

**DYING FROM ACUTE STROKE:  
ORCHESTRATING AN AUTOETHNOGRAPHIC SONATA OF CARE**

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## ABSTRACT

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This autoethnographic study draws together the experiences of the researcher and bereaved family members of patients who died in hospital following an acute stroke. It takes the form of a Sonata Framework that mirrors the author's narrative around the duration and onset of his mother's stroke, hospital care and ultimate discharge home to die. Although symptoms experienced by individuals with malignant and non-malignant disease are similar, evidence suggests the transition from acute to palliative care remains problematic for patients following an acute stroke, not least when seeking to identify when someone is nearing end of life.

A qualitative interview study aimed to explore the personal experiences of family members whose relative had died following admission to an acute stroke ward. In order to do this, six adult relatives of patients who died in hospital following an acute stroke were interviewed using a semi-structured interview schedule. Data were inductively analysed to produce basic, organising and global themes, and presented in the form of thematic networks: The Family Experience and Dying & Death. Further findings were deductively derived through the lens of the Sonata Framework.

Findings suggested shortfalls in the provision of palliative and end of life care following acute stroke, although areas of good practice were identified. Overall, participants were complimentary of the care provided to their family member although the transition from acute to palliative was variable. The quality of communication between patients, relatives and staff was patchy, with no evidence of engagement with the hospital palliative care team, nor any discussions instigated by staff relating to preferred place of death.

This study provided evidence of some improvement in local palliative and end of life care provision when compared with previous research, although gaps in such provision still exist. Staff should receive palliative and end of life care training, including communication skills training to identify individuals who may be nearing the end of life and to instigate timely conversations with their family members. Further research relating to the provision of palliative and end of life care for individuals following an acute stroke is recommended.

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## GLOSSARY OF TERMS

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**End of life care** (EofLC) is care that helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support (National Council for Palliative Care (NCPC) 2011).

**Family** – a group of people related by blood, marriage or a strong bond and important to the dying person. For the purpose of this study, family members are defined as people 'important to the dying person'.

**Gold Standards Framework (GSF) (2015)** is a systematic, evidence-based approach to optimising care for all patients approaching the end of life, delivered by generalist frontline care providers.

**Palliative care** (PC) relates to an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation (WHO) 2019).

**Stroke** is an abrupt onset of a focal neurological deficit secondary to a vascular event lasting more than 24 hours. It is also called cerebrovascular accident (CVA) or apoplexy. Stroke is the fourth most common cause of death occurring approximately 152,000 times a year in the United Kingdom (UK) amongst 1:6 men and 1:5 women (Stroke Association, 2017a). Acute stroke refers to the first 24-hour-period of a stroke event and is classified as either ischaemic (caused by thrombosis or embolism) or haemorrhagic (caused mainly by rupture of blood vessel or aneurysm) (WHO 2016). An acute stroke starts suddenly and tends to worsen rapidly. The acute phase is defined as the first 30 days after stroke, during which nearly one-third of patients will die (Roberts and Goldacre, 2003).

**SWAN** – an Individual Care Pathway (ICP) aimed to comfort patients and relatives in the last few days of life, part of which enables bereaved relatives to have keepsakes given such as locks of hair, handprints and photographs. The trust utilises the SWAN individual care pathway documentation as part of its provision for palliative and end of life care in conjunction with the introduction of the GSF (2015) across the site.

## ACKNOWLEDGMENTS

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Nelson Mandella (1918 - 2013) once declared, "*It always seems impossible until it's done,*" and there were certainly times during my doctoral journey when I feared this thesis would never be completed. The advice from others suggested I give up everything other than paid work whilst others questioned the purpose when it was unlikely to enhance my salary. I recoiled at the thought of failure and despite reducing a significant amount of that which I had previously done, I tried to maintain an element of normality, even when my head felt as though it was almost submerged. It's been hard and yet, with pure grit and sheer determination, I've come through. The journey's been an enjoyable and illuminating one, but it's been one of tremendous sacrifice too. Sacrificial in terms of time spent; few holidays or social outings, along with a reduced amount of time spent with others. To those individuals who have inspired and encouraged me with their support and enthusiasm over the past seven years I offer my heartfelt thanks. I remain indebted to you for your patience and your understanding.

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Finally, I dedicate this thesis to my late mother, Margaret who, having undergone a potentially life-saving bowel operation in mid-October 2004 suffered a catastrophic stroke on the 5<sup>th</sup> November and died at home just four days later following an acute admission to hospital. As a bereaved son and an experienced palliative care nurse it is time to share my story and I do so alongside the narratives of other relatives known to me only too briefly through my research. I remain indebted to them for their willingness to share such poignant and personal experiences whilst seeking a way through their own grief. *'Music expresses that which cannot be put into words and that which cannot remain silent'* (Victor Hugo, 1802 - 1885). Therefore, as I raise my conductor's baton before the orchestra and gathered audience, let the performance of this sonata of care now begin.

# **CHAPTER 1 – INTRODUCTION TO THE STUDY AND REVIEW OF THE LITERATURE**

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## **Chapter overview**

This chapter sets the scene for this autoethnographic study. I begin by presenting an overview of the study alongside an overview of each chapter. The reader is introduced to my professional, personal and familial experiences of palliative and end of life care following acute stroke. The chapter also offers a background to the context of stroke incidence, financial cost, mortality and care for dying patients. Through a comprehensive critical literature review, I highlight an evolving picture of inequity and gaps in the provision of palliative and end of life care of detriment to those diagnosed with a non-malignant disease, including acute stroke.

## **Overview of the study**

This autoethnographic study shares the story of my mother's untimely death and, through qualitative interviews, explore the palliative and end of life care experiences of family members whose relative had died from acute stroke following admission to an acute stroke ward. It takes the form of a Sonata Framework and draws on both evocative and analytic approaches to autoethnography. The objectives of the qualitative interview study, specific to family members' experiences were:

1. To gain an understanding of the availability, provision and delivery of palliative and end of life care in a stroke ward;
2. To explore thoughts and views about the quality of palliative and end of life care practices;
3. To determine whether palliative and end of life care needs for the patient and family members were met, and
4. To examine the transition from acute to palliative and end of life care within an acute stroke ward.

Although this thesis is structured slightly differently to a traditional thesis, it provides appropriate theoretical and practical direction to the reader and embeds the research within the context of my story, alongside the literature, methodology, data and findings. In this chapter, the study is in the context of professional, personal and familial experiences of palliative and end of life care in stroke provision and care, and the prevailing literature. It also introduces the use of a Sonata Framework which offers structure to the thesis and a framework to consider the narratives of both researcher and participants.

Chapter 2 - This emotive chapter focusses upon my autoethnographic account as a bereaved son and an experienced palliative and end of life care nurse working in a hospice. It considers my key memories as a child and the impact of my maternal grandfather's death following a stroke on both my mother and

me. In addition, it also focusses upon my mother's discharge home from hospital to die which remains at the heart of this research.

Chapter 3 - The implementation of a qualitative study with bereaved relatives is explained and defended in this chapter in the context of the autoethnographic literature. I also discuss, debate and justify the ontological, epistemological and philosophical perspectives borne of my positionality as a bereaved son and an experienced palliative and end of life care nurse. In addition, this chapter details the ethical considerations necessary to carry out a qualitative enquiry, utilising a semi-structured interview schedule as the preferred tool of choice.

Chapter 4 - As the preferred analytical method of choice, Attride-Stirling (2001) provides a two-stage framework which is modified in the context of this research. The first stage of this modified framework includes coding, identifying and conducting thematic networks. Trustworthiness is considered in the context of identifying and addressing researcher bias.

Chapter 5 - Within this section, the background of the participants is considered and the findings from the research are presented as part of the second stage of Attride-Stirling's (2001) analytical framework. The two global themes presented are **The Family Experience** and **Dying & Death**. The

data in the form of participant quotes is presented alongside my own narrative and experiences in the context of a modified Sonata Framework.

Chapter 6 - This chapter provides a discussion of the study findings considered in light of the study objectives based upon the narratives of the researcher and participants, within the context of the literature. It illuminates the existing provision of palliative and end of life care available when someone has suffered an acute stroke.

Chapter 7 - In this final chapter, I draw the Sonata of Care to a conclusion and provide a reflexive summary that draws this study within this thesis to a close. In doing so, I provide evidence of a contemporary, credible, relevant and honest study which demonstrates an original contribution to knowledge in the context of palliative and end of life care in stroke provision.

### **Background to the study**

As an adult son and an experienced senior nurse with over 25 years' experience in palliative and end of life care within the hospice movement, I experienced the death of my mother following admission to hospital with acute stroke in 2004. The modern hospice, founded by Dame Cicely Saunders in 1967 to care for individuals dying from cancer, now seeks to extend its reach; tackle inequalities to widen access; work within communities to build capacity

and resilience for those at the end of life, and empower the hospice sector to be strong, dynamic and responsive (Hospice UK, 2017a). My experiences of the inappropriate active interventions in my mother's dying phase in hospital resulted in me expediting her discharge home one Sunday evening. She died peacefully in her own bed 12 hours later. The professional and organisational obstacles would, I am quite certain, have appeared insurmountable for lay relatives in similar situations. It was clear to me that my mother was dying and as a keen supporter of my work within the hospice I also knew my mother's preferred place of care and death was in her own home. Both professional and personal experiences were the catalyst for this research alongside a desire to share my narrative with others in this autoethnographic study. This autoethnographic research draws together my experiences as the researcher and the bereaved family members of patients cared for within an acute stroke ward.

One in six people world-wide has a stroke in their lifetime (World Stroke Organisation, 2019) and despite advancements in treatment, stroke remains a leading cause of death and disability (Lutz & Green, 2016; Quadri, *et al.*, 2017; Kendall, *et al.*, 2018). Stroke occurs approximately 152,000 times a year in the United Kingdom (UK) (Stroke Association, 2017b) and a five-year survival mirrors that of cancer and heart failure. Although it has been identified that 10% of hospital inpatient consultations seen by palliative care services relate to patients with stroke (Stevens, *et al.*, 2007; Holloway, *et al.*, 2010) studies remain limited. Despite evidence supporting the need for

conversations about dying and death, the frequency of advance care planning has been reported as low, as does referral for palliative care unless an individual has already been placed upon an end of life care plan/pathway (Quardi, *et al.*, 2017).

Approximately 1% of National Health Service (NHS) inpatient episodes in 2010/11 were due to stroke (Stroke Association, 2013) with the average cost per patient being £45,409 in the first 12 months (Stroke Association, 2017a) and aggregate costs being £25.6 billion in the UK per annum. This is expected to rise to £43 billion in 2025 and to £75 billion in 2035 (Stroke Association, 2018). Despite stroke being the fourth largest cause of death in the UK (NHS England, 2019) the provision of palliative and end of life care remains variable across the UK (Harding, 2018).

Palliative care within stroke provision across the world has, to date, been largely restricted to short periods of care for dying patients with no integrated provision within stroke care. Yet, despite the potential benefits of a palliative care approach, patients and relatives continue to experience anxiety and decreased self-worth and feel they lack information (Steigleder, Kollmar and Ostgathe, 2019).

Caring for those nearing the end of life who have invariably been told, *'there's nothing more to be done'*, has traditionally been the expertise and business of hospices. In turn, the hospice movement has focussed upon the care and symptom management of those with cancer (World Health Organisation, 2004), to the detriment of those suffering from a non-malignant disease, including stroke. However, access to services along with the variability in provision of palliative and end of life care is inconsistent (Etkind, *et al.*, 2017) and often dependent upon not only an individual's diagnosis but their location. Unfortunately, those with a non-cancer diagnosis tend to have less access to palliative care and a poorer experience when nearing the end of life (Care Quality Commission, 2016). This is despite developments since the launch of the End of Life Care Strategy published by the Department of Health (DH) in 2008 and more recent achievements (National Council for Palliative Care (NCPC) 2015).

More is evidently required to ensure everyone receives high quality end of life care because groups of individuals are still being disadvantaged (Keogh, 2017). In 2015, palliative care in the UK was ranked as the best in the world in the Quality of Death Index of 80 countries (National Council for Palliative Care, 2015) although it topped the first publication produced in 2010. Yet, many health care professionals report receiving little if any training in this area (Ford, 2014; Dobson, 2017) with further education in communication skills for health care staff being highlighted (Steigleder, Kollmar and Ostgathe, 2019). The Royal College of Nursing (RCN) reported that patients were dying without



the dignity they deserved due to the limited numbers of staff with appropriate knowledge and skills to care for them (RCN, 2017).

Patients experiencing an acute stroke have been identified as having a high prevalence of palliative care needs (Burton, *et al.*, 2010; Steigleder, Kollmar and Ostgathe, 2019) and in parts of the UK such care has been adopted as key components of specialist stroke care (Gardiner, *et al.*, 2013; Steigleder, Kollmar and Ostgathe, 2019). The most common symptoms experienced by patients following a stroke are mirrored by other life limiting conditions requiring palliative care (Payne, *et al.*, 2010; Steigleder, Kollmar and Ostgathe, 2019). Therefore, it is evident equity of provision is still required between malignant and non-malignant diseases (Marie Curie, 2014).

In a study undertaken by Payne, *et al.*, (2010) within the stroke environment, no patient or family member reported requesting the initiation of palliative care and none recalled being offered the opportunity to take their loved one home. Burton and Payne (2012) determined that staff views, education and training, and communication skills supported by partnership collaboration are the basis for integrating palliative care and stroke care. Indeed, Payne, *et al.*, (2010) suggested specialist stroke services increased their expertise in delivering general palliative care, perhaps by appointing an advocate for championing these skills within the team.

Despite some evidence of good practice relating to the provision of palliative and end of life care amongst patients experiencing a stroke (Donnelly, 2014) equity remains variable with a postcode lottery evident across the UK. Whilst dying is a natural process and the provision of high-quality palliative and end of life care being essential (Quadri, *et al.*, 2018) and a priority (National Palliative and End of Life Care Partnership (NPELCP), 2015), there is little detail about how such care should be integrated into stroke care (Kendall, *et al.*, 2018; Steigleder, Kollmar and Ostgathe, 2019). Predicting when palliative and end of life care should be implemented amongst non-malignant diseases, including stroke, has been identified as problematic (Nunn, 2014) which could have been overcome by enhanced training amongst health care staff.

The transition from acute to palliative within stroke care is problematic (Gardiner, *et al.*, 2013) as is identifying when someone is nearing the end of their life with the need to discontinue inappropriate investigations and unnecessary treatments. Identifying a model of practice that supports the appropriate and timely integration of palliative care for stroke patients on the basis of need is essential (Stevens, *et al.*, 2007; Burton, *et al.*, 2010). Palliative and end of life care requires collaboration and cooperation to ensure improvements occur (NPELCP, 2015). Yet, despite a long history of difficulties identifying patients who are dying in acute hospitals (Higgs, 1999) a diagnosis usually occurs close to death with 50% of stroke patients dying within 24 hours of decisions being made (Gibbins, *et al.*, 2009). It is therefore not surprising that stroke specialists often consider palliative care only applicable in the dying

phase or when prognosis is uncertain (Steigleder, Kollmar and Ostgathe, 2019).

### **Critical literature review**

This critical literature review built upon a previous review undertaken by Stevens, *et al.*, (2007) which considered seven studies (appendix 1) relating to the palliative care needs for patients diagnosed with stroke and their caregivers. The initial search aimed to identify and review a variety of sources of literature reporting on the provision of palliative and/or end of life care, including the provision of care for individuals dying from an acute stroke. In addition, the search set out to identify and review United Kingdom (UK) based primary research reporting the experiences of family members whose relative died following an acute stroke.

The review identified only a small number of studies that specifically addressed the role of palliative care in the context of stroke patients. However, Stevens, *et al.* (2007) concluded that bridging the gap between palliative care and stroke services remains a challenge and configuring services was a significant issue to consider. Although gaps in the evidence base underpinning palliative and end of life care for stroke patients are evident, Cowey (2012) acknowledges areas of good practice do exist. However, the absence of a robust evidence base relating to palliative and end of life models of care for stroke patients has led to a lack of clinical guidance in the area (Gardiner, *et*

*al.*, 2013). The End of Life Care Strategy (DH, 2008) purported that how we care for the dying is an indicator of how we care for all sick and vulnerable people. Yet, little is known about the nature of palliative care provision neither in the acute sector nor more specifically in stroke units across the UK. Despite the prevalence of palliative care needs amongst stroke patients (Burton, *et al.*, 2010) little is known about the extent to which such care is consistent with the UK (Gardiner, *et al.*, 2013). Stevens, *et al.*, (2007) suggested future research should explore how stroke care is delivered, the training needs required and the optimum means of collaboration with specialist palliative care staff which pre-empted the publication of the End of Life Care Strategy (DH, 2008) promoting equity of provision for all, irrespective of diagnosis. It also advocated the need to increase public awareness of dying and death through individual discussions about end of life care (Cox, *et al.*, 2011).

## **Search methods**

In order to provide context and background to my journey and experiences to date an initial search of the literature was carried out, seeking to determine palliative and end of life provision within acute stroke care, along with the experiences of patients, relatives and staff. This initial search provided an interesting backdrop to the subject and provided the opportunity to further consider the parameters of this study. In time, a further review of the literature through critical appraisal following the work by Stevens, *et al.*, (2007) which concluded that bridging the gap between palliative care and stroke services is

a challenge but configuring services is also a significant issue to consider. An electronic search of articles in peer-reviewed journals listed in Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medline; SocINDEX; PsychInfo and Psycho Behavioural Sciences was conducted utilising EBSCO Host Databases. These repositories were deemed the most appropriate for the topic, although other databases were considered but excluded based on relevance. A review of abstracts of research-based publications was carried out and reference lists and bibliographies were also examined and utilised within the search parameters with the intention of assisting in locating additional relevant studies. To ensure the most relevant and appropriate literature was included, a clear inclusion and exclusion criteria was applied to the search (Aveyard, 2014).

### **Inclusion criteria**

- primary research studies written in English (papers written in other languages were not considered due to the limitations of time necessitating translation and interpretation based upon context);
- primary research studies involving adults aged 18 years or over;
- primary research studies relating to palliative and/or end of life care for stroke patients along with the experiences of bereaved family members;

- literature published in the UK between 2008 – 2019 being the period following the implementation and subsequent review of the End of Life Care Strategy (DH, 2008; 2014);
- primary quantitative and qualitative research in UK peer reviewed publications;
- UK government publications relating to palliative care, end of life and/or stroke care; available electronically as full text article with search terms appearing in one or more of either title, abstract or full text.

### **Exclusion criteria**

- stroke literature not associated with palliative and/or end of life care;
- unpublished literature, including theses.

### **Search parameters**

General search terms identified were *palliative, palliative care, end of life, end of life care, stroke, stroke care, CVA, cerebrovascular accident, hospice, hospital, acute, long term care, non-cancer, specialist palliative care, equity, access, health care needs and demands, health service accessibility*. The key words utilised for this review, which were a diverse set of related terms to capture the literature on the chosen topic (Bennett, 1999) were *palliative, end of life, end of life care, hospice, stroke, CVA*. The Boolean logic process *AND, OR* and *NOT* was utilised and full text and date search limiters assisted in the

optimisation of results. Neither truncation nor wild cards were used as part of this search.

### **Search outcome**

Date parameters were placed on each of the searches from the outset to cover literature following the publication of the End of Life Care Strategy (DH, 2008). Initial *basic* searches using EBSCO to retrieve literature from Cumulative Index to Nursing and Allied Health Literature (CINAHL); Medline; SocINDEX; PsychInfo and Psycho Behavioural Sciences databases produced significant results in excess of 3,300,000 citations for specific words. However, when using an *advanced* approach which combined search terms produced drastically reduced citations (Appendix 2). The same key search terms were utilised in further searches as combined (Appendix 3) and refined searches (Appendix 4). Replication of the process eventually resulted in the same citations being identified until eventually no new citations were identified.

Adams, *et al.*, (2012) recommend a process which aided the identification and selection of literature. This encourages researchers to carry out a primary search to identify qualities of literature available along with a refining of the search using specifically chosen search engines to narrow fields. This should be carried out alongside a hand search of journals and reference lists (Adams, *et al.*, 2012). Once undertaken, duplicates should be removed with a further filter being applied based upon selection criteria using title, abstract, key

words, time and place as additional filters. Only when this has been thoroughly carried out, should a selection of relevant papers be available.

The refined combined database search yielded 12 journal articles (Appendix 5) judged relevant to the study based upon title, abstract and full text examination (Dobrina, *et al.*, 2014). The majority of these studies were either qualitative or mixed methods in design. Further searching of the databases produced no new material. Preliminary reading of each of the papers provided insight into the context of the research and the strength of evidence within the study. The critical reviewing of individual research studies supports the strength of evidence within the topic investigated as each is judged upon its own merits whilst also being viewed collectively within the subject under investigation (Hibbert & Crookes, 1999). It was helpful to consider Caldwell, Henshaw and Taylor's (2005) framework (appendix 6) for reviewing and critiquing each research article and thus ensuring continuity. Based upon the hierarchy of different types of evidence proposed by Gray (1997), each of the articles was rated as level 5, being descriptive studies/reports, although any hierarchy is, at best, a guide, rather than a set of inflexible rules (Evans, 2003). Each study was undertaken by two or more researchers from varying professional backgrounds. Of the 12 research studies identified for this review, 3 were based on one larger study although the focus of these papers was different (Burton, *et al.*, 2010; Payne, *et al.*, 2010; Burton & Payne, 2012).



The ways in which people die and how long this takes varies considerably due to disease and other factors including frailty and social setting (NICE, 2015). Whilst some individuals deteriorate over a longer period, others may die suddenly and unexpectedly following a significant event (NICE, 2015). The provision of end of life care is riddled with inequity and inequalities (NCPC, 2015) not least as palliative and end of life care appears overwhelmingly dominated by people with cancer (NCPC, 2015). It appears those individuals experiencing an acute stroke continue to face inequality of service provision across the NHS, likened to a postcode lottery (Donnelly, 2014) first identified by Sir Kenneth Calman in 1995 (DH, 2005). The NCPC (2015) suggested there was significant inconsistency in quality of care with 40% of hospitals offering inadequate care or requiring improvement. There is evidence of a lack of clear leadership on end of life care within the government (NCPC, 2015) and the Kings Fund (2018) warns against a loss of momentum relating to the provision of such care.

The literature search identified a range of information associated with palliative and end of life care and stroke. Each paper was read four times and different coloured highlighters were utilised on the first and final readings, with comprehensive notes being made on the second and third read through. This assisted in reducing the quantity of text (Weber, 1990) in order to produce categories or themes, a familiar approach in qualitative research (Bryman, 2012). It is not unusual for each research paper to contain several themes and once identified a further merging is possible (Aveyard, 2014).

Themes were drawn from both research and non-research literature on each reading either inductively using interpretation or overtly identified by the researchers (Hsieh & Shannon, 2005). A final revision of the literature was undertaken to clarify terms and ensure accuracy of each theme (Gough, 2004). At this stage of the literature review, seven research papers were retained based upon their quality and relevance of the evidence (Gough, 2007). Themes drawn from the literature are considered under the headings of: organisation, delivery and inequalities in palliative and/or end of life care; terminology, definitions and understanding about palliative and/or end of life care; malignant and non-malignant disease; symptoms, clinical decision-making and survival time; stroke care; communication; and identifying dying.

### **Organisation, delivery and inequalities in palliative and/or end of life care**

The organisation and delivery of palliative and end of life care has historically suffered from underinvestment (Addicott & Ross, 2010). Yet, despite end of life care being designated a priority in England, Wales, Northern Ireland and Scotland (Cowey, 2012) austerity measures are evident across the NHS (Quilter-Pinner, 2018). The combination of the unprecedented squeeze on public spending and rising demand for services leaves the NHS facing the most significant financial challenge in its history (Kings Fund, 2011). The more recent £10b capital funding investment (Kings Fund, 2018a) along with the publication of the NHS 10 years plan (DH, 2019) are unlikely to impact

significantly on the funding or service provision for palliative and end of life care.

The provision of palliative and end of life care has traditionally emerged from the care of cancer patients (WHO, 2004; Clark, 2007; Burton, *et al.*, 2010). Although the End of Life Care Strategy (DH, 2008; 2014) recognised inequalities existed in access to end-of-life care for individuals with a non-malignant diagnosis, it was not explicit how specific needs of such patients were to be better met (Addicott & Ross, 2010). The Strategy (DH, 2008; 2014) outlined what good end of life care should look like and although progress has been made, the overall vision of the strategy had still not been achieved (Care Quality Commission (CQC), 2016a). The WHO (2018) approach to palliative and end of life care focusses on need rather than disease and yet, palliative care is not as high a government priority as it should be (Bruce, 2018).

Whilst traditionally viewed as a *Cinderella service* (Select Committee on Health, 2004), Stevens, *et al.*, (2007) and Marie Curie (2015) suggest there is increasing recognition that palliative care is an important component of health care services including non-malignant disease. For some patients an acute hospital may be the most appropriate place of care although an increasing proportion of individuals attending Accident and Emergency (A&E) may be approaching their last months or days of life (Hospice UK, 2017b). Yet, the quality of care for some people at the end of their life is not good enough

(Care Quality Commission, 2016a) and individuals are not dying in a place of their choosing (DH, 2017). Whilst the provision of palliative care for stroke patients is questionable and inequitable (The Scottish Partnership for Palliative Care (SPPC) (2007) people with a diagnosis other than cancer do not always experience good care towards the end of their life (CQC, 2016b). The lack of investment, reduction in public finances along with an ageing population requiring additional healthcare interventions in a variety of settings compounds the need for palliative and/or end of life care for all and is unlikely to resolve due to the ongoing fragmentation of services across different providers of care (National End of Life Care Programme, 2012). Continued inequalities amongst populations highlights that end of life care is variable (Alonso, *et al.*, 2016) and needs to improve (CQC, 2016a).

As a result of palliative care being delivered in a variety of ways and settings (Kings Fund, 2018b), it is not surprising there is a lack of consensus among health care professionals on when an individual other than a cancer patient might benefit from such interventions. Indeed, effective palliative and end of life care has been identified as requiring a comprehensive plan of care as one size does not fit all (Nunn, 2014). Evidence of palliative care for patients within a stroke context is scarce and end of life care for stroke patients and their families remains limited (Eriksson, *et al.*, 2016). However, approximately two thirds of patients die in hospital within one year following a stroke (Steigleder, Kollmar and Ostgathe, 2019).

## **Terminology, definitions and understanding about palliative and/or end of life care**

Eriksson, *et al.*, (2016) suggested contradictions and confusions exist around the term palliative care despite the WHO (2018) providing a clear global definition. This may be about phases of care although stroke patients have been studied to a limited extent when related to end of life care (Eriksson, *et al.*, 2016). However, *palliative care* and *end of life care* are terms often used interchangeably for care given as someone approaches the end of their life (Nunn, 2014). This may be due to an inability in accurately predicting when such care may be needed in the patient's journey (Nunn, 2014) and not least for individuals with a non-malignant disease. Despite staff recognising palliative care as being a component of stroke care, clarification would likely help them identify the time for appropriate transition to the service whilst also integrating the approach into stroke care, perhaps by using dedicated palliative care beds (Gardiner, *et al.*, 2013). Research on end of life care in stroke provision has been limited (Alonso, *et al.*, 2016). Kendall, *et al.*, (2018) purported some staff viewed palliative care as negative, applicable only to those clearly dying and associated with the withdrawal of treatment.

Burton & Payne (2012) acknowledged that palliative care and end of life care needed development outside of cancer services thus enabling a greater choice for those nearing the end of their life, although clarification of terminology was not always apparent. One study aimed to explore the determinants of

satisfaction on health and social care in the last 3 months and 3 days of life (Young, *et al.*, 2009) and yet there was no clarification of definition(s) utilised aside from those determined in the preceding twelve months (DH, 2008). The End of Life Care Strategy (DH, 2008) identified palliative care provision as part of end of life care whilst others purported end of life care to be a part of the wider provision of palliative care (Marie Curie Cancer Care, 2014).

### **Malignant and non-malignant disease**

Cancer is responsible for a quarter of deaths across the UK with over three quarters of these individuals served by specialist palliative care (SPC) (Willis, *et al.*, 2014). Stroke is the third most common cause of death in the UK, costing the NHS approximately £3billion each year with additional costs to the economy of a further £4billion in lost productivity, disability and informal care (NHS England, 2017). Despite a mortality rate of approximately 30% in acute stroke, with one in five patients dying within the first month (Quadri, *et al.*, 2017) little remains known about the palliative care needs of these individuals (Burton, *et al.*, 2010) including survival rates (Mead, Cowey & Scott (2013) with a paucity of literature considering the provision of such care (Mead, Cowey & Scott, 2013). Eriksson, *et al.*, (2016) concluded that differences in palliative care symptom management at the end of life between patients dying from stroke compared to those dying of cancer may have implications for clinical practice. Potentially, staff may need to pay more attention to the palliative and end of life care needs of patients dying from stroke along with

their family members (Eriksson, *et al.*, 2016). The ongoing challenge is to determine what services, including palliative and end of life care provision, stroke patients require (Stevens, *et al.*, 2007) and how such provision and access should be managed.

### **Symptoms, clinical decision-making and survival time**

Symptom management is essential in palliative care and those afflicted with stroke experience a range of symptoms impacting upon their quality of life (Eriksson, *et al.*, 2016). Referral to specialist palliative care includes assistance with symptom management and psychosocial aspects of end of life care planning (Quadri, *et al.*, 2017). The most common symptoms experienced by stroke patients are mirrored by other life limiting conditions requiring palliative care, including mobility difficulties, feeling weak, tired and sleepy, along with communication problems (Payne, *et al.*, 2010). None of the studies focussed specifically upon symptoms or clinical decision making, although several, including Gardiner, *et al.*, (2013) drew conclusions that stroke care and palliative care for cancer patients had commonalities.

Quadri, *et al.*, (2017) identified that the two most common contributing factors leading to death were raised intracranial pressure and aspiration pneumonia. Those individuals referred to palliative care had a longer survival time compared to those who were not. Those individuals who received enteral feeding were also significantly more likely to have a longer survival time.

Rejno, *et al.*, (2013) identified that abnormal breathing patterns and the sounds of mucous were the most stressful things for relatives to deal with. Interestingly, staff often confessed to being overoptimistic in order to motivate people (Kendall, *et al.*, 2018) whilst relatives expressed difficulties in deciding about treatment options (de Boer, *et al.*, 2015) and preferring to leave decisions to medical staff or simply 'go along' with decisions instigated by physicians.

### **Stroke care**

The Stroke Association (2018) indicated that over 100,000 strokes occur in the UK each year with one in four deaths in the UK being caused by a stroke in England and the second leading cause of death worldwide (WHO, 2017). Despite improvements in the treatment of stroke, a significant proportion of individuals die in the acute phase (Eriksson, *et al.*, 2016) with 21% dying within the first 30 days (Roberts, *et al.*, 2015) and often without appropriate care to meet all their end of life needs (Watts, 2012). Prognostication is surrounded by uncertainty (Roberts, *et al.*, 2015). Staff need to determine whether acute interventions are appropriate as these tend to postpone a palliative approach (Gardiner, *et al.*, 2011). Reducing suffering for both patient and family is important (Meleis, 2011) although acute interventionist care may not be the best for patients nearing the end of their life (Gardiner, *et al.*, 2011). Open, honest and frequent conversations between staff, patients and families about palliative and end of life care is essential and staff need to



ensure transition to end of life care is managed appropriately (Coombs, Addington-Hall and Long-Suthehall, 2012) and in a timely manner.

Although gaps in the evidence base underpinning end of life care for individuals experiencing a stroke are evident, Cowey (2012) acknowledges areas of good practice do exist. However, the absence of a robust evidence base relating to palliative and end of life models of care for stroke patients has led to a lack of clinical guidance in the area (Gardiner, *et al.*, 2013; Eriksson, *et al.*, 2016). The predominant philosophy for the stroke environment has relied upon an acute and rehabilitative evidence-base (Eriksson, *et al.*, 2016). As such, the unique characteristics of stroke patients suggest suddenness of onset in comparison to those experienced by cancer or chronic disease patients (Alonso, *et al.*, 2016) which may compound the identification of palliative care needs and a tendency to treat acutely and aggressively. There remains insufficient detail about how palliative care should be integrated into stroke care (Kendall *et al.*, 2018).

Acute stroke patients have been identified as having a high prevalence of palliative care needs (Burton, *et al.*, 2010) and in parts of the UK such care has been adopted as key components of specialist stroke care (Gardiner, *et al.*, 2013). In non-acute stroke, patients and professionals can consider end of life issues and interventions, including consideration of the preferred place of death (Burton, *et al.*, 2010) although most people will die in hospital

(Davidson and Gentry, 2013). This is viewed as good practice (DH, 2008) which aims to increase the number of individuals cared for and dying in the setting of their choice (Intercollegiate Stroke Working Party (ISWP) 2012; Young, *et al.*, 2009) including home, hospice or care home (ISWP, 2012; Cowey, 2012). Nonetheless, palliative care services and hospices are predominantly linked with cancer care (Payne, *et al.*, 2010) and those with non-malignant disease may have a poorer experience of care in the last phase of their life (CQC, 2016b). Too much variation still exists, not only due to an individual's diagnosis (Marie Curie, 2017) but also current wide geographical variations in the availability of such care (Finlay, 2019). Unfortunately, those dying following a stroke have unmet needs (Alonso, *et al.*, 2016) and therefore it is suggested specialist stroke services increase their expertise in delivering general palliative care, perhaps by appointing an advocate for championing these skills within the team. Collectively, there is little evidence of this being actioned (Payne, *et al.*, (2010) and the complexity of palliative care provision within stroke care was viewed as a specialism within a specialism (Burton & Payne, 2012).

