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Dying Through the Looking Glass… The Influence of Discursive Formations on End of Life Care

Joanne Atkinson

A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Professional Doctorate

February 2019

This thesis is dedicated to the memory of my father Edward Colligan

He is my inspiration. He was born under a wandering star…

Abstract

This research contributes to the professional understanding of the contextual conditions that exist in end of life care. Using a Foucauldian lens, this research explores the apparatus and *technologies* of power at play, and considers the impact of mainstream media on discursive practice in end of life care. Mass media campaigns have had a significant impact on end of life care, developing a sense of scandal and moral panic among the population. The research highlights the tensions, challenges and possibilities that emerge from the intersection between media and healthcare practice.

Foucauldian discourse analysis has provided a philosophical lens through which to view this research and explore the professional contexts in which we operate. Collection and analysis of media artefacts from journalistic press in the form of broadsheet newspapers and terrestrial television (factual outputs) were undertaken. In addition, self-recorded narratives from nine healthcare professionals working in end of life care were transcribed and analysed.

The findings have given rise to discourses that have been aligned to specific domains of understanding. *Technologies* enable us to highlight the way in which structures, and functions within political and social institutions, can manipulate populations or individuals, or indeed how power can shape human conduct. The *technologies* emerging from this thesis are: *technologies* of caring; *technologies* of power; *technologies* of self; *technologies* of representation and professional apparatus.

The mainstream media influences discursive practice in end of life care; therefore, professionals need an appreciation of how they might deal with the challenges and opportunities posed. Exposing dying and the discursive formations in this research offers a novel insight into how healthcare professionals are not immune to, but are part of, the influences that mediate how care is delivered at the end of life; how, indeed the media can have such a strong influence on perceptions and understanding.

Dance Me to the End of Love

Dance me to your beauty with a burning violin
Dance me through the panic till I'm gathered safely in
Lift me like an olive branch and be my homeward dove
Dance me to the end of love

Oh, let me see your beauty when the witnesses are gone
Let me feel you moving like they do in Babylon
Show me slowly what I only know the limits of
Dance me to the end of love

Dance me to the wedding now, dance me on and on
Dance me very tenderly and dance me very long
We're both of us beneath our love, we're both of us above
Dance me to the end of love

Dance me to the children who are asking to be born
Dance me through the curtains that our kisses have outworn
Raise a tent of shelter now, though every thread is torn
Dance me to the end of love

Dance me to your beauty with a burning violin
Dance me through the panic till I'm gathered safely in
Touch me with your naked hand or touch me with your glove
Dance me to the end of love

(**Leonard Cohen, 1984)**

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee / University Ethics Committee / external committee [*please indicate as appropriate*] on [*date*].

I declare that the Word Count of this Thesis is 59855 words

Name: Joanne Atkinson

Signature:

Date: 11th February 2019

2 Preface

Death, dying, how and when we die, and how we care for the dying are all concerns for contemporary society and health care practice. There is still a large gap between where people say they would prefer to die (at home) and where they actually die (Gomes et al., 2012). In 2016 almost half (46.9%) of people died in hospital (Public Health England, 2018). The demography of death is also changing. At the beginning of the twentieth century 90% of deaths occurred as a result of acute illnesses; now, conversely, 90% of patients die from a chronic disease with about half receiving treatment for at least thirty months before they die. Therefore, most people given the opportunity have time to plan for their care at the end of life (Taylor and Kurent, 2003; NHS England, 2014; Dixon et al., 2016).

Palliative care is an approach that is focused on the quality of life of patients and their families when they are facing advancing and life threatening illness. The relief of physical, psychosocial and spiritual problems, and the delivery of holistic care are at the core of palliative care (Sepulveda et al., 2002). In addition, it is important to recognise that palliative care is not an alternative or "other" care, but rather a complementary and a vital part of the patient's journey, especially as their disease advances (Faull and Caestecker, 2012; Mannix, 2017).

The rise of palliative care as a specialism could be categorised as a new discourse, born out of the fact that individuals with advanced disease need care delivered in a more holistic fashion than is the norm in clinical practice. Alongside this is the discipline of end of life care, which, like palliative care covers all sectors and settings (Department of Health (DH), 2008), and has arisen in response to the deepening crisis of caring for the dying.

Palliative care is a term that has many varied interpretations. However, it intrinsically includes the physical, emotional, social and spiritual care that is required at any time in a person's life when their death or mortality is an issue (Froggatt et al., 2006; Hanks et al., 2011). Patients have the right to access high quality care and should be enabled to exercise choice about

their preferred place of care at the end of their life (National Council of Palliative Care, 2010). While such choice is an aspiration, the ideal and reality at the end of life often differ (Agar and Currow, 2008) and the complexity of adhering to wishes in relation to preferred place of care and death cannot be underestimated (Costantini, 2008). End of life care services should support people to live as well as possible until their death. Despite driving forces to improve the quality of care at the end of life, articulated in successive policy documents (DH, 2007; 2008; 2010; 2011; 2012; NHS England, 2014) and guidance on how end of life care should be delivered (NHS England, 2014; 2016), there are still gaping inequalities in how and where people die.

As policy and practice drivers related to patient choice and place of death have clearly articulated the need for high quality end of life care, there has been an influx of tools and pathways that have evolved out of specialist palliative care. In clinical practice, evidence suggests that the integration of end of life tools such as the Preferred Place of Choice (Advance Care Plan), Deciding Right and the Liverpool Care Pathway (LCP) (Integrated Care of the Dying Pathway) was patchy in generalist areas (DH, 2011). More recently, fuelled by the media, we have seen a public outcry challenging end of life care and targeting the LCP, which has led to its dismantling (Watts, 2013; McCartney, 2012; Oliver, 2015). The demise of the LCP is linked to a failure in the implementation of good end of life care practice (Seymour and Horne, 2013; DH, 2013) and a concerted campaign across journalistic press (Seale, 2010; McCartney, 2012; Watts, 2013; Oliver, 2015; Seymour and Clark, 2018).

In addition, the perspectives of generalist nurses on the provision of quality end of life care is scant, or their voice remains silenced (Thompson et al., 2006) and the natural process of dying appears lost in advanced technology and medical interventions (Larkin, 2011). Tensions are apparent in the increasingly complex world of end of life care, with nationally driven initiatives being applied across all care settings. These difficult and challenging issues have to be viewed in the context of the sense of death being a failure, especially in the acute sector (Ellershaw and Wilkinson, 2011).

In their paper regarding the LCP *Pathway to Excellence*, Ellershaw and Wilkinson (2011) clearly articulate the importance of end of life care as a measure of the society we live in. However, the way in which death is experienced and perceived in society has shifted over time. This has had a direct influence on how and where people die, and how those grieving are supported (Kellehear, 2007). A clear and coherent view of death gives a corresponding social openness and identity to the grieving and those dying. Conversely, if death is hidden and dying sequestered, the community compassion and cohesion in relation to death and dying, which might once have been strong, may dwindle (Kellehear, 2007).

The good death is difficult to define; it is a dynamic concept, which evolves according to the time, culture and societal forces (Cottrell and Duggleby, 2016). Definitions of a good death have emerged out of the hospice movement and include: positive interpersonal relationships, the ability to meet the needs of the patient and their family, the promotion of choice and the extent to which social control is exerted over the dying process (Payne et al., 1996; Griggs, 2010; Mannix, 2017), with the management of dying predetermining a good death (Kellehear, 2007). Although the principle of a good death is ambiguous as it is dependent on the individual's beliefs and values, Costello (2006) contends that context and choice are important in shaping a person's experience of end of life. Furthermore, the physical environment, resources, knowing the person, and the philosophy and culture of care contribute significantly to quality end of life care (Casey et al., 2011). The National End of Life Care Programme (2010) reinforces these key principles in a study of hospital complaints at the end of life, finding that poor communication and lack of appropriate clinical care were significant causes of distress for patients and their family. This narrative is sustained in *Transforming End of Life Care in the Acute Hospital* (NHS England, 2015). Despite attempts to transfer best practice, tools and philosophy from hospices to hospitals, there are distinct problems related to the environment in which care is delivered and the different cultures of care (Ellershaw and Ward, 2003), with the organisation's priorities overshadowing patient-focused priorities (Borgstrom, 2015). The good hospital death appears to come

second to living longer with a life-threatening disease (Costello, 2006; Virdun et al., 2015). Control of death has been removed from the individual and shifted into the hands of healthcare professionals who, to an extent, determine the location and timing of death (Howarth, 2010). This is counterintuitive to what policy drivers are aiming for (DH, 2007; DH, 2008; DH, 2010; DH, 2011; DH, 2012; NHS England, 2014).

Born out of these challenges arising from palliative care in the acute sector, this study examines the competing and emerging discourses that impact upon care delivery at the end of life in acute settings. It seeks to provide original insights into the influence of mainstream media on healthcare professionals delivering care. This study highlights discursive practices in end of life care and provides insight into the challenges of achieving choice, comfort, holistic care and dignity no matter where the person dies. What follows is the story of three interlinked journeys; one personal, one philosophical and one conceptual, all of which provide a lens through which we can view end of life care.

2.1 A Personal Story

This journey has been a long one. The story of my professional and personal exposure to end of life care is influential in terms of the questions I have posed, the challenges I have faced and the lens I have used to uncover the said and the unsaid, as I have explored the social world of end of life care and come to terms with the revolution that has occurred in my understanding.

I am a nurse. I trained in 1981, when nurses undertook care and treatment as prescribed by more senior nurses and doctors. Having a questioning temperament but working in an unquestioning way was challenging. Nursing as a profession has evolved so much in the time I have been practising and now I find myself heading towards the end of a journey, which will offer new opportunities and challenges to nursing convention and tradition.

Following a broad range of experiences as a qualified nurse, and the birth of my children, I arrived in the regional specialist haematology service. Exposure to this challenging sphere of practice was informed by notions of patient-centredness, holistic palliative care and end of life care. During this period, I cared for people who had haematological malignancies; many of those with leukaemia were young people who needed specialist support through their cancer journey. It was at this point that the challenge and tensions of balancing treatment in advanced disease with palliative care came to the fore of my attention. This dynamic and demanding exposure to such difficult diseases, and tragic stories contrasting with invigorating successes, leaves its footprint on one's life; the way one loves, the way one thinks and the difference one wants to make.

In 1996, I became a Macmillan Nurse in the acute sector and my journey in palliative care continued. As the Calman-Hine Report (DH, 1995) gave rise to an explosive expansion of specialist cancer services, the time was right to help make a difference in developing and delivering a new palliative care service within a large acute NHS Trust. The challenge of delivering palliative care to such a diverse population was great, as was the burden of making a difference; in these formative years you were only as good as your last piece of advice. There were areas in the hospital setting where palliative care practitioners were deemed to be intruders; control of the patients with advanced disease was seated solely with the consultant in charge of the ward. These challenges were compounded by the case of Harold Shipman, a General Practitioner in Manchester, who killed elderly patients with high-dose opioids. This case promoted defensive prescribing when managing pain in advanced disease and constituted my first brush with the impact media can have on practice.

The roots of my knowledge of end of life care are clear; however, the value of the personal experience, of walking beside the sick and the dying, has had a significant impact and has honed my thinking into what it is today, thereby significantly shaping this thesis.

My grandmother, a very important, wise, intelligent and graceful woman, born before her time, was my mother's mother and my sister and I were her only grandchildren. She became sick 10 months before she died, aged 90, from congestive heart failure. As a specialist in palliative care I used my knowledge and skills to control her symptoms, working in partnership with the General Practitioner. She was hospitalised at her worst and had to take her own discharge in order that she could spend her final weeks at my mother's home, as the hospital would not agree to discharge her. She had a cardiac arrest after a day in the garden, polishing the silver and playing with her great grandchildren. We have moved a long way since 1996 – palliative care for all, not just for those with cancer, is a reality and patients have more choice about where they want to die.

In 2000, a close colleague and friend of mine died after a long illness and intensive surgery and chemotherapy – ovarian cancer with metastatic disease. Her cancer journey was long and tortuous; she struggled with the knowledge she had as a health professional and needed psychological support and symptom control from specialist palliative care. She died peacefully in a local hospice, in control until the end of her life. This was closely followed two years later by the death of my close friend and neighbour who died from acute leukaemia. "People with leukaemia don't die at home", we were told as her disease advanced, "it's too complicated". She did die at home, after a fight for her right to exercise her choice to do so; she was peaceful and surrounded by love.

Perhaps most important is the experience I have had as I have progressed through my doctoral studies; an experience that very nearly tipped me off the doctoral path, yet strangely has enriched my understanding and informed my considerations. They say that pursuing doctoral studies is a journey.

In July 2013, my younger sister was diagnosed with breast cancer for which she required high-dose chemotherapy, radiotherapy and further treatment with Herceptin. The trauma for our small, insular family was huge. My sister needed care and support, as did her husband and 11-year-old daughter. At the same time as caring for my sister, I was caring for my father in the

palliative stage of his chronic diseases. I spent my time caring for him and watching the frustration build as his condition deteriorated. We have moved forward since the death of my grandmother. My father exercised his choice and articulated his wishes to his General Practitioner, which were to die at home in his own bed with his family around him.

An interesting perspective has arisen out of my personal and contrasting exposure to health professionals dealing with advanced disease and life threatening diagnoses. My time spent in chemotherapy units and outpatient departments with a younger person has exposed me to a different use of language and metaphor.

Susan Sontag first talks about illness as metaphor (1991), with Walter et al. (1995) and Seale (1995) offering perspectives about dramatic death, heroic death and the “battle” that cancer is. These military metaphors spill into the media representation of cancer (Seale, 2001; Walter, 2010; Frith et al., 2013; Span, 2014). This is in direct contrast to the language of choice, peace and managed death that I experienced when accompanying my father to his medical and nursing appointments. I carry this insight, and the stark contrasts, with me on this journey.

2.2 A Philosophical Dawning

My research journey has been rather convoluted. I undertook a master’s programme that culminated in my researching the notion of expertise using a phenomenological methodology. The aim of the research was to explore how specialist education informed the development of expertise and thus impacted on care delivery in clinical practice (Atkinson and Tawse, 2007). Following on from this, it seemed that the next step would be finding answers and taking a more in-depth analysis of expertise in specialist practice. I began that next step and soon realised I was on the path to nowhere, for my heart was elsewhere.

End of life care is in the core of my personal and professional identity, as is the need for me to listen to all of the voices that inform how we deliver end of life care. Thinking through this, I realised that some voices are not heard; they are silenced. I needed to use a philosophical approach that did not try to give an answer, but illuminated the complexity of end of life care.

Postmodernism offered me the way forward. Having been “trained” as a nurse in the early years of my career, the context of everyday practice was firmly rooted in empirical research, protocols and guidelines, many of which emerged from custom and practice, or the medical paradigm. Nursing as a profession has evolved since 1981. My development as a specialist and an academic has promoted a questioning mind, driven to explore different perspectives, highlight the complexity of practice and acknowledge the existence of multiple truths. In essence, to challenge everyday aspects of healthcare delivery that are accepted as custom and practice, ‘the way things have always been done and therefore should remain unchanged’ (Nettleton, 2013). Postmodern thought rejects the idea of grand theories and metanarratives, recognising instead that reality, in this instance end of life care practice, is comprised of multiple voices, views and perspectives (Cheek, 2000). It denies the possibility of single truths and highlights the coexistence of multiple realities (Nettleton, 2013).

Thus, adopting a postmodernist approach to this study enables a reflexive approach to considering practice; an uncovering of the complexity of care and recognition of the said and unsaid without privileging any specific agenda (Cheek, 2000). In end of life care the voices of all stakeholders should be heard, not just that of the doctor, nurse or other healthcare professional, but the patients too. The critique of the medicalisation of death, described by Illich (1976) as one of dominance, with doctors being at the bedside medicalising the process of death and oppressing the patient, is perhaps an over simplification. Postmodernism offers new ways of understanding relationships, care, the way we live and the way we die. It offers plurality in terms of thoughts and multiple perspectives on reality, and an opportunity to view health and the way we deliver care differently (Cheek, 2000).

Cultured as a nurse within a hierarchical system, where technical knowledge was typically uncontested and power was firmly in the hands of the medical practitioner, I was attracted to Foucault for the challenges he poses to such assumptions and customs that are predominant in healthcare practice (Cheek and Porter, 1997; Dahlborg-Lyckhage and Liden, 2010). The work of Foucault has great resonance for the way in which healthcare is delivered, the power and knowledge hierarchies that infiltrate health and illness, and the regulation of bodies, professions and institutions.

Walking through the work of Foucault, I can see theoretical footprints in the way we design, deliver and control care at the end of life. As Foucauldian theory underpins the whole of this thesis, these footprints, which to me have resonance and meaning for this study, will appear throughout, providing an insight into Foucault's philosophy:

> *"…More than a mere intersection of things and words, an obscure web of things, and a manifest, visible coloured chain of words; I would like to show that discourse is not a slender surface of content, or confrontation, between a reality and a language…"*
>
> *(Foucault, 1972 p53/54)*

Foucault's definition of discourse is as much about ways of thinking and practices as it is about language, meaning and meaningful action. Yet, all social practices entail meaning, and meanings shape and influence what we do, our conduct, our practice. Foucault (1980) first suggested that discourses are interlinked with power, in that dominant or hegemonic discourses not only become reified as truth in a historically and cultural specific context, but also define the parameters of a particular issue or problem, and the direction of mainstream care. They both enable and constrain the production of knowledge; they allow for certain ways of thinking and doing while excluding alternatives (Cheek, 2000). This concept is illustrated in how we deliver care to the dying in a routinised, rehearsed and validated manner, and how the discursive articulation of death changes over time (Carpentier and van Brussel, 2012). When a discourse is manifested in a number of areas, such as language, institutions or practice, then it is evidence of discursive

formation. While the examination of discursive formations offers a surface meaning (Fox, 1997; van Brussel, 2010), discursive practices and frameworks, such as the way we order care delivery at the end of life, are created through and by discourses. We are directed to deliver care by policy drivers, and gold standard models of end of life care emerge from those deemed to be experts, and from iconic care delivery sectors such as the hospice. Foucault enables the authority of experts to be challenged and highlighted as a product of a discourse, which in turn may have silenced or excluded others (Cheek and Porter, 1997; Dahlborg-Lyckhage and Liden, 2010).

Discourse analysis is a relatively recent form of enquiry in relation to health care issues (Smith, 2007) and can offer new ways of seeing - a new lens, through which we can examine values and attitudes to issues in end of life care (O'Connor and Payne, 2006). It is timely in end of life care that we recognise that the reality of practice is made up of multiple voices, that death and dying are not only located in the body and controlled through medical knowledge, but orchestrated through human interaction and discursive practices (Lupton, 2012) deeply embedded in societal expectations and social relations (White, 2002).

The challenging arena of end of life care is fraught with contradictions and challenges. Using critical discourse analysis allows focus to be placed on the relations of power, dominance and inequality, and how and why they are reproduced or resisted by social groups (Van Dijk, 2008). It enables an understanding of multi-professional end of life care in the acute sector. For healthcare professionals, this is about why we do what we have always done, for example the dying patient being placed in a cubicle on an acute hospital ward. Alternatively, it is about why we find it difficult to change, why we find it difficult to challenge and why the philosophy in differing spheres of care remains resistant to change and apparatus that aims to improve practice. For patients, this is about choice and having a voice at the end of life – not being silenced. For professionals, it is about listening to that voice and enabling care delivery at the end of life to be the best it can be.

While many studies explore the implementation of tools in end of life care (Constantini et al., 2011; Jeong et al., 2010; Hockley et al., 2010; Dalkin et al., 2012; Chinthapalli, 2013; Borgstrom, 2015), the methodology I use here builds on these insights by offering differing perspectives on the conditions and experiences of delivering end of life care in the acute sector. End of life practices and experiences have to be considered in their historical and social context (Wodak and Meyer, 2010). Critical discourse analysis enables the examination of major discourses and uncovers emerging discourses, thereby establishing an in-depth understanding of the salient forces in end of life care. Insight into how discourses both enable and prevent the translation of apparatus between practice settings can then emerge, while I provide insight into the changing, shaping and challenging of dominant discourses. In turn, the ways in which apparatus gain momentum are dismantled and become a means of objectivisation of practice are uncovered.

2.3 A Conceptual Journey

At the outset of my doctoral journey, professional drivers and expectations drove me to consider how specialists communicate their expertise in generalist contexts. I was searching for universal truths about expertise and what “makes” an expert. The importance of the wider contextual influences on practice emerged from this initial work; I began thinking about my sphere of practice, end of life care, and grand truths about power and control; doctors and nurses controlling dying, with the voice of the nurse being diminished. As my conceptual journey has progressed, this simplistic understanding has developed to consider the multiplicity of truths and the discursive nature of death and dying, with power relationships being far more complex than initially envisaged.

The philosophical grounding emerged throughout my journey as a person, as a professional and as a researcher. However, great clarity and impetus emerged as I developed my critical reading around the subject of end of life care in mainstream media. The impact of the media on practice and on the

processes of control surrounding dying came to the forefront of my analytical endeavours. The influence of the media has been amplified as it ceases to be solely representative of a transparent window, a way of seeing into reality, and instead becomes an intrinsic part of controlling forces in society (Hall et al., 2013).

While the media is an important cultural resource and a primary mechanism by which individuals construct meanings of social phenomena (McInerney, 2007; Seale, 2002; Seale, 2010), it is also clear that the media privileges certain meanings over others. Embarking on research that uncovers discourses and social understanding at a time of great importance in end of life care has been stimulating, and of great resonance to current challenges for those working in the field. The opinions of healthcare professionals and the changes to the practice landscape as a result of the saturation of end of life care in the media has had significant impact over the period of this study.

2.4 Aim

To contribute to professional understanding of the contextual conditions necessary for the delivery of optimal end of life care in the acute care sector.

2.5 Objectives

1. To explore the emerging, competing and overlapping discourses that influence end of life care.
2. To consider the influence and impact of mainstream media on discursive practices in end of life care.
3. To explore how these discourses shape end of life care practices.

This chapter offers insight into my journey and how it has underpinned this research. My personal experience, professional expertise and the research journey have all brought me to this point. The next chapter will offer context related to the history and definitions of palliative care and end of life care. In addition, the policy and practices at play will be considered.

3 Context

This chapter offers contextual understanding of end of life care, including the evolution of palliative and end of life care, and an exploration of where people die. In addition, the definitions of palliative care and end of life care will be explored as well as the tensions, confusion and challenges for moving forward in the context of contemporary policy drivers.

3.1 Looking Back – The History

Understanding the history of palliative care and the emergence of end of life care as a discipline is important for this thesis. The history and culture direct us to where we are at this moment in time. Foucault talks of the evolution of medicine and the power associated with the institution:

> ***"…The medical gaze****, the separation of the person and disease, a way in which power is acted out and how "docile" bodies are created, Nineteenth Century medicine was haunted by that absolute eye that cadaverizes life and rediscovers in the corpse the frail, broken nervure of life (panoptic gaze)…*"
>
> *(Foucault, 2003 p204)*

The traditions and founding concepts of palliative care can be traced back to the middle ages. Travellers or crusaders who were ill or dying were offered care; this care was delivered by religious orders in hospices (Lutz, 2011). In fact, for those with advanced cancer, palliative care as we know it today was all that could be offered at one time. In medieval times the care of the body (cura corporis) was the domain of the doctor, whereas the care of the soul (cura animae) was the domain of the church or the priest (Bishop, 2013). Looking back through history, the understanding of death is interwoven with religious beliefs, societal expectations and exposure to the dying. Aries

(1981), observes that people commonly saw death and accepted it as part of normal life, while Turner (2008) describes the rampant nature of infectious disease and early death, making religious belief in the afterlife an important aspect of everyday existence. This is in direct contrast to modern society and the death denial that floats under the surface of our lives, with death having been described as one of the greatest taboos of the late twentieth century (Gorer, 1980; Mannix, 2017). Death and dying, and the notion of taboo will be explored in more detail in Chapter 4.

Over time, in end of life care, power has shifted from the dying person, with their beliefs and understanding of death, to the doctor, the professional and the institutional power of medicine. This shift was set against the institutional power of the church and in direct conflict with religious authority (Kellehear, 2007a). This conflict is illustrated when considering the use of dissection of the corpse as a means of research and discovery. Dissection flouted societal beliefs related to the sanctity and mystery of death and was seen at the time as an intrusion and violation of the soul (Lupton, 2012). Yet Foucault in *The Birth of the Clinic* (2003), names his chapter "Open up a Few Corpses" and discusses the emergence of medical knowledge in the light of anatomical dissection and organisation; the dawning of medical understanding and knowledge:

> "*When philosophy brought its torch into the midst of civilised peoples it was at last permitted to cast one's searching gaze upon the inanimate remains of the human body, and these fragments, once the vile prey of worms, became the fruitful source of the most useful truths"*
>
> *(Foucault, 2003 p153)*

During the nineteenth and twentieth centuries, the rise of hospital medicine continued, including the post-mortem as a means of establishing the pathological cause of disease and death (Armstrong, 1987). It is here that interesting parallels with the birth of palliative care can be made, in what can be considered the emergence of the palliative gaze. Turner (2008), discusses this intersection of the body and belief, of medicine and religion; the point at which human suffering and death become conjoined. The

conceptual understanding of a good death changed from being concerned about the soul to being more about the physical experience - the event that is death (Howarth, 2007). It has been proposed that modern medicine provides a dehumanised, mechanistic and technologically enhanced approach to care, undermining the experience and meaning of dying for the patient (Zimmerman and Wennberg, 2006; Berry et al., 2017). There has been an increasing trust in medical expertise, the knowledge of the doctor, their ability to relieve pain and cure illness, and the belief that hospital is the place to die in modern society (Howarth, 2007).

