal of time on the ward and was happy to talk to me and we had agreed on a date for an interview; but the opportunity was lost because of the events which transpired and culminated in Fred being readmitted to the stroke unit after his 'traumatic' transfer to the neurorehabilitation unit. After that point, Thelma became less willing to spend time away from Fred and, indeed, often took him off the ward when visiting. She remaining friendly and approachable but it did not feel right to intrude further.

In general, I found relatives difficult to involve and speculated about the reasons for this as follows:

- The length of visiting period – if relatives were only able to visit for short periods of time, then I would not intrude; on the grounds that I believed that it was more important for their attention to be taken by the person they were visiting and not by me. If they were accompanied by children or other family members, it was inappropriate to ask to speak to them on their own.

- The point in the patient's journey – I recall that conversations generally were easier to initiate and sustain once the patient was being prepared for discharge. In general, they were happier and more relaxed (although not always).

- Perceptions of relatives' wellbeing – I would like to think that I am sensitive to how people are feeling; picking up clues from their verbal and non-verbal communications; so if I perceived that they were anxious or distressed and clearly did not want to be distracted from the person visiting, then again, I did not intrude. However, I did try to demonstrate my understanding for their situation.

- My general discomfort and feelings of intrusiveness at a potentially very difficult time; as indicated above. These feelings resulted in my reluctance to be as persistent with relatives as I had occasionally been with the patients recruited into the study.

- Relatives' disinterest/reluctance to engage in conversation about the study – after initial introductions and explanations about what I was doing, it was usually obvious whether or not the relatives were sufficiently interested to participate. I did give out a few information booklets but that was as far as it went. They often commented that they knew about me and were pleased that their relative had someone to talk to; but this did not extend to them.

- I was an outsider and not a member of the health care team; therefore, I was of little value to relatives. There was clearly no perceived benefit in talking to me; evidenced in the comment made by someone once in response to asking me if I was in charge of the ward. When I replied that I wasn't, they dismissed me by saying that in that case, I was of no use to them.

Key informants – the nurses who had a tale to tell

Regarding the selection of key informants; I was thinking this morning about how I decided who to focus on and the criteria which I applied in requesting interviews with the nurses. I have reflected elsewhere on how some nurses and support workers were more approachable and accessible than others. Some were naturally (?) reticent and did not ask questions or offer information. I am certain that at some point, I will have spoken with everyone; but there were definitely those who were less visible in my fieldnotes. Some worked part-time, on specific shifts or days; or only on night duty. Therefore, those nurses who I encountered most frequently were naturally the ones present at the same time as I was. Nevertheless, I did select only about half of their number to interview. Again, as already indicated as a methodological issue, identifying mutually agreeable times to interview nurses was not easy and there were numerous occasions when interviews were cancelled, forgotten or just did not take place.

However, there was still one question to be answered and that is exactly why did I choose to focus on these nurses rather than others? Then it struck me, as many blindingly obvious things do eventually; my selection of key informants was based on similar criteria to those used by the staff to select patients for me. They had a story to tell and would be prepared to tell it. They had insights and experiences to share. They were talkative and friendly. In some ways, they were almost self-selecting; as they asked me questions or volunteered views, opinions and information without my asking. This reflects one of the challenges for me in articulating the methodological processes; I was not always aware of the processes taking place because they were just ‘usual’ ways of interacting with colleagues. It would be normal, during the course of a working day to offer information to others, exchange information, seek views, ask questions; and discuss problematic or contentious issues. The media for these interactions were exclusively verbal; handovers, chats in corridors and work spaces, team meetings etc. None or little of it would be recorded unless there was a specific reason for doing so. The nurses who communicated with me did so because it was a normal thing to do. Once we had established a rapport and any sense of threat had been dispelled or abated, then they would chat to me in much the same way as they did to each other. I was not excluded from group conversations and, indeed; there were a small number of occasions when individuals took me into their confidence.