### **Communication**

One of the key themes threading through several studies was communication (Payne, *et al.*, 2010; de Boer, *et al.*, 2015; Alonso, *et al.*, 2016; Eriksson, *et al.*, 2016; Mayland, *et al.*, 2016; Kendall, *et al.*, 2018). Whilst the majority of patients were satisfied, there were mixed responses from family members (Payne, *et al.*, 2010). Although many professionals gave time and listened and

communicated well, there was little evidence of future planning in the study by Kendall, *et al.*, (2018). Interestingly, the importance of honesty from professionals was very important as they were trusted to provide the right amount of information when needed. Approximately 80% of participants had experienced some form of communication problem (Burton & Payne, 2012) which compounded the understanding of palliative/end of life care and stroke care, leading to continued uncertainty. Patients' communication difficulties resulted in problems engaging with the decision-making process (Burton & Payne, 2012) consequentially leading to additional problems. One quarter of participants perceived that they were not involved at all in decision-making (Mayland, *et al.*, 2016) and in the study by Kendall, *et al.*, (2016) stroke patients or relatives experienced less communication relating to the transition to end of life care than cancer patients or relatives. O'Brien and Jack (2010) purported that poor communication between hospital and community staff influenced discharge for those who may wish to die at home.

Kendall, *et al.*, (2018) purported communication with informal caregivers and among staff was often challenging and therefore need to be supported and trained appropriately in open and honest communication. Rejno, *et al.*, (2013) identified that relatives valued information given to them allowing them to understand the situation although they did not wish for vulgarity and insensitivity (Rejno, *et al.*, 2013). Relatives suggested memory frequently betrayed them leaving them with blurs or blanks when recalling situations (Rejno, *et al.*, 2013).

## **Identifying dying**

Payne, *et al.*, (2010) identified care was not planned with family members and no instances were highlighted when they wouldn't have not wanted to be involved. This uncertainty was mirrored with vagueness about the reason for particular interventions, particularly when shifting from active rehabilitation to a general supportive approach. Good communication may have assisted with reducing such uncertainties, with the ability to make informed choices with the most appropriate information available. However, uncertainty did not immediately appear to trigger fears about dying, unlike a diagnosis of cancer. The Leadership Alliance for the Care of Dying People (LACDP) (2014) published an approach to the care of individuals in the last few days and hours of life, particularly focussing on the wishes of the dying person and their significant others (appendix 7).

Rejno, *et al.*, (2013) indicated that relatives preferred not to know when death was imminent, although they expressed a desire for clarity and straight forward answers as to what was to be expected. Alonso, *et al.*, (2016) reported variability in end of life care practice and in patients unable to communicate, decisions about transition to palliative care were based upon an existing living will or consent of a legal guardian following the presumed patient's will. Relatives expressed the importance of having someone alongside them during their vigil as it was important to remain with the dying person, perhaps holding their hand without disturbing them (Rejno, *et al.*, 2013).

Payne, *et al.*, (2010) noted that no patient or family member reported requesting the initiation of palliative care although when death was viewed as inevitable then this should be peaceful and dignified. However, none recalled being offered the opportunity to bring their loved one home. It would appear the transition from acute to palliative remains problematic, and in particular, when identifying someone as nearing the end of their life. This may be a result of a lack of clarity in defining specific approaches to care which would be enhanced by elucidation of appropriate definitions.

Following the review of the literature it appears the provision of palliative and end of life care for adult stroke patients across the UK remains inconsistent despite investment and improvements. The literature identified a number of examples of good practice in some areas of stroke and palliative care including treating patients and family members with dignity and respect (Mayland, *et al.*, 2016) although it did highlight improvements were still needed including the timely recognition and management of symptoms and the appropriate acknowledgement that an individual was nearing the end of life. Deficits in staff knowledge about palliative and end of life care certainly affect the provision of palliative and end of life care for stroke patients which means equity of service remains questionable. Such deficits are impacted upon further by lack of government clarity relating to palliative and end of life care, including poorly distributed funding (POSTnote, 2014).

All studies were conducted following the critical literature review carried out by Stevens, *et al.*, (2007) and after the implementation and dissemination of the End of Life Care Strategy (DH, 2008). Stevens, *et al.*, (2007) recommended further work to determine the impact of palliative and end of life care on stroke care which to some degree has been collectively undertaken in the studies considered as part of this literature review. Further recommendations include collaboration between stroke and palliative care specialists when undertaking research which is evidenced to have been embraced although findings cannot simply be transferred to the stroke environment (Rejno, *et al.*, 2013). Although a simple assessment tool to identify specific needs was identified as likely to positively contribute to the palliative and end of life care offered in the context of stroke care, this has not been disseminated within practice. Finally, support for the bereaved, along with appropriate training for staff, are important considerations to ensure equity of provision in the context of stroke care (Stevens, *et al.*, 2007). Again, a number of studies continue to recommend one or both recommendations as part of enhancing the experiences of both patients and their relatives (Burton, *et al.*, 2010; Alonso, *et al.*, 2013; Eriksson, *et al.*, 2016; Kendall, *et al.*, 2018).

### **Recommendations from the review of literature**

Amongst the recommendations from the review of the literature, communication deficits amongst health professionals need addressing as this has been seen to have a negative impact upon patients and their families at one of the most difficult times in their lives. It remains essential for

government and others to ensure palliative and end of life care is available for all, irrespective of diagnosis (DH, 2008; 2014). In order to enhance the provision of palliative and end of life care for patients and their family members, staff need to learn how to identify and respond to changes within stroke patients which suggest they may be dying and require a change in the focus of care. Recommendations include further work being required in seeking to address the deficits in palliative and end of life care provision for adult stroke patients across the UK (DH, 2008; 2014). This will ensure equity of access is possible at a time when individuals are often at their most vulnerable and when staff are struggling to identify when a transition of care is required. Until then, treatment and care provision remain a postcode lottery (Campbell, 2019; Stroke Association, 2019) with stroke patients often facing inequitable service provision when nearing the end of life despite improvements in care provision.

### **Sonata Framework**

Whilst carrying out the review of the literature, I came across use of a sonata-form of musical composition as a framework for thesis writing (Drake 2004). Drake's work lends support to the use of innovative frameworks for reporting nursing research. I chose to develop and apply a Sonata framework (Table 1 p.40) for this study, borne of my love of music. The purpose was to provide contextualisation and synthesis of my experience with interpretations of the personal experiences of family members whose relative died from an acute stroke following admission to hospital. Choosing any theoretical framework for

a study is often difficult (Iqbal, 2007) and researchers are encouraged to offer strong clear arguments for their choice (Allen, 2015).

The Sonata Framework comprises four parts with an additional beginning (prelude) and ending (coda). Its structure mirrors the narrative and duration of the onset of my mother’s stroke and subsequent untimely death. In musical terms, sonata form comprises four parts of varying length, speed, tone, pitch etc. which resonate with my narrative within this autoethnographic study. First and foremost, this framework offers an apology to other musicians as I include the addition of both prelude (introduction) and coda (ending). This sonata in modified form provides valuable structure to the study. Fellow musicians may find it necessary to lay aside their purist thoughts on the modification of this sonata in order to embrace the individual and combined voices of all those sharing their narratives.

**Table 1 – Sonata Framework**

<b>SONATA</b>	
<b>The Prelude</b>	Instrumental piece played as an introduction
<b>Part 1</b>	Allegro / Opening Sonata Quick – ‘allegro agitato’ as opposed to ‘allegro tranquillo’
<b>Part 2</b>	Slower ‘adagio’ = slowly OR ‘andante’ = moving along in a walking pace
<b>Part 3</b>	Main allegro/scherzo ‘swift moving piece of music’
<b>Part 4</b>	Usually an ‘allegro’ – a ‘triumphant and exhilarating’ ending
<b>The Coda</b>	Concluding passage of a piece or movement, typically forming an addition to the basic structure.



## **Chapter summary**

Evidence from the UK literature suggests some progress in the provision of palliative and end of life care, not least in acute stroke care. However, there is little evidence of the availability or quality of such care and neither are there any significant narratives from those who have experienced that care, including bereaved relatives. The evolving picture is one of inequity with gaps in the provision of palliative and end of life care for those diagnosed with a non-malignant disease, including acute stroke. The following chapter details the story of my childhood and a number of key influences upon my life at the time with the support of the Sonata Framework; the Prelude and Parts 1-4. I present the moving account of my mother's relationship with her father prior to and following his death from an acute stroke, mirrored by the story of my mother's death following an acute stroke and the urgency in seeking to get hospital staff to accept she was reaching the end of life and expedite her discharge home to die.

## CHAPTER 2 - MY AUTOETHNOGRAPHIC EXPERIENCE

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### Chapter overview

In this chapter, the Prelude and Parts 1-4 of the Sonata Framework offer a suitable opening to the performance of this autoethnography. The Prelude allows the reader the opportunity of learning about me and members of my family and about my career as a nurse working in palliative and end of life care with over 25 years' experience immersed in the hospice movement. It also reflects upon the impact my maternal grandfather had on my mother and I, and my mother's untimely death following an acute stroke.

Part One of the sonata is an *allegro* which can either be *allegro agitato* (agitated) or *allegro tranquillo* (tranquil). This *allegro agitato* considers the fateful day of my mother's stroke which came ten days following major surgery for a potentially life-limiting bowel tumour. Part Two is a slower movement in the form of an *adagio* which moves along in a walking pace and reflects the day following her admission to hospital. Part Three is the main part of the piece and once again takes the form of an *allegro*, a swift moving piece of music. This part mirrors the urgency of engaging with hospital staff to accept my mother's impending death and the determination to expedite her discharge home to die. Part Four, as with any traditional sonata, follows as a repeat *allegro* of Part One which is fast, albeit on this occasion, there is a triumphant and exhilarating feel to the music, which culminates in its conclusion. This

lends itself to the Christian belief of new life after death, something my mother firmly believed. The triumphant ending resonates with her belief in eternal life and the assurance of being united with those who have gone before. Finally, this sonata comprises a **coda** or 'rounding off' which seeks to reflect upon the contents of this chapter.

## **THE PRELUDE**

### ***On Being A Grandson***

My grandfather was a most humble, unassuming, poorly educated soul and yet, in an earthen Black Country sort of way, remarkably prophetic. We were extremely close; spending an abundance of time together. I visited my grandparents at every opportunity and their home was always the first stop on the return journey from our annual Cornish holiday when I would almost burst as we neared their house just half a mile away from where we lived. I recall my grandmother's eager embrace and her distinct smell as I was drawn into her ample frame and squeezed tightly. My grandfather's cuddle would follow. He knowingly and wisely stood back assuming second place to my grandmother. I loved him very much. The impact for good on my life has been quite extra-ordinary. Since his death when I was just ten years old, I've learned more about him and myself in the shadow of bereavement and loss which has enhanced my personal journey and my professional life as a hospice nurse and lecturer caring for those nearing the end of their life.

I was heartbroken when my grandfather died at the age of 79 years. His death affected my mother considerably. Her underlying anxiety and psychological trauma, which I knew little of at the time, presented initially with swallowing difficulties; a perceived lump in the throat; alongside radiating pain throughout the abdomen. Her supportive and extremely kind General Practitioner (GP) explained to my mother about grief as a human response to loss. As a hospice lecturer my knowledge of attachment theory and the impact on human relationships and the emotional attachment resulting (Bowlby, 1998) enables greater insight and I have since viewed my mother's experiences through a different lens. As a young teenager she explained her feelings to me which provided greater insight about her life and her ensuing coping strategies in bereavement. On one occasion she suggested, "*working with the dying is the closest you will get to dying without actually dying yourself*". Some thirty years on and with over 25 years' experience as a hospice nurse, I now realise she was absolutely right.



My grandfather was a Black Country man through and through; and yet despite his gender stereotypical views, my grandmother worked throughout her life. As a manual labourer in a local brickyard she worked extremely hard for most of their married life. '*Five thousand, five hundred for a day's stint*' she would frequently declare, but I appreciated little about operating

a manual press producing roofing tiles. *'They wouldn't 'av it today'*, she would quip, meaning the intensity of the labour she undertook 5 ½ days a week in addition to caring for her family and home which drained her body; both physically and mentally. She was right. Whoever *'they'* were would almost certainly not accept the conditions of service today nor the intense demands upon the human frame. She stood just 5 feet 3 inches tall and yet carried dozens of roof tiles at a time in her leather pinafore. *'They wouldn't 'av it today'*.

My grandparents met locally as youngsters and married at St. Michael's Church in Brierley Hill, a small town 2.5 miles from Dudley, in 1928. They had two children; my uncle, John William born in 1929 and my mother, Margaret Florence May, born in 1939. Both dependents left home when married and my grandparents celebrated their Golden Wedding Anniversary in 1977, twelve months early by mistake when I was just 7 years old. I remember that party distinctly. I cherish that faded photograph of me standing between them both in front of the sideboard in their sitting room. The vase of red roses on the sideboard remain ever fresh in my mind's eye. I distinctly remember leaning into my grandmother, feeling secure in her grasp. To me they were the perfect couple and yet, when older, I was told that my grandfather's enjoyment of beer and horseracing frequently resulted in verbal assaults from both sides with my grandfather retreating to bed in the afternoon to sleep off the effects of his inebriation.

My grandfather was a most generous, 'gentle' man. I idolised him. We spent many hours together and none more so than in the back garden which was given over to growing vegetables. I loved helping him and he knew it. I would constantly ask whether he was going to light a fire to burn garden waste. When he relented, which he invariably would do, I absolutely relished both prodding and poking the embers to encourage new flames. I have always been fascinated with fire. I still love the energy it produces; the intense heat; the dancing colours; the smoke and the choking smell. It's easy to get lost in thought staring into the flames.

Attendance at church was a seldom occurrence for my grandfather which he reserved only for weddings, funerals and the traditional Sunday School Anniversary. His church was his garden and his fellow parishioners were the neighbours and passers-by who engaged in conversation. He grew an abundance of chrysanthemums and dahlias each year. Rarely would I see him without a *pom* in his buttonhole. I recall the home-made wooden framed plastic covered *Heath Robinson* mini greenhouse cobbled together with a variety of acquired materials. The warm smell of ripening tomatoes was only marred by the fantasy about hidden spiders as I tentatively stepped inside to pick the abundance of fruit. I savoured the taste of each freshly picked tomato accompanied by one of my grandmother's ham sandwiches and a wedge of butcher's porkpie. Salty pork scratchings were an indulgence and a treat when purchased from the butchers at the top of the street, served from a large metal bowl on the counter.

My grandfather was a very generous soul. I recall him insisting my grandmother halved and re-plated his Sunday lunch before taking it to a workman watching a hole in the street; a rudimentary feature of health and safety of its time. He epitomised the values any Christian would aspire to. He never spoke ill of anyone preferring to keep his own counsel. Poorly educated, he left school aged thirteen, working until retirement aged 73. On the day he returned home from work for the last time he sat at the dining table, put his head into his hands and sobbed. I had never seen a man cry before. Quickly rebuked by my grandmother he said, *'I've worked all me life, Florrie, and now I ain't got 'er a job'*. He worked hard throughout his life, but I realise that had my grandmother not secured the majority of his wage each week, returning just a proportion to him, he would have smoked, consumed and gambled everything away. Yet, he was rarely happier than when sitting on the sofa in front of the gas fire with a copy of The Sun, pencil in hand *'to mark the winners'*, he said, and a few ounces of tobacco to gently replenish his pipe.

### ***My grandfather's final days following an acute stroke***

I am not completely sure of the details which led up to or followed my grandfather's stroke and yet, from an early age, I do recall being told he had bowel cancer. My mother gently told my sister and me that he had refused surgery which would have resulted in the formation of a stoma [colostomy]. *'Grandad doesn't want the operation at his age'*. Yet, despite that introductory conversation I don't recall any further discussions about him becoming less

well. Perhaps that was my mother's way of protecting us, or perchance it was too painful for her to consider. She was devoted to her father and in turn he idolised her.

At the age of seven or eight I recall the overwhelming embarrassment I felt when my mother disguised female sanitary towels in a shopping bag which I was handed without reference in readiness for the short walk to my grandparent's house. I knew little of their primary purpose, but she bought them to aid my grandfather's faecal incontinence. I hoped never to meet anyone on the journey who might enquire of the contents of the over-sized bag, disproportionate to me, which I struggled to carry. I never did. Passers-by merely made eye contact, smiled and at times muttered *'hello'*. My return journey home necessitated me carrying his heavily soiled garments disguised in several carrier bags to be handed to my mother upon arrival. It was my father who rinsed my grandfather's clothing to remove much of the heavy faecal blood soiling before placing them in the washing machine; thus, my mother was spared any further distress.

I remember seeing my grandfather in bed at home on the morning following the stroke. The distilled conversations between my parents and the doctor took place upstairs whilst I waited downstairs with my grandmother. Shortly afterwards, the doctor left and in due course the ambulance arrived. My grandfather was transferred to hospital in Dudley, a former workhouse and



maternity home, subsequently raised to the ground in the mid-1990's making way for private housing.

We all visited each evening; my sister and I being made to stand just inside the prefabricated ward whilst the adults gathered around my grandfather's bedside. We were typical siblings and found it difficult to get along without bickering and arguing. A cautionary glance from either parent, but usually our mother, suggested *'just wait 'til you get home'*, the threat being more effective than any potential telling-off behind closed doors. We were ushered to the bedside for just a few minutes at each visit, but it frightened me, and I remember resisting. My grandfather looked at me through the bedrails, gesturing to reach out his unaffected skeletal hand from beneath the bed sheets; but I couldn't understand what he was trying to say. His agitation, evidently borne of his frustration in trying to speak to me, was petrifying for me to see. His pleading eyes pierced my soul. *'Ca ... Ca ... Cap ...tain'* he spluttered. *'You see'*, said my mother, *'he knows it's you'*. His one eye was partially closed, and his mouth was drawn down on the one side resulting in him dribbling onto the pillow. My heart was pounding, and I became increasingly more apprehensive. I turned away looking towards the door, but my mother's protective hold on my shoulders remained firm.

The following evening as I approached the bed, my grandfather was facing the direction I approached. Our gaze met as I neared the bedside and I could

hear the jingling of coins beneath the bedsheets. My mother reached for my hand in joint acceptance of the pocket money which he had given my sister and I for years. I loved it when we would walk to the paper shop and I could choose a ten-penny mix. On the occasion a funeral cortege approached, he would remove his cap, reach for my hand, and we would stand in silence until it passed. The more my mother directed my hand towards his, the more I pulled away. In adulthood I reproach myself for rejecting him so cruelly. I saw the desperation in his eyes and all I hope is that he never saw the fear in mine. As I hesitantly kissed his cheek the stubble on his unshaven face felt so strange. *'Thank you'*, I muttered as I turned from the bed, hoping no-one noticed me recoiling. I knew he was going to die and as I hurried back to my earlier position at the entrance to the ward, I just wanted him to come home and for everything to be as it was.

My grandfather died just prior to us arriving on the evening of 10<sup>th</sup> June 1980 in the annex ward he was admitted to just a few days before at Burton Road Hospital in Dudley. I'd been allowed to miss a piano lesson on that Tuesday evening so we could all visit. I was a few paces ahead of the others on the gently sloping pathway to the wards outside the main building, each with twenty or so beds in traditional Nightingale formation. As I approached the *pre-fabs*, I saw the curtains being drawn around his bed space and recall thinking that visiting time was a strange time to be washing someone in hospital. It was only as we entered the ward that we were approached by a kindly nurse advising of his recent death. My mother was quite inconsolable,

although stoic. I didn't realise at the time just how important being with him at the time of his death would mean to her, nor how important being with someone at the end of their life would come to mean to me. Through that lens of experience, I hold greater insight, having cared for many hundreds of individuals nearing the end of their lives whilst also striving to support their family members in their bereavement.

We sought solace in the embrace of one another. The shadow of death had enveloped the scene and despite my mother's assurances that *'he'll look like he's sleeping'*, I vehemently refused to see my grandfather again. Death frightened me, and yet I desperately wanted to see him. I remained rooted to the spot. We held onto each other in a quintessentially English stiff-upper lip sort of way. We weren't a particularly tactile family. After several visits to the bedside by the rest of the family, my mother and uncle were encouraged to return the following day for any personal effects along with the death certificate. Both were to be collected from the office alongside the mortuary.

Life's experiences have moulded me over the years and although I was not old enough to fully understand at the time of my grandfather's death, I have come to realise the importance of individuals and of situations. The impact for good of others upon our lives is so very important. As weeks morph seamlessly into months which, in turn, merge into years, memories emerge perhaps as a result of the unconscious exploration of life and questioning about one's own

mortality. Each memory or little vignette allows the opportunity to consider scenes with maturity, experience, new knowledge, awareness, empathy and understanding. At the age of just ten, I was ignorant of such things when my grandfather died. As a 34-year-old man the untimely death of my mother shook my world despite the preceding years within the hospice teaching me a great deal about life and death. Education, new learning and life experiences have all impacted upon me and significant changes have taken place around me and within. Each new epiphany has stirred my soul, and despite the constant changes, a new song is created; each word echoing a new meaning to previous experiences and I realise that neither life nor I will ever be the same again; nor should we.

### ***On becoming a professional nurse***

Secure in my pushchair aged 2½ - 3 years old I recall the funeral cortege outside the local Independent Methodist Church at the top of my grandparent's street in Pensnett. My mother's response was limited to the simplest of explanations about death, but I watched expectantly for a metal crane to descend from the clouds, grab the *box in the black car* and lift it heavenwards. Such was my construct of heaven at the time. In the following weeks, I operated on my first teddy bear, Peter. I removed the small musical box inside and sutured the gaping material with rudimentary stitches, as would a trainee surgeon at the close of an operation. Peter's scars remain a permanent reminder to me of those carefree days at play.



My first day at primary school in Kingswinford was an exciting and yet most apprehensive time. After several practices getting dressed in my new uniform, I stood proudly on that morning, recalling the elderly couple who lived next door leaning over the fence to admire my attire. Seeking assurance, my mother agreed that I could take one of the little toggles from my favourite blanket or *bit o' comfort* as it was always referred. I secured the said item in the right pocket of my short trousers and took a new toggle to school each day for the next few months, until the blanket was almost bare.

I did not become a surgeon, but I have spent a lifetime, both personally and professionally, seeking to heal hearts and minds. My need for a *bit o' comfort* has diminished, and my understanding of separation theory has increased. Alongside a faith firmly rooted in the Methodist tradition my career within the hospice movement is not what I imagined as I entered 6<sup>th</sup> form having convinced myself of the worthiness of a teaching career, specialising in music and religious studies. Yet, both pastoral and clinical aspects of my life each impact for good on church, work and social parts of my world. As organist and celebrant at many dozens of funerals which parallel a career caring for the dying, my mother's prophetic words reverberate around my mind as do the words of hymns I play when I'm drawn to the piano at home or church or hospice. What did she see that was unknown to me and so very clear to her,

and what, if anything, can I learn from her now that she's gone? Perhaps it is only in the face of loss that I seek to listen for her voice as it fades and will eventually disappear as the passing of time separates the relationship we had and creates a new one as I get older.

*O love that wilt not let me go, I rest my weary soul in thee: I give thee back the life I owe, that in thine ocean depths its flow may richer, fuller be* (George Matheson, 1842 – 1906).

### ***My mother's untimely death from an acute stroke***

The following narrative provides the opportunity to contextualise my experiences in Sonata Form. Parts 1 – 4 of this work mirrors both pace and tone in the few days following my mother's stroke and untimely death. The initial agitation on that fateful day leads the reader into a slower pace during part 2 and a swifter pace in part 3 before the triumphant passage in part 4 leading to her death at home.

### **Part 1: *Allegro Agitato* - the fateful day of my mother's stroke**

The bedside telephone rang and as I reached for the handset the illuminated clock radio indicated it was 5.26am. My father's voice invaded the silence. '*I think your mother's had a stroke*'. '*What?*' I questioned, with escalated volume. '*I'm coming*'. I threw the handset back onto its cradle, pushed back the duvet with my feet, jumped out of bed, and lunged towards the wardrobe to find both jeans and a shirt. I grabbed pants and socks from the middle drawer of

the cupboard and picked up the abandoned pair of shoes from the night before. *'If it's a clot, she needs aspirin'* I told myself. I picked up the handset and telephoned my father. *'If she can swallow, given her two dispersible aspirin'*. I don't recall his response, but I repeated what I'd told him. *'Give her two aspirin. I'm coming'*.

I dressed in considerable haste, cleaning my teeth and brushing my hair, and found myself at the top of the staircase, holding onto the banister for support. *'I'm gonna fall'*, I thought. I tried to focus on the front door. My right hand slid along the rail and I arrived safely at the bottom. I leaned on the wall for support. *'I'm gonna faint'*. I didn't. As I focussed on the burglar alarm key pad I punched in the number. It was the right one. *'Thank God for that'*. I turned the key and opened the front door. The cold air hit me like an approaching train. I took a sharp breath. *'I'm gonna throw up'*, I said. *'Just deep breath'*, I uttered as I tried to calm myself down. I closed my eyes and inhaled deeply through my nose. I held onto the door handle for just a few seconds which helped stabilise my franticness. I opened my eyes, reached for the car keys and re-set the alarm, before slamming the front door and turning the key.

The cool air was a welcome relief. I don't recall the short drive to my parent's home aside from remembering I arrived without incident. I left the car partially abandoned at an angle on the driveway as I raced down the side path, unlocked the back gate and side kitchen door and entered. I ran up the stairs

ending up in the doorway of my parent's bedroom. My father was in an almost recumbent position on the bed alongside my mother. As he turned to me, I sensed the terror in his eyes and could almost smell his fear. The transition from son to nurse was instantaneous. I immediately took control.

My mother was bundled into the ambulance by two very kindly crew members. I was welcomed inside and directed to a seat. My father followed behind in the car. The straps securing my mother during the journey mirrored those restraining me from screaming out at the injustice of the stroke. My mother lay silent. Her eyes remained closed. My heart was pounding and as we journeyed, both movement and increasing temperature of the ambulance caused me to fear that I would pass out. The silent mantra, *'Deep breath. Just calm down. Deep breath'*, continued as did the fixed gaze towards my mother. I couldn't comprehend what I was seeing. How could this be happening? The short transfer to hospital felt almost funereal, as my mind raced ahead to the journey to the crematorium. Both ambulance and hearse moving with such dignity. As we passed the Methodist Church, little did I realise it would be just over a couple of weeks when we would bring her into that place for the final time when family and friends were crammed together to celebrate a life which had impacted for good on so many over the years. This was the place where she had sought comfort, solace, support and answers to questions following her own father's death. What would this place be now without her?



I was jolted from my thoughts as the ambulance pulled up outside the emergency department. My father arrived shortly afterwards and thus began the journey to save her life. The treatment involved scans, X-rays, medications, consultations and physical examinations, and yet it seemed like disjointed formality and learned behaviour. No one really spoke with a modicum of compassion towards my father or me, because the aggressive focus was saved for my mother. We became passive observers of an institution which is the envy of the world. I rebuked myself for allowing such critical thoughts to enter my mind.

As that fateful day progressed, I was convinced that neither family member nor professional could see she was dying. The automatic gear towards the acute, aggressive, rehabilitative treatment seemed almost unstoppable. In my silent devotions I prayed my mother's passing would be a peaceful one. She could not, nor would not, wish to survive with such physical and psychological impairment. The confusion amidst the silent conversations in my mind overwhelmed me. *'Was she dying? Was I in hospice-mode too soon? Was I denying her the opportunity to get better? Had I got it all wrong? Could she get better? How would she cope if she did survive?'*

Despite the dozens of people on that ward that day, I had never felt so isolated. I engaged in conversations but what I heard was little more than muffled noise although my responses maintained my professional veneer. I

was convincing myself as I was convincing others, until I gazed deep into my soul and saw a very dark and time-limited future. In the frantic-ness of my mind it was then I prayed that she would die. I loved her too much to bargain with God for her survival. No prayer is ever wasted.

My mother was transferred from the Emergency Department to the Emergency Admissions Unit (EAU) and then, late that evening, to the Stroke Ward. *'We'll take care of her now. Try not to worry'*. As I looked towards the bed, she appeared settled. *'Go on. Go home. Get some sleep. We'll look after her'*. Such were the kindly words of the night auxiliary nurse. Her eyes spoke far more than mere words. I'd known her for many years, and she knew me from the hospice, but I hadn't seen her for quite some while. *'Salt of the earth. 'Er's Black Country through and through that one'*, my grandmother would have said, and she would have been right. Visiting was restricted to set times and as no one said otherwise, the subtle affirmation of *'she'll be ok'* was cemented in our minds. Perhaps I had got it wrong? Perhaps she would improve over the next few days? We left the hospital to the sound of fireworks and a sky lit by coloured explosions. I remembered silently condemning the bonfire night revellers for making such noise and enjoying themselves whilst my mother lay in a hospital bed. Back home, sleep evaded me. There was to be little rest that night.

## **Part 2: *Adagio* - the day following admission to hospital**

My mother slept throughout the following day. On the surface, all felt calm. Her breathing was steady and regular, but my experiences of those individuals suffering a stroke was limited. All I was able to recall was the fatigue which followed the event and those uncomfortable times when I'd sought to understand the incomprehensible speech as I engaged with patients on the hospital wards. The transient memory of my grandfather's struggle with words flooded my mind, as I recalled the look of helplessness and frustration in his eyes. This must be much more severe, I pondered. '*At least he could speak*', I thought.

There were no signs of agitation. Her almost lifeless body was only just about determined under the amount of bedlinen she lay beneath. Despite nursing staff telling me she had vomited a couple of times overnight she now remained settled. The basics of care were evident. Her hair was brushed, albeit not as she would have attended to it herself, so I reached for the brush and attempted to correct the oversight. I sat for the remainder of the afternoon's visiting time, engaging in conversation with my father and others who entered the room. We obeyed the visiting rules, left the ward when the hand bell tolled just before finishing time, and returned again later that evening.

On return, staff advised that my mother had vomited again, but on this occasion, I questioned the necessity for such volumes of intravenous fluids

suggesting a reduction may ameliorate her symptoms. Their professional resistance affirmed their pro-active, aggressive interventions. It was clear they were intent on saving her life rather than soothing her soul. The nurse affirmed the hope that the physiotherapist would carry out an assessment on Monday morning. *'But she's dying'*, I said to myself. *'Why on earth can't you see that, or have I got it completely wrong?'* I took her favourite and now vomit-soiled dressing gown home to wash. She loved the feel of the soft, white, fluffy material as it brushed against her face and I reminded staff of its importance. *'I'll bring it back tomorrow lunchtime when I next visit'*. Nothing was said to the contrary, so I bid them farewell and left the ward.

### **Part 3: *Allegro/scherzo* - expediting my mother's discharge home**

The next morning being Sunday, I attended church as was the norm. Following the service, I walked the short distance to the hospital. Once again, I arrived in time for official visiting. I entered the ward. After engaging in simple pleasantries with staff whilst passing through the ward, I stopped at the open door of the side room where I had left my mother the evening before. The curtains to the window facing the road were open and although the room was partially dimmed the only shaft of light from the window cast a dappled effect across the bed. In the following moment, a spiritual foretaste of impending salvation flashed across my mind, and I felt suspended in time. All too briefly, I re-orientated and looked at the almost motionless figure outlined under the bed linen. The change I saw was immediate and sobering. My mother's frame

was diminished, and her complexion was waxen. She looked lifeless and then as I would in similar situations in clinical practice to determine whether someone was dead or alive, I watched expectantly for the rise and fall of her chest beneath the sheets to make sure she was breathing. In that moment, I realised my own breathing had stopped as I waited for her to breathe. I moved towards her and looked intensely at her face. The individual before me was physically alive but her spirit, the very essence of who she was, had gone. I gently lifted one of her eye lids and saw at once that her pupil was dilated. *'She's either stroked again or extended'*, I rationalised in my mind. There was no other explanation for the change I saw. It was evident to me that my mother was imminently dying.

I draped the freshly laundered dressing gown over the bed linen as she slept, tucking it gently underneath her chin. She loved to snuggle into the material as she felt its softness on her face. I withdrew from the room, acknowledging nursing staff with a smile and the briefest of eye contact and made my way into the main corridor to make phone calls. Each call was professionally framed with a gentle warning shot. I remained in professional mode throughout. *'I've just arrived at hospital from chapel and Mom appears less well this morning. I actually feel she's dying so if you want to say your good-byes, I suggest you come sooner rather than later'*. My composure belied my pounding heart as I summoned my father, sister and close family friends to the hospital. I returned to her bedside following the last conversation; staring at the almost lifeless outline of my mother. *'Dear God, what has she ever done to deserve this?'*

As the hours melted away, the battle to get my mother home gathered pace and I began to feel physically and psychologically exhausted. The frantic conversations which ensued between family members and professionals were shrouded in agitated tolerance. The staff defaulted into curative, rehabilitative mode whilst I was steering towards discharge home to die. *'That's where she would want to be'* I urged my father, looking straight into his eyes. I could sense the lost-ness and uncertainty which shrouded him. Eventually, he relented; for my sake, I'm quite sure, and not perhaps because he felt it was the right thing to do. He could sense and understand my desperation. With this, the staff agreed. Ironically, I felt for them. After all, the stroke consultant under whose name my mother had been admitted two days earlier hadn't even seen her yet.

As discharge arrangements were gathering pace, I passed both the doctor and ward sister in the hospital corridor on separate occasions. Quite co-incidentally and ironically, both instigated conversation and suggested similar. *'If it were my mother, I'd be doing exactly the same thing'*. I was incensed but remained professionally polite. *'It's a pity you didn't support me a little while ago'*, I replied. The silence which followed was palpable. After a nod of the head and clipped smile, we separated. I am hopeful both practitioners reflected on their part in the scenario. I certainly did.