While rooted in history, modern day palliative care emerged post-Second World War from the early work of Dame Cicely Saunders, who trained as a nurse and an almoner until she eventually became a doctor. After a difficult personal experience of supporting her friend in 1967, she opened St Christopher's Hospice, offering care for people who were dying. The hospice movement was born out of the lack of care for people with terminal cancer. The focus of treatment for these people at this time was on cure, and there was recognition of "medical neglect" for patients with terminal cancer, who at that time were sent home to die (Clark, 2007). Dame Cicely Saunders recognised the need for physical and emotional care to be intertwined, and the impact one has on the other (Clark, 2007). In addition, the growing medicalisation of death and dying was challenged with a different philosophy of care (Howarth, 2007). Bishop (2013) describes the notion of cure being the domain of doctors and of care being delivered not by doctors but by nurses. Dame Cicely Saunders brought to the clinic the concept of total pain and the kind of care needed to alleviate suffering for those who are dying.

In 1973, Dr Balfour Mount, a Canadian, first used the term palliative care in practice as way of capturing the need for quality care for people at the end of life. Across the medical fraternity acceptance of this approach of caring for individuals with advanced disease and of total care was not immediate. In 1987, palliative medicine was accepted as a medical speciality in the United Kingdom (UK). It has been a long and tortuous journey and some may say we are still on that journey. Death is still controlled and there is a sequesterisation of dying and death from the living, with hospitals and

hospices being where people die in contemporary society, despite policy drivers promoting choice (Gomes et al., 2011). However, the hospice philosophy offers more person-centred care than the myriad technological-based care solutions that are delivered in the hospital. When cure is not available, the patient receiving palliative care can expect total care; psychological, physical, spiritual and social modes of care to control their distress. Similarly, when discussing the concept of total pain, Clark (1999), describes how Foucault may paradoxically view holistic care as overbearing and a result of *le regard* - the all-seeing gaze - seeing human suffering as a new classification far from the original intentions of Dame Cicely Saunders.

The discipline of palliative care has emerged from the hospice setting, engaging professionals and patients alike, and driving forward quality care in advanced disease. With increasing referrals, and as people with chronic disease have begun to utilise palliative care services, there came a split whereby end of life care was separated from palliative care in response to poor care of the dying person (George et al., 2014). Looking at the history of palliative care and how it has emerged offers an understanding of its foundations and philosophy. Building on this, the following section considers the definitions of palliative care in contemporary practice.

3.2 Definitions of Palliative Care

Understanding the evolution and definitions of palliative care sheds some light upon how end of life care became a distinct discipline. The definition of palliative care has evolved alongside the development of palliative care practice:

> *"Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also*

applicable earlier in the course of the illness in conjunction with anticancer treatment".

(World Health Organisation (WHO), 1990)

While this definition has been very widely used, and certainly reflects the philosophy of care articulated by Dame Cicely Saunders, there have been numerous contestations, amendments, revisions and additions to it. More recently there has been a review of this definition by the WHO that more readily reflects the more contemporary notions of palliative care and the fact that it should be the right of every individual.

"Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death. Palliative care is explicitly recognised under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals".

(World Health Organisation, 2015)

Interestingly, the Oxford Textbook of Palliative Medicine makes a distinction between palliative care and palliative medicine, which it defines as:

"The study and management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus is quality of life"

(Hanks et al., 2011)

This differentiates between palliative care, which is the work of the multidisciplinary team, and palliative medicine, which is carried out solely by doctors (Bishop, 2013). In addition, Billings (1998), following the publication of the WHO definition, describes “active total care” as unhelpful, as doctors do not deliver partial or inactive care; he also argues that neither definition captures the professional contribution or expertise required to deliver palliative care and describes the palliative care physician as a specialist. This in turn has led to a distinction being made within clinical practice between non-specialist and specialist palliative care. While it is important to recognise the skills and expertise required to deliver holistic palliative care, Foucault may have viewed this as an attempt to discipline the discipline. The specialism of palliative care, in effect, has paradoxically been overtaken by medicine, with the WHO definition offering no clarity or guidance about prolongation of life and delaying death (Randall and Downie, 2006). This ambiguity has resulted in a lack of understanding, moral dilemmas and confusion from other health and care sectors, and indeed, from within the ranks of clinicians who are delivering palliative care and caring for those at the end of life. This has resulted in the emergence of end of life care as a distinct discipline, inextricably linked to, and embedded within, palliative care and needed to improve the quality of care delivered to people who are dying.

End of life care is a highly specialised domain of care and is required across all sectors of healthcare. This thesis is firmly rooted in the work of Michel Foucault, who talks about the notion of “discipline” as a way in which power can be exercised using apparatus and techniques; a way in which we can apply our practices to docile bodies. In his work Discipline and Punish (1991) he states the body is:

> *“…an object and a target of power… manipulated shaped and trained, which obeys, responds becomes skilful and increases its forces…”*
>
> (Foucault, 2001 p136)

That is not to say that the power sits in the hands of those delivering care; power in the hands of the patient can become enabling for some, even collaborative, sustaining the way in which care is delivered in partnership. With this in mind end of life care will be defined as a discipline throughout this thesis.

3.3 Defining End of Life Care

Defining end of life care is fraught with difficulties and contradictions, and has evolved over time, in the same vein as palliative care. End of life care encompasses the care for those with advanced and progressive illness for which there is no cure, meeting all of the needs of the patient and their family through to bereavement (DH, 2008).

Furthermore the General Medical Council (GMC) (2010) defines end of life care as when the person is likely to die in the next 12 months and includes: those who are imminently dying, have advanced incurable disease, increasing frailty and risk of sudden crisis or death. The breadth of such definitions and descriptors highlight the problem of how and when we can determine that a person is reaching the end of their lives. Recognising when the end of life is approaching is challenging and fraught with uncertainty (National Palliative and End of Life Care Partnership, 2015). Nevertheless, early and timely recognition that a person may be dying is important; it enables appropriate discussion to take place with the patient, their family and carers in relation to patients' choices, treatment decisions and specific needs (NHS Benchmarking Network, 2019).

Some the challenge occurs as a result of the different trajectories that we see as a person approaches the end of their lives. Those with long-term conditions live with their disease in relative good health until the last months and weeks of life. Conversely, others will have acute exacerbations of their chronic illness from which they will never fully recover, thus having a cumulative impact on their condition. Others may have persistent frailty with

a progressive and intractable decline, which may last for months or years (DH, 2008).

There is confusion of terms used to describe end of life care among health and social care professionals, who may use terms such as terminal care and hospice care. It is inevitable that the way care delivery is defined reflects historical development; changes in conceptual understanding, the development of expertise and diversity in definitions can problematize understanding (Gysels et al., 2013). Hui et al. (2014), in their systematic review of the literature that aimed to conceptualise terms used to determine end of life care, found broad terms that were commonly used but no consensus definition. In a qualitative survey undertaken by Gysels et al. (2013) across international contexts, 29 per cent of experts surveyed said there was no consensus for the definition of end of life care. In addition, there was agreement that the concept of end of life care had broadened over time, to encompass palliative care, and all diseases and disease trajectories. This broader definition is juxtaposed against the narrower definition, which includes those close to death. This contradiction leads to misunderstanding and conflicts.

The same confusion applies to the term palliative care. There is flux in the terminology; terminal care, palliative care, supportive care, hospice care and even end of life care are all terms that can become confused and misunderstood (Gott et al., 2012). The lack of consensus and understanding of the constantly changing nomenclature undermines care provision and confuses the way care is delivered to people who are most vulnerable at the end of their lives (Pastrana et al., 2008). Which patients - the elderly, those with a limited prognosis, serious illness, terminal illness and complex illness - should be having palliative care? Randall and Downie (2006) are clearly critical of the confused definitions of palliative care, rejecting the focus on symptom control and extoling the virtues of fairness and humanity without an elitist and idealistic perception of what palliative care is. This continues to be a contentious debate, with the European Association of Palliative Care only recently, in 2018, declining to agree with the definition of palliative care

published by the International Association of Hospice and Palliative Care in conjunction with the World Health Organisation.

As a result of this confusion, the relationship between death and dying and palliative care is strained (Pastrana et al., 2008). Has palliative care moved away from those who are imminently dying and end of life care emerged as a discipline in its own right?

This confusion around definitions and terms used to describe end of life care leads to misunderstanding of when and how we should be delivering such care. In addition, the number of patients who die or are reaching the end of life in hospitals, makes it a real challenge to ensure quality care for all. The next section will identify where people die and the numbers of people that die in hospital.

3.4 Where do people die?

The demography of death is changing. Age, cause of death and length of chronic illness all impact upon where and how people die (DH, 2008). While there are geographic variations in where people die (National Institute for Health and Care Excellence (NICE), 2015), the majority of expected deaths in the developed world occur within the hospital setting (Virdun et al., 2015). The End of Life Care Strategy (DH, 2008) captured the size of the challenge in relation to delivering end of life care in England, with 500,000 people dying each year, two thirds of whom being over the age of 75 and following a period of chronic illness. At this time most deaths, 58%, occurred in the hospital setting, 18% at home, 14% in care homes and 4% in hospices.

Trends of where people die change over time. There is a need to continually monitor such changes including any geographic and socioeconomic variations (Hunter and Orlovic, 2018). It is not sufficient to consider only the shift in numbers of where people die; closer analysis of trends in relation to place of death allows for greater ability to plan for care.

Gomes et al. (2012) articulate trends in place of death, finding a steady increase in deaths at home from 2004 (18.3%) to 2010 (20.8%), which shifted the trend of dying in hospital. The policy commitment and emphasis on end of life care may well have contributed to this trend (Gomes et al., 2012). We have seen this trend continue, with the most recent statistics reflecting that 46.9% of people die in hospital, 23.5% at home, 21.8% in care homes and 5.7% in hospice (Public Health England, 2018).

These statistics are set against the challenge of increasing numbers of very elderly people with chronic disease and increasing death rates per annum (Public Health England, 2018). The challenge this poses for end of life care in hospital will be considered in chapter 4.

3.5 Policy and Practice Drivers in the United Kingdom

Many policies have provided guidance and mandate for practice in end of life care, and the emergence of the discipline can be mapped against an evolving policy context. The first comprehensive cancer policy was called the Calman-Hine Report, which detailed a policy framework for commissioning cancer services (DH, 1995). It offered guidance on the principles of cancer care, the organisation of service delivery, the formation of cancer networks, and the need for access to specialist services and strong multi-disciplinary teams. As the first dedicated cancer policy in the United Kingdom, it undoubtedly positively influenced the implementation of palliative care, however much work remained to be done to develop effective implementation pathways (Haward, 2006). Subsequent policies and guidelines revisited the principles first articulated in the Calman-Hine Report. The Cancer Plan (DH, 2000) clearly stated the need for cancer services to build on existing initiatives and drivers for change, with an ambition to tackle inequalities, improve the patient journey, promote strong leadership, drive research forward and boost specialist palliative care services. The final point, relating to specialist palliative care, incorporates the enhancement of

relationships with charitable and voluntary sectors, with a commitment to funding which, in retrospect, was never followed through in its totality.

NICE offered various iterations of specific guidance for patients with chronic disease and specific cancers, and published Improving Supportive and Palliative Care for Adults with Cancer: The Manual (NICE, 2004). This guidance was specifically cancer-focused and articulated a commitment to improving support and palliative care with a strong patient focus, access to specialists, good communication and information, and an acknowledgment of the importance of physical, emotional, spiritual and social care to enhance quality of life.

The House of Commons Committee of Public Accounts (2005) reviewed the impact of the Cancer Plan and found inconsistent care delivery, little productive interface with primary care and change not being dovetailed with the evolving landscape of the NHS. The Cancer Reform Strategy (DH, 2007) tried to renew dynamic change in this area, with specific reference to early cancer diagnosis, better treatment, care and support for those living with and beyond cancer, and a stronger world-class commissioning commitment. There was little significant commitment, aside from a mention of palliative care and end of life care, in these policy documents.

While a significant shift in palliative care provision was evident alongside the aforementioned policy drivers, increasing necessity for a more mainstream approach to palliative care and end of life care was required in order to meet the demands of the disadvantaged at that time, with patients with advanced chronic disease, older people and those from ethnic minorities in particular having unmet needs (Kennedy et al., 2009). With this in mind, the Department of Health launched the NHS End of Life Care Programme in 2004. This was aimed at making good quality end of life care accessible for all people with advanced disease, promoting service re-design, practice development and innovation. In essence, the programme allowed a distinction to be made between palliative care and end of life care, the formulation of national standards and promoted partnership working (Kennedy et al., 2009). The evolution of such programmes and policies

sought to develop practice and determine the care delivered to patients at the end of life.

The End of Life Care Strategy (DH, 2008) followed on as result of the end of life care programme and it was not until this point that the profile of end of life care changed, heralding the first significant shift of palliative care away from cancer patients and the charitable sector, to mainstream care delivered in partnership for all patients with advanced disease.

In essence, the End of Life Care Strategy identified that people would be afforded the opportunity to discuss their needs and preferences as they approached the end of life, while also having access to specialist services (Borgstrom, 2016). The needs of carers were considered, which included listening to the carers' voice in order to offer support and service accessibility. The integration of care, accessibility of services and the facilitation of choice for patients to die where they wish, are core components in this policy. In addition, the need for research in end of life care and dedicated education and training was identified (DH, 2008).

The impact on where people die has been noticeable (Gomes et al., 2012) and is seen as an effort to respond to the increasing demographic burden of chronic disease and the frail elderly. This is a challenge that requires significant resources, planning of care and a shift to acknowledge that patients are reaching the end of their lives (Gomes et al., 2011). This key policy driver addressed significant priorities to facilitate the enhancement of care and effective commissioning and delivery of services (Seymour, 2012).

The confusion already alluded to that exists between palliative care and end of life care persists despite explicit policy around end of life care (Seymour, 2012). Gott et al. (2011) acknowledge the interchangeable use of terms as a symptom of confusion and an identity struggle in this field of care. This does not help professionals make the transition in terms of planning care and offering choice to patients, nor does it help the public understand the care landscape they are living and dying in.

While a dedicated policy commitment to end of life care was broadly welcomed in the professional field, there are clearly shortfalls. The increase in frail elderly people in society brings to bear the challenge of predicting death. It is an oversimplification to think that a question such as 'whether the patient is likely to die' is sufficient, given that some elderly people articulate their wish to die suddenly rather than be subjected to an undignified social death (Gott, 2008). The priority should be meeting unmet needs and providing integrated holistic care; a challenge we are still wrestling with in 2019.

The End of Life Care Strategy (DH, 2008), and its more recent iterations and reviews (DH, 2009; DH, 2010a; DH, 2011; DH, 2012; DH, 2015; DH, 2016) clearly articulated that the delivery of quality end of life care is a measure of how we care for the most sick and vulnerable people, and an indicator of how we measure the efficacy of health and social care services. Annual review of this strategy was undertaken by central government, with the first annual report (DH, 2009) commenting on the increased profile of end of life care, improved commissioning and the dovetailing of policy delivery with other areas such as dementia care (DH, 2009a). There is a specific ambition to reach out to disadvantaged groups, such as patients with chronic obstructive pulmonary disease or offenders in prison. The Fourth Annual Report on the End of Life Care Strategy (DH, 2012) built on prior policy recommendations and achievements, and reviewed the formation of the Dying Matters Coalition, electronic palliative care plans offering an insight into choice and preferences, and the VOICES digital storytelling project, which enabled patients by allowing insight and bereaved carers to have their voice heard.

More recently, some of the policy drivers to enhance care have been focused around unravelling tools applied as apparatus to orchestrate end of life care, namely the Liverpool Care Pathway for the Care of the Dying (LCP). This was systematically dismantled amid a fast-changing landscape and will be the subject of specific consideration and influence throughout this thesis. The LCP will be explored more fully in chapter 4. Moving forward, there has been a plethora of policies related to end of life care; Ambitions for Palliative and End of Life Care (National Palliative and End of Life Care Partnership, 2015)

being one such example; a collaboration of charitable, social and healthcare providers aiming to build on the End of Life Care Strategy, modernising it and taking into account the findings and recommendations of successive reports. This is also closely aligned to NHS England's Five Year Forward View and the need to lead and deliver care with a primary care focus, recognising the need to integrate health and social care systems and firmly base care delivery on local decision making (NHS England, 2014a).

The recent Transforming End of Life Care in Acute Hospitals (NHS England, 2015) demonstrates further cross-sector collaboration with the intention of putting into place the Ambitions Partnership Report (National Palliative and End of Life Care Partnership, 2015). This includes examples of best practice, electronic palliative care registers, rapid discharge to enable people to die at home and a commitment to the priorities of care. In addition, the Care of the Dying Adults (NICE, 2015) provides evidence-based guidelines upon which to base care and to enable generalists to predict dying, improve shared decision-making, and promote good symptom management. Central government (House of Commons Committee, 2015) has also highlighted the challenges of cost improvements and restricted funding for quality care at the end of life. The End of Life Care Audit – Dying in Hospital (Royal College of Physicians (RCP), 2016) also offers guidance on best practice, communication, care planning and holistic care. None of the aforementioned policies can be implemented without a skilled and competent workforce, which presents a key challenge for future service development (National Council of Palliative Care, 2016; RCP, 2016).

Public Health England, working in collaboration with the NHS, formed the National End of Life Care Intelligence Network (NEoLCIN) in 2016, which collects, collates and analyses quality indicators, patient numbers and cost information in end of life care across all sectors. This allows for the distribution of information, the formation of end of life care profiles and assists with decision-making and service development, with further guidance to commissioners for the shaping of local services being available (NHS England, 2016).

The implementation of these policy drivers has moulded practice in end of life care, problematising death and dying, shaping the way it is managed and the way care is delivered (Borgstrom, 2016). National policies, while offering the opportunity to develop and attract funding, also control service design, delivery and professional practice. Foucault's concept of governmentality determines how society is regulated through discipline and regimes that control and categorise people into manageable groups (Barker and Galanski, 2001). Policy is an apparatus, which enables the application of power emanating from the centre outward and allows the imposition, coordination and disciplining of individuals (van Brussel, 2010; Nilsson and Wallenstein, 2013).

> "…*this enclosed, segmented space, observed at every point, in which the individuals are inserted in a fixed place, in which the slightest movements are supervised, in which all events are recorded, in which an uninterrupted work of writing links the centre and periphery, in which power is exercised without division, according to a continuous hierarchical figure, in which each individual is constantly located, examined and distributed among the living beings, the sick and the dead…"* *(Foucault, 1991 p197)*

3.6 Moving Forward

The emergence of end of life care as a distinct sphere of clinical practice over recent years and the publication of the End of Life Care Strategy (DH, 2008), with its subsequent updates and iterations (DH, 2009; 2010a; 2011; 2012; NHS England, 2014, DH, 2015; 2016) has reiterated the UK's place as leading the global social movement to enhance care for those who are dying (Seymour, 2012). The strategy was launched in an attempt to engage with professionals in health and social care, and address the pressing demographic changes, the ageing population and the increase in chronic degenerative disease (NHS England, 2014). In 2015, end of life care in the

UK was ranked best in the world for both quality and availability of services (The Economist Intelligence Unit, 2015).

It is vitally important moving forward that there is institutional engagement in order to meet the responsibility for providing end of life care to all, especially for people who experience disadvantage (Seymour, 2012), be that socio-economic, cultural or indeed as a result of their diagnosis. Without dynamic advocates there is a risk that palliative care fails to reach those who are most in need at the end of their lives - those without a voice, those who are the disadvantaged dying, for example, the elderly with chronic degenerative disease, who comprise the greatest number of patients needing palliative care.

We are at a tipping point in terms of sustainability in the National Health Service, with policy drivers demanding reconfiguration of care delivery and patients to be at the heart of the NHS (NHS England, 2014a), yet we still have major inroads to make on the recommendations made in previous end of life care policies. The Five Year Forward view (NHS England, 2014a) puts compassion at the centre of care delivery, building on the work of Kellehear (2005), who talks about end of life care being a public health issue that needs to be addressed through communities, social connections and supportive relationships. More recently, Abel and Kelleher (2016) propose a model of care delivery for patients at the end of life that involves palliative care professionals divesting some of the work they undertake and forming closer partnerships with communities and volunteers. It is evident that there is still a dichotomy between how we deliver end of life care in reality and the drivers to configure services for the future. We must not lose sight of the lived experience of death and dying, understanding and extoling the strengths of multi-disciplinary care and the contribution that multiple voices can make to the patient journey (Seymour, 2012). This thesis will help uncover and develop understanding of the subjugated voices; the voices that are unheard and differ dependant on the moment in history, but can indeed change and enhance end of life care through their resistance.

The reality is that we are in different epidemiological times in terms of death and dying. If we look through history, the change is from sudden unexpected and contagious death to prolonged chronic, and to some extent, preventable death (Zimmerman, 2007). Aries (1981) notes that with the shifting of social practices dealing with death, dying shifted from the home and under the auspices of religious orders, to the hospital, under the control of the doctor where the discursive context of the dying person only amounts to the disease that they suffer from (Van Brussel and Carpentier, 2012). Concurrently, in terms of medical knowledge, there was a shift from the dead body being unable to reveal cause of death to being epistemologically normative; the font of all knowledge (Foucault, 2003), with the clinical gaze developing a domination of understanding the body reality (Howson, 2013). Moving to present times, we are in an era where we have seen many public health discourses claim that we can delay and prevent early death (Lupton, 2012), and that death is viewed as a failure. The question now is: how do we engage proactively as healthcare professionals to make sure that people reaching the end of their lives receive the care they need, without understanding our discursive practices and how they are shaped by external influences?

The challenges faced, the evidence on which we hinge practice, and the drivers that articulate the state and direction of end of life care are considerable. The following chapter will consider the literature, locate the research and focus on the contextual conditions that resonate in end of life and are relevant for this study.

4 Narrative Literature Review

This thesis contributes to professional understanding of the contextual conditions that influence end of life care in the acute setting; the influence and impact of mainstream media on discursive practices in end of life care; and how discourses shape end of life care practices. Having searched the literature, I begin with an overview of what constitutes a good death followed by international perspectives and end of life care in hospital. This will provide insight and appreciation of the complexity of how and why people die in the acute setting. There is a plethora of tools utilised in end of life care, largely generated through policy and practice drivers as discussed in chapter 3. The main tools influencing end of life care in hospital will be explored in this chapter (page 52).

The influence and impact of mainstream media is a core consideration for this research, so themes related to media and health, and the way we talk about death and dying are included on pages 62-70. How we deliver care at the end of life is influenced by societal perceptions of death and dying; understanding this broader context is important for this thesis, so death and dying, and the notion of taboo are also included in this review. These themes all have resonance for the aim of this thesis and are part of the contextual overlay that informs how professionals understand and orchestrate end of life care.

4.1 Search Strategy

A literature search was undertaken using electronic databases such as CINAHL, Web of Science, Medline and Pubmed. While Parahoo (2006) suggests a timeframe of 5-10 years as a guide for the age of work included in a review, seminal and influential work should be in included. This is important for this study as some of the literature informing the contextual understanding of end of life care is over 10 years old. It is important to note that the

literature review was refreshed and renewed as I progressed through this doctoral journey.

Literature related to the following search terms was included:

- End of life care AND Hospital
- Tools used in end of life care
- Pathways in end of life care
- Media and end of life care
- Metaphor and cancer care / end of life care
- Death and dying AND taboo
- Societal views of death and dying

As the landscape of end of life care has developed over the duration of this study, the engagement with the literature been responsive to such changes. For example, as the Liverpool Care Pathway (LCP) became a prevalent topic of research attention and in the media, specific searches were undertaken to encompass those terms.

4.2 The Good Death

The philosophy of hospital care, alongside the demands on the organisation of care, presents key challenges for end of life care (Casey et al., 2011). The definition of what constitutes a good death has arisen through the domain of specialist palliative care, with the ideal death being illustrated through the hospice movement and patient care delivered in this setting (Costello, 2006). A good death has been articulated as one that includes effective symptom control, good communication, shared decision-making, privacy, dignity and the acceptance of the end of life, with an emphasis on expertise and sensitive care (Brereton et al., 2012; Virdun et al., 2015). In reality the environment, social context and understanding of where people die can influence the perception of a good death, with the historical and cultural understanding of a good death being at the core of the individual's perception (Costello, 2006). Whichever way the end of a person's life is considered, a

good death is not a simple concept, being contingent not only on context but also on a person's expectations and the ability of services to deliver what is required (Payne et al., 1996; Lawton 2000; Thompson et al., 2006).

Kellehear (1990; 2007) articulates death as being about the whole person, including acknowledgment of the social world the person lives in and adding that those living with a chronic disease have lived in a medicalised world focused on interventions and treatments, and are well-versed in the hospital as an institution. Acceptance of death and living with an expected death contrasts with what may constitute a bad death - drama, trauma and chaos (Kristjanson, 2001). This echoes the thoughts of Walter et al. (1995) who discuss the dramatisation of death and the role of the media in shaping the understanding of death. Such influences have distilled into an anxiety regarding death and dying across society, fuelled by unrealistic expectations about the power of medicine being able to intervene and prevent death (Taylor and Chadwick, 2015; Mannix, 2017).

It is evident that the concept of a good death has been significantly influenced by the perceptions of palliative care practitioners working within the hospice setting, where the environment is designed to be homely (Lawton, 2000; Kristjanson, 2001; Walters, 2004; Higginson et al., 2013). The care is very different when comparing hospital and hospice, with hospice care being viewed as superior in terms of holistic patient-centred care with good communication and symptom control at its heart (Walters, 2004; Addington-Hall and O'Callaghan, 2009). Grande (2009) argues that the best of hospice care should be translated into the hospital setting, while Ellershaw and Ward (2003) recognise the challenges that this would raise. Regardless of the transferability of what is intrinsically a philosophy of care, we need to recognise that for many people, dying at home is the ideal (Gomes et al., 2015). However, in a changing and challenging landscape, planning for where people want to die is difficult and as a result, many die in hospital or care homes. The good death is premised on the ability to plan and predict general decline in order to access appropriate care. Increasing frailty and multiple morbidity in relation to long-term conditions make determining when the end of life is approaching more complex (Pollock and Seymour, 2018).

