Bringing Death Home:

Towards a deeper understanding of the implications of The End of Life Care Strategy for those individuals and organisations providing care in non-specialist settings.

KATHARINE JANE SCANLAN

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Abstract

My research uses a psychosocial approach to reach a deeper understanding of the experience of those providing end of life care in non-specialist settings and places this experience within the wider landscape of contemporary developments in care provision, with particular reference to the End of Life Care Strategy introduced by the Department of Health in 2008. One intention of the strategy is to ensure that those at the end of life have greater choice about where to die, including the option of remaining in a homely environment. An initial hypothesis was that the End of Life Care Strategy does not appear to adequately address the psychological and emotional impact of engaging in the kind of care it proposes. More specifically the view that death is the subject that we are most defended against as human beings, particularly in contemporary western society, is based on psychoanalytic considerations of our relationship with death and has implications and consequences for the individuals and organisations concerned.

A free association narrative approach was used to gather data from a small number of carers from care home settings. The data is presented in the form of case studies, end of life stories and a cross-case analysis, revealing emotional complexity and the significance of the relationship each carer has with death and dying. Identifying a range of unconscious defences in response to the carers' close proximity to death and dying I found evidence of a deep engagement with caring at the end of life, confirming personal and professional experience of a third tragic position elaborated within the thesis. Other findings include evidence of a strong vocational commitment to caring at the end of life, a powerful intertwining of personal and professional experience and a deep engagement with the emotional aspects of caring. The findings inform a number of recommendations.

Thesis Contents

Definition of Terms

Care Home: Whilst Froggatt (2009) uses the term 'care home' to encompass institutions providing personal care and nursing care, for the purpose of the project care homes refer to those providing personal care. Care Homes providing nursing care will be identified accordingly.

Abbreviations

- ELCS – End of Life care Strategy 2008
- LACDP – Leadership Alliance for the Care of Dying People
- LCP – Liverpool Care Pathway
- DNR – Do Not Resuscitate
- HCPC – Health Care Professions Council
- DoLS – Deprivation of Liberty Safeguards
- SALT – Speech and Language Team
- YTS – Youth Training Scheme
- GP – General Practitioner
- CQC – Care Qualities Commission
- DN's – District Nurses
- CPN's – Community Psychiatric Nurses
- NHS – National Health Service
- TLC – Tender Loving Care

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Audrey Vine (nee Cade) (02/04/1932 – 05/12/2008)

My late husband:

John Marshall Whitfield (30/06/1956 – 10/06/2006)

My Grandparents:

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Denis Scanlan

And last but not least my deepest thanks to the carers who shared their experiences so generously.

Dedicated To The Memory of John Marshall Whitfield
30th June 1956 – 10th June 2006

In Blackwater Woods

Look, the trees
are turning
their own bodies
into pillars

of light, are giving off the rich
fragrance of cinnamon
and fulfillment,

the long tapers
of cattails
are bursting and floating away over
the blue shoulders

of the ponds,
and every pond,
no matter what its
name is, is

nameless now.
Every year
Everything
I have ever learned

in my lifetime
leads back to this: the fires
and the black river of loss
whose other side

is salvation,
whose meaning
none of us will ever know.
To live in this world

you must be able
to do three things:
to love what is mortal;
to hold it

against your bones knowing
your own life depends on it;
and, when the time comes to let it go,
to let it go.

(**Mary Oliver,** *New and Selected Poems*, **Volume One, 2004**)

1   Chapter One: Introduction

1:1   A Strategy for Change

We showed an unmistakable tendency to put death on one side, to eliminate it from life. We tried to hush it up.

(Freud, 1915)

How and where we die and who might care for us when we do, has become a major preoccupation of our time. In particular, it has become a cause for government concern because of the needs of an ageing population and increasingly underfunded/under resourced health and social care services. Current attempts to respond differently to death in our society reflect our growing awareness of an ageing and dependent population. More people are living longer and needing greater levels of care through the aging and dying process. The department of health has responded by launching 'The End of Life Care Strategy' with the aim of improving the experience of all concerned with the end of an individual's life. The strategy is based on extensive consultation with health professionals, members of the general public and specialists in palliative care. The strategy acknowledges that although some people receive excellent care at the end of life, many do not:

Many people experience unnecessary pain and other symptoms. There are distressing reports of people not being treated with dignity and respect and many people do not die where they would choose to.

(End of Life Care Strategy, 2008, p. 9)

I first came across the End of Life Care Strategy shortly after its publication and not long after my own most recent experience of end of life care. When I read it for the first time it struck me as an ambitious and potentially revolutionary document. As a strategy it is aiming to address some of the most fundamental and problematic issues of our time. However as someone who has not only worked in a specialist palliative care service but also had three significant close encounters with end of life care, I felt compelled to look beneath the surface at what I know from experience to be a particularly intense and dramatic area of human experience. Having directly observed the struggles of technically competent and often highly trained individuals to negotiate

the interpersonal aspects of end of life issues, I was intrigued by the challenge that the strategy sets for all health and social care workers who find themselves in direct contact with those facing end of life issues and requiring end of life care.

The strategy is thorough with part one highlighting the challenges of end of life care and outlining the consequences of a lack of openness about death and dying in our society. It recommends a whole systems approach to the commissioning and delivery of integrated services and suggests that local approaches might play an active role in beginning to bring about a change in the attitude of the general public:

> *At a national level, the Department of Health will work with the National Council for Palliative Care to develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society*

(End of Life Care Strategy 2008, p. 11)

Part two focuses on care delivery and refers to the end of life care workforce with part three concentrating on the organizational aspect of making change happen. The strategy recognizes the need for the workforce to develop the necessary knowledge, skills and attitudes, suggesting that whilst caring for those at the end of life is challenging and emotionally demanding, it can be immensely satisfying:

> *A cultural shift in attitude and behaviour related to end of life care must be achieved within the health and social care workforce. Death is inevitable and does not necessarily constitute a failure of care. Indeed one of the key roles of health and social care staff is to help patients, as far as possible, to come to terms with the transition from life to death. Providing end of life care can evoke strong emotions amongst care givers. Although frequently sad, if staff have the necessary knowledge, skills and attitudes it can also be immensely rewarding.*

(End of Life Care Strategy 2008, p. 115)

The strategy requires that health and social care staff, recognize when someone is dying, encourage open discussion about wishes and needs and help patients come to terms with the transition from life to death. The importance of the patient's emotional, social and spiritual needs is acknowledged, as is the need for the dying person to be able to share their hopes and expectations and express their feelings of anger, guilt, sadness and reconciliation (End of Life Care Strategy, 2008).

The move to bring death home reflects a growing awareness of the limitations of hospital as a place to die for those who are reaching the end of their natural life. It also reflects the statement made by Barbara Monroe, a social worker and at the time Director of Education at St Christopher's Hospice. Acknowledging the success of the holistic hospice model and its rapid adoption in the years since St Christopher's opened its door in 1967 as remarkable, she makes it clear that the current provision is not enough to meet current needs and demands:

> *Dying won't be got 'right' in and by hospices alone. The drive now must not be so much about improving access to specialist palliative care as about improving wider systems of health and social care for everyone approaching the end of their lives. However, hospices provide a unique repository of expertise that should be utilised, not marginalised.*
>
> (Barbara Monroe, Kings Fund Report, 2009, p. 9)

The strategy developed, at least in part, as a response to the growing realisation that many individual experiences of end of life care have been less than ideal and at times traumatic and distressing, for the individual concerned as well as for relatives and loved ones/significant others.

In recent years the Mid Staffordshire Hospitals crisis of care (2009) and the subsequent public inquiry culminating in the Francis Report (2013), highlighted the emotional pain and distress caused to patients and their relatives by poor standards of care. Much of the evidence served as a salutary reminder that how people are cared for at the end of life is deeply significant, not only for them but also for the emotional and physical well-being of close family members and significant others. That the NHS as represented by the Mid Staffs Trust, having failed to keep death at bay compounded the failure by turning away from the dying and bereaved, has relevance to my thesis and to all who have responsibility for end of life care wherever it might be given.

The evidence given to the subsequent public inquiry by patients and relatives resonates with aspects of my own experience at a similar time in space, but in a different part of the country and therefore a different trust. It continues to resonate with the stories I hear on a regular basis from friends, colleagues, and casual acquaintances when I mention my research subject, suggesting universality to these experiences; often lived with quiet resignation and on a daily basis as personal tragedies rather than public scandal. The split represented by the evidence given to the Francis Inquiry (2013) on the one hand

and the high-quality standards of end of life care promoted in The End of Life Care Strategy on the other, represent two extremes of the possible responses to vulnerability, life threatening illness, end of life and death. My own experience of these extremes of care and the many points in between often determined by the uniqueness of the individuals (patient, carer, significant others) concerned, have prompted my interest in the emotional aspects of end of life care and in particular the experience(s) of carers providing end of life care in care homes within the expectations of the End of Life Care Strategy.

1:2   Beneath the Surface

I was a teenager when my paternal grandfather, to whom I was close, was resuscitated in hospital despite having advanced cancer in the mid nineteen-seventies. At the time I had a strong sense of this not being the death he would have chosen. A few years later as the mother of two young children, when my father became ill in his mid-fifties, I found myself appalled and deeply distressed by what appeared to be the inability of the health service to respond to his needs as a patient with a particularly aggressive and untreatable form of cancer.

His death in 1984 influenced me profoundly, prompting a life-defining engagement with issues of life-threatening illness, loss and the ensuing grief felt in different ways by members of my immediate family. Having previously worked as an assistant housemother in a small group children's home and later as a residential social worker in an adolescent unit, I decided to qualify as a social worker. I completed my final placement at our local hospice during the early days of the now well-established hospice movement, making a deep connection with the tenets and practices of palliative care. I returned to the hospice as Principal Social Worker in the mid-nineties having gained wider experience of both generic and children and families social work. The hospice had expanded to include a bedded unit and a well-established social work team that continued to flourish and expand as the Psychosocial Services Team.

Again when my husband was diagnosed with a terminal cancer at a very late stage in his illness in 2006, it was the place I turned to and turned to again when I realized that my mother had reached the final stages of Motor Neurone Disease in 2008. On both occasions it seemed to be the one place that could face the truth of what was happening

and contain the most painful of emotions. Each time I chose the hospice rather than home and have since found myself wondering why.

When my husband died in what felt like the middle of our lives, our initial denial of what was happening was compounded by misdiagnosis and in the end little time to adjust. Managing the diverse needs of my very sick husband, my seventeen-year-old daughter and my twelve-year old son was more than I could do alone. When my mother died I think I was still too fragile to bear another death without support, or to care for her in a way that would make her feel contained enough and therefore less afraid.

Living through these experiences of death and dying has left me with a strong sense of the range and complexity of factors that influence decision-making and our personal capacity to care. Our collective vulnerability and need for containment is perhaps the most powerful message, as is the need for support on a much wider scale in ways that offer choice and flexibility. Whilst not my first experience of the end of life within our health care system, my husband's death had such an impact that it prompted the beginning of an interest in the emotional and unconscious aspects of human experience that eventually found a home at the Tavistock.

The theoretical framework that has shaped my study is the same one that has made the most sense of my professional and personal experiences of the end of life. Made up of a number of related theoretical strands, some of which are more closely connected than others and yet all sharing a family tree rooted in the epistemology of psychoanalysis, it is a framework that has developed incrementally and in response to significant personal loss. Each loss has prompted a deeper level of engagement with theoretical knowledge creating a particularly powerful blend of learning that, whilst not always easy to cope with, has enabled me to engage with my chosen subject in a way that would not have been possible without the emotional experiences involved.

The themes that have dominated and continue to be of concern in our struggle to accommodate mortality and the end of life in modern and late modern society are intrinsically connected to these more painful aspects of being human. Theories of loss and grief including the work of Bowlby (1953, 1969, 1973, 1980); Kubler Ross (1970); Murray Parkes (1972, 1988, 2006); Worden (1991, 1996) and Silverman et al. (1996) are central to the practice of social work in palliative care as is the work of Cicely

Saunders (1990). The continuing relevance of these theories to all aspects of my subsequent personal and professional experience is indicative of their applicability, universality and durability.

With time and a growing awareness of the complexity of social work practice I became interested in the source of the theories that had become so central to my approach to practice and teaching. In particular I wanted to engage more fully with Freud's (1915, 1917) contribution to theories of loss and mourning and reach a deeper understanding of his work. Prompted by further significant personal loss and increasingly aware of the influence of the unconscious on myself and others I completed a master's degree in Psychoanalytic Studies, gaining a broader sense of the development of psychoanalytic thinking and its relevance to all aspects of life.

Understanding more about the powerful nature of defences against anxiety, their impact on individuals and organizations and the place of denial in maintaining a sense of security, I concluded that psychoanalytic knowledge has the potential to contribute to the expressed aims of the end of life care strategy at all levels - from the development of responsive and flexible policies and systems, to the understanding of, and provision for, the needs of those individuals and teams tasked with providing consistently compassionate high quality care for all those approaching the end of life (Cawthorne, 2009).

It was whilst completing my dissertation focusing on recent child death inquiries (Climbie and Baby P) that I came across the work of Cooper and other contemporary psychoanalytic/psychosocial thinkers. Having found that my deeper understanding of psychoanalysis confirmed it as the knowledge base that could connect with my experience of the inner and outer worlds of myself and others, including individuals, groups and organisations, I came to study at the Tavistock. Here I found that a psychosocial perspective provided the binocular lens through which to view them, whilst my studies enabled me to surface and articulate a continuing interest in end of life issues including a curiosity about whether or not my original hypothesis has relevance. At the same time my thinking about the aims of the strategy and the systems of care involved has been informed and influenced by the work of key psychodynamic and systemic thinkers including Menzies Lyth (1960, 1988); Dartington (2010); Cooper (2009, 2010) and Cooper and Lousada (2005).

This body of work has extended my thinking, as has the opportunity to engage with and learn from my own emotional experiences; resulting in a more focused consideration of the position of the strategy, including insight into the states of mind responsible for its development and implementation. Experiencing and reflecting on my own psychic states of mind when in close proximity to death and dying has contributed to the development of the project and my interest in the emotional experience of those caring at the end of life. It is an extension of the reflective practice that has been central to my career in social work, spanning more than thirty years and including roles as a practitioner, manager, and in recent years educator.

In addition to the names already mentioned, significant influences include the work of Klein (1948 - 1963); Bion (1962, 1970); Winnicott (1953, 1971); Jaques (1965); Obholzer and Roberts (1994) and Symington (1986). Their respective contributions to the development of the study will be elaborated on in Chapters Two and Three along with the theories of loss and grief already mentioned. Other contemporary work that has deepened and extended my understanding of the work of Klein and Bion and its meaning for human development and experience includes the work of Waddell (2002); Ogden (1982, 1989); Lawrence (2000) and Hinshelwood and Skogstad (2000). Their contribution to my elaboration of the tragic position and the possibilities beyond the paranoid schizoid and depressive positions will be located and considered. Other psychoanalytically informed work has stimulated my interest in the emerging field of psychosocial research, hyphen or no hyphen (Frosh and Baraitser 2008; Hoggett in Hoggett and Clarke, 2002), informed the design of the project and made it possible to develop the necessary research skills.

This psychoanalytic framework has prompted an in-depth consideration of the way that individual inner worlds interact with the organizations representing health and social care and are shaped by the wider environmental and cultural forces that determine how services to vulnerable people are delivered and received. It has caused me to question why the strategy has come into being at this particular time in our particular culture and prompted me to seek to understand the current context of end of life care, including the emphasis placed on the need for systems of health and social care to come together after many years functioning as separate services.

1:3   A Brief Psychosocial History of End of Life Care

Tracing the history of end of life care prior to and since the creation of the NHS is a useful starting point, contextualising my study and highlighting the need for a deeper engagement with the emotional aspects of caring at the end of life in the space that exists between specialist palliative care services, including hospices and busy NHS hospitals.

It is often said that it is not so very long ago, the beginning of the 20th century, that the majority of people died at home and that in general individuals were much more familiar with death. In writing I feel compelled to begin by taking a look beneath the surface of what, in the light of current concerns about the provision of care for older vulnerable people, is in danger of becoming a rose-tinted view of the past and a fiction (Harari, 2017) of our time.

The history of our relationship with death in the western world is well documented, with a number of writers telling a similar story from a range of perspectives (Aries, 1982; Walter, 1994; and Holloway, 2007). It is a history deeply embedded within the wider history of western culture and which, it could be argued, has determined its very course (Harari, (2017; MacGilchrist, 2009). An overview of a number of these accounts confirms that at least since the beginning of the previous century people living in the western world have become less familiar with death and that the end of life has increasingly become the domain of health care professionals (Gawande, 2014).

Changes over the centuries can be traced from the predominant view of the 15th to 17th centuries that death could happen to anyone, through the age of reason and the shifting of death from the frame of religion with its notions of sin and fate, to that of reason and the rationalization of death through the application of science and statistical probability. By the 20th century death is repackaged and described by Walter a sociologist, as 'split' between expert medical discourse and the bureaucratic procedures that support it, and what he describes as an 'intensely personal sense of loss' (Walter, 1994). Significant cultural shifts of the last century include the relocation of death from the home to the institution in the form of either hospital or care home, and the sanitizing and commercialisation of death corresponding with the decline of religious belief and ritual.

One outcome of this distancing from the processes of death is that it has made it more difficult to negotiate the later years and end of life, because of the range of potential medical options that promise hope and the possibility of more time. Our heroic quest for immortality makes us all susceptible, and the difficulties in communicating painful facts and managing the uncertainty so often involved can make it almost impossible for individuals to choose what is right for them (Gawande, 2014).

The history of vulnerable older people and end of life care is bound up with that of the Poor Law (1601), the Reformed Poor Law (1885) and later the National Assistance Act (1946) - at least up to a point. Although care was available in voluntary residential homes, either free or fee paying with the better off choosing to be cared for by their servants, there was little interest in the old or disabled. In 1929 Poor Law responsibilities transferred to local authorities, revealing many long stay older and disabled patients receiving minimal care. Whilst the discipline of geriatric medicine grew, it generally had little status and discrimination against older and disabled people continued to exist in the welfare state.

The upheaval of the Second World War revealed the needs of older and disabled people living in the community with minimal incomes and meagre access to care. During these years campaigning organisations emerged in response to this newly identified need and services began to improve. The Old Age and Widows Pensions Act (1940) introduced the system of supplementary pensions for the elderly and The Poor Law was finally abolished in 1948 as the National Assistance Board took over with means tested benefits. Local authorities were required to provide residential accommodation, to register and inspect private and voluntary care and provide or subsidise day centres etc. However whilst the NHS was free at point of delivery, social services were often poor, weakly regulated and means tested. The separation of health and social care can be traced from here (Thane, 1996).

During the 1950s and early 1960s three important surveys of end of life care were undertaken (Saunders, 2001). One, based on the observations of District Nurses (Marie Curie, 1952) revealed the 'appalling conditions of suffering and deprivation' among many cancer patients dying at home, whilst another discovered significant failures of care in many charitable homes (Hughes, 1960). The third, completed in a London hospital showed that much suffering remained unrelieved; leaving patients in physical

and mental distress and knowing that they were dying despite not being told (Hinton, 1963). In combination the reports revealed a picture of families struggling to balance a range of pressures and responsibilities, including fatigue and stress, as the result of caring over long periods; the impact of demographic changes on the family unit impacting on the capacity to care; and the kind of turning away from physical and emotional distress in a hospital setting that we have witnessed again at the beginning of the 21st century.

The reports argued for what was then referred to as terminal care to become a priority within the NHS, stimulating and strengthening a growing clinical interest in questions of terminal care which served slowly to draw further attention to the needs of those in the final stages of life. Although provision of care to the dying remained the primary concern of charitable organisations, by the early 1960s a new discourse of terminal care emerged. Clarke (2016) notes that it did so against a backdrop of policy neglect and clinical disinterest, which only dissipated slowly and reluctantly. The success of the hospice and palliative care movement is evident today and echoed in the words of Barbara Monroe (Monroe, B., in Addicott, R. and Ashton, R., 2010).

Two of the demographic shifts that must be acknowledged and run as themes throughout the thesis are the gendered aspects of care and the 'ghostly model' of the Victorian family (Smelser cited in Dartington, 1986). These are discussed in detail by Hollway (2006) and have a continuing significance beyond the project. All of those interviewed are women and women form the majority of the social care workforce. It is of interest and particularly gratifying personally that the founder of the modern hospice movement was a woman who started out as a nurse, became a social worker and ended up being a doctor. I would describe her as the ultimate boundary spanner (Williams, 2012) and a shining example of the difference that one person can make (Menzies Lyth, 1988; Saunders, 2006).

In recent years hospice care and specialist palliative care services have come to be highly valued and globally influential (Clark, 2016). Despite this there are parallels and differences worth observing between the history of older people and palliative care, as well as consequences for those allocated responsibility for the care of older vulnerable people. The criteria for hospice care at the present is primarily life threatening illness rather than old age, and hospices and their internal structures are generally more firmly

connected to the NHS and health care than home. In addition the very term specialist palliative care is not something likely to be available on the 'industrial scale' required to meet the needs of our ageing population.

As a specialist service, and I am anecdotally reminded of a hospice social work colleague who felt we offered what he described as a 'Rolls Royce' service to a few, hospices are viewed very positively by the general public. More than two-thirds of people (69%) in a poll of 2036 adults carried out for Help the Hospices regard hospices as 'a place that offers compassionate care' (Source: Populus (2013) 'Attitudes to hospice care'). There is considerable evidence to suggest that care homes hold a far more ambivalent position (Froggatt et al., 2009; Dartington, 2010).

1:4   The Turn Towards Home

Set within a mixed economy of care and subject to a succession of policy directives, Froggatt describes institutional forms of long term care for older people as 'marginalised and even mistrusted' (2009, p. 10). As Froggatt notes changes in funding, new regulation and inspection processes and the introduction of national minimum standards have led to a decline in the number of all types of care home, including those providing personal care and those providing nursing care, since the 1990s. Issues of funding include the availability of continuing funding for those with health care needs and limited, often personal, funding for personal care needs.

At a time when society is confronted by levels of vulnerability and dependency that threaten to overwhelm existing health and social care provision, the turn towards care homes to increasingly meet the needs of those at end of life offers a potential solution to one of the greatest challenges of the 21st century. Understanding more about the experiences of those caring for an increasingly older, more vulnerable, dependent and dying population corresponds with the need to understand more about the marginalised and ambiguous position that care homes occupy within our society.

It is important not to underestimate how powerful the emotions stirred up can be and to understand that for all of the discourse emphasising the positive aspects of accepting death as inevitable, I can identify an equal amount evidencing an overwhelming need to avoid and deny it for as long as possible. Nine years after the publication of the strategy

I open a major national paper to find an article that highlights how difficult it can be for even the most educated and well informed of us to speak with our loved ones about what is to come:

> *Death regrets: I have a few. Not things left unsaid. (Much is covered by "I love you".) But failing to face the inevitable; not making plans. He was terminally ill, for God's sake. Why did I not probe to find out exactly how long he had, so he didn't die alone? The last days are hard to predict, I was told. But I was scared, squeamish, didn't press to know more.*

Janice Turner, The Times, 2nd December 2017

How and where the work of caring at the end of life is positioned has implications for us all, as does understanding more about how those concerned defend against the anxiety stirred up by close proximity with the outcome of life (Ramsey, 2000). Whether or not the social systems within which end of life care is provided can respond in healthy rather than pathological ways to the emotional demands of the task(s) will determine the quality of end of life care. Considering the locating of care homes as central to the provision of end of life care seems timely and relevant particularly in light of the history of neglect, marginalization and ambivalence that can be traced in relation to the care of older vulnerable people and the services that provide for them (Holman et al., 2006; Froggatt, 2009; Dartington, 2006, 2010).

1:5   Unheard Voices

Along with the move to enable more people to die in a homely setting and/or their preferred place of care, engaging with the strategy in the light of recent personal experience led me to think about the implications for those providing end of life care in care homes. During my first reading I was immediately struck by what I felt was the inadequacy of the statement 'although frequently sad'. It seemed to be a way of making it acceptable for care staff to care for those at the end of life without fully acknowledging the emotional demands involved.

I considered the possibility that the strategy is representative of the policy observed by Cooper (2009b) that tends to construct a natural and inevitable order of things whilst omitting, disallowing, disavowing, obscuring or forgetting, in this case in particular, the emotional and political but also the epistemological and discursive aspects and

dimensions of end of life care. I also wanted to pursue an earlier exploration of the strategy involving an interview with a health care professional engaged in contributing to the implementation of the strategy.

Completing a free association narrative interview in preparation for the development of the project I had asked him to speak to me about his experience of the strategy. Analysing the data emerging I concluded that my interviewee's lived experience suggested that whilst some significant progress has been made in relation to end of life issues, perhaps most importantly that the need to improve the quality of end of life care has been officially acknowledged, the agenda for change is being driven by what appear to be complex and competing forces. It was also apparent that the 'civilized' attitude to death so clearly articulated by Freud (1915) remains at large in society, producing a deep resistance to the kind of change that the strategy promotes.

Furthermore, I found evidence to suggest the possibility of a third tragic position (Symington, 1986, p. 276; Lawrence, 2000, pp. 211-212) and concluded that this could be associated with hospice care. Dartington (2010) describes the split between health and social care as being about celebratory omnipotence and a distancing from vulnerability. Health is linked with the paranoid schizoid position and social care with the depressive. His work resonates with me and connects strongly with my own experience. Increasingly interested in the impact of the strategy on those providing care in ordinary residential settings and with an awareness of the significance of the support that might be needed, I began to develop the project.

My aim at this time was to gain a better understanding of what is most valuable to those negotiating the challenges and demands of the end of life care agenda, including the complexities involved in providing the kind of sensitive and attuned care that can meet the needs of the dying person and those closest to them. It was also to pursue the possibility of a third tragic position and whether or not this might be elaborated and tracked in the subjects of my research. With these aims in mind my research proposal posed the following questions within the framework of a psychoanalytically informed psychosocial project:

1. How do those interviewed experience caring at the end of life?

2. Taking the position that the individuals concerned are 'defended' subjects (Hollway and Jefferson, 2000, 2013) what individual conscious and unconscious anxieties and defences emerge in these narratives?

3. With reference to the range of data collected during individual interviews and subsequent participant observations do any patterns emerge in the nature and impact/consequences of these anxieties and defences?

4. Does the End of Life Care Strategy adequately capture the lived experience of end of life care as indicated by the emerging data?

5. If not, what implications might this have for the workers and organizations concerned?

6. Is there evidence to support the concept of a third 'tragic' position and if so how might this be defined and supported?

1:6 The Project

Six free association narrative interviews with care staff from four different residential care homes caring primarily for vulnerable older people form the heart of the project. This means that many of the end of life stories told involve people who are at the end of life primarily because they have reached the end of their natural lifespan. At the same time, the lived end of life experiences of those interviewed make it possible to think about the emotional aspects of end of life in relation to a broader range of circumstances.

The interviews contain references to personal as well as professional end of life experiences, including the death of a parent from a life threatening condition. They also refer to the end of life experiences of family, friends and colleagues as well as residents who have required care because of a pre-existing and ultimately life threatening condition. The study has been designed with the intention of gaining the deepest sense

of the end of life experiences of social care staff within the limits of ethical considerations.

Taking a psychosocial approach the study aims to consider these personal experiences of end of life care, whilst holding in mind the conscious and unconscious responses to serious illness, vulnerability and death influencing current efforts to reshape our health and social care services.

1:7 Organization of the Remaining Chapters

This chapter has offered an introduction to and context for the project with reference to the theoretical framework and literature informing its development. It indicates the need for the study and includes a discussion of the personal, professional, historical and social influences that have prompted my interest in the subject and shaped the project. Chapter Two provides an account of the reading that has deepened my understanding of the issues involved, informed my research questions and determined my approach and position as researcher. Literature relevant to the project, including aspects of psychoanalytically informed theories and concepts that make it possible to look beyond surface rationales to reach a deeper understanding of the complex processes involved in caring at the end of life, is discussed and reference is made to current research, reports and writing relevant to care homes and carers.

Chapter Three describes the methodology and design of the project, including an account of how data was collected and analysed. The contribution of the researcher's autobiographical work is considered, as are some of the concerns about psychoanalytically informed psychosocial research. The interviews that form the heart of the project are presented as case studies in Chapters Four and Five. Chapter Six focuses on a range of end of life stories extracted from the narrative interviews, identifying a number of themes that deepen understanding of the experience of what it means to care at the end of life in a care home setting. Chapter Seven offers a cross case analysis that responds to questions formulated in response to the themes emerging from individual narratives and Chapter Eight makes a number of assertions based on the range of findings, before drawing final conclusions and making recommendations.

2   Chapter Two: Literature Review

2:1   The Heart of It

Selecting literature relevant to my thesis has proved more problematic than I ever considered it might be. Envisaging a relatively simple process involving a systematic working through of associated texts, I have found myself either overwhelmed or facing an empty space; leaving me wondering how I might fit all of the pieces that seem to represent my subject together to form some kind of coherent whole. The following is an attempt to represent something of the many splinters that together indicate the breadth and depth contained within the project.

Where they really come together is in the collective narratives of those interviewed and this is something I had not fully anticipated. In the beginning I imagined that as the researcher and designer of the project I would somehow be in control of the process and data emerging. This has not been the case and the project, as I thought, a small, intimate and in depth study, has produced a vast wealth of information about what it means to care for those at the end of life that appears to be unrepresented as holistically elsewhere in the literature.

Locating the various pieces or fragments of what I have come to think of as the heart of the project has involved a process of narrowing down the reading to include relevant research most directly connected to, but often not necessarily strictly about, the subject. The sheer volume of research relevant to older people and the end of life is more than a little overwhelming. Despite this a far smaller body of work has focused on the emotional experiences of carers and even less on those providing end of life care for residents in care homes. In particular the amount of psychoanalytically informed research is limited, particularly in recent years, and it is this work that I have chosen to focus on because it engages directly with the anxieties and accompanying defences associated with close proximity to death and dying.

I begin by introducing some of the key documents and websites that relate to the ELCS to indicate the range of information available to health and social care workers, before introducing the work that initially drew me to my subject, including the body of psychoanalytically informed work that has enabled me to focus in on the emotional

aspects of caring at the end of life and to consider the systems of care and processes involved. The relevance and significance of my study is considered within this context. The final part of the review will consider additional literature with relevance to the findings emerging from the data and which has supported my analysis and conclusions.

This review sits within the wider context of contemporary literature that documents our ongoing cultural and social struggles to come to terms with our mortality, vulnerability and dependency on one another. Relevant work includes Harari's (2015) account of the challenges that we face in the future, including the amount of data that we are/will be increasingly required to process, and our escape into shared fictions. These include the fiction of immortality or as he proposes the actual possibility of immortality and the extent to which our inability to mourn has resulted in a loss of meaning across the democratic world (Bollas, 2018). Also relevant is the increasing tendency for the characteristics of the left hemisphere of the brain to have dominance over those of the right, leading to the favouring of information gathering as a substitute to knowledge gained from experience (MacGilchrist, 2010, p. 428). Reference to this work will be made in my summing up of the findings emerging from the data and used to expand on my conclusions and make recommendations. The states of mind represented in these works reflect some of the theoretical perspectives considered, including the concept of the assumptive world and the range of theories of loss and grief.

2:2 Surface Constructing a Monolith/ Strategy as Defence

The implementation of the End of Life Care Strategy requires ongoing monitoring to ensure and/or measure its success. Sophisticated methods for gathering and analysing data include the National End of Life Care Intelligence Network commissioned by the Department of Health, as pledged when the strategy was launched. The network has a number of key functions:

1. Provision of data and intelligence to support quality improvement
2. Provision of data and intelligence to support best use of resources
3. Sharing of best practice
4. Provision of evidence to guide delivery of care
5. Working with partners to develop best practice in end of life care
6. Working towards improved national data about end of life care

The network's website is a comprehensive and impressive piece of technology and in many ways gives a sense of the enormity of the task of providing and sustaining good quality end of life care for all, in keeping with the objectives of the strategy. What appears to be missing at present is the kind of attention to the emotional aspects of the project that may be a significant factor in determining the quality of care provided. It also begins to give a sense of the small scale of this particular study; focusing as it does on the narratives of six residential care home workers located in one particular region of the UK.

Other literature relevant to the project includes the National Occupational Standards for End of Life Care that details how care is to be delivered. The recent publication *End of Life Care – a Framework of National Occupational Standards* (Skills for Health 2010) aims to develop the workforce to work more effectively with people who are dying. This framework, which builds upon the *End of Life Care Strategy* (Department of Health 2008), sets out core principles and competences. These include person-centred practice, respecting client choice, demonstrating sensitive and supportive communication, and consideration of carers' and family members' needs. Yet again the website is impressive, containing a potentially overwhelming range of data. Again there appears to be little or no mention of the emotional demands of caring for those at the end of life and being in close proximity to death and dying.

The language used is upbeat reflecting a 'can do attitude' that has come to be considered an essential element of successful ventures. Indeed the phrase has passed in to general use and the Cambridge Dictionary definition is as follows:

> *If you have a "can-do" character or way of dealing with a problem you are very positive about your ability to achieve success.*

(Cambridge Dictionary, 2018)

This language is reflected again in the Skills for Care guide to delivering quality standards in care homes in the region in which the research was completed, given the title 'Achieving Success in End of Life Care' (2014). Within this hopeful and, with reference to Cooper, possibly 'sanitised' context of policy and guidance it is difficult to imagine how the pain, confusion, uncertainty and mess of real life might be easily expressed or acknowledged (Simmonds in Cooper, 2009b, p. 179). And yet the

messiness of the real world is never far away. Three significant examples in recent years include the Mid Staffordshire Hospitals Crisis and the subsequent public inquiry chaired by Lord Francis in 2013; the problems in a number of other trusts investigated and reported on by Keogh (2013); and the phasing out of the Liverpool Care Pathway following an independent review in the same year (2013). Each at least in part found and addressed concerns about the way older vulnerable people were cared for, particularly at the end of life, and indicate the complex emotional dynamics at play between policy, professionals, patients and their families. Key issues identified mirror some of the major findings of Keogh and Francis including the quality of communication between professionals and families and difficulties of diagnosing/determining when someone is dying.

In response to these concerns a report published in 2014 'One Chance to Get it Right' (LACDP, 2014) details the ways in which care for people who are dying should be responsive to the overall needs of individuals and their families. The five priorities for care replace the Liverpool Care Pathway, an earlier attempt to bring the best practices from hospices into other care settings, introduced in the last decade of the 20th century and phased out in the second decade of the 21st because of significant concerns about its interpretation and implementation. As an Ars Moriendi (1451-1450) for our time it represents an approach to caring for people in the last days and hours of life whilst making it the responsibility of each organisation to decide how to implement the priorities into daily practice. In addition to this the LACDP states that all staff having contact with dying people must have the skills to care for people effectively and with compassion (LACDP, 2014).

2:3   Our Greatest Fear/Death and Anxiety

Deeper explanations for such large-scale events played out in a public arena and the smaller myriad examples of the same breakdowns of care and connection occurring on a daily basis can be found in the body of theoretical work that has its origins in the work of Freud and is introduced in Chapter One. Theories of loss and grief, including theories of traumatic loss, are deeply connected to the body of psychoanalytic thinking that encompasses Klein's Object Relations (1946-1963), representing something of a family tree of interrelated ideas that extend understanding of the conscious and unconscious emotional aspects of human relationships and their significance in shaping our

experiences from the moment of our conception to the end of life. My thinking about the strategy, including the emotional impact on those providing end of life care in ordinary residential care homes, has been significantly shaped by particular aspects of theory and these are considered in more detail here:

> *No other discourse of knowledge stands ready to take an interest in something like cruelty – except what is called psychoanalysis.*

<div align="right">(Derrida 2002, p. 240)</div>

Writing in 1915 Freud traced the source of the established cultural and civilized attitude to death to its early and prehistoric origins, emphasising the primitive nature of our response to death and locating it in the conscious mind. Freud identifies the contradictory nature of our attitude towards death, suggesting that from a psychoanalytic perspective every one of us is convinced of his own immortality but at the same time consciously aware of the reality of the inevitability of death for self and others (1915, 1991, pp. 77-89).