Once the discharge paperwork was signed by my father, I hastened home to prepare for my mother's arrival. As I neared the exit, the ward sister shouted after me. *'If she improves, you can bring her back, you know.'* *'Of course, I knew'*, I thought. I turned and smiled. *'Yes. Thank you'*, I replied with a civility which probably came across quite sarcastically. Turning away I muttered, *'Bring her back? Over my dead body.'*

Friends and hospice colleagues were valiant in their efforts to ensure my mother's remaining hours were as comfortable as possible. My hospice colleagues located a pressure relieving mattress, incontinence sheets, catheter bags, mouth swabs and a plethora of other items which friends collected. These essential items weren't normally available at such short notice when expediting a discharge home from hospital. *'It's not what you know, it's who you know'*, my late grandmother would have said. She was right. I walked with deliberate haste to my car and drove to my parent's home to prepare for my mother's return.

#### **Part 4: *Allegro* - a 'triumphant and exhilarating' ending**

I dashed around the house preparing one thing and then another. Friends arrived having collected the items supplied by my hospice colleagues and they set to placing the mattress and remaking the bed. I remain indebted to those colleagues for their beneficence. Caring for my mother overnight without such essential items would have been very difficult and yet she was discharged

without so much as a spare catheter bag and the community team had not been informed of her impending death. Had it not been for such charity, we would have remained devoid of either practical help or resources.

The ambulance arrived home shortly before 6.00pm and yet, despite my mother's fragile medical condition and unconsciousness, she was transferred from the vehicle using the carrying chair, head flailing without support, as the crew struggled to get her upstairs. There was little dignity as her feet fell from the foot rests, legs akimbo. *'Where on earth is the dignity in this?'* I thought. *'At least she's home'*, I rationalised. She was such a dignified lady; hair always meticulously coiffured and subtle make-up and perfume the ever constant. I felt she was afforded little respect and treated as I imagined a carcass would be at the abattoir. It was pitiful to see and yet I felt helpless and unable to intervene. Had I created a fuss, they may have treated her less kindly. I remained silent which I deeply regret. Those friends who had collected the hospice items oversaw my mother's transfer into bed with such gentle, tender care. *'We're off now. Bye'*. The crew hastened away to either another job or a rest-break.

Several close friends visited that evening, including the minister from church who arrived to offer prayers. Despite the franticness of the preceding hours a peaceful calm befell the house. I was lost in thought for a few moments as the lounge clock struck once which caused me to look up. It was 11.30pm. My



father retired to bed, sleeping well over night alongside my mother despite my constant checks. Although in the comfort of my old bed, I didn't sleep. I was constantly listening for any changes in my mother's breathing which, at the slightest difference, hastened me to her bedside again. I attended to the practical duties of mouth care, catheter care and regular repositioning, seeking not to disturb my father. I'm still left wondering how I managed to sustain the practical care. Perhaps it was my almost constant silent prayers overnight? Perhaps it was the adrenalin that compensated for my lack of sleep? It doesn't matter. I did it. I'd got her home. That's what she would have wanted. That's what I needed. As the light tentatively appeared around the edges of the bedroom curtains, the loneliness of the night dissolved. I savoured the remaining time with my mother, cementing that very special bond we had shared for years. She had been my severest critic at times and yet my constant devotee. What more could I do for the woman who had borne me into this world but to care for her as she prepared to leave?

The end of my mother's life was comparatively swift, unfortunately expedited by a large faecal vomit indicative of bowel obstruction. Aspiration of faecal matter isn't conducive to a good death, but unconsciousness fortunately rendered her unaware. At least she was in her own bed. My mother's God-daughter, also a nurse, arrived shortly after 7am just in time to assist, which she did willingly. We bathed and changed her and replaced the soiled bed linen. There was an unspoken urgency in our work which we detected in one another's eyes. For a few minutes I was alone with my mother once again as

I knelt alongside her. I was aware of the distinct changes in her breathing and called to my father and friend downstairs. They hastened to the bedroom; my father positioning himself on the bed alongside my mother. We each listened as her breathing became increasingly laboured and noisy over the next few minutes. Each breath further separated from the previous until her final breath, only known in retrospect, was followed by the spontaneous noises which were so familiar to me as a hospice nurse, originating from the back of the throat. A quietness befell the room as we waited in silence, watching for any signs of life. I looked towards my father, breaking the silence only when I was sure. *'She's gone'*. I automatically glanced at the clock on the bedside table. It was 07.45am on Monday 8<sup>th</sup> November 2004. My mother was born on her father's birthday and departed life on her brother's.

*O Light that follow'st all my way, I yield my flick'ring torch to thee; my heart restores its borrowed ray, that in thy sunshine's blaze its day may brighter, fairer be* (George Matheson, 1842 – 1906).

### **Coda: Professional to the end**

A plethora of phone calls followed which included the GP, funeral director and coroner. Fortunately, my mother's doctor, also her former employer, had very kindly visited the previous evening following a conference which meant the need for a post-mortem would, I hoped, be significantly reduced. In the polite and yet formal cross examinations by the coroner on the telephone at my mother's bedside I explained the reasons for instigating discharge from hospital the evening before. He seemed assured that the evidence before him

excluded foul play. *'I see no reason to carry out a post-mortem based upon your mother's past medical history. I will advise the GP to issue the certificate without delay'*. I thanked him several times before replacing the receiver. *'Thank heaven'*, I sighed. *'At least she doesn't have to endure that [post-mortem]'*.

*O joy that seekest me through pain, I cannot close my heart to thee: I trace the rainbow through the rain, and feel the promise is not vain, that morn shall tearless be* (George Matheson, 1842 – 1906).

We filled the next few days with the plethora of practicalities which follow any death; funeral arrangements, probate, shopping for new suits and welcoming the almost constant stream of well-meaning visitors to the house. The number of cards with beautifully scribed sentiments emphasised others' shock and disbelief. Death changes us, and I am increasingly aware that my professional-self frequently portrays a stoic, cool, calm and perhaps emotionless facade to the world, whilst the inner-self feels the agony of suffering of others beyond words. Those who share our journey look into our eyes, feel our pain and hear that which remains unspoken, and yet they choose to remain close.

*O Cross that liftest up my head, I dare not ask to fly from thee; I lay in dust life's glory dead, and from the ground there blossoms red, life that shall endless be* (George Matheson, 1842 - 1906).

## **Chapter Summary**

The story of my mother's untimely death following an acute stroke alongside a desire to determine what, if any changes in the provision of palliative and

end of life care had taken place since, were the underpinning rationale for this autoethnographic study. Our shared experiences allow us the opportunity to engage with others; listen to their stories and to frame and reframe our own lives, despite our similarities and our differences. It was imperative that I heard the stories of other bereaved relatives having experienced the death of a close family member in hospital following an acute stroke. Therefore, the choice and importance of both research design and methodological approach, considered in the following chapter, are vital when inviting others to share their stories in a way that ensures their voices are heard; their confidence is maintained, and their narratives are allowed to harmonise with others.

## CHAPTER 3 - DESIGN AND METHODOLOGY

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### Chapter overview

This chapter provides an overview of the design and methodology, including the use of autoethnography as the chosen methodology, and its evocative and analytic approaches. In addition, I discuss the philosophical underpinnings of the study, including ontological and epistemological influences. My positionality as a researcher and reflexive considerations are presented. This chapter also offers justification for qualitative enquiry with bereaved relatives of those who have died following an acute stroke. The design and implementation of a qualitative interview study is presented.

### Methodological approach

While I decided to use the research methodology of autoethnography as something that is new, it could be questioned by some academic circles that the methodology not only builds upon familiar qualitative research practice but also fills an important space (Allen, 2015). The methods utilised in autoethnography vary considerably with individual autoethnographers offering different emphasis on *auto* (self), *ethno* (the cultural) and *graphy* (the application of research process) (Ellis, 2004). The term was first used in the 1970s (Hayano, 1979) describing studies of a personal nature with the researcher at the centre of the process. The term means different things to different people although researchers undertaking such an approach to

research will often use their personal experiences as primary data (Chang, 2008). Such a methodology challenges traditional writing convention (Wall, 2006) by enabling the writer to offer highly personalised experiences (Sparkes, 2000). Although autoethnography continues to be challenged for being self-indulgent, narcissistic, introspective and individualised (Anderson, 1997), and offering little social impact (Allen, 2015), personal experience methods are also seen as offering new and unique vantage points from which to make a contribution to social science (Wall, 2016). Chang (2008) purported autoethnography to be increasingly useful and a powerful tool for researchers dealing with human relations in multi-cultural settings. It enables the researcher to understand self and its connection to others (Chang, 2008).

Writing autoethnography and reading others' work frequently evokes self-reflection and self-examination (Nash, 2002) which in turn can lead to self-transformation; including healing from our emotional scars of the past. We all have a story to tell and for me autoethnography is about the heart and the head which I believe is the very essence of palliative and end of life care nursing. As the storyteller, or conductor of this sonata of care, I invite the reader to become part of my world as though washed over by the notes of an orchestral piece as the music fills the voids and crevices of experiences previously unseen or understood, nor words hitherto heard nor expressed. In turn, the reader is suitably positioned to reflect upon their life in the context of mine. At times, the reader of my narrative will observe other conversations

alongside my dialogue (Gadamer, 2000) and, in turn, this is likely to evoke a conversation with your inner self.

### **Evocative and analytic autoethnography**

As a qualitative research method, autoethnography is used to analyse people's lives (Mendez, 2013). It is often intimately related to a particular phenomenon and involves a back and forth movement between self and experience (McIlveen, 2008; Ellis, 2007). Evocative autoethnography aims toward researchers' introspection on a particular subject in order to allow readers to engage with the researcher's feeling and experiences. Analytic autoethnography, on the other hand, is more akin to objective writing and analysis of a particular group (Mendez, 2013). Although autoethnographic authors tend to appear on all points of an evocative-to-analytic continuum (Allen-Collinson, 2013; Wall, 2016) it is not unusual for researchers to embrace both evocative and analytic approaches within their work (Tedlock, 2013).

There is increasing evidence within the literature suggesting autoethnography is heading toward the evocative (Stahlke Wall, 2016). I am biased towards this approach as it has enabled me to immerse myself once again into my own narrative. Yet, there are elements of analytic autoethnography throughout this thesis which are evident in the narrative as I challenge and critique myself and others. At times, as memory falters, there have been parts of my story which I had forgotten. Having the opportunity to reflect deeply throughout this

journey has allowed an honesty to emerge which has allowed me to share my experiences as both a researcher and a bereaved relative.

My *calling* to care for the dying gave rise to me commencing nurse training in London in October 1990. Despite being offered a place from each of the three large teaching hospitals I initially applied to, I chose Guy's because it had a beautiful chapel and a most delightful pipe organ. I've always smiled when reflecting upon that decision, not least because music and nursing, and indeed my faith and nursing, have been intrinsically connected throughout my life. The years which followed resulted in me meeting some wonderful staff and patients, a number with whom I maintain contact today.

Following my interview for the role of staff nurse at Sobell House Hospice in Oxford in 1994, the senior nurse telephoned to offer me the job. "*Your interview was excellent, Andrew. You really made us laugh. We feel you'll make a wonderful hospice nurse*". Interesting, because from the outset of my nurse training, I was advised to steer clear of caring for the dying. "*Leave that to the women who are nearing retirement*", one retired former Guy's nurse urged me, but her words sharpened my resolve all the more. For over 25 years, my work within the hospice movement has meant I have been blessed to work alongside some wonderful colleagues and contribute to the care of many hundreds of individuals whose lives are nearing an end, along with their family and friends. Such experiences have impacted upon my life, often



without immediate awareness, but evident always on reflection. My desire to move away from home and experience life outside the Black Country led me to London, Oxford and my eventual return to the West Midlands. My journey has been a search for meaning; of both life and death. What I have found is a constant inequity in the provision of care for those nearing the end of their life; as a result of their diagnosis and their choice of where they wished to spend their final weeks and days. Those who know me, know that I abhor injustice and I claim little towards either local or national influence in the resulting years. Yet, for the Black Country lad who achieved few academic qualifications whilst at school and had little idea about a future career, my personal, professional, academic and spiritual maturity provides a platform for me to articulate more clearly than ever that diagnosis should never influence access to, nor the provision of, palliative and end of life care.

My story cannot be spoken by another and neither can I tell my mother's story. I can only narrate her journey through the lens of a devoted son and nurse. Over the years, I have reflected deeply about the sequence of events which led to my mother's stroke and her untimely death and as Ulmer (1989) suggests, realise the conditions for re-discovering the meanings of the past are created anew. Our stories evolve and change throughout our journey, and whilst maturity, new knowledge, interpretation and bias impact upon any narrative, I see life quite differently now. Perhaps my memory falters in bereavement? My maternal grandfather was not perfect, but to think of any imperfections previously spoken of by others still causes me pain. I safeguard

myself by sanitising my recollections of him as perhaps I continue to do following my mother's death. These new insights or epiphanies are deeply entrenched in Western thought (Denzin, 2014) and made up of both insignificant, moving scenes of an individual's life. Each life consists of multi-layered narratives, seen by each from their viewpoint. Our narratives can tell us so much about the lens through which we view our world and the lives of those around us. Yet, no other has our voice, nor the ability to tell our story.

The deep sense of conformity within me diametrically opposes the person who vehemently abhors injustice and will not be cajoled nor forced into conforming for conformities sake. We are fickle and erratic individuals, and although such fluctuations in ourselves may be disconcerting (Birhane, 2017), Descartes purported that we should have nothing to do with others in seeking to know oneself. Yet, I believe we learn more about *self* through our relationships with others as they inform our self-understanding. The ancient Zulu phrase, '*a person is a person through other persons*' certainly rings true within this study, evidenced in my personal life and my career. Our relationship with others is central to our being and this study considers not only the inequality and unfairness of the provision of palliative and end of life care for my mother, but also for other individuals with acute stroke along with the impact on and experiences of their loved ones. Rarely do we live in complete isolation of society or others.

The eminent authors Bochner and Ellis (2016) suggested autoethnography brings heightened awareness of and attention to human suffering, injustice, trauma and loss, for example. I do not believe another methodology would have enabled or empowered me to articulate my story and experiences as clearly nor embrace the thoughts, feelings, experiences and narratives of others. Despite the many experiences of loss, I recall no physical nor emotional pain worse than that which consumed me following the death of my mother. Yet, in writing this autoethnography, new epiphanies have allowed me the opportunity to re-live and re-frame many experiences some 15 years following my mother's death. I have done so in light of the knowledge I have gained and a critical eye as I have sought to challenge myself and others.

As part of this autoethnographic journey I have viewed the past in the context of the present and in doing so, allowed memory to re-open the door to the richness of the past (Chang, 2008). Individual stories are viewed through the lens of the writer and are often framed in the context of a bigger story of society interpreted through the lens of another or others. As such stories from the past are interpreted in the context of the present and the present is contextualised in the past (Chang, 2008). These stories are more than just a chronology of life events; they are full of personal meaning and the expressions people give to the meaning of experiences (Gaydos, 2005; Krauss, 2005). Human narrative in research demonstrates how life events affect people and in turn, how people give meaning to such experiences (Minichiello, *et al.*, 1999). There are times when memory falters and our recollections are

unreliable (Chang, 2008). Memories may also trigger extreme emotions in either the narrator or those who hear or read the narrative. The power of memory does not come from precision or accuracy in recalling (Hayler, 2011) but from how we relate to our constructions and re-constructions of the past in the present. As such, any potential limitations within the study are owned, acknowledged and celebrated.

### **Analytical Framework**

This study took an inductive approach to the analysis of interview data whilst also embracing a deductive approach when revisiting data through the lens of the Sonata Framework. A thematic approach offered by Attride-Stirling (2001) was modified and used to ensure data reduction and the devising of themes was clear. Steps 1-3 of this analytical framework are considered in Chapter 4 (Data Analysis) and step 4 is offered in Chapter 5 (Presentation of Study Findings).

### **Philosophical concerns**

At the outset of this research journey, I read that philosophical ideas often remain largely hidden during the research process (Wilson and Stutchbury, 2009) but I believe, and have learned, that it is important to justify the chosen research methodology through transparency. The philosophical and epistemological journey taken, resulting in my evolving positionality as a

researcher using autoethnography as a research methodology, is embedded throughout this study.

Researcher positionality is important and should be declared from the outset of the research process. The positionality of any researcher influences the process from the outset, from the consideration of the topic; the methodological approach; the searching of the literature; the gathering and analysis of data, to the presentation of findings. It is imperative for personal bias to be explored and offered to the reader to ensure honesty and integrity are affirmed. Philosophical assumptions of beliefs, values, ontology, epistemology and relationality must be explored since the subjectivity of research necessitate interpretation throughout the research process (Jackson, 2013). Personal assumptions shape research and our worldview, and therefore philosophical assumptions and researcher positionality influences methodological decision-making within research. However, it is not possible to expect researchers to remain value free and objective in their research (Bryman, 2012) and yet neither should research merely accept the personal biases of its practitioners. Equally, suppressing values is accepted as almost impossible today (Durkheim, 1938).

I am a white single male who has worked in a predominantly female profession for almost 30 years. I am aware that many of my male friends think differently to me and in turn, each has some understanding of the differences between

us. I'm interested in thoughts and feelings, which are very often considered to be female traits, although this does not deter me from continuing to make enquiry, irrespective of gender. From an early age I have learned what I understand to be right and wrong, but with age and experience, I believe right and wrong to be influenced by situation. Life is not merely black or white in my world. I see the world in terms of variations of grey and at times, I find myself diametrically opposed to individual family members, friends or colleagues. Yet, we remain in relationship with one another, retaining a mutual respect for one another.

The philosophical underpinning of this thesis stems from the work carried out by Bochner and Ellis (2016) relating to communication and how we negotiate and perform meaning in our lives. Engaging with bereaved individuals has allowed me the opportunity to hear their stories and reflect upon my own experiences of loss. It has also allowed me the opportunity to consider how we bring meaning to such experiences. The philosophical underpinning also stems from how we deal with the human condition and ultimately make sense of our lived experience (Bochner and Waugh, 1995). These practices are central to how we communicate and create meaning in our lives. Through the stories we create we are connected to others. In drawing others to us, *'we need texts that bear witness to that which they communicate, and which can deeply implicate the reader'* (Bochner and Ellis, 2016 p.936). The voices of others resonate with our own story, becoming one new story which others hear for the first time.

Early in my professional doctorate journey, I became enlightened about a number of methodologies which could have assisted in the production of a piece of credible academic writing. Yet, I soon toyed with the idea that autoethnography would be an excellent vehicle through which I could learn more about myself and others (Chang, 2008). As a hospice nurse and a child whose mother died from an acute stroke my story remains at the fore of this study. Alongside my story, the stories of other bereaved relatives whose family member suffered an acute stroke and died in a hospital setting are explored through qualitative interviews, resulting in this study not having a traditional approach to writing *autoethnography*. Nonetheless, there are several approaches to autoethnography (Chang, 2008) which include the use of others as co-participants in a study. In seeking to understand others, my hope is that the transition to understanding self can also be achieved (Chang, 2008).

### **Ontological and epistemological positioning**

It is important for researchers to position themselves regarding their perceptions of how things really are and how things really work. This professional doctorate journey has enabled me the opportunity to consider my underpinning philosophical beliefs. Whatever the researcher's position, reality or knowledge, the research process and its subsequent outcome will be impacted upon throughout. Similarly, I cannot comprehend that a single truth, devoid of constant change impacted upon my social, cultural, economic or political influence. The natural world is constantly evolving.

The philosophical study of the nature of being, or *ontology* (Scotland, 2012; Jackson 2013) is what Crotty (1998) purported is concerned with what constitutes reality, or '*what is*'. Reality is considered to be subjective and changeable as a likely result of cultural influences which frequently change. My ontological position has shaped my methodological decision-making. I believe reality to be fluid and as such, my preference for a qualitative approach embraces a subjective and interpretative positionality. I wanted to hear the stories of others and in turn, I have been able to offer new insights or perspectives on my own narrative whilst considering my own positionality on theirs. On reflection, I have learned a great deal about my 'self' from others. Reflecting upon the many journeys throughout my life, including primary and secondary schools, the large teaching hospital in London and my first experience as a qualified nurse at the hospice in Oxford, followed by over 22 years in the Black Country have enriched my empathy towards others and diminished any youthful desire to be first or noticed. I have, without deliberate intention, become a more passive and contented individual. Perhaps age and maturity have re-fashioned both interior and exterior 'self'. My thoughts have been refined, defined and re-defined, and although the primary focus of this autoethnography is my story and my experiences, it has been extremely important to me that the experiences and narrative of others, along with any similarity in relationship between us, or not, has a commonality in the shared experience of bereavement.



The epistemological position of this thesis is grounded in interpretivism which assumes access to reality, either given or socially constructed is only through social constructions such as language and shared meanings, for example. As such, researchers influence every aspect of the research process, from the topic selected to the creation of research questions, selection of the theoretical lens, method and overall methodology (Kramer-Kile, 2012). Epistemology considers the relationship between the investigator and what can be discovered (Howells, 2013) and questions including how reality can be known (Vasilachis de Gialdino, 2009). It is important for any interpretivist researcher to appreciate differences between people with the focus on meaning. Although multiple methods may be employed, interviews and observations are preferred. As such, meanings tend to emerge towards the end of the research process.

The very principle of research is seeking new knowledge and therefore, the ways in which knowledge is developed and tested is wholly dependent upon the methodology. Ultimately, the rigour of any methodology is intrinsically linked to the strength of the claim of new knowledge (Jackson, 2013). The goal of interpretivist research is to develop an understanding of the subjects and the topic, alongside a connection between the researcher, the way research is conducted and the research subjects. The study of interpretation and understanding, or *hermeneutics*, originates from the Greek word *hermeneuo* meaning to *translate* or *interpret*. The words we use have the power to either reveal or conceal (Socrates, 469 - 399 BC) and I have been

driven by the need to ensure the narratives of each of the bereaved relatives within this study are clear and unambiguous. The inextricable link between my ontological and epistemological views frame both my interpretation of reality of the world and my knowledge of such a world through sense-making and meaning. Such is the journey through this autoethnography which I chose to undertake because of how I view the world, something Crotty (2003) ruminates upon to understand *existence* and *reality*.

Hermeneutics has long been thought to be an important part of German philosopher, Martin Heidegger's (1889 - 1976) work. If we want to know what it means to exist or '*be*', then we need to start with '*self*'. What does it mean to '*be*'? If '*truth*' exists, what is it? How do we know actual truth? Does '*actual truth*' exist, and if it does, how do we know? During this doctoral journey I have striven to uncover meaning and to shine a light on the experiences of other bereaved relatives in the context of my own story as a bereaved son and an experienced palliative and end of life care nurse. My reality and my truth are shaped by me, borne of my experiences and what I understand and purport to know and feel. These influence who I am and how I view those around me, in a constantly changing world. Undeniably, our experience of the world is interpretive and yet as I strive for subjectivity, I have become increasingly aware of the evidence indicative of my own objective stance (Descartes, 1596 - 1650).

## **Reflexivity**

Reflexivity of any researcher is important as this seeks to address the implications of their methods, values, biases, and decisions for the knowledge of the social world they generate. By definition, reflexivity can be employed to establish criteria of rigour, thus increasing confidence, congruency and credibility (Bishop and Holmes, 2013). Yet, the lack of clarity defining reflexivity means it is a notoriously slippery concept (Bryman, 2008) and despite it representing a new chapter in qualitative research it remains poorly described and elusive (Palaganas, *et al.*, 2017).

Through the continuous process of self-reflection, I have sought to raise awareness within myself of my actions, my feelings and my perceptions (Anderson, 2008). I have striven to ensure that reflexivity resonates across the research process and throughout this thesis. In doing so, I am a changed person and I also believe, in my role as researcher, more transparent (Darawsheh, 2014) although it is much more than mere methodological self-visibility.

Contemporary epistemological debates about knowledge construction have strengthened the relevance of and need for reflexivity in qualitative research (Kingdon, 2005) although guidance on research reflexivity has not always been clearly articulated (Engward and Davis, 2015). Ultimately, reflexivity demonstrates that all research accounts are screened through the narrator's

eye (Kingdon, 2005). Subjectivity is inherent in the thought process of the researcher and I have constantly sought to limit possible bias, not least when collecting, analysing and presenting data. As such, evidence demonstrates that the use of reflexivity not only guides the research process but also seeks to limit researcher bias and subjectivity (Lambert, *et al.*, 2010). However, reflexivity is difficult (Alvesson and Skoldberg, 2009) which needs to be honed, applied and kept at the forefront of the researcher's mind.

I am aware that my own thoughts, feelings, assumptions and other biases, along with those of each of the participants I interviewed, have influenced me and in turn the research process, and ultimately the research findings. The time I have spent reflecting has, I believe, aided the quality of the research produced and enabled me to become more aware of my influences on the process. I have changed, and similar to the natural world, I have no doubt I will continue to be changed by influences upon me. By learning how to effectively influence others throughout the research process, individual researchers can make real strides towards improving not only our world but the world of those around us.

### **Rationale for an empirical study**

The fundamental basis of this autoethnographic study was the collection and analysis of experiential data (the researcher's and bereaved family narratives) within the context of a sonata framework. Whilst there is paucity in the

literature relating to a comprehensive history of autoethnography (Ellis and Bochner, 2000), interest in the method continues to grow (Chang, 2008; Ngunjiri, Hernandez and Chang, 2010). It is a method utilising the researcher's own data to analyse and interpret their own cultural assumptions (Chang, 2008). Autoethnographers frame and cast their vision over lived experiences whilst inviting others into conversation about the meanings of such events (Bochner and Ellis, 2016). These *emotional epiphanies* have frequently changed or deeply affected and influenced our perceptions of other people's lives too. Autoethnography also challenges traditional, analytic social scientists who speak of objectivity and detachment (Bochner and Ellis, 2016).

Whilst social scientists are sometimes dismissive of research that has no obvious connections with theory, literature acts as a proxy for theory because it is frequently implicit within the literature (Bryman, 2012). Theory is something which guides and influences the collection and analysis of data and it is this relationship between theory and research which leads to the use of deductive or inductive theory within a study. Knowledge gained through experience and the senses is one approach to empiricism whilst the accumulation of facts is also legitimate in its own right (Bryman, 2012).

Justification for the use of autoethnography as a method supports the personal narratives of the researcher and others who have experienced the death of a relative. Bochner and Ellis (2006) suggested they wanted their readers to feel

something. Similarly, I want those who immerse themselves in my narrative to not only read but to hear something. I therefore sought to bring together the individual voices of other bereaved family members and orchestrate them into one sonata. At times, it is only the solo voice that is heard, whilst on other occasions it is the harmonised voices that are brought to the fore. Each voice is imbued with personal experience (Blythe, *et al.*, 2012) and individual and collective narratives would lyrically enhance the understanding of others. This supported further inquiry with a view to merging bereaved family members' experiences with my own story. My relationship to potential participants was particularly important (Blythe, *et al.*, 2012). My positionality as researcher also remained key to acknowledging self in the search for truth and to viewing family experiences through the lens of my reality.

## **Qualitative interview study**

### **Aim and objectives**

The aim of this study was to explore the personal experiences of family members whose relative had died from acute stroke following admission to an acute stroke ward. For the purpose of this study, family members are defined as people 'important to the dying person'.

*Objectives specific to family members' experiences were:*

1. to gain an understanding of the availability, provision and delivery of palliative and end of life care in a stroke ward;

2. to explore thoughts and views about the quality of palliative and end of life care practices;
3. to determine whether palliative and end of life care needs for the patient and family members were met, and
4. to examine the transition from acute to palliative and end of life care within an acute stroke ward.

## **Methods**

### **Setting**

This study was carried out on a 23 bedded acute stroke ward in a large inner-city National Health Service Trust Hospital in the West Midlands. Prior to relocating and increasing bed capacity, the ward had one additional short-stay acute treatment room for emergencies transferred to the hospital. The trust utilises the SWAN individual care pathway documentation as part of its provision for palliative and end of life care and is introducing the Gold Standards Framework (GSF) (2015) across the site. In 2018, trust management agreed to the expansion of the Specialist Palliative Care Team (SPCT) to support its commitment to the delivery of palliative and end of life care across the organisation for all life limiting, progressive illnesses. The trust's End of Life Strategy (2018) also promoted the timely intervention of staff for individuals nearing the end of their life to either return home or to another care setting in line with national guidance (DH, 2008, 2014; The

Choice in End of Life Care Programme Board, 2015; National Palliative and End of Life Care Partnership, 2015-2020).

At the time this research was carried out, the ward had approximately 40 nursing staff and a lead consultant overseeing medical services. Other staff including physiotherapists, occupational therapists, speech and language therapists, doctors and social workers provided services to patients. Following an initial conversation with the Ward Manager and Lead Consultant towards the end of 2015, I learned that of the 500 – 550 admissions to the stroke ward each year, approximately 100 patients (20%) died in hospital. Although statistics for death from stroke constantly change, there are more than 100,000 strokes in the UK each year resulting in 38,000 deaths (NICE, 2019). Of these individuals, approximately 6% will have another stroke while still in hospital with 1 in 4 of individuals experiencing a stroke within five years (Stroke Association, 2018). An email requesting access to participants (appendix 8) was sent to the Ward Manager and Stroke Data Information Clerk with whom the researcher had previously met. Following a delayed response which necessitated a further approach, an email reply was received, advising support for and involvement in this study (appendix 9).

### **Ethical Considerations**

Ethical approval from the University of Wolverhampton Faculty of Education, Health and Wellbeing (FEHW) Ethics Committee was initially sought and



gained (appendix 10). Approval from the Health Research Authority National Research Ethics Service (NRES) (appendix 11) was also granted which led to permission being sought from the Research and Development (R&D) Department at the Trust. This took several months longer than anticipated due to staff absence and miscommunication. One minor change in the research proposal offering the public café at the trust as a venue to carry out an interview was considered a major amendment by the R&D team requiring resubmission to NRES. After a further 3 weeks of electronic communications and telephone calls, NRES advised that the amendment did not require resubmission and should merely be removed from the Participant Information Sheet. The trust's R&D department finally accepted this and agreed to the study proceeding (appendix 12). This was a most challenging and extremely frustrating time which delayed the study proceeding by almost four months.

Interviewing the bereaved is a sensitive research topic (Sque, Walker and Long-Sutehall, 2014) and has risk implications for both researcher and the researched (Beauchamp and Childress, 2009). A framework for ethical decision-making (Sque, Walker and Long-Sutehall, 2014) (appendix 13) provided clear guidance on important issues including recruitment, interviewing and follow-up/support. Participants agreeing to take part in the study signed two consent forms, with the participant and researcher retaining one copy each. Clear and accurate records were maintained throughout the research process. All data collected was secured at all times to ensure confidentiality. Data was stored on an encrypted memory stick in a locked

cabinet at the researcher's home and in a lockable briefcase during transit. Electronic information and data were backed-up using an external hard-drive and each document comprised an updated footer to ensure version control was maintained. Names and addresses were stored separately from other personal information (e.g. consent forms) including interview transcripts and secured in a locked filing cabinet. Only the researcher and research supervisory team had access to such information/data which also extended to any identifiable information that was anonymised within the study through use of participant's initials as a pseudonym to maintain confidentiality.

Participants were advised that before and during this qualitative interview study they had the opportunity to withdraw. Withdrawal following their interview (this being the selected method of data collection) was only possible in the following two weeks due to the anticipated amount of work in transcribing along with preliminary analysis in the early stages of the study. The university stated that all data should be stored for two years following completion of the professional doctorate and then destroyed in line with The University of Wolverhampton Guidance on Data Protection. Participants each received a thank you letter following interview and were offered a summary of the research on completion of the study. Each of the six participants agreed to receive a copy of the study summary; with four of the six participants wishing to share its content with family members and friends of the deceased.

## **Participants and recruitment**

The study aimed to recruit a purposive sample (Hansen, 2006; Bryman, 2012) of adult bereaved family members in accordance with the following inclusion and exclusion criteria:

### **Inclusion criteria**

- Adult family member identified as primary next of kin of a patient who has experienced an acute stroke and who has died following admission to the acute stroke ward at the trust between 1<sup>st</sup> January 2016 – 31<sup>st</sup> December 2016.
- Minimum of three months bereaved at the point of invitation to participate in the study.

### **Exclusion criteria**

- Family member identified as primary next of kin under 18 years of age.
- Family member identified as primary next of kin whose complaint about any aspect of service provision is ongoing.
- Family members unable to speak English, unless accompanied by another family member who can understand and speak English and are prepared to act as interpreter.

A purposive sample of eligible participants were identified by the stroke data and information officer and ward manager on the stroke ward with input from the consultant in the palliative care team with information extracted from the

local stroke register held by the trust. Purposive sampling offers researchers a degree of control with the aim of identifying and including information-rich cases in the study (Hansen, 2006). The study aimed to recruit 10% (n = 10) bereaved family members of patients admitted to the stroke ward over a 12-month period. There is no set percentage relating to the number of participants although it needs to be neither too large nor too small to address the research question (Hansen, 2006). Judging the appropriate sample size of a qualitative research study is relative but frequently requires in-depth study and smaller samples than quantitative research (Hansen, 2006). This population was considered appropriate for the study as each had experienced the death of a family member from an acute stroke which would be considered alongside the researcher's experiences and narrative.

Morton, *et al.*, (2012) advise the use of *participation rate* rather than *response rate* be used in order to judge study quality and validity. The rationale being that information relating to how the study population was contacted, the co-operation rate along with the refusal rate convey a more detailed picture. The 21<sup>st</sup> century has seen a variety of contributing factors to reduce participation rate (Galea and Tracey, 2007) and there are few strategies which researchers can employ to counteract the downward trends. A low response rate does not automatically mean study results have low validity (Morton, *et al.*, 2012) but it is important when reporting such details along with the success or not of attempting to raise response rates.