The next section explores the international picture of palliative care and end of life care, offering important contextual understanding and insight into how the UK is situated in this context.

4.3 International Context of Palliative Care

Viewing the provision of palliative care through an international lens offers perspectives on the size and scope of the challenge to provide for people in need across the globe. It also provides insight into where the UK sits in terms of how we deliver palliative care and end of life care. 85% of deaths worldwide occur in the developing world (Singer and Bowman, 2002). Clark (2007) considers the international provision of palliative care to be primarily for cancer patients in the developed and developing world. Political and societal challenges are found to be the main blockers to the delivery of palliative care, especially in the developing world, with only 35 countries integrating palliative care within mainstream health provision. Poor financial and material resources affect integration and development of palliative care, as do lack of public awareness, lack of government recognition, and poor education and training (Lynch and Clark, 2009). While there have been improvements in the last few years internationally, palliative care professionals demand a removal of these barriers in order to achieve integration and meet the demands of the population (Reville and Foxwell, 2014).

As in the UK, the global ageing population and the increase in long term conditions mean that we will continue to see increased demands on palliative care services in the future (Brerton et al., 2011). In developed countries like the UK, there is an international drive to reduce hospital stays, increase care available in the community and reduce the impact of lengthy hospital admissions (Higginson, 2013). Despite a steady decrease in hospital deaths in recent years, these remain relatively high in Europe (Hunter and Orlovic, 2018). A Cochrane Review of evidence from the UK, USA, Sweden, Norway, Spain, Canada and Australia concluded that increasing palliative care

services in the home significantly increases the chance of home death (Gomes and Calanzani et al., 2016).

Following a study that collated data from home, hospice and hospital settings, and included staffing ratios, education and training, end of life care in the UK has been identified as the best in the world (The Economist Intelligence Unit, 2015). Against this backdrop, the following paragraphs will consider end of life care in hospital in greater detail.

4.4 End of Life Care in Hospital

> *"…the medical gaze circulates within an enclosed space in which it is controlled only by itself; in sovereign fashion, it distributes to daily experience the knowledge that it has borrowed from afar and of which it has made itself both the point of concentration and the centre of diffusion…"* *(Foucault, 2003 p35)*

This study aims to consider the contextual conditions necessary for the delivery of optimal end of life care in the acute care sector. The broader context is therefore important, as is understanding where people die. As discussed in Chapter 3, the context of dying in hospital is thus important for setting the scene for this thesis. Despite policy drivers and creative service design and delivery to encourage and enable death in the person's stated preferred place, half of deaths in England occur in hospitals (Royal College of Physicians, 2016). Clark et al. (2014) identify that hospitalisation indicates a patient's deteriorating condition, especially in the ageing population, and articulate a pressing need for a change in hospital culture in order to identify people entering the last year of their life; this would enable patient choice and allow the individual to plan for their death where possible. This is only achievable with the development, availability and sustenance of robust services, focused on achieving this aim regardless of where the patient dies. Such choice is only available if we have the resources to deliver it (NHS England 2015a).

It is important to recognise that up to a third of people admitted to hospital in the last year of their lives are admitted inappropriately (Abel et al., 2009; Pollock, 2015). Indeed, some patients identify hospital as their place of choice, as it offers them hope of being able to improve their condition, feel better and also support their families (Robinson et al., 2015a). There is a pressing need to improve end of life care in hospital, and systemic factors that influence both access to care and the quality of care delivered. These include: individualising care, multidisciplinary working, the need for training and recognising when a patient is dying (Noble et al., 2018). Providing high-quality care for dying patients in hospital is vital if we are to meet the demands of the changing population and societal expectations (Virdun et al., 2015). Given the number of people who die in hospital, it is important that there is capacity and capability within teams to deliver end of life care. The next section considers access to palliative care at the end of life.

4.4.1 Access to Palliative Care Services

Successive research articles over a significant number of years identify the need for palliative care to be based on patient need and to not be disease specific (Higginson, 1997; Higginson and Addington-Hall, 1999; Field and Addington-Hall, 1999; Rosenwax et al., 2005; Murtagh et al., 2014; Gomez-Batiste et al., 2015; Seow et al., 2018). The reality is that for patients who are reaching the end of their life, and their families, there has been a chronic lack of representation of the need for services to support them. Many patients face inequitable conditions and significant barriers to accessing palliative care services. They may belong to vulnerable and disadvantaged groups, for example the homeless, or have unique needs and unique barriers (Stajduhar et al., 2019).

There are significant disparities in access to palliative care services that are largely contingent on the dying trajectory. A study by Seow et al. (2018), in relation to access to palliative care by disease trajectory, found that far more patients with cancer accessed the services than patients with chronic

disease and frailty. This is echoed in the work of Pollock and Seymour (2018), who found that older people with frailty and dementia were largely "invisible" to palliative care, with poor access to services, later referrals being more common in the elderly frail patient (Gardiner et al., 2012; Zimmerman et al., 2014; Bennett et al., 2016), and younger patients having greater access and utilisation (Rosenwax et al., 2016).

Increasing frailty and chronic disease make it difficult to determine that a person is reaching the end of life (Dixon and King et al., 2015; Pollock and Seymour, 2018). Many deaths of people who need palliative care occur in the hospital setting (Gomes et al., 2018). However the priority of care delivery in hospital is often managing an acute relapse or condition resulting in the palliative care needs of the patient being lost to the treatment imperative (Gott et al., 2013a). In order to manage the drive for active treatment at a time when the patient is dying and to ensure they have access to palliative care when needed, it is important to dispel uncertainty and recognise when that time has come (Noble et al., 2018). The challenge of recognising when a person is dying and managing symptoms in a timely way is considered in the following section.

4.4.2 Treatment, Symptoms and Recognising Dying

Patients are often admitted to hospital at the end of life because of lack of support, pain, symptoms and uncertainty. In hospital the focus is often on comorbidities and physical symptoms, and it appears in some areas to be a struggle to balance the therapeutic imperative and the need to deliver patient-centred care underpinned by honest, compassionate communication (Bloomer, 2019). This focus on medical management can often lead to symptoms, which are complex in chronic disease, being overlooked if only life-prolonging treatment is offered (Meffert et al., 2016). This focus on cure, the notion of death as a failure and the biomedical model that underpins care delivery in hospital, makes it a challenge to deliver holistic care focused on the needs of the individual (Virdun, 2015). Bereaved relatives have reported

the dying person being subjected to unnecessary medical interventions and being at higher risk of harm (Hunter and Orlovic, 2018).

Considering the numbers of people who die in the acute sector, hospital clinicians should be perfectly situated to identify patients who require palliative care (Filerman et al., 2019). Patterns of decline and typical illness trajectories can help professionals understand how people die and also allow for appropriate planning (Murray et al., 2005). While it is useful to consider such trajectories, they are indeed less predictable within the context of advancing treatments or chronic disease. Filerman et al. (2019) identified that the majority of the hospital nurses and doctors found it difficult to define when a patient is in the palliative phase of their disease process. This is understandable, as the balance between curative and active treatment, and palliative care is a challenge to navigate. Early referral to palliative care can help with this (Colombert et al., 2019).

Symptoms remain at the forefront of family concerns and patient anxieties as disease advances, and this contributes to the complexity of enabling patient choice. For example, worry about carer burden and difficult symptoms can influence people remaining at home; for those in hospital, unsatisfactory experiences can influence their decision to stay in hospital (Dixon and King et al., 2015). Generalists in palliative care often do not recognise symptoms when patients are in the palliative phase (Baillie et al., 2018). Even so, pain and symptoms outcomes are better for patients who are admitted to hospital, which helps ease distress (Eager et al., 2018).

Acknowledgement of dying is essential if we are to provide the holistic care needed at the end of life. Generalist nurses can take a passive role in recognising dying (Bloomer et al., 2013), even though they are better placed to deliver holistic care and should be engaged in making sure there is early referral to palliative care when needed (Filerman et al., 2019).

Communication is the cornerstone of good palliative care; the next section will consider the challenge of open, honest and compassionate communication at the end of life in hospital.

4.4.3 Communicating at the End of Life

Communicating with patients and their family at the end of life is important. It is only through exploring fears, anxieties and wishes that we can go some way to facilitate a peaceful death. Good communication is the main factor that can influence and improve end of life care in hospitals (Reid et al., 2015). End of life conversations in hospital should give the patient this opportunity to consider carefully their situation, future and make timely decisions (Bergenhotz et al., 2019). It is only through developing therapeutic relationships, exploring understanding with the patient, and appreciating how, when and what we say, that we can begin to address the issues that can contribute to a peaceful death (Bloomer et al., 2017).

There are challenges in hospital that undermine communication. The institutional mainframe of a hospital is geared to busy throughput of patients and noisy spaces, neither of which facilitate the time and space necessary to talk to vulnerable people (Caswell et al., 2015). The study by Caswell et al. (ibid.) found there to be good and bad practices when communicating with family carers, and that all wards in the study differed. There were, however, common themes identified, such as carers' impaired understanding of the complex language and euphemisms, and what seems to be a lack of confidence in some staff when communicating a prognosis. At times, there seemed to be an avoidance of discussions around end of life care (Rawlings, 2019). Of course, this is not helped when some patients – especially those who are older – trivialise their illness-related challenges and can be reluctant to engage in conversations (Im et al., 2019). Engaging with patients earlier in their disease trajectory and applying the principles of palliative care may help with communication, and embed relationships before there is a significant decline.

Communication is a dominant theme when considering the patient experience. For example, there are reports of poor quality information, lack of sensitivity, use of inaccessible language and poor delivery of bad news

(Robinson et al., 2014). Conversely, Gott et al. (2019) found that families reported that they valued people making an effort to form relationships, with empathy, kindness and understanding being manifested in healthcare professional interaction with patients. The next section will explore the experience of end of life care in the hospital setting.

4.4.4 Patient and Family Experience of End of Life Care in Hospital

The way hospital care is delivered and the associated institutional systems and processes cannot fail to influence the delivery of care at the end of life. There are positives and negatives to consider. However, we must recognise that it is sometimes the “little things” that matter; time to take care, comfort measures and kindness (Black et al., 2018). Set against a backdrop of increasing staff shortages and escalating pressures on care delivery, there is a risk that patients can feel like a disease or a commodity (Black et al., 2018). Busy staff may be unavailable and provide no condition updates, leaving it almost impossible to make informed decisions about treatment options and end of life care (Robinson et al., 2014).

Staff attitudes and leadership play a large part in being able to deliver a positive end of life experience (Johnston et al., 2015). In a large survey of bereaved relatives, good or excellent end of life care was reported. However, there was still a significant minority, who described end of life care as poor or very poor (Mayland et al., 2014). Similarly, Ó Coimin et al. (2019) found concerns about the quality of end of life care in hospital; relatives described poor communication and environment as key issues.

An understanding of what is important for the patient and their family will help develop and enhance the hospital as a place to die. Effective communication and shared decision making, undertaken with honesty, respect and empathy is important. Simple things are important too; they contribute to care being tailored to the individual and being holistic in the truest sense (Virdun et al., 2015; Donnelly et al., 2018). Those who have had experience of end of life

care in hospital rank expertise highly, wanting good physical care, symptom control and integrated care of high quality (Virdun et al., 2016).

Patients and their families are clear and consistent in articulating their needs. We need to listen and act to improve end of life care, and we need to ensure we can deliver high quality person-centred care. The education and training needs for the workforce must be addressed to challenge the hesitancy some healthcare practitioners have in engaging with patients at the end of life, improve communication and build expertise (Ó Coimin et al., 2019).

4.4.5 The Hospital Environment

As death approaches, many patients and their carers cannot sustain care at home, with hospital often being seen as the only alternative. The choice of where patients wish to die can thus change over time (Agar et al., 2008; Bloomer, 2019). However, the hospital environment does not lend itself to patient-focused dignified care at the end of life. Indeed, patients and their families report that being in hospital does not automatically mean that symptoms are adequately managed; that the admission itself adds more stress to a difficult situation; and that privacy and dignity is difficult to achieve (Robinson et al., 2014; Robinson et al., 2015; Pollock, 2015; Rawlings, 2019; Gott, 2019). Despite all of these factors, the concept of home can, for some patients, incorporate institutions and staff that become like family because that is where their care is delivered (Gott, 2014). Hospital offers the person the opportunity to be cared for, access to help if their condition changes and the feeling of being safe (Robinson et al., 2015a). For most people, however, wishing to die in hospital is the exception and is largely dependent on relationships they have built with their long-term healthcare team.

Such empathetic relationships offer sophisticated and contextualised knowledge of the patient's needs, with staff, patients and carers working in partnership (Gott et al., 2019). Despite this, the environment impacts upon social relationships with families, other patients and healthcare professionals (Robinson et al., 2015). The physical and organisational environment is not

conducive to being able to have meaningful conversations with patients. Using ward rounds to communicate, shedding responsibility for having difficult conversations, and being unable to have privacy and dignity maintained at the end of life on an open ward (Bergenhotz et al., 2019) are all factors that make a peaceful death in hospital difficult to achieve (Slayter et al., 2015).

Key tools have been used to operationalise end of life care in hospital; these are reviewed in the following section.

4.5 Implementing the Policies Through Tools

The End of Life Care Strategy (DH, 2008) as discussed in chapter three, has been described as a “watershed” moment for the integration of end of life care across all domains of health and social care (Kennedy et al., 2009). The rhetoric in subsequent policy articulates a commitment to deliver high quality care at the end of life, with a more personalised approach and real choice, preferences recognised, and cross-sector collaboration (NHS England, 2014, 2015; National Palliative and End of Life Care Partnership, 2015; DH, 2016). Despite this, there is still a disconnect between the identified need for end of life care and associated interventions, some of which have a scant evidence base (Sleeman et al., 2018). While the policy agendas reflect the institutional drive for high quality end of life care, it is the tools, guidelines and pathways that arise from such policies that facilitate implementation.

The rest of this section will introduce the implementation devices (tools) that have been key to the development and delivery of end of life care for the last decade. Their positive contribution to end of life care and their acknowledged limitations will be discussed.

4.5.1 Gold Standards Framework

The Gold Standards Framework (GSF) was developed in primary care in 2004 as a means of promoting quality palliative care through coordination of services and organisation of care. It was initially aimed at generalists delivering palliative and end of life care in the patient's place of choice, primarily with a view to reducing unnecessary hospital admissions (Thomas and Noble, 2007). While primary care was the initial setting in which the GSF was applied, it was also embraced by the nursing home sector. This use of a systematic and structured approach to care delivery at the end of life in nursing care homes decreased hospital admissions and increased adherence to protocol-driven care (Kinley et al., 2013). While this systematic review offers insight into the impact of the GSF in the nursing home setting and is from a limited evidence base, it does point to the need for future research, which needs to be focused on patient outcomes rather than administration and process (Addicott, 2010).

In meeting the challenges of delivering end of life care, the GSF has been an important resource in the organisation of care and an important model of good practice endorsed by the End of Life Care Strategy (DH, 2008). The GSF offers a stepwise systematic approach to the delivery of palliative care using the 'seven Cs': Communication, Coordination, Control of symptoms, Continuity, Continued learning, Carer support and Care in the dying phase. The GSF is reviewed and amended as a resource for practitioners working in end of life care (Gold Standards Framework, 2017).

The introduction of tools to identify, assess and plan care, and registers and care pathways to capture patients who require support, are all part of the GSF. Such tools have enhanced communication, for example, with out-of-hours care providers, and this has led to improvements in the delivery of seamless care (Mahmood-Yousuf et al., 2008; Shaw et al., 2010; Quinn and Thomas 2017). While it is arguable that the adoption of tools as part of the GSF can be time consuming (Walshe et al., 2008), it has helped to provide a national approach and given patients a choice, allowing them to voice their

decisions about where and how they want to die (Addicott, 2010). This is a positive step, which could be further enhanced by a better understanding of wider societal perceptions and their influence on the delivery of high quality end of life care (Mannix, 2017), as well as the need to change the culture of death and dying in professional practice (Hockley et al., 2010).

While policy drivers articulate the embedding of tools and apparatus such as the GSF to improve care at the end of life, the reality is that there are many mitigating factors that impact upon quality care within the institutional mainframe of where and how care can be delivered (Borgstrom and Walter, 2015). Given the importance of communication, articulated in the GSF, the importance of Advance Care Planning for helping people make decisions about their future care is considered in the next section.

4.5.2 Advance Care Planning

Increasing pressures on palliative and end of life care services are evident, largely due to changing demographics, which have resulted in a real challenge to providing access to palliative and end of life care for all who need it, especially those with chronic disease (Dalkin et al., 2016). Advance care planning is an essential aspect of end of life care (Addicott and Ross, 2010) and helps identify and respect patient wishes, decreasing the chance of problems in bereavement (Detering et al., 2010). Advance care planning is a voluntary process; a discussion between the patient and their care providers, which may or may not include their family and friends (Clarke and Seymour, 2010).

As a large proportion of people die in hospitals (Gomes et al., 2015), there is a need for such acute settings to deliver high quality end of life care, and elicit, record and facilitate the individual choices of patients and families towards the end of life (Higginson et al., 2010). The consequences of not doing so in a timely manner is a decreased uptake or referral to palliative care services (Seymour et al., 2010).

The patient's wishes can change over time. As place of death and what is ideal for that person is variable, it is wrong to presume that everybody wishes to die in their own home. For some people, home can be lonely and distressing; this significantly affects the quality of the person's death. Death at home does not always mean a good death (Pollock, 2015). Use of a procedural device or apparatus, such as advance care plans, must factor in not just where the patient wants to die but also their experience of dying.

Because of the challenges linked to predicting death and the difficult conversations associated with it, professionals can find it a challenge to introduce advance care planning in a timeframe that suits the patient's receptiveness and allows for the implementation of a whole systems approach to operationalising their wishes.

Advance care planning has to be used in a sophisticated way, making it more than just a procedural device that reflects the patient's clinical condition and the associated changes as they approach the end of life. Lupton (2012) discusses the power patients hold in clinical situations; fundamentally, an advance care plan can place power in the patient's hands, especially if conversations related to advance care planning are started early, truly reflect the patient wishes and are not in response to crisis or sudden deterioration (Lund et al., 2015). The principles of advance care planning can significantly contribute to quality care at the end of life (Deterring et al., 2010) however, the challenge is to embed the framework across the care delivery landscape, to ensure good communication and consistency of application (Jeong et al., 2010; Boyd et al., 2010; Hockley et al., 2010). This is especially challenging in the acute sector, where some areas of clinical practice are complex, dynamic and time-pressured (Lund et al., 2015).

Good communication is the key to the delivery of timely and appropriate advance care plans. Unfortunately, sensitive communication to elicit patient wishes often falls short, with the timeliness of such plans and the appropriateness of conversations undermining the principles of advance care planning (Boyd et al., 2010). The apparatus overtakes the person-centred principles of advance care planning in the drive to complete predetermined

questions and tick boxes, effectively undermining the principles of good end of life care (Seymour et al., 2010; Borgstrom and Walter, 2015). Advance care plans document patient choice. Communicating wishes is important; the next section will consider preferred priorities for care in more detail.

4.5.3 Preferred Priorities of Care

Preferred priorities of care gives people the chance to think about their future death, and an opportunity to discuss choices and the care preferred when they are dying. There are many different iterations dependant on local needs and documentation, however, their aim is the same: to have open and honest communication so all those involved in the patient's life and death understand their wishes. It is important to recognise that place of death is not simply about patient choice, but more about the complexities of dying, individual choice, environmental factors and availability of services (Constantini, 2008). Nevertheless, an essential consideration for a good death is people being able to die in the place they want to. People have a preference to die at "home", as determined by the individual, however, this is tinged with worry about dying alone and the burden placed on those who care for them (Seymour et al., 2010a). In order for the patient's choices and wishes to be realised, they must be discussed and captured so that all members of the professional team can make this achievable, and can circumvent professional and societal barriers that may stifle choice (Cox et al., 2011; Clarke and Seymour, 2010). One challenge is to ensure that a distinction is made between preferred place of care when the person is dying and preferred place of death (Agar et al., 2008). These can differ as people may want to be cared for in hospital but, as death approaches, may want to go home or to a hospice to die (Gerrard and Campbell, 2011).

Significantly, studies suggest that most people choose to be at home to die (Seamark et al., 2014). Lack of longitudinal data, flaws in reporting and design, and a focus on cancer have been identified as limitations in studies focusing on preferred place of death (Higginson and Sengupta, 2000). In

contrast, Hoare et al. (2015) argue that we should be cautious about assuming preferences for place of death, as missing data from those who do not express a preference may skew insight. Despite this, choice becomes less determined as death approaches; place of death and choices are ever changing, dependent on circumstances, changing condition and carer burden (Pollock, 2015; Munday et al., 2009; Gott et al., 2004). Professionals can also block patient choice, as can the availability of services and options being communicated poorly at inappropriate times (Munday et al., 2009).

Tools or apparatus that identify priorities and preferences have to be used and applied using a whole systems approach across health and social care, with clear recording and sharing of information, strong partnership working and integrated care delivery (NHS England, 2015a). This can be differentiated from the Advance Care Plan, which can include treatment decisions, emergency healthcare plans and wishes regarding treatment priorities.

The use of tools and the traction associated with their application is important for this research. The next section explores the literature related to the Liverpool Care Pathway (LCP). As I progressed through this research journey, the LCP emerged as a priority for practice and minimised other tools used in end of life care. The impact of this will be explored more fully in chapter eight (page 208).

4.5.4 Liverpool Care Pathway (LCP)

The LCP was developed to be a multi-professional resource that incorporated best practice guidance. Generated by hospice doctors for use in the hospital setting, it offered guidance for care delivery and a carefully constructed management plan for people in the last 48 hours of life, suitable for use by all involved in the delivery of end of life care, and an opportunity to transfer and translate hospice models of end of life care (Ellershaw and Wilkinson, 2011; Watts, 2012). The intention of the LCP was to offer much

greater coordination of care (Phillips et al., 2011) and an opportunity to be proactive, rather than reactive, in the way care is delivered at the end of life (Lhussier et al., 2007). In addition, guidance facilitated appropriate decision-making and standardised care like many integrated care pathways (Parry et al., 2013). The drive was to improve the quality of care when a person is dying and achieve a good death (Pugh et al., 2010; Philips et al., 2011). The LCP also offered a template for assessing the dying person and for managing their symptoms as an important part of end of life care. Death was legitimised as a reality, aiming to allow the focus of care to be changed. Conversely, the LCP was also seen as a weak tool, with no empirical evidence base and the potential to cause harm (Sleeman and Koffman et al., 2015).

The wholesale adoption of the LCP across all sectors was very rapid from the outset, with a scant evidence base (Phillips et al., 2011; Watts 2012; Chan and Webster, 2014), the driver being neoliberal eagerness (Borgstrom and Walter, 2015). Neoliberalism in health and social care has gained significant traction in recent years, with the promotion of patient choice in particular. Harvey (2015) discusses how the state should abstain from intervention, leaving as much as possible up to the individual, in turn the state should create and preserve an institutional framework to support such choices. Healthcare professionals shape the way in which services are designed, implemented and accessed (Borgstrom, 2015a). In addition, end of life care policies drive the development of apparatus allowing control of death and dying.

For many there were great positives to be taken from the LCP. Care for those who were imminently dying improved when its use was underpinned by education and support for healthcare professionals. A diagnosis of dying, which was dependent on the skills and expertise of clinicians, had to be made for patients to be placed on the LCP (Pugh et al., 2010). The LCP was introduced as a means to apply best practice when caring for patients at the end of life, and also an opportunity to ensure the pursuance of treatment is carefully considered (van der Heide et al., 2010).

Despite this, such widespread acceptance of the LCP prior to assessment and evaluation impacted on the evidence base and additionally compromised practice when the use and application of the LCP was brought into question (Currow and Abernethy, 2014; Di Leo et al., 2015; Hughes et al., 2013; Phillips et al., 2011). There was also evidence that some patients were inappropriately put on the LCP (Stocker and Close, 2013).

As early as 2009, comments were being made regarding the LCP only being as effective as the people that used it (Edmunds et al., 2009). It was portrayed as being responsible for everything that was wrong with end of life care, including poor access to education and training, lack of investment and poor communication skills (Seymour and Horne, 2013; Seymour and Clark, 2018). Regnard (2014), likened the demise of the LCP and the blame placed upon it for poor end of life care to the Highway Code being blamed for poor drivers, when instead poor communication and decision-making were at the root of the problem.

The British media began to highlight increasing numbers of examples of poor end of life care (Cole-King and Gilbert, 2011; Seymour and Clark 2018). The media campaign on the LCP was sustained; it discussed death, dying, incentives and dehydration. While many of these are dilemmas faced daily in end of life care, the media discussed them with such vivid and exaggerated commentary that it increased people's fear of having interventions at the end of life (McCartney, 2012). The intense exposure of the LCP in the media scared families and healthcare professionals alike by proposing that resources, rather than care, were the driving rationale for decision-making (Torjesen, 2013; Oliver, 2015). The LCP was presented by the media as being no more than a tick-box tool that could be used to achieve financial advantage (Jolly, 2013). Given the media influence on this subject, a public scandal in relation to end of life care was born, which, like many scandals, led to official reports, policy change and changes to professional practice (Lloyd et al., 2014; Borgstrom and Walter, 2015).

The furore that occurred in the media influenced the journey of this thesis; media is at the core of this research and the LCP became the beacon on

which public perceptions of end of life care were based. Hence, the influence of the LCP in the media artefacts (Chapter 7 page 171) and the reason that some of the other tools take less focus despite the fact that they are important for shaping end of life care. This issue is discussed in more detail in Chapter 8 (page 208).