A significant number of post Freudians take up this view, although not always from a Kleinian perspective, and place it in a wider context including Becker who asserts that this fear stems from our awareness of the dual nature of the human condition that represents the 'essence of man's condition' (1973, p. 24):

> *Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order blindly and dumbly to rot and disappear forever.*

<div align="right">(Becker, 1973, p. 6)</div>

Becker presents a compelling argument regarding what he refers to as the 'irony of man's condition' in which, because of our deepest need to be free of the anxiety of death and annihilation, we protect ourselves from the consequences of living full and unrepressed lives (1973, p. 66). Becker suggests that character development defends the individual against the idea of his or her own death. He describes how in the course of our development from childhood onwards, we protect ourselves, and our ideal idea of ourselves, through repression and similar defences, in order to feel warm and secure in our respective life situations.

The idea that all of our human efforts are driven by our anxiety about death is a theme that emerges in a range of psychoanalytically informed literature including the work of Castoriadis; Castoriadis, in Shamdasani and Munchow (1994); Obholzer and Roberts (1994); and Langs (2004). Becker's work has gathered momentum in recent years and research in social psychology is supporting the hypothesis that the content of the unconscious is primarily the denial of death which enlists the other drives such as sexuality and aggression, power and conformity, in order to protect us from the terror of our mortality and attempting to convince us of our immortality (Liechty, in Kauffman, 2002).

Like Freud, who used the term to describe our relationship with God and religion, Becker uses the concept of illusion to describe the way that human beings convince themselves that the world they live in is a safe place, arguing that the only way the average man can cope with existential anxiety is through repression and that without character traits there has to be 'full and open psychosis' 'because he has erected a massive wall of repressions to hide the problem of life and death' (Becker, 2003 p. 66). One of the questions that Becker raises is about the degree of illusion that is needed for one to live. Arguing that illusion is creative play at its highest level he claims that the loss of illusion is the equivalent of death and that the creation of a cultural illusion is a necessary if perhaps inevitably flawed project.

2:4   Love, Loss, Grief and Mourning

The theme is taken up by Parkes (1971) where it connects directly to theories of loss and grief and in particular Bowlby's work on attachment, separation and loss returning us to the significant influence of Klein and object relations. Klein was of course Bowlby's supervisor and Riviere (1883-1962) his analyst, and whilst his body of work is distinct the influence of object relations is apparent. Each theory describes our vulnerability and dependence as human beings and the intense emotions that dominate our close personal relationships.

Parkes' concept of the assumptive world is described by Kauffman as a psychological principle of the conservation of human reality or culture. The assumptive world includes all of human reality, our interpretation of the past, expectations of the future and our plans and prejudices. Connecting directly with the work of Freud and Becker it defines

human culture as an illusion based on belief through the construction of assumptive worlds.

The assumptive world order is the set of illusions that shelter the human soul

(Kauffman, 2002, p. 206)

Assumptive worlds consist of internal constructs developed as the result of our experiences of, and in, the world. Based on these experiences we come to believe certain things about the world that allow us to live with a sense of what is normal and expected. They provide us with a constancy of experience and an understanding of the world as a benevolent, meaningful place in which we are personally valued. The prospect of death and death itself with its associated losses inevitably threaten these beliefs, although the extent to which any individual assumptive world is disturbed will depend on a combination of factors. Understanding the transferential nature of the assumptive world as a mechanism of defence against existential anxiety is particularly relevant to a wider understanding of both organisational and individual emotional responses to death and dying (Liechty cited in Kauffman, 2002, p. 90).

This wider view of culture and its institutions in mediating personal loss and grief is useful when thinking about the systems of care involved in the implementation of the End of Life Care Strategy, and the position that care homes might represent will be considered towards the end of the chapter. In addition to Parkes' Theory of the Assumptive World other theories of loss including Kubler Ross's Stages of Grief, Worden's Tasks of Mourning and Parkes' Phases of Bereavement, make it possible to understand different aspects of loss and grief. Each has something to offer from insight into the demands and complexities of the grief process, to an understanding of the parallel processes of loss and grief, from the importance of emotional support, to a consideration of whether or not losses are being mourned or transformed into melancholia or its contemporary counterpart depression.

They also make it possible to understand that whilst the stigma associated with care homes may well be related to associations with the poorhouse of earlier times, (Dartington, 2006) at a deeper level the connection made is to universal and potent anxieties about death, vulnerability, dependence and the social stigma of loss.

Whilst these models of grief have held a dominant position for many years, Leader (2008) comments on their limitations with reference to Klein's sensitivity to loss, as do Klass et al. (1996) who propose a paradigm that acknowledges the need for continuing bonds with the deceased. Both texts acknowledge the complex and lifelong nature of grief and mourning (see diagram 1 for a visual representation that makes connections between theories of loss and the psychoanalytic concepts of positions and states of mind).

2:5   States of Mind and Psychic Positions

Of equal relevance is the significance of loss to the whole of human growth and development as emphasised by Waddell (2002) who uses Kleinian thinking to offer an account of the development of the inner world. Klein's work focuses on internal processes including Freud's theory of the death instinct, which she developed, whilst acknowledging the significance of early relationships in the development of the child's internal world, prompting a deeper consideration of external factors. A description by Riviere (1952) clarifies what is meant by the inner world and is relevant when thinking about the individual narrative accounts at the heart of my thesis:

> *The inner world is exclusively one of personal relations, in which nothing is external, in the sense that everything happening in it refers to the self, to the individual in whom it is a part. It is formed solely on the basis of the individual's own desires towards other persons and of his reactions to them as the object of his desires. This inner life originates at least at birth, and our inner world has its own development from birth onward, just as that to the external world has………Thus our loving and hating of others relates as much (and more crudely) to that aspect inside us as to those outside us.*
>
> (Riviere, 1952, p. 162)

Klein's theoretical developments, including her discovery of the paranoid schizoid and depressive positions, are as relevant to end of life as to all aspects of human development. The concept of the paranoid schizoid and depressive positions as states of mind as well as developmental phases is particularly helpful in understanding the ways that people cope with anxiety throughout life and in times of extreme emotional distress.

States of mind are not determined by chronological age but by the developmental progress an individual has made over the course of their life and within the context of

their emotional environment. For example, an adult may be in a state of mind that represents a much earlier stage of development. Indeed faced with a threat to our own survival or that of a significant other on whom we depend emotionally, we all have the capacity to return to a much earlier paranoid schizoid state of mind if only temporarily. Each position has a defining set of anxieties, defences against these anxieties and a particular way of object relating. From the paranoid schizoid position anxieties are about personal survival and the possibility of being destroyed, annihilated or simply no longer existing. This anxiety may result internally through the inner workings of the death instinct or in response to external conditions such as serious and potentially life-threatening illness or other painful or traumatic life events. Paranoid schizoid defences include denial, splitting, projection, identification, idealization and omnipotence. The depressive position represents a developmental shift in which the object is recognized as a whole person who can be both hated and loved. Anxieties are about the survival of the object with defences represented by ambivalence and depressive anxiety such as guilt, concern and reparation.

Whether the defences associated with each position organize themselves in a healthy or pathological way will depend on the degree of anxiety involved, the resources available and the unique life experiences and history of each individual. What we do know is that faced with intolerable levels of anxiety we employ whatever defences will allow us to maintain our mental/psychic equilibrium, that we all use defences to protect ourselves from psychic pain and that we oscillate between these two positions throughout our lives (Budd and Rusbridger, 2005 p. 13).

Klein's developmental account of the paranoid schizoid and depressive positions and the corresponding and fluctuating states of mind are elaborated by Bion (1962) who describes an oscillation and interplay between the two with developmental progress inevitably involving disruption and anxiety to some degree. Central to Bion's thinking about states of mind are the processes of containment and reverie so necessary to the infant's earliest emotional experience and development, relevant throughout life and, as I will go on to argue, particularly relevant to the end of life.

Containment is a theory of mental functioning that uses Klein's concept of projective identification to consider some of the earliest experiences involved in the development of the mind, including the capacity for symbolic thought. Ogden describes Bion's idea

of the 'container — contained' as a theory of the way we think rather than what we think about:

> *That is, how we process lived experience and what occurs psychically when we are unable to do psychological work with that experience.*
>
> (Ogden, 2004, p. 1354)

The earliest experiences of containment involve the mother receiving the baby's raw emotions or projections, processing them in her own mind and returning them to the baby in a more digestible state. The mother's attentive state is referred to as 'reverie' (Bion, 1967) and requires emotional availability and sensitive attunement to the baby (Sterne, 1985). Through the experience of being contained the baby takes in both the communication and the feeling of being understood. Containment has been recognized as essential to the processing of painful emotional experiences at any age, particularly those that are too unbearable to be thought about.

> *It refers to psychic processes through which painful experiences can be converted into reflective understanding rather than function as propellants for primitive defensive processes as described by Klein (1946).*
>
> (Krantz, 2015, p. 59)

2:6   A Mature Position

In 'Death and the Mid-Life Crisis', Jaques (1965) describes the way in which the infant's relation with life and death occurs in the setting of his survival and dependence on his external objects or primary caregivers. For Jaques, if love prevails the infant can work through grief, regaining security and achieving the depressive position, which he describes as the infantile equivalent of the notion of life. Under conditions of prevailing persecution the working through of the depressive position is inhibited to either a lesser or greater extent, resulting in a chaotic internal situation experienced as the infantile equivalent of the notion of death.

The extent or otherwise of the individual's ability to tolerate loss will depend on the quality of care they receive and the support available to them when faced with situations of loss. In addition to this internal situation some individuals, through circumstance and life events, will have to bear more loss than others and their resilience or vulnerability will be further determined by such variables as their age at the time of the loss, the

extent of the disruption to their assumptive world, the nature of what is lost and whether or not the loss was anticipated or unexpected (Fahlberg, cited in Howe, 1995, p. 135).

The development of the character as a defence against death will be mediated by these experiences, the corresponding explanations that are offered and the quality of emotional support available. Respective assumptive worlds will be more or less prepared for the possibility of death and for some an established relationship with death will already be an integral part of that world whilst for others it will be something that 'could never happen to me'.

In the same paper, Jaques considers the earlier achievement (or otherwise) of the depressive position and its reworking in midlife, a process of working through, as essential to the acceptance of personal mortality; describing the working through as a process of 'hate mitigated by love, envy mitigated by admiration and gratitude; of confidence and hope, not through denial but through the deep inner sense that the torment of grief and loss, of guilt and persecution, can be endured and overcome if faced by loving reparation' (p. 502).

It is this mature state of mind that Waddell (2002) describes but without the restrictions of chronological age. Whereas Jaques places mid-life at around thirty-five years of age with the process of transition running on for some years and varying between individuals, Waddell is clear that it makes more sense to think of it in terms of states of mind. It is this view of maturity with its emphasis on 'a person's capacity to bear intense emotional states and the extent to which it is possible to think about, and reflect on, psychic pain as a consequence of having found, and sustained, a relationship with external and internal figures who are able to do so' (p. 196) that is applied to the project.

It is impossible to fully represent Waddell's work here other than to say that it offers the most satisfying and accessible account of the possibilities for mental growth and emotional development across the life span that I have come across. It's emphasis on the contribution that a person's experience of bearing emotional pain from the very beginning, and in particular the success or failure of struggles with separation and loss including grief and mourning, makes to the achievement of a mature state of mind is central to my thesis.

It is in thinking further about mature states of mind, prompted by personal and professional experience, that I have become interested to find references to a possible third 'tragic' state of mind. I first came across the notion of a tragic position in the work of Symington (1986) and again in Lawrence's discussion of tragedy (2000) and consider it to be one of two significant developments in my understanding of psychoanalytic concepts. They represent a deeply personal version of Bion's description of learning from experience (1962) and are central to the thinking that underpins the project and my analysis of the data gathered. Symington's and subsequently Lawrence's account of the tragic position makes perfect sense in relation to my lived experience and as a result I began to consider its relevance to various aspects of end of life care.

Around the same time, having grasped the fundamentals of the paranoid schizoid and depressive positions identified by Klein, I found suddenly I really understood that we oscillate between them throughout our lives depending on what is happening to/for us emotionally. I could see how often at times we are moving rapidly between them and realised that Lawrence's view of the tragic position described aspects of my own emotional experience, as well as many of my encounters with individuals and organisations who I understood had been able to inhabit and tolerate this state of mind.

2:7   Elaborating the Tragic Position

Symington and Lawrence both refer to a 'tragic position' with Lawrence elaborating and extending Symington's definition. When I first came across Symington's view of the tragic position, described in relation to the position reached by one of his analysands as she comes to terms with the circumstances of her life, as the acceptance of 'la condition humaine' (Symington, 1986, pp. 275-276) it immediately struck me as having relevance to the death and dying, palliative and end of life care agenda. In Lawrence's expansion of the concept he suggests that only from the tragic position are we fully able to acknowledge our mortality and that whilst depressive position defences may appear more benign than paranoid schizoid ones, they are ultimately directed towards the denial of death/hope that life (eros) can prevail (Lawrence, 2000). I have since come to see the movement between the depressive position and the tragic position as something of a portal into a way of being present in the face of 'la condition humaine'/mortality/the end of life that can transform the quality of care/attention/mind that might be given.

Personal experience suggests that the capacity to hold the tragic position depends on the working through of an experience/experiences that have revealed the tragic nature of human existence or 'la condition humaine' and which could not be prevented by any individual heroic act or self-sacrifice. It involves accepting that there may be nothing we can do to alter the course of events. As such the tragic position represents a third position beyond the paranoid schizoid and depressive, available to those who have understood the limitations of life and worked through the psychic pain involved in accepting personal mortality to such an extent that it becomes possible to be in the presence of tragedy/tragic events without the need to move to action.

2:8   Anxiety, Defences and Systems of Care

For health and social care staff working with the sick and dying the intra-psychic world collides with the reality of the actual event of death, potentially prompting the heightening of death anxiety. Whilst Jaques (1955) and Menzies (1960) consider defensive processes from different perspectives, both offer a way of thinking about responses to the anxiety stirred up by close proximity to death that is relevant to the project. For Jaques organisations were concocted either consciously or unconsciously as a defence against psychotic anxieties, whereas for Menzies Lyth they were elicited by the anxieties intrinsic to the work that a particular organisation undertook. My theoretical framework suggests both views have something to offer when thinking about organisations providing care at the end of life. Completed in a hospital, Menzies Lyth's study is particularly relevant to the carers who are the subject of my thesis and is considered in some detail.

When Menzies and her colleagues, who had been asked by a general teaching hospital in London to help in developing new methods for the allocation of practical tasks, looked beyond the presenting problem, they began to identify high levels of tension, distress, and anxiety among the student nurses (1960, p. 97). Through an extensive interviewing process the team began to understand the nature of the anxiety and the reasons for its intensity. The nurses were bearing the full impact of the stresses arising from patient care and facing the reality of suffering and death on a daily basis. The nature of their work often required them to carry out what would generally be considered distasteful, disgusting and frightening tasks that brought them into close physical contact with patients and aroused strong and mixed feelings.

Feelings identified included: 'pity, compassion and love; guilt and anxiety; hatred and resentment of the patients who aroused these strong feelings and envy of the care given to the patient' (Menzies 1960, p. 46). Tracing the nurses' anxieties to the capacity of the work situation to stimulate early infantile phantasy situations and with direct reference to Klein's work on the emotional life of the infant, Menzies describes the opposing libidinal and aggressive feelings and impulses that represent the life and death instincts and influence the infant's psychic experience of objective reality, which in turn is influenced by the infant's own feelings, phantasies, moods and wishes.

According to Klein the phantasy world of the infant contains injured, damaged or dead objects and the atmosphere is charged with death and destruction, giving rise to great anxiety about the capacity of the libidinal forces to control aggressive impulses. In adult life these violent and intense feelings are generally contained but the stress of serious physical illness, dying and death with its accompanying psychological distress has the potential to trigger the early phantasy situations of those concerned (Klein, cited in Menzies, 1960, p. 98). The danger in the nursing situation is that the defensive techniques will be overwhelmed. For example, if the objective situation which symbolizes the phantasy situation, becomes almost or completely equated with the phantasy situation, then the individual concerned is at risk of consciously experiencing the full force of their primitive infantile anxieties.

Menzies identified a range of defences including projection, splitting, detachment, depersonalization, categorization, and denial of feelings and of the individual. When Menzies went on to consider the role of the organization in dealing with anxiety she found that the social systems that had evolved over time within the hospital in the form of hierarchies, rules, procedures, rotas and task lists, acted as supports for these defensive techniques and mechanisms:

> *The conclusion reached was that the social defence system represented the institutionalization of very primitive psychic defence mechanisms, a main characteristic of which is that they facilitate the evasion of anxiety, but contribute little to its true modification and reduction.*
> (Menzies, p. 117)

In a volume that brings together a range of contemporary applications of Menzies' seminal study (1960) and in response to the Francis Inquiry (2013), Evans (2015), writing as an employee of the NHS, argues that the 'rather obsessive institutional

defence of the 1950s and 1960s' has been supplanted with an even more primitive defence structure which has to deal with the patient's anxieties about illness, death, and fragmentation on the one hand and the Trust's or clinical service's concerns on the other. In the absence of structures and relationships that help contain anxieties he observes paranoid schizoid defences being used as anxiety and blame are pushed around the system. The defences represented include splitting, projection, denial, idealization, denigration and manic triumph and are worth holding in mind as the study unfolds and respective systems of care are considered. Other defence mechanisms include Steiner's concept of psychic retreats referred to in Chapter Three (Steiner, 1993).

There is a split of course as noted in Chapter One that stems from the 1940s (National Assistance Act 1946 – implemented in 1948, and the NHS established in 1948) between health and social care, with variable efforts being made to integrate the two (Health and Social Care Act, 2012); (Care Act, 2014); (Kings Fund Report. 2015). Dartington's (2010) work is particularly helpful in thinking about the way that services have been organised in response to vulnerability and dependence in recent years. Influenced by the systems psychodynamic approach of the Tavistock Institute, including the work of Menzies (later Menzies Lyth) and drawing from the personal experience of the debilitating illness of a close family member, he applies this thinking to the psychological and systemic dynamic involved in the management of vulnerability.

Observing that services around vulnerable people are dominated by two states of mind, dividing into the active and hopeful, or the passive and hopeless in response to individual vulnerability, he links his hypothesis to Kleinian psychoanalytic thinking. The first position or state of mind is identified with the heroic omnipotence that is a feature of the paranoid schizoid position and the second with the stoical impotence that is a feature of the depressive position. He suggests that traditionally health care has been more about fighting back and social care more about acceptance, but that in recent times social care is increasingly about short term interventions with dependency needs only being recognized at a late stage when palliative care is required (Dartington, 2010, p. 46).

Other insights include the conditions that make it possible to engage fully with the dependency of others without losing personal authority, the distinction between primitive and mature dependency and the importance of maintaining the boundary

conditions for an increased respect for dependency. Dartington suggests that we struggle to recognise dependency beyond the nursery and hospice and offers a critique of the National Vocational Standards and National Service Framework that seeks to standardise the provision of personal care. Written in the year the End of Life Care Strategy was introduced his work remains relevant to my study and the systems of care and carers represented.

It is of interest that in a lecture delivered as part of the Scottish Partnership for Palliative Care Annual Conference (2016 available on YouTube) Wilson defines gerontology as palliative care on an industrial scale (Wilson, 2016). The move to enable increasing numbers of older people to die in a homely setting rather than in hospital potentially shifts the provision of palliative care from hospital into the community, reducing the number of inappropriate admissions to busy accident and emergency departments and unsuitable hospital wards. The outcomes of this in terms of the quality of end of life care are well documented (Independent Review Of The Liverpool Care Pathway, 2013; Leadership Alliance for the Care of Dying People, 2014; Parliamentary and Health Service Ombudsman, 2015).

2:9   Care in Context

Far less has been written about the impact of the anxieties and defences described in the literature presented, on the care homes and carers providing care for residents nearing or at the end of life. In the UK two relatively recent psychoanalytically informed studies of the emotional challenges of providing institutional care for vulnerable adults, including those at or nearing the end of life, suggest the timeless and transferable quality of the defences identified by Menzies in the hospital setting. One of the studies involves a residential care home for older people (Jones et al., 2008) and the other a continuing care unit for older people (Holman et al., 2006). Both apply a Tavistock approach and identify disturbing and conflicting feelings amongst the staff and the use of routine and order to prevent residents expressing themselves.

Returning to Dartington's observation about the psychoanalytic position or states of mind held by health and social care organisations respectively, it could be argued that care homes occupy the stoical depressive position more securely than the NHS continuing care unit represented in one of the studies discussed. Nevertheless each of

the organisations studied convey a sense of the emotional heaviness and loss associated with becoming older, vulnerable and dependent in our society. The impact on the workers concerned raises questions about the qualities that make it possible to continue to care under such circumstances.

Care and caring has been the subject of intellectual inquiry as well as clinical and social concern in recent years. Hollway (2006) with reference to Klein's work confirms the capacity to care as rooted in a person's primary relationships, especially with its mother, and that this care is a prototype for the capacity to care:

> *This is because the experience of this care (good enough or not) creates the floor of everyone's self and lies at the heart of all dependency and all care receiving as well as care giving.*
>
> (Hollway, p.128)

Other aspects of her work are particularly relevant to my project, including the idea that care as a practice is crucial for developing a moral attitude and a moral vocabulary of care and that by engaging in the practice of care, care can grow into a disposition, and become part of our everyday thinking and doing (p. 10). Hollway also identifies the ability to love someone for who they are, without intruding into their otherness, as a core component of good-quality care. According to Hollway this kind of care need not connote suffering because it offers both pleasures and burdens. The carer recognizes his or her own needs as distinct, identifying with the other whilst recognising the separate existence of the person being cared for.

Academic discussion of the components of caring is countered by a range of reports and social comment that suggest care and caring has become undermined and financially unrewarding (Age UK 2014; CLG, 2016-2017). Dartington discusses some of the complexities involved in a paper that addresses issues of collaboration, and the integration of health and social care with an emphasis on our struggles with dependency and vulnerability (2006).

Writing in response to concerns about the lack of compassionate care shown to patients and families in the events leading up to the Francis Inquiry (2010, 2013), Ballatt and Campling (2011) engage with the physical and emotional demands involved in caring within the NHS at the present time. With reference to the defence mechanisms observed

by Menzies fifty years ago, they offer clear explanations of why in certain conditions seemingly caring staff can behave unkindly and even cruelly, and consider the conditions required to support kindness and compassion. Proposing a virtuous circle of kindness rooted in kinship, they emphasise the necessity of an explicit value base that can be thought about and applied in action at all levels of the organisation.

The failure to acknowledge the anxiety identified by Menzies is noted, as is the failure to create the kind of organisations that can facilitate the processing of the emotional aspects of the work. Every aspect of what Dartington (2011) describes in his foreword as a polemic is relevant to the project. In particular their expression of kinship as 'seeing oneself in the patient' or as a King's Fund Report puts it, 'seeing the person in the patient' (2008) and delivering the sort of care you would like for your family and friends, has direct relevance to the care home environment and the narratives of the carers interviewed. In addition, a whole chapter is devoted to end of life care and includes aspects of the literature presented in my review.

Being given access to the inner worlds of a small number of carers directly involved in providing end of life care within a care home setting has unearthed some of the deeper aspects of what it means to be a carer and the motivations involved. Searching for work that has relevance to the experiences represented in the data has led me to Kahn's (1992) development of the concept of psychological presence at work, including the ways in which members of an organisation draw deeply on personal experience in role situations. Through a synthesis of clinical and organizational literature including the work of Klein (1959), Winnicott (1965), Menzies (1975) and Miller and Rice (1967), Kahn makes it possible to articulate and present aspects of my findings as a potential model/state of being present at the end of life that recognises and values the particular qualities of care contained within the case studies, end of life stories and the cross case discussion.

Also relevant to my findings and conclusion are Winnicott's concept of the 'good enough mother' (1953) and two papers that consider issues of collaboration. Dartington (2006) considers collaboration from the perspective of the states of mind held by health and social care respectively whilst the other paper by Williams (2011) discusses the competencies and qualities necessary to collaborate effectively across organisational boundaries.

2:10 Related and Current Research

The move to improve the quality and outcomes of end of life care has prompted growing interest in care homes as providers of end of life care, with the publication of research articles reflecting the interdisciplinary and multidisciplinary nature of caring at the end of life. A major source of research is the International Observatory on End of Life Care based at Lancaster University. The aim of the observatory is to 'undertake high quality research, clinical studies, evaluation, education, advocacy and consultancy to improve palliative and end of life care for patients and family carers'. It works closely with the local health and social care community in the North West, as well as nationally and internationally and offers a range of methodological and theoretical expertise drawn from clinical and social science perspectives. Journals represented include: International Journal of Nursing Studies, Palliative Medicine, the International Journal of Palliative Nursing, Journal of Research in Nursing, and the European Journal of Palliative Care.

Professor Katherine Froggatt in conjunction with other researchers is a prolific producer of papers, all of which contribute significantly to a growing knowledge base (see list of publications at lancaster.ac.uk). Sheila Payne is another Lancaster based researcher who makes use of case study methods to 'examine processes and outcomes in dynamic healthcare organizations, where it is important to obtain multiple perspectives' (Payne et al., 2007). Other initiatives to improve the quality of life in care homes include a project called 'My Home Life', details of which can be accessed at myhomelife.org.uk. Achievements include leadership programmes and forums designed to enhance care in care homes and a report in conjunction with Help the Aged published online in 2006. Julienne Meyer is Executive Director (see Holman et al., 2006).

Other research closely connected to the emotional experience of carers and relevant to the project includes a Canadian study (Funk et al., 2017) and a qualitative study exploring the views of care home staff and community nurses on providing end of life care (Goddard et al., 2013). Examples of relevant studies accessed but not referenced directly in the thesis are included in the bibliography. Despite the almost overwhelming amount of end of life and care home related research available, my search has identified a small yet I would suggest significant gap in practice-near psychoanalytically informed research that seeks to engage with the emotional and unconscious aspects of the lived experience of carers in ordinary residential care homes.

2:11   Conclusion

My literature review suggests that on the one hand there is considerable interest and research into the provision of end of life care in care homes. On the other hand, a recent report (CLG, 2017) makes it clear that the sector is struggling to retain staff because of poor pay and working conditions, including a lack of training. In a wider sense, evidence from a number of sources suggests that at this time in our collective history we are struggling to create and maintain the kind of assumptive worlds that offer the necessary albeit illusory degree of emotional protection.

The task of caring for others at the end of life in hospital, at home or in a care home, brings those providing care close to the reality of death and the process of dying. Evidence suggests that there has been less progress than might have been anticipated in containing the emotional impact of being close to suffering in nursing (Tutton and Langstaff, in Armstrong and Rustin, 2015) and that whilst the emotional demands of working in a palliative care setting are more generally well understood (Vachon, 1995; Jones, 2001) and supported, there is less evidence to suggest that adequate provision has been made to fully support the identified needs of carers providing end of life care in care homes (Katz in Reynolds et al, 2002; Katz and Peace, 2003).

A number of indicators suggest that the foundations of the monolith representing attempts to meet the end of life care needs of our society are decidedly unstable. Despite its sizeable proportions the monolith may be unsustainable if the historical issues of neglect that have dominated the care of older people, including those at the end of life for many years, continue albeit in an altered form. The current and future context of end of life care will be discussed further in my final conclusion and with reference to the subjects of my study.

For now it seems sufficient to convey something of the emotional experience involved in recognising that the attention turned to those experiencing the effects of poor quality, and at times woefully inadequate, end of life care has resulted in what may be a splitting off of death and dying to a part of health and social care provision that has been in the past, and at the present time continues to be, undervalued and neglected. The

experiences represented in the study provide a valuable degree of insight and have the potential to contribute to a wider debate about health and social care provision.

3   Chapter Three: Methodology

Do I contradict myself?
Very well then I contradict myself,
(I am large, I contain multitudes.)

(Walt Whitman, 1855)

3:1   Towards A Deeper Understanding

In recent years the amount of quantitative data about how and where people reach the end of life has grown considerably. Data gathered about people and life events always has the potential to tell a story and to identify patterns and areas of concern within society. Indeed, we are increasingly subject to a whole range of virtually unavoidable data gathering processes that may or may not be used to improve the quality of our lives. At the same time a body of qualitative work, some of which is discussed in Chapter Two, is researching various aspects of the significant changes taking place in the provision and delivery of end of life care following the introduction of the End of Life Care Strategy. Having already established the purpose and value of this particular project in Chapter One, this chapter considers how the design of the project has made it possible to consider both individual and organizational aspects of end of life care. I begin by identifying my epistemological and heuristic position and how this has informed my decisions about the methods selected for the gathering and interpretation of data. The rest of the chapter will describe the way in which the project was designed and then allowed to unfold, including a discussion of the ethical issues involved, offering an account of the methods chosen and why, before considering the significance of the researcher's position in relation to the research subject and role of researcher. The chapter will conclude with a discussion of some of the concerns/controversies about the application of psychoanalytic theory outside of the clinic (Frosh, 2010), and a consideration of issues of validity, generalisability, reliability and replicability (Lincoln and Guba, cited in Bryman, 2001, p. 272).

The Professional Doctorate (D60) has offered a range of opportunities to develop as a reflexive researcher, including a period of organisational observation with reference to the framework developed by Hinshelwood and Skogstad (2000), exploring different epistemological and ontological approaches to research, and completing a policy and

research assignment that included the opportunity to trial a particular research method. As a result of these experiences I came to understand and appreciate the particular value of researching a subject about which I have considerable lived personal and professional experience and as Hunt (1989) suggests, the subjectivity and self-understanding (or at least the possibility of this) that is critical to well executed research.

Recognising the unconscious anxieties driving individual and organisational responses to death and dying elaborated in Chapter Two, it became essential to design a project that would enable me to gain access to the inner world of my research subjects and to position myself as researcher as a co-producer of meaning (Clarke and Hoggett, 2009, p. 8). Identifying an epistemological and ontological framework compatible with a psychosocial approach and offering an account of psychoanalysis that confirms it as an appropriate method of inquiry, has required an engagement with the philosophical debates and related accounts of psychoanalysis as a discipline, characterising the social sciences in recent years. My view that psychoanalysis and its application to social processes and systems has the capacity to illuminate and deepen our understanding of some of the most complex and troubling aspects of human experience is confirmed by Rustin, who considers the contribution and limitations of positivist and hermeneutic accounts of psychoanalysis before proposing that the critical realism of Roy Bhaskar (1978, 1979) offers a more adequate account.

Critical realism supports an ontological position that sees reality as stratified and differentiated and an epistemological understanding that knowledge of this complexity is inevitably filtered through the interpretive lens of social constructivism. Encompassing three ontological levels: the 'empirical', the 'actual' and the 'real', it embraces other disciplines in order to explore deeper causes for surface phenomena and supports the use of a range of research methods in order to do so. Acknowledging the need for a variety of modes of investigation Rustin notes:

> *It may well be that deep knowledge of human minds and emotions can be obtained* only *through reflection on interactions between one person and another. The aim of psychoanalysis has been to establish techniques which can enable this to be done consistently and reliably.*
>
> (Rustin, 1991, p.136)

Whilst Rustin offers a comprehensive discussion of the limitations of psychoanalysis as a science he concludes the chapter with the following statement:

> *It begins with a point (or points) of view regarding human nature and possibility, but then provides evidence and justification of its plausibility and claims. The density and richness of psychoanalytic accounts of human motivation have made it, in fact, into an exemplary form of moral reasoning.*
>
> (Rustin, 1991, p.142)

Psychoanalysis is founded on the discovery of complex subjectivity, making it an obvious choice and source of knowledge for researchers wanting to develop new methodologies for research that have the potential to explore the complexities of the individual and society in a way that can acknowledge them as two sides of the same thing. The epistemological framework of the project including the 'fit' between critical realism and psychoanalysis defines it as an empirical study situated within the developing field of psychosocial studies with its psychoanalytically informed methods and methodologies.

Whilst appreciating the 'newness' of critical realist approaches to research there is growing evidence to support their validity. In a volume outlining the consequences of applying a critical realist approach to the study of organisations, research strategy and design are considered with a particularly strong case made for the use of case studies (Edwards et al, 2014).

3:2   A Psychosocial Approach

Not unlike psychoanalysis, psychosocial studies have emerged as a complex and diverse field of study. Focusing on the interplay between the external social world and the inner world of the psyche, psychosocial studies is consequently drawn to psychoanalysis as the discipline 'that might offer convincing explanations of how the "out there" gets "in here" and vice versa (Frosh and Baraitser, 2008, p. 347). In doing so it builds on the tradition of interpretive ethnography and critical theory to offer an additional layer of interpretation and analysis.

Evidence of diversity and ongoing debate within the field can be found in the discussions that surround the use or otherwise of the hyphen (psychosocial or psycho-social) including the different positions taken by Frosh and Hoggett. For Frosh (2003), psychosocial studies without the hyphen studies provide 'a space in which notions that are conventionally distinguished – "individual" and "society" being the main ones – are instead thought of together, as intimately connected or possibly even the same thing' (p.1547). In contrast Hoggett (2008) writes: 'Neither psycho, nor social, the hyphen connotes what is "other than" both, that is, what is different from either of the two milieus that generate it'.

Despite these differences, including what is described as a particularly divisive debate about positive and negative forms of inquiry, Redman (2016) articulates what it is that makes psychosocial studies different from neighbouring fields of study. He identifies: the attention studies of the psychosocial pay to an unusually wide range of psychic and social phenomena; the field's emphasis on the density and relative autonomy of both subjective and social life; its trans-disciplinary ambitions and its commitment to hold in tension the 'negative' and 'the positive', a commitment that translates into the pursuit of psychosocial knowledge without guarantees.

The list is acknowledged to be neither exclusive, exhaustive or beyond dispute and he suggests that others would choose to include methodological innovations and an emphasis on affect, emotion, the irrational unconscious processes and strange and anomalous phenomena. These latter elements in particular have come to define my project, in the same way that my studies at the Tavistock under the guidance of Andrew Cooper situate it within a particular psychosocial research tradition. Just how much the psyche and the social are intertwined is a central theme structuring the narratives of those interviewed, who might be described as occupying the fuzzy space in between. With this in mind I have chosen not to use the hyphen.

3:3   Being Practice-Near

Cooper's work has been particularly influential and his elaboration of the concept of practice-near research has contributed to the development and execution of the project (Cooper 2009a, p. 431). Practice-near in this case has involved coming close not just to a small number of research subjects but also to the subjects of death, loss and grief

throughout the course of the project. In the process I have found myself subject to each of Cooper's examples of 'what happens when we get *close*, emotionally or physically to, people?'

It will be apparent that I chose to research the end of life because it has become a passion and it will become evident in the case studies that this is something shared with research subjects. The experience of interviewing and then living with the data elicited has brought me close to the end of life experiences shared, often stirring up my own and causing the boundaries between to become fluid in a way that has usefully informed the interpretive process. Managing the emotional experience has been challenging and intense at times, emphasising the need for reflexivity and regular containing supervision.

An example of losing my mind is included here (3:11) and demonstrates the value of having a theoretical, in this case psychoanalytically informed, account of what occurred between myself as researcher and Annie as research subject (Ogden 1992). Cooper (2009a) suggests that 'a test of whether or not something really is 'practice-near' might be whether or not the researcher feels themself to be changed as a person' (p. 432). I feel that I have passed the test and will include reflections on what has transpired/been transformed in my conclusion.

A fourth test concerns the discovery of complex particulars and the value of these in illuminating related cases. My efforts in collecting, analysing and presenting data have aimed to represent both without detracting from either.