A Participant Recruitment Pack (PRP) including letter of invitation (appendix 14), participant information sheet (PIS) (appendix 15), reply slip (appendix 16) and pre-paid addressed reply envelope was sent to each family member requesting their consideration to be interviewed. A total of 55 packs were sent out over a three-month period in seven phases until the desired recruitment number was achieved. Five packs were sent out for the first three waves and 10 packs were sent out on the remaining four occasions. The decision to increase the number of packs sent out was taken by the researcher and consultant leading the palliative care team due to the unexpected initial lower response rate than expected. If agreeable, recipients were advised to respond using the reply slip no later than 10 days following receipt of the invitation. Contact details for local bereavement support and counselling services (appendix 17) were also included in the pack. A total of 55 PRP's were sent out by 1<sup>st</sup> class mail costing £35.75 along with a self-addressed 2<sup>nd</sup> class stamped envelope costing £30.80. The total postage costs for this study were £66.55. Table 2 represents the dates PRP's were sent out along with the 6 responses received.

**Table 2** – Postage and response information

	<b>Number posted</b>	<b>Accumulative total posted</b>	<b>Number of Responses</b>
<b>18.05.18</b>	5	5	1
<b>01.06.18</b>	5	10	0
<b>15.06.18</b>	5	15	0
<b>29.06.18</b>	10	25	3
<b>16.07.18</b>	10	35	0
<b>27.07.18</b>	10	45	1
<b>08.08.18</b>	10	55	1

Primary data relating to date, time, setting and participant (Chang, 2008) were recorded as soon as a response had been received. Telephone contact was made with the family member upon receipt of their reply slip to arrange a mutually convenient date, time and venue for the interview. A further telephone call was made to the family member 24 hours prior to the interview to determine whether the arrangements previously made remained convenient. Travel expenses up to a maximum of £20.00 per person were offered to participants if the choice of venue for interview was not their home. Only one participant was eligible for travel expenses and, whilst accepting this, asked for this to be donated to the hospice where the researcher is employed.

### **Data collection**

This study collected data using semi-structured individual interviews (Chang, 2008); this method being the most common type of interview used in qualitative research (Holloway and Wheeler, 2010). Although not the usual research method for autoethnography (Chang, 2008) interviews are a powerful way to try and understand people (Al-Yateem, 2012). Data from participants are rich, accurate and as close as possible to reflecting the real phenomena being studied (Al-Yateem, 2012). Interviews produce second-order data (Hansen, 2006) as a result of a discussion relating to events in the past. As a method used in qualitative data collection, interviewing is a way of collecting information about the ways people understand both events and experiences in their lives (Hansen, 2006).

Data recording is extremely important in qualitative research (Hansen, 2006) and data management is essential for confident and accurate tracking. Well organised data invariably assists with data analysis and it is incredibly important to ensure it is recorded correctly (Hansen, 2006). Although there is significant information readily available about the recording of interviews (Fernandez and Griffiths, 2007) there is a lack of information on the impact of interviews on the quality of data obtained from participants (Al-Yateem, 2010). Sartre (1969) suggested people could be affected when observed by others and during interview the way we present ourselves may be different from what we are or how we behave normally. Therefore, by its very nature, the interview situation poses a threat to the quality of data obtained. It was imperative to ensure each situation was managed, or controlled, appropriately, to reduce factors that might affect the interview process (Al-Yateem, 2010). Amongst the controls applied were ensuring each participant felt comfortable and as relaxed as possible; potential risk of distractions and interruptions were anticipated and minimised; all documentation was prepared prior to each interview and the recording equipment was tested, with back-up strategies in place.

### **Semi-structured interviewing**

Although potentially time consuming, face-to-face exchanges between interviewer and interviewee enable nonverbal cues to be gathered. Interviews are a way of understanding people's lives (Doody and Noonan, 2013) and

remain the most common method of collecting qualitative research data (Moriarty, 2011) not least as a considerable amount of data can be obtained on one occasion. As a method, semi-structured interviewing was developed in the 1960's (Hansen, 2006) and often associated with inductive methodologies and as a dynamic tool reflect ongoing data collection and analysis (Hansen, 2006). It is important for the interviewer to draw on very different skills to those required in structured interviewing (Hansen, 2006) as it is important, they respond more spontaneously to the responses within the interview schedule. Responding appropriately, by demonstrating interest or curiosity, or by using humour and offering emotional support (Hansen, 2006) are skills which can enhance the collection of data from participants. When applied to autoethnography, Chang (2008, p104) believes interviews provide external data that gives contextual information to confirm, complement, or reject introspectively generated data.

Semi-structured interviews contain planned questions to maintain focus whilst seeking to avoid digression (Chang, 2008) although the interviewer is free to seek clarification (Doody and Noonan, 2013). Such an approach offers an inductive approach allowing the researcher to keep an open mind about '*the contours of what he or she needs to know*' (Bryman, 2012 p12). However, researchers may be discouraged from delving into private, too sensitive, or uncomfortable topics (Chang, 2008) and therefore they need to balance the need for information whilst minimising participant distress (Bentley and O'Connor, 2015). Interesting, Emmanuel, *et al.*, (2004) concluded that



interviewed bereaved carers experienced little stress when discussing death and dying, with an emerging body of evidence that participating in research about a family member's death is not necessarily distressing for participants (Bentley and O'Connor, 2015).

### **Potential impacts on participants**

Interviewers are the collection tool frequently shaped by their experiences, personal characteristics, knowledge and attributes (Hansen, 2006) with each potentially impacting upon the interviewee. Language is a very important aspect of interviewing, with both interviewer and interviewee requiring the capacity to convey meaning and understanding during the interaction (Hansen, 2006). Differences as overt as language spoken or as subtle as the inference or tone in which words are used may enhance or cause difficulty in the interview situation (Harris and Roberts, 2003). Whilst conscious of the difficulties of language, including health care related jargon, which may confuse people, I made conscious efforts to ensure the language and terminology used would be understood, mindful of verbal and non-verbal cues which might suggest something had not been understood or possibly required clarification.

Although familiar surroundings often help participants to be more relaxed (Moriarty, 2011) some participants may desire a neutral space. Indeed, the site of the interview is an important consideration as this may affect data

collection (Doody and Noonan, 2013). Interviews tend to take place in the home, workplace or public venues (Taylor and Bogdan, 1998) and in qualitative interviewing it is usual to allow each participant the opportunity to choose the location (Hansen, 2006). The key features are for the interview location to be relatively quiet, comfortable, safe and accessible (Hansen, 2006).

In this study, five interviews were carried out in the participant's home and one participant chose to be interviewed in a quiet room at the researcher's workplace as they knew other family members were constantly in attendance at home. A 'do not disturb' sign was placed on the outside of the closed door identifying that an interview was taking place inside the room. A lone worker procedure was utilised when interviewing participants in their homes (appendix 18). Of the five interviews carried out in the participants' home, two were conducted in either the kitchen or dining room, whilst two interviews took place in the lounge/sitting room. One participant requested the kitchen was used as they felt the coolness from the open door to the garden would help settle any nervousness relating to the impending interview. Only one interview was conducted with the participant accompanied by two family members, one of whom was watching a muted television in the same room whilst the interview was taking place.

## **Interview schedule**

An interview schedule containing 16 open-ended questions (appendix 19) was informed by the literature review. It was anticipated that each interview would last up to one hour, and potential participants were advised of this in the Participant Recruitment Pack. Two additional questions on the schedule enquired whether the participant had anything else they wished to share or ask the researcher. I familiarised myself with the schedule in order to prepare for the interview which is supported by Smith, Flowers and Larkin (2009) encouraging preparedness in order to engage, listen and respond appropriately in the interview. Writing notes during an interview can be distracting (Doody and Noonan, 2013) although writing key words and phrases does allow the researcher to reflect on the discussion at the end of or following the interview. Such jottings were discretely taken during each interview as a reminder to further question or to probe a point. Each participant was advised of this prior to the interview commencing and agreed to this taking place. Although I had decided to allow each question to proceed without interruption, I anticipated that probes and prompts might be required in order to encourage elaboration or to clarify a participant's response to a question (Holloway and Wheeler, 2010).

## **Relationship between researcher and participants**

The relationship and dynamic between interviewer and interviewee is important to create and maintain, and Kvale (2006) suggested an interview

with a charming, gentle, client-centred manner may create a close encounter where subjects unveil their private world. Yet, such a relationship has the potential to open up a more dangerous manipulation (Kvale, 2006) and therefore equality and mutual respect between the researcher and participant is essential (Holloway and Wheeler, 2010). This aids the building of trust and rapport with the interviewee, despite the short time frame from meeting to commencing the interview. I ensured the participant was comfortable prior to commencing and affirmed that they were able to take a rest whenever needed. I reminded participants that they were likely to feel tired at the end of the interview which aimed at demonstrating both an understanding and empathy from the outset of the interview. Once the participant was willing to continue, they were asked to sign two copies of a consent form (appendix 20); a copy to be retained by both interviewer and interviewee.

Interviews were recorded using a digital voice recorder with the participants' consent (Doody and Noonan, 2013). This was placed at an unobtrusive distance of approximately 0.5 - 1.00 metre between the participant and interviewer. The voice recorder was battery powered with additional batteries available if necessary. A second battery powered digital recorder was utilised alongside the primary voice recorder to reduce any potential loss of recordings. As a final back-up, a mobile phone was at hand to record the interview if both digital recorders failed. There were no difficulties with recording equipment during the interviews.

It was important for the researcher to maintain eye contact with the interviewee and demonstrate empathy and active listening skills as a way of assuring the participant that they were being listened to (Doody and Noonan, 2013). It was also essential for the interviewer to maintain a neutral demeanour and not demonstrate strong reactions to what the participant shared (Doody and Noonan, 2013). It was also crucial for each participant to have the opportunity to express their thoughts, feelings and opinions about their family member's experiences of palliative and end of life care, and for each to feel able to share their story.

Understandably, there is always potential for participants to feel some distress when discussing aspects of their experiences following the death of their family member and each participant was advised in advance that the interview could be both emotive and tiring (Sque, Walker and Long-Sutehall, 2014). I advised each participant that the interview would be paused if they requested a break or became upset or distressed. The recording equipment would be turned off during this time and the interview would only be resumed when the participant wished to continue. Or, if preferred, the interview would be rescheduled to a mutually convenient time. The recording equipment would only be turned back on when the participant had confirmed they were willing to continue. Verbal consent would be obtained again and recorded prior to resuming the interview. Although several participants became upset during the interview, they expressed a desire to continue and I did not feel any of the participants required follow up support as outlined in the PIS. I did not

determine there were any psychological or safeguarding concerns in relation to any of the interviewees, and therefore had no cause to contact their GP in order that follow-up post interview support could be arranged. At the close of each interview each interviewee was thanked for their participation.

Chang (2008) suggested the 4 W principle (when, who, what, where) works well as such details provided contextual information including the setting, the participants, along with other factors drawn to my attention prior to the interview. This refreshed my memory following engagement with each participant and within twenty-four hours, I wrote detailed notes to serve as a memory trigger (Hansen, 2006). These contained as much detail as possible about the participant, their surroundings, including smells, actions and events associated with each interview. The use of field notes, which serve many functions, is widely recommended in qualitative research as they provide a means of recording contextual information (Phillippi and Lauderdale, 2018). These subjective reflections are personal observations which assisted me in the development of individual narratives and analysis of transcripts based upon the participant, interview and surroundings. These notes also included critical reflections which were useful in later data analysis (Berger, 2015) and certainly enhanced the depth of qualitative findings (Phillippi and Lauderdale, 2018). These notes were placed alongside each transcript with back-up documents saved as hard and electronic copies (Hansen, 2006) and stored in an electronic digital safe. Pagination of notes and transcripts along with

version control of each document ensured data was managed appropriately, thus reducing the possibility of error.

### **Trustworthiness**

Research findings should be as trustworthy as possible (Graneheim and Lundman, 2004) as these are the bedrock of high-quality qualitative research (Birt, *et al.*, 2016). Positivists tend to question the trustworthiness for qualitative research (Shenton, 2004) as a likely result of their concepts of validity and reliability not being addressed in the same way in work termed *naturalistic*. Although disagreements exist, Lincoln and Guba (1985) offer four constructs accepted by many as appropriate for a variety of methodologies. Trustworthiness of any research study involves establishing credibility (confidence in the 'truth' of findings); transferability (applicability to other contexts); dependability (showing that findings are consistent and could be repeated) and confirmability (findings are shaped by respondents and not researcher bias, motivation or interest) (Lincoln and Guba, 1985). The authors have purported that credibility is arguably one of the most important in the establishment of trustworthiness in qualitative research (Lincoln and Guba, 1985). However, Graneheim and Lundman (2004) question the necessity to separate these out as each should be viewed as intertwined and interrelated. Similarly, Le Roux (2016) offers four criteria for consideration: evidence of *subjectivity*; the researcher should achieve *resonance* with the audience; the research should be *plausible* and make a *contribution* to social change. Ellis

and Bochner (2000) purported that rigour in autoethnography requires verisimilitude, and readers should relate to the writing because it is authentic and convincing.

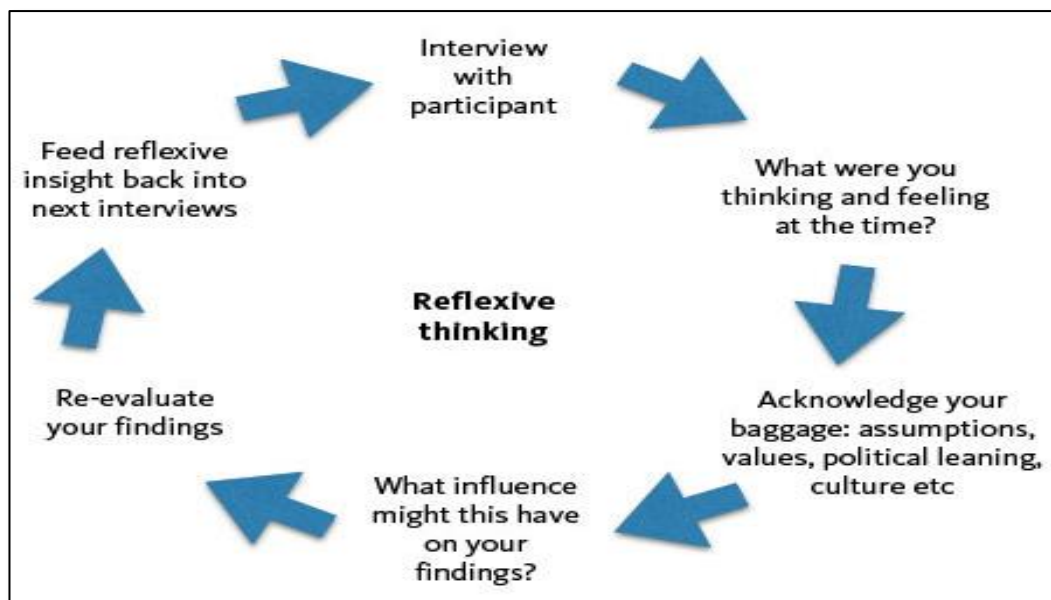
To ensure the trustworthiness of this study I consistently sought to ensure each aspect of Lincoln and Guba's (1985) evaluative criteria was acknowledged, achieved and maintained. I endeavoured to ensure the trustworthiness of this autoethnographic study was evidenced throughout the research process. Techniques to build trustworthiness included, purposive sampling; peer review and support; audit trail of research procedures and decisions; similar semi-structured interview schedule for each participant; carrying out all aspects of the research process with a reflexive awareness; searching for basic, organising and global themes in a sequential manner using Attride-Stirling's (2001) framework; presenting an in-depth discussion of findings and ensuring these paralleled the initial study aims and objectives.

Traditional criteria of validity and reliability are not always easily applied to autoethnography (Holt, 2003) and there are those who suggest the criteria used to judge autoethnography should not necessarily be the same as traditional criteria used to judge other qualitative research investigations (Garratt & Hodkinson, 1999; Sparkes, 2000). Ellis (2000) posits that autoethnographic research should engage readers' emotions and in turn, readers should be able to place themselves in the researcher's shoes and in turn perhaps receive some therapeutic value from engaging with it.



Autoethnographic narratives must be credible (Le Roux, 2016) whilst Lou (2013) indicated the importance of plausibility and contribution. Self-reflexivity and dialogue allow for a better understanding of self while maintaining conversation with others and I found it helpful to use a reflexive model devised by Wilkie (2015) (Table 3)

**Table 3** – Reflexive Model (Wilkie, 2015)



The authentic use of self is evidence of trustworthiness for any research (Wall, 2006) and this is evidenced throughout this study. However, Sparks (2000) believes that because different epistemological and ontological assumptions inform autoethnographic inquiry, the rigorous methodology and generalisability are not necessarily that which should be attained. Qualitative researchers are encouraged to consider thick description of the accounts of

culture which provides others the opportunity to make judgements about possible transferability (Lincoln and Guba, 1985). In qualitative research the trustworthiness of interpretations deals with establishing arguments for the most probable interpretations (Graneheim and Lundman, 2004) and increases when others are able to look for alternative interpretations. I regularly met with my supervisory team, sharing experiences and material which sought to demonstrate dependability (Lincoln and Guba, 1985). Although no formal auditing of the study was carried out, it was extremely helpful to have the opportunity to reflect, discuss and consider alternative approaches. It was also extremely important for me to demonstrate objectivity in the research process and to assure myself and others that personal views and values were acknowledged and addressed. Although complete objectivity is impossible in social research (Bryman, 2012) I consistently sought to demonstrate that I acted in good faith throughout the research process.

Member checking or respondent validation (Hansen, 2006) is primarily used in qualitative methodology (Lincoln and Guba, 1985) and involves sharing all findings (Cresswell and Plano-Clark, 2007) or just transcripts (Hansen, 2006) with participants, allowing them the opportunity to critically analyse and comment upon them. Changes can then be incorporated into the study findings along with a second round of analysis (Hansen, 2006). Lincoln and Guba (1985) consider member checks can bolster a study's credibility and yet although returning transcribed data to participants can be both affirming and cathartic for some participant's others dislike seeing their speech in text

(Forbat and Henderson, 2005). Atkinson (1997) implores researchers not to use respondent validation in an unthinking or uncritical manner as participants may have difficulties commenting upon transcripts. This may be as a result of shifting memory and narratives (Hansen, 2006) as participants seek to refresh, sanitise or amend responses. My preference was not to return interview transcripts to participants as this required the bereaved revisiting something which may be distressing (Harper and Cole, 2012). In addition, any post interview changes made by the participant would allow the opportunity to reframe what had been initially said or offer a completely different response in retrospect. From the outset of each meeting I reaffirmed to each participant that the interview was to be transcribed as soon as possible although there remained a window of opportunity for them to withdraw from the study should they so desire. This practice remains a basic principle of an individual's right to withdraw, without giving reasons (Melham, *et al.*, 2014) before, during or following the interview. No participant withdrew from the study and therefore all six interviews were transcribed and analysed.

### **Transcribing the data**

Audio recordings of interviews were to be transcribed by an administrative colleague working in palliative and end of life care. However, circumstances changed for this member of staff and following discussions with my supervisory team it was agreed that I transcribe the recordings, in preference to this work being undertaken by a company or another individual. This was a

long and arduous task but, on reflection, it ultimately provided me with the opportunity to re-engage with and familiarise myself more fully with the content of each audio recording.

Transcribing was carried out as soon as possible after each interview (Hansen, 2006) and optimally within 12 hours in order to maximise recall (Grbich, 1999). The *gold standard* (Hansen, 2006) is the detailing of all conversation in the order it was held alongside field notes. This was carried out in accordance with guidance offered by Denscombe (2007) who proposed three levels of initial reading. Firstly, reading in order to refresh the researcher's memory; secondly, reading transcripts in conjunction with field notes or similar, to place the material in context and finally, to enable for the reading between lines. As a novice transcriber and in preference to utilising a potentially more complicated system, I developed a set of abbreviations, italics, punctuation marks, symbols etc. (Table 4, p.109) which evolved as transcribing progressed.

**Table 4 – Transcribing Aid**

<b>Transcription Aid</b>	<b>Explanation</b>
Initial 'A'	Words spoken by the interviewer
Initial other than 'A'	Words spoken by the interviewee
01 - 06	Identity of participant transcript
... ..	Incomplete sentence
( <i>word or words in italics</i> )	Word or words written in italics within brackets indicate sounds other than talk, such as laughing, crying, pausing to think, etc.
Pause	Participant paused whilst speaking or pondered before answering
Additional initial, e.g. 'F' within the transcript	Confidential information relating to either the deceased, another relative, a health care professional or organisation

Transcripts were anonymised and a code assigned to each. Depending upon the scheduling of interviews there were times when one interview had not been fully transcribed, and a further interview was carried out. This led to feelings of anxiety at times, particularly as the transcribing was taking much longer than initially anticipated. It became clear during the transcribing of the first interview that specific words, phrases or themes were being used which mirrored experiences during my career and at the time of, and following, my mother's stroke. After several weeks of transcribing interviews and re-checking transcripts against the digital recordings, it was evident rudimentary analysis of the data had already begun. This heuristic approach, although not intentional from the outset, was the exploratory problem-solving technique which Saldana (2015) suggested is undertaken without specific formulas to follow. Prior to coding being carried out, I took the opportunity to pre-code the data (Layder, 1998) by using highlighting, circling and underlining of words or phrases in each transcript.

Each transcript was subjected to rigorous further review as I listened to the recording on two or three further occasions. I took the opportunity to correct typographical errors and punctuation inaccuracies whilst also adding recollections or reminders in brackets about the participant's emphasis on particular words, or their non-verbal responses, body language, or when they became upset or tearful during the interview. Saldana (2015) purported coding to be a cyclical act and once codes had been applied to each of the transcripts these were then categorised in order to produce a system or classification from the datum. Codes symbolically assign a '*summative, salient, essence-capturing, and/or evocative attribute*' for a portion of the data (Saldana, 2015 p3); most often undertaken during and after collection (Miles and Huberman, 1994).

There is potential for the *insider* researcher's study of participants to cause presumption (Blythe, *et al.*, 2012) and therefore a failure to maintain objectivity to ensure findings are accurate (Rooney, 2005). To guarantee transparency and accuracy of the data analysis process I approached a former colleague, also a doctoral graduate with considerable experience working in palliative and end of life care and education, to review parts of each transcript. At this point I provided two or three pages of anonymised, analysed transcript from each interview for review. The number of pages reviewed was based upon the total number of pages within each transcript. In addition, I met regularly with my supervisory team who offered support throughout the research process. Aside from our regular meetings, each maintained electronic

communication and offered constructive feedback on draft work. All went some considerable way in affirming dependability of the data analysed (Lincoln and Guba, 1985).

### **Chapter summary**

This autoethnographic research study is framed in the context of a desire to determine both past and present provision of palliative and end of life care in acute stroke care. This chapter has examined the methodological and philosophical underpinnings of the research and provided justification for an evocative and analytic approach in order to ensure the voices of both researcher and bereaved relatives are heard. As such, the choice of analytical method of the data in the context of qualitative research is considered in the following chapter.

## CHAPTER 4 - DATA ANALYSIS

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### **Chapter overview**

This chapter considers the analytical method of choice and offers justification for the use of Attride-Stirling's (2001) 3-stage approach to qualitative data analysis. The coding of data which results in the development of two *global* themes of *Family Experience* and *Dying & Death* is clearly articulated. Stage A (steps 1 – 3) of Attride-Stirling's (2001) analytical method are addressed within the chapter.

### **Analytical Method of Choice**

Although there are a variety of ways to analyse and interpret qualitative data it is the researcher who makes decisions based upon methodology of the study. Hansen (2006) suggested analysis is the process by which qualitative data is transformed into results, including new understandings, theories and statements about the empirical world. It is through the careful and skilful interweaving of data collection, analysis and interpretation that leads to a narratively engaging and culturally meaningful autoethnography (Chang, 2008). Autoethnographic data analysis and interpretation invariably involves shifting attention back and forth between personal narrative and the story of others; between the personal and the social context (Chang, 2008). In reality, data analysis and interpretation are often conducted concurrently and as such, activity is often intertwined. Yet, for qualitative data to yield meaningful results



it is essential analysis is undertaken methodically (Attride-Stirling, 2001) requiring researchers to disclose their methods of analysis, so techniques can be shared and improved.

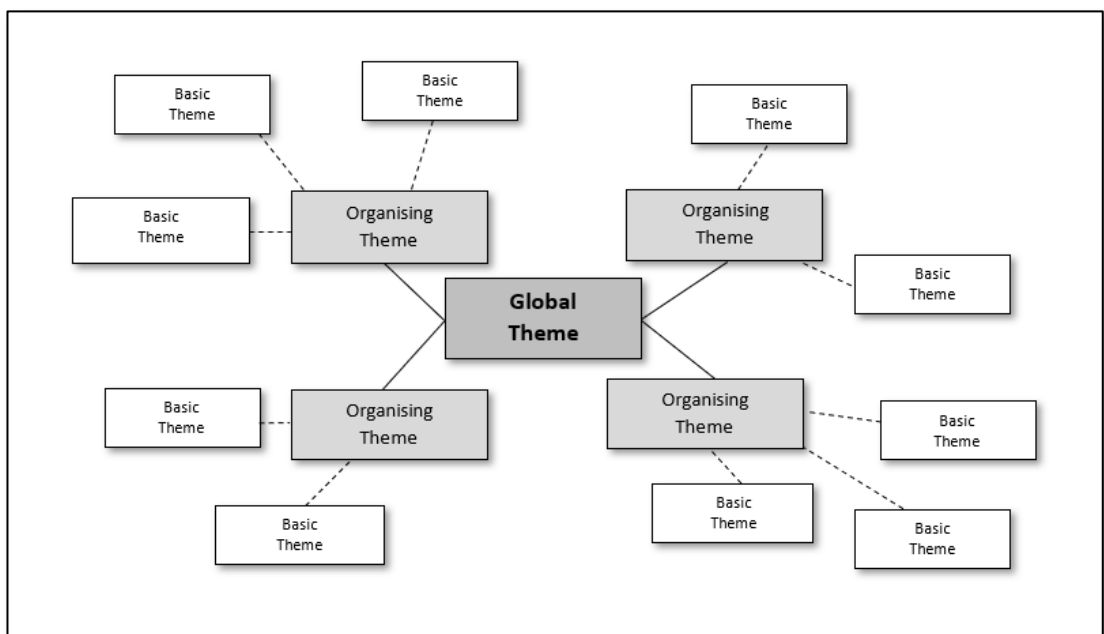
My preferred choice of analytical method, borne of a significant amount of reading around the subject area, was developed by Attride-Stirling (2001). This 3-stage approach is not the only way of conducting qualitative analysis (Attride-Stirling, 2001) although I immediately engaged with the logical approach presented as this resonated with my naturally organised personality. The process of analysis is split into three broad stages, although this study leaned towards the use of 2 stages (A & B) comprising 4 steps in modified form (Table 5, p114), rather than Attride-Stirling's original 6 step method. However, whilst acknowledging the importance of and help received from Attride-Stirling's analytical method, it is important to declare that I did not feel constrained by the method, hence the modification, and despite adhering to sequential progression, as I moved backwards and forward in step 3 'Construct Thematic Networks' several times to ensure I was satisfied with the themes extracted from the data and I had not overlooked anything. It remains pertinent to disclose that although Attride-Stirling's (2001) analytic method remained my preference, I was also drawn to the writings of Bryman (2012), Hansen (2006) and Chang (2008) who have informed my knowledge and skills whilst undertaking data analysis. Stage B of the method is applied in Chapter 7.

**Table 5** – Modified Analytical Method (Attride-Stirling, 2001)

<b>Analysis Stage A</b>	<b>The Analytic Steps</b>
<b>Step 1:</b> Code Material	c. Devise a coding framework
	d. Dissect text into text segments using the coding framework
<b>Step 2:</b> Identify Themes	c. Abstract themes from coded text segments
	d. Refine themes
<b>Step 3:</b> Construct Thematic Networks	g. Arrange themes
	h. Select Basic Themes
	i. Rearrange into Organising Themes
	j. Deduce Global Theme(s)
	k. Illustrate as thematic networks
	l. Verify and refine the network(s)
<b>Analysis Stage B</b>	<b>Exploration of text</b>
<b>Step 4:</b> Describe and Explore Thematic Networks	c. Describe the network
	d. Explore the network

Attride-Stirling’s (2001) thematic approach encourages the analysis of data from participants and therefore from the outset I sought to ensure the inductively derived data would be presented as thematic networks. This allowed the exploration and understanding of an issue and provided a way of organising a thematic analysis of the qualitative data. I systematically extracted the lowest premises (*basic themes*) within the text before grouping these into more abstract principles (*organising themes*). Finally, super-ordinate themes which encapsulate the principal metaphors within the text (*global themes*) were developed resulting in a clear visualisation of the collective narratives within this sonata of care. The sequential development of *basic, organising* and *global themes* (Figure 1, p.115) provided the opportunity to really engage with each transcript whilst developing my analytic skills. It

was extremely important for me to do justice to the narratives of the bereaved relatives I had interviewed to ensure I remained true to their story. I achieved this by immersing myself into their discourse, seeking to embrace both choice and use of language. I believe the visual appeal of Attride-Stirling's (2001) framework fundamentally enhances each narrative and enables the reader to engage with the essence of each inter-connected narrative. I developed two global themes: The Family Experience and Palliative & End of Life Care.



**Figure 1** – Thematic Networks (Attride-Stirling, 2001)

Whilst anxious about what data would be produced from interviewing bereaved family members, I soon began to feel a little overwhelmed at the quantity produced. There is overwhelming agreement amongst qualitative researchers that data reduction remains an important strategy (Attride-Stirling, 2001) and the process of reduction, refinement or narrowing the focus

of data collection is an extremely important one (Bryman, 2012). Without it, data management is virtually impossible. Therefore, unless the researcher reduces the corpus of information it is more or less impossible to interpret the material (Hansen, 2006; Bryman, 2012). Guidelines or expert direction to determine how many data are necessary to support a conclusion or interpretation in qualitative research do not exist (Taylor & Boydan, 1984). It therefore remains important for the researcher to self-regulate whilst moving through data analysis; not least in autoethnography (Chang, 2008) as themes extracted from the data become clearer.

## **Analysis Stage A: The Analytic Steps**

### **Step 1: Code Material**

The first step in a thematic network analysis is reducing data. The use of a coding framework is based on pre-established criteria, recurrent issues within the text, or a set of theoretical constructs explored systematically (Attride-Stirling, 2001). This may be undertaken inductively or deductively, and I began to code and sort the data inductively. As such there was no formal use of a coding framework, although I do acknowledge the potential influence of my lens as a health care professional and a bereaved relative. Nor did I use a specific computer programme, preferring my comparatively simple and yet effective approach. Recurrent words and phrases were noted and identified initially by highlighting in yellow (Appendix 21). Frequently appearing topics within the data tends to signify its importance in life (Chang, 2008) and these

single words or topics (Attride-Stirling, 2001) became the initial, if not rudimentary codes, extracted from the data. A Microsoft Excel table enabled the recording of words and phrases based upon the accumulative initial analysis of each transcript (Appendix 21).

Additional details were added to analysed transcripts which included when participants paused, coughed, laughed, or became tearful, for example. Inflections in their voice were noted and observations about non-verbal cues were also recorded. In addition, minor amendments were made to two transcripts having reflected upon what was initially transcribed and what was subsequently interpreted and concluded. The revisiting of transcripts enabled a greater familiarity with each whilst allowing the opportunity for me to step-back, albeit momentarily, into each experience, affording me the opportunity to reflect more deeply and with a little more objectivity with the passage of time.

## **Step 2: Identify Themes**

I carried out a second wave of analysis using blue highlighting (appendix 22) to differentiate this stage of analysis from the initial undertaking. This further analysis of each transcript allowed the opportunity to record more detailed words and phrases in the Excel spreadsheet used when beginning data analysis. The sequential use of the first interview analysis for the second interview (Hansen, 2006) proved helpful when identifying emerging themes

(Attride-Stirling, 2001; Bryman, 2012). The template from the second interview was then used for the third interview, and so on. This process was carried out for each of the six transcripts and aimed at ensuring continuity during the analytical process through the accumulation of basic themes (Attride-Stirling, 2001).

### **Step 3: Construct Thematic Networks**

For qualitative research to yield meaningful results it is essential that material gathered be analysed in a methodical way (Attride-Stirling (2001). Having read each transcript, and as part 3 of the method, I began to assemble identified basic themes into similar, coherent groupings. A total of 11 basic themes were developed into three middle order or *organising themes* which cluster basic themes into similar issues. On occasion, the organising theme was a direct use of one of the basic themes. Eventually, these organising themes were reduced further and merged into two *global themes* which are the super-ordinate themes grouping organising themes together. As such, these '*present an argument, a position or an assertion about a given issue or reality*' (Attride-Stirling, 2001 p389) and were initially incorporated into a table for ease of modifying (appendix 23). Although no hard and fast rules exist about the number of themes, Attride-Stirling (2001) suggested that more than 15 may prove too difficult to handle and fewer than four may not do justice to the data. The use of colour-coding to further differentiate between themes was applied and this was utilised when themes were re-presented as web-like

maps, to remove any suggestion of hierarchy, thus depicting salient themes at each level, whilst illustrating the relationships between them (Attride-Stirling, 2001).

Having completed the development of thematic networks from inductively derived data, I moved on, approaching the data deductively, and began to consider my own experiences as a bereaved relative and health care professional in the context of the narratives of others through the lens of the sonata framework, to determine whether possible similarities or disparities existed. Analysis Stage A of Attride-Stirling's (2001) thematic network had been completed.

### **Seeking to reduce researcher bias**

The qualitative researcher is the instrument for data collection and needs to take responsibility for not only gathering words but for analysing them (Cresswell, 2014). Every researcher brings with them a personal bias into their work and observations (Trochim, Donnelly, and Arora, 2016) and it is these experiences that shape the interpretations made through the analysis process (Cresswell and Plano Clark, 2007). Similarly, interpretation of data is influenced by the researcher's history (Graneheim and Lundman, 2004) and I was most diligent to ensure researcher bias was minimised (Blythe, *et al.*, 2012) and analytical objectivity maintained.