Reports and policy changes are a constant across health care. The response from central government to the crisis in end of life care in relation to the LCP was, therefore, commissioning of an independent review entitled More Care Less Pathway (DH, 2013). The review was led by Baroness Julia Neuberger, and highlighted that, while the LCP was derived from the hospice setting, healthcare professionals were using it as a set of instructions and prescriptions, which could lead to them losing sight of the patient.

Healthcare professionals' understanding of the LCP was influenced by the experience and expertise they had caring for patients at the end of life, with external challenges imposed by institutions of power, and the media further impacting upon perceptions and understanding (Twigger and Yardley, 2016).

In addition, using language such as "pathway" led the public to interpreting this as "leading" to death, with the perception that healthcare professionals were killing people (DH, 2013). While positive practice was noted in the review, the main findings included poor communication around death and dying, the lack of discussion, the driver to fill in forms, and using apparatus to control and orchestrate practice. The key finding was that all patients at the end of life should have their own personalised care plan; that the LCP should be phased out and that there should be a system-wide approach to improving end of life care.

In response to the independent review, all major stakeholders in end of life care formed a partnership and published One Chance to Get it Right (Leadership Alliance for the Care of Dying People, 2014). This was a written response to the review, which largely agreed to its conclusions, finding that the core of the care plan should include recognising dying, sensitive communication, respect, dignity and the involvement of the person and their loved ones in decision-making. The *One Chance to Get it Right - One Year*

on Report (DH, 2015), reviewed progress in relation to commissioning services that are fit for purpose, sharing knowledge and good practice, and assuring quality; all of the aforementioned being underpinned by robust education, training and research.

While the drivers for such policy change are clearly focused on better care for the dying patient, an unintended consequence of the transfer of hospice care into the acute setting has allowed the apparatus to become the priority (Borgstrom, 2015). Orchestrating care through the completion of pre-prescribed tools can impact upon individualised care, with institutional priorities and control demanding the completion of such without proper understanding and engagement. Communication and personalised care are, as such, deemed to be of secondary importance to a task-oriented approach and the completion of forms and tools (Di Leo et al., 2015). Such scaling-up of a hospice philosophy and care across primary care and the acute sector has risks. While such apparatus have made significant contributions to improving care, the inherent risk in their use is clear; timeliness and appropriateness of the intervention can make apparatus a blunt instrument that undermines rather than enhances end of life care (Seymour et al., 2010).

The notion of choice, and the engagement of dying patients and their families where possible, are inextricably linked with tools and apparatus, as people at the end of life are corralled into a healthcare system that forces them to have a voice even if they do not want one (Borgstrom and Walter, 2015). Much of the rhetoric around the problems associated with such choice in the dying phase is as a result of a whole systems' bureaucratic application within a neoliberal health economy, where patient choice is not free but dictated by institutional control and those in power (Armstrong, 1987; Borgstrom and Walter, 2015).

While the tools that have been discussed in this chapter all contribute to the tapestry of how end of life care is managed and delivered, the LCP emerged as a key solution to managing care at the very end of life. Perceptions of death and dying are important and inform the contextual understanding of

both the public and healthcare professionals. Death, dying and the notion of a taboo are explored in the next section.

4.6 Death and Dying - A Modern Day Taboo?

Death and dying have to be viewed within the context of socio-cultural values, political beliefs and historical experiences (Kellehear, 2007a; van Brussel and Carpentier, 2012). Death is an inevitability and it can be argued a societal taboo. The very notion of a taboo describes a separation from everyday existence, a lack of societal understanding and appreciation and, most importantly, lack of engagement – with death often being sequestrated or hidden and denied (Conway, 2008). Conversely, there has been a re-engagement with death and dying in recent years; for example, the emergence of death cafes. The reinvigoration of societal awareness of death and dying is, however, not without controversy, tensions and dilemmas, and sees a parallel social and professional movement to open the dialogue and demystify death and dying. This therefore begs the question as to whether there is a taboo at all. This is a pivotal issue for this study to consider; how indeed, could mainstream media have such an influence if there was a taboo around death and dying?

Death is often considered to be the loss of a battle against illness (Cottrell and Duggleby, 2016); something to be resisted, postponed and denied (Clark, 2002). Currently, people often live well into old age. Traditional views on death and dying have changed, with a blurring of the boundaries of living well and dying slowly, especially for the very elderly with cumulative frailty, living with or dying from chronic illness (Gellie, 2014). Such medicalisation of death has led to the emergence of disciplines like palliative care and end of life care that, in turn, have become medicalised (Clark, 2002).

The questions of whether death-denial is something that has emerged in the late twentieth and twenty-first century, or whether the historical and social evolution of dealing with death and dying allowed for medical control of death to emerge, remains unanswered (Timmermans, 2005; Mannix 2017). Death

was once a celebration of an individual's life; an event that engaged the whole community (Gellie, 2014), while the contemporary solitary nature of death is more like an invisible act (Aries, 1981). Dying occurred in private within the home and preparation for death was undertaken according to the religious convention of the time (Kellehear, 2007a). The introduction of death certification allowed institutional control, exposure and surveillance of death, the process and functions of which made it difficult to continue the informal community death orchestrated by neighbours and families.

Aries (1981) discusses how the discourse of death changed in the early twentieth century, from being orchestrated by friends, relatives and neighbours, who discussed the death of those around them with little if any interference from medicine or the state, to the reverse, whereby informal carers and those around them were silenced. Armstrong (1987), building on the work of Foucault, considers this an oversimplification, as power is not simply something that supresses discourse but also produces it. There are times when silence is part of discourse and not a manifestation of repression, but a time to reflect and construct and re-energise a new discourse.

Discourses of health and illness changed from the second part of the twentieth century, referring less to religious meaning and more to science and medicine. Indeed, Turner (2008) argues that medicine could be deemed to have replaced religion. The decrease in religiosity appears to have influenced understanding about the inevitability of death and it could be argued that dying and ageing people are sequestered both geographically and socially, with institutions being the instrument of sequestration (Froggatt, 2001). This begs the question: is the postmodern discourse of death denying dying and the dying process to such a point that dying becomes invisible for most? (Cottrell and Duggleby, 2016). The denial of death manifests through spatial and social segregation (Elias, 1985) in terms of how we deliver care, for example, the cubicle in the hospital setting and nursing homes for the elderly. While such segregation continues, it is worth noting that there are many more informal carers, caring at home as we see prolonged phases of frailty in the very elderly living with, and dying from chronic disease (Pollock and Seymour, 2018).

The segregation of death is closely related to its medicalisation. However, it would be an oversimplification to assert that this is a result of death-denial only. It is more likely to be an indication of structural conditions and discourses that affect and inform society (Elias, 1985). Walter (1991) elaborates on the notion of the "modern death" and taboo, and aligns the notion of taboo closely to a social fear, which can be deconstructed in terms of the values of society (Lee, 2008). In his seminal work, Walter (1991) clearly articulates the need to bring the death taboo up-to-date, to account for the complexity of current attitudes and practices related to death and dying. Since the 1960's we have seen an emergence of a more open, expressive and expansive culture. Changing attitudes have allowed for a re-engagement with death; a re-discovery of the taboo as a direct result of the evolution of social and demographic structures. Death taboo is less a societal imperative than it is an individual problematic (Walter, 1991; Wildfeuer et al., 2015); it is the individual that is threatened by death, which of course is a product of the society we live in and dominant discourses. Furthermore, it is argued that the media and medicine have the most power to influence understanding and interpretation of modern death, and within these structures there are clear and public manifestations of death anxiety (Walter, 1991).

Palliative care professionals can potentiate the death-denial thesis. They devote their professional practice to undermining this denial of death, including among other healthcare professionals. Zimmerman and Rodin (2004), acknowledge that much of the furore around death-denial emanates from the rhetoric of poor care for the dying patient and their family. They also highlight that in the clinical literature they examined, it is assumed that Western society is death denying. In contrast, the sociological literature considered whether we are death denying or not; a concept virtually ignored in the clinical literature. By presenting an unbalanced debate, the clinical literature reinforces the death denial thesis, which in turn could be interpreted as a means of augmenting institutional power and the associated *technologies* controlling modern-day death and dying. Concomitantly, conversations about death and dying are changing, with the National Council of Palliative Care promoting death cafes and Dying Matters Week, and the

success of texts such as *With the End in Mind: Dying Death and Wisdom in an Age of Denial* (Mannix, 2017), which make such conversations accessible to all. As far back as 1984, Kellehear argued that not talking about death arose not from death-denial but was more about the need not to disrupt social relationships and conduct. He stated:

> *"…it is a strange taboo that is proclaimed by every pundit in the land and when virtually no Sunday is without at least one newspaper discussing death, bereavements hospices or funerals"*
>
> (Kellehear 1984, in Walter, 1991 p294)

Yet, over thirty years later, the dialogue is more open but the media remains peppered with dramatic accounts of dying.

Conversely, the medicalisation of death means that great numbers of people die in hospital, which can be seen as cloaking death away from the public gaze (Mellor and Shilling, 1993). In addition, we have to consider why people want to die in hospital when it is their wish; they may be fearful of pain, uncontrolled symptoms and loss of their loved ones. In order to facilitate choice of how and where we die, healthcare professionals must recognise that the denial and taboo theses are directly counterpoised with acceptance of death as normal part of life, which is at the core of the palliative care movement. Zimmerman (2012) captures this, viewing empathetic palliative care professionals as disciplining dying individuals and their families into accepting death and believing in their transformation through this acceptance of death. Alternatively, patients may indeed seek control and medicalisation of their death. In this case, rather than being a struggle for power in any coercive sense, there is a collaboration and collusion, which manifests as medical dominance (Lupton, 2009).

Timmermans (2005), discusses the notion of death brokering; making death more acceptable, exploring the tensions and contradictions in end of life care, finding the balance between curing and letting go, and achieving a good death however that may be individually determined. Healthcare professionals are navigating a field imbued with cultural, religious and

medical controversies. Part of the dying process is that the patient's journey has to be touched in some form or fashion by medicine, so inevitably being exposed to such controversies.

Medicine manages the physiological and psychological aspects of the dying process. Armstrong (1987), substantiated by Foucault (2003), notes that this is partly a cultural legacy as the corpse is the font of medical knowledge. Kellehear (2008) asserts in response that the construction of death and dying must include cultural perspectives and that dying as a social relationship. However, the historical medicalising context remains key to understanding how everyday assumptions inform people's understanding of death and dying (Kellehear, 2008).

If death is removed from the public space and placed in institutions, and individuals inform the way they die (Howarth, 2010), then the care that is delivered has to be viewed in the context of how dramatic death of ordinary people is portrayed in the media (Walter et al., 1995). The professionals who care for people at the end of life are, however, just as influenced by these broader discourses and it is not unreasonable to assume that this might be impacting upon end of life care practice.

The professional / public interface has recently been brought to the fore by Kate Grainger, a consultant in elderly medicine, who has blogged her way through her terminal cancer experience, using Twitter avidly and exposing her dying to the world through written and television media. Kate actively worked to break down the taboo related to dying until her death. She would like to be remembered for her positive impact and not as a failure because she has died (Grainger, 2014). The medium that Kate Grainger predominantly used to communicate and share her experience was Twitter. Twitter, as a vehicle to enhance the public visibility of death and dying, has led to the creation of a social and public space, and communities that share and acquire knowledge (O'Connor et al., 2014); in other words a place where death can be talked about more openly.

While the debate that we may or may not be a death-denying society continues, openly talking about death is important if we are to dispel myths

and allow people space to determine the way they might want to die (Mannix, 2017). However, the language used to describe and illustrate dying and death can be both reassuring and confusing in equal measure. The use of metaphor when we communicate will be considered in the following section.

4.7 Talking The Talk – Metaphor

> *"…the great metaphor of the book that one opens, that one pores over and reads in order to know nature, is merely the reverse and visible side of another transference, and a much deeper one, which forces language to reside in the world."*
>
> *(Foucault, 2002 p39)*

While the efficacy of quality end of life care is reliant upon good communication as a cornerstone, we persist in using language in a creative way, offering metaphorical substitutions in difficult situations (Harrington, 2012). The notion of metaphor and the use of language in cancer care intruded upon my personal journey in an unwelcome way and influenced my thinking during this doctoral journey. My personal experience, walking alongside family members when they were seriously ill, highlighted the contrasting language used in practice. Firstly, in the young woman with cancer (my sister), the aggressive, military and sometimes violent metaphors used influenced her thinking and approach to living through her treatment for breast cancer. In sharp contrast, my elderly father, with advanced chronic disease, was on a journey often described as requiring stoicism and acceptance. It is this experience of listening to the language used in two different contexts that, while also listening to the voices in this research, sparked my interest in the use of metaphor.

A metaphor can be defined as a way of talking about and thinking about one thing in terms of another, with the assumption that there is a similarity linking the two concepts (Semino et al., 2015). Imagery and metaphor are no strangers to communication in healthcare and are often used by patients, families, professionals and the media to capture the experience of living with

a disease; such use of metaphor is particularly prolific and powerful in cancer (Harrington, 2012).

The use of metaphor when communicating with people who are in difficult situations can make the concepts, which are often difficult to understand, more accessible to those without medical knowledge and understanding (Czechmeister, 1994; Kirklin, 2007). In addition, the difficult adjustment to living with dying can throw patients and their families into a chaotic and frenetic state; using metaphor can allow an understanding and provide a mechanism to appreciate their feelings and experiences (Reisfield and Wilson, 2004; Byrne, 2008). While healthcare professionals find communicating in difficult situations challenging, both personally and professionally, the use of analogies and metaphor can conversely confuse and disable peoples' cognition of their situation (Casarett et al., 2010).

Coming to terms with death, and the challenges associated with communicating with patients and their families at this time cannot be underestimated. Yet using language, which some is unclear and difficult to grasp, can make the situation more difficult to manage. Acknowledging that everybody is different, Semino et al. (2015) argue that there are two distinct metaphors when talking to patients with advanced disease: violence and journey, which resonate with my personal experiences.

Violence metaphors are thought to be disempowering, leading to a sense of failure, yet they are used frequently in policy documents and by healthcare professionals, sometimes detrimentally so (Semino et al., 2015). Span (2014), reiterates this, considering death the ultimate enemy, resulting in war-like metaphors about a long-fought, valiant battle, with people lying bloodied and battered on the battlefield rather than at peace.

In contrast, journey metaphors appear to cause less distress and promote the notion of companionship (Semino et al., 2015). Life as journey is such a common metaphor for how we live our lives that it can be mapped over the cancer journey like a transfer (Reisfield and Wilson, 2004). The journey metaphor can also give the illusion of travelling safely until the end of life (Byock, 2015) and the sense of failure is not as evident using this kind of

metaphor. What is evident from this research is that all patients are different and we must consider what metaphor should be used in each personal context, rather than rely upon what healthcare professionals deem to be the most appropriate, namely the tried and tested metaphors, commonly used, which different people understand at different levels.

In contrast, Gibbs and Franks (2002) consider metaphor as a linguistic tool that can be used to effectively communicate to patients suffering both physically and psychologically. Metaphor can help people make sense of their illness and find personal meaning when used sensitively and respectfully, as indeed we use metaphors as part of everyday language. Metaphors are familiar, allowing people to consider their illness as part of life's journey; they are grounded in the experience of the embodied world (Gibbs and Franks, 2002; Skott, 2002; Harrington, 2012).

While metaphor can illuminate and elucidate complex and difficult issues, equally they can compound and underline stigma and negativity (Penson and Scapira et al., 2004). Sontag (1991) considered the "punitive" notions of disease in her seminal work *Illness as Metaphor.* Here, she talks of cancer as a disease that is guilty of causing distress, and the notions of the fight and crusade against cancer. Sontag describes the emergence of metaphor and societal perceptions, and offers a historical perspective and comparison with such diseases as tuberculosis. An important perspective towards the understanding of metaphor as an influential linguistic tool, her discussion about military metaphor must be viewed in the context of her own experience (Czechmeister, 1994). For a person to exert control and choice over their own death, it is vital that they understand the illness (Van Brussel and Carpentier, 2012).

Healthcare practitioners use complex metaphor structures to speak to patients and describe their treatment choices (Lupton, 2012). Yet, perhaps one of the most influential patient voices in end of life care in recent times was that of Kate Grainger. Kate captured the use of metaphor from a patient's perspective:

> *"…In my world cancer is not a fight at all… Some days cancer has the upper hand, other days I do… 'she lost her brave fight'… if anyone utters these words after my death, wherever I am I will curse them..."*
>
> *(Grainger, 2014)*

Kate goes on to say that military language has permeated the media, cancer care, charities and everyday life, and that bravery implies some kind of choice; being placed on a "courage" pedestal does not help with living. Other patients have offered similar views, with the words used when describing their cancer experience leaving them feeling wanting, inadequate and "*dirty*" (Gubar, 2015).

Following death, people are sometimes described as having "succumbed" to the disease and "lost their fight after a valiant battle"; is this a metaphorical description of death and indicative of a death-defying culture (Span, 2014)? Sontag (1991) talks of societal denial of death, with disease being a precursor to dying and therefore something to hide; couching living with and dying from advanced disease in a metaphorical miasma allows us to hide behind the words and deny the reality of the situation. This is echoed in the work of Lhussier (2009) who states that, when considering long-term conditions, discourses talk of living disease-free, or dying, but not quality of life when living with the condition; denial of death makes a fitful dying "journey" difficult.

It is clear that the use of metaphors when communicating with cancer patients can have a profound effect both positively and negatively. On one hand, metaphors can give a degree of coherence and understanding to illness and frailty; on the other, there is a risk of misunderstanding, and collusion and a failure to challenge the situation (Reisfield and Wilson, 2004). That is not to say that the patient cannot make emotional progress in the face of metaphorical fighting, denying and finally accepting death (Seale, 1995). In fact, Seale (1995) talks of heroic death whereby the person demonstrates great courage from within in the eventual facing of their own death.

4.8 The Media - Representation and Health

Television, radio, newspapers, magazines and social media constantly influence our understanding of health and the health economy (Seale, 2002), forming a platform through which we live our lives. Such influence is powerful, yet is underpinned by values that dictate the selection of what is covered and how it is covered (Bell, 1991).

Mass media is influential on everyday life, allowing expression and reinforcement of social norms and values (Lhussier, 2009; Seale, 2002, 2010). However, the presentation of health in the media is not neutral. It is not just dissemination of information, but instead is information mediated through moral, political, environmental and social filters, coloured by ideology and, in some instances, for commercial gain (Kilgore, 1996; Alasuutari, 1999).

In addition, television absorbs, challenges and informs the audience. There is however a necessity to recognise that inevitably, the whole story isn't given to the viewer and that they have to use their knowledge, experience and understanding to complete the picture portrayed by the programme (Seale, 2002). That being said, there is no doubt that television can reinforce our values; society delivering knowledge and proposed truths to the individual (Lhussier, 2009).

The way consumers receive the media means that they can be considered an audience, which is partly constructed by the message and stories put out by editors. Audiences are receptive to having a sense of community, as changing social hierarchies have disaggregated communities (Alasuutari, 1999). News media, which is in particular consumed in the public sphere, helps individuals form bonds and attachments to ways of thinking (Seale, 2002), forming a sense of common understanding and a sense of community (Anderson, 1991). Neroni (2015) describes an active public sphere, where

outputs are discussed and disseminated through engaged and informed people. In contrast, the passive public engages and observes the active sphere rather like empty vessels, accepting particular representations and interpretations uncritically. These become discursive constructs of a particular view, a particular institution or a particular gaze (Alasuutari, 1999).

Seale, in his seminal work *Media and Health* (2002), discusses the need to understand the influence of the media and the juxtapositions that are employed to add colour to story:

> *"The media set up and deploy a variety of oppositions to generate the entertaining tensions involved in media health portrayals. Heroes and villains, pleasure and pain, safety and danger, disaster and repair, life and death..."*
>
> *(Seale, 2002, p27)*

The news media campaigns related to end of life care can be likened to the above, with the audience being treated as a passive vessel that can interpret and reinterpret, adopting new perspectives and configurations. The media often uses metaphor and numbers to maximise impact (Seale, 2002); using metaphors (Sontag, 1991; Span, 2014) or language that is aligned to sporting struggles (Seale, 2001). In addition, the size of the problem emphasises cases of unmet need or lack of care. For some people, death is considered as entertainment; the sensational nature of the reportage and the morbid curiosity is a fascination (Kellehear, 2005).

It should be noted that the mass media has delivered many positive campaigns related to health and lifestyles, including prevention and early detection, for example, in relation to AIDS and mental illness. The media coverage of death and dying does provide us with educational benefits, but the caveats above, in relation to what is reported and how, need to be considered (Howarth, 2007). Although death and dying are covered in mass media (Walter et al., 1995) the corpse often remains hidden from view, with censorship and public interest being cited as the reasoning behind this (Lupton, 2012). For many, this potentiates the mystery associated with death

and dying, and some have argued that the media has somewhat supplanted religion in terms of understanding death and dying (Walter, 2005).

One example of the above is the media reporting of the LCP, which is discussed by Watts (2013) and which resulted in reticence and uncertainty in both the general public and the professionals working with patients at the end of life (Chinthpalli, 2013). The scope and breadth of media coverage has been extensive; over a six-month period in 2012 to 2013, 64 reports related to end of life care and the LCP, only one of which was positive (Watts, 2013). Indeed, much of the coverage was sensationalist, leading to misunderstanding and the perpetuation of falsehoods when contrasted with everyday reality (Seale, 2002).

Such media campaigns are based on the use of emotive language have a significant impact upon patients, carers and healthcare professionals (McCartney, 2012). When a campaign occurs, such as the one we have seen in relation to end of life care, journalists have been said to behave like a “pack”, using each other’s coverage to build interest and profile (Seale, 2010). The rhetoric used by the media instils fear, rather than encouraging discussion about end of life care, and potentiates myths about palliative care being about the withdrawal of food and fluids (Oliver, 2015). In addition, the spectre of financial considerations was highlighted in this particular media campaign, causing distress for those caring for dying patients and distrust in medical and nursing care delivery (McCartney, 2014; Oliver, 2015).

The Daily Mail campaign on end of life care and the LCP has been critiqued and commented upon extensively (McCartney, 2012; Watts, 2013; Seymour and Horne, 2013; McCartney, 2014; Oliver, 2015; George et al., 2014, Seymour and Clark, 2018). While the content, language and impact of such coverage have been considered, it is also vital that there is an acknowledgment of the consequences for patients, carers and staff caring for the dying patient (McCartney, 2012). In addition, campaigns such as this are juxtaposed with the drive and commentary related to good care delivery at the end of life. It is vital to acknowledge both the challenges and errors related to care and communication through the LCP, and public and

professional concerns (Seymour and Horne, 2013; Oliver, 2015). It is equally important to challenge the thesis that end of life care is driven by the need to free up beds, gain financial rewards and withdraw food and fluids. Pawson (2002) articulates the impact of media on policy, with a deliberate dismantling of policy occurring if there are newsworthy reasons to do so. Intrinsically, the policy drivers that underpinned the apparatus used in end of life care have been systematically targeted through media coverage, as has the discipline of palliative care.

The focus for some media has been on the dying body, the grotesque dying – physical deterioration; beautiful death – closely aligned with choice at the end of life and glamorous dying (McInerney, 2007). The glamourous celebrity death is deemed to be very newsworthy and, as such, is influential on public perceptions of death and dying, providing the opportunity to consider the life of the celebrity through shared grief (Frith et al., 2012).

The death of Jade Goody in 2009 was widely covered with accessibility to her and coverage of her death, undermining the notion of a death taboo (Woodthorpe, 2010) and the notion of the lonely death that media coverage can supplant on the public consciousness (Seale, 2004). Such celebrity coverage allows the audience to walk the journey with the dying individual (Woodthorpe, 2010) and sensationalise the story, increasing public perceptions of death and dying, enhancing understanding and allowing the voice of the dying person to be heard (Walter, 2010). This particular spectacle was constructed in part by the dying person to make money; in fact, Jade's journey resulted in the kind of heroic death articulated by Seale (2002).

There is no doubt that dramatised dying is becoming increasingly graphic in news media. The public respond to this by countering every discourse about the dead body with a discourse that helps us cope more readily with death and dying in order to fight against the rising death anxiety born out of an increasingly secular society (Foltyn, 2008). We have moved on significantly in a short time in the way we communicate through new technology and different media sources enabling the sharing of blogs, vlogs and sound bites

of the dying across the world. Such sharing through both news media and social media is important, as the continued sequestration of dying has until recently inhibited societal understanding and therefore imagery, words and pictures are needed to build a shared insight (Seale, 2002).

Gazing across the field of literature pertinent to this thesis has highlighted the relevant emergent themes. The policy drivers discussed in chapter three can be seen as instruments of control that influence end of life care in the hospital setting. The tools discussed in this chapter can be conceptualised as apparatus; devices offering measurable outcomes in end of life care and designed to challenge practice and change thinking. They are a manifestation of the power of the institution allowing monitoring, control and surveillance of end of life care. The influence of the media and its use of language are important and, in order to understand the influence of both over death and dying processes, engagement in the writings of Foucault are introduced in the following section.

5 Foucauldian Insights

The research journey undertaken as part of this doctorate has challenged the very essence of my understanding as a nurse. For many nurse researchers, understanding practice, the patient journey, care delivery and so forth is enhanced through qualitative research. Participants' voices have direct implications for the research topic being explored, giving answers and informing practice. At the start of this long convoluted journey, I too was looking for direct answers; the 'so what'. Then I began to explore the work of Michel Foucault through the lens of a practitioner turned academic whose heart remains in end of life care.