3:4   An Emerging Project

In the same way that my epistemological position and psychosocial approach has evolved over time, the opportunity to observe a significant aspect of the implementation of the strategy and then to interview a small number of the care workers involved as a separate activity, emerged as a direct consequence of my initial exploratory interview. The interview, with a Palliative Care Educator tasked with delivering a two-day training programme designed for managers and champions of end of life care, with the intention of improving the quality of end of life care across the region, was arranged with the aim of learning more about the impact of the ELCS (2008). The interview provided an

opportunity to 'test run' the Free Association Narrative Interview approach to interviewing that became my main data gathering method for the project.

During this interview it become apparent that many of the carers who would be attending the bespoke training were likely to have been close to death on a regular basis as part of their everyday caring role. In addition and although I think I already knew this, an example of an 'unthought known' (Bollas, 1987), the thought surfaced that the voices of this particular group of social care workers are less often represented than others within health and social care. I decided to pursue the possibility of engaging with them directly, developing my research proposal accordingly.

My original research proposal included eight interviews to be completed through the psychoanalytically informed method of interviewing developed by Hollway and Jefferson (2000), and a period of participant observation (Hinshelwood and Skogstad, 2000; Likierman, 1997), to be completed within a selected and consenting care home. As the project progressed and it became apparent that the interviews completed contained a wealth of rich and complex data, it was agreed in supervision that my efforts would focus on the analysis and interpretation of this material.

3:5   Gaining Ethical Approval

In order to proceed with the project I needed to gain ethical approval, making it necessary to consider how best to approach participants, inform them about the project and address issues of consent and confidentiality. For this purpose I produced an information sheet designed to inform participants about the project and the interview process and to seek their consent to being interviewed (see appendices). The form included my contact details and those of the Tavistock and who should be contacted in the case of any concerns arising.

My application made it clear that participants would be drawn from care homes actively engaged in providing end of life care, and currently involved in a regional project to improve the quality of end of life care by increasing the opportunities for individuals to die in their preferred place of care. Including the possibility of organisational observations at that time, I specified that observations would focus specifically on the culture and systems of care within the care home and be undertaken as unobtrusively as

possible and with consent. I also made provision for the interviewee to decide where they would prefer to be interviewed.

The main requirement of potential interviewees was that they be involved in the direct provision of end of life care and be willing and consenting participants with a degree of experience in the field. In addition to the information sheets and consent forms, I decided that introducing my project at the planned two-day training event would give potential participants the chance to begin to think about the project and tell me whether or not they might be willing to be interviewed. I attended two of these two-day events, gathering the names of those expressing an interest and willing to be contacted in the future informally during coffee and lunch breaks, using a form to collect names and the contact details of those interested in participating.

3:6   Making Contact

This proved to be a useful approach in preparing the way, identifying me as someone with a professional interest in palliative and end of life care who, whilst not directly connected to the hospice, had close associations with it. Later, working from the list of names obtained I began to contact individuals who had expressed an interest directly by telephone. An interesting process of evolvement and self-selection/elimination ensued, requiring persistence and organisation in following up busy or absent but potentially willing participants.

It is perhaps interesting to think that those most defended about the subject would choose either consciously or unconsciously not to be interviewed without considerable preparation and support, if at all, although this probably is the subject of another project. A potential ethical and personal dilemma arose when I realised that the next name on the list was the manager of the care/nursing home that we had identified as suitable for my mother. At the time of referral my mother was reaching the final stages of Motor Neurone Disease and the home had an infection amongst the residents, meaning that she could not be transferred there from hospital. The manager knew nothing of this connection and had expressed an interest in being interviewed. I contacted the home but she was not available. It was suggested I leave a message or call back.

I felt relieved and yet at the same time a strong pull to pursue an interview, whilst sensing that this was inappropriate in some way, particularly as I had not intended to include nursing homes. As soon as I made the contact I realised that I had an unresolved personal agenda and that whilst I would have managed this within the ethical boundaries of the project, interviewing her would have felt inappropriate and potentially unethical at least in my mind. As it happened the manager never returned my call and I made a conscious decision not to pursue the possibility of an interview. Whilst I have written extensively about my own experiences of end of life throughout the project, I have never been in a position where it felt appropriate or became necessary to share these with those being interviewed, although I know that the emotion of them became a part of the transference and countertransference of every interview in some way.

Another early interview arranged with a night shift worker reminded me of the place of the project in the lives of potential or actual interviewees. Arranging the interview to take place during the night shift I set off in the dark to travel to a part of the county that is completely unknown to me. When I eventually arrived at the venue having driven particularly winding and unfamiliar roads, the worker I had arranged to meet with was unavailable, having fallen the previous week and broken an ankle.

The experience was a salutary and timely reminder of my place, and the significance of the project, in the busy lives of my chosen group of participants. Again a suggestion that I might be contacted and the interview rearranged was not taken up. The experience also caused me to reflect on what it might feel like to be a night shift worker caring at the end of life, in the dark with fewer people immediately available to be called upon. It is also possible that I could have tried harder to rearrange this interview and recognise the place fear and anxiety held in this particular situation (Gilmour, in Clarke and Hoggett, 2009).

The six interviews that have come to form the heart of the study are with care staff from four different residential care homes representing the mixed economy of care, with two being privately owned and two part of a large not-for-profit organisation. Each care home cares primarily for vulnerable older people, meaning that many of the end of life experiences involve people who are at the end of life because they have reached the end of their natural lifespan. At the same time the lived end of life experiences of those interviewed make it possible to think about the emotional aspects of end of life in

relation to a broader range of circumstances. The narratives contain references to personal as well as professional end of life experiences, including the death of a parent. They also refer to the end of life experiences of family, friends and colleagues as well as residents who have required care because of a pre-existing and life-limiting condition. The study was designed with the intention of gaining the deepest sense of the end of life experiences of social care staff within the limits of ethical considerations. The range, depth and complexity of the data gathered reflect this.

Three of the interviews are with managers/leaders of end of life care within their respective homes and three with workers who have agreed to be champions of end of life care within their respective care homes (See diagram 2 for details). Each interview is presented as an individual case study and divided between two chapters with conclusions drawn at the end of each chapter. These conclusions are integrated into the wider conclusions reached in the final chapter.

3:7   A Systematic and Reflective Methodology

Within my conceptual and methodological framework the following methods have been used to gather, analyse and interpret data, representing an approach that combines inductive and deductive reasoning:

3:7.1. The Poetry of Existence

All interviews were completed using The Free Association Narrative Interview (FANI) approach. FANI is an adaptation of the biographical interpretive method developed by German sociologists when interviewing survivors of the holocaust and developed by Chamberlain et al., (2000). The FANI is based on the psychoanalytic method of free association with the aim of eliciting a narrative that is structured by unconscious rather than conscious logic. It is an approach that allows the interviewee to choose, at least at a conscious level, what is disclosed during the interview and to speak freely and openly at length.

FANI has four main principles and these were followed in each interview. The principle of open-ended questions encourages the second principle, which is to elicit a story. Each of the interviews completed began with an invitation to 'tell me about your experiences

of end of life care' and in each case a story/narrative emerged with the lightest of prompting. A third principle is to avoid the use of why questions and a fourth to use participants' ordering and phrasing.

A social worker for many years, I am familiar and comfortable with the experience of listening to the narratives of defended subjects and have a deep sense of the value of creating a safe and containing space, often for those unfamiliar with the opportunity to speak about their experience in such a way. It stems primarily from learning from experience about the need that people have and the benefits of being able to speak about/share painful emotional (often traumatic and potentially unspeakable) experiences and how to create the conditions that make this possible.

In particular, listening to the bereaved tell their story as part of the grief process has made it possible to recognise what an essential part of the process of working through loss and grief it is and how powerful. The value of allowing people to speak without unnecessary interruptions, to have their own thoughts, and choose their starting point, as a way of understanding preoccupations and anxieties is something that I have come to have a deep appreciation of and respect for. Connecting with the psychoanalytic concepts of reverie and containment (Bion, 1962) it makes perfect sense to me that it has become increasingly recognised as a psychosocial research method.

I particularly like Bollas's (2018) description of the technique as used in analysis:

> *S/he may think s/he is simply recollecting the events of the day but as s/he speaks s/he produces chains of ideas that are governed by an unconscious logic; his or her manifest ideas appear in a sequence that reveals latent thoughts. To quote Virginia s/he enters the "poetry of existence".*
>
> (Bollas, 2018, p. 69)

This is a lyrical description that goes some way towards describing the beauty of a method that makes it possible for participants/interviewees to be reconnected with the self in a way that supports a freedom of expression not so easily available in other forms or methods of counselling and interviewing:

> *To discover, or rediscover, the pleasure of language constitutes an important emotional experience; verbal articulation releases suffocated affects and*

emotions that have been buried, foreclosed and compromised by degraded forms of thinking and a loss of interest in speech itself.

<div align="right">(Bollas, 2018, p. 70)</div>

The following quote suggests that this has long been understood and has relevance to us all:

> *Give sorrow words. The grief that does not speak*
> *Whispers the o'er-fraught heart, and bids it break.*

<div align="right">(Malcolm in *Macbeth*, by William Shakespeare, 1564-1616)</div>

3:7.2. A Particular Kind of Listening

My approach to data processing, interpretation and analysis has developed as an eclectic mix of established ways of doing qualitative research, adapted to meet the needs of the psychosocial positioning of the project. Along the way a number of approaches have been considered and rejected because of their lack of fit with the research methods and their unsuitability for capturing particular complexities contained within the data. An early decision to do my own transcribing proved invaluable in becoming familiar with each narrative, including the emotional tone and subtleties of intonation and speech. In keeping with the method, psychoanalytic interpretation did not take place in the interview. Indeed whilst attention was paid to the dynamics between interviewer and interviewee, the experience of the interview as a therapeutic and containing experience made total immersion in the experience essential. Notes made immediately after the interviews captured my emotional experience of each interview and have served as data in addition to the interview transcriptions.

Transcribing the interviews myself proved to be an intense and somewhat exhausting experience but invaluable in representing the first stage of data analysis (Hollway and Jefferson, 2000; Clarke, 2002). The transcribing process involved listening to each interview intently and over time before listening again to ensure that each narrative had been captured and represented accurately, and again to detect the emotional tone and subtleties of intonation and speech. The impact of this immersion is noted by Hollway and Jefferson (2000) and referred to by Clarke (2002). I have found that their experience of interviewees appearing in dreams and waking fantasies has continued throughout the research process as the participants have become increasingly known through my repeated engagement with and interpretation of the transcripts, in the

preparation of case studies, end of life stories and cross-case analysis supported by what Cooper describes as:

> *an internal process in the researcher, a kind of 'reverie' in fact, that comes to her aid in the form of memory of another shift of perspective*

<div align="right">(Cooper, 2009a, p. 438)</div>

The example given by Cooper involves questions of race whereas for me the process has related to aspects of loss, grief and death. As Cooper notes, such shifts involve the researcher in taking up a 'third position' with respect to the data.

3:7.3 Thematic Analysis; Codes, Categories, Patterns and Themes

Other processes have involved coding transcripts in detail to begin to identify categories, patterns of experience and themes emerging from each interview. Aware of the potential of this process to fragment the data I found Braun and Clarke's (2006) paper on thematic analysis, in which they argue that thematic analysis should be an approach within its own right rather than merely a tool across different qualitative methods including grounded theory, particularly helpful. The flexibility offered by this approach seemed compatible with the explicit epistemological framework of the project, making it possible to combine inductive and deductive paradigms of analysis whilst staying close to the data.

Themes identified in and across the narratives were used to structure the individual case studies presented in Chapters Four and Five, allowing for the difference between narratives to be represented along with a sense of the individuality and uniqueness of each carer. These were then clustered according to their significance across the narratives and used to form the additional questions that structure the cross-case analysis presented in Chapter Seven. Having recognised the significance of the range of end of life stories told across the narratives, a decision was made after discussion in supervision to include a chapter presenting them in their own right in order to capture the meaning of them as fully as possible.

3:7.4 Case Studies

The decision to include a case study of each carer stems directly from Cooper's thinking about practice-near research:

> *A key lesson from doing practice-near research is thus that each and every situation or context is unique and particular and must be understood - 'apprehended' in its own terms.*
>
> (Cooper, 2009a, p. 440)

It also represents an attempt to remain faithful to one of the central thrusts of the project: to represent the voices of the participants as authentically as possible (Hollway and Jefferson, 2000, p. 3). The case studies have developed from my close reading of transcripts, reference to field notes and memories of each participant's presence during interview, and with reference to some of the key psychoanalytic concepts informing the project including the work of Klein, Dartington and Waddell.

In addition, the work of Yin (2004) and Stake (2006) has been helpful in considering the benefits and possible criticisms of the case study method informing my decision to present data in the form of individual case stories, a collection of end of life stories and a cross-case analysis. Yin's paper summarises seven key points to be taken into account when using the case study method (2004, pp. 1-25).

His first summary point identifies the strength of the case study as its ability to examine in depth a 'case' within its 'real-life' context with additional considerations condensed into a further six points. The second notes that the case study is best applied when research addresses descriptive or explanatory questions and aims to produce a first-hand understanding of people and events. The third indicates the investigator's skill and expertise in pursuing a line of inquiry at the same time that data is being gathered.

Summary four involves defining and justifying the choice of single or multiple case studies with five addressing the issue of case selection and viability. Six considers the question of triangulation and seven emphasises the need for data to be presented formally and explicitly in a variety of data arrays set apart from the case study narrative. Summary eight concludes that case study analysis can rely on several techniques and be presented throughout a case study as an argument is built that addresses the research

question (Yin, 2004, pp. 1-21).

The overall design of my methodology responds to these considerations and aims to address some of the concerns and criticisms of the case study method, whilst ensuring that the case studies represent the qualities inherent in the method. In addition the case studies are influenced by, rather than situated in, the method of narrative analysis and the relevance of the method to the subject and theoretical framework of the project can be found in the blend of representation, analysis and interpretation underpinning their production (Mishler, 1995; Kim, 2016).

3:7.5 Cross-Case Analysis: A Quintain

In choosing to include six single case studies and a cross-case analysis I have been guided by Stake's (2006) consideration of multiple case study analysis.

For Stake multi case research starts with what he refers to as the 'quintain'. Having struggled initially with this term, even seeking to identify an alternative way of describing the phenomena, I have come to appreciate the full meaning of the word. Described as a target but not a bull's eye, the quintain can be held in mind whilst individual cases are explored in detail before the quintain (in the project this is identified as the relationship each participant has with death and dying) is returned to and explored in some depth. In this way the quintain represents a target, which is not too narrow and not too broad, avoiding closed or narrow mindedness on the one hand and overwhelming complexity on the other.

Having studied the single cases I began to understand more about the quintain and formulated further questions to be put to the data through the processes of coding, categorising and patterning described earlier (Cooper, 2014). These questions are used as headings in the structure of the cross-case analysis.

> *But if the study is designed as a qualitative multicase study, then the individual cases should be studied to learn about their self-centering, complexity, and situational uniqueness. Thus each case is to be understood in depth, giving little immediate attention to the quintain.*
>
> (Stake, 2006, p.6)

Stake describes the shift of focus between the single case and the quintain as an epistemological dilemma (p.9). My project design is an attempt to maintain a balance between the two with the intention of representing both as fully as possible. The richness of data concerning the end of life, emerging in the individual narratives, is captured as fully as possible in Chapter Six. Diagram 3 gives a sense of the processes and timescales involved.

3:8   Ethical Encounters

> *What I've become aware of is that you have people who've been doing end of life care for many years and almost feel that you're teaching aunty/granny to suck eggs, they've been doing this for many years and it's just paperwork telling us what we already know.*
>
> (Palliative Care Educator, 2012)

Choosing to use the Free Association Narrative Interview method of data collection developed by Hollway and Jefferson (2000, 2013) has enabled me to negotiate ethical encounters and considerations, and to build on my earlier positive experience of its application to an interview with a health professional about the End of Life Care Strategy. Hollway and Jefferson use Klein's work to develop a theory of the defended subject viewing both researcher and researched from this perspective. In viewing both as anxious, defended subjects, unconscious inter-subjectivity is acknowledged and the role position of the researcher as expert is amended accordingly.

Central to the project are the core values and ethical principles that underpin social work practice (BASW, 2012), the universities code of practice for research ethics (UEL 2015 – 2016), and the work that relates specifically to the ethics of researching psychosocial subjects (Hollway and Jefferson, (2013, pp. 77 -95). Ethical issues are not new to qualitative researchers and Hunt stresses the need for researchers to remain 'both empathetically and ethically attuned to any persons who are the object of investigation to ensure the privacy of their communication' (Hunt, 1989, p. 84). Likewise, Hollway and Jefferson turn to the codes of ethics of both the British Psychological Society and the British Sociological Society in thinking through some of the ethical issues raised by their methodological approach (Hollway and Jefferson, 2013, p. 89). Implementing these values and ethics into the research process has seemed easy at times and far more complex at others.

Some of the ethical issues considered by Hollway and Jefferson have not been immediately relevant. I offered no financial incentive, simply offering the opportunity to speak about end of life experiences with the aim of reaching a deeper understanding of what it means to care for others at the end of life in a homely/generalist setting, and sharing my findings within appropriate arenas/forums. I was however aware of issues of power within the systems of health and social care and wanted to find ways of balancing the imposition of the machinery of the End of Life Care Strategy on those who, as the above quote suggests, care for those at or nearing the end of life on a daily basis.

The concept of doing no harm and serving the best interests of participants whilst respecting their rights has been a focus throughout. As someone researching from a very particular position in relation to the habitus of palliative and end of life care (Bourdieu, 1995), I have had the privilege of using my experience and knowledge of the subject to understand and minimize the distortions affecting the interview relationship. As a self-funding student, driven solely by professional and personal interest, I have also been fortunate to be in a position to design and conduct my research independently and without the constraint of an externally imposed agenda.

In thinking about transparency it has been helpful to access Beedell's discussion in Clarke and Hoggett (p. 101-118). As with other aspects of the project I have a sense of transparency emerging without needing to be explicitly stated. A conscious decision not to emphasise my personal and professional history, unless this was specifically requested, meant that my capacity to contain the emotional content of the interviews was conveyed largely by my presence at the two-day training events.

Incidental to the day and in the background except when discussing the project informally, my interest and ease with the subject of death and dying will have been conveyed at both a conscious and unconscious level. I have since come to appreciate how much was conveyed subliminally and the contribution that this made to the level of trust between researcher and researched subject, and subsequently proved invaluable to the quality of data shared in the interviews; facilitating and supporting the opportunity for expression. I am also aware that my associations with the hospice may have imposed a subtle form of censorship (Bourdieu, cited in Beedell, in Clarke and Hoggett, p. 111), influencing what was and wasn't said to some degree.

This approach developed instinctively and intuitively, yet when thought about and articulated can be expressed as a desire not to burden those interviewed with any sense of my own relationship with the end of life but to convey a deeper connection based on a sense of shared experience(s). In the same way I have found the concept of using myself as a research tool helpful in utilising my emotional involvement in the project. I have made use of my feelings, identifying with Jervis's description of becoming temporarily lost and requiring help from 'others' to retain my objectivity, aiming at all times to manage the processes involved with personal and professional integrity (Jervis, in Clarke and Hoggett, p. 145-163).

Conscious fears about interviewing have centred on technical details, including my use of unfamiliar technology and finding my way to unfamiliar venues on time rather than on the subject of the research. Again I believe this has been helpful in addressing issues of power, as has the opportunity for interviewees to choose, in keeping with one of the main thrusts of the ELCS strategy, their preferred place of interview.

The concept of reflexivity and the idea of the reflexive researcher are central to the development of ethically sound psychosocial studies. Frosh and Baraitser argue that reflexivity is a priority at this stage in its development (Frosh and Baraitser, 2008, p. 350). The need for a critical approach based on a process of sustained reflection, which includes the researcher's emotional involvement with the research and the affective relationship between the researcher and the researched, along with a suspicion of the production of knowledge itself, is emphasized throughout the literature (Frosh and Baraitser, 2008; Clarke and Hoggett, 2009; Hunt, 1989; Hollway and Jefferson, (2000, 2013).

3:9   Considerations and Limitations

My project is small, based around six interviews with residential care home staff drawn from a particular region, selected without regard to issues of gender, age or race, emphasising particularisation more than generalisation. The fact that they are all white British women, and each one has been employed in their respective care home for a number of years with the shortest period being eight years and the longest thirty-three, suggests that geography and local/regional demographics have contributed significantly to the question of generalisability. This adds strength in terms of validity but also

limitations in terms of relevance and applicability of conclusions drawn to more diverse groups. Countering concerns are the simplicity and potential for replicability of the project in other parts of the country and with other carers.

One of the main challenges for any qualitative research method has been whether or not it can achieve the position of credibility afforded to more 'scientifically' valued methods of quantitative research. Data produced through interpretive methods of research, including psychoanalytical psychosocial methodologies, is not easily measured against the traditional terms used to establish the quality of quantitative research. Alternative primary criteria for assessing qualitative research in general, including psychoanalytic psychosocial research, are proposed by Lincoln and Guba (in Bryman, 2001, p. 272) who posit that the trustworthiness of a research study is important in evaluating its worth and incorporates the four sub criteria of credibility, transferability, dependability and confirmability.

According to Lincoln and Guba the first three are achievable within the bounds of a well-structured and meticulously executed research project whilst the last, confirmability, depends on the researcher's account of their interest and investment in the project (Clarke and Hoggett, 2009, p.7). Developments within psychosocial studies emphasise the importance of well-documented accounts, reflexivity and the recognition of the vulnerability of research participants discussed in the chapter.

Other potential limitations of the study include the size of the sample and the issues of generalisability highlighted. These are addressed at least in part by the recommendations made in Chapter Eight.

3:10   Part of The Story

Developing as a reflexive researcher has made it possible, and then essential, to make use of my own experiences of end of life care through the use of autobiography as an additional and innovative psychosocial research method. It is a method that makes it possible to identify the researcher's part in the research process beyond the traditional position of objectivity, to an explicit engagement with dynamic inter-subjective, unconscious processes (Frosh and Baraitser, 2008, p. 352). Prior to and during the early days of the project my autobiographical writing contributed to the beginnings of

realising that my experience might become a research project, and later to the emergence of my initial hypothesis, formulated later as a central research question.

Since then I have written on a regular basis as the project has developed, stirring up thoughts and emotions in response to different aspects of the research process and the spaces in between (Winnicott, 1971). Writing has made it possible to bring these thoughts and emotions to consciousness, to be thought about in ways that have supported and deepened my engagement with the data emerging and process what I recognise as my own continuing working through of loss. Much of this writing has been shared with my supervisors, enriching discussion and making it possible to distinguish between my own thoughts and those of the interviewees (Jervis, in Hoggett and Clarke). Here I am writing about my father towards the end of his life as he leaves hospital to be cared for at home:

My sister and I agreed that if at all possible we should try and get him home. We also agreed that my mother should not have to manage his care alone. We both knew that she couldn't.

A solution emerged when a close friend of my sister, a trained nurse who had previously cared for someone at the end of life, offered to come and stay in my parents' home and provide nursing care supporting my sister and mother. I had little choice other than to stay at home and care for my children and visit whenever possible. This is what happened and I can still grasp the sense of relief when I was able to oversee his discharge from the hospital. Satisfied that this was in hand and an ambulance ready to take him home I cycled as quickly as possible to my parents' house to be there when he arrived. I experienced it as a dreamlike journey, pedalling frantically but seeming to travel in slow motion, with a strange sense of elation at our success in setting him free. We may as well have sprung him from prison.

Knowing he was safe and home I have the sense that I relaxed a bit and allowed the care to unfold. There were times of peace and deep satisfaction. The children visited him briefly and I spent time with him when he was still lucid. He said how proud he had been to have two beautiful daughters, how much he had loved my mother and how he wanted us to look after her. There were also times of real suffering and for my mother watching this, horror. During the last days of his life he became very distressed and

agitated for a period. My mother described how he had raged around the bedroom and been impossible to calm. I am almost certain that without my sister's friend an ambulance or the GP would have been called at this point and he would have probably died in hospital.

The crisis was endured because of the calm and steady presence of someone who cared about what was happening but could stand back from the intense emotions of family relationships. In the event my father died peacefully at home during the evening of the 23rd July. In retrospect I'm not sure about the effectiveness of his pain relief and whether this would have been managed better today. As it was I think our family GP responded appropriately at this time although he had made it clear at an earlier stage that he didn't think we should talk to my father about what was happening to him. He had been our family doctor for many years and I know that my mother, so at a loss as to "how to do this", was particularly open to his advice. In 1984 our local hospice was in its earliest days consisting of a small number of hospital support nurses and a day centre. It was never mentioned in relation to my father.

On the night he died I was at home with my children. My husband was out and the friend I had spent the evening with, talking about my father, stayed so that I could go by taxi to my parents' home within a few minutes of his death. When I arrived I was able to help my mother wash him and get him ready to leave his home for the last time. It is difficult to fully describe just how much being able to perform this ritual meant to us both. It was at the time, and remains now, one of the most significant things I have ever done. It felt completely right and appropriate and something that we could do for him before we had to let him go. It was a way of beginning to love him beyond life. I remember the difference in our approaches to the task, my mother rather brisk and purposeful and me tentative and wanting to take my time. This may be because I had missed his last hours and minutes and simply wanted more time to say my goodbyes. Either way it was a deeply meaningful experience.

It will be apparent from this short section of autobiographical writing completed during the life of the project, yet describing an event occurring years before the implementation of the strategy, how closely my own experiences of the end of life identify with and yet are different and distinct from the experiences of those interviewed, as well as those whose end of life experiences are represented within the narrative accounts. I have also

written about the end of life experiences of my husband (2006) and my mother (2008) including my responses to these life-changing events (Scanlan, 2016). Each experience has contributed in its own way to the project and using autobiography as a research method has made it possible for them to be processed and used to deepen understanding and enhance the project, as well as enabling me to respond to participants with 'accurate' compassion and insight (Hollway and Jefferson, p. 165).

3:11 A Lesson from the Underworld

In completing the thesis for submission I decided to conduct a review of the project, choosing to listen to the interviews in full as a way of gathering my thoughts, reflecting on the whole process and applying the reflexivity that has informed the project from the beginning. I always understood the interview with Annie (see 4:1) to be a particular example of becoming psychically mixed up with another person and this is acknowledged in the case study. Listening again to the interview, I realised I had missed a most significant detail. Annie refers to the death of her parents during the interview but what I had 'forgotten' about when constructing her case study was that in the first part of what became a long interview she referred to the death of her son.

On hearing this I felt shocked and more than a little disturbed, incredulous really, that I had overlooked such a significant detail and one offering further explanation of Annie's relationship with death. Searching the transcript of the interview I discovered the relevant section tucked away at the back of the folder. Compelled to consider this oversight or as I began to think of it, 'psychic turning away' (Steiner, 1993), I checked diaries and notebooks, revealing to myself a period when I had been particularly concerned about the emotional wellbeing of my own son as he negotiated university life whilst grieving for his father, who died when he was just twelve years old.

In this 'dialogue of the unconscious' (Ferenczi, cited in Haynal, 2002, p. 57) there is much to be learned and understood about the complexities determining individual positions and states of mind in relation to death, and what it means to be a defended and emotionally vulnerable researcher. The pain of experiencing the loss of a son projected onto someone who, despite a deep connection with the tragic position and death, was unable at this particular time to even consider the possibility let alone contain the emotional experience for Annie.

The above explanation goes beyond traditional notions of generalisability in acknowledging the differences and complexity contained within ordinary psychosocial phenomena, and further justifies the focus of this particular project/study. For a visual representation, see diagram 4.

3:12   Controversies

Finally, it seems important to acknowledge the controversies that have surrounded the application of psychoanalytic theory in, and to, psychosocial research (Frosh and Baraitser, 2008; Parker, 2010). Both question the use of psychoanalytic concepts outside of the clinic and whilst Clarke emphasises the importance of a theoretical framework and understanding of the subject (2002), I am mindful that I am not a trained psychoanalyst and aware of the need to maintain a 'knowing ambivalence about theory' (Cooper and Lousada, 2005, pp. 2010-213). The importance of retaining the capacity to think openly and draw on my own observations and emotional experience has guided my engagement with the data, and supervision with my supervisors and fellow students has offered opportunities for the kind of reflexivity that supports the application of and thinking and rethinking of 'cherished psychoanalytic ideas' (Frosh and Baraitser, 2008, p. 363) whilst guarding against the misuse of 'wild analysis' (Hunt, 1989, p. 84).

3:13   Conclusions

The psychoanalytically informed framework of the study has made it possible to engage with the layers of complexity and levels of emotional experience involved in caring at the end of life. The methods selected have ensured a methodical and systematic approach to the data emerging and supported the reflexive process through the use of autobiography and containing supervision. In turn this has made it possible to access my internal supervisor, developed over years of learning from and reflecting on experience (Bower, 2003). It will be apparent that despite all of this, during and at the end of writing and reviewing the project, I became aware of material that I had buried. The revelation is included in this chapter as an example of researcher vulnerability, the importance of reflexivity, and as a valuable reminder of the extent of the defences involved and what I have come to think of as the treachery of the unconscious mind.

3:14   Addendum: Responding to an Unforeseen Ethical Issue

An ethical issue/dilemma arising in the processing and presentation of the data involves two of the carers who work closely together and who share related material in their respective narratives. This makes it highly likely that if they were to read the thesis, they could identify one another and in doing so have access to material shared individually and confidentially.

After careful consideration and with reference to Hollway and Jefferson (2013, pp. 84 - 85), I have concluded that the value of the research as presented in its current form within the thesis outweighs any harm that might be done to those concerned. The likelihood of harm being done is assessed in part on my experience of the carers and discussions undertaken when seeking and gaining their consent, in particular the information given and discussed prior to the interviews about the issue of confidentiality.

Each interviewee was given the opportunity to be interviewed in an alternative setting yet chose to be interviewed consecutively. It was apparent both before and after the interviews that at least some of the interview experience had been discussed prior to interview and would be after, as part of a close and supportive, professional and work-based relationship.

Finally, in order to limit the potential for harm to either party arising from the connections made during the individual interviews, all efforts have been made to anonymise the material as fully as possible. Any subsequent dissemination of the research findings will take this issue into account and be presented in such a way as to ensure complete anonymity. If any concerns are raised by the presentation of the data in the thesis, they will be responded to within the spirit and ethical framework of the project as elaborated in Chapter 3: 8. Any future research will pre-empt the issue.

4   Chapter Four – Managers

4:1   Annie - Warrior Hero

There are always these moments in life when the limits of suffering are reached and we become heroes and heroines.

(Katherine Mansfield, 1888-1923)

4:1.1   The Interview

Arriving at the prearranged time confirmed by letter and a follow-up phone call, I am asked to wait in a room to the side of the reception area in the main building. This room, a comfortable sitting/waiting/meeting room, is outside of the main residents' area and separated by electronically operated doors. In contrast to other homes visited Hilltop is purpose-built and described in more detail during the interview. When Annie eventually comes to speak to me (after not too long although I am made to wait and given a coffee) she appears to be unclear about why I have come to speak to her and asks me to explain what it is that I want.

As I talk about my project and the purpose of the study Annie begins to speak and I realise that the interview has begun and quickly turn on the tape recorder. This is the least formal start to an interview, which turns out to be longer than any other and far-reaching in its scope and breadth. As Annie begins to tell me about how she came to work in social care I realise that I have passed a test and been approved as someone who can have access (although perhaps guarded at least initially) to Annie's experience as a carer/manager. Annie speaks quietly and I have to listen intently to catch everything that is said.

4:1.2   Getting Started

Annie begins her narrative with an account of how she came to leave her home in Scotland in her early twenties to find work in England. Although at this time Annie had worked mainly in factories, she had loved volunteering in a care home for older people whilst still at school. Following a season working in a holiday camp Annie moves to a larger city with a friend who knows that Annie wants to work in care. The same friend tells Annie about a temporary position in a local authority social services run care home,

where she already works. The care home is beginning to accommodate women as well as men and whilst women carers can care for the men, only female carers are allowed to care for the female residents. An initial two-week position is extended and eventually becomes permanent.

Annie remembers that caring was totally different at that time, with fewer rules and regulations and no risk assessments. She describes it as very relaxed but also physically demanding work as residents were lifted without hoists. When the care home is taken over by a charity Annie is promoted and receives support with her dyslexia, which she feels until then has held her back. When a decision is made to combine two existing homes and move the residents and staff into purpose-built accommodation, Annie is heavily involved in the move and promoted from Deputy Manager to Personal Care Manager and later becomes the Registered Manager. Annie describes the day the residents moved in to the newly finished home:

And then the residents moved in and their faces when they got off the bus, you've got to remember they were living in a place where the toilet was down the corridor and they had to get washed in a bowl and they looked in and their faces lit up, everything was spot on, it was brand new, it was gorgeous, in my own words it was like a five star hotel.

Annie explains that some residents were disappointed because the atmosphere was not as friendly as in the old home and, because the new home had been advertised as a new care facility for people with dementia, some residents found this upsetting. The care home accommodates up to seventy-five residents divided between three bungalows and now caters primarily for those with dementia. As the narrative unfolds it becomes apparent that Annie is willing to do battle to make sure that her residents are treated with dignity and respect. Annie's narrative is significantly shaped by the fact that all residents living in the care home have some degree of dementia.

4:1.3   Caring at the end of life

Hilltop House has always looked after residents to end of life, it's not new to us.

Annie is clear that when someone is admitted it is with the intention that they will be cared for, as far as is reasonably possible, until the end of life:

I won't take people just to fill my beds you know, I've got to be, I want people in Hilltop House where it's as much as possible, you can never be a hundred per cent where, as much per cent as possible that I'm gonna be able to care for them till they die.

Annie goes on to explain that before someone gets discharged from hospital or admitted to the home a full assessment is done:

I've got to be, the last thing I want is to say, yeah, send them home, send them home and I canna meet their needs, then we're going to move that person again, you know, but the only time we canna meet their needs is if they need a drip or things like that, anybody in end of life, we can meet their needs.

Annie believes strongly that people should be able to choose where they want to die and stresses the importance of advanced care planning at an early stage following diagnosis for those with dementia. Annie is positive about the move to encourage more people to complete advance directives:

I hope we get a lot more people putting it in place before they get a dementia and putting these in, so we actually know what these people want at the end.

Whilst Annie shares a number of end of life stories during her narrative including those of both of her parents (see chapter seven), the emphasis is on her role as a manager of care at the end of life. Caring at the end of life is spoken of within the wider context of the challenges of caring for residents with dementia, often in combination with other health conditions, and Annie's understanding of dementia as a terminal diagnosis. There are two brief glimpses of Annie caring at the end of life. One is when she speaks of her mother, the other is when Annie mentions in passing that if a resident is at end of life and alone and no one else is available, Annie or her deputy would go and sit with them.

4:1.4   Dementia

At times it seems as if dementia rather than the end of life is the main focus of Annie's narrative and the impact of dementia on the task of caring is a theme throughout:

People don't realise, you can die with dementia, with dementia here, that's the illness, the brain shuts down, and, and that's what folk don't understand.

It becomes evident that as far as Annie is concerned dementia is significantly misunderstood and that this has an impact on individual responses, including those of professionals and the wider systems of care:

A lot of GPs don't understand the effects of dementia and that flaw or that lack of training affects residents at end of life.

Annie's narrative includes a number of accounts of the challenges involved in meeting the needs of residents living with dementia. These include making sure that residents receive the quality of care that any older vulnerable person might be expected to receive; the importance of thinking together about what might be triggering particularly challenging behaviour; responding to the emotional needs of residents who are struggling to express themselves; and supporting staff who find themselves the subject of particularly challenging/aggressive behaviour:

The carer collapsed in the dining room so other staff called for an ambulance, it was the shock, she was only there for a few hours, it was the shock, she was just in shock from getting karate chopped, now we lock it, but that lady would have been labelled aggressive somewhere else, she's not aggressive, she's not challenging, she was upset with the carer for a split second.

The difficulties in thinking about the needs of both parties in this situation are highlighted in Annie's response.