Although no research can possibly remain value free (Bryman, 2012) each transcript was dealt with in a similar way to reduce questionable process or bias. Each interview transcript was read electronically, initially adding annotations in the right-hand margin whilst highlighting in yellow any words which resonated with or appeared significant at the time. Further analysis of the transcripts was undertaken in the order the initial analysis was conducted. Again, this methodical approach reinforced a sequential analysis of the data. On this occasion, additional annotations were added alongside further highlighting, this time in blue, thus differentiating from the initial analysis.

I undertook the same process for each of the transcripts during which it became evident that themes were being generated in my mind, as commonalities appeared across transcripts. I spent some considerable time reflecting in my role as researcher (Hansen, 2006), by considering each interview and recording details in accompanying notes to demonstrate credible reflexivity throughout the study. Once completed, I spent time re-reading all transcripts to refresh my memory whilst identifying words which resonated with me from each narrative.

Methodologically, autoethnography is nebulous and as such does not lend itself to a linear process (Chang, 2008) and neither does analysis of the data (Polit and Beck, 2004) as each inquiry is distinctive, with results depending upon the skills and insights of the researcher (Hoskins and Mariano, 2004).



Very little can be made from data in its raw form but through the process of content analysis new learning and knowledge can be achieved and there were times when I repeated tasks or noticed that tasks overlapped. However, I believe each allowed the opportunity to inform, influence and modify the other. Whilst seeking to maintain an objective positionality and having collected all the data, I quickly learned that through its organisation by labelling and classifying I became most enthused by the process and eager to progress. Having begun the process with some trepidation, I became more excited about the potential findings determined through the journey of analysis to that point. The following chapter describes and explores the thematic networks, identified in Stage B of Attride-Stirling's (2001) analytic steps.

### **Chapter Summary**

Attride-Stirling's analytical model (2001) has been considered and justified as an integral part of this study. This chapter has allowed articulation of debate and affirmed the importance of ensuring the narratives of both researcher and participants are clearly heard and considered fully in the context of the provision of palliative and end of life care in acute stroke. This detailed platform offers context to the presentation of study findings in the following chapter.

## CHAPTER 5 - PRESENTATION OF STUDY FINDINGS

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### **Chapter overview**

The skilful interweaving of data collection, analysis and interpretation ultimately leads to the production of narratively engaging and culturally meaningful autoethnography (Chang, 2008). This chapter presents the interview data from six participants as part of this autoethnographic study, each having the opportunity of sharing their story with me. Data is presented under the headings of two *global* themes: The Family Experience and Dying & Death following the use of Attride-Stirling's (2001) analytic method, with each considering sub-headings taken from the *organising* themes. This chapter describes and explores each network in detail (data analysis step 4). The origins of participant quotes are represented by pseudonyms 01 – 06.

### **Background of the participants**

The population comprised five female and one male participant, with their relationship to the deceased identified below (Table 6, p.123) which also details the gender of the family member experiencing the stroke.

**Table 6** - Gender of patient along with their relationship to next of kin

<b>Participant</b>	<b>Primary Next of Kin</b>	<b>Deceased</b>
<b>01</b>	Female (Wife)	Male (Husband)
<b>02</b>	Female (Daughter)	Male (Father)
<b>03</b>	Female (Niece)	Female (Aunt)
<b>04</b>	Female (Daughter)	Female (Mother)
<b>05</b>	Male (Husband)	Female (Wife)
<b>06</b>	Female (Partner)	Male (Partner)

Table 7 details the length of time following admission of the patient to their death and the length of time between the death of the patient and the interview with the primary next of kin.

**Table 7** – Length of time from admission to death and length of time participants were bereaved

<b>Participant</b>	<b>Length of time from admission to death</b>	<b>Length of time participants were bereaved</b>
<b>01</b>	18 days	17 months
<b>02</b>	40 days	Not known
<b>03</b>	2 days	Not known
<b>04</b>	<1 day	18 months
<b>05</b>	4 days	13 months
<b>06</b>	7 days	12 months
<b>Average length of hospital stay</b>	12 days	15 months

The findings obtained from interviewing primary next of kin whose relative died in hospital following an acute stroke appeared rich in detail. Whilst undertaking data analysis it became clear that the honesty and poignancy of

what participants shared could inadvertently be diminished or reduced if the reporting of such narratives was sanitised. Direct quotes can be most poignant and representative (Anderson, 2010) and one of the underpinning principles of this study was for participants' narratives to remain at the heart of this sonata of care, and as such, their individual and collective voices and their emotions are presented, and frequently remain in their purest forms.

Participants provided a wealth of information about their relative including the events leading up to their stroke; their admission to hospital; the care provided by staff, and the time leading up to their death. There were aspects of each participant's narrative which resonated with my story, although this varied in frequency and intensity. At times the links were tentative whilst at other times the situations described, and the narrative used, could have been my own. Listening to one participant's recollections was, at times, as though I were listening to parts of my own story in terms of its presentation, including the four days from their relative's acute stroke to their death. Although this participant's story resonated deeply within me, I consciously repositioned myself to ensure objectivity and ultimately reduce bias which I was mindful may have diluted rather than distilled the narratives of other participants.

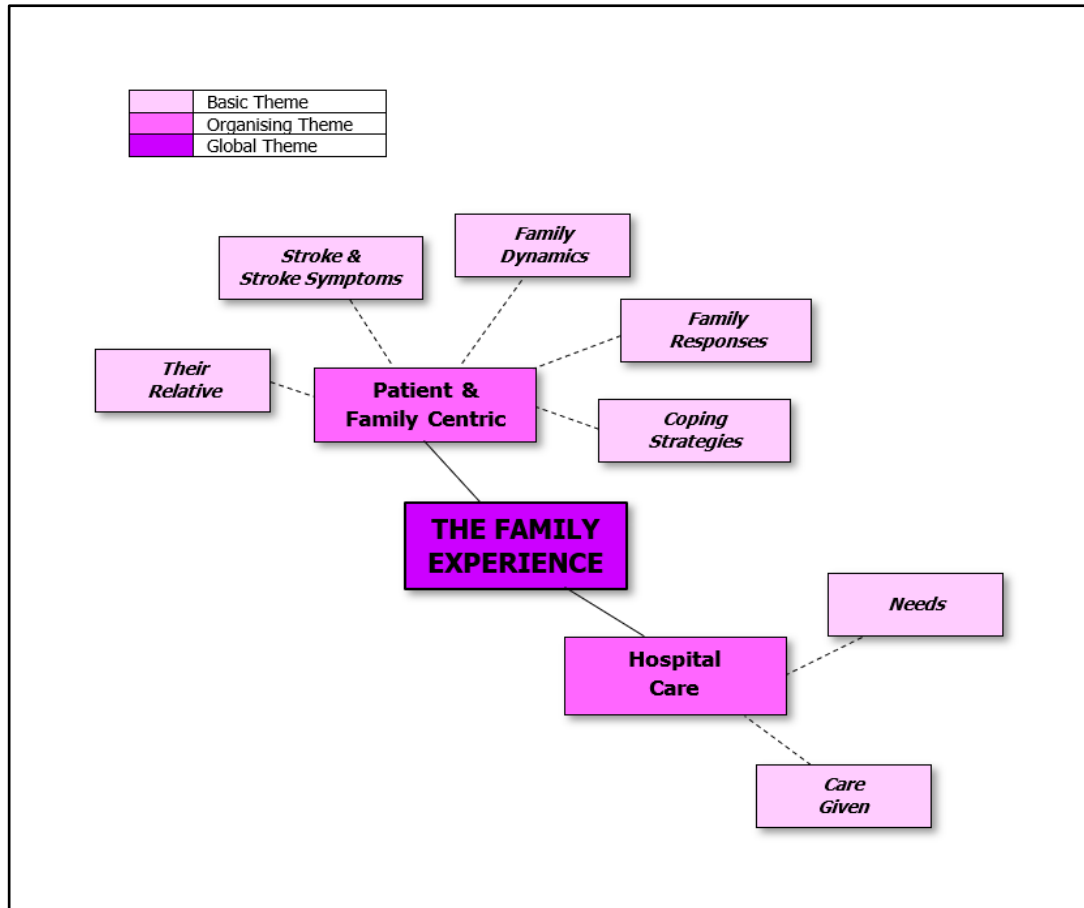
## Stage B: Exploration of text

### *Step 4: Describe and Explore Thematic Networks*

Inductively derived findings are presented as two thematic networks, each comprising a *global* theme in **BOLD CAPITAL LETTERS**; *organising* themes in **bold** and *basic* themes in ***bold italics***. Further, each network is presented using associated colours from the colour palate (appendix 24) with the **GLOBAL THEME** in purple; the **organising themes** in fuchsia, and the ***basic themes*** in violet. The purpose of this is to aid the reader to visually identify component parts of each thematic network. In addition, each **GLOBAL THEME** is connected to **organising themes** with a solid line whilst **organising themes** are linked to ***basic themes*** using a dotted line. Again, the purpose being to aid the reader's visualisation of the themes generated from the data.

### **Thematic Network for THE FAMILY EXPERIENCE**

The first global theme **THE FAMILY EXPERIENCE** (Figure 2, p.126) comprises organising themes of **Patient & Family Centric** and **Hospital Care**. The former reflected participants' recollections of their family member and the latter concerned issues relating to the hospital admission.



**Figure 2 – Thematic Network for The Family Experience**

### **Patient & Family Centric**

Several participants spoke about the personality of *their relative*, specific traits or characteristics which they shared with tremendous sincerity and at times with humour. For example, participant 02 recalled, '[She was] *very kind ... a wonderful character...somebody who people respected*' whilst participant 03 reminisced, '*She was a great influence on me. A very proud lady*'. Participant 04 reminisced with a noticeable chuckle. '*She could be a bit cantankerous when she wanted to be [laughs]*' and participant 06 reminisced about their partner and said, '*He was a comedian...he was a tormentor, a joker ... [but] he could be pig-headed [smile, laughs]*'.

Some conversation instigated by the participants focused on faith belief or religion when speaking about their family members. Participant 03 told me of their beliefs saying,

*We're Roman Catholics, and, you know, they kept coming to see her, the priests, and we sat with her ... we believe as Roman Catholics that you go to something ... much more, I mean, I know, I know not everybody has got that ... we think we go to somewhere better. I think she went to somewhere better ... we only stayed about ten minutes ... to say our goodbye's ... and just say a prayer ... and wish her a speedy journey.*

Participant 02 spoke fondly of their parent and the upbringing and influence received when a child, including the ethical issues which influenced them. *'He brought us up to respect other people and have all those, the right morals and ethics'* (02). The bond between parent and child was evidenced by the many examples this participant shared with me, but it was clear they were not wanting their relative to suffer at the end of life. Participant 03 also told me, *'I didn't want her to suffer in any way'*, whilst participant 02 reaffirmed their thoughts by adding,

*The kindest thing is to, to let them go. Now, I'm not one for saying ... people should be treated and [nervous laugh] and aided to die but I think the fine line sometimes of almost being cruel to let somebody have to go on for two and a half weeks without nourishment or anything else.*

Each participant spoke of their relative's **stroke & stroke symptoms** alongside any pre-existing conditions or co-morbidities which their family member suffered from in the years or months leading up to their acute stroke. Participant 02 told me their family member had experienced several smaller strokes previously, but each time had returned home from hospital with no

long-term side effects. Participant 06 said their partner had undergone major surgery to correct poor circulation in their leg which could have resulted in amputation, in addition to mild vascular dementia. Similarly, participant 03 recalled struggling to get a GP to refer their family member to a consultant after months of escalating symptoms suggesting vascular dementia following several trans-ischaemic attacks (TIA's) in the past.

All participants spoke about the lead up to their family member's stroke and the majority told me about any symptoms/interventions prior to and following the stroke. Participant 01 vividly recalled walking into the kitchen to find their partner at the sink. *'R was rubbing his face and when he looked up, his eyes [pause to compose self]...so I rang 999. It was his eyes that gave it all away'* (01). I was able to see the pain of this relived experience in this participant's face. The suddenness of the stroke and the effects on family members were expressed by several individuals. Participant 02 told me their relative was *'very fit and well and it [the stroke] was a complete surprise to us ... he had a really bad headache ... his speech was starting to slur'* (02).

Participant 04 indicated their family member was only saying *'the odd couple of words'* as they were transferred to hospital by ambulance *'but by the time we got to hospital she'd stopped speaking'* (04). Participant 01 said their partner was *'frightened and vulnerable'* whilst participant 05 told me of the shock of their partner's illness; *'She'd shown no sign of any complaint before'*.



Their family member was a fit and active individual who rarely visited the GP and had never been admitted to hospital previously. *'I don't think it was a minor stroke. It was a serious stroke.'*

Three participants spoke about instinctively knowing something was wrong and that their family member was ill. One participant said they knew something was wrong but felt guilty after shouting at their partner for causing a flood in the bathroom whilst attempting to shower with the door to the cubicle open. It was only in retrospect when, the following morning, they awoke to their partner making noises and having seizures that they knew something was terribly wrong. This participant told me, *'I treble nine'd...it seemed to take ages for them [paramedics] to come. When they carried him down them stairs [pointing] he was very, very vacant. It was though he just stared. He didn't recognise me'*(06). Participant 04 said, *'I heard a slight groan and found her on the downstairs toilet floor. I went to her and then I realised it was serious'*(04). *'When I got there,'* participant 02 told me, *'I knew his speech was starting to slur...so I got the 999'*(02).

Several participants spoke about their relationship with other members and the **family dynamics** which either existed prior to or following the stroke. Participants told me that communication difficulties and fractious relationships between family members triggered a number of responses following the stroke, including anger or disengagement, as a possible consequence of

feeling frightened and/or frustrated. Participant 04 told me of a younger sibling who had distanced themselves from their mother several years before which added to the pressure of others. Yet, participant 02 spoke of the closeness of their family and the collective between siblings as well as their relationship with their father which resulted in them taking it in turns to stay at the hospital without leaving his bedside.

One participant told me that their stepchildren were very supportive even though they lived a considerable distance away. *'I'm not the mother ... it's [a] slightly different relationship'* (01). Participant 03 spoke of the tension between family members prior to their relative's admission to hospital, although each agreed that staff *'made him [their relative] comfortable'*. *'I feel really guilty'* participant 06 told me. *'I did get a bit irate with him [their relative]'*. Due to long standing medical conditions, exacerbated by the developing stroke, the participant acknowledged the difficulties of being a carer whilst managing a relationship with a stepchild who is *'very overpowering ... and ... got attitude'* (06).

Each participant spoke about **family responses** to the patient's stroke including how they personally felt; often leaving them feeling shocked and in a state of disbelief. Participant 05 spoke of the impact of their relative's stroke on them, saying, *'it happened so quickly and so suddenly ... I didn't know if I was coming or going'*, and participant 04 said they had been unable to take

things in as a likely consequence of the shock following their family member's stroke.

*He [doctor] tried to explain to me what had happened. He tried his hardest to explain to me. I know he was trying to tell me that there was very little chance that she would come out of it. But he did say "but you never can tell. She may come out of it" and my brain picked up on that (04).*

Participant 05 and their partner had been out for a pub lunch and returned home when the stroke occurred, whilst participant 02 told me their family member had been watching television with their partner who complained about a headache. *'I thought, this has happened twice before. It wasn't such a shock at this point'* (02).

Participants spoke about their ***coping strategies*** following their family member's stroke. Participant 02 told me that family members were concerned about their relative being in hospital. *'We didn't want my father to be on his own at any point'* (02). This participant said they did not have any concerns about either nursing or medical care, but members of the family felt able to cope with their relative's hospital admission by ensuring he was not alone at any time.

Participant 03 told me that whilst their relative was in hospital and unable to speak, they regularly recalled things that their partner had said to them. *'He*

used to say, "you're the strongest. You can cope". Participant 05 said they managed to cope following their partner's stroke because,

*I know how to cope with the single life. I miss her tremendously ... but, I can cope 'cus I always used to. I'm moving. It's too big a house for me. I'm moving to an apartment just up the road. I have photographs all around to remind me of her (05).*

Participant 04 recalled the times they and their relative had coped with difficult situations in the past by laughing hysterically together whilst participant 01 spoke of coping in bereavement because having married in older age '[we] found each other ... and had a wonderful life [together]'. Each became emotional and at times fought back tears, but then either laughed or apologised for getting upset. Participant 03 and participant 06 recalled funny situations and conversations with family members whilst sitting with their loved one in hospital. 'We laughed and joked as you do'(06) whilst participant 03 chuckled when telling me, 'she was always losing her ruddy teeth [laughs]. Oh God. Her teeth were always going missing. I'd find them in the bin [laughs]. She only had one tooth. She looked like Nanny McPhee'(03).

## **Hospital Care**

Participants shared their individual and collective thoughts about the hospital **care given** which included recollections about the staff who cared for their family member. Participant 03 reflected and said, 'they made you feel as though you were the only one that, you know, that she was important. They're wonderful. I can't speak highly enough of the service that we've been given'.

Similarly, participant 05 told me, '[They] *couldn't do enough for her or for that matter ... for people like myself. I remember one of the nurses ... saying, "Would you like something to eat?". I hadn't thought of that. You don't think of things like that.*

When participants reflected upon the patient being cared for in hospital, the majority were complimentary of hospital staff. Participant 03 told me, '*they [staff] were wonderful ... they were absolutely wonderful ... couldn't have done any more. I mean, they were really professional, and they were very caring. I've got only praise for the staff. They were absolutely marvelous.*' Other participants spoke about how busy staff were on the wards as well as the pressures on the NHS, including the need for more resources. However, despite existing NHS hardships and staff shortages, participant 05 felt members of the ward staff were '*doing their best under the circumstances*' and added, '*they're so run off their feet and they've got no [money] ... short on resources ... and they made you feel as though you were the only one that, you know, that she was important. They're wonderful*' (05).

When speaking specifically about the care given by members of the nursing staff, participant 05 said,

*I couldn't fault it [the care] at all. They were excellent, the nurses were. The treatment she had when we arrived at the hospital ... was first class. They [staff] always came regularly to see her and move her. They didn't leave her for a very long time for any length of time. The service we got from them [staff] was first rate. I can't fault the hospital in any way. I*

*don't think there was anything I could have found fault in them at all. I think they did all they could under a very difficult situation (05).*

Participant 06 reflected for a few moments and then spoke very emotively about the tenderness shown to their relative whilst on the stroke ward.

*I can say he didn't want for nothing. They [nurses] turned, they changed [patient] every two hours which I think is extremely good ... considering how hard they have to work. He [patient] always smelled nice. He'd got his aftershave on. They gave him all the care. From what I could see they were amazing with him. I wouldn't have a bad word said about 'em (06).*

However, although not critical of staff, participant 01 offered a very considered response to the care provided in the stroke ward. *'I had to say they were, most time, they were ok, urm, they're doing the best they can. I don't think there's probably enough staff' (01).* Participant 03 conveyed similar feelings, saying, *'They're [staff] so run off their feet ... and they've got no ... short on resources'* whilst participant 01 concluded by telling me, *'I feel that the staff do, the majority, follow text book ... some can see beyond that ... [but] everyone's running around in a hospital without stopping to think'.*

When asked to consider the quality of care provided on the stroke ward, all participants complimented staff for the care shown to their family member. One participant said, *'it depends what you call quality care. But you're numb. You really are...quality isn't thought of at the time'* (05). Participant 02 told me,

*I would describe quality care as providing the support to and the attention that is needed to the patient and to the family...and I would expect someone to be treated how you would want to be treated. So, if you went into comb my father's hair, I would expect somebody to talk to him and say, "I'm just going to comb your hair", and speak to him as though he would know what was going on [if conscious]'.*

Participants spoke about specific care given to their relative including assistance with personal hygiene, administration of medication, food and fluids, as well as help with toileting, in addition to the care given just before and after death. On most occasions, interventions were deemed to be appropriate and timely. However, one participant spoke about repeated attempts to insert a naso-gastric (NG) tube by staff who they thought were either not trained in the technique or who were apprehensive about undertaking the task. This participant was upset when she recalled one intervention of hospital staff.

*They [staff] were holding my father down on the bed trying to get this tube in three or four times and so, I was in there trying to help ... and every time they went to put the tube down my father was going like this [waves arms demonstratively] because it was making him gag. The more and more it was trying to happen the more that unfortunately it distressed my father...he still knew what was going on although he couldn't speak (02).*

Other examples of the interventions of hospital staff included providing drinks, refreshments and even bed linen for family members when staying overnight. Overall, all participants agreed that staff provided appropriate care when it was needed. *'He always smelled nice,'* said participant 06 when recalling how nursing staff applied aftershave to her partner after assisting with his personal

hygiene. *'They gave him all the care. From what I could see they were amazing with him'*(06).

Participant 02 spoke very movingly about their parent's time in hospital and the care received by staff, and just how helpless they felt at the time by not being able to do anything to change the situation.

*You're watching someone effectively suffer and die and somebody saying there's nothing they can do about it. The care was very, very good. Once my father was moved into the room, the separate room ... the nurses were very, it was more, they were very caring and they changed, I suppose at that point it was also caring towards the family. They [the staff] were there if we needed them but not there if we didn't. They would have done anything that they could have ... to have helped ... they weren't intrusive into a very private situation. It took four or five of us to hold him down on the bed ... and it wasn't very nice. I feel really bad that I didn't understand what dad wanted [becomes extremely choked] but nobody else did. We didn't feel that maybe if we weren't there that things would have been different. Dad was looked after in the best way he could* (02).

Participant 03 said *'the staff were kindness itself and they allowed her [patient] to die with dignity'* whilst another participant told me, *'a nurse was with her [when she died] ... and she wasn't conscious ... it happened so fast'*(04).

Participants spoke about their **needs** alongside wider family needs during the time their relative was in hospital. Participant 02 felt their family needed as much information as possible at the time, whilst others spoke of hospital staff telling them so much, they were unable to take it all in. One family member had been in and out of hospital several times in the run up to their stroke and participant 03 said they were annoyed at *'fighting the establishment all the*



*time. I didn't seem to have any help at all off my GP. It was a lot of pressure on me really.* It was only when their family member was admitted to hospital following their stroke that the participant felt supported.

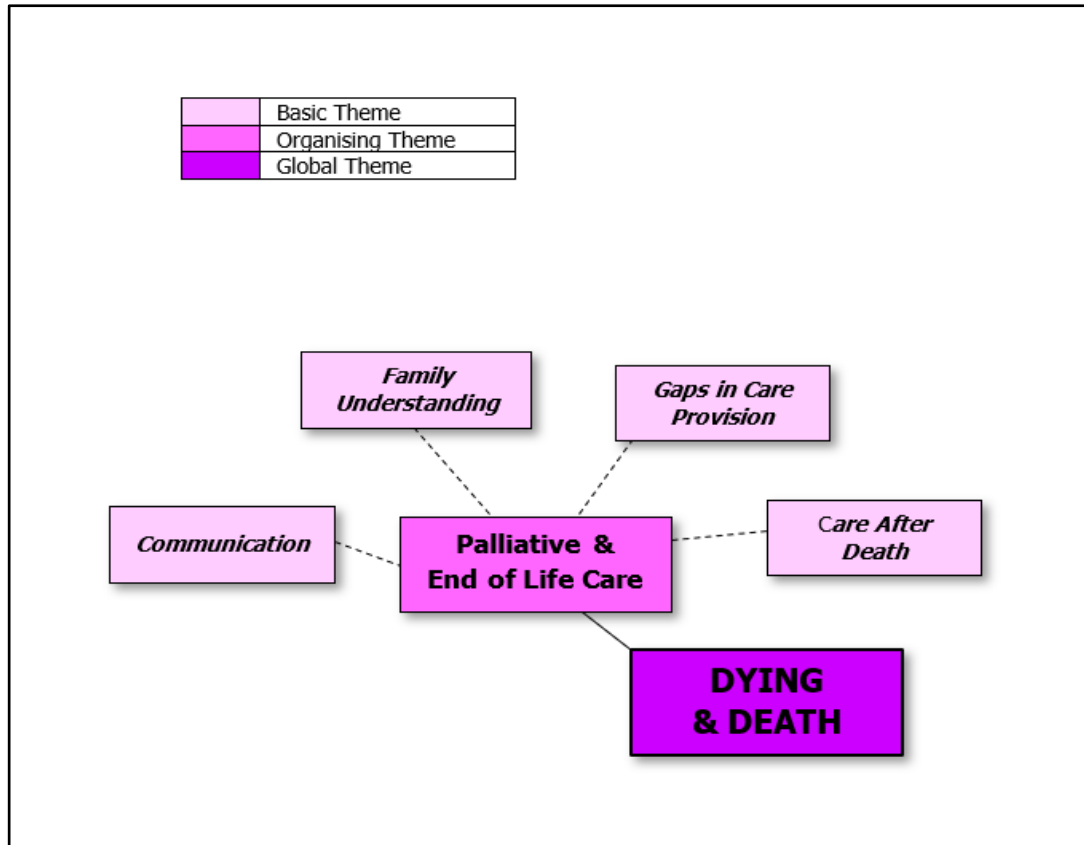
I perceived that visiting times on the stroke ward were generally waived for participants and other family members wishing to visit. For some, however, there were concerns. One participant (01) told me they were not advised when they were able to visit, and another participant (04) said that no one had indicated otherwise, so they only visited during specified hours. The remaining participants told me they visited at any time, even late at night or the early hours of the morning. Participant 04 was left waiting for a telephone call at home to advise when they could visit their family member. The telephone call was not made, and a friend then subsequently visited the ward and was advised the patient, admitted earlier that day, was unknown to them. This caused frustration and anger at what was deemed *'that's time she [visitor] lost that she could have spent with Mom'* (04).

When reflecting upon their relationship with hospital staff, participant 06 expressed concern about the conduct of a member of staff when communicating with the family. *'The ward sister came in to us all sitting there, and she got a bit irate. Her attitude was wrong. To me that's not professional. She was a little sharp'* (06). This situation had resulted from the relatives asking nursing staff to undertake specific tasks for their family member which

appeared to have been considered demanding. Following the disagreement, the situation was resolved very swiftly. No participant spoke about a situation which led to a long-term difficulty or fractured relationship between family members or hospital staff. Overall, participants told me that they were pleased with the care provided to their relative, themselves and other family members.

### **Thematic Network for DYING & DEATH**

The second global theme which I labelled **DYING & DEATH** (Figure 3, p.139) comprises **Palliative & End of Life Care** as the organising theme. This contains participants' thoughts and feelings about communication between themselves and hospital staff, family understanding of palliative and end of life care and the transition from acute to palliative, including the deterioration and death of their family member. It also comprises participants' views about gaps in the provision of care and the care offered following their relative's death.



**Figure 3 - Thematic Network for Dying & Death**

### **Palliative & End of Life Care**

Participants discussed a range of positive and negative *communication* issues which related to their relative's admission to hospital. Participant 01 raised concerns about the difficulties of trying to have a conversation with medical staff, compounded by limited visiting hours; *'You'd got to try and catch the consultants on the round and you'd only got so much visiting time ... you can't go in before that'*(01). This participant felt they would have known more had hospital staff taken the time to update them about their family member's condition and became tearful when recalling the phone call received from hospital staff.

*They called me ... they called me twice... on the evening. I think he'd already died at that point. They said they were, you know, with him. They didn't say to me "look, he hasn't got long". No one expected him to die. No one ever mentioned to me that he might die (01).*

Participant 02 felt staff did their best when communicating with them and other family members but also said, *'some people are better at communicating than others'*. When reflecting upon the way bad news was broken to them, participants appeared objective and at times constructively critical of hospital staff. Participant 02 told me,

*They said to us, urm, "look, I think you need to, to understand that, that your father isn't going to get better". [The consultant] didn't actually say ... "I'm afraid he's going to die" it was more, "well, you know, it's not a positive outlook".*

With quiet resolve, participant 02 said, *'You have to accept that [bad news] at that point however difficult it's going to be'*. No participant recalled hospital staff instigating or leading a conversation about their family member deteriorating or dying. Rather, it appeared that family members were required to initiate such conversations.

There were two participants who appeared reluctant to say the words *die*, *dying* or *death*. Participant 04 offered a clear example when they told me, *'they'd [staff] rung through, in the early hours of the morning to say she was ... she wasn't, you know ... they didn't think she was going to last, and did I want to go?'* Participant 03 also appeared reticent when telling me that a

member of hospital staff had telephoned and alluded to the fact their family member was dying, and when eventually met at the ward door, apparently the nurse did not use the word *died* either. *'They [staff] phoned me ... and said, "She's ready to go [die]. She's going" and urrr, we got there just after she died. She [nurse] met me at the [ward] door and gave me a big love... "I'm sorry. She's gone [died] "'*. Only one participant told me that hospital staff had actually been honest and used the terminology concerning the likelihood of their family member dying. *'The specialist ... was quite open about it [dying] ... he said she would die. He was the one person who did mention the fact that she would die'(05)*.

Despite the apparent reluctance of hospital staff and participants to discuss, or use specific words relating to dying and death, participants shared examples of the openness and honesty of hospital staff. *'If I asked a question, it was answered ... and not just brushed off. It was answered in full. They [doctors] answered every question you threw at 'em' (06)*. Similarly, participant 05 reflected on the communication between hospital staff and members of their family. *'Staff communicated with you ... they were very good. They gave me a pamphlet to tell me exactly. The specialist was extremely good in explaining ... in detail what had happened'(05)*.

***Family understanding*** of several issues associated with the care of their relative were evident during interview. Participants spoke of conversations

about palliative and end of life care although there appeared some confusion or unfamiliarity with these terms. When participants were invited during interview to consider their understanding of palliative and end of life care or the provision of such care for their relative, several key observations were made. According to participants' accounts, the terms *palliative care* and/or *end of life care* were seldom used by staff and when they were, participant 02 felt, *'it was not really explained by staff'*. Participant 02 associated palliative care with hospices which, in turn, they believed was where someone was admitted for end of life care. Another participant told me that palliative care was, *'when someone's got no chance of really living and it's to help them to survive, you know, keep going and not be in pain and be looked after urrm, and where they can, cheer them up either coming out. End of life care is nearer the end than palliative care'* (04).

Participant 06 shared their thoughts about palliative care which they understood helped clients who were *'passing away to be comfortable, pain free and clean, whilst also considering relatives, too'*. Participant 02 told me they thought palliative care was, *'when someone is actually dying ... it would be cancer and it's terminal ... palliative care is, it's something that somebody might mention but doesn't really tell you what it means. It's [palliative care] a word ... you associate with hospices'* (02). Other participants had similar thoughts. Participant 04 said, *'I suppose end of life care is, is nearer the end than palliative care, if you see what I mean. Palliative care can, you know, be a length of time where end of life care is right ... right at the end'* (04).

However, participant 06 knew all about palliative care having had experience as a paid carer in the past. They told me,

*It's [palliative care] to help those clients that are passing away to be ... as comfortable, painless, cleanliness, all care given, but also to look after the relatives too. To me, you start with palliative care and it goes into the end of life care (06).*

Participants tended to associate the word *palliative* with *cancer* and provided only when someone was *'in the process of dying'* (01) whilst *palliative care* meant *'letting people die with dignity and being pain free'* and allowing family members the privacy to be with their loved one *'to be able to say good-bye'* (03). When considering any differences in terminology, participant 04 told me that palliative care could potentially be offered for a length of time whilst another participant believed *'palliative care moved into end of life care'* (06).

Participants' accounts gave insight into their understanding of palliative and end of life care with regard to their relative. Participant 06 was adamant that hospital staff had not spoken with them or another family member about their partner nearing the end of life. *'No one had those conversations'* (06) and therefore when death came *'it was a tremendous shock'* (05). Other participants spoke about a conversation or conversations with members of staff. One participant felt a doctor's explanation helped to facilitate understanding amongst family members whilst another participant evidently understood their family member was dying from what hospital staff had said. Participant 04 spoke of a conversation with the doctor when they were told,

*'half her brain has gone, and she's also got gaps from when she's had the previous stroke'*. This participant said their family member was *'very, very poorly towards the end of her life'* (04). When recalling the lead up to the stroke and the subsequent symptoms, participant 06 told me,

*He'd [patient] had a massive bleed at the front of his head. He was having lots of seizure ... you would see [his] arms come up. His temperature was going up. He was just clammy all over. You can physically see the changes [when someone is nearing the end of life] (06).*

Participant 03 was very emotional as they narrated their family member's struggles towards the end of their life. *'It was very hard to watch ... she was really struggling to breathe and that was really difficult to watch ... she was gasping for breath. They suspected she'd had another bleed and she may not regain consciousness'* (03).

Each participant told me of the length of time from hospital admission to death, following acute stroke. One participant's relative died within 24 hours of admission to hospital; three patients died in the first week (2, 3 and 4 days respectively following admission) whilst the other two relatives died at 18 days and 40 days. Irrespective of the time between the stroke occurring and the individual dying, participants' collective perceptions were that it had happened very quickly. *'My father had deteriorated quite quickly'* participant 02 told me, whilst participant 04 said, *'it [death] happened so fast, you know'*. After spending a few moments in thought, participant 05 said, *'In our case ... it*



*happened so quickly and so suddenly. She was like, one minute alive, the next minute she was dead. Just like that'*(05).

Participants disclosed what appears to be ***gaps in care provision*** and experienced different approaches when their family member was nearing the end of life. One participant recalled being told their family member was going to die (05) whilst another participant left the ward without staff engaging in conversation and then being telephoned at home by a nurse less than half an hour later advising that their family member had just died.