Considering Foucault's *oeuvre* is challenging. His thinking changed over time, he never presented his work as complete and, as would be expected, never presented a set of guidelines and continually reviewed his work (Fadyl et al., 2012). Foucault's thinking is difficult to understand; his discussion the very antithesis of convention; often paradoxical – with some criticising such contradictions, complications and inconsistencies (Downing, 2008).

Having spent many years as a practitioner and latterly as an academic, living my professional life caring for and talking about the dying, my professional evolution was based on the concrete; orchestrated through protocols, guidelines and pathways. Therefore, it was with great trepidation that I wandered into the world of Foucault, feeling his meaning and seeing his theoretical footprints throughout my work:

> *"Do you think that I would keep so persistently to my task, if I were not preparing – with a rather shaky hand – a labyrinth into which I can venture, in which I can move my discourse, open up underground passages, forcing it to go far from itself, finding overhangs that reduce and deform its itinerary, in which I can lose myself…"*
>
> *(Foucault, 1972 p17)*

In fact, this research journey and the evolution of my thinking puts me in mind of Foucault's famous statement *"do not ask who I am and do not ask*

me to remain the same" (Foucault, 1972, p19). The journey I am on is truly transformative in terms of understanding, perceptions and, indeed, my professional persona.

Examining the overarching concepts articulated by Foucault has provided a philosophical lens to examine the notion of control in end of life care, especially in terms of the inextricable relationship between knowledge and power and the notion of control of the patient through their dying process. Foucault's rejection of the idea of a universal understanding, which is beyond history and society, offers key insights into the cultural evolution of the medical and nursing professions – the "how we are where we are". In addition, the discourse and not the subject that speaks it, produces knowledge, and subjects may produce particular truths, but they are operating within the limits of a particular episteme, a discursive formation, a regime of truth (Hall et al., 2013).

5.1 Foucault's Footsteps

Foucault's thinking emerged in France in the 1960s and early 1970s, when Marxism offered critical insights into ideas and concepts largely related to the evolution of class structures, economic forces and production (McHoul and Grace, 1993). Foucault was more interested in Nietzsche's genealogy of morals, in which he rejects the notion of rational man and the concept of absolute truth. Foucault moved beyond Marxist theory and pursued more critical theory in which social practices and knowledge are inextricably linked with power (Olssen, 2004). The next sections explore Foucault's philosophy, the changes in his thinking and the concepts relevant to this research.

5.2 Archaeology and Genealogy

Understanding the transitions evident in Foucault's work is essential if we are to appreciate the scope, depth and breadth of his philosophies. Foucault

explores histories of sexuality, the penal and prison system, the evolution of medicine and *Madness and Civilisation*. Throughout these histories, Foucault approaches his work using what he terms Archaeology and Genealogy.

Archaeology, as defined by Foucault, is a method to analyse the history of thought, an approach that uncovers distinct historical periods and considers their structure, influence and, in turn, order of discourse (Garland, 2014). This gave rise to the term “episteme”, an epistemological structure that orchestrated how people thought, how theories were generated and importantly, how discourse was formed (Garland, 2014). Foucault postulates that these are the conditions necessary for a system of thought to be born and integrated, under which statements are regulated to define a distinct field of knowledge; a history not of specifics but of conditions that enable the occurrence of phenomena, thinking or people (Downing, 2008). We have seen in palliative care and end of life care shifts in thinking as the dominant discourse changes and discursive formations emerge, leading to changes in practice; the emergence of end of life care as a distinct discipline is an example. The archaeology is not a chronological concept that maps the evolution of thoughts or phenomena in a linear manner, but more a way of thinking at a given time and space:

> *“It has broken up the long series formed by the progress of consciousness, or the teleology of reason, or the evolution of human thought; it has questioned the themes of convergence and culmination; it has doubted the possibility of creating totalities. It has led to the individualisation of different series, which are juxtaposed to one another, follow one another, overlap and intersect, without one being able to reduce to a linear schema…”*
>
> *(Foucault, 1972 p9)*

Foucault studied these subjects across history, examining how scientific discourse and knowledge shapes the way we live and how discursive practices are orchestrated within social apparatus. In palliative care, we can see how societal institutions, the scientific institution of medicine and the

secularisation of society have been influential in terms of the formation of the discipline and its development.

Rabinow (1991) states that there is no pre- and post-archaeology and genealogy. Foucault's thinking evolved with the first phase of his corpus talking of archaeology, examining many perspectives of historically situated contexts, making sense of the how, and progressing to genealogy. This considers how people are situated in the social world; the two concepts are building on each other.

Genealogy is focused on the history of the present; how we have arrived at where we are. It is an analysis of the emergence of practices and institutions as they have arisen out of specific moments in time, conflicts, struggles and allegiances (Garland, 2014). It is a critical examination of the history of politics and culture, their underpinning theory and methods, and taken for granted scientific constructs. While Lyotard (1984) aligned the postmodern condition with the decline of the authority of the grand narrative, Foucault argues that regimes of truth need to be considered in the context of the complexity and diversity of the social world we live in:

> *"Each Society has its regime of truth, its 'general politics' of truth that is, the types of discourse which it accepts and makes function as true: the mechanisms and instances which enable one to distinguish false and true statements, the means by which each is sanctioned; the techniques and procedures accorded value in the acquaintance of truth: the status of those who are charged with saying what counts as true…"* *(Foucault 1984 p73)*

There is no absolute truth, just an ever-changing gaze that history is not teleological, so contradicting the traditional conceptions of history and the bourgeois perceptions of progress, where progress and change was compressed into one universal political theory (Carr, 2016). This is particularly important when considering the discipline of science, when the theories of continuism (a single rationale for change) and progressivism (one theory being superior to the last theory) were replaced, allowing space for thinkers to understand the place for multiple realities (McHoul and Grace,

1993; Beckett et al., 2017). Foucault's theoretical position denotes that scientific knowledge is not the absolute truth, and that the way we understand and think in a given age is contingent on the discourse and knowledge of the day (Hook, 2001). It is this theoretical thread that runs throughout my thesis, examining the discourses that inform end of life care in current times.

5.3 Theories, Notions and Nuances

When embarking on this research journey (a metaphor I am comfortable with) and considering the landscape of end of life care, the philosophy of Foucault and his concepts resonated strongly with the challenges for end of life care. This is because Foucault makes possible inquiry that goes beyond normal professional boundaries (Springer and Clinton, 2015), and in effect enables me to step outside my comfort zone, and the boundaries and normalities to which I am accustomed:

> *"It was not my intention on the basis of a particular type of knowledge or body of ideas to draw up a picture of a period, or to reconstitute the spirit of a century. What I wished to do was to present side by side, a definite number of elements: the knowledge of living beings, the knowledge of the laws of language, and the knowledge of economic facts, and to relate them to the philosophical discourse that was contemporary…"* *(Foucault, 2002 pXI)*

This Foucauldian footprint reflects how a complex discipline, like end of life care, can be considered from multiple perspectives and realities. Springer and Clinton (2015) discuss the need for researchers to "sensitise" themselves to Foucault's philosophy in order to operationalise them in any given project. They highlight that using Foucauldian discourse analysis does not follow logical steps and sequences seen in some research processes but is more an immersion in Foucault's concepts. For this reason, I will consider the key concepts of Foucault for this research and contextualise them for end

of life care. These will include power, disciplinary power, knowledge, discourse and the subject.

5.3.1 Power

Foucault asserts that power and knowledge are inextricably linked. Power cannot exist without the construction of knowledge, and knowledge cannot exist without power relations (Foucault, 1991). Foucault views power as positive and productive rather than repressive in nature (Peterson and Bunton, 1997):

> *"What makes power hold good, what makes it accepted, is simply the fact that it doesn't weigh on us as a force that says no, but that it traverses and produces things, it induces pleasure, forms knowledge, produces discourse. It needs to be considered as productive network that runs through the whole social body, much more than as a negative instance whose function is repression…"*
>
> *(Foucault, 1984 p61)*

There is no central point of power, or power holder. Power exists through a network, a web that creates forces that interact causing tensions within and among individuals, groups and populations (Powers, 2007). Many different forms of power exist in our society: legal, economic, military and medical powers are all exercised through certain *technologies* of operation based on the notion of scientific truths (Caldwell, 2007; Besley, 2015). Such scientific truths, Foucault (2002) argues, are contingent on a place in space and time, on history and culture, and cannot be viewed independently of these things. When considering the discipline of end of life care and the evolution of this sphere of practice, it is essential that the conditions in which it operates and grows, be considered. The underpinning philosophy for this thesis is clear, but at the same time, the notions discussed are at odds with the hierarchical manner in which I was cultured as a nurse. Thoughts of this come to the fore when discussing power, as in clinical practice, the notions of institutional control and professional power and dominance are still evident. Foucault

would argue that this is due to the conditions, culture and time we find ourselves in. He articulates power very clearly as being productive in nature rather than only negative and coercive (Foucault, 1991), with power influencing life processes, births, death, sickness and disease (Foucault, 1976; McHoul and Grace, 1993). This pervasive notion of power can be productive and opens up opportunities, challenges long held perceptions, and provides novel insights into the discipline of end of life care:

> *"Power would no longer be dealing simply with legal subjects over whom the ultimate domination was death, but with the living beings, and the mastery it would be able to exercise over them would have to be applied at the level of life itself; it was the taking charge of life, more than the threat of death, that gave power its access even to the body…"* *(Foucault, 1976 p142/143).*

5.3.2 Disciplinary Power

In *Discipline and Punish* (1991)*,* Foucault discusses the notion of power. Disciplinary power historically referred to the total sovereign power that allowed punishment of the individual for any wrongdoing in society. Disciplinary power is not a distinct entity in Foucault's eyes, however, it is important to recognise the role of disciplinary power when considering end of life care. Disciplinary power is visible in practice and, while it captures the notion of law and order, it also reflects the power held in institutions and disciplines such as medicine; there are both similarities and differences. Mechanisms of disciplinary power pervade all aspects of modern society:

> "*…not that the beautiful totality of the individual is amputated, repressed or altered by our social order, it is rather that the individual is carefully fabricated within it according to a whole technique of forces and bodies…"* *(Foucault, 1991 p217).*

Such mechanisms of power are orchestrated through instruments and techniques across institutions that serve to control the individual with

technologies of surveillance, promoting self-discipline in particular (Rabinow, 1991). Foucault argues that such techniques and instruments can promote "docile bodies", individuals that behave in ways that are deemed acceptable, becoming an easily manipulated subject on whom disciplinary forces are exerted. *Technologies* of power include the notion of the *Panopticon* apparatus, through which disciplines control and mould the human body.

Disciplinary practices include the spatial distribution and hierarchical observation of individuals; a gaze focused on the person, usually by being corralled together (Foucault, 1991), for example, in hospitals or prisons. Further disciplinary practices are exerted through control of activities of the body and cultivation of certain types of bodies; normalising judgements by comparing individuals with others and so establishing behavioural and physical norms (Nettleton, 2013). Furthermore, through the organisation of training and learning, and finally the general coordination of all of these as part of bigger machinery. Institutions and social structures contribute to control individuals through the production of knowledge, which sustains power (McHoul and Grace, 1993; Downing, 2008).

Resistance to power, and conflicts that occur as a result, are as important as the strategies used to exert that power; such struggle at the point of issue in fact offers opportunity for great change. Power is mobile and contingent on time and place (Schirato et al., 2012). Resistance itself changes over time and coalesces against priorities as they emerge. Resistance is more effective over technologies of power, rather than power itself, as these are the instruments that exert power and allow for the formation of knowledge (Rabinow, 1991; McHoul and Grace, 1993; Schirato, 2012). We can see such resistance in different spheres of practice where disciplines challenge the norms and change is enabled. We can also see resistance when patients assert control over their treatment options and challenge medical opinion:

> *"…in a system of discipline the child is more individualised than the adult, the patient more than the healthy man, the madman and the delinquent more than the normal and non-delinquent…"*
>
> *(Foucault, 1991 p193)*

5.3.3 Knowledge

Knowledge and power are inextricably linked:

> *"Power produces knowledge… that power and knowledge directly imply one another; there is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations…"*
>
> *(Foucault, 1991 p27)*

Knowledge emerges through epistemes and discursive formations, and knowledge and power are inextricably linked; in fact, disciplinary power is often termed power/knowledge (Foucault, 1976). Subjugated knowledge refers to hidden truths rather than just dominant truth narratives (Hook, 2001). Foucault (1980 p93) states that subjugated knowledges are:

> *"…those that are disqualified as inadequate to their task or insufficiently elaborate: naïve knowledges located low down on the hierarchy…"*

Truth in turn depends on *technologies*, apparatus, institutional and discursive practices. These are important concepts for this thesis; I have considered how knowledge and power have evolved through the history of palliative care to form the discipline that we have today. In addition, the relevance of these concepts can be seen when considering the tools in end of life care, which are apparatus that emerge to control and dictate how care is delivered. These concepts will also emerge through further discussion and analysis of the research findings and are particularly reflected in the *"Looking Glass"* (Page 188).

Many truths coexist at any given time. How a truth becomes dominant can be uncovered through considering the discourse. Discourse "*acts as a point of articulation between power and knowledge, this is where they are joined together"* (Foucault, 1976, p100). I will explore the dominant discourses around end of life care, how they form and function, which are privileged and

subjugated in different times / places in the context of the historical and cultural backdrops already explored.

5.3.4 Discourse

Discourses are about texts and terminologies, and are inextricably linked with power and knowledge. They are assemblages of words and practices, which can represent both the instrument of power and, concurrently, the organisation of resistance to power. A discourse can produce and sustain power but can also undermine and uncover it, just as silences can sustain or uncover power and resistance (Powers, 2007). Discourse cannot be reduced to texts alone; they are embodied both in technical processes in institutions, such as the last rites for the dying person, or the ward round in a hospital, and in non-discursive ways such as historical events (Dame Cicely Saunder's work) (Peterson and Bunton, 1997).

Foucauldian discourse analysis allows for the exploration of the professional contexts in which we operate. It allows us to view the complexities of practice through a different lens; to view practice outside of existing boundaries, what shapes practice and how discourses operate to influence how we speak and think about practice (Springer and Clinton, 2015). Foucauldian discourse analysis allows for the consideration of the necessary conditions in time and space that allow a discipline to flourish. An example of this in relation to end of life care, are the conditions that have allowed for the discipline of medicine to impact upon the control of death, which in the past was held by the church. The secularisation of society has led to changes in power and knowledge in relation to death and dying.

Recognition needs to be given to subjugated knowledges, which Foucault describes as historical events and constructs that have been buried or disguised, or indeed knowledges that have been deemed too unworthy to be included in the hierarchy:

> *"…a whole set of knowledges have been disqualified as inadequate to their task or insufficiently elaborated… it is through the reappearance of this knowledge, of these local popular knowledges, these disqualified knowledges that criticism performs its work…"*
>
> *(Foucault, 1980 p82)*

In end of life care, subjugated knowledges have changed over time and will continue to shift. We have seen such changes with the emergence of end of life doulas, who assist with the dying process, are community based, and aim to help families through the process of caring for their loved one while recognising death as a natural process. This is just one example of normalising and focusing on death in the person's chosen community. In the acute sector, when caring for people at the end of life, we have seen the voice of the patient being subjugated. Despite offering a lens through which we can view the lived experience of death and dying, their voice is located low down in the hierarchy of knowledge, below that of science.

5.3.5 The Subject

The Subject is a consequence of the power relations and discursive mechanisms of its time, contingent on the historical conditions, transformations and discontinuities that the individual is exposed to (McHoul and Grace, 1993; Garland, 2014). In end of life care, the individual can be subjectified as a dying patient. This closes some discursive possibilities, such as being well, or having a fully functioning body or mind, independent of medical interferences. However, it opens up other possibilities, including the development of autonomy in the context of their disease and utilising the medical knowledge they absorb to become experts on themselves. Any such emerging discourse does contain within itself the possibilities of both emancipation and disciplining.

In the *History of Sexuality,* Foucault talks of subject production being affected by the primacy of scientific knowledge (Foucault, 1976). We can see in the

relationships formed between patients and healthcare professionals at the end of life how this is effectuated, as the patient can become the medicalised subject. In addition, the knowledge the subject has of themselves enables humans to turn on themselves and become subjects (Rabinow, 1991).

Individuals are made into subjects through disciplinary power. This process is referred to as subjectification. The geneaology of subjectification is very complex and explored in depth in Foucault's discussions on sex (Foucault, 1976). Of specific interest for this thesis is the way in which the subject can be transformed through dividing practices, scientific classification and subjectification (Foucault, 1982; Rabinow, 1991). The term 'dividing practices' describes techniques of domination that are employed and enacted to control the individual. Considering such tactics, alongside scientific classification whereby the body is treated as a thing and object, distinct resonance for the exploration and understanding of clinical practice can be seen. One such example in end of life care is the 'right to die' movement. It could be argued that institutional control over the individual's choice of when to die, and the associated policies and protocols, are dividing practices that control the individual (McDorman, 2005). In addition, policies, pathways and protocols drive practice and assert control in some respects. Foucault's concept of apparatus is discussed below and offers insight into how and where we deliver care.

5.3.6 Apparatus

Apparatus (*dispositif*) in Foucault's eyes describes:

> *"…a device or devices that are used to produce, maintain or exercise power within the social body – the purpose being control and management of the population … This is what the apparatus consists in: strategies of relations of forces supporting and supported by types of knowledge…"* *(Foucault 1980 p196)*

In terms of the cultural, environmental and organisational influences that impact upon end of life care, the concepts of apparatus and technologies need to be considered. Power is a matter of the production of truth, and truth emerges bound to apparatuses like prisons, hospitals, clinics and schools. While the environment has been clearly identified as an important aspect of a good death (Casey et al., 2011), control of the dying is still orchestrated by medical and nursing experts and many people die in the acute sector (Gomes et al., 2011). Institutions such as hospitals, where most people die, form part of the control of the sick and, as such, constitute apparatus, alongside the tools and guidelines that emerge from clinical practice.

Foucault's perception of the elements of the apparatus as "*the sum of the said and unsaid"* (Foucault, 1980 p194) is constituted through a mixed economy of power and knowledge. Such constructs – the apparatus – are initially formed in a reactive fashion as result of a crisis, in response to a problem; the crisis being the quality of end of life care delivered in hospital. Hospital end of life care has always been compared to that in the hospice setting and palliative care units, with learning from such specialist areas being a specific driver (Taylor and Chadwick, 2015). Using the tools and guidelines that have emerged practically and philosophically from the hospice setting, and transposing them into the acute sector, constitutes a way of controlling care of the dying, albeit while attempting to enhance the patient experience.

The adoption of such apparatus and a generalisation of this to everyday practice transforms them into a *technologie* of power, applicable to other situations. The concept of apparatus is of particular resonance for this study. Tools have been designed in specialist palliative care where the environment and philosophy is drastically different to the acute sector. Yet, there is an assumption that such apparatus are transferable when the philosophy and culture of care are not.

5.4 Foucauldian Research in Healthcare

Foucault's work has long been recognised for posing challenges to some of the taken for granted assumptions and embedded practices in health and social care (Cheek and Porter, 1997). It presents an important tool and opportunity for researchers who want to critically analyse health and healthcare practice, particularly through the examination of prevailing discourses that lie below, or beside, day-to-day practices. (Fadyl et al., 2012).

Exposing the discursive nature of health uncovers new ways of seeing healthcare practice. It also provides opportunity to understand power relations in a more nuanced, complex and dynamic way, appreciating how resistance can bring about change (Cheek and Porter, 1997). Alongside this, Foucauldian thought also highlights subjectification practices and experiences at play in clinical encounters (Powell and Chen, 2017).

Using a Foucauldian approach to research is challenging; there are no pre-determined methodological standards or templates that can be adhered to. It does however, allow the researcher to unravel prior, ingrained understandings in healthcare, in a way that opens up more productive possibilities (Dias and Janjuan, 2018).

Understanding how Foucauldian philosophy and theory dovetails with death, illness and dying is important for this thesis. Many have written about how Foucault's theories offer a lens through which to view health and illness, its evolution and the delivery of end of life care. The paragraphs below highlight those who have informed my thinking.

Foucault's work makes a great contribution to understanding how social coherence evolved, through the institutional power of the church and state, into the life we see today (Turner, 2008). Rose (2001) discusses the understanding that can be drawn from the history of biopolitics. The rise of expertise and clinical medicine alongside technologies, techniques and apparatus all serve to control the way our health is determined and more

generally the way we live. Control of risk for the population and the staving off and control of ageing is re-shaping the way we live (ibid.) and without doubt, the way we die. Foucault's concept of the medical gaze, where the disease and the person are separated and priority is given to the physical (Foucault, 2003), includes the notion of surveillance. Surveillance in modern healthcare is not necessarily negative but can be deemed to be empowering for patients and carers, and can also include self-surveillance for both healthcare professionals and families (Forbat et al., 2009). Apparatus used in end of life care can form part of the surveillance network and, similarly, can be viewed as a means of orchestrating diffuse networks of power or empowering people to have a voice.

Springer and Clinton (2015) offer insight into how using Foucault's work to underpin research offers wider perspectives for the uncertainties we face in everyday practice, thus improving the patient experience through more enabling practices (Crowe, 2004). While exploring the research undertaken particularly but not exclusively by other nurses, my approach to this research was reaffirmed and informed. A study into approaches used in discourse analysis found most papers used a critical approach; this offered disciplinary insight but did not necessarily inform my methodological decision-making (Traynor, 2005). In contrast, a paper exploring the use of interviews as text in Foucauldian discourse analysis, confirmed my stance taken in relation to self-recorded narratives as a data source. Fadyl et al. (2012) discuss the tensions of using interviews in Foucauldian studies. I have used self-recorded narratives to avoid what they describe as active subjectification, which can occur in a research interview. In my research, the interview is considered a source, just like any other text from which discourse and its effects can be studied (Fadyl et al., 2012).

Armstrong (1987) argues that truth and silence in death and dying do not lie in opposition, and that this offers insight into the emergence of the dying patient as an individual, rather than as a corpse – the root of medical knowledge. This has been built upon by other researchers. For example, Zimmerman (2004, 2007) elaborates on the death denial thesis. Building on the work of Foucault and Armstrong, she argues that it is important to look at

how the term ‘death denial’ is used in the literature and how it links with broader discourses, urging against an oversimplification of death denial and its influence on the “way to die”. This work was revisited in a further discourse analysis, in which the discourse of acceptance of dying was described as a “productive power” (Zimmerman, 2012). Engagement with death is important if we are to practice in a way that meets patient needs (Ziimmerman, 2012). I have discussed the demographic challenges in end of life care in Chapter three. In relation to this, Osterlind (2011) describes how increasing numbers of older people fear frailty and ultimately death, and how there is an intertwining of death and life for these people, where death is silenced (Osterlind, 2011).

This is just a glimpse into health research that uses Foucault’s philosophy; it is an insight into theories that have informed my thinking. The next section explores research that has focused on Foucault and the media.

5.5 Foucault and the Media

The importance of the media and the impact and influence it has on end of life care is a key focus of this thesis. The media both contributes to knowledge and is encouraged, through institutional pressures, to construct a particular understanding (Crowe, 2005). This reporting is also influenced by the agendas of interest groups and lobbyists who directly target journalists (Seale, 2010). While media as a vehicle towards understanding is considered in Chapter four (p71), the Foucauldian research on media influences that has informed my deliberations throughout this journey is considered below.

Thorpe (2008) considers media discourse and technologies of the self among young women who are snowboarders. The exploration of the discursive construction of femininity is aligned to a sexist discourse. This paper acknowledges very clearly that the media is one form of power and influence. The impact of images used in this research is contingent on the discursive formations at play (ibid.). Appreciating the media as a form of (albeit powerful) influence contributed to the decision I made to include it in

this research alongside the self-recorded narratives that capture the voices of healthcare professionals.

Discursive representations of death and dying in print media have been found to report dramatic and heroic dying (Seale, 1995). Contemporary dying is portrayed as intolerable and horrific, and condemned as unacceptable (McInerney, 2006). A heroic discourse emerged in McInerney's (2006) research, through which reform of the assisted dying legislation was demanded through the media and at the behest of the "requested death" movement. This resonates significantly with the media coverage of end of life care, especially the LCP, driving forward a sense of scandal and need for reform.

Couch et al. (2015) explore media as a form of social control from a public health perspective, and discuss the notion of spectacle and the fact that this persists in mass media. Foucault (1991, p 3) in *Discipline and Punish* talks of the "*body of the condemned"* and describes graphically death as a spectacle. It is this concept of spectacle and drama in the media that led me to consider its impact on the individual and the resulting escalation and change in practice Sensationalist discourses promulgated by the media, across many different domains, can lead to a sense of scandal. Lloyd et al. (2017), in their international study, explore the causes and consequences of media scandals involving nursing homes for older people. They clearly articulate the short-term result of scandals being government action, stating *"scandals play an important role in welfare reforms".*

However, the impact of the media on self-reported narratives of healthcare professionals in end of life care remained unexplored at the beginning of this project. The sense of scandal in end of life care emerges through the *technologies* of representation (chapter seven, p157) and the repercussions of this are discussed in chapter eight.

5.6 Resonance and Reasoning for End of Life Care

The philosophy and works of Foucault and its resonance for end of life care has engaged and entranced me throughout this journey. Foucault articulates clearly that power operates within the medical encounter as a disciplinary power through observation, measurement and comparison of the individual against the norm (Peterson and Bunton, 2007). In the context of the dying patient, this kind of observation, measurement, monitoring and documenting has been mostly operationalised through apparatus such as the LCP. However, such apparatus fails to acknowledge the ways in which patients may or may not want to engage in such medicalising processes (Lupton, 2009). This is a pertinent point for the dying patient, who often feels insecure at the end of life, with the doctor's presence offering control, structure and reassurance, which in turn can be empowering (Forbat, 2009).