4:1.5   Emotion

The emotion contained within Annie's narrative is often difficult to detect, and is overlaid by the frustration that I have since come to realise enables Annie to find the energy to fulfil her demanding and complex role. Despite this and on closer reading, it is possible to identify a range of emotions, with occasional moments of tenderness that suggest that Annie connects deeply with the lives of her residents. The following description reflects a range of emotions, including some frustration with the systems of care involved, tempered by a degree of 'black' humour as in Annie's description of a resident who has died and is being collected by the undertakers:

Yes it's sad to watch somebody die, it's sad to be with them and it's sad for the person, we've done everything we can for that person from the day they come in here to the end of their life, and my staff take pride in that, that they've done that, but you see folk don't see that side of it, you know and residents here are, are, until they go right out that door, treated with dignity, you know even, sometimes the undertakers come, and one of them come and they had this trolley thing, a trolley, and I went "what's that?", I said, "they're not going out in that". They said, "what do you mean?", I said, "they're not going out in that, like a bag of spuds", and they went and they got another thing.

The following is in response to the death of a resident after she has been removed to hospital because, having come out, the ambulance crew had no choice but to take her in despite the home wanting to keep her:

The consequences of that are that the lady died in hospital on her own with strangers and we cared for her here for two years, that was absolutely devastating.

A particularly moving account involves a resident who has had a difficult relationship with his family and whose mother is now dying in another care home. Annie intervenes and makes it possible for him to visit her to say his goodbyes and later arranges for a member of staff to accompany him to her funeral. Annie also speaks about others whose lives have been difficult emphasising the need to show compassion and respect, only sharing confidential information on a need to know basis.

4:1.6   Professional Relationships

Annie's experience of relationships with other professionals is mixed:

Never have any issues with the district nurses, always supportive and they're busy, they're just as busy as doctors, they're just as busy as hospitals you know, they come, they've got other things to do, they a, we can ring them out of hours (pause) they, they, for them.

In contrast, GPs are referred to on a number of occasions as a particular source of frustration:

A lot of the GPs can't take no or don't have any understanding, it's as if they've got no training.

Annie's narrative makes reference to a range of professional relationships including ambulance crews, funeral directors and police officers, with Annie giving examples of some of the inter professional issues arising reflecting varying degrees of understanding of the needs of residents. CPNs and a consultant psychiatrist are considered to be a vital source of support:

We've got the CPNs and everything so actual mental health needs we're supported greatly, absolutely fantastic, intensive home care team, everybody.

She (psychiatrist) respects us, she knows exactly what we do here, she knows the knowledge we've got because she comes and talks to us, she has a clinic.

And the lament again:

If only we could get the GPs on board, that's the only thing.

4:1.7   Home

I've never heard a resident or a family want them in hospital to die.

Annie has a strong sense of the significance of home and of the compromises that life can impose:

To me everybody should have a right to die at home and when they come in here, it's the home they've got, it'll no be ideal for some people you know I've lived up here a number of years but my home's still in Scotland, do you know what I mean but to me I still want to die, I don't mean in Scotland, in my home, and if I end up in residential care I want to be in the home to die with people that know me and people surrounding me and I'm hoping in the future we get these, what do they call them now, directives.

Annie's sense of what she wants for herself is a form of 'caring as if' as she speaks of her hope that more people will complete advance directives:

I want to live in my home or I want to, I don't mind going into residential, I want to be buried, I want to be cremated, I want to end my life where I live at home, but in a residential home or my actual home, and put all that in place and that would cut all this, cut all this argument about who makes this decision and who makes that decision, but we're getting quite a lot of new lasting power of attorney, we used, we used to always get them but we're getting quite a few now so that's, that's, good as well, 'cos they've obviously discussed that when they didn't have a dementia.

Annie conveys her sense of just how important home becomes for those with dementia:

And that is the main thing for me, you know to care, because the thing is this is their home. People with dementia you don't want to move around.

And when it is suggested a deceased resident leaves via the back door:

This is her home. Would she go out the back door if she was at home on an estate? So why would she, so it's all about understanding, even after they die you've got to treat them as people.

4:1.8   In Defence of Care and Carers

Annie speaks with some anger and passion on behalf of carers. In her own words:

I think in this profession the fact is we get a lot of (pause) press when something goes wrong, we don't get enough press for the good things we do, we don't get enough acknowledgement for the good things we do, but something goes wrong and that's it, we're front page of paper, we're, and it's not just talked about for a while, it's forever you know, this home was abusing these ladies so everybody's suddenly abusing people, you know everyone is tarred with the same brush and it's really, but if a hospital, you've got a hospital no meeting standards or something, all hospitals don't get labelled like that.

We're no classed as professional and that's the problem, that's the whole problem, we're no classed as professionals and doctors'll listen to nurses more than they'll listen to my staff but my staff are more qualified than nurses to tell them about that resident, we are no recognised as professionals, you know and the concept some people, I remember I was, I was watching some care thing (name of programme) I don't know why I was watching that, and they were on about some woman, well you canna get a job, go be a carer. I was so angry, you know they've got more skills than, a lot of people, they need more skills than a lot of people because they care for people with dementia but they're no recognised.

It's quite a complex job you're caring for everybody and it's about building up relationships.

They counsel relatives, they've got to know everything about dementia, they, they've got to look at situations before it happens so they can avoid it happening, erm they've, they've got to, the only thing they haven't got to do is give injections and things like that, the seniors give education, they help the district nurses, they do everything er, peg feed people, they do all that erm but it's no recognised in their wages and that's no (the company's) fault, it's the government's fault because the government don't recognise what residential homes does, all the government does is complain about us, I mean that's something again, they complain about us so, and (the company) would pay staff more if they got more off the local authority, but they don't, so, so it's quite a sad

situation for society to have, you know we should be looking after our elderly people, we should be rewarding the people, and we don't. I mean you can ask any carer, people'll go "I don't how you can do that", it's a common acknowledgement.

4:1.9   Supporting Families

People are all different, every single family is different, every resident's different, some people come in to here with a story book and go through it with you something like that, some people will come in with nothing about their life, think it's none of your business, no matter how much you explain to them it helps us to look after them better, they'll not, but you don't know what sort of life they've had, so you canna push people 'cos everybody's nay had a happy childhood with (pause) you don't know what's happened there, you cannae push people, so I think if people are really reluctant is explain why you need this information, how it will help you deal with the resident, have they discussed, you can ask the questions, but if they don't want to tell you, you don't push it because you don't know what's happened in that person's life and you don't want to.

4:1.10 Boundaries

In many ways at least initially there appears to be less blurring and dissolving of boundaries in this narrative. Annie has lived away from the country she still considers home for many years. However over time and with close and repeated reading of and listening to the transcribed interview, I have become aware of the impact of significant aspects of Annie's personal experience that are closer to the surface than is immediately apparent:

So me dad ended up in residential care, he ended up in a nursing home, 'cos when we found out he had the bowel cancer as well he went in a nursing home em but me mam wanted to die at home, she had all backup plans, but dad never really spoke about where he wanted to be and he died in the nursing home, no in hospital, he actually died where he lived, so, a lot of people's got experiences like that, you know up in Scotland and I think people who have experiences like that good or bad need to be telling people.

I am curious about a lengthy account toward the end of the interview in which Annie describes following a resident who has left the care home alone. It is unexpected

coming towards the end of the interview and seems extraordinary until I make the connection between this, and Annie's account of her father as he becomes increasingly demented and wants to return to a place where he used to live:

I tried to explain, look he thinks that's where he lives, but he canna get out in the middle of the night, silly old fool, nay understanding whatsoever. Sadly me dad got cancer of the bowel erm and then he started getting quite aggressive towards me mum for the simple fact, locking doors and doing all things like that you know em so he got sectioned and then they were a bit and then they were going to take him home again, but he was nay better than he was, mam had nay more understanding than she did so the cycle would have just, at the door again, me mam would have locked the door, there would have been another incident and he could've hurt me mum and me mum never, and she couldn't understand, let him go, you know, just let him go, let him do this, let him do that, just let him go erm you know he'd want to go out the back door in the garden when it was snowing, you know and she went silly fool now wants to go and do the garden and it's full of snow, and I'm just let him go out.

And Annie follows:

*I followed a lady, she'd followed a relative out of here they said to me she's gone, she won't come back, she's right down there so I said let me go, so I followed that lady for four hours, for four hours, she had me right down HR, right down TDR, E, (*local landmarks*), she had me everywhere and all I done was follow her to keep her safe or anything.*

In the telling Annie doesn't connect this event with her own experience, suggesting that at a conscious level she remains unaware of a deeper unconscious connection and processing of her own loss.

4:1.11 Battlegrounds and Sites of Confusion

Annie's narrative reveals a number of potential or actual battlegrounds and sites of confusion. These often involve the boundary between the care home and other services and Annie takes on the role of warrior and defender on behalf of her staff and residents:

You don't suddenly give up on them, you, you and I'll row with medical professionals and anybody else because I be, just get so frustrated.

My staff would'na have done that, have challenged the doctor, that's the issue I have here and it's like they think the doctor's God, well I'm sorry the doctors are not, and I don't hesitate to complain if I'm not happy I will complain because I think if I don't, if we don't stick up for residents, who will?

You know you do get some crap homes I've no doubt, but sometimes it's no the care home's fault, sometimes it's the leadership, you know, I get, in some homes I go to and they don't stick up (pause) for residents, I get frustrated sometimes about how relatives speak to staff, I'll not have relatives speak to me staff, do you know, if they come here they do a good job, and I'll no let them speak to them, I'll pull them up and stuff like that, I say if you've got any issues you come and talk to me, that's what I get paid for, but you don't swear at them, they don't swear at you I don't expect you to swear at them so.

Sites of confusion include the status of DNRs between hospital and care homes:

Folk think that because they've got a DNR and they go and fracture their hip we shouldn't be sending them off to hospital, yet it's, it's, it's, crazy you know and yet some think the DNR stops the minute they come out of the ambulance, you know when they come here and then you get others saying we need to get another one, nobody knows what they are doing.

The need for DoLS and the paperwork and time involved in arranging them:

I don't know but I just think it's getting beyond a joke now you know and (hesitates briefly) particularly that at end of life care you need a DoLS, people are going to start dying in hospital again.

As well as problems that can arise if a resident dies before being identified as being at the end of life by a GP:

We knew it was gonna come to end of life, no put them on end of life until they stop eating and stuff, things like that, and they were taking sips, this and that, got the GP and he said it's gonna come you know but she's no quite at that stage, it's a matter of TLC, okay erm, this lady deteriorated quite rapidly and died, emergency care practitioners came in because she wasna on end of life they rung the police, the police came and it was classed as a sudden death.

The CQC implications of being in red because of the number of deaths within the home:

I don't understand it, how can I be, are you calling me a murderer, of course not I, I went what do you want me to do when I'm in a red for deaths, send them off to hospital so that they die there, so they're no classed as a Hilltop House death?

I sat and laughed and thought well I just don't know how to, to me I should have been in the green, 'cos there was more people dying at home, where they want, crazy, (pause) so you're fighting battles all the time, it's like you go to (local hospice), you do all this training, it's good the training that you're given but they don't know all these little bits.

Annie stresses her priorities:

I want to deal with residents and no more paper work, it's just ridiculous, which takes me away from residents and people on end of life, so now if someone's on end of life care or that I've got to set up a DoLS whereas to me the important thing is to care for that person in bed and make them happy.

4:1.12 Reflective Summary

My initial relief at being accepted and Annie's need to convey as much as possible about her experience and the challenges she faces on behalf of her residents, combine to produce an interview that spreads across the best part of a day. Annie's narrative seems at times particularly unstructured and chaotic, and I find the interview an intense and by the end exhausting and somewhat disorientating experience. In retrospect I understand that Annie allowed me glimpses of her inner life and the inner world of the care home. At one point in the middle of Annie's narrative I am taken through the doors and given a tour of the home, including glimpses of residents and staff. In being unavailable for a

second visit I also feel that she was maintaining her personal and professional defences by resisting my attempt to make a deeper connection.

Annie has been a carer and manager in what is essentially the same care home for thirty-three years and has come to inhabit her role in a particular and unique way. As manager of a relatively large care home, primarily providing care for those living with dementia, Annie has become a fierce advocate for the rights of her residents and defender of others who work there. At the same time Annie has been close to and contains within her (embodies) deeply personal experiences of dementia and caring at the end of life. Whilst Annie's assumed role as defender gives her actions and approach something of a heroic quality, I have a sense that some of Annie's professionally focused anger and frustration consists of missiles of unprocessed psychic pain and distress, disguised and often used to some good effect and as reparation in the service of her residents and carers (see 3:11 re extent of this).

As noted earlier Annie's narrative is dominated by her years of experience of caring for residents with dementia. It has been particularly difficult to distinguish extracts that relate specifically to end of life care from those that are more about living with and caring for those with dementia. Significant in this merging is the understanding of dementia as a life-limiting or terminal condition. The length of time that someone may live with the condition is difficult to determine, whereas the guidance around end of life care makes it necessary for a decision to be made about the period that constitutes the end of someone's life. I am reminded of the words of Andrew Cooper:

> *Emotional responses to tragic and disturbing events may be individually and*
> *socially 'legible' but equally they may not, evoking our most primitive anxieties*
> *and panicky inchoate social impulses to defend ourselves.*
>
> (Cooper, p, 180)

The emotional demands of being a manager in such circumstances are hard to quantify and yet crucial to think about. For example, in responding to the needs of the resident in the incident where a carer receives a karate chop and collapses, Annie seems somehow detached and cut off from the needs of the carer and this is reflected in her detachment from her own emotional experience. It is clear that there are potentially unthinkable and

unbearable aspects of the work and whilst opportunities are available to think about residents, similar opportunities are less available for staff.

I remain curious about my own sense of disorientation following the interview. Setting off on a train journey that evening I discovered that I had unconsciously placed my handbag from the day, containing my train ticket, in a cupboard at home. I felt at the time as if I had, if only briefly, lost my mind, and only later recognised that a lack of opportunity to process the experience of being in close contact with Annie's mind and the subject of dementia had disturbed my own.

4.2   Josie - Noble Spirit

These are conditions of our existence which we cannot change. What we can do is adopt a noble spirit, such a spirit as befits a good person, so that we may bear up bravely under all that fortune sends us and bring our wills into tune with nature's.

(Letters from a Stoic, Seneca, 65 AD)

4:2.1   Getting Started

This is the first of the two interviews completed at Rainbow's End. Josie has chosen to be interviewed before Margaret although I meet with them both to discuss how we will proceed. A room that is usually an extra sitting room for residents has been made available for the occasion. Once the interview is underway our time together is uninterrupted and the room provides a confidential and relaxing atmosphere. The room is long and thin and we choose to sit at the end furthest away from the door and close to the window. Our chairs are positioned at a slight angle and with a comfortable amount of space in between.

Josie appears to be confident and clear about the purpose and focus of the interview. Josie's confidence prompts me to take up an equally confident role as interviewer (although I feel comfortable expressing my anxieties and lack of experience in using the voice recorder). Having assumed a level of professional competence I quickly realise that I feel comfortable in the role and, although I have no script as such, confident about my intentions and choice of free narrative approach.

Josie begins by introducing herself and explaining that she has been at Rainbow's End for about eighteen years. Prior to this she worked as a painter and decorator and laughs as she remarks on her change of direction. When Josie is looking for work a friend tells her about a job at Rainbow's End. Josie begins by working night shifts and fairly quickly experiences her first death.

4:2.2   Becoming a Carer/Caring at the end of life

In Josie's narrative becoming a carer and caring at the end of life are almost simultaneous experiences. An early and unexpected end of life experience has a significant impact on Josie:

So my first experience of death was a gentlemen that as far as I knew had a urine infection, I was just covering one afternoon shift and he was sat in the lounge quite okay and I'd gone to get him his pudding and I went in the kitchen and came back and he'd actually passed away in the chair in the middle of a lounge full of people across the teatime so and that was quite shocking to be honest there was only sort of like two of us on and with it being quite a small home so we had to put him in a wheelchair and take him down to his room. I'd just finished my period that day to be honest and I was that shocked I came on for another week after that.

Josie's narrative gives a strong sense of her developing experience of caring at the end of life and of the external changes that have meant that more residents are cared for at Rainbow's End until the end of life.

Yeah going from painting and decorating that was my first experience ever so I didn't expect them to sort of like to groan when the air came out or anything like that so yeah it was quite shocking but yeah I had a little cry (laughs) and things like that but yeah it was dealt with quite well and since then well we've had, I've become quite an expert to be honest, we usually have about three people pass away a year on average you know, it always seems to be you know if you look in our death book it always seems to be in, in like little sort of bursts of sort of like maybe two expected and one unexpected and then there won't be any for the rest of the year, it always seems to be in threes, I don't know why it's just amazing I have, must have had about forty deaths in the past eighteen years that I've actually been there for and dealt with so there's been all different types.

When I first started and the doctor came out if someone wasn't very well and said I think they're at end of life, when I first started they used to say take them into hospital but now even the doctors will sort of like say d'you know there's nothing the hospital can do they'd probably be more, get more infections in the hospital do you know and

they've been sort of like helping us to be fair to sort of like make sure that everything's here.

We always make sure the window's open and we never cover anyone up who's passed away because none of us like that we always the first thing we do (coughs) excuse me is make sure the window's open and we always say it's so that the spirit can pass and I don't know I think a lot of homes tend to do that I don't know it might just be us.

Towards the end of the interview Josie reflects more on becoming a carer:

I wouldn't even have thought that I would have done that seventeen like eighteen years ago being a painter and decorator I didn't have no patience the thought of even seeing somebody else's pooh ugh even my mum and dad said I can't believe that I mean they'd said to me if you don't hurry up and get a job we're going to kick you out and I'd literally gone from painting and decorating, worked in a fish house for two weeks over Easter and I'd gone on to spraying pub furniture and sort of like fireplaces and things and then my friend rang and said "we've got a job on nights" and they'd sort of like sort of like looked at my reference and she the owner had said "oh I see you used to be a painter and decorator do you fancy doing a couple of nights and starting to decorate the home" you know and I think that's initially why they took me on and then I started working nights and then I gradually went on to days and then em just started loving the job yeah I mean you don't do caring for the pay 'cos it's crap int it to be fair so yeah summat in me changed I wish to be fair.

I don't know what changed it was just getting to know the elderly falling in love with my job (falling in love with the elderly!) and more training, the more stuff I did the more you had different insight into things and a combination of everything really yeah now I'll probably retire and go straight into a discounted room here I couldn't even imagine going to another home to be honest not at all (pause) no so yeah I love it (laughs).

4:2.3   Home

We have twenty when we're full. We're registered for twenty, it's a nice number to be fair, as I say we are one of the smaller ones in (name of town) so (pause) yeah you know it's quite a nice number to be fair everyone's like your grandma or granddad and the residents have been here for quite a long time and if they come for short stays then they do tend to stay to be fair unless they go back home.

Because it's small I like to think it's a lot more personal and you just treat everyone as if they're your grandma or granddad and always think would you want somebody doing that to yours you hear all these sort of like stories about other care homes and things like that and I know some of them in (name of town) are really big they've got like fifty beds some of em you know it's like they probably don't even remember half the names do you know like so I think ours is a lot better being smaller to be fair definitely yeah (pause) yeah I think the care's better as well yeah I do (laughs) I mean it might not be but I do like to think that the care is a lot better in a smaller home 'cos it's more sort of like personal we've got to know the residents more personally rather than them just being sort of like somebody filling a room do you know yeah (laughs).

4:2.4   Emotion

Josie's narrative is rich with emotion and there is a quality to her account that suggests she has developed a capacity to process her emotional experience in a pragmatic/stoical kind of way. It includes her description of the psychosomatic shock resulting from her first end of life experience:

I can still remember the way that his head fell back and looked at me now yeah it's not something you get out of your head especially like a sudden one or a not very nice one.

The distress and guilt provoked by a failed attempt at resuscitation:

Unfortunately, we didn't manage to bring her back and I'd gone and broke a rib which freaked me out at the time.

And the sense of satisfaction prompted by 'a good death':

She'd actually passed away with her daughter just on like a one to one and her daughter had come downstairs and said I think my mum's gone and that was really nice because er because she wanted her family there and things.

Josie also recalls getting into trouble with a GP, before she really knew what to do when a death occurred, for telling a family that their relative had died before the death was officially declared. Josie says she will never forget this.

The sudden ones aren't nice but we don't get them very often I know some of the older girls that have been here longer than me one of them experienced an internal bleed and that wasn't very nice, she's, she's yeah, she didn't I think that put her off you know caring she found that really difficult but I think I don't know it's (pause) if you can't have a laugh about it d'you know and a joke afterwards just to sort of like lighten the mood then it just makes you think doesn't it and once you start thinking about it, it, I think it affects you.

Josie's use of humour as a way of coping is evident throughout, suggesting that this is an established approach contributing to her apparent resilience.

The satisfaction of knowing that anybody that comes into a care home it is sort of probably the last place they'll ever live and they come in here and obviously they don't leave until they've passed away really and I do get satisfaction from knowing in their last few years or months of their life have been sort of like happy pain free d'you know and its things like that well I don't know surely anybody would (pause) yeah I do get satisfaction if I know that personally I've given them a good sort of like comfortable pain free death in line with sort of like what they wanted then I'm happy at that and I'll sort of make sure that they all get it if I can.

4:2.5   Difficult Conversations

And then we did the course and it was like how are we going to sit down and ask the residents them questions do you know and I mean you can't just say like right today I want to talk about you know, you've got to pick your moment because you know like everyone's different and I mean even planning the care plan, I mean we had one relative one day any plans about end of life and she didn't want to talk about it and she

couldn't even bear to think of her mum discussing her death do you know she didn't want to give anything away it upset her just that question, I had to actually write in it "unable to discuss this" as the family was quite upset and then as it turned out that lady we just sort of started up the conversation and she sort of like was becoming like more forthcoming you know I want this and I want that and we was just like jotting it down but yeah I think the residents are easier to talk to than the relatives.

With the residents it's just about picking the right time you know and things like that and I think sometimes saying that somebody's passed away recently or talking about somebody being ill they sort of like come forward then and say "do you know when I'm ill" or "when I'm passing away" they want to do this or that yeah they was really approachable and I can see why it's better to do it as soon as they come and before their memory starts fading I can imagine that being quite difficult for the relatives. We've had one lady that actually lost her daughter, they'd done this advanced care plan and she'd lost her daughter and it was her son-in-law that was having to deal with everything and he didn't really know as much about it/his mother-in-law as obviously his wife did but he come to us and said did she say any songs or say anything specific about what she wanted to do and things like that yeah.

4:2.6   Supporting Families

So you get some relatives who want to be here all the time and then others that don't want to be you know they say just ring me when it's over because I want to remember my mum or dad how they were d'you know, not wanting to see them suffer like that so yeah (laughs).

4:2.7   Supporting Staff

We tend to talk about it to our friends I mean being a manager if somebody has sort of like passed away I do discuss it with the staff but then nobody's ever come to me and said you know I'm finding it real hard can I talk about it, do you know they just tend to get on with it and talk about it sort of like between us 'cos we're all quite friendly out of work as well so I think that helps, d'you know you can just sort of like say oh I remember when so and so yeah or if they've got any questions I think that's I don't know.

K: You mean if staff have got questions…

V: Yeah I mean they'll say it personally I mean not as a manager.

It may be that for some, as described below, this informal approach is not enough:

I mean we have had a girl what's just left and she actually complained to CQC and she said that the em that when residents are at end of life she thinks it sort of like thinks that it can be classed as neglect, and the CQC had wrote to us and said we've had this information of concern and we want you to look into it.

And you know they wrote back to us and said your investigation (information!) was fine and they've got no concerns but being inexperienced and young it might be seen as being neglectful.

I mean if she'd come to us and said d'you know why aren't you feeding him? You know things like that we might have been able to answer some questions without her sort of like thinking and 'cos she hadn't done her end of life she was quite sort of like new so she must of found that quite difficult to watch when it just looks as if someone is wasting away in front of your eyes yeah (pause) but where training comes.

4:2.8   A Good Death

I do enjoy it to be honest and since the course at (local hospice) obviously I know when somebody has had a good death or a bad death, which is sort of like not an expression I'd have known before.

Over the past two years really we've had sort of like ninety per cent of residents pass away here that have had the hospital beds, they've been given the right pain relief, we have the district nurses coming in every day so they've had good deaths, we haven't really had anybody that's…unless it's been sudden.

4:2.9   Boundaries

I see these residents more than I ever saw my grandparents and I do feel guilty about that 'cos I was like always at work always, I mean even when I went on maternity leave I couldn't find anybody to take over as manager so I had four weeks maternity leave and then I came straight back to work so the residents that we've got have seen my son grow up and I mean he's nearly ten now, so yeah summat changed in me and I've become a lot more sort of compassionate and caring and then I think having my son, that made me rethink about my grandparents 'cos obviously if it want for them I wouldn't of sort of like be here and you know just sort of like over the years things changed have I do wish that I'd spent more time with my grandparents, and it makes me mad d'you know when some of the relatives don't come and see theirs and it's like they only come maybe once every six or eight weeks something like that and I was probably as bad to be fair.

My mum's got all that what type of funeral, my mum's got all my details. I'm a single mum you see so my sisters are married and they've got husbands then I've already told mum that just from going to resident's funerals that I want a humanist funeral mum and I don't want this and I don't want that because I didn't have a partner at the time, she's actually got it all written in case anything happens (laughs) so like even my thoughts on funerals that we attend even that's changed like changed my thoughts on what I actually want you know so I can see why they don't want peg feeding.

4:2.10 Systems of Care

There's been a number to be fair where they've been into hospital for two or three weeks where we've myself and Margaret we've actually rang our-self, there's been a number to be fair and said look if there's nothing more to be done for this person can you please let him come home to us you know until it's time for them to sort of like pass on, and sometimes it's worked and we've managed to get them back and other times they've said they're too poorly to move and then we've felt guilty at them passing away in the hospital do you know when really if the doctor sort of like had of, it er tends to be the locum doctors more that don't really know the home or know us, so if it's on a weekend or a night and it's sometimes as if they can't be bothered and it's like oh yeah we'll send them in do you know, whereas others if it's your own GP that knows the

resident and knows us then they'll say there's not much we can do but obviously and just TLC and they'll go they can stay here and I'll go and put the just in case kit and things into place.

Josie describes an occasion when an ambulance is called because of concerns about a longstanding resident and considerable efforts have to be made by the care home to ensure that necessary paperwork is found in order to prevent an unwanted, by all concerned, admission to hospital. This end of life story is told in full in Chapter Seven.

4:2.11 Reflective Summary

Josie's familiarity with death and the end of life has grown through her experiences of caring within the home, moving from physical and emotional shock to the capacity to be present and attentive to the needs of a particular resident (see example in Chapter Seven) at the end of his life. The end of life stories included in Josie's narrative reflect the complex range of factors involved in achieving what might be considered a good death, including the impact of wider systems of care. In addition Josie's narrative contains a number of examples of the subtle and complex skills involved in the task of caring at the end of life, including responding to the needs of families and other carers.

My experience of Josie as a manager and carer is of someone who, having found herself taking up the role through a combination of fate and circumstance, has found a place to grow emotionally and make use of life skills acquired elsewhere. During the interview I found myself reassured by her presence, recognising that she embodies a stoical approach allowing her to cope even when under pressure. Although Josie is employed by the owner of the care home it seems that her sense of authority in her role is an internal one, enabling her to manage the primary tasks of the care home with a firm sense of her own efficacy.

Possible unconscious responses to the anxiety provoked by such close proximity to death in this relatively small care home include the system of informal support for staff, that appears to have grown organically but in a way that has perhaps come to represent something of a closed system. Opportunities for processing some of the more difficult and unthinkable aspects of caring at the end of life seem limited and for those less stoical perhaps unbearable, as in the case of the young girl who leaves and then makes a complaint to the CQC. Another potentially defensive practice involves doing paperwork when sitting with a resident who is nearing the end of life. It may be that this makes the

end of life something mundane and more bearable or is simply a practical way of passing the time. Either way, thinking about its function and meaning will ensure it is not used as a distraction from the needs of the dying person.

4:3   Doreen – At Home

To go back to the house metaphor, Bion's model tells us why we need to rest in our maternal home before we can have our own.

(Di Ceglie, in Budd and Rusbridger, 2005, p, 103)

This interview takes place in the care home where Doreen is manager, during a typically busy morning. One of the bedrooms has been made available for the interview and Doreen explains that the last occupier of the room died recently. We sit at one end of the room by a window in chairs that are placed to create a sense of intimacy yet offering an appropriate degree of personal space. Doreen requires the lightest of prompts to begin speaking and this continues throughout the interview. I have a sense of entering an inner sanctum and of the choice of setting being a way of making sure that I am a safe person to speak to about the end of life (a trustworthy/substantial/non-leaky container). As the interview progresses I feel that I have managed to pass the test. The interview is summarised under the broad headings of emerging themes. I reflect on transference and countertransference between interviewer and interviewee and include my emotional responses to the data.

4:3.1   Getting Started

Doreen is keen to tell me about a recent incident involving a contested DNR form in place for a resident who is taken to hospital and subsequently dies after being resuscitated. Doreen explains that her concern is both professional and personal as her Gran is a resident in the home and also has a signed DNR form. Doreen has reported the incident to the safeguarding team. The issue is about whether or not the forms are the right colour even though many doctors' surgeries do not have colour printers and so are using black and white forms as the supply of coloured forms runs out.

Doreen is concerned that residents and other individuals who think they have clearly stated their wishes will have these wishes disregarded because the form is not the right colour. Another issue is that the decision seems to be considered a clinical one if a resident is admitted to hospital and can be made by the doctor on duty once the patient has been observed for a minimum of twelve hours. Doreen goes on to explain that the doctor of another resident with a long-term condition had said that the GP can make the DNR decision without the resident's consent. Doreen is concerned about this interpretation and feels that wherever possible significant others should be consulted when an individual lacks capacity and that it shouldn't just be a clinical decision, because of the possible impact on those concerned.

Interviewer Response

I know immediately that this issue remains close to the surface for me. When my mother was reaching the end of her life I had experienced what I perceived as a particularly inept and insensitive DNR discussion with a hospital registrar who informed me that she could go off at any time. I make a conscious effort to remain focused on the interview and the data emerging rather than becoming preoccupied by my own thoughts/feelings about DNR s (see fig 4 in Chapter Three). My own defended behaviour at the time meant that I failed to ask whether or not she would be resuscitated or whose decision this would be.

The importance of taking family/loved ones into consideration is a theme throughout the interview, as is the way in which care is extended to them at the end of a resident's life. It connects strongly with the holding/managing of personal/professional dimensions of care that are central to this interview.

4:3.2   Becoming a Carer/Manager

Doreen has been at Sea View since 1991 beginning on a YTS and becoming a deputy manager after six months. Following a seven-year move to another home (same owner at the time) she returned to Sea View in 2006 as the manager. Asked to say more about starting out as a carer, Doreen describes herself as not doing very well at school with grades but always being able to speak to people. During a first job selling fruit and vegetables before starting college, Doreen found that she loved the elderly customers

who kept bringing her hot soup because of the cold. Following a visit to the careers office she is interviewed by the manager of a care home where she has played with her brass band the previous day, and is accepted for the scheme:

I explained to the manager that I had actually it was me I'd come yesterday in the brass band and I just got it, I did a YTS, I absolutely loved it.

Doreen's youthful enthusiasm shines out here full of anticipation and warmth and she goes onto say:

I'm not a typical manager I don't think.

4:3.3   Caring at the End of Life

Throughout the course of the interview the accumulated extent of Doreen's experience of caring at the end of life becomes evident. Doreen puts her current approach to end of life down to an interweaving of age and experience and explains that as a younger person she found caring at the end of life quite difficult:

It is part of it I found it quite difficult when I was younger because I thought I don't know whether I can do this you know somebody passing away, but I look at it differently now because instead of erm looking like oh somebody's passed away and it's awful 'cos they've passed away that was probably me younger experience, now it's like I want to make sure that it's a blessing if somebody passes away that we give them the best that we can so you try and look at it as more of a positive.

Doreen makes it clear that she considers care at the end of life significant and different to everyday care giving:

End of life is something very different and needs to be special I think and you need to have the all the dedication, everything comes out of you, everything to make sure the person's looked after to the best of your ability and that everybody's supported within that as well.

The extent of what can be done to support families, and the significance of the end of life within the context of a whole life lived is captured as Doreen describes the care offered to the family of an older man with dementia who becomes agitated towards the end of life, triggering traumatic memories for him and his adult children:

I spent a lot of time talking with them about their childhood and erm letting them speak, letting them get their emotions out about what had happened and how was they feeling now and hopefully they understood that their father isn't probably aware of what's happening now, he'd always been a gentleman apparently that hit out and was a drinker and when he'd come home there was a lot of sort of like hitting and domestic shouting swearing, and when the gentleman was at end of life and was er quite verbal and shouting things like he had done when they was younger and they found it quite difficult.

Doreen is able to intervene when she feels that the level of distress may be too hard for his daughter to bear, suggesting that she takes a break before working together with another experienced colleague to settle the resident. Doreen also spends time with his son giving him time to speak about his father and their family history.

The impact of the end of life care agenda can be seen as Doreen reflects on what has changed over the years:

I wouldn't say we do more caring at the end of life because even when I worked at the Cedars erm there's always been that element of care.

Doreen has a strong sense of what is required to provide sensitively attuned care:

It's only experience and maybe knowing the person as much as possible, say like you had an agency staff come in and erm they was with the person, they don't know the person, erm they don't know their erm anything as such about them, I wouldn't like that for my clients, I wouldn't want agency staff coming in it's got to be our own who are there always and giving them the time and space.

As I say you have to deal with things as they happen and hope that your experience means you do the right thing really.

4:3.4   End of Life Narratives

Erm end of life experiences em is they're all different they're, all it just sort of like erm depends on how the clients are.

Doreen's narrative includes a number of the end of life experiences of specific residents. They range from residents who have chosen to be admitted to hospital as their health deteriorates, to those who have been cared for in the care home where multidisciplinary working has ensured a 'good death', those where Doreen has taken a significant role supporting relatives whilst ensuring the dying person's emotional wellbeing and one in particular where Doreen is with a resident as he dies. He is a man who has no relatives and has lived in the care home for a number of years. Some narratives emphasise the importance of working closely with other health care professionals to make sure that end of life care needs are met effectively. Others involve Doreen working within her professional role to avoid/avert a breakdown in the system of care (see Chapter Seven).

4:3.5   Emotion

Doreen describes herself as a very emotional person who loves her job and who has found it difficult to manage work/home boundaries at times, having to learn from experience that it's simply not possible to do it all. Doreen places emotion at the heart of what it means to be a carer and remembers being told by a deputy manager years ago that she wouldn't get very far because she is 'too emotional' and 'too emotionally attached':

I said I don't think we can do the job without emotionally giving all that we give erm I don't know I think I will do okay in me lifetime I didn't know then but yeah you have to be emotionally attached sometimes erm because that's who we are we care, we're in the job to care about people and I think that if I shed a tear I'm not weak in any way, I'm just showing my emotion.

Speaking about the end of life of a particular resident Doreen's narrative follows an emotional trajectory, with the emotional impact on Doreen and other carers involved

becoming conflated and muddled together, conveying a sense of the painful and uncontained feelings of those concerned. For Doreen:

Well because I felt that maybe something more could have been done certainly for the last half an hour of this lady's life it sort of, sort of like stayed with me but yeah it's very emotional erm you know er I think I said I said to somebody else I think it was about three days after when I got to sleep at night time.

And for others involved with the same resident:

Sometimes the carers find it difficult erm I had a lady that's maybe a couple of years ago now erm and the girls found it quite difficult.

Doreen has gone in to support the carer but finds herself overwhelmed with emotion:

At the time the carers that was on supported me in a way because they said are you okay and I called the ECP and district nurses did come.

When the district nurses and emergency care practitioner arrive Doreen offers an explanation for her reaction:

I knew them and they said are you ok and I said I don't know why I've just been overcome with emotion I think we've looked after this lady for such a long time, she's part of our family.