Appendix 7: Interview topic guides

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Interview topic guide

In-depth interviews will be linked to issues raised during periods of observation and ensuing discussions but it is anticipated that the interviews will explore the following broad topics:

Patients:

- The experience of having a stroke – what happened
- How they feel about what has happened to them
- Who they are able to express their feelings with, when and how
- What it is that helps – what is important
- How it helps
- Any concerns or difficulties experienced in expressing their feelings and having their emotional needs addressed

Relatives:

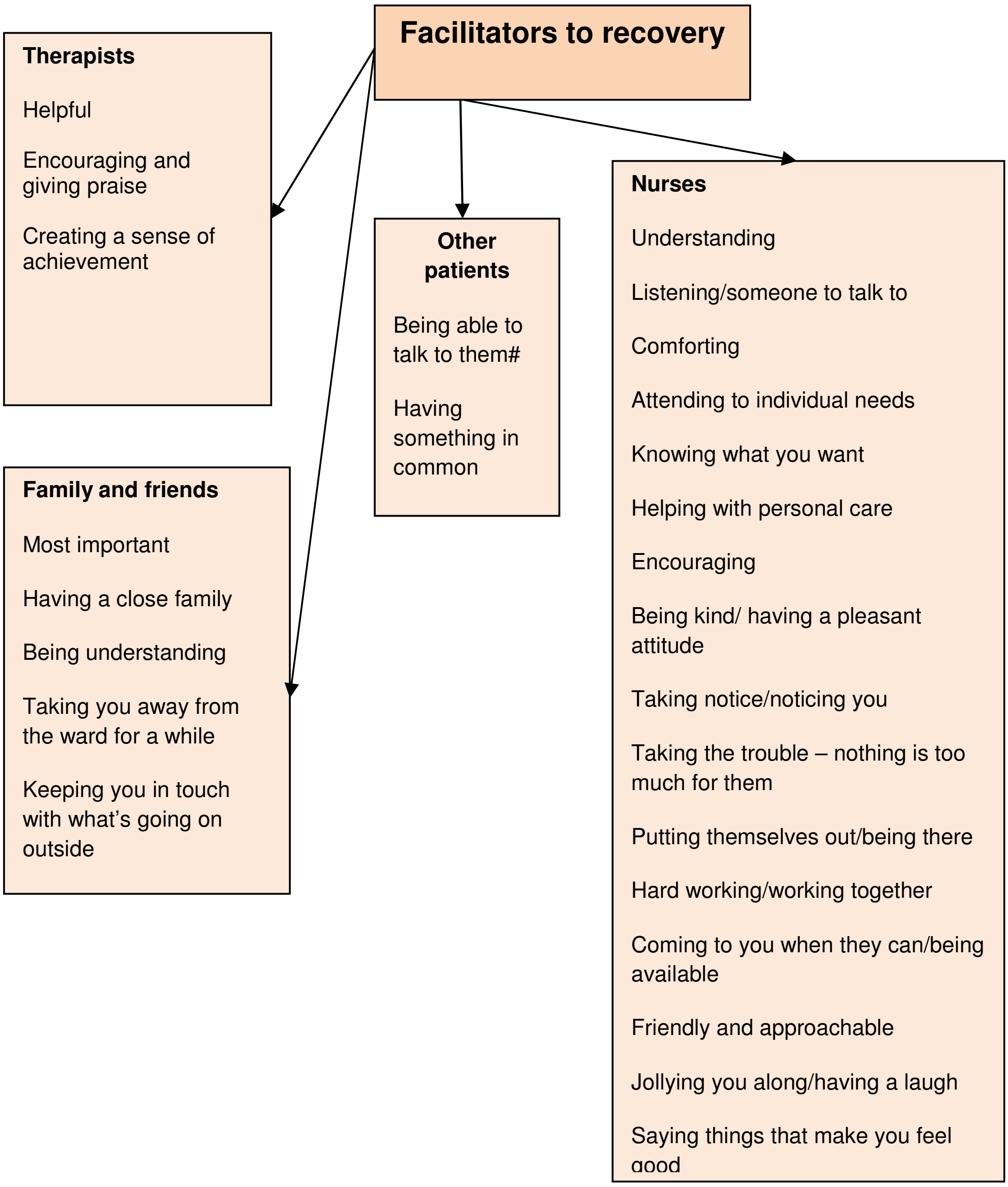
- Their perceptions of their relative's experience of a stroke and how they themselves have been affected by this
- How they feel about what has happened to their relative and to themselves
- Who they are able to express their feelings with, when and how
- What it is that helps – what's important
- How it helps
- Any concerns or difficulties experienced in expressing their feelings and having their emotional needs addressed

Nurses:

- The experience of having a stroke – what they understand about its effects on a person and their relatives
- What they think the patient and their relatives feel about the stroke and its effects
- How they themselves feel about it
- With whom a person affected by a stroke and their relatives are able to express their feelings, when and how
- What is it that helps – what's important
- How it helps
- Any difficulties they may face in enabling patients and relatives to express their feelings and in addressing perceived emotional needs

Appendix 8: Additional concept maps relating to patients' and relatives perceptions of recovery

8a: Patients' perceptions of facilitators to recovery and sources of support



Facilitators to recovery

Therapists

- Helpful
- Encouraging and giving praise
- Creating a sense of achievement

Other patients

- Being able to talk to them#
- Having something in common

Nurses

- Understanding
- Listening/someone to talk to
- Comforting
- Attending to individual needs
- Knowing what you want
- Helping with personal care
- Encouraging
- Being kind/ having a pleasant attitude
- Taking notice/noticing you
- Taking the trouble – nothing is too much for them
- Putting themselves out/being there
- Hard working/working together
- Coming to you when they can/being available
- Friendly and approachable
- Jollying you along/having a laugh
- Saying things that make you feel good

Family and friends

- Most important
- Having a close family
- Being understanding
- Taking you away from the ward for a while
- Keeping you in touch with what's going on outside

8b: Patients' perceptions of challenges to recovery

Challenges to recovery

Being separated from family and friends

- Missing home and friends
- Wanting to be at home
- Family not being able to visit

Negative emotions

- Feeling low and negative
- Changeable emotional state
- Can't see a way forward

Tiredness and physical discomfort

- Tiredness resulting from activity
- Tiredness preventing activity
- Discomfort due to being sat out for long periods

The ward environment and other patients

- Noisy and disturbing patients
- Not sleep and having sleep disturbed by other patients
- Noisy visitors – too many of them
- Noisy televisions
- Other patients being so ill and dependent – creating a morbid atmosphere