The individual at the end of life can turn themselves into a subject. This is an active process whereby the individual is exposed to historically situated cultural influences throughout the dying process, which impress on them how they should think and be at the end of life. Foucault describes the long and complicated process of subjectification as *"operations on peoples own bodies, on their souls and on their thoughts and on their own conduct"* (1982a p18). This results in some self-understanding, which is mediated by external influences. Disciplinary practice creates an environment where patients lie silent for fear of interrupting the doctor. This silent and submissive role that patients may engage in is exacerbated at the end of life, due to a layer of vulnerability and at times despair. However, this may be what the patient expects and demands of healthcare professionals at the end of life; they may want to be "cared for" (Lupton, 2009). In fact, the patient through their wishes and requests may control the doctor.

The power of doctors, unlimited medicine, the environment and priorities of care delivery in the acute setting, alongside the culture and systems, make it very difficult for patients at the end of life to leave hospital (Taylor and Chadwick, 2015). It remains a challenge then to juxtapose the hospice and hospital and expect that the apparatus, namely the environment and the tools

that arise to enhance care delivery, can be applied and transferred across such very different sectors.

Death is deeply embedded in social relations and social structures, which are in turn contingent upon culture (Lupton, 2012). As we look at the discipline of medicine, scientific classification and scientific truths, we can see how practice has evolved in end of life care and the discursive changes that have occurred (Carpentier and Van Brussel, 2012). In the moment in history I have lived through in palliative care, the voice of the patient has become louder; choice is more of a reality, an expectation, or indeed a disciplinary pressure and true multi-professional working is embedded.

In end of life care, power is implicit within therapeutic relationships. In some cases, the patient as a subject is a docile body, which is inscribed as reaching the end of life. Conversely, the subject, in a multiplicity of power relations, reproduces power. *Technologies* or flows of power run through the whole of the social body in end of life care. Resistance to power facilitates the production of knowledge and indeed radical change; power emerges through the apparatus that are utilised to orchestrate care at the end of life.

When considering end of life care in hospital, Foucault's thoughts on dividing practices come to the fore. The disciplinary nature of spatial distribution, sequestering patients who are at the end of life in the acute setting and furthermore, denying choice, impacts upon the individual's control; the autonomy of dying. The impact of such practices upon end of life care is compounded by the clinical gaze, which requires *technologies* of power and apparatus to be utilised. The use of apparatus facilitates surveillance; impacts can be measured and reported upon, and practices changed and adjusted.

The concepts articulated in this chapter give the reader insight into Foucault's thinking and the complexity of the knowledge and power nexus at the end of life. It is through analysing discourses that complex power relations can be explored. Discourse analysis allows voices to be heard, even the voices that are silenced, or directly disqualified as inadequate. Illumination and exploration of discourses allows the interplay between them

and the way that they are communicated to be shared, thus allowing greater understanding to be uncovered (O'Connor and Payne, 2008).

5.7 Critics and Sceptics

Foucault's work is not without its detractors. In terms of the influence on nursing and practice issues in the professional healthcare arena, Cheek and Porter (1997) debate whether the philosophy of Foucault offers great opportunity for the future, or whether ambiguity and uncertainty undermine the resonance of his work for healthcare. Cheek (2000), clearly articulates the positive benefits of the application of Foucault to nursing practice. Conversely, Porter articulates that, while it helps us to establish what is wrong with where we are now, it contributes little to where we are going in the future. This debate is underpinned by Foucault's notion of knowledge and power, with the two inextricably linked and knowledge not being deemed independent or progressive in terms of future developments (Cheek and Porter, 1997).

Foucault's work is a point of contention for many who work within a feminist paradigm, with a masculine perspective being levied at the work of Foucault by theorists such as Sandra Lee Bartky (Downing, 2008). This is interesting, as even for some feminist sociologists who have drawn on the work of Foucault, there are distinct tensions. While Foucault's work is interested in how disenfranchised subjects are exposed to power and how it is constructed, feminists argue that his work is rooted more in the masculine domain, with little attention being paid to the discursive formations that construct their social roles (Downing, 2008).

Perhaps the critique with the most resonance for my research is that levied at the notion of 'discourse' and the way that Foucault represents the discourse as subjugating individuals. It is posited that this offers scant acknowledgement to the fact that a patient is a person living inside a body, with agency (Peterson and Bunton, 1997). Based on Foucault's works, the concept of the "*docile body*" that is caught in the "*clinical gaze*" is very

familiar to those who subscribe to the notions of medicalization (Foucault, 1991, 1993). Armstrong (1984), sustains this critique of patients as docile bodies and passive participants, whose bodies are inscribed by modern medicine, while Shilling (1991) contends that there is a need to appreciate the lived experience of the body to understand how people respond to the clinical gaze and have an active part in their care through networks of power (Lupton, 2012).

Bearing in mind such criticism, this thesis will actively engage with the notion of resistance, which places agency in the hands of the oppressed, so that individuals are not only the fruit of prevalent discourses, but can also resist them.

This chapter has explored the philosophy of Foucault and the concepts that have particular resonance for this research. In addition, I have offered insight into other research using Foucauldian theory and have explored the impact of this on my thinking. The next chapter outlines my methods and how I have operationalised this research.

6 Methods

6.1 Introduction

This chapter will describe the methods and the procedural devices used in this research, from recruitment and sampling of research participants and analysis of written/audio-visual texts, focusing on developing a deeper understanding of the contextual conditions and discursive turns and trends in end of life care. In order to uncover the competing and overlapping discourses that influence practice, and shape and influence the apparatus employed in end of life care, an analysis of mainstream media was undertaken and healthcare professionals were asked to create self-recorded narratives.

6.2 Giving Rise to the Data

The manner in which the media portrays medical and nursing professions in relation to the dying process makes an important contribution to public and professional opinion, and has long been recognised (Lupton and McClean, 1998; Seale, 2002; McCartney, 2012; Watts, 2013; Torjeson, 2013; Sleeman, 2013). This is discussed more fully in chapter four (p 71). In this research, media artefacts and self-recorded narratives from healthcare professionals are used as data; this juxtaposition provides a novel approach to uncovering the discourses that underpin discursive practice in end of life care. The two datasets were collected concurrently.

6.3 Self-Recorded Narratives

This method of data collection, rather than unstructured interviews, was undertaken in an attempt to address what Arminen (2000) classes as the hidden role of the analyst. I have worked for many years in palliative care

and therefore am a known member of a designated community with cultural intelligence and insight (Rapley, 2007). I am also personally very well known in the area in which the research was undertaken, which might also have influenced the data. This strategy allowed me to maximise the potential afforded by such familiarity, enabling access to research participants, while minimising any impact on their contribution.

Self-recorded narratives are likely to give rise to naturally-occurring talk (Gordon, 2013) in line with the underlying philosophy of Foucauldian discourse analysis (explored more fully in chapter five (p 85). The aim of the recorded narratives was to explore how practitioners are positioned in the social world of clinical practice at a given time. These reflect the operation of discourses and the influence of thoughts practice and assumptions (Hook, 2001).

The self-recorded narrative method allows time for the participant to pause and reflect on issues that may be emotive, and time to consider how to capture the experience of practice in end of life. They allow for the consideration of everyday issues using retrospective reflection, flexibility and freedom; an important issue for busy healthcare practitioners to engage in the research project. Additionally, the recordings were undertaken in the participant's place of choice, so minimising the impact of work demands and environment. The participatory nature of self-recording narratives also allows for the constructing of the personal experience, rather than being directed by the researcher (Crozier and Cassell, 2016). They minimise the problems that may arise, as the researcher asking active questions can direct and shape the discursive situation, potentially influencing the data (Cruickshank, 2012). Recordings are particularly useful in that they are permanently accessible, and allow replay, transcription and extensive study that can be revisited and constantly analysed.

Practitioners who expressed an interest in being part of this research study were all given an information sheet **(Appendix 1)**. Those who agreed to participate met with the researcher on a one-to-one basis to discuss any queries arising from the information given. They were given a consent form

(Appendix 2), which outlined to all participants that they could withdraw from the study at any time.

A digital voice recorder was given to each person for a period of two weeks. The recordings were not continuous as they were undertaken when and where the participant saw fit. Some participants required a longer period to undertake their recorded narratives; three digital voice were recorders between participants until all had completed their narratives. Recordings took place between July and October 2013. Recordings were of varying lengths, from 15 to 90 minutes, so generated a significant amount of transcribed data.

6.3.1 Sampling – Participants for Self-Recorded Narratives

Self-recorded narratives were undertaken by healthcare professionals who care for people at the end of life in the acute setting. Participants recorded their insights into the challenges they face in everyday practice.

To operationalise the recorded narratives and engage with potential participants, I presented the research aims at two meetings in the local cancer centre. The cancer centre is situated in a large NHS Trust and has a regional reach, serving the population of the Northeast of England for local cancer services and tertiary services for rare and complex cancers. Within the Trust, there is a large multidisciplinary specialist palliative care team, covering both primary and secondary care delivery settings. The meetings attended were the multidisciplinary team meeting for Oncology and Haematology teams and the Specialist Palliative Care team meeting.

Following the meeting with oncology and palliative care teams, potential participants were invited to contact me by email or telephone. At this point, each person was given verbal information about the research study and invited to participate. These discussions were held in the clinical area and were supportive, with due regard being given to my profile as an experienced professional working within palliative and end of life care.

A purposive expert sample of healthcare professionals was used for this research; the participants were selected for their particular characteristics (Mason, 2002). **Table 1** presents the skills, experience and expertise of participants.

Table 1 Eligibility Criteria

Criteria	Rationale
Qualified healthcare professionals.	Able to consider the issues of delivering end of life care as part of challenging role
Working in the acute sector.	Appreciate the landscape of end of life care in the acute sector.
Working in cancer care or palliative care.	Exposure to patients at the end of life as part of everyday practice
Experience and expertise in end of life care.	Understand the evolution of end of life care and the contextual conditions associated with it.

The sample was therefore a convenience sample, which is adequate because 19 attendees were encouraged to participate in this research and were also encouraged to contact me to discuss participation. Nine participants contacted me following these meetings (**Table 2**), three further potential participants contacted me but following discussion where excluded as they felt unable to commit to recording narratives.

Nine participants were selected. This sample size is consistent with those used in similar studies and is contingent on what is required to uncover the discourse (Wood and Kroger, 2000). Recruitment to the study was not problematic. While other qualitative approaches may have a favoured larger sample, the volume of data from the recorded narratives is adequate for discourse analysis, due to the depth of analysis and the fact that discourses transcend individual narratives (ibid.). In this study, it is anticipated that a larger sample size might have led to greater repetition of the key findings, rather than new discursive insights.

6.3.1.1 Participants Profile

Participants were recruited using the criteria in **Table 1**. As the analysis progressed, there was a modification to the sample, a strategy which can be employed in discourse analysis (Wood and Kroger, 2000). As engagement within the specialist centre was key to recruitment prior to commencing the research, an awareness of the study developed, which harnessed interest and generated discussion. A team of nurses working primarily in the community setting approached me; they clearly articulated how they contributed to and worked closely with the palliative care team in the hospital to provide seamless patient care. As a result of this, two palliative care clinical nurse specialists in the community setting asked to be included in the study, with the justification that their practice significantly contributed to promoting quality patient care at the end of life, enabling choice of where people die and understanding the social, cultural and practice conditions in end of life care. This is an acceptable practice in discourse analysis; the modification to the sample provided the opportunity to include additional perspectives relevant for this study (ibid.).

Table 2 Participants

Participant No.	Job Role	Specialism	Experience
1	Consultant	Haematology	Specialist Heamatology Consultant with extensive experience of end of life care, particularly with (although not exclusively) in younger people with acute leukaemia.
2	Consultant	Palliative Care	Consultant on the hospital palliative care team with a background in primary care, insights into end of life care from multiple perspectives.
3	Staff Nurse	Cancer Centre	Senior staff nurse with some managerial responsibilities, broad experience of working in cancer care and specialist haematology, palliative care link nurse for the area worked in.
4	Staff Nurse	Cancer Centre	Junior staff nurse experience working in the cancer centre with a broad range of people with life limiting an terminal conditions
5	Clinical Nurse Specialist	Haematology	Specialist with knowledge of end of life care for younger people
6	Clinical Nurse Specialist	Cancer	Specialist with knowledge of end of life care across age groups
7	Clinical Nurse Specialist	Palliative Care	Specialist within the acute setting in palliative care and end of life care
8	Clinical Nurse Specialist	Palliative Care	Community palliative care and end of life care (community)
9	Clinical Nurse Specialist	Palliative Care	Community palliative care and end of life care (community)

6.4 Media Artefacts

News media is inextricably linked with social groups and the power held within them (Richardson, 2007). When considering contentious and emotive issues such as end of life care, the influence of media on social values, opinions, politics and public understanding offers insight in to what Richardson (2007) terms a dialectical relationship between the consumption of the media and social practices. Readers interpret the meaning of the media outputs using their understanding of the social world. The same outputs then go on to form and shape the readers knowledge and understanding. The ideological interests served through media discourses (Fairclough, 2001; Fowler, 2007) and the power of such texts to shape understanding, opinion and beliefs, offers a rich and novel perspective for end of life care. I have included newspaper artefacts as data.

Discourse in media consists of both the written word, and its interpretation and the way in which it informs how we live within the social world (Cheek, 2000; Fairclough, 2001; Fowler, 2007; van Dijk, 2008; Lean, 2008). This impact of the media on social spaces and practice transforms and occupies social contexts (Schirato, et al., 2012), changing and influencing how we practice.

Gellie (2014) argues that in modern society we are saturated through the media with death and dying. In order to capture the breadth of impact of such media influences I included mainstream terrestrial television factual documentaries for consideration.

6.4.1 Justification of Media Sources

The way people engage and consume media is constantly changing. We live in a world that is awash with different media sources, all of which shape social constructs and norms (Seale, 2010). I was practising as a clinical nurse specialist in palliative care when the Harold Shipman scandal was

reported, which impacted greatly on professional practice. Shipman was a GP and killed over 200 of his patients. Media coverage was immense and the consequent influence on my personal practice was very evident. Patients were anxious, doctors were concerned about the scrutiny their practice was under, and a sea-change occurred in general practice (Baker, 2004). It was this extreme event that initially led me to consider the inclusion of media sources in my research. Coincidentally the media spectacle related to the LCP took off at the inception of my research, with sensational headlines escalating “trenchant criticism” across the British press (Watts, 2013).

The media analysis intended to capture the accessible news media that people were most exposed to on a daily basis. I included headlines and factual television outputs, which contribute to the formation of knowledge (Lhussier, 2009). When discussing death in the news, Walter (1995) states that documentaries are used for their representation of the ordinary and mundane, whereas news media is in direct contrast to this. The two data sources offered a lens through which to view the influence of the media.

6.4.2 Sampling – Media

Mainstream media, specifically broadsheet press from a cross-section of political standpoints, has been analysed to uncover the social and cultural discourses that influence care delivery in end of life care.

A purposive sample of highly circulated national newspapers, including Sunday newspapers was selected. These genres were selected to include quality newspapers, traditionally printed as broadsheets with a more factual journalistic intent and a readership that would more likely influence practitioners and have resonance to the study. The broadsheets have a more middle-class and professional readership (Patterson et al., 2016), with differing political leanings. The newspapers selected were the Times, Independent, Guardian, Observer and the associated Sunday papers. In terms of data collection, I did not use any journalistic databases, largely

because this is not a quantitative analysis with any claims to generalisability. Instead, I aimed to highlight the discourses influencing practice through the way the media represents end of life care. In addition, visual images and pictures associated with news stories are not available for analysis on databases such as LexisNexis (Peel, 2013). In other words, the sample attempted to capture what is seen by the person who is browsing through broadsheet newspapers, rather than purchasing them and interrogating content on specific subjects.

The timeframe for collection of newspaper articles was August 2012 to April 2013. At this point in time, the media storm over the LCP levied open criticism and negativity flagrantly across the news media (McCartney, 2012; Watts, 2013; Oliver, 2015). One of the major proponents of this media storm was the Daily Mail. At this point, I adjusted the sample to include the Daily Mail, a middle-market tabloid less focused on serious coverage and more on lifestyle. Its readership has been identified as being primarily made up of middle-class older persons (Patterson, 2016). This adjustment of sample, as Wood and Kroger (2000) articulate, was made in order to achieve a more thorough analysis of discourse, due to the campaign that was launched by this newspaper in relation to end of life care. Tabloid newspapers, which historically offer a more sensationalist perspective, were not included in this study. The readership of the newspapers included is described in **Table 3**.

Table 3 Newspaper Circulation Numbers

Newspaper	Readership
Daily Mail	1,688,727
Sunday Times	861,000
The Times	396,621
The Independent	61,338
The Guardian	185,249
The Telegraph	494,675

(Figures taken from Press Gazette for February 2015)

6.4.2.1 Inclusion criteria

Print articles were included if the main focus was end of life care and if they were broadly within the sampling timeframe. The study includes 38 newspaper artefacts with eleven being excluded. Exclusion occurred if the article selected by title appeared to be related to end of life care but the content was not.

Table 4 Newspaper Artefacts

Artefact Number	Date	Newspaper	Headline
1	31/12/12	Daily Mail	60 000 Put on Death Pathway Without Being Told
2	31/12/12	Daily Mail	A Crass Intervention
3	5/11/12	Daily Mail	Cancer Expert Brands Care Pathway “The Most Corrupt Practice in British Medicine”
4	23/8/12	Guardian	Death is Not the Enemy
5	10/3/13	Sunday Times	So Tell Me: How Do You Want to Die?
6	6/4/13	Daily Mail	Why I Carry a Do Not Resuscitate Card by Joan Bakewell
7	5/4/13	Daily Mail	Death Pathway Damned: Mail Campaign Vindicated in Devastating Report on Scandal of End of Life Care Treatment
8	4/11/12	Sunday Times	Death Target Nets One Hospital £ 1 Million
9	26/8/12	Sunday Times	Don’t Mourn for Me.
10	9/9/12	Sunday Times	Even Losing a Loved One can Have a Good Ending
11	6/11/12	Telegraph	Frail Patient on Death Pathway Recovered After a Sip of Water, Peers Told
12	23/8/12	Telegraph	Goodbye World, Had Some Fun
13	14/1/13	Telegraph	The Liverpool Care Pathway to Dignity in Death
14	14/1/13	Telegraph	Hospitals Treating Liverpool Care pathway as “Just Another Thing to Do”
15	13/4/13	Times	A Hotel Life is Ritzy, But a Hotel Death is Tragic
16	9/1/13	Daily Mail	How I Saved my Father from Death Pathway by Tory MP
17	15/1/13	Guardian	Lady Neuberger to Investigate Claims on Care for Dying Patients
18	15/1/13	Telegraph	Liverpool Care Pathway: Finding the Best Way to Face Our Final Days
19	23/8/12	Independent	MP’s Must Ensure No-one Else is Denied the Right to Die
20	11/5/13 *	Sunday Times	My Very Modern Death
21	8/9/12	Times	New Health Minister Supports Right to Die
22	8/9/12	Times	New Minister Speaks out for Right to Die
23	17/8/12	Guardian	Would You Be Happy to Live Like Tony Nicklinson?

24	17/8/12	Guardian	Paralysed Right-To-Die Campaigners Lose Case
25	17/8/12	Independent	Tony Nicklinson Vows to Fight On As Court Rejects his Plea to Die
26	17/8/12	Telegraph	Condemned to a Life of Torture by Right to Die Ruling
27	17/8/12	Times	Face of a Man Refused the Right to Die
28	17/8/12	Independent	A Fate Worse than Death
29	23/8/12	Guardian	Paralysed Campaigner Dies Days After Court Denied His Help to Take His Own Life
30	23/8/12	Times	Right to Die Campaigner Finds Victory in Death
31	14/1/13	Telegraph	The Liverpool Care Pathway to Dignity in Death
32	13/4/13	Times	The Cult of the Corpse is Just a Pagan Relic
33	23/8/12	Independent	Tony Nicklinson Gets His Wish
34	23/8/12	Independent	Right to Die Campaigner Who Took His Case to the High Court
35	3/11/12	Daily Mail	Victory for Care Pathway Families
36	23/8/12	Independent	With Family at His Side
37	13/10/12	Daily Mail	A Pathway to Euthanasia? Family Revive Father Dr's Said Wasn't Worth Saving
38	27/10/12	Daily Mail	Hospitals Bribed to Put Patients on Pathway to Death. Cash Incentives for NHS Trusts That Meet LCP Targets

Artefact 20 was included outside of the data collection window as the article was written by Kate Grainger, largely as a response to the media furore above.

In addition to the consideration of newspapers in this study, I included journalistic television programmes from terrestrial (non-satellite) television, specifically related to end of life care, from August 2012 to April 2013. The rationale being that this would influence practitioners in the everyday clinical arena and also the interactions they have with patients and their families. The criteria for inclusion were that programmes should be non-fictional, journalistic or documentary in their intent. The television artefacts for this data collection period are outlined in **Table 5**.

Table 5 Television Artefacts

Date	Channel	Title
22/8/12	BBC1 6pm	BBC News
5/3/13	Channel 4 8pm	Dispatches: Death on the Wards
12/4/13	BBC2 9pm	Alive Rankin Faces Death – A Culture Show Special

6.5 Analysis

As Parker (1992) discusses, any discourse analysis should go beyond the texts, media and images, or anything that is laden with meaning, can give meaning, embed discourse or structure our view of the world. The complexity of discourse has to be reflected in any analytical process undertaken.

All data was analysed using overarching analytic steps, which are outlined on page 113. Data analysis was undertaken sequentially at the outset and I have presented the data analysis process in the same manner. Initially, I analysed the recorded narratives as described; the iterative nature of moving through the process of data analysis is discussed more fully in the following section.

Analysis of the media and television artefacts followed analysis of the recorded narratives. The media data sources were handled differently initially in terms of how I engaged with them as a researcher; reading, listening and watching. Further details of this process are discussed on page 110.The emergence of discursive formations and the *technologies* described in the findings chapter occurred as I progressed through the analytic framework.

The analysis of data accrued through this research study reflects the philosophical underpinnings articulated throughout this thesis. In addition, care has been taken not to be too prescriptive in the analytic framework used; this is to avoid missing discursive subtlety (Hook, 2001) and so losing the importance of how the discourse operates (Fadyl et al., 2012).

6.5.1 Recorded Narratives Data Analysis

The content of the recorded narratives was determined by the individual in terms of discussion, observations and insights into end of life care. I transcribed verbatim the recorded narratives; this was essential to allow full immersion in the data. Participants recorded the interviews in sections, so careful listening and transcription was very important. In addition to the words used, I also noted emotive tones, pauses, sighs and emphasis that emerged from the recordings.

The volume of data generated through the recorded narratives was significant. Having analytic steps was key to focus the data analysis process. At the outset, I analysed one transcript at a time; I listened to the recorded narrative, both to the participant's voice and the content, two or three times depending on the complexity and length of the recording. Following transcription, the text was read and re-read, and sometimes the recordings were re-listened to. This was an interesting and challenging process, resulting in a significant amount of data. In addition, I developed a familiarity with the language used and its context, which helped me to develop asensitivity to what was said, implied or omitted (Wood and Kroger, 2000).

My insights into the field of end of life care had to be moderated when aspects of the recorded narratives provoked a reaction from me as a researcher. One example is the emergence of economic drivers and the discourse of economic power. Having always considered patient-centredness as a key driver in my own practice, I found it very difficult to listen to data that highlighted the drive to respond to policy and procedure in order to accrue income for the Healthcare Trust. When this occurred, I followed the recommendations of Wood and Kroger (2000) and asked **why**, rather than making a judgement of **what** the meaning was. This allowed for the development of different perspectives, meaning, associations and connotations. Although the volume of data was at first overwhelming and the transcription very time consuming, this immersion in the data allowed me to embark on the analysis in a meaningful way.

Discourse analysis is challenging and I drew on the work of key theorists in this field to inform my thinking and theory application, working through the data to elicit the conversations or statements and produce the text. Following this, the iterative nature of data analysis could be described as messy and was certainly not linear. As I progressed through the data, I interpreted, re-interpreted and reconstructed meaning, moving from “the what” to “the why”. This process was contingent on my experience and expertise in the discipline and I became more reflexive as I progressed through the data.

Transcription is a vital step in the data analysis process. It allows for the transformation of spoken discourse into a form that is ready for analysis and reanalysis (Wood and Kroger, 2000). Turning the recordings into text requires care, but is a necessary first step, however time consuming. Using a third-party transcriber undermines the researcher’s engagement with the recordings and indeed, the recordings and transcripts had to be revisited numerous times to absorb all of the literal understanding possible.

Transcription is more than just a translation of recorded words into text; it has to maintain the integrity of the way in which the participant was delivering the spoken word. The work of Parker (1992) clearly articulates this. In order that all of the participants were considered using the same strategy, Poland’s

(2002) approach was selected to ensure a verbatim account, including pauses, laughing, coughing, interruptions, garbled speech, emphasis and held sounds. This allowed for the spoken word, once transcribed, to be scrutinised, and for consideration to be given to *how* the words are said, as much as *what* is said, without developing or editing the text in any way. In-depth transcription and engagement with the data helped to maintain a sense of meaning and prevent losing any discursive subtlety.

The approach to analysis of the recorded narratives was also used for the media artefacts and is reflected in the following stages. This analytic framework is underpinned by a broad range of reading around discourse analysis, however it is largely based on the work of Parker (1992; 1994), Burman (1996), and Aldred and Burman (2005).

The formation of this analytic framework evolved as much from what is discourse analysis as what is not (Antaki et al., 2003). In addition, I hesitate to use the word 'framework', since it contradicts Foucault in terms of rigid adherence and structure. However, it is a means to illuminating the discourses and it is not sequential in terms of progressing through stages. In addition, prior to any discourse analysis, a degree of conceptual and philosophical understanding must be brought to bear (Parker, 1992).