Doreen is clear about the place of emotion in a caring setting and articulates this with clarity and conviction:

To be emotionally attached is not a weakness, I think it's a strength because we support people with their emotions, what they're going through as well and I've shed a few tears with relatives and even with my proprietor.

Later and speaking about supporting staff:

Yeah I mean I think there would always be a supervisor in charge anyway within a care home I mean we're on call for our night staff and my night staff have been here over

five, ten years some of them so and anything that we do we, even at staff meetings we discuss if they've got any concerns we do it just on a erm like this morning just speaking with a carer we say "everything all right, how are you feeling" you know "just talk me through it", okay "are you quite happy with that?"

4:3.6   Home

More than in any of the other interviews there is a sense of the traditional (modern) boundaries between home and work blurring and at times dissolving completely. There is a sense of permanence and stability and the care home becoming a kind of second home, or simply a second home with the capacity to accommodate family members as required:

Even though it's not my home, I don't own it I do in a way because it's my home, it is what I and the staff have built up to be as homely as possible, home from home.

It seems that Doreen carries a blueprint of home in her heart and mind. She has also brought home in to the care home. Her father works in the home and her grandmother (Nan) lives there. A sense of homeliness and intimacy pervades the interview and it becomes apparent that it has enabled Doreen to create a containing space capable of holding and sustaining others:

I always said when you're looking after somebody always think what would you want for your Nana and Granddad, what would you want for your mother and your father, if it's not like that when you're delivering the care you always strive for better and if you think like that you won't go far wrong.

4:3.7   Boundaries

The idea of firm boundaries becomes questionable and more than a little suspicious, making it seem as if connections have been denied through the emphasising and enforcing of notions of separateness and separation. The boundaries between professional and personal, home and work, employer and employee, experienced and inexperienced blur, merge and dissolve at times without catastrophic effect and often creating opportunities for emotional connection:

I've shed a few tears with relatives and even with my proprietor erm I looked after his mum erm at The Cedars where she lived, she was 101 and erm she passed away and erm I had to tell the proprietor that his mum had passed away.

The interview reveals much about the way that Doreen's approach to end of life care has been informed by personal as well as professional experience. Again Doreen's blueprint for supporting others at the end of life is at least in part drawn from being with her grandfather, as he is cared for at the end of his life in a local hospice.

4:3.8 History and Context

There is a growing recognition of the need for history taking in getting to know as much as possible about each resident, something that Doreen emphasises earlier in the interview. This provides a context for the care that is offered including care given at the end of life:

When we go to people's funerals we learn all this information about them whereas we should try and gather that and have that information, so two of our girls went on a course with the local authority and they're just starting now to try and gather as much information on people or when people can tell themselves about everything and then just put that down, so that if that person does get dementia and they can't remember then we can just trigger off their memories or something because we've got that information to start with.

4:3.9 Denial

Just how difficult it can be to have the kind of conversations that might determine how a life ends becomes apparent as Doreen continues:

And then erm also within that is end of life, if they, if people, clients sometimes find it very difficult to discuss, some absolutely know what they want and we have a, I want this and I want it and they're, and some people find it really difficult, even the relatives find it really difficult discussing it because they don't want to believe that they're going to pass away.

4:3.10 Systems of Care

The significant contribution that care homes can and do make to the wider systems of care for those at the end of life are evident in Doreen's narrative, as is a clear sense of what is required to ensure effectiveness and sustainability:

I would think I would hope that in care homes everywhere erm you would always have your experienced carers, managers, supervisors that erm you know, do what we do and make sure that district nurses and people are all involved erm I think by the forums and listening to getting the minutes from the meeting I can speak to managers when I've done training courses and things like that, I think there's things that do go wrong erm but I've been fortunate enough that nothing, that if something has happened we've been able to rectify whatever that is at the time and on the day like with this medication, you know going and getting a GP, you know it was an hour and a half but the situation was sorted erm.

4:3.11 Professional Relationships

The essential nature of building good relationships with GPs and DNs is a theme throughout and is a feature of the longstanding stability created by continuity. Doreen says that she has been 'lucky' as most people have died with dignity and respect. The interview reveals the subtle, fluid and responsive nature of individually attuned care as professionals work together through relationships supported by close contact and communication, rather than driven by guidelines and procedures:

You have to make decisions, I'll always ring up the district nurses and just let them know what's going on and keep them informed and I did with the doctor as well, just to make sure they was fully aware of what was going on as well erm so you're all working together really, yeah.

4:3.12 Reflective Summary

Entering Doreen's world and being in a position to listen to her experiences of end of life care is a profound and at times, deeply emotional experience. As an interview it reveals so much about the qualities required to be the kind of person who can care at the end of life, and not only care as an individual but also support others to do the same. The interview captures the complexity involved in being a carer and part of the professional system of care. Doreen demonstrates commitment, learning from experience, a strong and fundamentally 'good' internal model of home, and the capacity to reflect in action.

For Doreen caring at the end of life is not new. It is something that she has learned about through her experience of working as a carer over a period of twenty-seven years. Her familiarity with the end of life means she is less defended than I might have supposed although defences are evident, particularly as Doreen discusses her Nan, who has become a resident, and the death of a resident who has lived in the home for some time, and whom Doreen feels has died with some degree of pain/distress. Detectable defences are subtle and depressive, focusing on the possibility of something to be done rather than contemplating whether or not doing something is better than doing nothing, or perhaps more accurately something that might look like not enough. Examples of this can be found in the end of life stories presented and discussed in the next chapter.

The defences evidenced here are part of a social system that has developed to protect all concerned from the anxiety of facing dying/the end of life empty handed (defenceless), and with little to offer other than self and what has in the past been referred to as TLC. Rather than voicing concerns about what it might mean to a resident to be taken to hospital in an ambulance, to then be left waiting in a corridor for hours before dying in an unfamiliar place in the presence of strangers, Doreen and other carers seem powerless to resist the 'big other', in this case the NHS, taking over in an unthinking, demanding compliance, kind of way.

I am left thinking that this is a perfect example of the master being usurped by his emissary (MacGilchrist, 2009). I am also left thinking about the blurring of boundaries that perhaps isn't really blurring at all. I wonder if this could happen to Doreen's nan in the absence of one individual with the strength and passion required to resist enough to

prevent an inappropriate admission. This is not a criticism but a question about what might be necessary to ensure that appropriate attention/consideration is given to every case/resident.

For those cared for at the end of life within the home the quality of care available extends to encompass the most intimate of physical needs, from the mouth swabbing that is understood to be such an essential part of care for the dying person, to the emotional support that can facilitate the grieving process for those left behind.

To quote Dartington:

> *The care relationship - no doubt destructive when it goes wrong in a certain*
> *number of well documented cases - is remarkable for its empathetic robustness*
> *and persistence against the odds, and this is not so well documented.*
>
> (2010, p. 148)

4:4 Chapter Summary

The case studies presented represent three unique individuals who have experience of, and a commitment to, providing end of life care within a homely, generalist, care home setting. Whilst the strategy has made it more possible for them to continue to do what they would prefer to do and often have done for residents at the end of life, it seems that each contain within them a deep understanding of the value of this for residents, families and carers that goes beyond strategy and government expectations.

5 Chapter Five - Champions

5:1 Margaret – Brave Heart

Individuals vary in the extent to which they are able, as they grow older, to modify or abandon their early defence mechanisms and develop other methods of dealing with their anxieties.

(Menzies Lyth, 1988 p. 64)

5:1.1 The Interview

This is the second interview completed at Rainbow's End and the second in the series of interviews. It takes place in the care home where Margaret is a senior worker and a champion for end of life care and in the same room as the interview I have just completed with Josie (see Chapter Four). Margaret has already waved from the window of the kitchen as I arrive for the interview. A little uncertain after taking a while to find the home, this filled me with a sense of being waited for with eager anticipation as well as some anxiety. Of all the interviewees Margaret is perhaps the least confident about the relevance of what she might be able to tell me yet still willing to be interviewed. An expressed fear is that her colleague and manager, Josie, will have had more to say. I reassure her and explain that my interest is in her experience, emphasising that it is not a test of knowledge. Reassuring her makes me feel the need to appear confident in my own abilities as an interviewer and I calm myself by drawing on my experience and focusing on the purpose of the interview. There is a sense of Margaret finding the opportunity to talk and be listened to therapeutic as well as unnerving (anxiety provoking).

5:1.2 Getting Started

Margaret chooses the beginning of her career as the starting point of her narrative. It is a different home where more residents have dementia, Alzheimer's, behavioural problems. Margaret is seventeen years old and describes it as hard work:

I mean they was quite violent there and d'you know stuff like that and I was only (slight hesitation) my first death I saw I was only 17 cos you could care, at that time, you was allowed to care when you were 17 but you can't now can you em?

There is a sense of Margaret having been exposed to some of the more difficult aspects of what it can mean to be a carer in what is remembered as a harsher environment. Margaret's first experience of the end of life comes when she is sent to check on a resident in their room. She describes her reaction upon realising that they are dead:

I remember going in the room, and I've never seen like a dead body in my life, and I'd gone upstairs to check, 'cos like I was new like, "can you go and check on so and so", and I'd gone upstairs and I'd gone in and I knew straight away 'cos the room felt like empty, do you know like there was someone there but I felt on my own, and my palms was sweating and I was like ohhhhhh (intake of breath) d'you know, and I ran downstairs and I was like I think she's died, and they all went running upstairs and she had done.

Margaret goes on to say that she has never forgotten the name of this person, a woman called M, and never will. After this first death Margaret says that she can't really remember. She leaves this job after two years and comes to work at Rainbow's End in 2002, initially as a carer but then as a senior. It is at this point that a number of sudden deaths occur in succession. Margaret describes these deaths as nice and peaceful and says that she likes the palliative care side of her work. She also says that she wouldn't like to work in a nursing home because there is not so much interaction. She likes being able to take residents out and do stuff with them.

Margaret describes Rainbow's End as a 'genuinely nice place' and says that she loves working there, that a colleague's mother-in-law died in the home, and that although at one point she did get fed up and go back to the previous home she returned because it was a hard job there and mentally draining. Later Margaret talks about the violence at The Grange and remembers being hit in the stomach by a male resident, but makes it clear that she considers this to be because she approached him without adequate preparation.

5.1:3 Becoming a Carer

My mum said when I said I've got a job as a carer she said, "you can't even wipe your own arse never mind anybody else's you'll last five minutes" that's what she said, that's right.

You just do, 'cos you go on so many courses and you, you've it's life experience innit, what you know and what you've seen over the years. It's like I've been a carer since I was seventeen, I'm thirty-four d'you know I've seen a lot of things throughout the years, do you know I know my job, I'm not saying I'm the best carer in the world but I know my job and I know what I'm doing and I love my job so, and for some and so an eighteen year old girl who's never seen anything like that, it looks different, some things do from what I see to what they see, 'cos they don't understand 'cos they're just young themselves aren't they cos they don't, they don't know (pause)really.

5:1.4 Caring at the End of Life

Margaret speaks about the most recent death at Rainbow's End, describing the man who died as a favourite although she says she knows that she shouldn't have favourites. She describes a man with no family who has a septic leg ulcer who requires TLC (tender loving care) because there is nothing more that can be done for him. He has been prescribed Oramorph (liquid morphine) and Margaret knows that he doesn't have long because:

You know, 'cos you can tell can't you?

Josie is sitting with the man with Margaret 'popping in'. When Josie pulls the alarm Margaret joins her and they are both with him when he dies five minutes later. Josie is holding his hand and Margaret is stroking his head. Margaret describes it as nice because that's how they like it. Margaret speaks collectively for example 'we don't', before saying that she would hate anybody to die alone and that although you come in to the world on your own, she always likes somebody with them. Margaret goes on to say that although a lot of families like to sit with their relatives, others don't:

But then when you've got people they don't want to sit there because they don't like seeing things like that which some people don't, because they don't d'you know it's not everybody's cup of tea is it?

Margaret goes on to speak about the death of a man with a different religious faith and how strange this seemed when they had to call his church and wait for the minister, who came from another city. After this she says that she can't remember. I gently suggest that Margaret might want to think more about when she first started caring:

K: You might want to talk a bit more about when you first started out and you were in a different kind of setting where it wasn't so peaceful and (pause) you were quite young as well and you know maybe…

Her initial response is to say that she can't remember and I suggest it might be hard to remember. Margaret then begins to talk about how it used to be, including the fact that more deaths took place in hospital. Because of this there have been a lot of deaths at Rainbow's End but not earlier at The Grange. Almost immediately Margaret does remember 'a little lady':

Her family were lovely, we, I really got on with them really well they used to buy birthday presents and everything, and she'd bought me these gold earrings for my birthday, and I was only young and erm, she was (pause) quite poorly at the time, so the decision that I made was to call 999, and they came, they took her, and still to this day I feel so guilty because she died in the ambulance down (name of local road) and if I hadn't of, if I don't know, if I'd maybe done it in a different way, at the time, she'd have died where she should have done in her own home, in her bed, and I still feel bad (emphasised) about that now d'you know, yeah, yeah but I didn't know what I knew back then, so it was sort of like, I don't know, but we always, I don't know, we always like to be with them, always I don't know.

Once remembered this is clearly a significant experience for Margaret and it is apparent that the painful emotions felt at the time surface in the remembering.

Margaret goes on to talk about caring for residents for whom medical intervention has become palliative and the sense of responsibility around the withdrawing of food and drink and medication under the supervision of a GP. Margaret talks about how new staff

can misinterpret this, and why there is a need to offer an explanation. Margaret also talks about the number of residents who have died recently with leg ulcers. She doesn't understand this and describes feeling angry when a resident is in agony and not much seems to be being done about it. This is in contrast to her feelings about a new member of staff who, after leaving, reported Rainbow's End to the CQC. The concerns reported were about the withdrawing of food and drink (not much being done). Margaret's feelings about the person who has left are dominated by anger about how her complaints might impact on the home, rather than empathy for an inexperienced member of staff who may be finding it difficult to cope.

Margaret describes a resident whose husband came to stay with her in the home. His wife has cancer and their daughter decides to move her to a nursing home because they can administer pain relief and Rainbow's End can't (I wonder if it would have been possible for the DN team to administer this in the care home if a request had been made). This means that when she doesn't have long left although he can visit, they can't be together. Margaret goes on to emphasise the importance of pain control in relation to cancer before talking about her mother-in-law, who has recently died from lung cancer. The death takes place in hospital and Margaret describes it as awful. Margaret says that she would have looked after her if she had been able to go home but also says that because she was diabetic this was not possible. Margaret's grandfather also died from lung cancer and Margaret was going to look after him but he too died in hospital. Margaret says that she likes looking after people like that.

When Margaret's mother-in-law (who has lung cancer) tells Margaret that she won't be here (alive) for her birthday Margaret tells her not to worry and that she will see it. Margaret now feels certain that she knew because:

Some people do know they're dying don't they and they say, they say to you I'm going and they know, and it's like and we've had like, in the past, I was freaked out at the time 'cos I was only young but she was a hundred she was in that room there, and she was like laid there, and they sort of reach up to the corner and they look at the corner, you know like when a baby smiles, like when they've got wind, and they're looking up in the corner as if somebody's there waiting for them.

Margaret wonders if there might be something waiting but goes on to say that she is frightened to death of dying herself and that she couldn't do it all the time:

I love doing it but I'm frightened, I hate anything to do with death myself (pause) because it frightens the life out of me, I don't know why but it really does, I'm scared of dying, well everybody is I suppose (pause) but I've got this horrible, oh it just frightens me, I don't know, it's just not, I don't know strange.

Margaret goes on to say that although the peaceful experiences of death at Rainbow's End have made her feel better about dying, it is the thought of leaving her little girl 'and stuff like that' that makes her so frightened of dying. At the same time she describes herself as hardened to it because of the number of times it has happened.

She also gives a sense of the responsibility involved:

There's, that point d'you know where you've got to decide for yourself whether, they should, be having these fluids and stuff like that, and do you that's hard d'you know because you're playing god with somebody's life aren't you, you know it, I don't know, it just seems like I don't know it seems like...

Margaret pauses and is lost for words.

5:1.5 Emotion

Margaret describes always crying in the past when somebody died and says that she still does, especially if it is someone who has been a favourite. Margaret describes herself as becoming hardened to it over the years before saying again that she still cries, particularly when it is someone she has known for a long time and has become like a friend or affects a family that she has become close to. Margaret describes herself as a bit soppy and daft and as someone who gets attached to some people more than others, including other care staff. For Margaret this is just part of what it means to be human.

Later in her narrative Margaret describes a greater openness within the care home when a resident dies, before talking about how difficult it can be to switch off:

You just sort of you go home, you can't just switch off and think, you know if you work like in a supermarket nowt'ed happen bad like that but, you go home and then you're sat there like oh d'you know and that's a hard part of the job.

Margaret says that despite the emotional demands she doesn't want to do anything else and has signed up to do her deputy manager's course. Passing the maths test to get onto the course has been a great personal achievement and Margaret is feeling really proud that she can get started. Margaret explains that it is the closeness of the staff team that makes it possible to cope:

Yeah, you go to Josie for anything yeah and we all talk because we're all real close and we all get on, we don't have a lot of staff change we don't have a changeover of staff, so we keep, if you start here you don't tend to go really and if you do you end up coming back.

5:1.6   Boundaries

Margaret's narrative shifts between her personal and professional experiences of end of life care. These boundaries dissolve as she talks about a number of colleagues whose mothers have died at Rainbow's End. Speaking about how sad it is when someone dies even if it has been the nicest death, Margaret moves seamlessly into describing helping a colleague who is caring for her mother who has cancer, in her daughter's home. Margaret says how hard this must have been and how hard she found it when she went to help for a day. Margaret becomes openly emotional as she remembers that her colleague cared for her mother day and night whilst continuing to care for her two children. Margaret feels this must have been awful.

5:1.7   Home (and not home)

Margaret's contrasting experiences of care and care homes are significant throughout, as is her understanding of the need that she has for a relationship with those she is caring for:

When I came here I was just shocked at like it been such a chilled out home and nobody you never got smacked you know nobody did that, d'you know I thought all homes were

like that because I'd never, that was my first job up there, yeah, so I didn't really know that there was all these other homes that didn't have locked doors 'cos we didn't at the time, but we have had over the years we've had residents who've been d'you know escapees so we've had like locks put on the doors and stuff and when I came here none of this was here 'cos we didn't need it so, but as the years have gone on, we've took people who've got, we've had more people with dementia and stuff and really so, yeah everything was locked up there, you had a key for everything, like a prison d'you know , yeah.

5:1.8   Reflections and Analysis

In writing Margaret's case study I have found it difficult to separate her narrative into headings. Margaret immediately focuses on her experiences of caring at the end of life and on reflection I find it is primarily structured by her ambiguous relationship with death and the end of life. Anxiety and ambivalence are expressed throughout; sometimes openly, sometimes through her choice of words and contrasting descriptions of herself as a carer. It becomes apparent that for Margaret being in close proximity to suffering and the end of life necessitates moving between different states of mind, in order to defend herself when her openness and sensitivity to the needs of others becomes too much to bear.

Margaret's open admission that she is frightened of dying and hates anything to do with death, for herself, indicates something of the extent of her ambivalence and her narrative includes a number of end of life situations that she has found distressing and potentially traumatic, although this is reflected more in her choice of words than the emotional tone of the interview. Such contradictions suggest that unconscious defences hold sway and may dominate in the absence of appropriate support and supervision.

It is of interest that at the beginning of the interview Margaret can only remember recent deaths at Rainbow's End, describing them as 'nice and peaceful'. It is only after being given time and space to remember that Margaret is able to recall an early experience of end of life that has had a lasting impact/left a deep impression (yet was initially inaccessible), and to recount more recent experiences that have been more difficult to cope with.

5:2   Sarah – A Continuing Bond

The process does not end, but in different ways bereavement affects the mourner for the rest of his or her life. People are changed by the experience; they do not get over it, and part of the change is a transformed but continuing relationship with the deceased.

(Klass et al., 1996, p, 19)

5:2.1   The Interview

The interview takes place in the care home in which I have previously interviewed Annie, in the same room just off the reception area and entrance. Sarah explains that she has limited time and the interview has something of a hurried feel throughout. Originally arranged for an earlier date, when I arrived at the care home Sarah came to explain that she was needed to oversee the dispensing of medication and it would not be possible to complete the interview. We agreed that it would be best to rearrange and the interview takes place on New Year's Eve rather than the 19th November. Although time is now available, Sarah conveys a sense of urgency about returning to her work. This is shorter than most of the other interviews and I experience it as an intense outpouring driven by the opportunity to speak freely and be heard.

5:2.2   Getting Started/The Personal

Having started to talk about the death of her father during our first meeting, Sarah returns immediately to this subject; beginning at the start of her previous narrative as if this has been held in her mind, poised and ready to spill out, since we last met. This was Sarah's first experience of the end of life and her telling of it has an immediacy that further suggests it holds a central place in her mind. It makes it difficult to separate Sarah's narrative into the kind of headings that identify themselves more readily in other interviews. Her narrative emerging more as a stream of consciousness that crosses personal and professional boundaries, Sarah engages immediately with caring at the end of life at the deepest and most intimate level. The following was spoken with barely a breath taken:

So really erm my first experience erm of experience of somebody passing er somebody passing away was just before I ever came to work in to care was my own father em and we were informed on a on a er late Saturday that er he would probably not make it

through the night when in actual fact it took until about half past eight on the following Wednesday morning so for although all that period of time he still was made to believe it was still that Saturday visit we never let him know erm that the day changed we never left we all stayed there just leaving the room and coming back in erm he was quite sleepy because he'd had a massive stroke erm and we didn't quite realize how much he was actually hearing or, or taking in at all anyway until the last really latter stage when you're all quite tired and quite er on edge and frustrated and I happened to say to my mum who was across the bed from me, we were immediate to dad and my sisters were this side and I actually said I'm sorry mum I'm a bit fed up I don't even know that he knows I'm here and I just you know and this hand came from nowhere which he was on wires and different things and he just tapped the top of my head you know it wasn't a hard ? And it must have took an awful lot of strength to do because of the way he was and he always used to pat me head and I've kept that with me to believe that there's as much proof as I need in my myself to know that the hearing's the last organ to go therefore now working in care and sometimes supporting erm a lot of our residents that have made the choice that they want to be supported in the latter parts of the stages here at Hilltop House I make sure all professionals that are visiting, all carers that are going in there speak and treat that person as though they were in the prime of life erm including them and making sure that anything inappropriate is discussed out of hearing range really so that they haven't got to within their silence be laid there possibly being frightened to death thinking "is this it this it who's this who's this" and not knowing so every entry to that room is it's only me I'm only popping in to see how you're doing we're just going to make sure you're alright or this is a GP or this is a nurse, we're just coming to do this, talking to that person as though they were in their prime not including them at all because I really think that they can hear us.

Sarah's account is particularly evocative and through the telling I experience a strong sense of the hospital room, the body of her father and the emotions present within the room.

5:2.3   Caring At the End of Life

The following is a seamless continuation of the above, indicating the impact of Sarah's personal experience of the end of life on the quality of care she now gives to residents:

I would hate to add to any uncertainty that they might be experiencing just because they can't tell me, so that was my main thing that I like to take it with me really and other things that I've had I've had a lady that used to love her music, loved her music erm and she didn't really like to sleep in a bed erm she used to get out of bed and lay on the floor and when she was at her last part of her life and she chose to be here we had it as a as a mattress on the floor with all her ordinary bedding her lovely duvets and everything itself but the mattress on the floor and we had what we call our sensory unit in there what had all the lovely colours but we were playing the music that (adhered?) to what she liked and when everybody was coming first people that hadn't been at all any doctor that's thinking "why on earth is she on the floor" this was because that's where she preferred to be before she wasn't able to make that decision so we made sure that that bed it just looked like a lovely bed with all her fluffy pillows and her lovely flowery bedding but it was on the floor on that mattress and everybody followed in to that and she was made as comfortable as possible her music still played everything just for her as it would have been if she'd been okay.

Sarah is keen to emphasise the importance of touch and sensory experience in the absence of speech as part of personal care:

Do you know that was another one erm really I think that the touch using touch erm is a real personal thing and sometimes erm when you're giving personal care giving you know the extra little bit of you know the moisturisers the ones that they've always liked, they might have always liked their Oil of Ulay or their Max Factor or you know their smelly Yardley's and lily of the valley that sort of thing that can still be applied to the hands in the creams gently, it's touch and it's a nice comforting feel but they can still be able to smell that and it might be their smell everything's normal, everything's fine oh I am still getting my normal creams, I don't know whether that's relevant to yourself but I just I think it's important erm do you know what I mean?

5:2.4   Systems of Care

Sarah is clear about the focus of her role and how it fits into the wider systems of care, speaking of colleagues in terms of their respective roles with particular reference to district nurses who, Sarah feels, have the same understanding about the limitations of hospital as a place to die.

You see we've got to remember this that all the way though this we aren't or nurses we have a really good support from our DN Team the GPs so we don't make any medical decisions, we, we'll have pain relief that'll make sure that person's comfortable but it's not for us to administer. We can just say the person looks a little bit more unsettled than they have been with everything else has been normal as to what we would normally see but we can see there is a little bit unsettled, can you come along and have a look just to make sure there's nothing else going on that we're not aware of they will come and say well in actual fact they just maybe need this this and they can make that decision and they can make that person comfortable erm through what a medical person would know, all we can do is monitor that person and care for that person as we can, as carers but as I say we wouldn't be able to do any of this and even make it possible to have a person be cared for here at ET at end of life if we didn't have the support of the medical team and we do, the DNs who are absolutely fantastic who again see that it's not a place to have your last moments on a trolley possibly in a corridor and that again that isn't no reflection or criticism of a hospital it's what on earth they can't make a bed on a ward available if there isn't one can they so yeah we're a, we're are a little part of a big picture and I do feel our job is as equally important to make sure that it's nice and comfortable and less worrying for that person erm so it's an important role just part of a role that a lot of people fill you know.

It seems that Sarah has a strong sense of the value of working collaboratively to meet the needs of those at the end of life and thinks of her colleagues with respect, gratitude and clarity about respective roles.

5:2.5   Making space for death

Sarah recalls how she felt as she left the hospital after her father had died:

I remember walking out of that hospital and everything was normal people getting in lifts to visit, people were just getting out of their cars, people were just walking round, (gasp) do you know what's happened, do you realise my father's just passed away but life goes on and all those people weren't aware of that and it was the worst feeling ever.

Once again this informs Sarah's approach to the end of life as the memory of her own experience prompts her to think about how significant others might be feeling, and the effect on them of the quality of end of life care given, including how a death is acknowledged/borne witness to:

It's a big deal this is your mum, your dad, your granny, your granddad, it's a big deal you know it's not just well actually it likes as if that's happening because you know we've seen it before, we say you need to be here I think that this could be happening we're gonna get we're gonna make sure the nurses are here because they need to know everything possible's been done if this is gonna happen and it's not just oh the norm d'you know what I mean it's not the norm it's a really big deal you know an, and, and it's got to be made as special as such for that person and for and for that family d'you know to be able to grieve from they need to know that everything was done and everything was right that you know does, does that make sense to you?

Sarah emphasises the impact on her of learning through experience and the way in which since her father's death, the end of life care has become a passion for her:

That was again nothing I've learnt from here but I brought in because well that was my personal experience so when we were asked to be involved in this it was a passion really because I think well yeah it's a big deal we all make a big deal because so and so's had a baby you know we're all really fussy but we all need to be as equally mortified that so and so's passed away because it's a big deal you know.

5:2.6   Personal/Professional

As Sarah begins to talk about the changes that have taken place in funerals from the Victorian era to the present time, and emphasising the trend towards colours and personal choice, she returns to the personal as she mentions the death of a friend:

I've recently lost my friend the same age as myself to cancer and erm she knew that it was actually - it was coming so she made all her own arrangements erm and her family found it difficult em to talk about it to that to tell her what she wanted and what she didn't want but that was what she wanted and when I went to her funeral and it was all the Beatles music and you know everybody had to have a little bit of green and she had a carriage because she wanted a, she'd always wanted a wedding carriage (and horse?) but she'd never had that but she got her coach party for that and for everyone to party on afterwards. That was a big thing, it wasn't a case of oh they want to party because they're not bothered, it was, that was her way of having her party.

Yet again the boundary between the personal and professional dissolves as Sarah continues immediately with the importance of gathering as much information as possible whilst a person can talk so that this can be returned to when necessary:

D'you remember us talking and I know you wasn't very happy about talking but we talked and we said what you knew mum wanted and you got all those little bits is there anything you'd like to add to that now and sometimes now I'd say ninety per cent, they're really glad that they got a chance to ask their mam at that point and to say well she did actually say so and so, did you remember us asking, she'd said "what the hell you asking us for do you know something I don't know?" but I'm glad I've asked it now, but then there's still family that won't even touch on that but that's got to be equally respected as well y'know so I think it's just really liaising with the family and the person and just finding out what's important because at the end it's too late to find out, you know, you've got to try and just say well all the way through care this is important we can carry on with that if you're happy for us to carry on with that, do you know what I mean?

Asked to say more Sarah returns to the personal as a way of saying that she finds it difficult when families don't want to discuss:

I find it difficult when they don't want to, I really think because as a person now I've spoken to my mum and I've spoken to my children cos erm you don't have to be old to pass away any more do you, to make sure that they know things that are important to me because it's again a passion that I have to make sure and they say "oh mother don't you dare start telling us" and I say "well I just want you to, make sure you know this

and make sure you know that" because for me as a person I don't want to be put in a grave so I don't want to be buried or cremated and scattered in a graveyard, I want 'em just to cremate me but I want them to scatter where we can get permission, somewhere nice, where we've done summat good, where it's sunny, where it's lovely, where we've had fun, because the last thing I don't want them to always feel they have to come and be sad all the time I think it's not just the day or this is the anniversary when mum passed away we need to go there and take flowers, no, they might just have a day where they're sad and think one day but if they're not sad for fifty two weeks of the year that'd be fantastic for me because the last thing I want them to be is sad but that's just my choice so yeah I can get a bit upset inside when I just when they won't talk to me or they won't just ask any questions but I can also respect that.

Sarah goes on to speak further about the difficulties of finding out from relatives what a resident who is no longer themselves might want, or might have wanted before their dementia, whilst respecting their right not to speak. Sarah understands the difficulties but feels it is important and describes how she might pursue such a conversation. Immediately following on from this Sarah identifies another aspect that she considers to be important:

5:2.7   Dying Alone

I think it's equally important to make sure that the last minutes that that person's last minutes are as, as important to me as this, as their minutes now, d'you know. I'd hate I'd hate, I'd hate to think any one of the residents here were on their own and I can one hundred and ten per cent make sure that that's, that that's, a big thing that we make sure nobody's on their own, there's somebody there you know because I'd hate for that, I'd hate for them to be frightened - I'd really hate that.

Although Sarah holds this as a personal belief she also recognises the significance that it has for other care staff:

I think it's just a personal belief of mine erm, I think that erm at that last, at that last minute, I do think that when, that there is somewhere else to go there is something else to happen, erm, we're so unique sort of as people, we are, surely there must be more to this and erm (pause) or if it is that we simply just go to sleep and em, it's equally as

important to make sure there's somebody there to say night as you're going to sleep anyway d'you know, d'you know what I mean yeah and that all the carers that in't just me, all the carers here, we do because we've erm done the training it's something that we can share with the care staff to make sure the care staff of - they're all obviously seeing it as well because they're involved in the care, it's not just a certain person's they're all involved in the care they, they get as upset because they've looked after that person and it's to them their still losing somebody close because they've cared for that person and so it's important to them because they want to make things right, they'd want to make sure as well that nobody's on their own erm know what I mean, so yeah it's a general thing that, a general observation.

As well as for close family/significant others:

It's the first thing they say you know if they haven't got, if they're travelling and they haven't got or they've said I can't come or I won't be able to be there "who was with them" that's the first thing they always seems to ask "who was with them" so it's an important thing you know actually I think it's a question they always or "was they by themselves" it seems to be a big question that everyone says who was there - so yeah I think it's important somebody is yeah - yeah – (very quietly) -yeah.

5:2.8   Emotion

Again I always seem to go full circle and go back - I don't know what I'd have done if the nurses and the doctors had started crying when my dad passed away in hospital but I aren't gonna say or tell myself that those nurses or doctors didn't care or that they weren't bothered and just said "oh he's died let's get another one in" I don't think they felt like that at all - but they had to be composed erm and so it would have been difficult for them to say "are you alright can I get you a drink have a few moments you stay there and do this" - it would have been difficult for them as well so again it's that little bit of professionalism trying to just compose yourself where you can. You can't help your eyes filling up, you can't help you, your you can't help that but you can just try and be strong for the family so that you can reassure and support properly the last thing you want is for them to have to give you a love and so you'll be alright (laughs) really, no it is difficult it's not easy at all, it's not easy at all.

Sarah describes her way of coping as she moves between her professional role and personal life:

You're drained you really are you find it really hard and then you've got to you've got to move on and then you go home from work erm you hand over to the next shift and you go home from work and it you, you know you haven't just got off I aren't saying working on a till aint important but you haven't just got off a till you've, actually somebody's just died and you've and you've actually experienced and suffered a loss yourself but because you're not a family member you've had to disconnect from that but go home as though it's a normal day or go straight to the shops from work or go and get petrol on your way home or go and do your jobs ready to come back tomorrow for another day and that can be real difficult and I aren't gonna tell you you don't have your moment - because you do you know and you think sometimes it leaves you feeling how lucky you are at home and yer sort of like realise you know you've got - you're fortunate to still have your mam and your dad well I haven't got me dad but (difficult to hear this bit) you know you're fortunate in that way but, you can't be disconnected 100 per cent you still have your minute and I aren't gonna pretend I don't have my minute I do have me minute, I go home and have a bath and when I come out of there red eyed it's 'cos I've had a shower and had me hair washed and stuff so it's for that reason it's discussed it's to try and have that minute because you have to have that minute otherwise you'd have nothing in here all the time you'd have no room you'd have no shelf space left for everything else so you have to have that minute to sort of like - stack summat away in a box for good but erm yeah so that is a big thing yeah I do have them moments I certainly do and I know I speak for the rest of the staff they have to have that minute as well - yeah.

The significance of the work and the sense of alienation it can create are captured in the following excerpt:

You'll be you can be sat and you've still got to socialise you've still got a life and people I'll be oh well I've been doing this today and I've been doing that oh well I tell you what I could have gone barmy today because so and so had this and that's happened, and you're listening and you're thinking well actually today I've seen somebody take their last breaths and I've sort of like sat and made sure they're comfortable whilst that was happening and then I've supported a family but I can't tell

them that, but I can take great pride inside think it for a minute and think well yeah and think I can do that still I can support them people that need me to support but you don't know but today I've done that actually and I can take pride in that although I can't tell em I can sit inside and think um do you know what I mean. So sometimes it's better because secretly inside it's like my big secret yeah aha - even though I can't brag about because guess what if I were even allowed to you'd probably get the wrong response you'd get "oh god, god" and "what was it like" as if a big horrible thing had happened when in actual fact it had been lovely for that person and the family had found it lovely because we'd had everything that they wanted and they were happy with that if you can be happy does that make sense, so yeah, but yeah it is a big deal.

Just how closely Sarah's relationship with the end of life and her role as carer has been formed by personal experience is apparent as she speaks again of the death of her father:

Because his wasn't and yes they'd given us a room but looking back on it now and I didn't have any experience in care know what I mean 'cos he was there and I could have asked things now I know that that was gonna happen.

As is the strength of the powerful defences that we need to protect us as we face the loss of our personal assumptive world:

I still believed he wasn't gonna die I still believed he just looked normal and actually after he'd took his last breaths I still held on to him and saying ohh well he'll breathe again in a minute because the breaths were so far between I kept thinking oh he's gunnu in a minute and if you like I grabbed hold of us head and I was no he'll be fine in a minute, I was in denial really em I didn't have no experience of that so yeah.