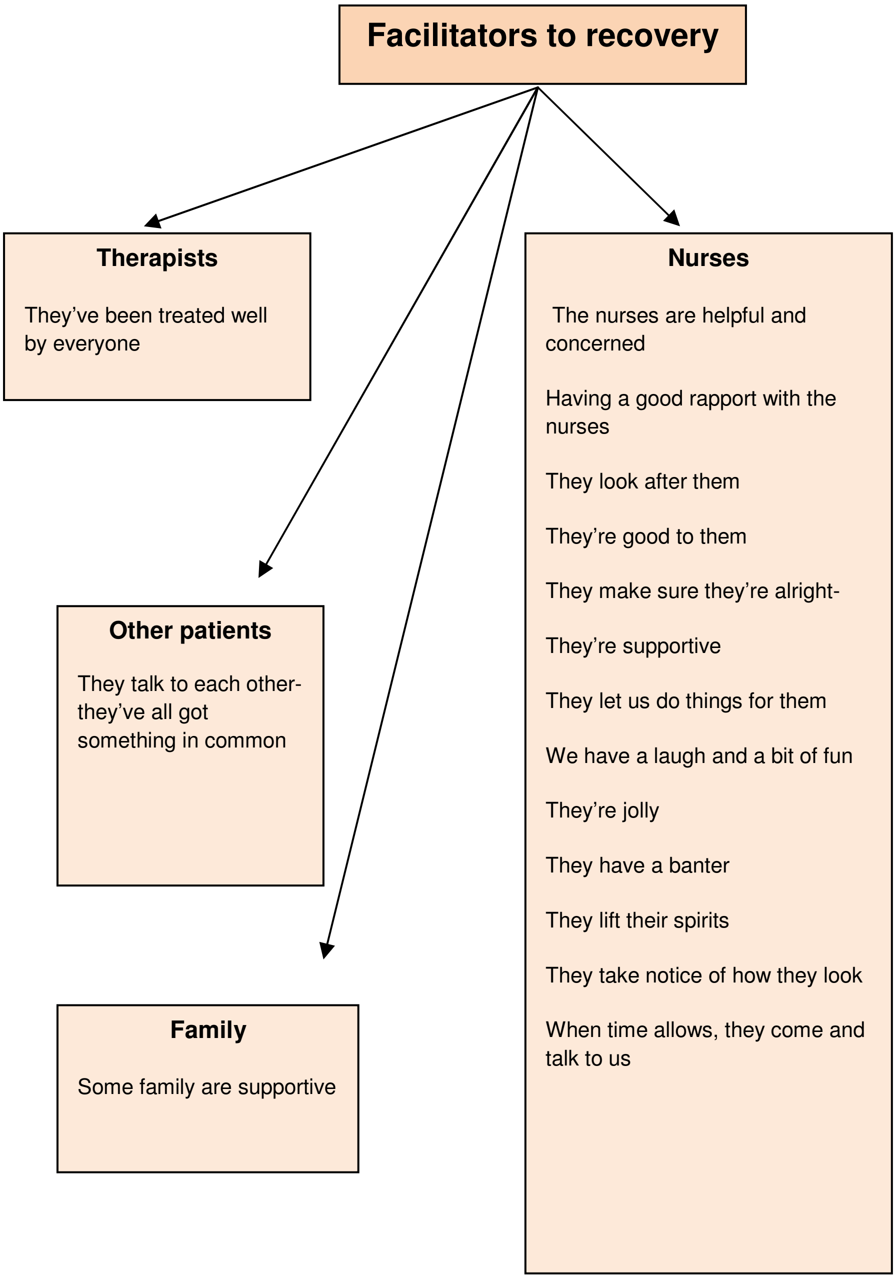
Wanting more therapy input

- Not getting enough therapy
- Not getting enough help to mobilise
- Making slow progress
- Conflict of priorities with therapists

Boredom and frustration

- Having nothing to do and doing nothing
- Spending too much time thinking
- Frustrated at slow recovery
- Frustrated at not being able to communicate effectively
- Being impatient

8c: Relatives' perceptions of facilitators to recovery



Facilitators to recovery

Therapists

They've been treated well by everyone

Other patients

They talk to each other- they've all got something in common

Family

Some family are supportive

Nurses

The nurses are helpful and concerned

Having a good rapport with the nurses

They look after them

They're good to them

They make sure they're alright-

They're supportive

They let us do things for them

We have a laugh and a bit of fun

They're jolly

They have a banter

They lift their spirits

They take notice of how they look

When time allows, they come and talk to us

8d: Relatives' perceptions of challenges to recovery

Challenges to recovery

The patient's physical and mental wellbeing

Nurses not responding to requests to put the patient back to bed when they're tired - this is uncaring

Worrying that they won't recover

Thinking that they're not improving

Thinking that they're deteriorating

Thinking that they're not getting enough therapy

Worrying about their emotional wellbeing and state of mind

Other patients' behaviours or conditions upset them

They're frustrated at not being able to communicate

Their personality has changed

The nurses don't seem to be as concerned about their physical wellbeing as I am – they don't seem to notice the things that I notice

Their own physical and mental wellbeing

Not knowing if you should be doing anything to help feeling apprehensive about being pushy (offering assistance)

Thinking that the nurses aren't doing enough to help (even though you really know that they are)

Not being able to do anything to help (feeling powerless)

Being worried about leaving them alone

Not being listened to; having to keeping telling them – (trying to share knowledge of the patient's usual health)

Being worried about being able to carry on

Not knowing what else to do with myself if I didn't visit (we did everything together)

Having to visit because no-one else does

Some family are unsupportive and not helpful

Needing support too; feeling very alone

Not sleeping and feeling exhausted

Visiting every day is very tiring – it's hard work

They take their anger and frustration out on me

8e: Norman, the atypical case

Core belief

I'm a poorly man

Personal attributes

Pessimism

Depression

Hopelessness

Self-pity

Helplessness

Facilitators of recovery:

Being helped and cared for

Having the company and comfort of family

Resting and staying in bed

Not sitting out for long periods

Having help to dress and having other things done for me

Being fed

Just being loved and cared for

Being able to stay in close touch with family

Having people realise that I am ill

Being paid attention

Challenges to recovery:

Unkind and uncaring nurses who won't spend time with me

Family being discouraged from helping with my care needs

Not understanding or accepting the reason for therapy actions/activities

Being made to get up and sit in a chair for long periods

Not being able to go back to bed when I want

Not being able to walk

Therapists not doing enough to help me walk

Not being able to do things and having to ask for help

Feeling forsaken and abandoned by family

Family not visiting for long enough and not prioritising my needs over theirs

Having to rely on strangers for company

Being in turmoil

Wanting to die

Hurtful use of humour – 'tormenting'

Being always close to tears

Not being able to smile

Feeling very low and frustrated

Feeling that everything's gone

Not being able to see the point

Not being able to concentrate

Having blank days when my mind wanders