The process of analysis was considered carefully and constructed in order that recordings could be transferred to text, but also that the same structure could be used to consider the textual content of the written media artefacts.

The development of associations is an essential part of illuminating discourse (Parker 1992, 1994). Burman (1996) describes associations and the development of links through the identification of subjects and nouns, whereas Aldred and Burman (2005) discuss making connections and listening to the silenced voice in their work with children. The analytic framework below also highlights 'winners' and 'losers', power, knowledge and hierarchy, and follows the work of Parker (1992). This allows the exploration of what Foucault (1972) would term as the imposition, distribution and operation of power through language, and the reinforcement or undermining of institutions through discourse.

Following these broad directions, the following analytical steps were undertaken. Although the steps are presented sequentially for the sake of clarity, they were undertaken iteratively in order to ensure all discursive subtleties were uncovered.

1. Textual production – reflecting on the process, my interactions and positions; exploring initial connotations of the recording or media as an artefact. Objects of study were converted to texts to enable analysis. Use of language, the use of the passive voice (reification) and the use of colourful and descriptive language highlighting the strength of the discourse. Immersion at this stage sought to uncover why particular images or phrases were used.

2. Develop associations – broad meanings, associations and connotations, reflecting on the likely perspectives from which they are derived (researcher perspectives are relevant in 1 and 2). As I progressed through the recorded narratives, I developed a deep appreciation of what the participants said but also how the narratives related to each other. An example of the transcription and initial analysis notes is in **Appendix 3.**

3. Identify and describe objects "constructed" in order to understand the world that the text illuminates. Explicit and implicit references, relationships and associations that are implied, so highlighting the discourses in the text and in turn linking with the discourse evident in the wider world. **Appendix 3** includes notes that reflect how I made associations about how language and content was constructed and differed depending on the position (in the social world) of the participant.

4. Explore the different subject positions, identifying the roles and responsibilities that are aligned to these positions; the voice of each position; what the person is talking about; what they are saying and not saying.

5. Consideration of the understandings and assumptions that form connections, and whether there are alternative versions of discourses in the text. Construct a picture of the area this discourse represents. Consider contrasting discourses, where they overlap and where they are the same. Look at how the discourses emerged, have changed and are dominant.

6. Consideration of the philosophy, values and institutions that are strengthened or weakened by the discourses uncovered.

7. Explore gains and losses within each discourse; highlight any relations of hierarchy, including knowledge and / or authority. In the context of this research, which professions gain and lose from the discourse? Who would be the proponents and objectors to the discourse? Highlight hidden relations of power.

8. Consider the political, social and cultural resonance of the discourses identified; the functionality, the challenge to institutions, technologies and apparatus. Elicit how the discourse connects with other discourses that subjugate others and change practice.

This analytic framework was developed following the work of Antaki et al. (2003). Using this analytic structure, the risk of under-analysis, namely the pointing out of themes, and overemphasis, characterised by picking and choosing quotes in isolation, was prevented. Instead, I used the structure described above, which allows movement between the micro and macro perspectives. Specific data extraction was prevented and discourses were not just illuminated but set in a historical, social and cultural context. The iterative nature of data analysis has been described on page 109. **Appendix 3** gives an example of this process, moving through textual analysis to consideration of the emerging discourses and back again, working reflexively across different datasets and narratives. The discourses were considered through a Foucauldian lens, which was challenging, as I have already talked of my professional enculturation, and had to mediate my long-held views and experience. I considered the values sustained and those commonly held across recorded narratives, the power dynamics associated with such

values, and institutional perspectives resulting in the discourses and *technologies* presented in the findings chapter (page 121).

6.5.2 Media Data Analysis

Analysis of media representations of end of life care in this research project uncovers how they contribute to the formation and sustaining of social understanding, discursive practices and power (Waisbord, 2014). The media, as Foucault perceives it, is a source of representation that orchestrates power relations and the way we and society see ourselves, legitimising discursive regimes of truth, while denying and falsifying other ways of thinking and being. Orgad (2012) reiterates this thinking, describing the legitimising of people, places, disciplines, voices, thinking and objects, while others are considered powerless and illegitimate. While the same analytic steps for the narrative analysis were used to analyse the media artefacts, it was also necessary to categorise the artefacts using the steps outlined below.

6.5.2.1 Newspapers

The steps followed allowed an analysis, not just of the article itself but also of the impact of where it was situated and the associated imagery. Articles were removed from the broadsheet, scanned and logged. Analysis of the newspaper artefacts commenced after all of the data was collected.

News artefacts were subjected to an initial detailed descriptive analysis, enabling the identification of patterns and trends in reporting and representation, using steps one and two of the framework above. Bearing in mind the analysis is focused on discourse, each printed artefact was categorised as follows:

1. Newspaper
2. Year and month
3. Day of week
4. Type of article - Headline, feature, news item, letter to editor, opinion piece
5. Visual material (pictures)
6. Sources quoted
7. Position in paper
8. Relationship to any other news article
9. Type of audience - reflected in the readership each paper having its own ideological stance.

(Adapted from Cheek, 2000; Lupton and McClean, 1998)

A more detailed analysis was undertaken and included the use of language, tone of the article, visual imagery and its impact, how the news was represented, sources quoted and subjects captured (Cheek, 2000, Van Dijk, 2009).

The newspaper artefacts were read and reread, then transcribed using the categories described above. The data analysis allowed the uncovering of more than just the language, which is a socially and historically situated concept, both socially shaped and social-shaping (Fairclough, 1995). An example of the initial newspaper analysis is shown in **Appendix 4**. The news articles were explored in their broader context, the landscape the media exists in, how they are read, what are the drivers, who has a voice or not, and who is worthy of reporting (Van Dijk, 2009). This element of analysing media artefacts was complex; social practices, and cultural and historical influences impact upon the media, in the way they shape the context they are published in, while also influencing society through changing the views and opinions of their readers.

With a view to the textual content, Cheek (2000) describes the struggle to examine media artefacts discursively. I explored the text in media artefacts in the same fashion as for the recorded narratives, moving iteratively and reflexively through the data. This was an essential strategy and was

undertaken using the lens of contemporary practice in end of life care. The recorded narratives were analysed first, so when the media was analysed links were made between the two datasets; the analytic framework allowing for this. The emergence of discursive formations occurred as I progressed data analysis using the analytic framework iteratively for all data sources. Some discursive formations, for example, that of the economic rewards in end of life care, were strongly sustained in the media, whereas others were less so. This is further discussed in the Findings chapter (page 148).

6.5.2.2 Television

Television can be considered as text for analysis like other media (Weaver et al., 2013), and is a part and a product of modern society (Parker et al., 1999). The television artefacts were recorded and notes taken, which included details of when and where it was broadcast. The recorded programmes were watched over and over in order to immerse myself in the data. Notes were made which, unlike the other media artefacts and the recorded narratives, were not a verbatim representation of all of the content. The content was examined in the light of the discursive formations from the recorded narratives and media artefacts in order to sustain or offer contrasting perspectives. The narrative in the television artefacts that was important for this research was noted verbatim in order to capture the dominant values, ideas and beliefs expressed, which in turn, offers insight into how that may be received and understood by the viewer (ibid.). The analysis of the television artefacts differed significantly from the recorded narratives and the media artefacts. The visual impact, sounds and environment offered another layer of understanding of the multiple layers that make up the discourse (ibid.). The television artefacts contributed significantly to recognising and understanding the discursive formations in end of life care. An example of initial analysis of the television artefacts is shown in **Appendix 5**.

Chapter five in this thesis looks at Foucauldian insights, and the data analysis process naturally echoes the philosophical underpinnings of the

research. The analytic framework allows for the consideration of the networks of power and knowledge infused, informed and created by and through the discourses uncovered. The *technologies* in operation, such as those of surveillance, assessing the patient, documenting conditions, personal details, and illness and wellness, allow power to be infused into clinical practice. In turn, power / knowledge is exercised through the processes put in place to manage clinical practice, and apparatus are used to produce and maintain power in a social body, such as clinical practice, in order to manage and control (Foucault, 1980). The framework has allowed for the illuminating of dominant discourses and the taken for granted influences they pose for clinical practice, with at times acceptance and diminished resistance (Stonehouse et al., 2015).

6.6 Ethical Considerations

Ethical approval was sought and granted from Northumbria University Ethics Committee, following amendments to associated documentation (**Appendix 6**). Prior to commencement of the research study, research and development approval was also required from the NHS trust in which the staff to be included in the study were employed. This proved to be a long and convoluted process, which included outlines and rationale for meeting research awareness training, Caldicott guardian, funding requirements and University sponsorship. The research governance process in place was clearly designed to meet the requirements of empirical studies and randomised controlled trials supported by funding bodies. In addition to navigating this process for a small qualitative study, the Trust required a principal investigator to be named, who was an employee. I had worked closely with the Lead Nurse for Palliative Care in relation to this study and she was happy to be named as the Trust Lead for the project. Full approval was granted once all requirements were met (**Appendix 7**).

Participants' narratives were recorded on digital recorders and the data was transported by myself to the University for downloading onto a computer,

then was deleted from the digital voice recorders. Participants were asked to undertake their recording in a private and confidential environment. Data was stored on a password protected university server. All transcripts and any documents were anonymised; person and place names were removed during transcription. Numbers, the key for which is only available to me as the researcher, replaced people's names. Any direct quotations or comments that are used in the thesis or any subsequent publications or presentations will be anonymised. The printed data was stored securely in a locked cabinet at Northumbria University. The transcripts will be kept for three years following completion and then destroyed.

It is recognised that this is a sensitive and emotive sphere of practice. While participants worked within cancer services and palliative care, this does not detract from the fact that they may require support (Higginson, 2016). Having specialist experience in palliative care allowed me to reassure participants and support any individuals that required debrief, or deconstruction of difficult situations. In the interest of completeness, two practitioners wanted to discuss further their interaction with the research project within the scope of the recorded narratives. For both, the discussions were rooted within the challenges they face in everyday practice, with one participant having personal experience that resonated with her reflections on practice. I offered both practitioners appropriate support discussing and exploring the challenges. The support was undertaken when I met with participants to retrieve the recordings; in addition, participants were advised to contact me if required, as advised on the information sheet. As the study examines discourses emerging from practice, participants could have been sensitive to the fact that their practice or practice arena would be exposed. Reassurance was given regarding anonymity and confidentiality in order to protect their identity (Silverman, 2011).

6.7 Closing the Loop

The findings have been presented to the Trust in which this research was undertaken. This was done informally, to staff from the palliative care team and the cancer centre, including those who took part in the research, and more formally in a presentation to a regional palliative care conference **(Appendix 8).** The response from participants was very positive; they recognised what I was reporting and there was much discussion around the influence of media on the patients and their families, and how this impacted on professional practice. Some of the examples discussed proved to be very emotive. The more formal presentation had a two-fold effect. Firstly, engagement with the research and sharing of findings, which were positively received; and secondly, as a peer and role model, the promotion of nurse-led research with others contemplating developing their practice and profile. In addition to sharing the results with the participants, I have presented at a regional research conference, which was largely medical. Expert participants entered into discussion following my presentation, particularly commenting on the need to recognise media impact and potentials for moral panic **(Appendix 9).** For completeness I have included my poster for Palliative Care Congress **(Appendix 10).**

6.8 Conclusion

This chapter has considered the procedural devices used to give rise to the data. They are commensurate with the philosophical underpinnings of this thesis. This is particularly so for the analytic framework, which was designed to coalesce the work of the key theorists identified and offer the best approach for this research project, analysing the data through a Foucauldian lens. Ethical considerations and challenges have been explored as a key part of the research process. The following chapter will explore the findings of this research study.

7 Findings

This chapter details my research findings, shedding light on the discourses that have emerged from the analysis of both the self-recorded narratives and the media artefacts.

7.1 Concepts and Terminology

At any moment in time discourses change; they are contingent on historical context, a context that for end of life care is pivotal; a time where demand has never been greater, understanding still needs development, and workforce and resources are finite. The findings from the recorded narratives and media artefacts have given rise to discourses, which I have aligned to specific domains of understanding - *technologies.*

The idea of *technologies* reflects the Foucauldian thought that, historically, science and the bastions of knowledge were used to control individuals, particularly in institutional settings, such as the hospital (Foucault, 1993). Foucault's use of the word was a consequence of his way of thinking about power and changed as his thinking evolved; he used the terms *techniques* and *technologies* interchangeably. *Techniques* was more commonly used in the period when Foucault explored the archaeology of knowledge (1992); progressing to the term *technologie* in his later work on the consideration of modern power relations (Foucault, 1982a). *Technologies* enable us to highlight the way in which structures and functions within political and social institutions can manipulate populations or individuals, or indeed, how power can shape human conduct (Behrent, 2013). In this thesis, I use *technologies* as a methodological tool; a way of considering how power shapes conduct in practice. Akin to the thoughts of Foucault in his later years (Foucault, 1984a), *technologies* in this thesis shape discourses, which exist within them but emerge and interact with others.

Foucault did not focus on the repressive nature of power controlling human behaviour, but on the symbiotic relationship that can stimulate and nurture power, individual behaviour and conduct in all aspects of life (Foucault, 1980). For end of life care such *technologies* encompass life, living, death and dying, how we die, and the impact on all those involved. In addition, the tools and drivers we use in practice, those by which practitioners are judged and measured, those which help to assess the patient and those which orchestrate and measure our practice, are included in professional apparatus *(dispositif).* Foucault uses the term *dispositif* to refer to the institutional, physical and administrative mechanisms, and the knowledge associated with these that control and maintain power within specific social and institutional contexts (ibid.). *Dispositif*, reflects the demanding nature of apparatus, which emerge from a variety of sources, land in the clinical setting, and are applied across professional practice, controlling and directing how care can and should be delivered.

Foucault articulated four main interlinked types of *technologies*: *technologie*s of production, *technologies* of signs and symptoms, *technologies* of power and *technologies* of the self (Besley, 2005). These “categories” were not in reference to the churn created in social contexts by the creeping assimilation of technology into everyday life, but more so a means of capturing how truth, power and knowledge change and adapt individuals, and the contexts within which they exist. The *technologies* captured in this thesis consider the above for end of life care; how we deliver care and how individuals respond to the contextual conditions they are exposed to.

Technologies don’t function separately; they are intertwined. The typologies of *technologies* that have arisen from this research are: caring, power, self, representation and professional apparatus. These frame the remainder of this chapter. The discourses interlink in discursive formations. How we interact and communicate in practice is both a reflection of prevalent discourses, and helps shape new discursive formations, which come alive in the media in particular. As I became immersed in the data and progressed through the analysis phases, the discourses initially were assigned over simplified terms. However, as data analysis progressed through the iterative

process described in chapter six, they grew, morphing into a more visible entity, linking with one another until becoming recognisable as being situated within *technologies.* The *technologies* are discussed in this chapter alongside the discourses that have emerged from the data. For each *technologie* represented in the findings, I will present first the findings from the recorded narratives, then the printed media artefacts, followed by the television artefacts. The findings from each will be presented in a different font. The following section explores *technologies* of caring, which includes the challenges of treatment in advanced disease and living with dying.

7.2 Technologies of Caring

Technologies of caring encompass the emerging discourses that have given voice to the cared for, and the carers who are caring, whether lay people caring for their loved ones, or the healthcare professionals who are dealing with the complexities of delivering care to patients and their families at the end of life. The discourses overlap, and include the drive and challenges of the therapeutic imperative; living with dying, in which people are clear about their expectations of end of life care.

7.2.1 The Therapeutic Imperative

Patients who are reaching the end of their lives are living through a phase of their illness in which their condition can be rapidly changing and their physical condition may be particularly difficult to manage (Addington-Hall, 2002). For those caring for the patients, particularly with cancer, there is often a focus on treatment as long as curative intent remains a key driver. When patient outcomes turn from being one of cure and remission to palliative, then it can be to be difficult for the shift to be made:

> *"I would prefer that we could (pause) have a conversation that we feel is the most clinically appropriate without necessarily having to go into*

that area and, erm… (long pause) talk so frankly about the mechanism of death" (Participant One)

For those who work in areas where active cancer treatment is delivered when considering their contribution to end of life care, their focus turned to treatment decisions rather than the holistic view of a patient's wishes:

> *"I am mindful of an elderly lady that I was treating (tut) and whom I have known well for a number of months. We had had a number of conversations about the fact that that the… (protracted pause) patient didn't want to have chemotherapy to treat her… (protracted) acute myeloid leukaemia and preferred to take a more, erm (pause) supportive approach. We managed her effectively with recurrent transfusions, platelet transfusions (sighs) but it became clear that she was requiring an increasing number of hospital admissions and overall her condition was deteriorating"* (Participant One)

This particular patient had made the decision not to have treatment, yet for this case (and this disease), no chemotherapy did not mean no treatment, but was instead substituted with repeated hospital visits, admissions and interventions with the carer being involved:

> *"…her daughter had been present at the vast majority of her outpatient consultations and I felt we were very much on the same page (emphasised) (intake of breath). When the patient was admitted for the final time she had a very significant pneumonia (pause) and she was treated with broad spectrum antibiotics. But it became clear that these were not likely to be effective and in my view further treatment was futile."* (Participant One)

This narrative excerpt sustains the discourse of the therapeutic imperative being the drive for the healthcare professional delivering treatment interventions, even as the patient is imminently dying. The daughter is deemed to be on the "*same page",* a turn of phrase denoting mutual understanding. This refers to the page that the doctor deems to be the right page, in which they are in control, continuing to offer interventions until the

very last days and hours of life. The language used is that of finality (Freidrichsen et al., 2002) with the word futile denoting the end of this stage of the patient's life, as treatment is no longer capable of fulfilling its curative intent. The fact that delivering comfort measures to ensure the patient dies where they want and how they want is far from futile does not feature in this discourse. The body has been inscribed by the doctor as being in the final throes of life, inscribed as dying, yet despite this, the patient is given antibiotics. The discourse of the therapeutic imperative influences the management of this process, through assessment and monitoring of the patient, and surveillance of the dying subject. In addition, from a genealogical perspective, the non-discursive mechanisms of power, such as how the hospital is organised and geared to care for the dying patient (Powell, 2011) dictates that care is delivered in this way.

The challenge of 'changing gear' is a term used in palliative care as disease advances. Resistance to stopping active treatment in a dynamic area of care in the acute setting sustains the discourse of the treatment imperative; this is echoed throughout my findings. In particular, in this quote, the needs of the family take precedence; the difficulty of having conversations about the withdrawal of treatment shines through, so instead, treatment of underlying catastrophic infections continue:

> *"…Well we'll just keep giving them antibiotics for a few days, we're just keeping the antifungal treatments for a few more days, just so the families don't feel as if we're pulling out straight away. You're either doing end of life care or you're not. Yes it's nice to be kept comfortable. I don't think Ambisone, I don't think Caspofungin, I don't think Tazocin are things that keep you comfortable. Some of the patients feel grossly unwell with these antifungals and antibiotics yet we still, for the sake of cushioning it for the family, persevere with them…"* (Participant Three)

In addition;

> *"…We get a lot of patients, emm, that come in who've undergone a hell of a lot of treatment (swallow) and they're tired, they're, they're fed*

up, emm, we're pumping them full of drugs, emm, to try and, and help to make them better and it's who actually makes that decision that enough is enough. Emm, the patient has a massive influence on that but as well it's the doctors … there is no clear guidance (noticeable intake of breath); it's almost like we have to pin somebody down to make a decision…" (Participant Four)

Here, the culture of cure and the challenges of ending treatment are evident. Many healthcare professionals feel ill equipped to stop active treatment, especially in areas where there may be complex chemotherapeutic and technological interventions available. The notion of "we could try this…" prevails, impacting on timely conversations and withdrawal of treatment.

Despite experience and expertise, the challenges of dealing with patients who are intensively treated for their cancer and are reaching the end of their lives cannot be denied:

"…we often find we are in the situation where patients have had intensive chemotherapy before and are experiencing severe infection sometimes requiring admission to intensive care, where end of life care discussions and patient's wishes are being discussed at quite an acute time. This can obviously lead to distress for the families, patient may not always be involved in these discussions if they are intubated and can be quite unexpected from a family's point of view…" (Participant Five)

Often end of life care can be lost in the drive to treat a disease that is not controlled. From a palliative care perspective, the key to engaging the patient and their families in such discussions, in order to ensure their wishes are known, is not to deny death but to engage with it, however the timing of such discussions can be challenging:

"…I think sometimes it's hard (pause) to find the exact time point for when you need to start planning for a patient's end of life. I often feel it is something you have got to help a patient think about from diagnosis

> *...I feel as a nurse it is really important that I get to know my patients and their families, and their wishes…"* (Participant Five)

The hospital environment is geared towards diagnosis and treatment, although as seen from the literature, the acute sector is where most people die (Royal College of Physicians, 2016). Those with chronic disease enter hospital as their disease advances and many die without ever being formally identified as approaching the end of life (Clark et al., 2014). The institutional constructs within the acute sector enable rapid patient throughput. The focus is on results and targets, which impacts to some extent on the healthcare professional's ability to build relationships; this would facilitate conversations about where the patient wants to be and what their wishes are. There is a need to 'grasp this nettle' and have the conversations with patients and their families around the advancing of disease. An institutionally embedded drive for treatment may inhibit the conversations, as death and dying do not fit with the cultural imperatives and results-based outcome emphasis of acute settings:

> *"…my frustration is at the apathy within some areas of the acute sector where end of life care isn't actually seen as their job, emm, that ward staff, particularly nursing and medical staff, have when it comes to decision making. Emm. You know, I think people who know the patient well, which is usually the junior doctors and nurses (noticeable intake of breath… pause) are able to make a decision or raise an awareness that somebody may be approaching end of life… Those conversations have to be done by the most senior person, which …that's the difficulty, we can't always get them on board and sometimes it's too late…"* (Participant Seven)

While the medical discourse and power associated with decision making at the end of life overlaps with the treatment imperative discourse, it is clear that the drive for treatment, and management of care is infused with power relations and discursive formations; the way we practice, communicate and organise informs how we deliver care. This very clearly echoes what Lupton (2012) described as networks of power in clinical practice. Foucault talks of

the enabling nature of power, and we see this in end of life care; healthcare professionals, patients and families, all driving the therapeutic discourse at different times and in different ways. In the next narrative excerpt, a doctor working in palliative medicine talks of how challenging it is to support a friend with terminal cancer, thus illustrating that the therapeutic imperative operates on many levels:

> *"…I had a very strong desire to help my friend accept what is happening to her and to think about the future and prepare memory boxes for her children, erm, and to plan for her own death, however her response as a non-medical person has been to, erm, be extraordinarily positive, consider herself being cured by the chemotherapy and hoping for a miracle… she is taking this approach in full knowledge of the facts and this is her chosen way of doing this…"* (Participant Two)

The therapeutic imperative discourse is sustained in the media artefacts, influencing readers and informing understanding through representation. Within the media, journalists profess that their contribution follows a professional code through which they reveal social truths (Hall et al., 2013). Discourses define the events represented in the media despite the existence of a journalistic code; therefore the claims of truth made through the media have to be viewed as tentative (Hall et al., 2013). In addition, the political stance of the media considered adds additional complexity and competing and overlapping discourses. Nevertheless, the influence of journalists and the media cannot be denied, with institutional apparatus and techniques associated with news production and dissemination informing the evolution of power and knowledge (Hall et al., 2013).

Acceptance that the end of life is approaching can be undermined by the therapeutic imperative discourse as can be heard through the voices in this research. This leads to confusing messages for the families of the dying person as they look on and are told their loved ones are being treated when a contrary picture lies in front of them.

The following media artefacts sustain and contribute to the therapeutic imperative discourse.

Artefact Four:

Betts H. (2012) Headline – **Death is Not The Enemy**. Sub title: Medicine's obsession of keeping alive people who are ready to die is inhumane and inhuman. **Guardian** (page 2). Picture - The article is situated below a picture of Tony Nicklinson, a right to die campaigner, with a banner reading 'Peace at Last'.

> *"…My grandmother is clearly dying, trapped in some pained transitional state. Her face and body have taken on the skeletal appearance of a memento mori. She sleeps most of the time. When awake, her eyes have a lost look within her stilled body, as if in appeal. She cannot hear and increasingly refuses to eat and drink. She is ready. The medical services, however, are not and are engaged in an aggressive battle to resurrect her. The individual they appear to be fighting is my grandmother herself…"*

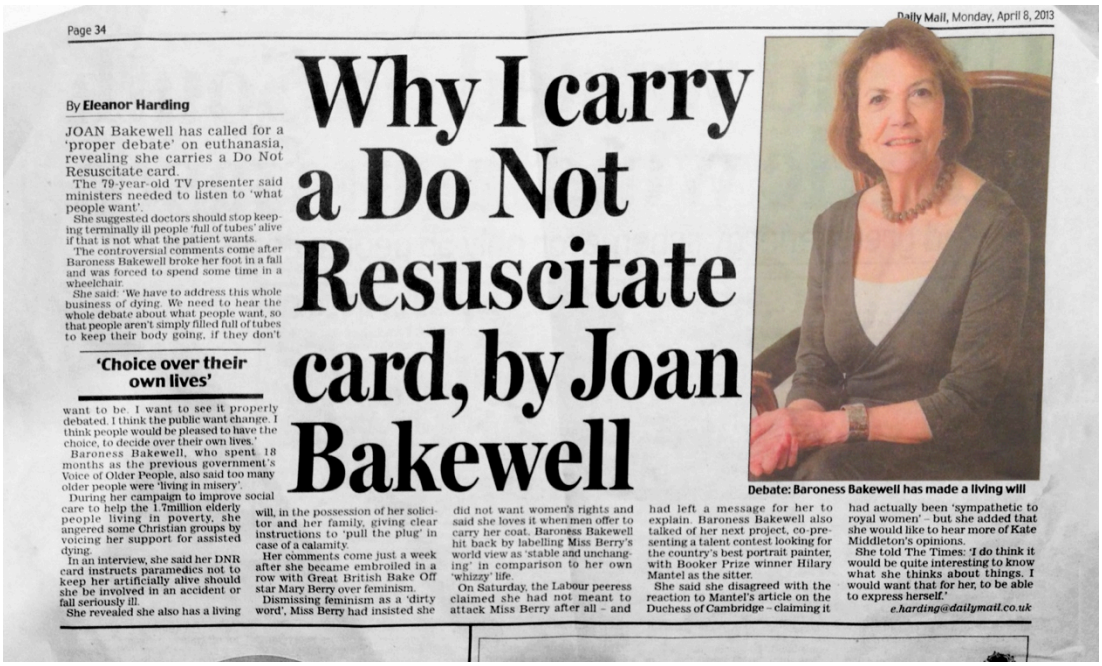
This is a very powerful picture that is painted through words on a page read by thousands of people, healthcare professionals and patients alike, which itself includes contradictions and influential metaphorical language. The article is situated on page two in the newspaper with a full page dedicated to the words and picture; such editorial decisions inform the readership, profile and impact of the article. This article, while emotive and powerful, is situated beside a half-page picture of Tony Nicklinson smiling with his wife. The editorial intent is thus to link the article with the right to die debate, even though the written article is actually about treatment and allowing people to die naturally. This is an example of a media practice sustaining dominant discourse around the right to die; while not explicit, the unsaid is as powerful as the said.