At this point there is a knock on the door and Sarah is told that she is needed to sort out some medication. I realise that the interview will end and encourage Sarah to finish what she was saying. The interview concludes with a clear and unambiguous statement about what motivates Sarah to do what she does:

So I didn't appreciate that for him but now I would so I don't feel it was I feel it was a big thing for me dad because he still had us all around and if he could he knew we were all there but I'd just make sure now that that person'd be talked to a lot more d'you

know what I mean? I'd do a lot more of that and every time I do it I'm thinking that the reason that I do it and the reason that I've come here to this is maybe if he was out there and he said I, I bet you'd be good at that because I only ever did in retail and I came from retail to this and I did support his mum and he'd seen me help his mum with him em but I hadn't done it as a profession so I feel it was him because I don't, I still can't believe today all my friends that I worked in the retail saying "what do you wanna go and do that for?" but now I haven't got enough hours in a day from walking in to this building eight hours turns in to two, I never have enough time for anything there's just not enough time to do things because it's people d'you know what I mean?

Sarah explains that because she is on shift she will have to go and we say goodbye with the option of meeting again.

I am left wondering about the sense of urgency that has shaped this interview and whether or not the interruption has been pre-arranged. Rereading the transcript of the interview I move to wondering if Sarah will ever have enough time to make reparation for the death of her father. Something stirs in me as an understanding of the often unconscious process of working through that I can see/feel I have been, and perhaps always will be, engaged in rises to the surface.

5:2.9   Reflective Summary

Sarah's narrative begins and ends with the death of her father, strongly suggesting that it is this lived experience that drives and determines the quality of her relationship with the end of life, including the way she has come to inhabit her role as a senior carer. Sarah has the capacity to be acutely attuned to the needs of a dying person, a sensitivity resulting from being alongside her father at the end of his life and realising later the powerful defences that shaped that experience. Her subsequent openness results in a level of emotional experience that has to be processed for Sarah to be able to continue to care with the same degree of sensitivity and attunement/reverie (Bion, 1962, 1963, 1965; Stern, 1985).

Sarah's description of the work of being alongside the dying as her secret and the connection she makes between birth and death are reminders that there are things that become unspeakable for those who have had the experience, because they are

unthinkable for those who have not. Although Sarah has identified personal ways of processing her emotions and understands the need to do so, this seems to be a solitary process providing fewer opportunities for the kind of processing relevant to her professional role. Despite Sarah's conscious awareness of her reasons for changing career, the intensity of her commitment suggests that there is an on-going working through of loss that is unconscious yet barely beneath the surface; resulting in a level of anxiety not immediately apparent yet detectable in the narrative.

5:3   Lisa – Heart and Mind/Learning from Experience

'The discipline of palliative care, just like that of poetry, matures with time and effort. It requires a listening heart, a patient soul, and a trust in experience, layer upon layer.'

(Frank Brennan, 2012, p, 116-9)

5:3.1   The Interview

The interview takes place in the care home where Lisa works, at Lisa's request. The care home accommodates forty-eight people either in the main building or the specialist dementia unit. The focus is on caring for residents with dementia including those at the end of life. The home is situated in a quiet residential suburb and in pleasantly green surroundings. This is my sixth interview and whilst I have a sense of anticipation I feel more relaxed, having found my way with ease and a parking place within the grounds close to the entrance. The reception area is light, airy and busy with a mix of staff and residents. As I wait for Lisa to arrive my attention is drawn to two residents who are passing in front of the reception desk. They approach one another and in a moment of recognition begin to dance together as if at a tea dance. The interaction is brief and it quickly becomes evident that they are both preoccupied with their own inner worlds, and yet it seems to me that for a moment each has responded to the other and in doing so shared a moment that condenses past and present in a way both can enjoy. This strikes me in my informal observer role as a transient moment of delight as well as great poignancy. Soon after Lisa arrives and we make our way to a large room, suitable for training and large meetings, at the top of the building, which is essentially a large residential house.

5:3.2 Getting Started

Lisa begins by explaining that although she is the deputy manager she has been acting manager for the last seven months and is currently in the process of handing over and returning to her deputy manager role. Lisa adds that she is also a care mapper and has done a lot of end of life training at the local hospice. Asked to speak about her experiences of end of life care Lisa describes it as one of the most rewarding parts of the job that, although can be sad, can be made enjoyable. Lisa goes on to describe the range of methods the home uses to gather information about the needs and preferences of relatives. This includes attempting early discussion following admission about the end of life wishes of individual residents, whilst at the same time accepting that some residents and families may not be ready to have such conversations. Lisa identifies it as one of the most sensitive subjects and says that she tends to get the feel of whether it is the right time to try and discuss individual preferences or even broach the subject.

Lisa emphasises the efforts that are made to gather personal information about residents, including those who lack capacity, emphasising the difference between standard hospital care and the more personal care that is given at Lavender Hill. Lisa goes on to explain that her mum died when she was twenty-one and that this is where her interest in end of life care began.

5:3.3 The Personal

Lisa gives a detailed account of her experience of the end of her mother's life/death in hospital following a long and difficult illness involving lots of treatments and operations. The shock that she feels when told that her mum will die soon is painfully evident:

I remember mum being given some morphine and then they said, "I don't think it'll be long now" after that and then suddenly it wasn't.

Lisa goes on to say that the only way she could cope *"the only way I can get my head round it that mum suddenly isn't there"* is to begin to talk about what she will do with her mum's clothes when she gets home, knowing that her mum always liked to be organised:

And I knew she could hear me 'cos they all say about hearing being the last and I knew my mum could hear me and I wanted him, she always wanted to be organised, she wanted me to be organised and I, I, was always organised so in a way I wanted to give her reassurance that I was organised and with me saying about her clothes and her jewellery you know her personal possessions I was hoping she would hear me that I'm saying charity shop and what charity shop so she would get consolation from that and maybe it would be our last chance in my mind our last chance we'd work together.

Lisa remembers how she and her mum would always organise practical household tasks together, such as cooking and cleaning:

So like for me it was the last time we could work together, packing and you know my dad's going no, no, you know making out she's dead already, please don't, but that's how I knew how my mum would've recognised things and how she would've understood and my last way of working with her.

Later as Lisa discusses the implementation of the now discontinued Pathway 2000, perhaps more widely known as the Liverpool Care Pathway, it is her personal experience of end of life care that informs and determines her response:

Well when my Grandma was dying and she was nil by mouth they done it at the hospice well we were rubbing ice on her lips because her lips were sore just like that, me mam used to drink maybe bottles and bottles of water or lemonade a day we knew she was so dry and it was like the Pathway 2000 she's not having anything to eat or drink, I think I don't think so, so I do think that's the biggest change what I've seen, you know end of life normally it's not just TLC it's palliative care, you do whatever you can.

5:3.4 Becoming a Carer

Lisa's personal experience of the end of life prompts a change of career and determines the way in which she takes up and holds the role of carer:

I think when my mum died I re-evaluated my life, time to move on made changes and it was caring that I got in to.

Lisa describes how she experienced the care given:

I never witnessed anything any bad practice, it was just very cold and I can't even say why it made me go in to the caring profession, my sister was a nurse, she was a nurse at the time and I went to see her at work one day and I thought you know I quite like this, I quite like how these people are being looked after.

And her view of what it means to be a carer:

When people said oh they're only a carer, I'm only a carer getting paid minimum wage now when I hear people say I'm only a carer I say excuse me but I'm prouder to be a carer than a deputy manager and I am, I really am.

Lisa recognises that the nursing skills she picked up along the way can give confidence as one relative remarked:

"I can see you're from a nursing background" and I said, "I'm not a nurse, I'm a carer with a heart" and they said, "but you've got a lot of clinical ways" with you and I thought that's from my nursing, cos I'd worked for so many years in a nursing background, and I wasn't offended but I, again I wanted to be a carer with a heart more than one with a nursing background.

And emphasises what she considers to be most necessary to the quality of end of life care:

You don't need to be a specialist to give end of life care, again it comes from your heart and it comes from your experience and it comes from just being able to look after somebody (pause) and I think just having, be aware that not everybody's the same, very person-centred, and just keeping your views to yourself.

5:3.5   Caring at The End of Life

Lisa's first caring role is in a nursing home setting where her experience of end of life care is limited to assisting nursing staff rather than having direct involvement. Later

working as a carer in a young disabled unit Lisa has a broader experience of caring for those with a life-limiting diagnosis, including the range of individual emotional responses from acceptance to depression:

It's such an interest to me how death can be so different for each individual and how we manage and how we handle it and then again it comes up to your end of life care and you come saying that this person was very, very positive and they don't want the doom and gloom, they want the happier, they don't want staff members coming in and feeling sorry for their selves or for them, they want staff members to come in happy and possibly celebrate what short time they've got left, and if we've only got that evidence then that would be put in the support plan or they might be people who do kind of say the kindest words, want to be reminded all the time that they're end of life and they do want a bit of sympathy erm and they do want to say they've only got a few weeks to live, get that documented in the care programme because that person who's coming out of one room I think, they may be real happy and that'll upset them because they want to be quite quiet, or sad or something like that and then when I went into residential care erm and I got made up to a senior carer, so I got more involved and I absolutely loved it and then I went to the local home and I did a six week one day a week course at (name of local hospice).

The course and the hospice have a significant influence on Lisa:

I'd done that hospice course, I was totally into end of life care and they showed us round you know and how amazing I found the hospice and how personally centred it was and how sensitive it was and lovely gardens and so tranquil and then I'd come back to work and see, I've always said hospitals are clinical and homes are homely, to me you went from a nurse in hospital to the homes that are homely and then you went to a hospice which is like home and tranquil like for the word hospice and then I continued to be senior erm and then I worked round and I worked a lot of years again working in a nursing home but I just felt me, personally I learnt a lot from the nursing, I couldn't get involved as much as I wanted to in end of life care because of the nurse's role requirement and that's when I come here.

The extent of the influence of Lisa's personal experience on her development as a carer is evident as she speaks about the nature of care that might be given at the end of life:

I really, really, have got a passion for is end of life care, you know to giving Vaseline on the lips, to putting cream on the feet, and that's not just about pressure care it's about all that tenderness and that closeness, what you build, you know they don't want asking and they maybe can't feel it but they maybe can and it's just that and it's just that I feel sometimes what families look for, it's not them coming and saying well they've had x amount of fluids, that goes without saying you know, they've been position changed you know that goes without saying, it's the personal touches, well today I've been with your mum and I've given her a nice little hand massage with her creams, are there any creams that your mum liked, hand creams you know foot cream anything you know like that anything what she really liked, her favourite perfume, she might like a little bit of spray on her, only very, very, delicate you know, someone like lavender on the pillow, you know to relax, I think that's so important just the personal things because I know when my mum died there was nothing personal.

Lisa places particular emphasis on the importance of mouth care:

I do think it's a way of offering comfort, because I can't (pause) you, you can verbalise and talk to people, you can wash them and dress them, you know em, the sensitive area of the mouth I just feel is something what I feel I wouldn't want to let them down, make them feel worse, you know er and er I don't they just might, I hate the thought of anybody being so thirsty, but again I don't know because maybe it's there sense is going and they're deteriorating you know they might not have that taste anymore, they might not have that sense that they're thirsty.

The significance of being physically present with the person at end of life is remarked upon:

Quite often I've sat and done paperwork while I've been sat with clients while they're at end of life, you know I've just been there saying "are you okay there?" and people they sometimes laugh at me because I'm talking as if they are going to give them/me an answer but how do I know they're not answering but that they just can't verbally say it? In their head they might be saying Lisa yes I'm absolutely fine or Lisa no I'm not well but they can't answer a question if you don't ask it, does that make sense?

As is Lisa's intention to recommence discussions/teaching with key workers with the aim of further improving end of life care:

Now I've gone to deputy I'm going to be doing some more care programme training and one thing I'm implementing which I do want to bring back in because I haven't done it for seven/eight months is the end of life you know discussing with them as key workers, how they can implement better end of life and there might be something what that person shared with them you know maybe given them a bath when they're talking where there might be something personal they've shared, well write it down, get it in the end of life, they might not know then but six months down the line when end of life has been mentioned it's there, it's relevant and you don't remember personal things like that all the time so that's what I'm going to implement when I do the care programme training is the you know get them more involved in the end of life care because it's nothing to be frightened of it's more it's one of the most vital parts of care, you know you're born you know with a midwife, you die with somebody looking after you then (pause) you know.

Lisa recalls the approach prior to the implementation of the End of Life Care Strategy:

Eight years ago they did, it was a case of, oh if they're dying they've got to go into hospital and they've got to die in hospital or something like that whereas now, your doctors, the families, even hospitals say we don't really want them to die in a hospital, it's clinical, get them to the home, so that's the big change I've seen over the years.

And notes some of the changes and diversions along the way:

Coming in for end of life care is very personalised erm it's certainly more recognised and I know this sounds daft but now what I mean end of life care was diagnosed years ago, you know you was dying and that was it you know just look after them, give the comfort, remember the old TLC, whereas now end of life care now is not end of life anymore, it is, but there's lots of things you can implement which make it again, I know I'm going on about personal care, but people are so different in end of life and the families are, you know, you know it's palliative care, it used to be like the Pathway 2000, stop all medications maybe get, they might have three months to live, stop all the

medications and everything erm I haven't heard of that pathway, I haven't heard of anybody for a number of years being discharged being discharged to us on the Pathway 2000 because it's what's the word?

We agree it has been phased out following a review (2013).

Speaking on the subject of dying alone:

You're more likely to have somebody with you in a care setting like I've said I'll go and sit with them and do my paper work while I'm just doing that I'm talking away and things, so I'd say certainly for the better, I think end of life care has improved massively.

One of the things that Lisa has learned and reminds other carers of is the importance of not making assumptions, and this includes those about whether or not a resident wants to have someone present when they die:

We just assumed that they always wanted somebody there with them because that seemed the nice and caring thing to do, whereas now it'd be like, you've got to see that they might not like somebody there, might want to die alone (pause) and that's the information we need to find.

5:3.6   Supporting Staff

We've got nobody that, who I feel shies away from it end of life because they're encouraged and I encourage them to be open about it and talk about their feelings and if they're upset they're upset they don't have to hide their feelings, they don't have to have what they would say I'm alright, I'm ok, if they're upset share that if that's how they feel, a couple of times it's teatime and you're by yourself and you need to get your head around it because they might be seeing their families as well and if, in a few minutes time, and I think it's something to remember is how the staff have coped, think we're not all aloof and stand-offish and quite cold, I think certainly from my experience families respond and relate more to the worker, the staff and that. Gone are the days of the stiff upper lip, oh yes because somebody's died I've got to be okay, you don't, talk about it and they talk about it privately with me, or maybe another staff member if you want to, sometimes I say have a cup of tea, don't you know it's, and we do, you know we

do more to get the staff included a lot, as I said they do care wise, but to talk about their feelings.

The appropriate sharing of emotion is encouraged:

And there's things you remember and I've often said to the staff when we come out of, you know when the family was crying there, you could cry with them you know. 'Cos I've seen staff, I can't cry, I can't cry, (whole bit hard to get) and I'm like cry with them. If you, you obviously feel the need to cry, you're crying for that dead person or you're crying for their grief, share it with them, you know, share, share it.

Lisa also recognises her own support needs and the reassurance of knowing that she has access to this if needs be:

Yeah if I found a very distressing early death or end of life care, I know I've got somebody just to talk to, other deputies to talk to, area managers to speak to, I've got a head office who I could ring up and say I can speak to anybody really.

5:3.7   Supporting Families

It seems that Lisa's personal experience has enabled her to think about the needs of families:

One thing I did implement here is a family room so it's for, it's got lovely furniture in, for families who live away and if they come in to visit their loved ones in their latter days, hours, or something they can sleep over here, they can stay and they can live in that family room, they've got you know wash facilities, tea making facilities, it's a very quiet area where they go, very comfy, very cosy.

Her choice of words reflect her desire to make reparation for her own, and her mother's, experience in a more clinical hospital setting:

We let them have hot food whatever they want to eat and drink and I believe you grow that special bond there as well and I just think it's so reassuring that they see that their loved ones are being cared for.

I can still see that bed now as I'm talking and I do not want anybody to feel like that with us, in our care who we've looked after, you know the bed might not be possibly brilliantly made underneath, it might just have a nice cover on, but that bedroom will look likes it's lived in, not that it's a final death place or something like that, you know and that is a strong belief of mine. I think, as I say the reason, the resources, the training, standing, the level of care, everything has improved massively over the years erm and if I do see any areas where there's room for improvement, it's down to the individual you know.

5:3.8 Emotion

Emotion is central to Lisa's narrative account and references can be found under each heading in the case study. Feelings are acknowledged, used to inform practice, and responded to in others. Fear, sadness, satisfaction and love for the job are all covered and expressions of emotion expected and facilitated:

You teach from your experiences, to me end of life care isn't a text book written exam erm training procedure you can learn you, you learn from other experiences and you learn from the heart, you know you've got your text book stuff what you've got to go by but for it to be such a sensitive area, from the heart, I'm very proud here of the staff and things like that and how they cope and how they manage and the support they receive if need be.

I think it was her way of coping erm cos it's not just about hands on care is it? There's emotion, it's not just the physical care there's emotional care as well and the empathy and everything else and I certainly think at the time, end of life is more sensitive now.

I always remember because we had that eclipse recently and the last eclipse we had before this about eight or nine years before that I was at with that lady for that eclipse and she said," I know I've not got long left to ... but I'm hoping you've got longer left than I have and I hope you see another eclipse and if you do think of me".

Lisa does remember, highlighting the lasting impact of the emotional aspects of caring:

I did I thought of her and then she couldn't even smoke a cigarette but she said Lisa can you light that cig so I can just smell it and she died a couple of days later.

And I do think certainly in my view of what I witness you can see if your care comes from your heart or if it's just your role, you know (pause) I just see it as one thing, very special care or whatever you can say to give to that person whether they've had a good life, a bad life, a privileged life, a poor life? It's not relative, they've become part of my life, the staff's life and I just think that's one final goodbye we can give by just making them feel so cared for.

5:3.9   On Death

People probably think, how can you get pleasure out of end of life but I believe you can, you know. I do believe you can whether, whatever your thoughts are (or you normally acknowledgement) you've got to experience things to share your experiences with people, to share, yeah you know and I've been present with staff when somebody's passed away and they have had very different thoughts to me, to discuss them, it's not black and white is it? You know some people might find it very sort of distressing, I don't see the distress in time of death, erm so my (pause) my experience I share I highlight the positive not the, the negative.

I could talk for hours about death and me experiences, I've seen a lot of people die you know, I've got a lot of thoughts and a lot of values what I've picked up from Mum, from Nana, you know, do I want to go and see the neighbour dead, in you know the front room, in the parlour, you know going back years, I've got a lot of values and different people's values, I've met a lot of families over the years, been with people who've died, they've given me my thoughts and values.

Lisa also speaks on the subject of euthanasia/assisted dying and it is clear that she has thought about the issues involved deeply and is able to distinguish her personal views from her professional role:

I believe in it for myself, I would never put my views on anybody and if people are saying I don't believe in it, I aren't going to argue the toss and say well I do, I tend to keep quiet erm (pause) and not because I'm frightened of people disagreeing or

agreeing with me, it's a sensitive issue and everybody, if they've got strong opinions of it, 'cos they're very passionate and got strong feelings erm again like I said nobody would change my point of view apart from (name of hospice educator) so I'm saying a fellow worker who didn't believe in it, discussing it and arguing about it, well not arguing because you lose control, discussing it and showing your different points of view, you can share your points of view about things but I think that is a very sensitive issue, because people can get upset about it.

Lisa appears able to contemplate her own death in a way that her family are not ready to think about:

You see I talk to them about death and they say, "oh mum don't talk about death" but why, let's talk about it, don't be frightened of it and I think because I experienced my mum dying I want to share my experiences with them.

And has tried to plan ahead because of the possibility that she may die suddenly:

I've suffered with high blood pressure for years and I've always been warned by GPs, you could have a massive stroke but that hasn't, that hasn't inspired me to think every day's gonna be my last, I don't think, oh god I've got to be careful I'm gonna have a stroke any minute, no, carry on and enjoy it because if something happened I have my, my family bits, have insight into what I want, it's not written there in black and white but you know I said I want to go with a family funeral because it's what I've seen are good, that's the songs I've said, I've said what I want them to wear, so I feel like I've given them enough information.

An element of humour is injected into the narrative as she describes choosing a funeral plan:

It's only because I saw a pen, oh and you get fifty pounds of M and S vouchers if you go with them (laughter again) ooh might buy a dress and get buried in it.

5:3.10 Home

Towards the end of the interview I make reference to the title of my thesis prompting the following response from Lisa:

We say about coming out of hospital, coming home, that's what the older generation did and I still think death comes home, you know, and that's even if it's a hospice, death is coming home 'cos it's their home, you know because, I know that so many, they try so many ways for even specialised treatment for, my mam was allowed to come home on Mother's Day. She came home on oxygen, a specialised wheelchair, they were like don't leave her out lying around just a couple of hours, can you give her her medication, dad was shown how to give her her medication and all like that because it was Mother's Day and it was clear that she would never ever, that she wouldn't outlive that week and the summer, and she died in between then, but I did mind not seeing her on Mother's Day, that then twenty years ago was allowed, so, they do bring death home.

5:3.11 Reflective Summary

At the end of my time with Lisa I am left with a deep feeling of admiration and respect. I realise that I have had some underlying reluctance to return to this narrative and having done so found completing the case study a moving experience. The narrative is rich and densely interconnected meaning that much of the material included under a particular heading has relevance to other areas. For example Lisa's personal experience pervades the narrative, merging with the professional and informing Lisa's development as a carer; determining the way that she thinks about the needs of residents, their families and other carers. It would seem that as a carer Lisa embodies the tragic position, inhabiting it comfortably and with a sense of purpose and positive energy, in her words 'passion'. At the time I found the interview heart-warming and life affirming. Writing in 2018 with a more developed sense of the project and what the tragic position might involve, I realise just how powerfully Lisa's narrative connects with the concept.

Engaging with the language and emotion conveyed in Lisa's narrative has prompted the notion of a reframing of such terms as 'advanced care planning' and 'preferred place of care' and the possibility of thinking more along the lines of wishes and feelings. It

would seem that Lisa's ability to speak so openly about her beliefs along with her positive response to the end of life has made it possible to think about the end of life afresh.

5:3.12 Chapter Summary

The carers represented in Chapter Five all express a firm commitment to the provision of end of life care within their respective care home and yet the narratives make it apparent that each has a unique relationship with death, dying and the end of life. Differences and similarities are explored further in Chapters Six and Seven.

6 Chapter Six – End of Life Stories

Working intimately with people who are dying can put one in touch with personal loss; unresolved feelings and anxieties may be evoked by the death of someone we are caring for professionally.

(Speck, in Obholzer and Roberts, 1994, p. 94)

6.1 Introduction

In contrast to the case studies, the end of life stories told in the narratives are ordered to reflect each interviewee's relationship with death and the end of life. My sense of this has emerged in my processing of the data (coding and identifying themes) and writing up of the individual case studies. Whilst all of the participants have experienced some degree of personal loss, those experiencing the death of a parent include Annie who has lost both parents, Sarah whose father died following a stroke and Lisa whose mother died after a long illness.

In addition, Margaret's narrative tells of the deaths of her mother-in-law and her grandfather who both died in hospital from lung cancer; Doreen describes being present at the death of her grandfather who died from cancer in the local hospice; and Josie's narrative makes reference to the death of her grandmother in hospital. Margaret also expresses her admiration for a friend and colleague taking time off from work, to care for her mother who has cancer, in her own home. The place that the personal accounts of the end of life occupy in the respective narratives seems particularly significant in defining the nature of each individual's relationship with death.

Whereas Margaret and Josie share a number of end of life stories concerning the experience of residents, Lisa and Sarah's narratives are structured around their close personal end of life stories. Sarah's narrative includes only one other specific account of care given to a resident at the end of life and Lisa's other stories focus on the details of care given to a range of individuals nearing the end of life, including a relationship that she builds over time with a young disabled person in a unit for younger people with a disability. Excerpts from these stories can be found in the respective case studies and are discussed here with the purpose of placing them within the range of the end of life stories shared across the narratives, rather than to repeat what has already been included elsewhere.

6.2   Personal

Lisa is twenty-one when her mother dies in hospital after a long and difficult illness. It is a life-changing experience for Lisa and it is apparent throughout her narrative that this close personal experience continues to inform every aspect of her approach to the end of life. Later when her grandma is cared for in the local hospice, she observes and appreciates the palliative care that is given. In addition she has many years of experience of caring in different settings and has attended training courses at the local hospice. These have given her the opportunity to discuss euthanasia, consider her own position and contemplate her own death.

Sarah's account of the death of her father in hospital following a massive stroke is intense and deeply emotional. Again this represents a life-changing experience for Sarah, and aspects of the end of his life significantly inform her approach to caring for residents at the end of life. Closer in time than the death of Lisa's mother, as well as sudden and unexpected, I have a strong sense that Sarah's sensitive and attuned care is a form of working through and an unconscious, if barely beneath the surface, form of reparation for the circumstances/fact of his death.

Annie refers to the deaths of her parents within the wider content of her narrative and with no detectable alteration of tone, or expression of emotion. Having lived away from the place she considers to be home for more than thirty years, Annie's experience of the end of her parents' lives involves returning to intervene at key points to arrange care for her father, who develops dementia but later dies from cancer in a nursing home, and taking time off to care for her mother at the end of her life. Details shared about the end of her mother's life are apparently divulged to illustrate the quality of care available to her mother in Annie's country of origin:

I went up because she was getting near the end of life and I went up and the call system on a night, I just used to buzz it and they'd help me to reposition me mum or change me mum and they were there within twenty minutes and that cost me mam three pound a week, er, doctors come in and nurses they put, give her end of life drugs, the doctor came every day, he was sat with me mum, obviously he knew me mum for years, he sat with me mum and the end was absolutely excellent care, they done everything for me mam to stay at home and not to be in pain.

Margaret describes aspects of the end of her mother-in-law's life spent in hospital because she was diabetic. Margaret explains that it would have been dangerous for her to be at home. She died about a month before the interview and having been given three months to live, only lived for six weeks. Margaret says that if it had been possible she would have wanted to care for her because she likes it. Margaret also says she would care for any of her family at home and would have liked to care for her grandfather, but he also died in hospital.

Margaret considers end of life care in hospital a different experience and describes wanting to do things differently, in particular the drinks being given to her mother-in-law seemed too thick. Margaret says that she would care for any member of her family like that and would leave work, with Josie's agreement, to be able to do it. When prompted Margaret recounts a conversation with her mother-in-law. Her mother-in-law says that she won't see her birthday and Margaret tells her that she will and not to worry. Her mother-in-law dies before her birthday, confirming to Margaret that she knew she was going to die. Margaret explains that she has had this experience with other people at end of life.

Doreen is present when her grandfather dies in the local hospice:

Seeing the dedication in (name of local hospice) with my grandad and I was actually there when he passed away and I supported my family as much as I possibly could do erm it's little things like that em I always said when you're looking after somebody always think what would you want for your nana and grandad, what would you want for your mother and your father, if it's not like that when you're delivering the care you always strive better and if you don't if you think like that you won't go far wrong.

Josie remembers her grandparents and regrets not spending more time with them, but the only direct reference to their end of life experience is in relation to the limitations on visiting and contact when her grandma is cared for in hospital.

6.3   Professional

I have chosen to group the stories shared across the narratives under headings that offer some description of the circumstances of the resident and the impact on the carer.

6:3.1 Physically close and shocking

Josie shares a number of end of life stories that involve potentially disturbing close contact with a dying person.

Josie's first experience of death is not long after she begins to work at the care home and involves a man who died in the lounge whilst she had gone to get his pudding. Josie realises that she missed end of life signs because of her lack of experience at the time. Josie was physically and emotionally shocked by this experience. She describes having to move him in a wheelchair and her surprise when he made a sound as if still alive that, a colleague told her, was just air being released.

Another involves a lady who collapses suddenly in her bedroom:

There's been sudden deaths I've had to give (em) one lady that had just collapsed in her bedroom we had to give her (em) CPR which was another experience that I'd not come across before unfortunately we didn't manage to bring her back and I'd gone and broke a rib which freaked me out at the time (pause) but yeah but we've had all different ones but after doing the course like more recent there's been a lot more since the big push for people to pass away here there's been a lot more sort of like deaths here like it's very rare that they actually go into the hospital (pause) very rare.

Another shocking/surprising death involves a man with heart failure who appears to be dead but then recovers enough to sit up and drink a can of coke and eat a banana before dying twenty minutes later. Josie describes panic and surprise as well as the need to involve the police because the death is classed as sudden.

A resident who has been in hospital and on returning to the home feels unwell:

And why they sort of like I mean I'm trying to think of a gentleman you know that we had recently he'd been in hospital because he wasn't very well and he'd come out of hospital and he'd come back on the teatime and he'd come back by ambulance and he'd come and sat in here and he said "oh I don't feel very well I feel a bit breathless" and I said "are you sure do you want a couple of puffs on your inhaler?" and he said "yeah" and he said "I think I'm dying" and I was like you've just got back from the hospital do

you know how can you be dying they've just discharged you and we've given him some of his inhaler and he'd just about half an hour later he said "I need to go to my bedroom" and erm his daughter was a nurse and she'd said if owt happens to my dad he doesn't want resuscitating so if you find him just go for a little ten minute walk until he's passed away because there was nothing written in place just go for a walk until he's passed away, and we were like no we can't do that hopefully it'll never happen and we took him in his bedroom and he just died on me and Margaret, and he knew, they get this sense of foreboding or whatever.

Josie says that they then had to call the doctor and because he had nothing in place (DNR) they had to work on him for half an hour.

Margaret's first experience of death is included under this heading.

Margaret is seventeen years old and working in a care home providing care for residents with dementia. Margaret is asked to check on the resident concerned so goes upstairs alone and discovers the person has died. Margaret says she knew immediately that something was wrong and had a strong sense that although someone was there the room was empty. Margaret describes feeling alone and her palms sweating. She is physically shocked and breathes in deeply before running downstairs to tell other carers. Margaret has never forgotten the lady concerned and freely recalled her name in retelling this event.

Margaret remembers a lady of a hundred who died in the home in the past when Margaret was younger 'only young'. The experience freaked her out at the time. Margaret indicates the room the lady was in, which is in close proximity to the interview room, and describes how she was lying in the bed and looking at the corner of the room as if someone was waiting for her. Margaret describes this as being like when a baby smiles when they have wind. It's as if someone was calling to her. Margaret has seen this a few times and it makes her wonder if someone is calling and waiting. This is when Margaret goes on to say that she is frightened to death of dying herself, that she hates anything to do with death and that it frightens the life out of her. This death conveys something about Margaret's state of mind as it could also be placed under the heading of a good death.

6:3.2   A Good Death

Josie explains that since the training at the local hospice she has a concept of what a good death might be:

A lady passed away a couple of years ago and I'd like to think that she had a really good death. Very close, she lived with her daughter at home she was very close to her daughter found it very difficult to adjust to her being in here d'you know they both felt like sort of like guilty and when it came to her passing away her family was here all the time, I mean we was letting them have meals and everything and they'd all come down for a cig and em (pause) her daughter had stayed upstairs on her own and her daughter had said look mum it's time to go do you know like there's just you and me here now and she'd actually passed away with her daughter just on like a one to one and her daughter had come downstairs and said I think my mum's gone and that was really nice because er because she wanted her family there and things.

Sarah offers her version of what might be considered to be a good death:

I would hate to add to any uncertainty that they might be experiencing just because they can't tell me, so that was my main thing that I like to take it with me really and other things that I've had I've had a lady that used to love her music, loved her music erm and she didn't really like to sleep in a bed erm she used to get out of bed and lay on the floor and when she was at her last part of her life and she chose to be here we had it as a as a mattress on the floor with all her ordinary bedding, her lovely duvets and everything itself but the mattress on the floor and we had what we call our sensory unit in there what had all the lovely colours but we were playing the music that (adhered?) to what she liked and when everybody was coming first people that hadn't been at all any doctor that's thinking "why on earth is she on the floor?" this was because that's where she preferred to be before, she wasn't able to make that decision so we made sure that that bed it just looked like a lovely bed with all her fluffy pillows and her lovely flowery bedding but it was on the floor on that mattress and everybody followed into that and she was made as comfortable as possible her music still played everything just for her as it would have been if she'd been okay.

Doreen's narrative includes this account of what might be considered a 'Good Death'. It is also relevant to the heading 'not dying alone':

I remember being sat with him and the gentleman went to church and had erm you know quite religious as well, had a learning disability erm but we knew what he wanted we knew he liked James Bond and he loved the songs? of praise and I had, I had a feeling, his one to one had gone for his tea and I said, "go and have your tea and if there's anything I'll ring the buzzer" and he wanted to be present, I opened you know I opened the window and I put one of his church music ? as though he was in church and then I had his bible, and I read the Lord's Prayer and I was just stroking his face and a tear rolled down his eye and he passed away, now that will always stick with me and I think he?(it) gave he?(it) gave a very good friend of his a lot of comfort it's like turning? into a positive experience, I don't know why I did it or, I just I just knew so I just put the music on loud turned it off and did that and for me that just, I don't know it was just something that I think he would have loved even though he was passing, I cry all the time when I, you know I do.

6:3.3   Not Dying Alone

Josie's narrative includes the account of the case of a gentleman with no relatives, who lived with his parents until they died and whose only point of contact is his solicitor. Josie knows that he is at end of life so he has a hospital bed and a radio to listen to when he has to be alone. Josie takes her office work into his room and sits with him whenever she can so that he isn't alone. Josie describes him dying with both her and Margaret holding his hands.

Margaret offers her own account of his death, describing the resident as a 'favourite' whilst acknowledging that she is not really supposed to have favourites. Again the fact that he has no relatives is remarked upon. Margaret explains that he has a bad leg ulcer that is making his body septic and it has been agreed that nothing more can be done. Margaret describes him as requiring just TLC. He has been prescribed Oramorph (liquid morphine). Margaret knows that Josie is sitting with him and Margaret joins her in response to the alarm being pulled. Finding Josie holding his hand Margaret remains and strokes his head and after about five minutes he dies with them both present.

Margaret describes his death as nice and how they like it because someone is with him and he is not alone:

We always like to be with them, always I don't know.

6:3.4   And those who do:

Josie tells of a man who is at end of life with staff spending as much time with him as possible, but who dies when a check is being made on other residents. On this occasion Josie contacts the family about the death before the GP and is reprimanded, because of the need to have the death confirmed by a medical practitioner before anyone else is notified.

And of a lady who is admitted to hospital following a stroke and is then sent to a nursing home rather than back to the care home where she wants to be. Josie describes it as 'gutting' that she died after being dropped off and feels that the lady's needs were not met.

Having initially struggled to recall earlier deaths, Margaret vividly remembers a lady from the previous care home with whom she has built a good relationship. The lady and her family gave Margaret birthday presents including gold earrings for a recent birthday. Margaret describes herself as young and lacking experience at the time. When this lady becomes unwell Margaret decides to call 999. She still regrets that the lady died in the ambulance on the way to the hospital. Margaret emphasises how bad she still feels about what happened and wonders if, had she done things differently, the lady might have died in the home in her own bed. Margaret reiterates that they always like to be with the residents at end of life.

Doreen's narrative tells of two residents who because of existing medial conditions, COPD and heart failure, are admitted to hospital as they deteriorate and subsequently die amongst strangers. Doreen describes this as unfortunate.

6:3.5   Problems in the System

Josie remembers the following problematic situation:

With one lady you know her family had expressed and written down that they didn't want her to go back into hospital she was a hundred and one and obviously they wanted her to pass away here, she'd been with us for about twelve years and we didn't know at the time 'cos this was just after doing that course I think and er we wanted her to stay here and she'd not been very well and she'd started to be sick I think and the girls on the night had rang an ambulance and the ambulance staff had said well obviously she does need to go into hospital but you've got this letter that here that says you know, the letter had been signed by the person but we didn't have a copy of the power of attorney letter and that's what we needed so we had to ring the family and they had to race here from (local town) or somewhere and bring this letter then they was happy not to take her yeah so luckily she did stay with us and by the teatime she was in a hospital bed and the doctor had done the just in case kit and everything so she did pass away here and in the end it did work out alright. Yeah I think if it's a locum GP so they can still sort of say like admit them and that causes bed blocking and you know it's more stressful on the person and especially if they've got dementia or something or like they've been with us all them years and they get shipped off somewhere to pass away.