When speaking about palliative care, end of life care, or dying and death several participants had similar experiences. Overall, staff did not engage in conversation with participants about a shift from active to palliative/end of life care. It appeared hospital staff tended not to talk about palliative and end of life care if either the patient or the family members failed to offer cues in the first instance. Participant 01 was adamant that staff did not raise the subject and told me *'nobody mentioned a palliative approach ... nobody mentioned caring for him in the end of his life'*. No participant recalled a discussion about palliative or end of life care being instigated by hospital staff and when asked if palliative or end of life care had ever been mentioned, participant 05 replied, *'No, not at any time'*. Similarly, participant 06 pondered the question and said, *'No, I don't think they [staff] ever asked us that [palliative and end of life care]'*.

Participant 06 suggested there were no discussions about preferred place of care or death, and just a few days later, after a call to the ward early the following morning, they were advised their family member remained comfortable. However, just 20 minutes afterwards, a nurse telephoned from the ward advising that the family member had actually passed away. This participant and their family were very upset at the possibility that their relative was on their own when they died. '*We don't know whether he was on his own [when he died] or a nurse was with him*' (06). After a few moments trying to compose themselves having become emotional, the participant said, '*I didn't want him on his own*'. For other participants, it would seem no conversations took place about a preferred place of care or death, as each spoke about either being surprised or shocked when the death of their relative occurred.

No participant recalled any involvement of the palliative care team during their family member's hospital admission. Similarly, no participant was able to recall a conversation with a member of the palliative care team, but it is unclear whether stroke ward staff liaised with these specialists. Similarly, no participant recalled any mention of hospice nor a conversation by stroke ward staff about a potential transfer to a hospice or potential discharge home for their family member to die. However, when reflecting upon the care provided towards their family member's end of life, two participants had considered whether hospital was the right environment. Participant 02 spoke of the care offered towards the end of their father's life and recalls a family member asking hospital staff, '*is there a possibility my father could come home* [to

die].?’ After lengthy discussions with a ward doctor, it was decided the best place of care for both patient and family members was in hospital as transfer home may have been too distressing. Participant 01 appeared quite sure when they told me, *‘had I for one-minute thought...he was days away or hours away [from dying] [becomes choked and unable to speak] ... I’ve got him in a wooden box [cremated remains] with his old cardi thrown over him [in the lounge]’*.

When asked about ***care after death***, participant 05 reflected upon the telephone call from a nurse on the stroke ward which they received after the death of their family member. When they returned to the ward, the nurse *‘gave me a big love’* (05). Their family member had already received personal care after death and a bible and vase of flowers placed on the table alongside the bed. The participant was appreciative of the care given and recalls the window of the side room being open which they spoke of as a tradition in some hospitals to allow the spirit of the deceased to be set free. Participant 04 recalled being told their relative had died. *‘I didn’t go back after they’d said, “do you want to see the body?” I didn’t want to see [her]. I wanted to remember’*.

Participant 01 told me, *‘I think he’d already died’* when the nurse telephoned, but they recalled racing to the hospital and finding the main entrance closed. The participant recalled their partner had been moved into a side room when

they arrived on the ward but was unsure whether this had been done prior to or following their death. Another participant told me, '*we [the family] know that the team looked after him as best as they could in a time of death. They [hospital staff] knew it was important for us to be there [when he died]*' (02). '*We got there just after she died. She was still warm ... and even then, they [nurses] were kindness itself like she was the only person in the hospital. The nurse made it really personal. She said, "your aunt's died and I'm very sorry"*' (03). Participant 05 recalled the early morning telephone call from nurses on the ward. He told me,

*When she actually died, they [staff] were very understanding of the situation ... very sympathetic towards me ... they were obviously properly trained ... they knew exactly how to deal with you. You didn't feel there was anyone else there, only you* (05).

No participant spoke specifically about bereavement although during the interviews, two participants offered indirect thoughts which offered me a little insight into the impact of the death of their relative upon their lives. '*I always promised her I would be with her when she died, so I feel really awkward about that ... I wish I'd been there longer*' (04). Although I did not ask the participant to expand upon this during the interview, I drew the conclusion from their response, alongside their non-verbal cues, with eyes cast to the floor and a lowered tone of voice, that they may be struggling with the broken promise. Another participant told me, but only as I was leaving their house, that they were struggling to live alone in such a large property, so had decided to move into a newly built apartment a short distance away. '*It's one of those*

*apartments where there's a communal area, too'* (05) they said. Another participant told me that their partner's cremated remains were to have been interred at the local crematorium, *'but he's not going until I go'* she said, with a smile. It appeared they got a great deal of comfort from having the cremated remains at home.

When asked towards the close of the interview if participants had any questions, four specifically expressed interest in the study and asked what I hoped would happen as a result of the study. Participant 01 told me that their sister had asked why they were taking part and expressed concern that it would upset her again, by bringing memories to the fore. The participant said she had been very apprehensive in the days leading up to the interview and having told their partner's sister of the impending meeting with me said with a broad smile, *'and I've done it'* (01). Participant 02 recalled the death of a child and said that their previous experiences had helped them deal with the deterioration, dying and subsequent death of their parent following the stroke. All participants expressed a desire to receive a summary report once the study was completed with participants 03 and 04 specifically wishing to share it with their family members.

### **Findings through the lens of the Sonata Framework**

Participants shared their narratives, and each impacted upon me at varying levels depending upon content or scenario. I feel extremely privileged to have

had the opportunity to engage with these individuals and to listen to their stories. Of the experiences shared, there were several narratives which resonated with me; one participant told me about their partner's stroke which led to their death over a period of just four days. The similarity of this story to my own, including the way it was conveyed, necessitated a strength from within to ensure I remained professional and not tearful as the participant spoke.

*... and here's a case of four days. In four days, it all happened. I suppose ... for her ... it was the best thing that could happen. But for the next of kin like myself ... it was the worst thing that could happen. It sounds a bit emotional, but urrr, I couldn't say goodbye to her (05).*

In the context of the Sonata Framework, I extracted participant quotes which particularly resonated with me in terms of variations in length, speed, tone and pitch of each narrative (Table 8, p.151). This offered the opportunity for me to consider my narrative alongside those of each participant and in doing so, compare experiences of palliative and end of life care in acute stroke, notwithstanding the intervening years.

**Table 8** – Sonata Framework Annotated

<b>SONATA FRAMEWORK</b>	
<p><b>The Prelude</b> An instrumental piece played as an introduction</p>	<p><i>'She rarely had to go to the doctor's' (05)</i></p> <p><i>'[He was] very fit and well and it (the stroke) was a complete surprise to us' (02)</i></p> <p><i>'[We got] together in later life. I had to prove myself to his children' (01)</i></p> <p><i>'She was a counsellor and became the first Mayor. She was great influence on me' (03)</i></p> <p><i>'We had a very happy life together. A wonderful life. She'd already been married and I'd resolved to be a bachelor' (05)</i></p>
<p><b>Part 1</b> Allegro / Opening Sonata Quick – 'allegro agitato' as opposed to 'allegro tranquillo'</p>	<p><i>'Shock ... stress ... your head's in a bit of a fog' (01)</i></p> <p><i>'you're numb one minute and urm, the next minute your mind is thinking very quickly and you've got a ... conglomeration of thoughts going through your mind. None of which are quite rationale' (05)</i></p> <p><i>'... and everyone's running around in a hospital without stopping to think' (01)</i></p> <p><i>'one day merges into the next ... it seemed a flash but then it seemed an eternity at the time' (05)</i></p>
<p><b>Part 2</b> Slower 'adagio' = slowly OR 'andante' = moving along in a walking pace</p>	<p><i>'I didn't want her to suffer in any way'. It was very difficult watching her' (03)</i></p> <p><i>'I think they realised we understood the situation. We were always calm. We never...broke down when the nurses were present. We obviously saw the situation and ...kept the situation to ourselves, I suppose' (05)</i></p>
<p><b>Part 3</b> Main allegro/scherzo 'swift moving piece of music'</p>	<p><i>'It was quick. Maybe that was the consolation, 'cus she would have never wanted to survive with a severe stroke. She was a very active lady' (05)</i></p>

	<i>'...it's a very strange, hard thing to say because you want them to live but you want them to die at the same time. It was just awful to watch'(02)</i>
<b>Part 4</b> Usually an 'allegro' – a 'triumphant and exhilarating' ending	<i>'... we believe as Roman Catholics that you go to something ... we think we go to somewhere ... I think she went to somewhere better'(03)</i>  <i>'The kindest thing is to, to let them go'(02)</i>
<b>The Coda</b> the concluding passage of a piece or movement, typically forming an addition to the basic structure.	<i>'In a strange way it was a positive experience. He's gone, but rather than than having two, three years of no life at all and living and not living ... and not being dad anymore ... he wouldn't have wanted that' (02)</i>  <i>'In four days, it all happened. Urm, I suppose the only thing I would comment and say, briefly, is that probably for her it was the best thing that could happen. But for the next of kin like myself and, it was the worst thing that could happen'(05)</i>

Through the lens of the Sonata Framework I have been able to further analyse participants' accounts of palliative and end of life care in the context of my experiences. The sections of a sonata tend to carry two themes which present and re-present throughout the piece. Similarly, the themes extracted from the data from participant narratives present and re-present. It is these themes which, when considered alongside my narrative as a bereaved relative and nurse lecturer working in palliative and end of life care, represent a sonata of care which embraces the harmonised experiences in the context of the harmonised experiences of palliative and end of life care following acute stroke.



## **Prelude**

Participants shared stories of the childhood, adulthood and character of their relative and I felt particularly moved by the narratives each conveyed as I heard about family relationships and the dynamics between members. Each narrative was unique and allowed me the opportunity to hear something of the very essence of the person prior to engaging again at the point the stroke occurred. Participants touched on memories of their family member which had, perhaps, just come to the fore as they were being interviewed. Two participants became tearful and asked for time to compose themselves prior to continuing, but neither wanted to suspended or re-arrange the interview. Allowing opportunity for participants to reminisce and settle into the interview was a valuable strategy as we engaged together.

## **Part 1: Allegro**

This opening part of a sonata is always quick. It is described as *allegro agitato* as opposed to *allegro tranquillo*. This was reflected in each of the participant's narratives as they described the suddenness of their family member's stroke and how they reacted, often as the person who found them or was contacted in the first instance. The variations in length, speed, tone and pitch of each narrative offered similarities although each remains unique. The juxtaposition from the established pace of life to the shock experienced when the stroke occurred was significant. For several participants the length of time, as with the onset of their family member's stroke, had happened with little, if any,

warning. Yet, on reflection for two participants, there had been tell-tale signs; the headaches, the slightly confused conversations, the forgetfulness or the visual impairments. Variations in tone and pitch were also noted within the narratives, as each participant spoke of the severity, intensity and presentation of post-stroke symptoms; some family members requiring pain relief and sedation, whilst others were symptom free and required nothing other than nursing care.

## **Part 2: Adagio**

This slower section of the sonata, sometimes described as though it were *in a singing style*, suggests moving forward at just a walking pace. The franticness of the situation has dissipated and there is a sense of numbness or disbelief at what has happened. This cushioning tends to provide the opportunity to stand back and reflect on the gravity and reality of the situation because life is changed and can, nor will, be the same again.

Participants spoke about sitting alongside their family member whilst in hospital or returning home and lying awake at night worrying about them. On occasions, time felt as though it was suspended, and participants spoke about feeling confused, disorientated and at times unable to accurately recall specific things that had happened prior to and following their family member's stroke. There was variable length of time during this part of the sonata. For some, it lasted just a few hours whilst for others it lasted days or weeks.

### **Part 3: Allegro/scherzo**

This section of the sonata is a swift moving piece of music which contains a great deal of activity and tends to repeat aspects from Part One. Participants spoke of their thoughts and feelings, along with their conversations with other family members and hospital staff. It was evident from the narratives shared that frustrations appeared and yet, despite the dawning realisation of what had happened, there remained a constant uncertainty about the immediate and distant future. Alongside this ran periods of disbelief and loneliness, as though on the peripheries, merely observing and not being involved.

For several participants as with myself, it provided a little breathing space in order to allow the situation to imbed itself into my reality, whatever the reality to each. In the context of hearing other narratives, on a couple of occasions I found myself distanced a little from what participants were telling me, as though I'd just momentarily stepped back to the hours or days following my mother's stroke. I was listening, understanding and acknowledging what was being said, but for that split second, I was somewhere else. On reflection, I realised it was the scenarios which particularly resonated with me when this happened.

### **Part 4: Allegro**

This final section of a traditional sonata is usually fast, albeit on this occasion it heralds a triumphant and exhilarating ending. Participants spoke of their

family member's impending death and the activities which busied staff; perhaps used as a distraction to the conversations they should have been having with family members with whom they had chosen not to engage. Participants spoke of the shock and at times the juxtaposition of the relief of their family member's death. Only one participant spoke about death in terms of a new life or beginning rather than an ending, evidently based upon a particular religious or faith belief. This scenario particularly resonated with me; mirroring in part my own thoughts, feelings and experiences.

My experiences of the death of my mother and the overwhelming relief were that she did not survive beyond four days with severe brain damage and physical disability. My mother's faith as a practicing Christian allowed her to believe in life after death; a life which meant she would once again see those who had died, including her father and mother. This brought her tremendous strength and comfort in life, and although unconscious and unlikely to be aware of anything which happened in the last 48 hours of her life, I remain extremely relieved that she did not survive. The triumphant and exhilarating end to my mother's life came with death and ultimately new life beyond her stroke where I believe she rests in the presence of God with all those who have gone before.

## **Coda**

A traditional sonata does not contain a coda and as such, music purists will likely question the need to add an ending within this framework. Although there is no need for one, I have added it to aid the narrative. The Sonata Framework was developed specifically for this study and it allows the opportunity for me to reflect upon my journey along with the narratives of co-participants in my research; individuals I had not met previously and with whom I am unlikely to meet again. Our shared experience is the death of a family member following an acute stroke. Our bond is unique. I listened to the detailed and emotive narratives of each participant and yet all they knew of me was my background as a hospice nurse and the undertaking of a professional doctorate.

The death of each of our relatives following an acute stroke was different although similarities were evident. We are examples of society and the culture therein. We either resist dying and death or we accept and embrace it. Although there is commonality in our shared experience, each experience remains unique. We all have a story to tell and our story not only influences us, but it impacts upon others too. Death comes to all, and my experiences as a nurse lecturer in palliative and end of life care and as a bereaved son allow me to elevate my voice with some authority. No one can know my story; no one can speak my narrative, and no one has the capacity to fully understand the impact of an experience on the individual, because it's our story, viewed

through our own experiences and our understanding. As such, this additional coda within this sonata framework possibly allows for a newly constructed or reframed meaning to be given in the context of non-malignant disease and the provision of palliative and end of life care for everyone and not merely those with a malignant disease.

### **Chapter summary**

The presentation of interview data from six participants as part of this autoethnographic study is evidenced within this chapter, following the use of Attride-Stirling's (2001) analytic method, producing two *global* themes: The Family Experience and Dying & Death. The harmonisation and reverberation of participant voices on occasions mirrors my experiences and recollections of my mother's untimely death following an acute stroke. Each narrative echoes the poignancy of a loss, whatever the circumstance or the relationship, whilst the modified Sonata Framework enables the tone, pitch and pace of each experience to be heard and felt. This chapter has described and explored each network in detail (data analysis step 4) and I am hopeful that the harmonised narratives have allowed the reader the opportunity to immerse themselves into a shared experience. Our individual and collective narratives which are represented within the themes from this research are considered in the following chapter.

## CHAPTER 6 - DISCUSSION OF STUDY FINDINGS

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### Chapter overview

This chapter critically discusses the narratives of both researcher and participants and throws light on the existing provision of palliative and end of life care available when someone has suffered an acute stroke. The objectives specific to this research relate to participant's experiences following their family member's acute stroke and are considered in light of the literature.

This research was undertaken on the back of work previously carried out by Stevens, *et al.*, (2007) which considered available literature associated with palliative care in stroke provision. Amongst the recommendations for future research the authors suggested further qualitative studies were carried out to explore the experiences of patients and relatives on the management and delivery of palliative care. In addition, an understanding of the kind of palliative care stroke patients want or need was required. Within this research the experiences of both researcher and participants are viewed in the context of previous findings and provide a reasonably up-to-date picture of the availability, provision and delivery of palliative and end of life care in the context of a stroke ward. In addition, the quality of palliative and end of life care practices are drawn to the fore. It also illuminates whether palliative and end of life care needs for the patient and family members were met and determines whether transition from acute to palliative and end of life care within an acute stroke ward occurred.

The recent publication of the NHS Long Term Plan (DH, 2019) recognised the importance of palliative and end of life care and although it highlighted a decrease in the overall number of deaths since 2006, variations still exist due to age and cause. A group of Midlands trusts was reported to be among the 10 worst performers in the UK with patients waiting on trolleys and ambulances queued outside emergency departments with crews unable to handover to hospital staff (Triggle, 2020). Alongside these pressures, the breaching of government set waiting times appear to be placing front line NHS staff in highly pressurised situations, adding to escalations in sickness absence and staff burnout (West, 2016; RCN, 2017; BMJ, 2018). Despite such difficulties, at least two local trusts have introduced an end of life care strategy to help guide generalist and specialist hospital staff in the identification of those requiring palliative and end of life care upon arrival in the emergency department. Collaboration between acute and palliative specialists is essential aiming to ensure individuals with palliative and end of life care needs are seen as quickly as possible and returned home with additional support or admitted for symptom management or when actively dying. However, difficulties associated with the 'revolving door' between acute and community care is evidently unresolved.

Alongside the reported worsening of ambulance response times (Nuffield Trust, 2020; BBC 2020) and NHS England (2020) suggesting all ambulance services will meet all targets by 2021, few initiatives appear to have taken place when dealing with those nearing the end of life. In the North East,



Macmillan Cancer Support set up a pilot project with the ambulance service which cut the number of end of life admissions to hospital as a direct result of the sharing of information and the training of front-line staff (Stephenson, 2020). Findings from this research indicate ambulance crew members arrived in a timely manner despite participants' perception of time being affected, as a likely result of stress felt at the time. Participants recalled ambulance staff being professional, competent, efficient and empathetic, and carried out a thorough assessment of participants' relatives prior to transfer to hospital.

Despite the majority of people preferring to remain at home at the end of life, over 1.6million emergency admissions of those in the last year of life took place in 2016 costing the NHS £2.5billion (Marie Curie, 2018). Ongoing concerns about too few hospital beds in the system, financial constraints, severe workforce shortages and rising demands on healthcare (King's Fund, 2020) are almost constantly in the media. Marie Curie (2018) suggested an additional £2billion and 8,000 hospital beds dedicated to the dying would be needed by 2038 as a result of emergencies arising towards the end of life. Difficulties faced by emergency departments continue to impact across hospitals as staff seek to discharge patients back into the community and admit the sickest patients. There appears little resolution to the staff and financial crisis facing the NHS at present in spite of government assurances of the impending recruitment of additional nurses and other allied healthcare professionals (NHS England, 2020).

Consecutive governments have spoken of the importance of appropriate resources within the NHS, including staffing and funding. The more recent election of a new conservative government in December 2019 with a manifesto confirming an additional £34billion funding for frontline NHS services. Yet, the accuracy of other commitments including 40 new hospitals over ten years and an additional 50,000 nurses by the end of the next parliament has been strongly contested (NHS Confederation, 2020). There appear to be no new initiatives within the NHS to support the care of those individuals nearing the end of life and no ring-fenced budgets provided for either malignant or non-malignant diseases. Therefore, until the importance of palliative and end of life care is recognised outside of the hospice movement as an essential part of care for all at the point of need, irrespective of diagnosis, its provision will continue to be provided on an ad-hoc basis.

Findings from this research highlight participants' concern about the lack of funds and limited resources which they feel directly impacted upon the care their relative received. Despite hospital staff appearing to work hard and being complimented by participants, frequently providing examples of good care, one participant in this study found their relative shivering in bed. This was raised as a concern with a member of nursing staff who responded by saying there were no blankets in the linen cupboard. The overwhelming plea from participants, which mirrors calls from members of the public across the UK, is for the appropriate funding of the NHS which, according to a number of prominent campaigners, is not failing, but is being failed (Watson, 2019). It is

unacceptable for patients to suffer in ways which are otherwise avoidable with the appropriate funding of the health service. As a nurse with over 30 years' experience, I find it incomprehensible that a member of my profession sought to prove a point by showing a relative an empty linen cupboard and yet failed to locate a blanket for a shivering patient from another ward. This suggests a lack of empathy, compassion, professionalism and understanding of the philosophy of nursing (Hassmiller, 2017; NMC, 2018), and I question whether any amount of additional funding or training would prevent this from happening again.

Although standards for stroke care can be found across Europe and other parts of the world (Rejno, Danielson, and Berg, 2013) the experiences of participants in this study utilising one NHS trust hospital are not consistent. The unpredictability of each stroke and the uniqueness of each experience means findings from non-specific stroke research cannot simply be transferred to the stroke context (Rejno, Danielson and Berg, 2012). The immediate care received by the relatives of participants included clinical examination and investigations, with each being transferred to the stroke ward in what participants generally perceived to be a timely manner. Despite the pro-active interventions including thrombolysis, rehydration, computer-tomography scans and X-rays, and no participants' relative appeared to be referred to the palliative care team and none was discharged home, to a hospice or nursing home to die.

Shock and disbelief are widely reported at the time a stroke occurs and is mirrored in the experiences of the participants in this study, with few symptoms being evidenced in the lead up to the acute event (Rejno, Danielson and Berg, 2013). Amongst the pre-stroke symptoms experienced by relatives of those participating in this study were headaches, mild confusion, numbness and slurred speech. In the hours following the stroke, participants reported their relative was unable to speak, co-ordinate movement, swallow food or fluid or appeared to lose consciousness soon after admission to hospital. This research highlights the unpredictability of symptoms and at times the inconsistency in how these were managed by medical and nursing staff in the lead up to or following the stroke. A consultation with one GP in the days leading up to one stroke event resulted in one participant's relative being treated for vertigo.

The quality of palliative and end of life care provision is often reflected in the awareness of staff to the needs of those evidently nearing the end of life; the symptom management available in the last few weeks, days and hours of life alongside the support offered to the bereaved. The quality of care should be reflected in the knowledge, skill and compassion of every member of hospital staff coming into contact with someone nearing the end of their life or has died, including those who are bereaved. The End of Life Care Strategy (DH, 2008) purported that palliative and end of life care should be universally available (Almack, *et al.*, 2012) and offered on the basis of need and irrespective of diagnosis with the transition from acute to palliative and end of

life care, when required, being seamless. My experiences of the care offered by one acute trust hospital to my mother in A&E and the subsequent lack of palliative and end of life care was generally poor. Although similar stories are evidenced within the media from time to time, the findings from this research demonstrate the level of service and care received from hospital staff was generally good, although participants were critical of some aspects of care provided by individual staff members.

In recent years, caring for those nearing the end of life has caused staff significant concern in the wake of criticisms of hospital staff in the media and the subsequent abolishment of the Liverpool Care Pathway (Neuberger, 2013). Hospital staff were left devoid of guidance on how to care for individuals nearing the end of life and perhaps anxious about their involvement when someone was nearing the end of life. Perhaps medical and nursing defaulted into acute mode preferring to be seen to be doing as much as possible in light of Harold Shipman's conviction for murder. The reluctance of hospital staff to prescribe opioids and other end of life medications frequently used within the hospice is evident. Participants spoke of staff giving morphine only when they requested staff intervene and the use of a syringe driver was only mentioned by one participant who spoke of her relative's *'long, protracted death, which you wouldn't do to an animal'* (participant 02). Although individual trusts produced interim guidance and eventually introduced individual care pathways supported at national level (NICE, 2015), it appears medical and nursing staff may have been apprehensive about potential accusations of their use. The

more recent investigation of over 450 patient deaths at Gosport Hospital during the 1990's has evidently left staff feeling vulnerable. Yet, nursing staff at the local trust were either unfamiliar with the implementation and use of the SWAN individual care pathway or possibly awaited a decision from a more senior member of the medical team to raise the possibility of its use. Whatever the cause of the failure in identifying when someone is nearing the end of life and having conversations with colleagues or relatives, it is unacceptable, and likely indicative of hospital culture which favours the aggressive, active treatment of someone with little apparent consideration that someone may be dying.

Regrettably, there were few examples of staff engaging in conversation with relatives about patients nearing the end of life. It may be that nursing and medical staff seek to maintain a more acute focus and desire to save lives in the face of impending death. Yet, despite such a distraction and brief respite this research provides evidence of little consistency in the transition from acute to palliative and end of life care, with decisions about life and death being made by senior clinicians. Overall, nurses appear to remain reticent about end of life care, defaulting to medical staff to either raise the subject or answer relative's questions and concerns. There was no consistency in conversations being triggered when someone was nearing the end of life and nor was there any consistency in the use of the SWAN individualised care pathway. This is deeply concerning, not least because nurses and carers tend to be in direct contact with patients more regularly than medical staff and yet it would seem

that those medical staff are the ones nursing staff look to when bad news is to be given.

Following the call for staff to treat patients and relatives with more respect and to be educated and trained in palliative and end of life care (Neuberger, 2013), this research finds few changes reflected in clinical practice. Although several participants commended nursing staff for their attention to detail when offering care to their family member and themselves, the provision of high-quality palliative and end of life care was not evidenced. Participants shared examples of the kindness and sensitivity of individual staff by the use of someone's favourite aftershave applied following care; taking the time to comb a patient's hair after being repositioned; talking to an unconscious patient during care or the placing of a special teddy bear alongside one dying person. I believe these to be the qualities of good nursing care and not merely associated with palliative and end of life care. Offering food and beverages to relatives was a tradition which I was taught as a student nurse 30 years ago. Yet, the sensitivity of one nurse towards one participant by stepping aside from the probable norm and potentially placing themselves in line for criticism and offering them food as they sat alongside their dying relative is what nursing should involve. I believe it is borne of an innate sensitivity, humanity and courage, and in my experience of post-registration nurse training over the past decade, I am not convinced undergraduate nurse or medical training has pin-pointed the specifics of ensuring such skills are taught and reflected in practice. The use of touch between healthcare professionals, patients and

relatives is a sensitive and complex issue within multi-cultural, multi-ethnic society. Yet, under particular circumstances, patients and relatives have indicated that touch improved empathetic clinician-patient communication (Cocksedge, 2013). Evidence from this research clearly demonstrates a hug given to one participant by a member of the nursing staff was found to be very comforting following their relative's death.

It is reassuring to hear participants describe hospital staff as caring and kind, and equally reassuring that there were no criticisms of the symptom management of their relative despite interventions being requested at times. However, no participants had a nursing or medical background and were not in a position to pick up on omissions in the provision of care and symptom management that I did during my mothers' admission to hospital. The examples of care participants specifically recalled, despite the busy-ness of any hospital ward or the level or status of the health care professional, still have the potential to impact for good in the memory of the bereaved. Such beneficence demonstrates an attempt by hospital staff to meet the spiritual needs of those individuals in their care and this research provides numerous examples of sensitive, kind and compassionate care shown to patients and their relatives by hospital staff.

In the study undertaken by Payne, *et al.*, (2007) within the stroke environment, no patient or family member reported requesting the initiation



of palliative care and none recalled being offered the opportunity to take their loved one home. Over a decade on, the participants I interviewed were unable to recall a conversation instigated by hospital staff about palliative or end of life care despite the NHS affirming a patient's right to express where they wish to receive care and where they want to die (NHS, 2019a). In addition, despite two participants approaching staff about the possibility of their relative returning home, which was not considered possible at the time, no member of hospital staff instigated a conversation with participants or their relatives, and discharge did not take place. The participants in this research were unable to identify any changes in the approach to the care of their relative nor any involvement of the hospital palliative care team. This was despite many hospitals having specialist palliative care staff working alongside and helping colleagues to care for people nearing the end of their life (NHS, 2019b). Such care would demonstrate a tailored, individualised approach to high quality care for all, and although this research provides examples of participants being complimentary of staff, it fails to identify the high quality-provision of palliative and end of life care within the stroke environment.

It is well recorded that most individuals nearing the end of life would prefer to be cared for and die at home surrounded by family and friends (DH, 2008; Macmillan, 2013; Ali, *et al.*, 2019) and yet most people will die in hospital or care home (Age UK, 2013). VOICES (2016) identified that 1 in 10 people rated the care provided by hospital doctors and nurses as poor with 30% of respondents stating the quality of care by place of death was poor. The

majority of participants in this research were not with their relative when they died which, they told me, had caused distress and evoked feelings of guilt. No participant recalled being told their relative was imminently dying nor were they encouraged by hospital staff to stay with them even as they were leaving the ward after visiting time had ended. This research identified that no participant was spoken to by nursing staff about their relative nearing the end of life and none was offered the opportunity to take their relative home to die. For one participant, having promised their relative they would be with them at the end of life, they have been traumatically affected by not being able to honour such a promise. The failure of hospital staff to engage in open and honest conversations about dying and death continue to impact negatively on patients' wishes and their relatives ongoing psychological and physical wellbeing in bereavement.

In 2016, an audit by the Royal College of Physicians (RCP) reported that hospitals were not informing family members that their relative was about to die, with one in 20 individuals feeling left in the dark. The evidence from this research indicates most participants were not spoken to by hospital staff about the possibility of their relative nearing the end of life. Despite improvements in end of life care provision since the abolition of the LCP, the Royal College of Physicians reported 'unacceptable variations' across the country with deficiencies evidenced between day and night as well as weekend provision of specialist palliative and end of life care (RCP, 2016). Communication training for hospital staff engaging with someone who is dying should not be reserved

for medical and nursing staff, but include porters, catering and domestic staff (Knapton, 2016).

Bereavement is one of the hardest things people will go through (Stroke Association, 2017) and although bereavement support is seen as an essential component of palliative care it is not systematically applied (Hudson, *et al.*, 2017) across healthcare. Shock and disbelief are often automatic responses to a sudden, life-changing event; which offer the individual a little inertia in the wake of a relative's sudden illness. However, the physical manifestation of symptoms, including pain, is not uncommon as bereaved individuals adjust to life without their loved one (Cruse Bereavement Care, 2020; Marie Curie, 2020). Bereavement is often a very frightening and isolating time and yet no participant recalled being offered bereavement follow up care by either the hospital or their GP.

### **Cadence: drawing a conclusion**

Epicurus (341 BC – 270 BC) declared, '*death is of no concern to us, for while we exist death is not present and when death is present, we no longer exist*' (Ra, 2011). Almost two millennia later the End of Life Care Strategy (DH, 2008) promoted the provision of high-quality care for all adults at the end of life in England by stating individuals should be given more choice about where they wanted to live and die. Although the strategy originally identified the lack of open communication between patients, relatives and health and social care

staff (Kalmack, *et al.*, 2012) little appears to have changed. Following a review of the strategy in 2014 and despite evidenced engagement of palliative and end of life care across malignant and non-malignant diseases, dying and death appear to remain taboo subjects (Miller, 2017) with many of us going to great lengths to avoid talking about them (Peacock, 2014). Patients and relatives frequently turn to health professionals for guidance and yet there remains a call for staff to be appropriately trained in responding to such conversations. With more than half of Britons being unaware of their loved one's end of life wishes (Dying Matters Coalition, 2014), the chief executive of Sue Ryder (2018) suggested a national conversation about dying and death is required. This has still to be achieved despite local actions. Yet, until the confusion about terminology is resolved, with people frequently not understanding what is meant by palliative care (Miller, 2018), we remain at the mercy of a postcode lottery despite the relentless calls for timely, individualised, quality care at the end of life.

This research set out to explore the personal experiences of family members whose relative had died from an acute stroke following admission to hospital. It has achieved this by highlighting the narratives of participants whose family member suffered a stroke and required admission to the acute stroke ward. In addition, the objectives of this research have all been achieved. Participant's experiences following a family member's acute stroke have been identified in relation to the availability, provision and delivery of palliative and end of life care in a stroke ward. Furthermore, the quality of palliative and end of life

care practice has been considered in light of participants identifying whether such care needs were met. Finally, the transition from acute to palliative and end of life care within an acute stroke ward has also been examined. Following interview, one participant thanked me for allowing them the opportunity to take part in this research saying, *'if there's anything that can help just one ... that can change and help just one person ... then it's worth it'*. I am hopeful that the findings from this study will be embraced in the spirit they are presented in order to further enhance the quality, provision and availability of palliative care for all those nearing the end of life, irrespective of diagnosis.

### **Implications of the study findings**

Evidence from this research supports the need for hospital staff to be trained in identifying the palliative and end of life care needs of those with a non-malignant disease, including stroke. Similarly, health care staff should be given the knowledge and skills to ensure they can effectively engage in conversation with patients and their relatives about dying and death. Monumental changes are needed in the UK if a societal shift to ensure conversations regarding dying and death take place amongst health care professionals, patients and their significant others. A reluctance to engage in such conversations is evident despite previous research and reports supporting the need for open and honest conversations in health care. Preparing patients and their significant others for end of life care will go some way to confronting the taboo of dying and death.

Despite evidence from a number of influential bodies over the last 15 years (DH, 2008; DH, 2014; VOICES, 2016; RCN, 2017; Hospice UK, 2018; RCP, 2019) there is much more to be achieved when caring for individuals with non-malignant disease in hospital, including stroke. Further research into the palliative care needs of individuals following a stroke is imperative, as is the training of nursing, medical and allied health care professionals in the fundamentals of palliative and end of life care provision in the acute setting, identified in 2017 by the National End of Life Care Programme Board. Recommendations to change nursing and medical undergraduate and postgraduate curricula to promote and improve patient choice and quality of care (DH, 2017) are yet to fully materialise.