Other incidents concern: a lady who is left without pain relief for forty-eight hours whilst a decision is made about which GP practice is responsible for her care; a lady with cancer who has to move from the care home to a nursing home following an admission to hospital. Her husband then moves into the care home and goes up to the nursing home to visit his wife every day. Although his wife is unable to eat anything he is charged for the meals that he has whilst visiting. Margaret also tells this story and finds it sad that the couple could not be together; and a lady who was visited by her GP and considered to be at end of life and therefore not to be resuscitated. It then takes four weeks for the DNR to be signed by the GP. Concerns are that this could result in the lady being taken to hospital and/or resuscitated inappropriately simply because of an administrative delay.

Annie's first example of end of life care involves a resident who has cancer, is known to be deteriorating, and is being nursed in bed. Annie explains that when the 'lady's' condition worsens a carer on duty asks the GP to visit. Instead an ambulance is called and the lady is taken to hospital (the ambulance crew are required to do this) where she deteriorates further. Although it is agreed that she will return to Hilltop, she becomes too ill to be moved again and dies in hospital. Annie is upset and frustrated about this

and is working closely with the district nurses, who agree that this shouldn't have happened and agree to liaise with GPs in the future to avoid unnecessary admissions at or towards the end of life.

Doreen recalls reporting a GP when young and relatively inexperienced because she feels the GP has been disrespectful. Raising concerns as they arise is something that she continues to do when necessary

6:3.6 Difficult Lives

Apart from Sarah's each narrative contains examples of lives that have included some difficulty. These include a man who has had a difficult relationship with his daughter who, when told that he is at the end of his life and asked if she had any wishes for what might happen after his death, tells Josie that for all she cares he could be placed in a bin liner and thrown off a very high local bridge over a tidal river. Josie finds it difficult to respond to (shocking but also understandable), realising she needs to balance caring for the patient with respecting the needs and wishes of his family.

Margaret tells of a lady who murdered her husband and refuses pain relief to the end of her life. Margaret describes kissing her and caring for her as she would any other resident.

Doreen describes the end of life of a man who has had a difficult, abusive relationship with his family. When he becomes aggressive towards the end of his life Doreen spends time calming him and supporting his children, who are upset and need to talk.

Annie's narrative includes accounts of two residents who have unfinished business: one whose son has a terminal illness and the other whose mother is dying in another care home. Her descriptions of facilitating contact and supporting them to say their individual goodbyes in the case of the son (after a difficult life of addiction and abuse) and the mother (who has dementia but is grieving for her son) are particularly moving.

6:3.7   Difficult Deaths

As well as good deaths there are ones that are difficult. These include: the death of a lady who is described as having just given up. This death occurs a week and a day after Josie's first experience of death. The lady is in bed and Josie is holding her hand. Josie describes her looking up as if at someone and saying 'no' and then looking at Josie just as she dies, with a single tear rolling down her face; and a difficult death involving an internal bleed that has a significant impact on the carer involved. Josie describes the carer as being 'put off' by what happened and it is quite possible to conclude that in fact she was deeply traumatised by the experience.

Margaret describes another one of her favourites, as one of a few who have died recently with bad ulcers (leg). The lady's toe had gone black and initially the decision was to operate (in Margaret's words chop part of her leg off) but then it was felt that she wouldn't survive the operation. Margaret felt very sorry for the lady, as it appeared that nobody seemed to be doing very much for her. Margaret describes her as being in agony with a very black toe that was spreading up her foot. When Margaret covers for another member of staff who is ill she walks in to wake the lady as usual, and finds that she has died. Margaret had not expected this. She describes the lady as a 'right laugh' and how she would wake her by saying 'good morning treacle'. Margaret doesn't understand how they (ulcers) can get so bad that nothing can be done.

Doreen's narrative tells of a lady who appears to be struggling and in distress as she dies:

I was with her holding her hand and talking to her but after she passed away the emotion that I was overcome with, because I just thought that something more could have maybe have been done in medication just to help you know all types of medication for the agitation and pain or distress ...erm so yeah that lady will always stay with me that I think a little bit more could've been done erm but she still had me holding her hand and talking her through and making sure no not making sure everything was okay, but trying to ease as much as possible that everything was going to be okay erm but yeah that was quite difficult I think a couple of years ago.

6:3.8   A Stranger at Home

Josie's and Margaret's narratives recall the death of a gentleman who has only come to the home for a short stay and about whom little is known, other than that he has a special religion. It is unclear what this is but when he dies unexpectedly the staff follow instruction to call his religious leader, and to wait until the necessary end of life practices/rituals are completed. Josie questions whether she should have noticed that this man wasn't very well.Margaret describes not being able to do anything to the body after death, and the strangeness of not knowing what has occurred in the room as the person designated was left alone with the deceased. Margaret feels compelled to stay until after the end of her shift (it was evening), waiting until the ritual is completed to go home.

6:3.9   Difference

Other stories of difference include Josie's account of a Cantonese gentleman who has many relatives visiting and bringing him food, and Lisa's concern about a Jewish resident whose Rabbi has to be contacted to prepare the body after her death. Lisa is concerned because she has known this resident for some time and feels that she would not want her body, including faecal matter, to be given such intimate care by someone Lisa considers to be a stranger.

6:3.10 Choosing How to Die

The narratives include references to the importance of residents having a DNR in place and the potential consequences if they don't. In addition, Josie tells of a lady who refuses peg feeding (Josie's care home don't offer this) so that she can return to the care home for end of life care. This means that whilst carers are unable to give her any food or drink, they can care for her until she dies. Josie feels that this resident has a nice death, in keeping with what she has chosen.

6.4   Conclusion

Rather than criticizing staff, we need to understand why and how complex emotions enter into care work.

(Jones et al., 2008)

Whilst some of the end of life stories included represent what might be considered sad yet rewarding (ELCS), others are far less straightforward. It is likely that some deaths will be too painful to think about in the absence of a safe and containing space. They happen in the moment and those present respond as the situation requires at the time, and yet the circumstances and emotional demands involved will mean that unconscious defences are drawn on to a greater or lesser degree simply in order to cope. The deaths are then recounted as events rather than reflected upon as experiences, limiting opportunities for processing and thinking about the detail of the care given at the time. In combination they convey something of the range and complexity of the lives of care home inhabitants, and the extent of the skills and qualities that those involved in the delivery of care require in order to respond attentively and compassionately to each individual. When the prevailing conditions make it possible for a carer who has become familiar with the processes involved in the end of life, and who is in that moment not afraid and can be present without, or with less need to defend the self, then the care given can be focused more fully on the needs of the person who is dying. Kahn's (1992, p. 322) concept of psychological presence is particularly relevant here and will be considered further in the conclusion to Chapter Seven and again in the conclusions drawn in Chapter Eight.

Somewhere in between the 'good death' and the death that is too painful to be thought about, is the possibility of a 'good enough' death that allows for a good death to be held in mind and strived for whilst accepting that for varied and often complex reasons, including the life that the dying person has lived, this may not always be possible. It is an idea that draws from Winnicott's concept of the 'good enough Mother' (1953, 1971) and takes into account the context of the dying person's whole life and in particular how they may want/choose to die.

A final thought and one that will be returned to in my conclusion, are the references made to belief and ritual. These include the idea expressed by all participants that no one should die alone; the idea of opening a window when someone dies and the sense that this might be common practice; and the practices that are not rituals in the sense of being applied to all deaths but that might represent a sense of ritual for a particular death, as in the cases of favourite music being played, holding the dying person's hand and stroking the dying person's head. I would suggest that these represent a relationship between the dying person and the person who is alongside caring, and as such have

meaning and emotional purpose beyond the simplicity of the action itself, as does the practice of kissing a resident good night and saying 'god bless'.

7   Chapter Seven – Cross-Case Analysis

Whether everything actually is a part of everything, or whether we have a human capacity for seeing everything as part of everything, it all becomes more complex as it becomes better known, and it cries out for being better known still.

(Stake, 2006, p. 7)

7.1   Cross-Case Analysis Using Questions Developed in Response to the Themes arising from Individual Interviews/Case Studies.

The questions are arranged to address the themes arising and to bring together the findings of the individual interviews in a way that makes it possible to consider similarities and differences and begin to reflect on the meaning of these. The reading of this chapter will be enhanced through close reading of and cross-referencing with the individual interviews where indicated. Themes where it is possible to make generalisations across cases will be addressed initially, with themes that are relevant but less universal dealt with later and before I comment on my findings in relation to all of the questions.

7:1.1   How do those interviewed take up the opportunity to speak freely about the experience of caring at the end of life?

The opportunity to speak freely is mostly taken up with little or no hesitation, although each interviewee responds according to their conscious and unconscious preoccupations. The exception to this is Annie, who is initially apprehensive, requiring me to restate the purpose of my research and leaving me uncertain as to whether or not the interview might continue. There is a point when I realise that Annie has decided to proceed, meaning that the interview begins in a somewhat haphazard way. I recall feeling at the time that I had worked hard to gain some degree of credibility and acceptance as someone who might be trustworthy enough to speak to.

As noted earlier all of the interviews take place within the care home in which each carer is based. No-one considers taking up the offer of an alternative and neutral space, and I am struck by these individual but somehow collective responses, that are made without hesitation and no evidence of doubt about the suitability of each respective care

home as a venue for the interview. At a conscious level there are pragmatic and task related reasons to support such a choice. It means that time is not lost and the interviewee can be called upon if needed, as in the case of Annie and Sarah, and/or return to duties as soon as the interview is finished. At a deeper unconscious or at least unthought and unexpressed level I understand it to be somehow essential that I am willing to enter, at least in part, the environment where care, including end of life care, is given. In each case I have a strong sense that this is a significant factor in establishing the emotional context of the interview.

The interviewees are left to choose where the interview might be within the care home and the choice in each case seems significant and again determined by conscious and unconscious motives. As with other aspects of the methodology, my approach is an attempt to inhabit my role as researcher respectfully allowing those concerned as much control and self-efficacy as possible. There are different levels of entry/access in each case reflecting a range of possible interpretations.

Sarah and Annie are both interviewed in a sitting room off the main entrance and reception area, before the doors that are the entrance into the main living space of the home.

7:1.2. What can the data tell us about how those interviewed came to the role of carer?

Individual motives for becoming a carer include differences and similarities, although each interviewee's taking up of the role is unique to the particular circumstances of the individual concerned. Sarah's change of career is directly related to the death of her father, whilst for Lisa the death of her mother sets in motion a process of connected thoughts and experiences that lead to a change of career and the beginning of a relationship with caring at the end of life.

Josie comes to the role of carer almost by accident and is shocked both emotionally and physically when she experiences her first death.

Margaret recalls her mother's words when she begins to work as a carer:

"You can't even wipe your own arse never mind anybody else's you'll last five minutes"
that's what she said, that's right.

Her first job is in a challenging care environment and she is physically assaulted, a harsh reminder that the word 'care' describes a wide and complex range of tasks (I note that I feel her vulnerability in the interview and feel reassured that she has Josie as her manager, prompting thoughts of caring for the carers).

Annie has her first experience of working with older people before leaving school and realises that this is something that she loves. At the time of her interview Annie is manager of a care home that is an altered version of the care home where she first worked as a carer. During the interview Annie shares her history as a carer and her narrative describes some of the significant changes that have taken place over time in the way that care is organised and delivered. Of all the interviewees she is the only one who lives away from what she considers to be her home (Scotland).

Doreen takes up her first caring role because she has discovered an affinity with older people. Her delight at becoming a YTS employee in a care home associated with the home where she is now manager is evident in the corresponding part of her narrative. As Doreen's narrative unfolds, the extent to which becoming a carer has shaped her conscious and unconscious life/world becomes evident.

7:1.3   What does the data tell us about how those interviewed inhabit the role of carer?

Within the framework and standards of care (Care Standards) each interviewee inhabits the role of carer uniquely and yet there are generalisations that can be made. The dictionary definition of 'inhabit' is 'to live there', and an example given is of actors who become the character/role as if they live the life of the character. I have chosen to use inhabit as a way of describing the sense expressed individually, and yet with similar effect in each narrative, of coming to the role of carer as a life choice with an identification that goes beyond a particular job or place of work.

Although the 'quintain' includes managers and senior carers, each one has worked as a carer before progressing further and it is the self as carer that dominates the narratives. Josie has been a carer in the same home for eighteen years and describes a process of

change from a time before taking up the role, when she had no patience and couldn't imagine dealing with someone else's poo, to starting to love the job and finding that 'something in me changed'.

Having previously been a carer in a more challenging setting, Margaret inhabits the role with the knowledge gained from painful experience that there are limits to her capacity to care. Margaret's narrative includes ambivalence and contradiction. At one point she confesses that she is scared to death of dying but at the same time loves being a carer in her current role. Margaret's narrative demonstrates the significance of a facilitating environment and the need for containment.

Doreen approaches the role of carer with a youthful exuberance that remains but is transformed through years of experience into an emotionally and physically engaged taking up of the role of manager (hands and heart on), whose embodiment of what it means to care extends to all aspects of her life.

Annie takes up the role as a young adult and continues as a manager in an updated version of the care home where she began her career. Annie's embodiment of the role of carer is multi-dimensional, representing the complexity of the role and the demands made of those who take up the position of boundary spanner between systems of care.

For Lisa and Sarah the move to becoming a carer as previously noted is in response to the death of a parent, and in both cases the close lived experience of being present at the death of a parent. Their respective embodiment of the carer role conveys something of the complexity of conscious and unconscious motivations that underpin all of human behaviour and actions (Bollas, 2018). Although Lisa changes career to become a carer she has subsequently gathered a number of years of experience of caring in different settings, including nursing homes. Recognised by an appreciative relative as possessing nursing skills, Lisa is quick to identify herself as a carer with a heart rather than a nurse, suggesting her complete physical and emotional embodiment of the caring role.

Sarah appears to inhabit the role of carer, particularly for those at the end of life, with a passion and energy directed towards the father for whom she feels she might have done more. Her sense that she will never have enough time suggests a grief that remains unresolved. Lisa's narrative indicates that she has had more opportunity to work

through her loss, but as with all loss and grief the reasons for this will be specific to her particular circumstances, including the meaning of the loss. One possibility is that the long illness Lisa describes before her mother dies allowed for grief work to be done pre-bereavement and that Sarah retains the sense of shock and denial that she describes as at the time of her father's sudden and unexpected death.

Fully inhabiting the role of carer appears to involve a process of becoming a particular kind of person.

7:1.4 What do those interviewed communicate about their experiences of end of life care?

There is so much to capture here that I am concerned that I may be unable to adequately represent the full range of findings. What follows is my best attempt to represent what is communicated about the experience of caring at the end of life in each narrative. More may follow as an addendum if I come to find this necessary at a later stage.

Josie describes her first experience of a resident dying and the psychosomatic shock she sustains in response to this event at the beginning of her narrative. A significant factor seems to be a lack of preparation and the circumstances of the death, which appears to be unexpected at least to Josie, and occurs in the midst of a busy lunchtime. Josie describes the difficulties managing the body and her surprise at the way the body responds. Josie's narrative details the end of life circumstances of eighteen residents and includes deaths where Josie is present as well as examples of cases involving wider systems of care or other carers, highlighting some of the difficulties/issues that can arise.

Read collectively they communicate something of the range of circumstances that caring at the end of life can involve as well as information about the physical and emotional demands placed on the carer. Emotions experienced by Josie include shock, guilt, feeling awful and regret as well as sadness and the satisfaction of knowing that a resident has had a comfortable pain-free death in keeping with what they wanted. Josie also describes a familiarity with death itself that makes it possible to sit beside residents in their final hours and to be with them at the point of death (see case study), whilst

acknowledging the 'not nice' feelings aroused when a resident appeared to die in some degree of pain.

Margaret's narrative includes personal and professional experiences of the end of life although it is the professional ones that Margaret appears to have the closest direct involvement with, as her mother-in-law and grandfather both die in hospital. Margaret communicates a commitment to and love of caring at the end of life. Despite this, when Margaret speaks of more personal experiences of end of life the fear of dying that she expresses for herself becomes more tangible. It is evident that Margaret has a good and supportive relationship with Josie, and I sense that this is a factor enabling Margaret to cope with the demands of caring for residents at the end of life. Margaret describes herself as hardened to the work but this is contradicted by her emotional responses, which are conveyed with a tenderness (she likes to engage with patients) that communicates a sense of openness and an element of vulnerability.

Annie's narrative is dominated by many of the challenges she faces as a manager of a care home where the majority of residents have some degree of dementia. Annie is a fierce advocate for her residents and battles hard to ensure that their needs are met as fully as possible by the wider systems of care. Annie communicates something of her personal experiences of the end of life as she describes the respective illnesses and deaths of her parents. Annie's narrative includes a number of end of life stories including those of her parents. Each is communicated from a similar position that seems to represent a need to defend the rights of the individuals concerned. I am left wondering if this is how Annie copes with what might represent 'an impossible task' that, without the energy required to do battle, would seem overwhelming and even hopeless because of its deep unacknowledged connection to the loss of her parents.

Sarah's narrative is intense and infused with the loss of her father. Spoken with a strong sense of purpose that drives her efforts to be attuned to the needs of those at the end of life, it suggests an emotional connection to the work beyond vocation. Sarah emphasises the personal aspects of care and stresses the importance of finding out what has mattered to the person being cared for. This includes the smallest intimate details such as preferred perfume, preferred sleeping arrangements and musical preferences.

Descriptions of care given in her narrative include the use of touch, the importance of communicating with the person even though they may be in an unresponsive state, and

the significance of the small caring touches such as giving a comforting goodnight kiss, as a mother might to a child. They are evidence of the capacity to be attuned to the state of mind of the individual concerned and to ensure that others who might be involved in their care understand and respect this. The emotional cost of caring in this way is apparent when Sarah speaks of her emotions following the death of a resident.

Where other narratives refer to caring about residents 'as if they are your nana or grandad', Doreen is actually caring for her nan who is one of the residents, as is her nan's sister. It would seem that the presence of a close relative enhances Doreen's capacity for thinking and feeling about end of life issues for all residents because they become, or are already, personal. Communicated within Doreen's narrative is the sense that care has always been this close, suggesting something of Doreen's earliest experiences of care and her inner world.

Doreen openly acknowledges her anxiety about the anticipated death of her nan, understanding that she will be vulnerable and in need of support when this happens. Her understanding of the needs of relatives and significant others at the end of life is indicative of a capacity for identification with others that can tolerate and make space for differences as well as similarities (Hollway, 2006, p, 21).

It is evident that Doreen has learned much of what she knows about caring at the end of life from experience and observing others, including care that she has considered disrespectful. The importance of reflection to support this learning from experience is emphasised, as is the need to take action when appropriate. Doreen's narrative communicates the emotional impact of caring at the end of life both for her and for other carers/workers (as well as residents and their families) and gives a strong sense of her capacity to remain open and available to herself and others, suggesting that she has developed effective ways of processing the psychic pain involved.

Lisa's narrative communicates the range and complexity of emotions involved in caring at the end of life, from sadness through to the sense of reward that comes from being able to care for the dying person in the way they wish to be cared for, and the understanding that other staff may be frightened of being close to death and dying. The importance of finding out about the wishes of the person is emphasised throughout and

Lisa describes a number of ways this kind of care might be given, including responding to requests for a particular food wish even if what is asked for is unlikely to be eaten.

Lisa speaks of tenderness and closeness as well as the passion that she has for caring at the end of life. This is in contrast to her sense of the lack of any personal touches in the care that her mum received when she died in hospital. The impact of this experience, lacking in comfort, cosiness or passion, is powerfully communicated and informs the quality of the care that Lisa wants the residents to be given at Lavender Hill. In communicating what is offered to families, Lisa chooses the words comfy and cosy in a way that conveys the absence of both for her at the end of her mother's life.

Lisa's narrative communicates a deep engagement with end of life including thinking about her own death and funeral, the subject of euthanasia and being alongside others, including a younger disabled person, as they reach the end of life.

7:1.5 What observations can be made about the emotional experience of each interviewee?

Whilst each interviewee's emotional experience is unique and difficult to fully capture in a relatively brief interview, a level of emotional experience is present in all of the narratives that relates directly to caring for those at the end of life. I am reminded of a quote from Julian Barnes' book *Levels of Life* (2013) in which he writes about his experience of the loss of his wife:

> *Early in life, the world divides crudely into those who have had sex and those who haven't. Later into those who have known love, and those who haven't. Later still – at least if we are lucky (or on the other hand, unlucky) – it divides into those who have endured grief, and those who haven't. These divisions are absolute; they are tropics we cross.*
>
> (Julian Barnes, 2013, p. 67)

There are divisions between those interviewed. Three have lost parents and responded with the uniqueness and similarities that define grief, whilst others remain more or less anxious about the prospect of facing significant loss. And yet all of those interviewed have cared for those at the end of life and been present when a person has died, and it seems that this experience may represent another tropic we cross. I would suggest there is a level of life defined by engaging with the lived experience of caring at the end of life.

7:1.6 What states of mind are represented in the respective narratives?

The descriptions of the states of mind represented within each interview take into account the ever-shifting nature of mental states represented in the work of Klein and Bion. It is also worth noting that the interview conditions represented a facilitating (Winnicott, 1965) and potentially containing (Bion, 1961) environment, making it possible for the interviewees to speak in a relatively stress/anxiety free environment (Winnicott, 1965) supporting a predominately mature state of mind. Other states of mind emerge as the interviewees speak freely about their experiences of end of life.

At the same time and as Waddell (2002) notes, each person's experience has its own complex specificity and this is apparent throughout. Taking this into account, it remains possible to identify and represent the states of mind or positions from which each interviewee experiences caring at the end of life (see diagram 5).

Margaret's state of mind oscillates between the paranoid schizoid and depressive positions. There are times when her anxiety about death and her own mortality come to the surface, as does her need to form a relationship offering some degree of reciprocity. Margaret's narrative suggests that the presence of a mature and emotionally supportive manager (Josie) enables her to hold the depressive position with a sensitivity to the needs of others that stems at least in part from her own vulnerability and emotional ability.

Josie's state of mind might be described as more stoical suggesting that she can hold the depressive position securely and to the benefit of others. It is when Josie describes experiences involving anxiety and close personal contact with those at end of life, including her first experience of close contact with a dead body, an unsuccessful resuscitation, and her failure to contact a GP following a death, that oscillation to the paranoid schizoid position becomes apparent. This is also apparent when she speaks about the possibility of seeing the dead body of a close relative and when she imagines her own death.

Annie's narrative represents more complex states of mind, where the depressive position has a manic quality that serves to defend Annie against the full impact of her personal

losses. In addition it is possible that Annie introjects the psychic distress that is projected on a daily basis by residents who have lost or are losing their minds, and that with little opportunity to process these experiences and the unconscious psychic pain involved, this is defended against through action.

Sarah's narrative suggests a state of mind dominated by the working through of the depressive position, and at times she appears overwhelmed by the reparative urges that represent one of the main methods of overcoming depressive anxiety. From this state of mind/position she offers care that is almost exquisitely attuned to the needs of the person being cared for at the end of life. The emotional cost of caring with such intensity is hard to quantify but suggests the value of emotional support in bearing the psychic pain that connects so closely to the death of her father, if this quality of caring is to be sustained over time. Indeed I would suggest that in the absence of this, stress and burnout might become inevitable, particularly if other close personal loss occurs or a work situation arises in which Sarah is flooded with intense and unmanageable anxiety through symbolic equation (Menzies Lyth, 1988, p. 50).

There is a sense that Doreen has lived her life from the depressive position and I am curious to know more about her early life and experiences of being cared for as a baby and small child. Rare retreats to a more paranoid schizoid position communicated in her narrative retain elements of a depressive state of mind, as she balances concern for her own emotional needs with efforts to ensure that others might meet the needs of those whom she is temporarily unavailable to. It would seem that her years of experience as a carer have produced a particularly mature state of mind and as she proudly claims, an embodiment of the role of manager that may or may not be typical in a care home setting.

Of all of those interviewed Lisa appears to have worked through the depressive position by way of a deep engagement with death, including a consideration of her own mortality, to what I describe as the tragic position (see Chapter One). From this position it would seem that she is able to be sensitive to the needs of those at the end of life, recognise the needs of others who are less familiar with and may even be frightened by death, and act as a container for their anxieties and emotional distress. There is some evidence to suggest that the organisation in which Lisa is employed offers a level of emotional support that may contribute to her state of mind.

7:1.7 Does the data provide evidence of anxieties and defences in response to caring at the end of life and if so what forms do these anxieties and defences take?

The data does provide evidence of anxiety and defences. On the whole the anxieties and defences are depressive although in particularly stressful moments/situations more paranoid schizoid defences become apparent. From the depressive position defences appear subtle and relatively benign. It should be remembered that defences are not necessarily pathological and at times the form taken is not inappropriately protective, particularly if the defence enables the carer concerned to maintain their emotional equilibrium. I include doing paperwork whilst sitting alongside a dying person as a particular form of depressive defence and one that may be appropriate to the situation if it makes it possible to remain alongside the dying person. This is probably a whole area for further elaboration and discussion.

See question 9 for a discussion of care, identification and the unwitting defences that might be mobilised in the face of painful feelings. It is interesting and relevant that Hollway selects the example of a dying person to illustrate this (2006: 15).

7:1.8 What can the data tell us about how anxieties are contained and understood?

Perhaps most striking across the narratives is what appears to be an absence of more formal structures of support that offer acknowledgement of and containment for the emotional aspects of caring at the end of life. Whilst each narrative contains evidence of informal structures of support these vary between the care homes represented and form a significant aspect of the culture of each.

In the relatively small care home where Josie and Margaret are manager and senior carer, and the staff group is relatively stable and close-knit, a degree of containment appears to be offered through familiarity and friendship. There is little sense of a formal hierarchy and Josie's approach to her role and engagement with the primary task makes her an accessible source of support. When transcribing Josie's narrative I noticed a typo. Rather than 'manager' I had typed 'Momager' and at the time decided this was an almost Freudian slip that captured my impression of the management styles of both Josie and Doreen, and their respective embodiment of the carer/manager/mother role.

Doreen's narrative suggests that she considers responding to the emotional needs of staff to be a significant part of her role. Doreen considers the home to be her home and her taking up of the manager role is well represented by my typo. Both narratives suggest that anxiety is contained at least to some degree by their presence and respective capacities to respond emotionally to the anxieties aroused by the work. At the same time the emotional environment offers some level of containment.

The demands of the care environment communicated in Annie's narrative suggest that the work can involve high levels of anxiety on a daily basis. Annie's role as manager involves her in various potentially boundary-spanning activities, many of which are related to caring for residents at the end of life. Whilst some relationships with the wider systems of care involved are supportive others are problematic and anxiety provoking, either because of defences inherent within parts of the system or the defended behaviour of particular individuals, or at times a combination of individual and organisational defences. Some of Annie's frustration relates directly to the failure of collaborative working because of these defences. Although Annie has access to a supportive management structure, she appears to gain more emotional support and containment from the psychiatrist who visits to help the care team think about the needs of residents. Few if any opportunities appear to be available for personal reflection and containment.

Sarah is a senior care worker in the same care home/complex as Annie. Whilst Sarah's anxieties are deeply personal and stirred by her particular relationship with the end of life and its associated losses, her emotional needs are identifiable and understandable within the theoretical framework underpinning the project. Sarah has an emotional openness and potentially obsessive commitment to the work, creating the conditions that make the possibility of stress and burnout more likely and highlighting the valuable, and it could be argued essential, nature of an environment offering space for reflection and containment. Instead Sarah's narrative conveys a sense of alienation and isolation as she is left to process the most painful aspects of the work alone.

Lisa's narrative has a different emotional quality suggesting that many of the anxieties stirred up by closeness to death and dying have been faced and accommodated. It would seem, as Cooper suggests, that the tragic is an effort at 'learning from experience', at achieving some better mastery of complex human predicaments and dilemmas (Cooper, 2018, 9), in this case that of facing and being able to be with death without anxiety.

7:1.9 What do the narratives tell us about how those interviewed experience the concept of home?

Something of a split is represented within the narratives between those who project their own experience of home into the care home and those who consider the care home primarily in terms of the residents. Evidence of this can be found in the individual case studies. It is an observation that connects directly with the psychoanalytic concept of identification (Hollway, 2006, p. 14). The capacity for identification is connected to empathy, compassion and concern for others. However as Hollway notes the possibility that accurate identification might be compromised is a concern, particularly in situations involving painful feelings (see responses to question 10).

7:1.10 What if any observations can be made about personal/professional boundaries**?**

Whether conscious or unconscious the narratives suggest that the boundaries between the personal and professional are particularly fluid, not only at an unconscious level but for all of those interviewed conscious and enacted in some way. The effects of such fluidity include the caring as if it was your nana (Doreen), grandad, grandma (Margaret, Josie), mother or father (Doreen), physically caring for family members within the home (Doreen) and working alongside family members (Doreen). Further evidence of this as accepted practice at least in some care homes can be found in Margaret's narrative when she speaks of a carer whose mother became a resident and died in the home. Both Josie and Annie remark that when they reach a certain age they will simply become residents within their respective care homes.

Speck writes that 'one of the unconscious attractions of working with dying people is that the work-role can serve to maintain the fantasy that death only happens to other people' (Speck in Obholzer and Roberts, 1994, p. 94). Caring for vulnerable people at the end of life serves to emphasise the universality of death and brings those caring in that environment close to personal mortality, with only the defence of degrees of youth as protection. The narratives of those interviewed represent a range of deeply personal and individual positions in relation to this knowledge and these positions determine the extent to which each individual concerned can engage with those at the end of life, contain the

anxiety aroused by close proximity to death and dying, and support others who may be less experienced and/or anxious and afraid.

7:1.11 What can the narratives tell us about what might be considered to represent a good death?

Each narrative contains an example of or in some cases examples of what each narrator thinks of as a good death. For Lisa and Sarah their understanding of what this might involve has grown from their personal experiences of death and dying and a felt lack of things that would have made the death of a parent more bearable at the time. Josie has only been introduced to the concept relatively recently during hospice based bespoke training and yet has a number of examples of what she now understands to be a good death. Although Margaret seems less convinced that death could be good she is also clear that for her someone being present with the dying person is a touchstone.

The good death that Annie refers to is that of her mother, in her own home, pain free, with GP and carer support available and with Annie present, although interestingly this death is described briefly and almost in passing. It is only now that I realise it is probably one of the most concise and accurate examples shared. Doreen's narrative includes a number of examples in which it is quietly apparent that she has been instrumental in creating the circumstances of a good death, suggesting that she has a strong sense of the concept gathered from years of experience. Other narratives (Annie, Josie) suggest similar, with key interventions including steps taken to ensure a resident can remain in the care home rather than being removed unnecessarily to hospital.

Each care home makes it possible for relatives to be present and to stay for as long as necessary whilst also recognising that for some this is too much, and as noted earlier aims to ensure that for those who are alone someone is present. Some of the most moving accounts of end of life involve the narrator being present in the absence of family or significant others (Josie, Doreen). Sarah and Lisa's narratives highlight the significance for them of the personalised care that is attentive to the needs and preferences of each individual, and they speak of using creams and scents and personal items, in creating the conditions that they consider an essential component of a good death.

7:1.12 What does the data tell us about the impact of The End of Life Strategy? With particular reference to:

a) The systems of care referred to in the narratives.

The end of life care strategy has implications across health and social care services although some services are more closely connected and implicated than others. Those referred to within the narratives include: district nurses, GPs, Hospitals (in particular emergency admissions and admitting wards), the ambulance service, Community Mental Health and other specialist teams within the health service such as MacMillan Nurses and the SALT team. Each narrative emphasises the essential role that district nurses play in making it possible to provide palliative care in the care home for residents at the end of life. The narratives suggest a level of cooperation and communication that is appropriately focused on residents whilst offering a degree of mutual support through the quality of the professional relationships built as a result.

GPs are equally significant and yet for a number of reasons their involvement appears at times to be more problematic. Some narratives indicate possible reasons such as: individual differences between GPs (Annie), a lack of understanding of the needs/condition of residents and for some a degree of fear (Annie), and the systems for allocating GPs to residents who move in to a care home (Josie). Locum GPs who don't know a particular resident can cause difficulties including unnecessary admissions to hospital (Josie) whilst it is also apparent that there are examples of GPs who know the residents and have built good relationships with the carers and care homes (Margaret, Annie, Josie, Doreen).

Some of the difficult deaths included in Chapter Six highlight points in the system where bureaucracy including paperwork can distract from the needs of the individual, leaving all concerned in potentially difficult and distressing situations, such as when an attempt has to be made to resuscitate in the absence of an advanced directive/required form. In the same way ambulance crew seem to be required to transport a resident to hospital once they have been called out. I realise in writing that I am now unclear about why this has to be. It appears to be an area where the course of care can be altered by one action and is one of the areas of confusion identified in Annie's narrative and case study.

These areas of confusion include the need for DoLS (considered not fit for purpose in 2014 and to be replaced by Liberty Protection Safeguards when time allows), and the amount of paperwork required before a resident lacking capacity and requiring restraint

beyond the scope of the Mental Capacity Act, 2005, can be transferred or admitted from hospital. Local Adult Safeguarding teams can support and advise but this remains a complex and demanding aspect of care for care home managers. Annie's narrative in particular refers to the amount of time taken up by such issues and the unhelpfulness of other bureaucratic measures, including the CQC's monitoring of deaths in care homes that seems unable to acknowledge that one of the aims is for more older vulnerable people to die in their preferred place of care. Annie is disbelieving when told she is in the red.

b) Those interviewed.

The overwhelming message from the narratives is that whilst the End of Life Care Strategy offers a framework to support the delivery of end of life in care homes, caring at the end of life is not new to any of those interviewed. The framework, with its associated developments including the introduction of a 'just in case box', clear protocols around decision making, increased access to hospital beds and the support and input of community-based district nurses and other specialist teams, is welcomed by those interviewed.

Josie, Margaret and Doreen specifically refer to the bespoke training delivered by members of the education team from the local hospice as part of the regional project to improve the quality of end of life care. Lisa's narrative details her longstanding interest in end of life care and both Doreen and Lisa have had direct experience of hospice-based end of life care prior to attending the training. It is a picture that confirms the feeling, shared by the palliative care educator interviewed in preparation for the project, that at least in part he will be 'teaching aunty/granny to suck eggs'. It is probably worth acknowledging that there is always value in being able to suck eggs better and for care staff to have the time and opportunity to develop, reflect on and extend existing skills and practice.

All interviewees welcome the move to enable more people to die in their preferred place of care and are keen for residents who are nearing the end of life to be cared for in the place they consider to be their home. Although not always specifically stated in the narratives, the descriptions of care given at the end of life suggest that being able to care for residents to the end can be deeply satisfying particularly when the conditions represent what is perceived to be a 'good death'. Conversely when residents die in hospital or in one

case in an ambulance on the way to hospital, sometimes perhaps unavoidably, regret is felt and the experience remembered even after many years.

7:1.13 Do the narratives contain evidence of mature and creative responses to the end of life?

The narratives contain a number of examples of care given at the end of life that move beyond simply being present, and represent the capacity to be present and sensitively attuned. It is a distinction that highlights the complexity and subtlety or delicacy (Kahn, 1992, p. 346) of some of the defences detectable in the narrative accounts, and signifies the possibility of a third tragic position reached through the processing/working through of personal suffering.

The potential for the paranoid schizoid position to dominate or at least be in oscillation with the depressive can never be discounted, and it is apparent from some of the descriptions of end of life experiences that in certain circumstances those concerned will be physically and emotionally overwhelmed by the events surrounding a death. Conversely when the end of life experience is expected, the person is known and the carer is comfortable and unafraid and/or appropriately supported, care is more likely to be given from the depressive position and appropriately focused on the needs of the person who is dying.