Successive governments have consistently failed to secure adequate finances for our National Health Service, and we stand at a pivotal moment in health care once again. Reduced staffing, budgetary cuts, a reliance on healthcare targets to demonstrate good practice, as well as a burgeoning demand due to an ageing and expanding population. Action is immediately needed at both local and national levels to ensure everyone requiring palliative and end of life care, including those experiencing an acute stroke, are identified and treated appropriately in a timely manner. It is essential for clinicians to have a modicum of knowledge and skill in palliative and end of life care to ensure decisions regarding both active interventions are considered alongside an urgency to identify when someone is nearing the end of life. Health care professionals must not only raise the bar when providing care but also be

empowered to both individually and collectively raise their voice to engage others in conversation about what is important to them towards the end of their life. In the absence of such conversations, patients and their significant others are unable to make decisions in the face of impending death. New policy needs to be innovative and relevant and not merely a reinvention of previous reports and recommendations on the provision of palliative and end of life care. There should be no discrimination between the availability and provision of palliative and end of life care for those with malignant or non-malignant diseases (DH, 2008; WHO, 2017).

### **Limitations of the study**

This was a small autoethnographic study which considered the experiences of both researcher and other family members following their relative's admission to hospital having experienced a stroke. All participants were white and spoke English and as such the sample was not ethnically or culturally representative of the city the trust serves. The recollections and personal biases of individual participants may have influenced the findings. The literature review was limited to works of UK origin, although this beneficially allowed for contextual synthesis of study findings. Researcher bias has been acknowledged and addressed throughout, although I accept that no researcher is able to remain totally bias free. The impact of this research may be small and local, however there is potential for a much wider dissemination of the findings. I am hopeful that these and other potential limitations may be the inspiration for another

researcher to undertake a study relating to palliative and end of life care associated with stroke provision.

### **Chapter summary**

The narratives of both researcher and participants have been critically analysed in the context of the existing provision of palliative and end of life care available when someone has suffered an acute stroke. The objectives specific to this research relate to participant's experiences following their family member's acute stroke and are considered in light of the literature. Yet, despite advances over the last decade or so, there is still essential work which needs to be addressed and undertaken. Government funding needs increasing; staff training relating to palliative and end of life care provision in the acute setting, including communicating with the dying and their family members, is paramount in order to enhance the quality of care for those experiencing an acute stroke. Evidence suggests conversations about preferred place of death are still not being instigated by nursing staff who, traditionally, turn to medical colleagues, including junior doctors or the consultant if such conversations are needed. Despite a preference to remain at home, most of us will die in hospital or institution, because we have either chosen not to engage in a conversation about the end of our life or we may have deferred any decision. As a result, hospital staff are likely to remain reticent at the point an acute stroke occurs, defaulting into curative rather than palliative and of life care mode.



## CHAPTER 7 - REFLECTIVE SUMMARY

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### **Chapter overview**

This chapter provides a reflexive summary drawing this study within this thesis to a close. It identifies several key aspects of the researcher's background and intention, which evidences the importance to ensure the narratives of others, during the analytical process, were not sanitised nor generalised. Remaining true to individual narratives in the context of this study has resulted in findings which are contemporary, credible, relevant and honest. I also make clear the original contribution to knowledge borne of the study findings and completion of this thesis.

Reflexivity is not a new concept and has been utilised in the research literature of many fields (Dodgson, 2019). Reflexivity is about turning the investigative lens towards oneself which enables a fuller understanding of one's attitudes, values and biases and their influence upon the research process (Anderson, 2008; Patnaik, 2013). Yet, reflexivity practice can be some of the most challenging and important work in qualitative research (Mitchell, *et al.*, 2018). As such, I have embraced reflexivity to consider my own experiences, attitudes and emotions and possible impact upon participants, the research process and specifically the subsequent analysis of data. I have constantly striven to bracket my biases and attitudes and have maintained a reflective journal to assist me in these endeavours. Transparency is a key component of research evidenced throughout the journey and I have also been keen to ensure that I

constantly examined the relationality of me as researcher to the research, and alongside my supervisory team, have sought to maintain a diligent and critical eye over the process, including any social, ethical and political considerations (Dogdson, 2015; Mitchell, *et al.*, 2018).

Knowledge is not separate from the knower and therefore an examination of the epistemological foundations of knowledge claims made is essential to understanding my reality as researcher and my influence upon the research process (Patnaik, 2013). As a very likely influence of the quality of engagement with others in the palliative and end of life care environment, I declare a leaning towards qualitative methodologies and a liking of autoethnography based upon that which I had read, but not experienced, prior to commencing this professional doctorate. I have learned more about reflexivity whilst carrying out the research process than I knew previously. Indeed, Dodgson (2019) concurs, suggesting learning to be reflexive takes time and one gets better at it with each successive encounter.

Reflexivity may be employed to ensure trustworthiness by considering and applying the criteria of credibility, transferability, dependability and confirmability. However, achieving reflexivity is perhaps easier said than done. It has been an important and integral part of this research that my voice has been heard, but how much is heard depends upon the framing of any research in the context of how, where and if it is received. The primary source of data

within this study is the narrative following my mother's post-surgical stroke and subsequent death along with the stories of other bereaved relatives whose family member died following an acute stroke. The decision to include the voices of others has, I conclude, added to the inter-subjectivity of this qualitative research and the discourse of palliative and end of life care in the context of stroke provision. The amount of data generated was considerable requiring meticulous attention to detail in its management. Although I set out on this journey with pre-conceived ideas about what I may find, I made a deliberate effort to lay my presumptions and assumptions to one side in an attempt to reduce researcher bias (Bryman, 2012). As such, the reflexivity throughout the research process is frequently evidenced. At times the vast amount of data generated felt overwhelmingly unmanageable and yet my innate attention to detail and early meticulous record-keeping paid dividends as the study and writing-up gained momentum.

One of my overarching concerns was that I collected, managed and interpreted data correctly and the consequences of not achieving this weighed heavy upon my mind. I sought to maintain a critical, reflective approach to the analysing of each transcript, constantly questioning myself and the interpretations I placed upon the narratives of others. Was I doing these stories justice? Was my interpretation true to the narrative? Was I remaining true to each participant as I framed the analysis within the context of my own and other participants' narratives? Of course, interpretation of any text involves multiple meanings (Patton, 1990) and as such, from the outset of the

process, my positionality is made clear. The fundamental principles underpinning this research frequently came to mind affirming that interpretations are constructed, and reality only exists in the meaning given by the individual (Foster, McAllister and O'Brien, 2006). As a researcher, healthcare professional and a son, I have consciously sought to position myself objectively. However, my research is not merely my own story, nor do I feel it to be overtly self-indulgent, narcissistic nor introspective, as a number of authors might suggest (Atkinson, 1997; Coffey, 1999). The story of my mother's stroke which includes her admission to hospital and her subsequent death, has brought family members and friends into the narrative, and I have done so without their permission. I have striven to ensure I have remained as objective as possible, despite the variable emotions raised throughout this study. Ellis and Bochner (2016, p219) advised autoethnographic researchers to,

*plunge in, using all the senses available to you, feeling the story's tensions, experiencing its dilemmas or contradiction, and living in its reality. When you engage with a story in this way, you allow yourself to consider the ways in which this story relates to your life and to find in that connection some truth about yourself - especially the good that you are seeking.*

I invited others to be part of this sonata of care and as such, it was my responsibility as conductor of a more intricate piece of music, to ensure individual voices, either in unison or harmony, were heard. Sometimes there is a distinct clarity whilst at other times there may only just be discernible elements of tone, pitch or pace. This has not happened by coincidence; it was

my intention. It was important to me that my voice did not dominate other participants (Bochner & Ellis, 2016) because of the emotive narrative and nor was I to be too analytical when embracing the stories of others. Each life is precious to someone; no loss greater than any other. Yesterday's memories become the stories in the present and reminders in the future. We all have a story to tell and each has a reason for sharing it. My hope is that the harmonisation of voices identified in this sonata of care impact for good for generations to come.

It has been extremely important to me to remain true to the voice of each participant and I have wrestled at times with seeking to make sure that what individuals shared was conveyed correctly, appropriately and in context of their narrative. I have excavated what Chang (2008) considered to be contradictions and similarities, coming to realise that meanings do not appear in the data as ready-made answers. I have thoroughly searched for these in my attempt to honour those who have relied upon me to share their stories and have striven to consider the similarities and differences between myself as researcher and the participants I engaged with at interview (Berger, 2015). However, it has concentrated my mind because I have been me as the generator, collector and interpreter of that data. Whilst striving to ensure researcher objectivity, I have constantly reminded myself of my positionality and the countless bias which have influenced this research.

The voices of all participants accompany my own story and, collectively, we have something to say about our experiences of care as individuals of those we have loved and lost as they have neared the end of their life. We have seen first-hand, through individual lenses, the impact of care on our family members, and in turn, on our experiences as bereaved relatives. Our individual narratives become a shared, collective experience, and our voices are the ones to orchestrate changes where changes are needed. The collective narratives in this Sonata paint an audible picture of actual experience in the context of our loved one's deterioration and subsequent death. My story is the only one I am aware of which considers a mother's death from the perspective of a son whose background in palliative and end of life care spent in the hospice movement. My professional knowledge and skills meant I was able to instigate a discharge home to die, which I knew my mother would have wanted. I was able to call on friends and colleagues to help. Of the participants who shared their stories with me, none were able to do similar even though the preference for a home death was neither articulated and neither did staff seek to determine whether hospital or home was the preferred place of death for the individual in their care.

The cultural identity of palliative and end of life care, borne of the care provided within the hospice movement and invariably to individuals with cancer, is evident in both provider and recipient. Such narratives echo across the generations and in time, consideration is given to the broadening of the skills and knowledge for those with non-malignant disease. Our personal

stories each add a rich dimension to the collective narrative. However, neither data nor individual narrative can stand in isolation of the other and no cultural meaning is ever to be found within the data, but rather it is formulated in the researcher's mind (Chang, 2008).

### **Original contribution to knowledge**

My experiences as a bereaved son and experienced palliative care nurse have, through the story shared, articulated that which has not been previously heard. To my knowledge, the development and use of a Sonata Framework in doctoral research, for purposes beyond the reporting of research, and in the context of determining the provision and quality of palliative and end of life care in acute stroke provision has not been undertaken previously. Alongside, the harmonised voices of the participants within this study have provided new insights into the provision and quality of palliative and end of life care within acute stroke care. The themes extracted from the data and considered in relation to the literature and my experiences affirmed previous research and uncovered prevailing gaps and shortcomings in care in the context of today's society and provision of healthcare. These original contributions to knowledge provide a firm foundation to determine the voices of medical, nursing and other health care staff providing care, including palliative and end of life care, within the stroke environment.

## **Concluding summary**

The story of my mother's untimely death was borne of a desire to share my experiences with others; seeking to ensure that which was previously unspoken was now heard. Sharing my story has moved me from my safe, comfortable space to the very core of the essence of who I am. I wanted to do something new. I wanted to push the boundaries, step aside from the well-trodden, familiar research path to generate a unique narrative from start to finish; from prelude to coda. It's been a story of joy, deep sadness, new learning and determination. My approach has challenged others and me. Yet, this research isn't just about my story and neither do I agree that it has merely been a self-indulgent focus upon self. I have searched for understanding of others through my lens. It was important to me to draw other voices into this research and in doing so to orchestrate a collective narrative. As strangers we are united in our shared experience, with each narrative spoken and each voice heard. This sonata of care is finished. The audience is now free to leave.



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Young, A., Rogers, A., Dent, L. and Addington-Hall, J. (2009) Experiences of hospital care reported by bereaved relatives of patients after a stroke: a retrospective survey using the VOICES questionnaire. *Journal of Advanced Nursing*. 65(10) pp.2161-2

## APPENDICES

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### **Appendix 1 – Seven research studies identified by Stevens, *et al.*, (2007)**

Addington-Hall, *et al.*, (1995) - UK | Retrospective interview survey

Anderson, *et al.*, (1995) - Sweden | Prospective survey

Anderson, *et al.*, (1995) - Australia | One-year longitudinal study using interviews and questionnaires

Addington-Hall, *et al.*, (1998) - UK | Retrospective interview survey

Teno, *et al.*, (2001) - US | Postal survey

Jack, *et al.*, (2004) - UK | Retrospective case study review

Rogers and Addington-Hall (2005) UK | Non-participant observational study

**Source:** Stevens, T., Payne, S.A., Burton, C., Addington-Hall, J. and Jones, A. (2007) Palliative care in stroke: a critical review of the literature. *Palliative Medicine*. 21 pp.323-331.

## Appendix 2 - Initial Database Search

<b>Initial Advanced Database Search (2008 – 2019)</b>	<b>EBSCO</b>
No. of search hits – Palliative	101,260
No. of search hits – Palliative Care	81,990
No. of search hits – End of life	66,841
No. of search hits – End of life care	62,819
No. of search hits – Stroke	292,832
No. of search hits – Stroke care	8,891
No. of search hits – CVA	3,685
No. of search hits – Cerebrovascular Accident	109,534
No. of search hits – Hospice	42,806
No. of search hits – Hospital	3,326,006
No. of search hits – Acute	780,014
No. of search hits – Long Term Care	48,879
No. of search hits – Non-Cancer	5,506
No. of search hits – Specialist Palliative Care	2,5947
No. of search hits – Equity	38,389
No. of search hits – Access	399,326
No. of search hits – Health Care Needs	12,863
No. of search hits – Health Service Accessibility	109,260

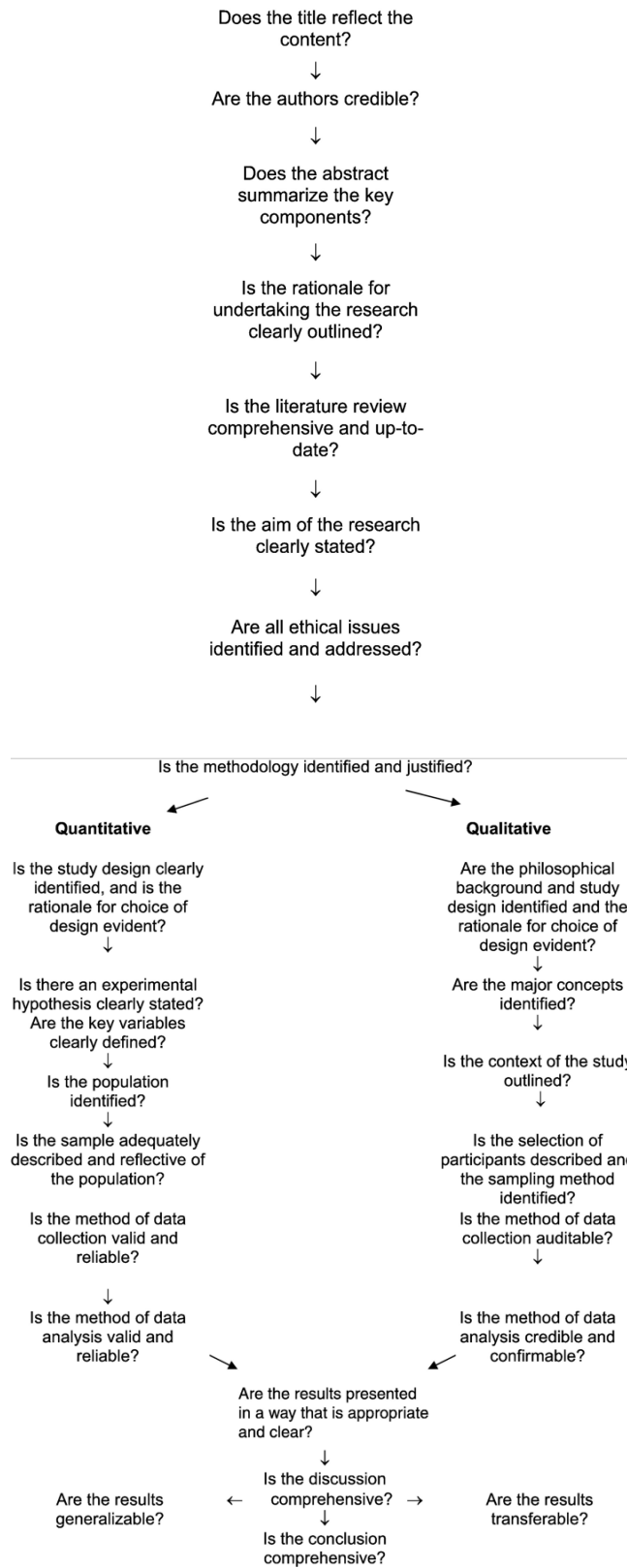
### Appendix 3 - Combined Advanced Database Search

<b>Combined Advanced Database Search (2008 – 2019)</b>	<b>EBSCO</b>
No. of search hits – Palliative Care AND End of Life Care	42,4147
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care	94
No. of search hits – Palliative Care AND End of Life Care AND CVA	4
No. of search hits – Palliative Care AND End of Life Care AND Cerebrovascular Accidents	89
No. of search hits – Palliative Care AND End of Life Care AND Hospice	8,912
No. of search hits – Palliative Care AND End of Life Care AND Hospital	12,429
No. of search hits – Palliative Care AND End of Life Care AND Acute	2,171
No. of search hits – Palliative Care AND End of Life Care AND Long-Term Care	923
No. of search hits – Palliative Care AND End of Life Care AND Non-Cancer	276
No. of search hits – Palliative Care AND End of Life Care AND Specialist Palliative Care	1,696
No. of search hits – Palliative Care AND End of Life Care AND Equity	137
No. of search hits – Palliative Care AND End of Life Care AND Access	2,542
No. of search hits – Palliative Care AND End of Life Care AND Health Care Needs	760
No. of search hits – Palliative Care AND End of Life Care AND Health Service Accessibility	1,628

#### Appendix 4 - Refined Advanced Combined Database Search

<b>Refined Advanced Combined Database Search (2008 – 2019)</b>	<b>EBSCO</b>
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND CVA	1
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Hospice	15
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Hospital	52
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Acute	48
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Long-Term Care	1
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Equity	0
No. of search hits – Palliative Care AND End of Life Care AND Stroke Care AND Access	5

## Appendix 5 – Framework for critiquing health research



Caldwell, K., Henshaw, L. and Taylor, G. (2005) Developing a framework for critiquing health research. *Journal of Health, Social and Environmental Issues*. 6(1) pp.45-54.

## Appendix 6 - Overview of studies

Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Potential Themes	Findings and/or conclusions	Recommendations
Young, A. J Rogers, A Dent, L Addington-Hall, J  2009  England	<b>Aim</b> Quantitative Survey – (pt satisfaction) population based over 6/12 in June 2003 of bereaved relatives of stroke pts  Tool = VOICES II questionnaire  Ethical approval obtained  <b>AIM</b> - To explore the determinants of satisfaction with health and social care services in the last 3 months and 3 days of life as reported by bereaved relatives of those who died from a stroke in an institutional setting.	Random sample of stroke informants registering a stroke death in 4 PCTs (n=493) in London in 2003	183 informants (37%)	Bereaved relatives of stroke patients who died in an institutional setting	Hospital care in the last 3/12 and H&Social Care in the last 2/7  Satisfaction of care  Venue of death	Bereaved relatives of people who died following stroke were more likely to rate care as 'excellent' if they considered deceased person's and/or their own needs were met during the last 3/12 and last 3/7 of life  Limitations – data utilised was 5 years old in 2009 (now 10 years old)  Some bereaved people do change their views during bereavement	Service providers will need to increasingly commission a range of services to meet individual needs as set out in the Strategy
Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Potential Themes	Findings and/or conclusions	Recommendations
Burton, C Payne, S Addington-Hall, J Jones, A  2010  England	<b>Aim</b> Mixed methods two-phase  Prospective study of hospital admissions  Ethical approval obtained  <b>AIM</b> - To identify the palliative care needs of stroke pts	To identify the p/care needs in a consecutive cohort of acute stroke patients  All acute stroke pts admitted to either of 2 acute hospitals in UK city (?population)  Children and subarachnoid haem. pts were excluded. Dementia or severe psychiatric pts were excluded if no family member provided consent.  Recruitment over 9/12  290 patients / 191 recruited	Recruitment = 65.8% (n=191)  (lost to follow up, declined, died, cognitive impairment with no family consent, incorrect diagnosis, rapid discharge)	Stroke patients  27.5% aged less than 65yrs  Suggested to be typical of a stroke population! – What does that mean?	Definitions  Symptoms  Integration of services, including clinical decision making  Tools  Policy & Guidance	Acute stroke pts have a high prevalence of p/care needs  Acute stroke units should use the SPARC for needs assessment	Stroke Policy Use a validated tool Combined approached to care



Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Themes	Findings and/or conclusions	Critique
Payne, S Burton, C Addington-Hall, J Jones, A 2010 England	<b>Aim</b> Qualitative Purposive sampled patients not referred to p/c team Interviews (approx. 20 mins) Data collected between Oct 2006 and June 2007 Ethical approval obtained <i><b>AIMS</b> - To identify patients' and family members' experiences of acute stroke and their preferences for eolc.</i>	191 sequential cases (pts and family members) from two district general hospitals in Sheffield	28 patients (n=13 with high disability) and (n=15 with low disability) 25 family members Total = 53 (27.7% of n=191) or 18.27% if n=290)	Acute stroke patients Family members	<b>2 main themes:</b> Comm & info provision Facing uncertainty and EoFL preferences	Two main themes – communication & information provision AND facing uncertainty & end of life preferences	Consideration of venue for care to ensure equity of service between cancer and stroke patients.
Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Potential Themes	Findings and/or conclusions	Recommendations
Burton, C Payne, S 2012 North of England	<b>Aim</b> Mixed methods of 2 studies Survey and interviews Rational for study was gap between recommendations from cancer pt EoLC and p/c for stroke pts The study aimed to develop a programme theory to explain the integration of p/care and acute stroke care around the needs, experiences and preferences of pts and family	n = 191 consecutive cohort of acute adult stroke admissions n = 53 interview (28 pts and 25 adult family members) ranging from 39 -47 minutes n = 29 staff from a range of profs across three hospital based stroke services in the north of England participated in a group interview conducted on each site	n=191 (although in a previous study total population was 290) 191 = 100% 191 of 290 = 65.8%	Stroke patients Family members Preferences and experiences	<b>Themes:</b> Clinical legitimacy Capacity for P/care Working with families Early integration of p/care Recognising complexity Recognising death	The authors report this framework to be the first, empirical explanation of the integration of palliative and acute stroke care.	Not specified



	Ethical approval was obtained <b>AIM</b> - To illuminate the experiences of the next of kin from the sudden and unexpected death of a relative from stroke					Contradictions and arbitrary memories when searching for understanding		
<b>Author(s), year and country of origin</b>	<b>Design</b> <b>Aim</b>	<b>Sampling strategy, total population and environment</b>	<b>Response rate</b>	<b>Characteristics of respondents</b>	<b>Potential Themes</b>	<b>Findings and/or conclusions</b>	<b>Recommendations</b>	
de Boer, M.E Depla, M Wojtkowiak, J Visser, M.C Widdershoven, Guy, A.M Francke, A.L Hertogh, Cess M.P.H 2015 Netherlands	Qualitative Exploratory - based upon grounded theory Dec 2011 - March 2013 <b>AIM</b> - To elaborate on the perspectives of relatives as key participants in the decision-making process in the acute phase after severe stroke and to understand their involvement in treatment decisions in life threatening situations.	15 relatives of stroke patients 1:1 interviews Open ended questions Purposive sampling Dutch speakers only	15 relatives	It is unclear whether relatives are pre or post bereaved	Making choices under time pressure Feeling of 'who am I' to decide Reluctance in saying 'let her/him die' Coping with unexpected changes	Enhance communication between physicians and relatives. Limitations of the study include recruitment being retrospective.	Not specified	
<b>Author(s), year and country of origin</b>	<b>Design</b> <b>Aim</b>	<b>Sampling strategy, total population and environment</b>	<b>Response rate</b>	<b>Characteristics of respondents</b>	<b>Potential Themes</b>	<b>Findings and/or conclusions</b>	<b>Recommendations</b>	
Alonso, A Ebert, A Dorr, D Buchheidt, D Hennerici, M.G Szabo, K 2016 Germany	Observational cohort study Retrospectively analysed records 2011 - 2014 Ethical approval obtained <b>AIM</b> - To describe and analyse EOLD of dying stroke pts who died during an in-	4425 patients admitted of which 120 died on the 29 bedded stroke unit	120 records (0.027%)	N/A - deceased persons hospital records	DNAR status PT transition to palliative care Advanced directives	Death caused by stroke is unexpected Symptoms evident with therapy restriction	Not specified	

Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Potential Themes	Findings and/or conclusions	Recommendations
Eriksson, H Milberg, A Hjelm, K Friedrichsen, M 2016 Sweden	<i>hospital stay on the stroke unit</i> <b>Design</b> <b>Aim</b> Retrospective comparative registry study Nov 2011 - Oct 2012 Ethical approval obtained <b>AIM</b> - To study the EoLC during the last week of life for pts who died from a stroke in comparison to cancer	3252 patients Deaths in hospital and nursing home Mean age = 83.5yrs (60% female)	N/A	Pts who had a stroke as main cause of death, who had died in hospital or NH, and whose death was expected. Stroke pts were matched with a registered pt who had died of cancer in the same period.	Prevalence of symptoms/management Communication with pts and family	There are differences in p/care at the EoL between stroke and cancer pts regarding symptom management, communication and bereavement follow-up.	Further studies in this area are needed.
Mayland, C.R Mulholland, H Gambles, M Ellershaw, J Stewart, K 2016 England	<b>Design</b> <b>Aim</b> Quantitative data Post bereavement survey to bereaved relatives 1 <sup>st</sup> May - 30 <sup>th</sup> June 2013 Ethical approval was not required <b>AIM</b> - Within the context of the National Care of the Dying Audit - Hospitals, to evaluate quality of care provided to dying pts and their families in acute hospital (rel perception)	3141 eligible next of kin, of which 2313 were eligible 130 acute trusts (being 90% of those eligible) with a total of 6580 data sets	37.1% (n=858)	Bereaved relatives	Symptom control Communication Overall impressions that dying pt and family were treated with dignity and respect.	Generally, symptoms were perceived to be well controlled  Unmet information needs  A small but significant minority perceived poor quality of pt care with clear and timely communication needed.	Further research regarding the management of fluids and hydration in the dying is needed. This would improve HCP confidence and encourage discussions with pts and family. Using the NCDAAH CODE questionnaire would be worthwhile.
Quadri, S.Z Huynh, T Cappelen-Smith, C Wijesuriva, N	<b>Design</b> <b>Aim</b> Retrospective study of all stroke deaths	123 pts identified from 1067 stroke admissions	N/A	N/A - deceased persons hospital records	Type of stroke Enteral feeding	ACP was very low	Future research is required to determine the level of pt and family satisfaction, quality of

Author(s), year and country of origin	Design	Sampling strategy, total population and environment	Response rate	Characteristics of respondents	Potential Themes	Findings and/or conclusions	Recommendations
Mamun, A Beran, R.G McDougall, A.J Cordato, D 2017 Australia	January 2014 - December 2015 Ethical approval from South Western Sydney LHDHR Ethics Committee <i>AIM - To review stroke deaths in a large, tertiary referral hospital; frequency of pre-existing ACP; associations between palliative care referral rates, commencement of EOLCP, stroke type and survival time from admission</i>	Stroke pts and informal/formal care givers Purposive sample 3 participating stroke units in central Scotland 219 pts admitted to the 3 stroke units	34 pts recruited to the qual study with 99 interviews conducted over the first year of the stroke. Between 1/2 and 2/3 of questionnaires were returned	Stroke pts, informal and formal care-givers and health or social care professionals.	Language spoken at home (49% spoke a language other than English at home)	P/care referral and EofLCP were commenced in less than 50% of pts Mean survival from P/care referral for stroke was 7.5days (similar to European study) Survival was significantly longer in those pts commenced on enteral feeding.	care and cost benefits achieved by EOLCP in stroke.
Kendall, M Conwey, E Mead, G Barber, M McApline, C Stott, D.J Boyd, K Murray, S-A 2018 Scotland	Mixed methods longitudinal study In-depth serial, qualitative interviews (2 experienced female qual researchers carried out interview with Pt and caregiver Questionnaires Data linkage June 2014 - January 2015 <i>AIM - To explore patterns of death of all pts with total anterior circulation syndrome admitted to 3 stroke units in central Scotland.</i>				Findings regularly reviewed by two lay advisory groups Anxiety of family and friends Low self-worth Lack of information Difficulty sharing feelings and emotional distress	Major stroke brings likelihood of death with little preparation Planning should be offered P/care principles should be practiced Avoid use of term 'palliative care' or re-frame Limitations - pts recruited only from Scotland / all white population No formal training in P&EofLC had been received in any of the 3 stroke environments (although some online learning was available)	Not specified

## **Appendix 7 - The Leadership Alliance for the Care of Dying People (2014) Five New Principles for Care**

The LACDP has published a new approach to caring for people in the last few days and hours of life

The Five new Priorities for Care are:

1. The possibility that a person may die within the coming days and hours is recognised and communicated clearly, decisions about care are made in accordance with the person's needs and wishes, and these are reviewed and revised regularly.
2. Sensitive communication takes place between staff and the person who is dying and those important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care.
4. The people important to the dying person are listened to and their needs are respected.
5. Care is tailored to the individual and delivered with compassion – with an individual care plan in place

<https://www.england.nhs.uk/ourwork/qual-clin-lead/lac/>

## Appendix 8 - Letter to Ward Manager, Stroke Ward

Dr Alexandra Hopkins RN PhD MSc MBA RNT RCNT DANS  
Dean of the Faculty of Education Health and Wellbeing

University of Wolverhampton  
Millennium City Building  
City Campus Wulfruna (South)  
Wolverhampton  
WV1 1LY

Telephone Codes  
UK: 01902 Abroad: +44 1902

Switchboard: 321000  
Fax: 518660

Internet: [www.wlv.ac.uk](http://www.wlv.ac.uk)

20<sup>th</sup> March 2017

Dear [REDACTED]

**Re: Proposed Research Study - Dying from acute stroke: orchestrating an autoethnographic sonata of care**

As part of my Professional Doctorate in Health & Wellbeing course at the University of Wolverhampton I am proposing to conduct a research project into the experiences of family members of stroke patients who died following admission to hospital. To do this I require your support/help with identifying the sample for the study. This information can be found on the Stroke Register held by [REDACTED] NHS Foundation Trust. If you agree to take part this will involve accessing the Stroke Register, identifying the population from 1<sup>st</sup> January 2016 – 31<sup>st</sup> December 2016 and determining a sample of individuals who meet the criteria for the study. You will then be required to send a recruitment pack to each potential participant inviting them to join the study.

The potential benefits of this research include adding to the body of knowledge in the area of palliative and end of life care for patients who die as a result of an acute stroke. It is also expected to make recommendations for service improvement, policy and clinical practice, offering guidance on the provision and timely implementation of palliative and end of life care for dying patients and the grieving family.

I am therefore writing to seek your permission to conduct this study in association with the Stroke Ward [REDACTED] with the relatives of deceased patients. I would be most grateful if you could forward a letter (address below) agreeing to allow me access in order that I may include a copy in my Research Proposal to the University of Wolverhampton.

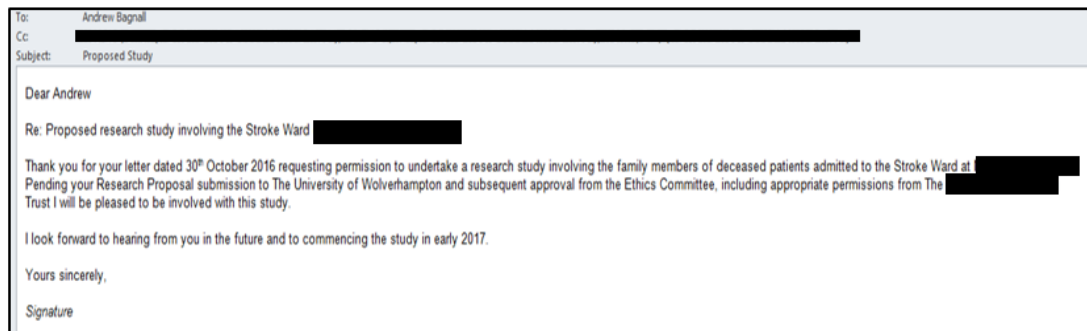
I look forward to hearing from you.

Yours sincerely  
[REDACTED]

Andrew J. Bagnall - Researcher (Tel. 01902 774561)  
Address: Compton Hospice Education & Training Centre, The Cedars, 39 Compton Road West,  
Compton, Wolverhampton, WV3 9DW

Version 2 (20.03.17)

## Appendix 9 - Email received from Ward Manager





## Appendix 10 - Ethical Approval, University of Wolverhampton



Date 25<sup>th</sup> April 2017

Andrew Bagnall (Professor Magi Sque)  
University of Wolverhampton  
FEHW

Dear Andrew Bagnall (Professor Magi Sque)

**Re: Dying from acute stroke: orchestrating an autoethnographic sonata of care (Care at the end of life following an acute stroke) submitted to The Faculty of Education, Health and Wellbeing Ethics Panel (Health Professions, Psychology, Social Work & Social Care)**

The Faculty Ethics Panel (Health Professions, Psychology, Social Work & Social Care) has considered and reviewed your submission.

On review your Research Proposal was passed and the Panel believes that the ethical issues inherent in your study have been adequately considered and addressed. Therefore the Panel is giving you full ethical approval for your study (Code 1 - Approved). We would like to wish you every success with the project.

Yours sincerely

*H Paniagua*

Dr. H. Paniagua PhD, MSc, BSc (Hons) Cert. Ed. RN RM  
Chair – Ethics Panel

*Richard Darby*

Dr Richard Darby PhD, BSc  
Chair – Ethics Panel

## Appendix 11 - Health Research Authority (HRA) Approval



**Health Research Authority**

**West Midlands - Black Country Research Ethics Committee**

The Old Chapel  
Royal Standard Place  
Nottingham  
NG1 6FS

**Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval**

24 November 2017

Mr Andrew John Bagnall  
Researcher  
Compton Hospice  
Compton Hospice Education & Training Centre  
The Cedars  
39 Compton Road West  
WV3 9DW

Dear Mr Bagnall

<b>Study title:</b>	<b>Dying from acute stroke: orchestrating an autoethnographic sonata of care</b>
<b>REC reference:</b>	<b>17/WM/0346</b>
<b>IRAS project ID:</b>	<b>228637</b>

Thank you for your response of 17<sup>th</sup> November 2017, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by Dr Julian Sonksen.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further

information, or wish to make a request to postpone publication, please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request.

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).*

*Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.*

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of management permissions from host organisations*

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact [hra\\_studyregistration@nhs.net](mailto:hra_studyregistration@nhs.net). The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### Ethical review of research sites

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity Insurance]		09 August 2017
Interview schedules or topic guides for participants [Interview Schedule]	2	12 September 2017
IRAS Application Form [IRAS_Form_13092017]		13 September 2017
Letter from sponsor		03 August 2017
Letters of invitation to participant [Letter of invitation to participants]	3	29 October 2017
Other [Sonata Framework]	1	03 August 2017
Other [Framework for Ethical Approval]	1	03 August 2017
Other [Email Response from Stroke Ward Manager]	1	03 August 2017
Other [Letter Requesting Access to Stroke Ward]	1	03 August 2017
Other [References for IRAS]	1	03 August 2017
Other [Lone Worker Strategy]	2	12 September 2017
Other [Bereavement Support and Counselling Contact Details]	2	12 September 2017
Other [Letter of invitation (Dr Marlow)]	2	30 October 2017
Other [Letter of response to Dr Julian Sonksen]	2	30 October 2017
Other [Reply Slip]	3	09 October 2017
Other [Letter of thanks to participants]	3	09 October 2017
Other [Dr Julian Sonksen letter ]	3	09 November 2017
Participant consent form	2	31 August 2017
Participant information sheet (PIS)	5	30 October 2017
Research protocol or project proposal [Research Proposal]	2	31 August 2017
Summary CV for Chief Investigator (CI) [Andrew Bagnall CV (IRAS)]	1	02 August 2017
Summary CV for student [CV Andrew Bagnall]		18 August 2017
Summary CV for supervisor (student research) [CV Prof Magi Sque]		09 August 2017

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

17/WM/0346

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.


Yours sincerely



Dr Julian Sonksen  
Acting Chair

Email: [nrescommittee.westmidlands-blackcountry@nhs.net](mailto:nrescommittee.westmidlands-blackcountry@nhs.net)

## Appendix 12 – Trust Research & Development Approval Letter

The Royal Wolverhampton   
NHS Trust

28<sup>th</sup> February 2018

Mr Andrew Bagnall  
Compton Hospice Education & Training Centre  
The Cedars  
39 Compton Road West  
Compton  
Wolverhampton  
WV3 9DW

Research & Development Directorate  
The Chestnuts  
Wolverhampton  
West Midlands  
WV10 0QP

Tel: 01902 695065  
Fax: 01902 695682

Dear Mr Bagnall

RE: IRAS 228637

Confirmation of Capacity and Capability at The Royal Wolverhampton NHS Trust

**R&D Number:** 17NEUR05

**Study Title:** Dying from acute stroke: orchestrating an autoethnographic sonata of care.

This letter confirms that the Royal Wolverhampton NHS Trust has the capacity and capability to deliver the above referenced study.

We have agreed with the Sponsor to start this study on a date to be agreed with the sponsor directly with the Research Delivery Team when they give the green light to begin.

**Obligations:**

<b>Recruitment Target/Delivery</b>	10
<b>Support Services Terms of Agreement</b>	N/A
<b>MPE Report</b>	N/A
<b>Information Governance</b>	No PID data to leave site

Chairman: Jeremy Vanes  
Chief Executive: David Loughton CBE  
Preventing Infection - Protecting Patients

A Teaching Trust of the University of Birmingham  
Safe & Effective | Kind & Caring | Exceeding Expectation



Version 2

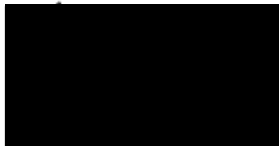
<b>Equipment Requirements</b>	Any equipment provided on loan or to keep by the Sponsor must be registered with the R&D Governance Team.  (add PAC testing and extra requirements as necessary)
<b>Training and Education</b>	CVs and GCP training must be refreshed every 2 years to be compliant with R&D SOPs.

*Please ensure your research delivery team lead (e.g. lead research nurse) notifies the Project Management Team of the SIV date (if not already occurred) and the green light date agreed with Sponsor via email address [rwht-tr.rdpmtteam@nhs.net](mailto:rwht-tr.rdpmtteam@nhs.net).*

As Principal Investigator for this study, it is your responsibility to ensure you keep up to date with the relevant Royal Wolverhampton NHS Trust policies and procedures and specific R&D Directorate Standard Operating Procedures.

Please note any changes to the study documents can only be initiated following further approval from the HRA via an amendment. The Research & Development Directorate must also be notified of any changes to the study or the documents.

I would like to wish you every success with the study.



R&D Directorate Manager

c.c. Dr C Marlow, Consultant in Palliative Medicine, Deanesly Centre, RWT.  
Mr D Bailey, Directorate Manager, RWT.  
Professor M Sque, R&D.

Version 2

## Appendix 13 - Framework for Ethical Decision Making

Ethical considerations	Practical strategies
<b>Participant identification and recruitment</b>	
Access, confidentiality	Formally obtain the support of a key person to undertake the role of identifying potential participants and disseminating pre-prepared recruitment packs on behalf of the research team.
Regard	Recruit potential participants in a serial manner, e.g. send out a maximum of five recruitment packs at any one time so that participants are not kept waiting for long periods before the research interview.
Respect, relevance	Consider participant inclusion criteria of bereaved no less than three months and no more than 12 months at the time of recruitment to the study.
Compassion	Include a covering letter that introduces the study in a personalised way by taking familiarity into consideration.
Informed choice	Provide clear written and web-based information about the researchers and the study. Include an invitation to contact the researcher. Demonstrate timely responsiveness to any potential questions or queries.
Non-coercion	Provide a minimum of 10 days for participants to decide about joining the study.
<b>The research interview</b>	
Choice, respect	Agree a convenient date, time and venue for the research interview. Avoid dates that coincide with any significant family events or anniversaries.
Safety	Implement a study site policy for researchers working alone in advance of the interview encounter.
Safety, support	Competent researcher with experience of conducting sensitive research interviews and supporting the bereaved.
Choice, privacy	Provide the option of an interview face-to-face or remotely, for example via telephone.
Informed consent	Provide an overview of the study and present opportunity for participants to ask questions. Explain how the interview will proceed. Obtain written agreement to audio-record the interview and to use anonymous quotes in any presentation of the research. Provide participants with a copy of the signed consent form to keep.
Support	Discuss and agree avenues of post-interview support prior to the interview commencing.
Support	Observe/listen for signs of distress during the interview. Discuss the option of pausing the recording or stopping the interview. Plan a natural break for refreshments.
Confidentiality, anonymity	Ensure audio-recordings and transcripts are securely stored and electronic data is password protected. Assign a study code at the point of transcription.



Post interview follow-up care	
Support	Arrange a convenient time to telephone the participant (normally in 24 to 48 hours) to check on any issues the interview may have raised and to answer any questions.
Support	Compile information about local support organisations. Offer this to participants if they consider it helpful and/or direct them to appropriate professionals to discuss any issues of concern.
Support	Establish if participants wish their General Practitioner (GP) to be informed about their participation in the study and obtain written consent to proceed. Provide GP with information about the study at the time of notification.
Appreciation	Send participants a personal thank you letter and offer an executive summary of the research findings.
Involvement	Provide participants with an opportunity to evaluate their experience of participating in bereavement research.
Support	Determine support for the researcher from an individual with whom they feel comfortable, and who is suitably qualified to provide support. Plan a debriefing session after each interview encounter. Utilise reflexive notes to guide the discussion.

**Source:** Sque, M., Walker, W. and Long-Suthehall, T. (2014) Research with bereaved families: A framework for ethical decision-making. *Nursing Ethics*. 21(8) pp.946-955.

## Appendix 14 - Letter of Invitation to Participants



Dr Alexandra Hopkins RN PhD MSc MBA RNT RCNT DAN5  
Dean of the Faculty of Education Health and Wellbeing

University of Wolverhampton  
Millennium City Building  
City Campus ~~Wolverhampton~~ (South)  
Wolverhampton  
WV1 1LY

Telephone Codes  
UK: 01902 Abroad: +44 1902

Switchboard: 321000  
Fax: 518660

Internet: [www.wlv.ac.uk](http://www.wlv.ac.uk)

Compton Hospice Education & Training Centre  
The Cedars  
39 Compton Road West  
Compton  
WOLVERHAMPTON  
WV3 9DW

Date (to be added)

Dear (name to be added)

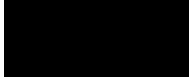
Re: Care at the end of life following acute stroke

I am writing to invite you to participate in a research project which I am conducting as part of a Professional Doctorate in Health & Wellbeing course at the University of Wolverhampton. I enclose a Participant Information Sheet which explains the title and aims of the project and what taking part will involve.

If you are willing to be interviewed, the interview would last up to 1 hour. The interview would either take place in your home or another local preferred location at a time convenient to yourself. A summary report will be written of the findings which you may wish to receive.

If you would like to take part in this study, please complete and return the enclosed reply slip using the stamped addressed envelope no later than 10 days following receipt of this letter. I will then contact you to arrange a convenient date and time to meet. If you would prefer not to be involved, please ignore/destroy this letter.

Yours sincerely |



Andrew J. Bagnall  
Researcher

Enc. Participant Information Pack

## **Appendix 15 - Participant Information Sheet**

Study No: [insert as appropriate]

Study Title: Care at the end of life following acute stroke

Dear [name with appropriate title]

I am inviting you to take part in a research study. The study aims to explore the personal experiences of family members whose relative died from an acute stroke following admission to the Stroke Ward (Ward B12) at New Cross Hospital in Wolverhampton.

This Participant Information Sheet explains the purpose of the study, why you are being asked to take part, and what is involved.

**Please read this information and letter and discuss it with others if you wish. Please take time to decide whether or not you want to take part. I will be very happy to explain anything that is not clear.**

### **What is the purpose of the study?**

The study aims to investigate the end of life care and hospital experiences of bereaved adults whose family member died following admission to hospital after a stroke. The information gained will help to meet the needs of patients and family members who experienced end of life care in a hospital setting.

### **Who is running the study?**

I am carrying out this research project as a student researcher at The University of Wolverhampton under the supervision of and with the support of an experienced advisory team.

**Why have I been chosen for this study?**

You have been chosen to take part in this study as a relative of a person who died in hospital following admission with a stroke. By sharing your experiences you could help healthcare professionals further understand how best to provide end of life care and support for patients and their families.

**Do I have to take part?**

No, it is your choice whether you would like to take part. You are under no obligation to do so. It is something you may want to discuss with your family or close friends. If you agree to take part, you can withdraw at any time without giving a reason.

**What would happen to me if I take part?**

I am asking you to share your hospital experiences which would be audio-recorded with your permission. This would be done through an interview with me. The interview will be carried out at a time and place convenient to us both. This may be your home or, if you prefer, a relative or friend's home. You may prefer to meet at New Cross Hospital or Compton Hospice where I work, or another environment which is familiar to you. Wherever we agree to meet for the interview the room should be quiet and somewhere our conversation is not overheard or disturbed.

I would explain the study before starting the interview and you would have the opportunity to ask questions. I will then ask you to sign a consent form to show that you have agreed to take part in the study. You would be given a copy of the signed Consent Form. The interview would be audio-recorded to provide an accurate record of the experiences you share with me.

During the interview, we will discuss your experience of hospital care; your views about the care provided; your needs during this time, whether they were met and if not, what you feel was missing.

If English is not your first language and you would prefer to have a relative or friend translate for you, I would be pleased to talk with you and this individual prior to the interview.

The interview is expected to last no longer than two hours. However, if you wish to take a break or to finish the interview at any point, you only need to tell me and do not need to give reasons for stopping the interview.

Interviews can be emotionally tiring and you may like to have a member of your family or a friend with you during the interview, or to have someone whom you can talk to afterwards. Please also find attached contact details for local support organisations that you may find beneficial.

**Would my taking part in this study be kept confidential?**

Anything you say will be treated as confidential. All information collected will be kept in the strictest confidence. Your name is not recorded anywhere within the study and will not be identifiable from the published results.

**After the interview**

After the interview I will listen to the audio-recording. The information will be transcribed by an administrative colleague at the hospice and analysed by myself. The audio-recording will be retained for a minimum of two years in accordance with University of Wolverhampton regulations and then destroyed.

You will receive a thank you letter and I will be happy to provide you with a summary of the research on completion of the study.

**Complaints about any aspect of this project should be addressed to:**

Dr Alexandra Hopkins, Dean of the Faculty of Education Health and Wellbeing,  
University of Wolverhampton, Millennium City Building, City Campus Wulfruna  
(South), Wolverhampton, WV1 1LY

**Contact for further information**

If you would like to discuss anything or have further questions at any time, please do not hesitate in contacting me on 01902 774561 and leave a voicemail message if necessary. I will return your call as soon as possible.

**Thank you for taking the time to read this information.**

**This Participant Information Sheet is for you to keep.**

**Andrew J. Bagnall**

**Researcher**

## Appendix 16 - Reply Slip

### Reply Slip

Study No: [Insert appropriate text]

**Study Title:** Care at the end of life following acute stroke

I am willing to talk to Andrew about my experiences in a face-to-face interview

**Your name:** (Please print)

---

**Signature:**

---

**Date:**

---

**Your telephone contact number:**

---

**Email address:**

---

**Best time to contact you:**

Morning / Afternoon / Evening (please circle)

**Preferred contact method:** |

Telephone / Email (please circle)

## **Appendix 17 - Bereavement Support List**

**Bereavement Support and Counselling is provided by the following organisations which family members may find helpful:**

**Bereavement Services**, City of Wolverhampton Council, Civic Centre, St Peters Square, Wolverhampton WV1 1SD Tel. 01902 554992

**Compton Hospice Bereavement Services**, The Cedars, 39 Compton Road West, Wolverhampton WV3 9DW Tel. 0845 2255 497

**Cruse Bereavement Care**, 45 Queen Street, Wolverhampton, WV1 3BJ Tel. 01902 420055

Information about other local and national organisations offering counselling support can either be located on the internet or at your GP Practice.



## **Appendix 18 - University of Wolverhampton Lone Worker Strategy for Researchers**

### **Guidance Notes for Researchers**

#### **Conducting Data Collection Off-Campus and Working Alone**

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These guidelines are primarily intended to help assure the safety of researchers who conduct interviews alone with participants, particularly when such work is undertaken off campus. Compliance with this guidance should assist in:

- Protecting researchers by reducing their risk of exposure to physical threat or abuse.
- Preventing researchers from being placed in a situation in which they might be vulnerable to accusations of improper behaviour
- Protecting participants by providing researchers with advice on best practice in this area.

### **1. Design of Research and Risk Assessment**

Before undertaking data collection as a lone researcher, particularly off-campus, a risk assessment should be conducted taking into account the key questions below to minimise the risks in undertaking research work on behalf of the university. It may be necessary to amend or redesign proposals following such an assessment.

- **Method:** Is it necessary to collect data in a one-to-one context, or would an alternative methodology be more appropriate? Is it possible for researchers to work in pairs?
- **Interview location:** Where should interviews take place? A public place may be a safer option than the participant's home.
- **Researchers:** Who should conduct the interviews? Which researcher(s) have the appropriate skills/experience?
- **Participants:** Who are they? Are they members of a vulnerable or potentially dangerous group?

## **2. Preparation for Lone Working Off-Campus**

### **2.1 Understanding the Environment**

- Wherever possible, researchers should review a map of the area, or visit the location in advance.
- Knowing in advance the location of hubs of activity such as shops, pubs, schools or the local police station may provide researchers with a possible escape route should this be necessary.
- Researchers should be aware of any social or cultural tensions in the area.
- If travelling by car, researchers should consider the safest place to park, eg. a well-lit area after dark.
- If using public transport, researchers should check its reliability and also carry the telephone number of a reputable local taxi firm.

### **2.2 Understanding Participants**

Researchers should take time to investigate and understand the individual circumstances of participants before conducting an off-campus interview. If appropriate, researchers should be aware of the psychological/behavioural history of interviewees. Being aware of potentially volatile individuals and/or circumstances in advance can help researchers to plan accordingly.

### **2.3 Training**

- New staff should have general training on conducting off-campus interviews, and basic interview skills during their induction period. This may include accompanying a more experienced colleague on an off-campus visit.
- Researchers conducting off-campus interviews should be trained in techniques for handling threats, abuse or compromising situations.
- Some research may require additional specific training such as understanding cultural/religious norms.

## **3. Precautions When Conducting Interviews Off-Campus**

### **3.1 Personal Safety**

The personal safety of researchers working off-campus is paramount and should be considered more important than the successful completion of the interviews.

Researchers **SHOULD NOT:**

- Enter someone's home if they feel uncomfortable or unsafe.
- Enter a house if the person they have arranged to see is not there.
- Undertake an interview or assessment in a bedroom.
- Give a personal telephone number or address to an interviewee.

Researchers **SHOULD:**

- Ask a colleague to accompany them if they feel uncomfortable.
- Upon arrival, explain their research role and the conditions of confidentiality to the interviewee(s) and offer them the opportunity to ask questions.
- Consider an appropriate exit strategy (what to say etc) should they wish to terminate an interview early.
- Take steps to leave a situation immediately if they feel unsafe or uncomfortable.
- Adopt a friendly and professional manner when conducting interviews but be careful not to be over-familiar.
- Ask for household pets to be shut in another room if their presence during the interview is a cause of concern.

### **3.2 Maintaining Contact**

It is essential that researchers conducting off-campus interviews maintain contact with a nominated colleague (PI or other if researcher is PI).

The Researcher should ensure the nominated colleague knows the following:

- Name, address and telephone contact of interviewee(s)/destination.
- Researcher's mobile telephone number.
- Time of leaving the office.
- Method of transport to interview location (car registration if appropriate).
- Time of interview and expected duration of visit.

Researchers should contact their PI when they arrive at the interview location, particularly if this is out of hours. In the presence of the interviewee, the Researcher should inform their nominated colleague where they are and who they are with.

If at any point during the interview, the researcher feels unsafe; they should excuse themselves, go to another room, and call for assistance using their mobile phone. Codes may be agreed in advance to convey the need for support in a confidential manner.

Once the interview has been completed, the researcher should contact their nominated colleague at an agreed time to let them know they have left safely. If the interview is still in progress when the deadline for contacting their nominated colleague approaches, the researcher should contact their nominated colleague to inform them.

If the deadline passes and the researcher has not been in contact, their nominated colleague should ring the mobile phone of the researcher. If there is no answer, the nominated colleague should ring again 10 minutes later. If there is still no reply, the Director of Research and Enterprise must be informed. With the agreement of the Director of Research and Enterprise, two members of staff from the department may proceed to the interview location to check on the researcher's safety.

### **3.3 Mobile Telephones**

All researchers who conduct off-campus interviews should be provided with a mobile telephone. Mobile telephones should be left switched on throughout

the interview. Researchers should bear in mind that mobile telephones are sometimes out of range and cannot be depended upon entirely. Over reliance on mobile telephones must not substitute for proper training in inter-personal skills and personal safety techniques.

### **3.4 Personal Alarms**

All researchers who conduct off-campus interviews should be provided with a personal alarm. Researchers should carry the alarm in their pocket or hand (not in their bag or briefcase) so that it is easily accessible.

### **3.5 Identification Card**

All researchers who conduct off-campus visits should carry an official identity card with photograph. It is good practice to invite interviewees to check the card.

### **3.6 Money**

Researchers should always carry enough money for expected and unexpected expenses, including the use of taxis. However, it is sensible not to appear to be carrying a lot of money. Researchers should also carry a phone card in case they need to use a public telephone.

## **4. Debriefing and Support Following Off-Campus Interviews**

When off-campus interviews are complete, it is likely to be helpful for researchers to reflect on their adherence to safety guidelines and raise any difficulties encountered during the project. Where necessary, individual experiences should be used to inform the design of future projects/interview protocols.

Any incidents that occur during the interviews should be formally recorded and dealt with immediately. Serious incidents should be discussed with safety officers or professional associations. If violent or traumatic incidents have occurred which may have some impact on the physical and/or psychological well-being of researchers, these should be reported to the appropriate department (e.g. health and safety officer, occupational health, counsellors, police).

Formal arrangements should be in place for researchers to be accompanied by a colleague for subsequent interviews if there have been any incidents giving cause for concern on the first occasion.

## **5. Further Information**

This is not intended to be an exhaustive list of considerations when planning research involving working alone off-campus. However, it is hoped that these guidelines will encourage researchers to adopt best practice and familiarise themselves with the relevant safety issues.

## Appendix 19 - Interview Schedule

1. Could you tell me a little bit about (*name of person who died*), including his/her role within the family, and what they meant to you at the time of their death?
2. What led to (*name*)'s admission to the acute stroke ward at New Cross Hospital?
3. What is your understanding of 'palliative care'?
4. What is your understanding of 'end of life care'?
5. Can you tell me about your experiences of the end of life care given to (*name*) during his/her time on the acute stroke ward?
6. Tell me about how the hospital staff cared for (*name*) in the last few days of his/her life.
7. What care and support did you receive from hospital staff during (*name*)'s time on the acute stroke ward?
8. What are your thoughts about how staff communicated with you as a relative?
9. What do you remember most about the care given to (*name of person who died*)?
10. What do you remember most about the care given to you as a relative?
11. Would you describe this as 'quality care'? If yes, in what way(s)?
12. What, if anything could have been done differently for (*name of person who died*)?
13. What, if anything could have been done differently for you as a relative?
14. Do you remember whether you or (*name*) was asked about where he/she wanted to be cared for? For example, some people choose to be at home, in a nursing home, stay in hospital or transfer to a hospice.

### **To ask only if not specifically revealed during the interview:**

15. *Did anyone talk to you or (name of person who died) about palliative or end of life care?*
16. *Did anyone mention involving the palliative care team at the hospital?*

### **In summary:**

17. Is there anything else you would like to tell me?
18. Just before the interview ends, do you have any questions you want to ask me?

Thank you agreeing to meet me and for allowing me to interview you. I am most appreciative of your time and for sharing your experiences with me.

## Appendix 20 - Participant Consent Form

### Participant Consent Form

Study No: [Insert appropriate text]

Study Title: Care at the end of life following acute stroke

Please initial box

1. I confirm that I have read and understood the contents of the Participant Information Pack for the above study. I have had the opportunity to consider the information, and have had the opportunity to ask questions and have them answered satisfactorily.

Yes

2. I understand that my participation is voluntary and that I am free to withdraw from the study at any time, without giving any reason.

Yes

3. I agree that anything I may say during the course of the interview may be used as anonymous quotes in any presentation of the research (verbal presentation or written publication).

Yes

4. I agree to take part in the above study and to the interview being audio-recorded.

Yes

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date and signature

\_\_\_\_\_  
Name of Researcher

\_\_\_\_\_  
Date and signature

1 copy to remain with Participant, 1 copy for Researcher



## Appendix 21 - Example of coding the data using a highlighting technique

<p>150 getting a tube down into him to enable him to get food and of course he was  151 deteriorating at that point, so that was very important. Now, unfortunately, he, <b>they</b>  152 <b>struggled to get that in</b>. They didn't. <b>I don't think in all fairness that they probably had</b>  153 <b>enough experienced people to be able to do that</b> at that particular time because my  154 father was very uncomfortable, <b>they couldn't do it which made him very nervous</b>..</p>	<p><b>AB</b> Andrew Bagnall NG tube for feeding</p> <p><b>AB</b> Andrew Bagnall Insert the NG tube to feed <b>gt</b></p>
<p>155 A Ok..  156 D ___ and, and then it took a few times to do, they got it in and then he pulled it out  157 and from then on things seemed to deteriorate and he then, I believe, he had another  158 stroke.</p>	
<p>159 A Oh, I see.  160 D So, it's a little bit of err, <b>we were hoping it was going to be ok</b> but there, it was  161 a strange feeling that, at the time, I can remember distinctly thinking, <b>'I hope that, that</b>  162 <b>not, that, trying to put the tube in, and all the stress</b></p>	
<p>163 A Ok  164 D ___ and everything else hasn't caused that extra stroke. Now, it might not have  165 been but at that particular time there was an area of concern from us and the family  166 that, well, 'why's he had a stroke again?' But <b>he went through an awful lot of discomfort</b>  167 and everything else. That aside obviously, we then went into a situation where <b>the</b>  168 <b>consultant said</b>, 'Look. We, <b>he, is deteriorating</b>. He's not improving now and, basically,  169 you know, we are at the point now when we'll do what we can' but they, <b>they were</b>  170 <b>still feeding him because they'd actually given him an operation to put the</b>..</p>	<p><b>AB</b> Andrew Bagnall insertion of PEG tube</p>
<p>171 A PEG.  172 D ___ the PEG  173 A Peg tube  174 D ___ yes, yes, and that was delayed again, so it was a little bit, a little bit of anxiety  175 was going on. One, because of the fact that <b>they couldn't get the tube in through his</b>  176 <b>nose to feed him</b> and secondly, because <b>they couldn't do the PEG straight way</b>  177 because of staffing and, and, and things like that. So, <b>the end result may never have</b>  178 <b>been any different but you always have this doubt</b> as to, you know, why, if, and I  179 remember having to sort of speak to them. 'Now look, <b>You need to do this operation</b>  180 <b>because I don't want my father to be a statistic</b>. Ummm. I'd already previously, when  181 my mother had been ill and had to go through a lot of discussions and things at  182 hospital at Walsall, but as I say that's an aside. So, there was, there's a little bit of...  183 (huh)... anxiety and I guess from our point of view concern and worry because <b>at that</b>  184 <b>stage we were hoping that he was still going to survive but then we came to the stage</b>  185 <b>when we were told that things weren't going to go in the right direction</b>. Umm, and he,  186 obviously, <b>you have to accept that at that point however difficult it's going to be</b>.  187 Umm, he was then in a ward, <b>he was in a room on his own to start with when he was</b>  188 <b>hopefully going to go through recovery</b>. Then <b>he was then in a ward with four people</b>.  189 <b>That was quite distressing in actual fact</b>, umm, whilst he was still in there, because he  190 was moving about a lot. <b>It was quite difficult. There were other people in there making</b>  191 <b>noises</b> and that and I appreciate you know goodness me <b>not everyone can have a</b>  192 <b>private room</b> and this was just prior to, prior to, going to a private room. So, he <b>he</b>  193 <b>was very distressed which made the family very distressed and and it was almost</b>,  194 <b>you know, 'Oh dad, if you're not going to survive' we wanted him to go sooner than</b>  195 <b>later</b></p>	<p><b>AB</b> Andrew Bagnall Communication with hospital staff</p>
<p>196 A Yeh  197 D ___ in, in a way because <b>you're watching someone effectively suffer and die and</b>  198 <b>somebody saying there's nothing they can do about it</b>. And I think the hardest thing  199 is... (swallows to compose self)... excuse me..</p>	<p><b>AB</b> Andrew Bagnall Admitted into single room / ?improved or stabilised and transferred into 4 bedded ward.</p> <p><b>AB</b> Andrew Bagnall Shared ward or single room</p> <p><b>AB</b> Andrew Bagnall Very emotive – death v survival (similar to A/B)</p>

## Appendix 22 - Truncated extract from Excel spreadsheet of developing basic themes

	A	B	C	D	E	F	G	H
1	Themes							
2	Family Dynamics	Married for 64 years; you never want to get to the point where you want to resent looking after somebody						
3	Family response to pt's stroke	Initially not partici... Not such a shock at... We were hoping t'l I don't want my fat'l You're watching so None of us (family) We stayed wit						
4	Personality of the patient	Strong, well man	Father figure	Advisory role	Family orientated	Traditinal values. V	Very kind	Respected by
5	Instinctively knowing something was wrong	It was obvious it wa... He was deterioratin... We could look and Even though he coi... Nursing staff couldn't possibly know that because th						
6	Timeframe from stroke to death	5 - 6 weeks						
7	Symptoms	Affected brain, shor	Pre-stroke really ba	Slurring speech	He went into hospi	Severe stroke	He couldn't feed,	Stress (due to
8	Def of P/care	The word isn't ment... Maybe PC is sometf... It's a word you associate with hospices						
9	Def of EofLC	It depends what tha... It all depends ... what the person who is sadly passing away is capable of doing and what they need						
10	Interventions of the ward	NG tube insertions	PEG insertion	They stopped feeding him and giving him water				
11	Potential discharge home	He kept saying wher... Consultant - not sure that's going to be of any benefit to him						
12	Improvement in condition							
13	Thoughts about care given	They (the staff) wen... The staff did everyt... From a palliative point of view I don't think they could have done much more in all honest						
14	Ward environment	Admitted into signle... Noisy						
15	Communication	We went in an the c... The consultant said... You have to try an... Communication wa... In general everybo... Consultant said, 'v... There was a b						
16	Staff / hospital / NHS	They couldn't do the... He was in a room or... Once my father w... They were very goc... It was just maybe t... If you have to go... Resources is a						
17	Physical help required by pt	The care was very ve... Everyone was tryin... nor would my m... I'm sure that my father would have been a bag of bones at the end...we						
18	Patients being cared for in hospital	They weren't doing... My father wouldn't... All we wanted wa... We didn't feel that... It wasn't because v... Dad was looked af... The team ther						
19	Was the care offered 'quality' care?	They were there if v... They would have d... Generally it was v... Quality care = supp... Respect for the pe... The quality but in my eyes is actu						
20	After death							
21	Prefered place of care / death	We said, 'Is there a... There was never an... My father kept say... It was only when we knew... That my father wasn't going to be with us f						
22	Interventions	Attempted insertior... (although deteriora... He was then move... Swan - (emotive) r... Every time they w... Insertion of PEG - He eventually						
23	Ethical issues	There's a balance of... if we give him too... My father was a gc... Physical restraint (p... It took four or five... I'm not saying ... pi... Suffering - to						
24	Family needs	It was vital that my f... (important) to know it was important t... In a strange way it... You want them to live but you want them to die at t						
25	Mention of hospice	No... If you say hospice, you think of a place to go for death, don't you? I would.						
26	Shift from active to PC/EofLC	Subtle ... they were... It wasn't PC they w... We were waiting f... The kindest thing it to, to let them go						
27	Decision making at the end of life	He (the consultant) said, 'actually you don't make that decision, we do' (re withdrawing treatment)						
28	Involvement of the PC Team	Unsure - possibly (although no evidence)						
29	Coping strategies	I think the braing has a very clever mechanism in that it enables you to be able to put things in boxes and not to porget but to put th						
30	Open visiting	Yes						
31	Interesting in the study	Yes						
32								
33								

**Appendix 23 - Table of Initial Basic, Organising and Global Themes  
derived from interview data**

<b>Basic Theme</b>	<b>Organising Theme (and associated basic themes)</b>	<b>Global Theme (and associated organising themes)</b>
<p>Family dynamics Family response to pt's stroke Personality of pt Instinctively knowing something was wrong Timeframe from stroke to death Symptoms Def of P/care Def of EofLC Interventions of the ward Potential discharge home Improvement in condition Thoughts about care given Ward environment Communication Staff / hospital / NHS Physical help required by pt Pt being cared for in hospital Was the care offered 'quality care'? After death Preferred place of care / death Interventions Ethical issues Family needs Mention of hospice? Shift from active to PC/EofLC Decision making at the end of life Involvement of the PC team Coping strategies Comorbidities Faith belief Open visiting Interest in the study</p>	<p><b>PATIENT &amp; FAMILY</b> Family dynamics / Instinctively knowing something was wrong / Family response to pt's stroke / Family needs / Coping strategies Personality of pt / Comorbidities</p> <p><b>STROKE &amp; SYMPTOMS</b> Timeframe from stroke to death Symptoms / Improvement in condition / Comorbidities</p> <p><b>DEFINITIONS &amp; COMMUNICATION</b> Def of P/care / Def of EofLC / Communication</p> <p><b>HOSPITAL / CARE / INTERVENTIONS</b> Staff / hospital / NHS   Pt being cared for in hospital / Was the care offered 'quality care'? / Interventions of the ward / Physical help required by pt / Ward environment / Was the care offered 'quality care'? / Interventions / Open visiting</p> <p><b>DYING/DEATH</b> Preferred place of care &amp; death / Potential discharge home / Mention of hospice? / After death / Involvement of the PC team</p> <p><b>FAITH / ETHICS</b> Faith belief / Ethical issues / Decision making at the end of life / Shift from active to PC/EofLC</p>	<p><b>THE FAMILY EXPERIENCE</b> Patient &amp; Family Centric Hospital Care</p> <p><b>DYING &amp; DEATH</b> Palliative &amp; End of Life Care</p>

## Appendix 24 – Colour Palette

white	champagne	palepink	paleblue
pear	apricot	cerise	azure
lime	orange	ruby	cerulean
yellowgreen	copper	crimson	steelblue
beige	salmon	rosepink	aqua
khaki	redorange	magenta	turquoise
olive	rust	redviolet	seagreen
umber	sienna	plum	aquamarine
ivory	seashell	violet	emerald
lemon	peach	fuchsia	jade
yellow	coral	purple	palegreen
gold	indianred	eggplant	applegreen
cream	pink	lavender	green
amber	red	amethyst	forestgreen
goldenrod	carmine	blueviolet	celadon
ocher	maroon	indigo	sage
bisque	mistyrose	babyblue	slate
tan	oldrose	skyblue	mauve
bronze	rosybrown	blue	taupe
sepia	rosewood	ultramarine	silver
brown			grey

Colour Palette <http://sh-yndesign.blogspot.com/p/blog-page.html>