In certain circumstances when the carer concerned is fully in touch with the tragic position, the care given might be particularly sensitively attuned to the needs of the end of life situation. In the absence of defences the needs of the dying person in their environment can be engaged with creatively and the possibilities of the caring relationship and the unique and particular death of the individual fully realised.

It becomes apparent that it is only when death no longer has to be defended against, that a space emerges for a particular death to be thought about and responded to with the needs of the dying person in mind.

8 Chapter Eight – Findings and Conclusions

There is but one freedom, to put oneself right with death. After that, everything is possible.

Think constantly and fearfully about death and you will be miserable. Think carefully about death and you can find a meaning which will enable you to face life.

8:1   Findings/Assertions

This small group of carers are bound together because they share the experience of providing end of life care in a care home setting. Reaching a deeper understanding of the emotional experience of this group of individuals, and from that to make tentative assertions that might apply to the wider group of care workers providing end of life care in care homes within the aims and objectives of the end of life care strategy, is perhaps overly presumptuous. However a number of assertions follow formulated with reference to both the particular and the general findings emerging from my processing of the data following the methods described in Chapter Three. They are that:

- Within a facilitating and ethically bound interview environment the opportunity to speak freely about the experience of caring at the end of life was valued and taken up fully, giving voice to a group of people who despite their significant contribution to society are perhaps less frequently heard than others.

- The opportunity to ensure more residents can die within the care home if this is their preferred place of care is valued positively and actively pursued.

- Each participant considers the role of carer as significant if not central to their sense of identity suggesting that by engaging in the practice of care, caring can become a disposition and a way of thinking and doing (Hollway, p. 10, loc. 415).

- For those interviewed caring at the end of life is considered an integral part of caring for older vulnerable people in care homes, and being close to death and the end of life is not a new or even unfamiliar experience and for some has been an essential part of being a carer from the beginning.

- As such death and the end of life have become more familiar and therefore in general less defended against than anticipated, although with different positions represented in each participant's relationship with death.

- Defences can be identified and there are patterns to these that are helpful in understanding individual relationships with/to the end of life.

- Caring and being cared for at the end of life involves a relationship and the quality of the relationship will be determined at least in part by the relationship that each person has with death and dying.

- The nature of each individual's relationship with death is determined by unique personal characteristics and experiences including the extent to which losses, including close personal losses, have been mourned and integrated.

- There are degrees of vulnerability, resulting from certain losses, and in particular what might represent traumatic loss, involved in caring at the end of life that require the most robust of emotionally containing structures for carers to be adequately supported.

- The relationship each individual has with death is not static and the positions and states of mind held at any time are subject to oscillation(s) depending on the complex dynamics involved in caring for others and the demands of each life and end of life situation encountered, whether it is in a professional or personal context.

- There is evidence of a third tragic position (Lawrence, 2000; Symington, 1986) contained within the data and further elaborated throughout the thesis. Defined as an acceptance of death including personal mortality, it is a position or state of mind supporting a capacity to be fully psychologically present (Kahn, 1992) for/with others who are facing death and the end of life. In other words to be with dying rather than compelled to defend against it from either the paranoid schizoid or the depressive position.

- Caring from what I have proposed as the tragic position creates the capacity for reverie/attunement with the dying person. Indeed it represents the position/state of mind that makes this possible.

- Whilst the concept of a good death is helpful and something to be strived for, the concept of a 'good enough' death may be helpful in managing the reality of what might be achievable within a particular set of circumstances, including what might have been a difficult life and death.

- The words sad and rewarding (ELCS) don't fully convey the range of emotions involved in caring at the end of life or the range and variety of end of life situations occurring in an everyday care home on a regular basis.

- An understanding of and access to the tragic position as defined in the thesis, is relevant to all aspects of end of life care and has the potential to support and sustain the vision and aims of the End of Life Care Strategy.

8:2   Additional Findings/Observations Relevant to the Thesis

- There is evidence to suggest the homely environment of the care home makes it possible for individual authority in role to be held more securely than in larger and more hierarchical settings.

- Kinship emerges as a model of care where the boundaries between the personal and professional are understood and permitted to be more fluid and permeable than in models that emphasise professionalism.

- Where the systems of support within a care home are informal and based on friendships and longstanding relationships between colleagues, the care home may come to represent something of a closed system making it difficult for others to enter and gain the support necessary to care effectively.

- Whilst humour, including black humour, can be a valuable and at times not inappropriate defence, in the absence of opportunities to reflect on painful

experience from a more vulnerable position it can limit opportunities to fully process emotion.

- Despite the range of sensitive and death-accepting practice, there appears to be limited opportunity for reflection and the processing of loss beyond the informal or deeply private. The informal risks a degree of desensitisation, whilst the latter can create a sense of alienation and isolation.

- There may well be benefits from being on the edge of wider health and social care provision and care homes have much to offer to collaborative relationships beyond traditional hierarchical relationships. A significant aspect of this positioning is a greater acceptance (depressive/tragic position) of dependency and death.

- It is difficult to quantify and fully honour the often skilful and complex work undertaken with close relatives and significant others shared in the narratives as part of the care of the dying person. The theoretical framework underpinning the project offers strong evidence of the benefits of such work in supporting the process of grieving and in enabling those concerned to maintain emotional equilibrium as assumptive worlds are disturbed and/or shattered.

- In some cases and situations one person can make all the difference to how a life ends.

8.3 Surprising the Soul

Many of these findings are worthy of further discussion or even becoming the subject of another research project. However, in drawing my final conclusions I return to my original hypothesis and the aim of the project that developed as a result. I posed a number of questions under the heading of the project, and designed a methodology to support my aim of reaching a deeper understanding of the experience of those providing end of life care in non-specialist settings. The data gathered subsequently from a small number of carers has produced an abundance of rich, multi-layered narratives of experience represented in the body of the thesis. My conclusion reflects on the answers to the questions posed, the extent to which they have been answered, and my position as

a defended researcher researching the subject that, evidence suggests, we are most defended against.

As I write, my sister and her husband have just returned from a week spent caring for his mother. She is eighty-six years old, recently diagnosed with Alzheimer's and struggling to cope after a period in rehabilitation following two falls at home. The 'Reablement' Team have been working to get her back on her feet but during the last week at home she has often been in severe pain and distress. Her three sons, whose father died suddenly when the eldest was thirteen and the youngest five, are all struggling to come to terms with their mother's decline. Although one son lives close by he works full time. They are all considering the option of residential care.

As an end of life story of our time it connects with others told here and some version of it will be experienced by many of us at some point in our lives. How the next weeks and months are negotiated will be determined by the capacity of all concerned to face the inevitability of her death and respond to her increasing vulnerability and dependency, whilst negotiating the complex array of choices that make it possible to avoid and deny death until the very end (Dartington, 2008; Gawande, 2014).

The opportunity to surface the potential and creative possibilities contained within care homes has surprised my soul (Lawrence, 2000) and shaped the recommendations made at the end of the chapter. Being practice-near has made it possible to reach a deeper understanding of the carers and organisations studied and to glimpse the hope identified by Kubler Ross (1970) as a stage of dying.

8: 4   A Deeper Understanding

The narratives, end of life stories and cross-case analysis representing the heart of the thesis contribute to a deeper understanding of the complex conscious and unconscious processes involved in caring at the end of life, confirming the value of 'understanding-"apprehending" every unique situation or context in its own terms' (Cooper, 2012, p. 440). Along with the complex particularities, significant patterns and resemblances emerge from the unique cases, situations and contexts represented that make it possible to identify a number of generalisations more widely applicable to individuals and

organisations engaged in providing care for those at the end of life, and with relevance to us all.

The concept of psychological presence at work (Kahn, 1992) adds an additional layer of understanding of how those interviewed experience caring at the end of life. Described as a concept that 'subsumes' motivation it highlights the significance and satisfaction of the personal meaning gained from performing tasks and role authentically. It is an appropriately deep and insightful explanation of the passion and commitment to caring at the end of life expressed in the case studies.

Each case study contains evidence of degrees of psychological presence in role which for Kahn (1992) involves being physically present either alone or with others, cognitively vigilant and empathically connected to others within the service of the work they are doing. In the case studies the degree of psychological presence depends on the carer's unique relationship with death and dying. Described by Kahn as an experiential state in which the individual's thoughts and feelings, creativity, beliefs, values and personal connections become available to others, it involves being vulnerable, taking risks and feeling anxiety.

For those caring at the end of life being fully attentive means not needing to defend against the anxiety involved, having empathy through the process of projective identification and access to all aspects and dimensions of the self beyond the boundaries of internal defences (Klein, 1959; Menzies Lyth, 1975). It also means being vulnerable, taking risks and having the capacity to bear the anxiety stirred up by close proximity to death.

8:5   Death, Dying and the Tragic Position

The experiential state of being fully there and fully vulnerable during role performance in caring at the end of life connects directly with the state of mind represented by the tragic position, elaborated and tracked throughout the thesis. Both are influenced by the delicate interplay between individual and situational factors including the conditions created by organisations. Kahn describes his model as delicate, in that psychological presence may be fleeting, and yet robust in understanding how individuals occupy their

roles. It is useful to think about the states of mind and positions that determine the quality of end of life care in a similar way.

The unique and complex configurations (see Diagram 5) representing the relationship each carer has with death and dying revealed in the case studies, conveys a sense of the often subtle and at times barely detectable oscillations between the paranoid schizoid, depressive and tragic positions and the complex interplay of personal, situational, including organisational, forces involved. Whilst being close to death and dying creates opportunities to learn from the experience and become less defended as a result, it is this 'delicate' and unique relationship that will determine each individual's capacity to be psychologically present and undefended at the end of life, as will access to the containing experiences that make it possible to process emotionally painful experience.

For those who have acquired a 'tragic view of life' through some form of personal suffering the tragic position becomes a state of mind and position of oscillation, representing what Cooper describes as an effort at 'learning from experience' in the tradition of tragic drama (2018, p. 9). When this learning has involved the experience of death and in particular the death of someone close, then the learning supports a depth of relationship with death that can be accessed to enhance the quality of care given at the end of life. Whether or not this is possible depends on the complex range of factors described.

The tragic position is complex and brings to mind an observation made by Derrida:

> *Every time you try to stabilise the meaning of a thing, to fix it in its missionary position, the thing itself, if there is anything at all to it, slip away.*
>
> (Derrida 1997:31)

Full elaboration will require further time and attention and will be the subject of a future paper. In the meantime attempting to capture it as fully as possible for the purpose of the thesis I propose the following; achieved by way of a close and often intimate experience of death and dying worked through to the extent that the tragic position can be held and used in the service of others without the need to defend against the psychic pain involved. Another possible way to describe it is as 'the capacity for reverie/attunement with those immediately affected in the presence of mortality'.

The significance of the tragic position to every aspect of end of life care cannot be overstated. It is a state of mind from which Keats's (1817) concept of negative capability (when a man is capable of being in uncertainties, mysteries, doubts, without any irritable reaching after fact and reason, elaborated by Bion, 1970) as the ability to tolerate the pain and confusion of not knowing, rather than imposing ready-made or omnipotent certainties upon an ambiguous situation or emotional challenge, becomes possible and accessible.

Many of the failures in communication reported in the various reports and inquiries that document failures in end of life care relate to an anxious reaching for certainties rather than tolerating the anxiety and pain involved in not knowing. In the absence of a mature relationship with death the same becomes true of all communications about death and dying (see appendix 3).

From the tragic position it becomes possible to recognise the subtle and not so subtle ways that defences against death, both paranoid schizoid and depressive, shape responses to vulnerability and dependency, and to begin to consider kinder ways to care for those who will not recover and who we know will become increasingly dependent and in need of total care.

8:6   Beyond 'Sad' and 'Good'

The narratives and end of life stories contain a range of complex particulars (Cooper, 2010) including a register of emotional experience extending far beyond the 'sad' and 'rewarding' used to describe the feelings associated with caring at the end of life in The End of Life Care Strategy. Sad is just one of a constellation of emotions emerging in relation to the end of life experiences represented in the data. Other emotions include shock, fear, regret, distress, satisfaction, pride and overwhelming grief. The complexities involved indicate the need for a wider vocabulary and depth of understanding of the challenges involved in providing end of life care for older vulnerable people.

In the same way, a deeper understanding of the complex range of situations and circumstances determining the outcome of a particular death makes it possible to think beyond the split between 'good' and 'bad' deaths that has tended to dominate recent

discourse. The space in between makes room for deaths and end of life experiences that are better represented by Winnicott's (1971) concept of what might be 'good enough' for a particular person in a particular set of circumstances at a particular time.

8:7   Sites of Meaning and Mourning

In recent years a number of contemporary psychoanalytic thinkers, along with others writing from associated perspectives including neuroscience, have voiced concern about a collective loss of the capacity for mourning (Leader, 2009; Bollas, 2018) and the consequences of this in our society and across the western world. The potential of care homes as places where death can be faced and thought about, losses acknowledged and mourned, and rituals created and observed in ways that offer hope and meaning, is simply and beautifully captured in the experiences of those interviewed, suggesting there is much to be learned from a closer engagement with the end of life and death itself.

Again, the capacity to think about these close and intimate experiences of end of life care is essential if the potential richness, meaning, affirmation of life and possibilities for reparation and redemption that engaging with death can bring about are to be realised as fully as possible.

8:8   Repositioning Care Homes

It is now more than ten years since the ten-year ELCS was published (July, 2008). During the intervening years there has been a range of government led activity including reports, reviews and investigations (CQC, 20016; NCPC, 2015, 2016, IPPR, 2018 are examples) and a range of initiatives across statutory and voluntary sectors. Despite this, whilst it is clear progress has been made and, "compared to the rest of the world, and across the population as a whole, England is a good place to die" (IPPR report 2018), there is a consensus that more needs to be done to rebalance care away from hospitals and towards primary and community care including care homes. Most significantly the IPPR reports that whilst considerable scope exists to improve the way end of life care is delivered, substantial financial investment is needed for this to happen, not least in social care.

In the meantime emphasis has been placed on the need for all staff (specialist and non-specialist) to be prepared to care at the end of life. In 2015 the National Palliative and End of Life Care Partnership identified within a national framework for local action 2015 – 2020. One of the six ambitions is that 'all staff are prepared to care'. Whether or not they are is the title of an NCPC report, 'Staff prepared to care?' (2016). Predating the IPPR report, it emphasises the commitment to workforce planning and development necessary if all staff are truly to care for those at the end of life and the need for social care to be appropriately valued.

With the non-specialist settings and carers represented in the project, in mind, I return to Menzies Lyth and an essay titled 'Thoughts on the maternal role in contemporary society' (1975) in which she considers society's relationship with death with reference to: (Freud 1915, 1917; Klein, 1940; Abraham, 1924; and Gwynne and Miller, 1975). Identifying the personal and private defences and socially structured defence mechanisms discussed in Chapter Two, Menzies Lyth describes the way society splits off and institutionalises problems that are too difficult to confront, impoverishing both the person with the problem and their caretakers in the process.

Her description of the result of this 'that the institutional care takers are not well supported and the quality of care tends to be low' resonates strongly with current concerns about the status and funding of social care, including the pay and working conditions of carers and the quality of some care given. It is an account that offers explanations for some of the primitive, potentially psychotic and destructive social processes of contemporary society stirred up by anxieties about dependency and mortality, including those identified within the NHS by Evans (2015) in Chapter One.

Although the subject of Menzies Lyth's essay is her concern about the context provided by society at the time of writing for the maternal role and those caring at the beginning of life, parallels can be drawn with the context provided by society for those caring at the end of life in the present. How care homes are funded, valued and positioned in the years to come will determine whether the potential contained within the End of Life Care Strategy achieves its full potential. Essential to the process will be a mature acceptance of dependence and vulnerability (Dartington, 2010) and the development of policies that acknowledge our deepest mortal needs.

Caring at the end of life is precious work and my thesis contains evidence of sensitively attuned end of life care indicating that it is not only hospice and specialist care services that can get it right. It is apparent that care homes contain the capacity to shelter souls (Kauffman, 2002), offer kinship and compassionate care (Ballatt and Campling, 2011), model relationship-based approaches to management (Trevithick, 2014) and develop carers who possess the characteristics of effective boundary spanners (Williams, 2012). Supporting and sustaining this capacity will require close attention to the emotional aspects of the work and the application of innovative thinking to the creative space between hospitals and hospices/specialist palliative care services (Winnicott, 1971).

Current constraints on care homes as organisations include low status, poor pay and inequity across the range of care home provision including variable access to training. The thesis contains evidence of both good and good enough end of life care provided and supported by those with the capacity to care from the tragic position. Significant characteristics of the carers concerned include a close relationship with death and dying, acknowledgement of and engagement with the emotional aspects of the work and a strong vocational commitment to end of life care. Facilitating conditions within each care home are variable and primarily created by the personal and professional qualities of the staff available, the quality of support from other professionals and whether or not the home is run privately or as part of a wider not for profit organisation. Creating environments and networks offering support and containment of the defences and anxiety involved in providing end of life care in non-specialist settings will ensure these characteristics and conditions are appropriately valued and replicated across the sector.

8:9   Recommendations:

The findings of the project are timely and have much to offer to the transformation and sustainability of the end of life care agenda. The following recommendations are ambitious in their scope and reach, as well as deliberately politically challenging in the broadest sense.

I believe they are essential to the provision of the quality of end of life care that we would each hope for, and crucial if the intentions and impact of the End of Life Care Strategy are to be fully realised with benefits for all.

1. The findings of the project, including the significance of the tragic position to all aspects end of life care, to be disseminated as widely as possible through engagement with policy makers, end of life care organisations, including those referenced in the thesis, and papers/articles produced for publication in academic and professional journals etc.

2. Training focused on the complex personal and professional interactions identified in the project, including the significance of individual and organisational states of mind and psychic positions to the quality of care delivered, to be made available to all involved in the provision and delivery of end of life care.

3. This knowledge to be used to strengthen the impact of the ELCS through the positioning/repositioning of care homes and social care within the wider provision of health and social care services, with particular attention to issues of funding, equity and consistency across the sector.

4. The emotional aspects of caring to be placed at the heart of every system of health and social care as a matter of urgency.

5. Further research to replicate the project in other parts of the country with carers selected to reflect the diversity of the wider population, and to explore ways in which containing/reflective experiences can be made consistently and sustainably available to all carers caring at the end of life.

6. To ensure the voices of those providing end of life care in care homes, including those offering nursing care, continue to be heard, with all possible forums and methods for optimising opportunities to share, process and learn from experience.

7. A whole life approach to the emotional aspects of human development to be adopted across all major institutions, including health and social care, education and political organisations, including what it means to become increasingly vulnerable and dependent towards the end of life, and the value of becoming a mature adult.

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<u>Appendices</u>

Appendix 1. List of Diagrams

Diagram 1. A Theoretical Framework

Theories of Loss and Grief					States of Mind & Positions	Oscillation Between Positions/ States of Mind
Kubler Ross 1969	Bowlby 1970	Murray Parkes 1971	Worden 1982	Klass, Silverman, Nickman 1996	Klein 1935, 1940, 1946	Bion 1962
Stages	Phasic Model	Phases	Tasks	A New Model of Grief	Developmental and Life Long	
Denial & Isolation	Shock & Numbness	Alarm	To Accept the Reality of the Loss	Continuing Bonds	Paranoid Schizoid	
Anger	Yearning and Searching	Searching	To Experience the Pain or Emotional Aspects of Loss	Continuing Bonds		Lifelong Oscillation Between PS and D Positions Mediated by Emotional Experience Including Love and Hate and Loss and grief
Depression	Despair and Disorganisation	Mitigation	To Adjust to an Environment in Which the Deceased is Missing	Continuing Bonds	Depressive	
Acceptance	Reorganisation & Recovery	Anger & Guilt	To Relocate The Dead Person Within One's Life & Find ways to Memorize Them	Continuing Bonds	Tragic Position Symington 1986, Lawrence 2000	
Hope		Gaining a New Identity		Continuing Bonds		

Diagram 2. Interview Information

Name Gender and Ethnicity	Professional Role	Details of Care Home	History as a Carer	Interview Length	Interview Setting
Annie Female White British	Registered Manager	A large 'not for profit' purpose built home	Thirty five years from carer to manager	1 x 1 Interview over 5 and a half hours	Visitors Sitting Room off the main reception area
Sarah Female White British	Senior Carer	As above A care complex with seventy two beds	Eight years following a career in Retail and the death of her father	Initial interview re-arranged 1 x 1 hour and five minutes	As above
Josie White British Female	Registered Manager	A smaller privately owned home with 20 beds	Eighteen years in the same care home following change of career	1x1 hour and ten minutes	A sitting room that has been made available within the home
Margaret Female White British	Senior Carer	As above	Began to work as a carer when seventeen years old	1 x 1 hour and eight minutes	As above
Doreen Female White British	Registered Manager	A privately owned home caring for up to twenty six residents	Began caring as a school leaver on a YTS	1 x 1 hour and thirty three minutes	A bedroom in which a resident died the previous week
Lisa Female White British	Acting Manager returning to Deputy role	A 'not for profit' care home in a large house	Became a carer in her early twenties after her mother's death	1 x 1 hour and forty five minutes	A training room at the top of the home

Diagram 3 **Data Analysis Process**

Interviews Completed (April 2015 - April 2016)

Transcribed (November 2015 - December 2016)

Coding, Memos and Themes Identified (January 2016 - April 2017)

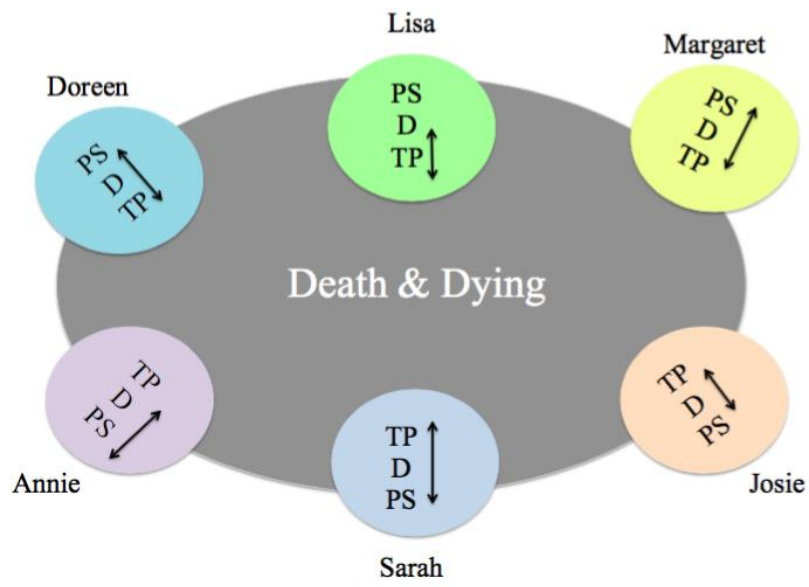Case Studies, End of Life Stories (April 2017 - April 2018)

Cross Case Analysis (May - June 2018)

Auto-ethnographic writing and journals completed throughout.

Diagram 4. Unconscious Defences in Action

Denial -
Doesn't Want
To Know

Inner World
Response

Connection

Pre-occupied

Objective Recognition

Subjective
Reaction
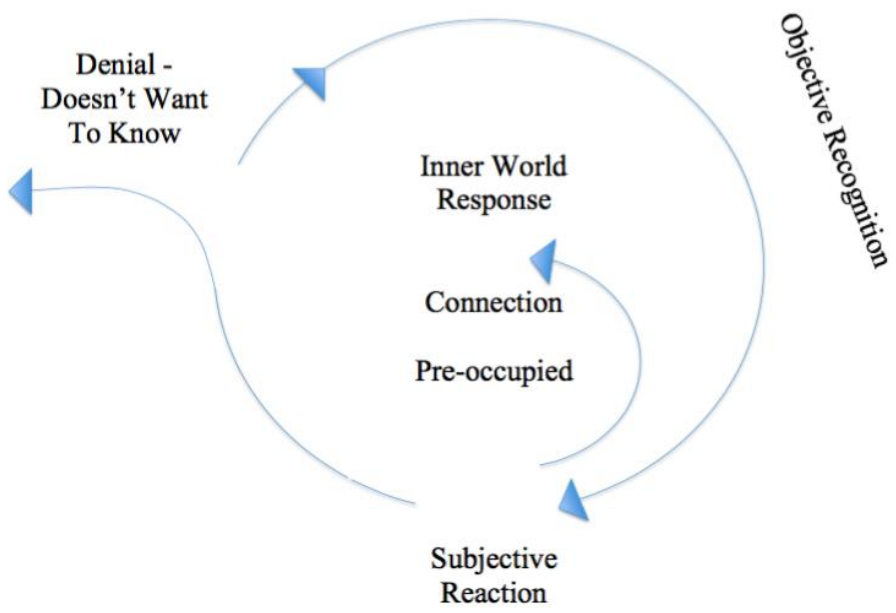
Diagram 5. States of Mind/Positions

Appendix 2. From raw data to theme

My approach to data analysis has followed the stages detailed by Cooper in his working paper Data Analysis 1 (2014) although with some detours (and interesting diversions) made in response to the ideas arising from the different stages of processing and analysis. An example of the route taken in moving from a piece of raw data to a theme(s) is included here.

Stage 1: Excerpt from transcribed interview with Josie

J: So my friend she'd been here since 1990 so she asked if I wanted, I was looking for a job at the time so I started on night shifts here.

This is coded as 'a change of career' with the following memo attached:

Code 1. A change of career

Memo 1: Josie explains that she used to be a painter and decorator (as well as other jobs including working in a fish house) so becoming a carer was 'quite a change'.

Memo 1:a. Josie explains that her parents had said that if she didn't get a job they would kick her out so in the beginning a pragmatic move rather than a career choice.

Stage Two:

Coding across the data obtained reveals similarities and differences in what comes to be identified as the theme of becoming a carer. Codes from each interview are clustered accordingly around this theme prompting a number of questions designed to interrogate the data further. Questions elaborating this theme include:

1. How do those interviewed take up the opportunity to speak freely about the experience of caring at the end of life?

2. What can the data tell us about how those interviewed came to the role of carer?

3. What does the data tell us about how those interviewed inhabit the role of carer

Stage Three:

At certain points I find myself overwhelmed by the data emerging, using supervision to think about how best to organise an abundance of 'rich and thick' material from the interview transcripts. I decide to use different lenses to process and present the data and begin to construct the individual case studies (aiming to follow the unconscious structuring of the interviews in doing so), collect together all of the end of life stories told across the interviews, and formulate the set of questions used to structure the cross-case analysis.

Throughout the process the theoretical framework of the project is held in mind whilst remembering what Rustin (1991, p. 130-131) describes as the observational core of analytic procedure, drawing on my experience of observational methods in my responses to, and interpretation of the raw data.

Appendix 3. The tragic position and end of life/difficult conversations/discussions

Access to the tragic position is an essential requirement if the kind of conversations proposed in the End of Life Care strategy, and advocated by those encouraging the wider population to discuss death and dying more openly, are to be engaged in in any meaningful or compassionate way. Of course there are many levels to these discussions and it is perfectly possible for death and dying to be discussed as an abstract idea and as something that is inevitable, without accessing the tragic position. For such a discussion to move to a deeper level at least one of the individuals present has to be able to hold the tragic position firmly and with ease and yet with an appropriate degree of respect for its significance, in particular the emotional pain that might be involved. Thinking about the range of difficult conversations that might be necessary in relation to the end of life and which take place on a daily basis, it is possible to consider the oscillations that might be present in any given communication.

For example, the consultant who has to convey to the daughter of a patient with motor neurone disease his view that her mother should not be resuscitated if a crisis occurs, but who lacks the emotional capacity to bear the emotional distress involved.

Registrar: 'You do know that people like this can go off at any time.' (D/PS)

Patient's daughter: 'You mean she could die at any moment.' (D/PS)

The daughter is shocked and distressed. She hadn't realised that things have reached this stage. She holds the depressive position with the paranoid schizoid undermining her attempts to grasp the full meaning of what is being conveyed. The registrar becomes uncomfortable and appears to be at a loss as to how to continue. Any attempts to respond appropriately are prevented as he retreats to the paranoid schizoid position, mumbles something about the condition and how breathing is affected and hurries off (D/PS). At its best the communication may represent a 'warning shot across the bows' but on this occasion the pain experienced is unacknowledged and uncontained and a significant moment in the care of this particular patient and their family is lost. A tragic position response would involve responding emotionally in the moment without the need to move to action.

Appendix 4. Letter of Approval

03 March 2014
Dear Katharine,

Project Title:	**Bringing death home: Towards a deeper understanding of the implications of the End of Life Care Strategy for those (individuals and organisations) providing end of life care in non-specialist settings.**
Researcher(s):	**Katharine Scanlan**
Principal Investigator:	**Professor Andrew Cooper**

I am writing to confirm that the application for the aforementioned proposed research study received ethical approval from the University Research Ethics Committee (UREC) on **Monday 3rd March 2014.**

Should any significant adverse events or considerable changes occur in connection with this research project that may consequently alter relevant ethical considerations, this must be reported immediately to UREC. Subsequent to such changes an Ethical Amendment Form should be completed and submitted to UREC.

Approved Research Site

I am pleased to confirm that the approval of the proposed research applies to the following research site.

Research Site	Principal Investigator / Local Collaborator
Care homes in the Yorkshire and Humber region	Professor Andrew Cooper

Approved Documents

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

Document	*Version*	*Date*
UREC Application Form	2.0	03 March 2014
Participant Information Sheet	2.0	03 March 2014
Consent Form	1.0	09 December 2013
Interview schedule	2.0	03 March 2014
Research diaries	2.0	03 March 2014
Care home approach letter and permission slip	1.0	03 March 2014

Approval is given on the understanding that the <u>UEL Code of Good Practice in Research</u> is adhered to.

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

Yours sincerely,

ulleteau

Ethics Integrity Manager

University Research Ethics Committee (UREC)

Email: **researchethics@uel.ac.uk**

The Tavistock and Portman **NHS**
NHS Foundation Trust

Information sheet for participants

The project is carried out under the auspices of The Tavistock and Portman NHS Foundation Trust and the University of East London (UEL) Cass School of Education and Communities. The Principal Investigator is Professor Andrew Cooper and the researcher is Katharine Scanlan. For contact details see below.

Thank you for agreeing to participate in this research project; this sheet will give you the details you need about the project including how to give or withdraw permission and what taking part will include. Should you require further information or want to discuss in more detail what participation will mean for you then please call me on 07708961320

The research

The title of the project is: "Bringing Death Home", with the subheading," towards a deeper understanding of the implications of the End of Life Care Strategy for those (individuals and organizations) providing end of life care in non-specialist settings". Hearing the voices of individuals involved in providing end of life care in such settings is central to the project as is being able to spend time observing the care home environment as well as the wider systems within which end of life care is taking place.

 The interview

As a participant you are agreeing to be interviewed about your experiences of end of life care. The time allowed for each interview will be up to two hours although the period will be flexible in meeting the individual needs of each interviewee. During an initial interview you will be invited to talk freely and openly about your experiences of end of life care. A subsequent interview will provide an opportunity for the researcher to enable the interviewee to expand on significant aspects and themes emerging from the initial interview. The interviews will be audio recorded and transcribed so that emerging themes can be identified and analysed. You will only be asked to give details that you feel comfortable discussing and can stop the interview at any time, either for a short break or to withdraw from the study completely.

Confidentiality

Any information you give will remain confidential and will not be disclosed **except** where safeguarding issues or imminent harm to self or others arise. If such issues are disclosed then the relevant safeguarding policies will be implemented and you will be kept informed in line with organisational and national policy.

Given the small number of participants (approximately 8) it is important that you realise that whilst every effort will be made to anonymise the data, some details in the

publicly available Doctoral thesis could lead to your being identified by others working with the project. At no point will your name be disclosed, as a participant without your permission and interviews will be undertaken at a neutral venue of your choosing.

The confidentiality of material is subject to legal limitations and in exceptional circumstances may be subject to legally enforced disclosure.

Permission

Your involvement in this project is totally voluntary and your permission can be withdrawn at any time. In such circumstances any unprocessed material you have given will be removed from the study and destroyed. All data gained through this study will be stored, used and destroyed in compliance with the Data Protection Guidelines of both the Tavistock and Portman NHS trust and the University of East London (UEL).

Available support

As described above the aim of the project is to gain a deeper understanding of the implications of the End of Life Care Strategy on those providing care in non-specialist settings. The project stems from an awareness of the challenges that end of life issues present to us all as potentially vulnerable human beings. The possibility that talking about end of life care may raise feelings of distress in participants is acknowledged and provision made accordingly. The interviews can be stopped at any time for a short break, rearranged at a later date or terminated altogether. Time will be made available at the end of the interview to debrief and should you find that the interview raises unanticipated issues or an unexpected emotional response appropriate support will be made available as required.

How to complain

If at anytime you find that you are unhappy with my conduct or any aspect of the study you can contact either:

Professor Andrew Cooper: Andrew Cooper by emailing ACooper@tavi-port.nhs.uk

Or UEL via researchethics@uel.ac.uk

Once again thank you for your involvement.

Katharine Scanlan

Katharine@scanlan.karoo.co.uk

Appendix 6. Letter sent to Participant

The Tavistock and Portman **NHS**
NHS Foundation Trust

UEL
University of
East London

<div align="right">
Address

Phone Number

E mail
</div>

Dear ……………………

"Bringing Death Home", with the subheading," towards a deeper understanding of the implications of the End of Life Care Strategy for those (individuals and organizations) providing end of life care in non-specialist settings".

Further to our discussion about the research project I am embarking on, I am sending you the information sheet and permission slip as promised. You should read this information sheet carefully before completing the permission slip. If you have any queries about the details or need clarification on any matter then please contact me at the address given on this letter.

In signing and returning the permission slip attached to this letter you give full and informed consent to participating in the project. If you wish to withdraw at any time then please write to me confirming that you wish to leave the project and have any unprocessed data you have supplied removed.

The data collected will be used to complete a Professional Doctorate dissertation and may be used to submit papers to Journals or conferences. The results of the project will be used to reach a deeper understanding of the experience of those providing end of life

care in care homes. The knowledge gained may be used to formulate recommendations about best to support and sustain those concerned.

The permission slip can be returned by hand or in the postage paid envelope provided. Once I receive this I will be contacting you to discuss a mutually convenient time and place to carry out the interview. Please ensure that you provide a telephone number and times when it would be convenient to call.

Many thanks for agreeing to be interviewed and I look forward to seeing you soon.

Yours sincerely,

Katharine Scanlan

Appendix 7. Participant Permission Slip

The Tavistock and Portman **NHS**
NHS Foundation Trust

Permission slip

I ……………………………………………….. hereby agree and give full and informed consent to participating in the study.

Furthermore I understand that: *(please tick each relevant box)*

☐　　This research study is undertaken as part of a Doctoral Thesis registered with the Tavistock and Portman NHS Trust and the University of East London (UEL).

☐　　Participation is voluntary and that I can withdraw my consent at any time.

☐　　The interview will be recorded, transcribed, stored and deleted in accordance with the Data Protection Guidelines of the Tavistock and Portman NHS Trust and the University of East London (UEL).

☐　　Whilst every effort will be made to disguise identities and sources of information the nature of the study means that complete anonymity cannot be guaranteed.

☐　　If I disclose information that raises safeguarding issues, or indicates harm to self or others, the relevant safeguarding policies will be implemented and confidentiality cannot be guaranteed in these circumstances.

☐   The data provided may form part of papers submitted to professional journals and conferences and will be publicly available as a Doctoral Thesis.

Signature ………………………………………………………………….

Date …………………………………………………………………

Appendix 8.   Participant Contact Details

The Tavistock and Portman **NHS**
NHS Foundation Trust

UEL
University of
East London

Research Participant Contact Details

Address: …………………………………………………………………..

                 …………………………………………………………………..

                 …………………………………………………………………..

Tel No   …………………………………………..

best time to call …………………………………………

Email   ……………………………………………………………………….