The treatment imperative is used in the artefacts associated with the right to die campaign, this can be seen if the following artefact.

Artefact Six:

Harding E. (2013) Headline - **Why I Carry a Do Not Resuscitate Card**, by Joan Bakewell. **Daily Mail** (page 34).

Picture - Colour picture of Joan Bakewell looking statesperson- like.



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Daily Mail, Monday, April 8, 2013

Why I carry a Do Not Resuscitate card, by Joan Bakewell

By Eleanor Harding

JOAN Bakewell has called for a 'proper debate' on euthanasia, revealing she carries a Do Not Resuscitate card.

The 79-year-old TV presenter said ministers needed to listen to 'what people want'.

She suggested doctors should stop keeping terminally ill people 'full of tubes' alive if that is not what the patient wants.

The controversial comments come after Baroness Bakewell broke her foot in a fall and was forced to spend some time in a wheelchair.

She said: 'We have to address this whole business of dying. We need to hear the whole debate about what people want, so that people aren't simply filled full of tubes to keep their body going, if they don't want to be. I want to see it properly debated. I think the public want change. I think people would be pleased to have the choice, to decide over their own lives.'

'Choice over their own lives'

Baroness Bakewell, who spent 18 months as the previous government's Voice of Older People, also said too many older people were 'living in misery'.

During her campaign to improve social care to help the 1.7million elderly people living in poverty, she angered some Christian groups by voicing her support for assisted dying.

In an interview, she said her DNR card instructs paramedics not to keep her artificially alive should she be involved in an accident or fall seriously ill.

She revealed she also has a living will, in the possession of her solicitor and her family, giving clear instructions to 'pull the plug' in case of a calamity.

Her comments come just a week after she became embroiled in a row with Great British Bake Off star Mary Berry over feminism.

Dismissing feminism as a 'dirty word', Miss Berry had insisted she did not want women's rights and said she loves it when men offer to carry her coat. Baroness Bakewell hit back by labelling Miss Berry's world view as 'stable and unchanging' in comparison to her own 'whizzy' life.

On Saturday, the Labour peeress claimed she had not meant to attack Miss Berry after all – and had left a message for her to explain. Baroness Bakewell also talked of her next project, co-presenting a talent contest looking for the country's best portrait painter, with Booker Prize winner Hilary Mantel as the sitter.

She said she disagreed with the reaction to Mantel's article on the Duchess of Cambridge – claiming it had actually been 'sympathetic to royal women' – but she added that she would like to hear more of Kate Middleton's opinions.

She told The Times: 'I do think it would be quite interesting to know what she thinks about things. I would want that for her, to be able to express herself.'

e.harding@dailymail.co.uk

Debate: Baroness Bakewell has made a living will

> *"…doctors should stop keeping terminally ill people full of tubes alive if that is not what the patient wants…"*

The content of the article and the associated imagery paint the picture of authority, with comments implying that Joan Bakewell's commentary has resonance because of her previous governmental role. While remaining unsaid, institutional control in relation to death emanates from the article. Her full title, Baroness Bakewell, is used, as is her government appointment, implying that her perceptions about death and dying are aligned to the elderly who need a voice; an advocate.

"…Baroness Bakewell who spent eighteen months as the previous government's Voice of Older People…"

Surface level understanding may point to the fact that older people need representation and are voiceless. Their opinion is deemed not to qualify; not to be of scientific value in the hierarchy of knowledge. Their knowledge as such is subjugated and disqualified (Foucault, 1980).

The therapeutic imperative articulates clearly the challenge of caring for people at the end of life when treatment is stopped or indeed continued. There is interconnectivity throughout these findings between all discourses. The following section considers the challenge of living with dying.

7.2.2 Living with Dying

Living with dying in the context of these findings is multifactorial. There are those who are living with the dying process, are actively dying, or are walking alongside their loved ones as they die. Living with dying also has resonance for healthcare professionals who live and work every day with the dying process. This impacts on the individuals, and their sense of wellbeing and anxiety (Peters et al., 2013), especially when active treatment is being pursued in order to stave off the inevitability of death.

This discourse overlaps and intertwines with the other discourses, and is informed by the historical and cultural contexts that have changed the way society views death and dying. Individuals rather than communities take priority, and the treatment imperative closely aligned to the sovereignty of medical science fights the inevitability of death (Howarth and Jupp, 1996).

The discourse of living with dying is heard through the voices of healthcare professionals. They echo the voices of patients and their families as they think about the culture of death and dying, and they live with it too:

"… It has been a very difficult experience and, erm, seeing it from a personal point of view and not just a professional point of view

especially in somebody young with small children… I think our culture and society has lots of different demands on an individual when they are dying (tuts) and seeing my friend respond to all of these external demands has been both, erm, very upsetting but also caused me to reflect on the palliative care, inverted commas, right way of being…" (Participant Two)

Some healthcare professionals consider the impact of living with dying from a personal perspective; they talk about the experience of the patient and their family. However, the personal impact manifested in the emotive language they used:

"…From a nurse's point of view I know how distressing it is for me to watch and feel somebody who is not related to me but you've got a bond with, who you've looked after all this length of time. So if you've lived with and loved that person for years and years and years and you're watching them (pause). I can't think of anything worse than being scared, in pain, knowing that you're going to die and not to have something just to make you comfortable, to take that fear away, must be horrendous (sighs). (Participant Three)

Dealing with death and dying on a day to day basis impacts on the professionals living with it; the difficulties of supporting patients and their families is dominant in this discourse:

"…They would be frightened some of them, but some have accepted it, emm, but some haven't accepted it, some don't accept it and, and that's extremely difficult to deal with and that side of communication (noticeable intake of breath) when you're communicating with families, friends, emm, relatives and the patient themselves it is often difficult…" (Participant Four)

The challenges for staff caring for dying patients in the acute sector are reflected throughout the narratives. For patients and their families living with dying, the narratives illuminate the need for communication in a timely

manner and the need to be given choices, and the notion of the good death emerges and is firmly counterbalanced with treatment imperatives.

Most people still die in the hospital setting (Gomes and Calanzani et al., 2015). The literature suggests that determining where people want to die hinges on good communication and honesty. Only then will patients have choice about where and how they want to die (Clarke and Seymour, 2010; Higginson et al., 2010). In the acute sector, where the treatment imperative pervades, conversations can be superseded by crisis and rapid deterioration, which confounds the patient voice and is distressing for all involved:

> *"… I suppose because of the acute nature of the diseases that we deal with, emm, patients can become very poorly very quickly and, often, emm, slip into a deep sleep and when it happens as quickly like that as it usually does (noticeable breath), you miss that window of opportunity to discuss with the patient (swallow)…"* (Participant Four)

Nevertheless, despite the deterioration trajectory, timely discussions can enable patient choice and ensure they can maintain a degree of control over their life until they die. Healthcare professionals and their reticence to take the opportunity to voice their concerns about changes in condition can deny the patient an opportunity to engage in timely discussions. The mention of death and dying and the denial of "normal" death are often not faced by healthcare professionals (Mannix, 2017).

> *"… I already have a relationship with them when we have to start discussions. I always believe it is best (hesitant) to talk to patients about their wishes as early as possible, if patients are ready to do so in terms of helping them come to terms with the palliative approach to their disease…"* (Participant Five)

It is key that patients feel they have control over where and, as much as possible, how they die. Howarth (1998) defines control as being a key component of a "good death". In order to attain a sense of control at the end of life, the individual needs to have a degree of choice (Powell, 2011). The two are inextricably linked. The discursive constructs and practices that

represent control and choice are multifactorial and rooted in historical context. The complexity is such that it can viewed as difficult to integrate into practice in end of life care.

> *"…Certainly, erm, society and, erm, culture and religion all have, erm, all have expectations on, erm, the individual patient, erm, and also the staff delivering care. But the real challenge of those expectations is the inconsistency of those expectations…"* (Participant Two)

The discourse 'living with dying' emanates from the media artefacts; the notion of suffering is sensationally represented as a key component of dying and used as leverage in the assisted dying debate.

Artefact Nine:

Driscoll M (2012) Headline – **Don't Mourn for Me - I am Already Dead**. **Sunday Times** (page 2).

Picture - Colour picture of Tony Nicklinson with his baby as a young man; parachuting; and with an anguished face. The imagery used offers the reader insights into the life he had and the life he has lost. The emotive title implies a living death.

2 NEWS REVIEW

Stroke victim Tony Nicklinson died days after a court refused to allow him to end his suffering. His wife tells **Margarette Driscoll** of his haunting last words as the fight drained from him

Don't mourn for me – I am already dead

"…he hated life as a dribbling dependent and had long sought to die, but his disability left him physically unable to commit suicide…"

Communication and choice emerge from the media as in the recorded narratives, with any emphasis being negative due to poor communication.

Artefact Four:

Betts H. (2012) Headline – **Death is Not The Enemy**. Sub title: Medicine's obsession of keeping alive people who are ready to die is inhumane and inhuman. **Guardian** (page 2).

Picture - The article is situated below a picture of Tony Nicklinson, a right to campaigner, with a banner reading 'Peace at Last':

"...The situation I am proposing is still more fundamental, involving not killing people but letting them die with dignity in conditions of their choosing..."

Artefact Eighteen:

Bruce F. (2013) Headline – **Liverpool Care Pathway: Finding the Best Way to Face Our Final Days**. **Telegraph** (page 4).

Picture - two old persons' hands joined.

"… If we believe that every life matters, then every death matters, and the manner of every death too. I know this only too well from my mother's passing – it took her several heart-rending weeks to die after being put on a "medical care pathway" which I neither understood nor had the opportunity to discuss with doctors. In the years since, I have

often asked myself: If those discussions had taken place, might I have helped to prevent her from suffering as she did…?"

The media artefacts overall take a negative view of dying and the care associated with end of life. This will become more evident when considering the *technologies* of representation and especially the sensationalist discourse. However, there are journalists who use their experience of end of life care more positively to inform their journalistic outputs.

Artefact Five:

Mills E. (2013) Headline - **So Tell Me: How Do You Want to Die? Sunday Times** (page 4).

Picture - children picking daffodils on a summer day in a field; inset - a Marie Curie Nurse. The imagery is positive and engaging.

4 NEWS REVIEW

So tell me: how do you want to die?

More than half of us end our days in hospital. But a night shift with a Marie Curie nurse shows how being cared for at home can take the fear out of death

ELEANOR MILLS

Daffodils at a quid a bunch — it must be spring. As they slowly turn from buds to yellow glory, the days lengthen, and they'll soon be nodding in the breeze.

Daffodils are also blooming across billboards and television screens, symbolising the Marie Curie cancer care charity's annual fundraising drive for its nurses. This year its campaign slogan is "Your last moments should mean as much as your first" — a sentiment brought to life by a short film (to watch it, go to youtube.com/user/mariecurieuk) that contrasts the first smile of a tiny baby with the last smile of a dying oldie; the first steps of a toddler with the last grin of an old man; a newborn's tiny fingers encircling a parent's large ones with a wrinkled hand being lovingly stroked at the end of life.

Too often we celebrate those baby firsts but neglect the precious final moments of old age, and this bias is reflected in the way we care for the dying. The UK employs 41,339 midwives and only 5,750 palliative care one can ever put a time on anyone's life — no one has a right to do that or to limit it in any way. But it's fair to say he's not long for this world," she said, and I took this to mean he was unlikely to die in the next few hours.

Nursing a dying patient in their own home, I discovered, is incredibly intimate. Marie Curie provides a free service for families nursing their loved ones, giving respite care by looking after the sick person between 10pm and 7am so the main carers can get some much-needed sleep. Since the charity's first campaign in 1986, £61.5m has been raised to support its work.

Brian was lying in a hospital bed in the centre of the family's living room. His son Tony, 44, had stopped working as a fork-lift truck driver so he could care for his father full-time, while Pauline, Brian's wife, went out to work as a receptionist for a local undertaker.

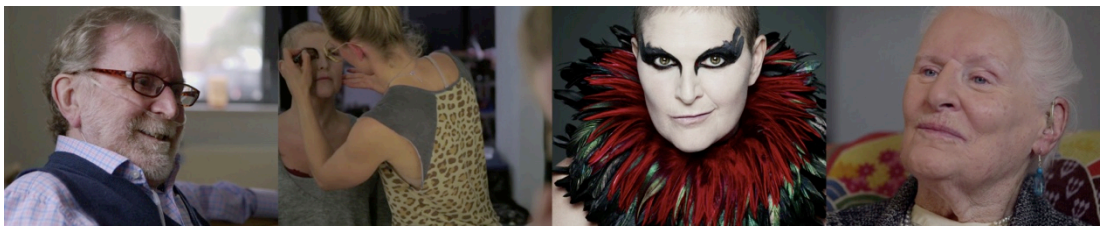
Claire has 25 years of experience as a district nurse and a teacher of nursing, but she retired several years ago. Nowadays, for two nights each week, she leaves her busi-

ARIEL SKELLEY

The Marie Curie charity believes that the dying should be with family at home, and its nurses, such as Claire Beecham, inset, help to make this possible

> *"…one of the only sources of comfort in the ensuing fog of grief is the knowledge that you did everything you possibly could for the person who had gone…"*

Insights into death and dying are powerful. They make the reader consider their own mortality; they sustain the living with dying discourse when they are portrayed through the media. This is specifically manifested in the television artefact **Alive Rankin Faces Death – A Culture Show Special**. In this, the photographer captures the lives of people who are dying through photography and interviews. The artistic and metaphorical images used throughout are visually impactful.



Rankin talks of his personal fear of death and dying and recognises that death is part of life:

> **"…When you click the shutter you are capturing life, it's a memory you have made… this is an exhibition about death and life. I want to photograph people who are staring death in the face and see what I can learn from them about life…"**

The programme is really about living with dying, with each patient with a terminal illness having a different way of living with dying. All of the participants talk of their experience in a rich and real way:

> Sandra – "…***You only get one chance to express yourself; we can taste, we can feel each other's love. It's amazing…"***

Wilko – "…**There is no future but you are alive**…"

Diana – "…**Things begin, they grow, are alive, end and it's the most ordinary thing in the world. Why be frightened of it?**"

The influence of the media and indeed the artistic and metaphorical images used is very powerful when considering living with dying. Power, in its many forms and operations in end of life care, is considered in the following section.

7.3 *Technologies* of Power

> *"…medicine offers modern man the obstinate, yet reassuring face of his finitude; in it, death is endlessly repeated, but it is also exorcised; and although it carelessly reminds man of the limit that he bears within him, it also speaks to him of that technical world that is the armed, positive, full of the finitude…"*
>
> *(Foucault, 2003 p198)*

Technologies of power have a strong voice in this thesis. Power manifests itself through the *technologies* in which it is exercised and the discourses reflect the power of the institution. In addition, power and knowledge emerge in the medicalisation of death, mediating death and dying through both professional practice and institutional drivers. The main discourses emerging from this research are institutional, medical and an economic discourse that is a consequence of the constructs of the NHS and how services are commissioned and delivered. These are detailed in turn below.

7.3.1 Institutional Power

Foucault's view of the institution as a social structure, through which power is exercised in order to shape norms, and control practices and individuals, includes medicine, but also the clergy, architecture and the justice system. Medicine is "organised like the clergy, and invested, at the level of man's bodily health" (Foucault, 2003 p36). The clergy "with power of men's souls" (ibid.), shares features with architecture, which determines how and where we live and die, and the justice system that tells us what is right and wrong, and how we should be punished. Power networks are not all punitive; in fact the institutions assert their authority through and with the community and the individual. Within the recorded narratives, there is an emergence of institutional power, which is reflected across all *technologies*, particularly in the *technologies* of the self, and moves away from purely medical control of end of life care:

> *"…Just had an MDT [Multi-Disciplinary Team meeting] and, erm, had a patient who, erm, is reaching the end of life whose son is a, erm, Catholic priest and the challenge is around the Catholic churches teaching around, around end of life care and the LCP and the way, erm, our practice is sort of influenced by very fixed beliefs regarding the LCP and fluids at the end of life…"* (Participant Two)

The Catholic faith teaches that death is part of life and that any deliberate act to hasten or shorten a person's life is against the doctrine. Palliative care as a discipline to promote quality of life is accepted, however the LCP was openly criticised by the Catholic Church. In terms of the networks of power, the control and choices sustained by clergy and religion has primacy over those of the individual.

The drivers for good end of life care and the use of apparatus on which we base patient care delivery is owned by the institution, and is influenced through the discourses that dominate at that point in time and within that social context:

> *"…The positive outcome of the increased publicity, erm, is that it is very much on the Trust's agenda now. They are being driven by complaints and, erm, publicity but actually we have a very good end of*

life tool, erm, and if the Trust is helping us, erm, roll it out across all staff then that can only be good for patient care…" (Participant Two)

The tensions of working in an acute environment when patients are reaching the end of life are well documented, with conflicting demands that are difficult to deal with, causing competing priorities, which then influence care for those who are the least able to resist. Institutional needs, and need for control, supersede the patient's needs, although the rhetoric is that institutional priorities are there to drive quality patient care. This is often the case, however, for the sickest and least able, the demands and needs of the organisation can have significant adverse impacts, for example:

> *"…A lady who was transferred to us from another ward, erm, palliative and in the dying phase and we took over her end of life care basically, erm, not something I agreed with at the time. I felt she should have stayed with the team that knew her on the ward but because of bed issues and things we didn't really have much choice…"* (Participant Six)

The apparatus that control the delivery of care in the health service, including policies, procedures and guidelines, direct and control care, and to an extent offer a means of surveillance, as checks and balances monitor the delivery of care according to measurable outputs:

> *"…Obviously in terms of end of life care we have to adhere to the Trust policies and guidelines; that's how care is directed, obviously we feed into that of course but the direction is given to us…"* (Participant Seven)

The place of death emerges through the narratives, as healthcare professionals capture what patients and their families say to them about where they want to die. Understanding for the nurse, the doctor and the patient are influenced through discursive practice, for example, perceptions that the meaning of a hospice is finality and giving up rather than acceptance, hope and comfort:

> *"…He chose, he was given the option: do you want to die at home; do you want to die in hospital or a hospice? He didn't want to go to a hospice because of the big stigma he said towards it. He said you know I don't feel, wouldn't feel comfortable there…"* (Participant Three)

While the patient's misperceptions are highlighted in this narrative, these notions are potentiated by the sense of meaning passed on through those caring from them in the acute sector as well as lay beliefs:

> *"…I find that for most patients there is still a misconception about hospices; I do find that with many patients that when you mention hospices they immediately think that that means they are dying and so many of them (pause) do find it's not something they want to consider early on in their treatment. (Deep breath)* (Participant Five)

The media artefacts echo the institutional discourse, presenting their perceptions of the cultural and societal script to the world as a reality (Howarth, 2010) adopted by some and rejected by others. The institutional discourse permeates through both the words and pictures used.

Artefact Three:

Doughty S. et al. (2012) Headline – **Cancer Expert Brands Care Pathway "the most corrupt practice in British Medicine"** Subtitle – I wouldn't be treated in a hospital here he says. **Daily Mail** (page 4).

Picture – Photograph of a late-middle aged doctor well-dressed, looking sage and statesmanlike, giving the impression of knowledge and institutional status.

Page 4 Daily Mail, Monday, November 5, 2012

Cancer expert brands Care Pathway 'the most corrupt practice in British medicine'

I wouldn't be treated in a hospital here, he says

Critic: Professor Mark Glaser

> *"…A senior cancer specialist yesterday condemned the controversial Liverpool Care Pathway as a corrupt and scandalous system used to free hospital beds of the old and sick… the professor, who treated Mo Mowlam during her last illness…"*

The reference to this consultant having delivered cancer treatment to a government minister is an attempt to add gravitas to his commentary, with institutional power being at the heart of government and the reference to Mo Mowlam reinforcing his standing and expertise.

Such institutional references and interviews with people working in the institutions that orchestrate our society persist throughout the media artefacts. There is specific reference to the hospitals, the regulators and those in charge of patient care being called into question or the profile they hold being used to sustain opinion.

Artefact Seven:

Doughty S et al. (2013) Headline – **Death Pathway Damned: Mail Campaign Vindicated in Devastating Report on Scandal of End of Life Treatment**. **Daily Mail** (page 4).

Picture – Colour photograph of a thin pale young woman with eyes shut and a small child holding her hand:

> *"…Lady Neuberger said a new system of "guides and alerts should be individually tailored to patients backed by medical professionals and patients and inspected by the Care Quality Commission. But there are still serious concerns over whether the discredited regulator is able to properly monitor patient care…"*

In the artefact below, the author talks eloquently about the death of her partner. Despite this, the essence of his importance is captured through the institutional power that has proliferated his professional life.

Artefact Ten:

Stuart F. (2012) Headline – **Even Losing a Loved One Can have a Good Ending**. **Sunday Times** (page 4).

Picture – Small photograph of the article author.

> *"… Derek, who was Tony Blair's economic advisor, died at the end of July. At his funeral, Sir Mervyn King, governor of the Bank of England, spoke of separations always being painful, whether in life or death…"*

Technologies of power and the institutions manifest in the television media artefacts. The *BBC News* on 22nd August 2012 covers the death of Tony Nicklinson, with the newsreader stating:

> **"…his solicitor read a statement saying he was heartbroken and the fight seemed to go out of him that he could not be killed at a time of his choosing by a doctor… high court judges want parliament to decide because this is a moral and ethical debate for society…"**

In this excerpt, the institutions that control dying are deemed to be law and medicine, and are reinforced as being able to control this process. Closely

linked to institutional power is the discourse of medical power. The following section will discuss findings that sustain the medical discourse.

7.3.2 Medical Power

Foucault (2003) describes how modern medicine came to understand and develop knowledge of illness, disease, ill health and health through monitoring and surveillance, classifying and ordering patients into categories. The *technologies* of power that produce and regulate the subject as a patient emanate through the recorded narratives in this thesis. While end of life care is more multidisciplinary than other specialisms, the power of the medical voice speaks strongly throughout the discourses. People (subjects) are being submitted to surveillance that inscribes them as patients (Forbat, 2009). This is part of the discursive practices that uphold medical power and is captured through the narratives:

> *"…If I have had a conversation with a patient and talked about death and dying, and talked about the… and particularly talked about the imminence of death, I do not always have a conversation with that patient about the rights and wrongs of CPR. Because to me by implication we have made a decision that CPR would be futile in this case and I am in no obligation to offer futile treatment which I think will (pause) in fact disadvantage the patient and make less peaceful (emphasised)…"* (Participant One)

While doctors may rightly view the patient as their responsibility, the notion of collective discussion among all healthcare professionals, and the patient and their family, allows for greater choice and better communication in end of life care:

> *"…They view the palliative care team as being there to support them… there's very much still this opinion of 'what can they tell me? We've been doing this for years', a lot of kind of defence, of they own the patients… I've even heard senior consultants make comments*

such as 'whatever did we do before we had palliative care patients' in a sarcastic manner…" (Participant Six)

The integration of palliative care teams in the acute sector can be fraught with tensions and collaborative working is key. Consultants for the patient can refuse to involve the palliative care team (Oliver, 2018) should there be a need to refer complex patients and / or their families for specialist palliative care support at the end of life. Rather than commodification and subjectification of a patient, communication, collaboration and the focus on patient care should be at the core of decision-making:

> *"…You know I think people who know the patient well, which is usually the junior doctors and nurses (noticeable intake of breath) are able to make a decision or raise an awareness that somebody may be approaching end of life. I think the difficulty is facilitating those difficult conversations with the patient and their family. Those conversations have to be done by the most senior person, which is usually the consultant or registrar, and I think that's the difficulty and the frustration that we can't always get them on board, emm, to have those conversations until sometimes it's too late…"* (Participant 7)

The media artefacts illustrate the patients' care being in the hands of the doctors and the control of death and dying is implied throughout. However, juxtaposed against this is the fact that doctors get the "blame" for the problems that occur. There is also a close alignment with the institutional discourse in terms of medical power associated with patient care and service delivery. Doctors are socialised and educated to take control of patient care; the institution reinforces this through the way care is institutionally orchestrated.

Artefact Four:

Betts H. (2012) Headline – **Death is Not The Enemy**. Sub title: Medicine's obsession of keeping alive people who are ready to die is inhumane and inhuman. **Guardian** (page 2).

Picture - The article is situated below a picture of Tony Nicklinson, a right to campaigner, with a banner reading ‘Peace at Last’:

> *“…It was Ivan Illich “Limits to Medicine” that first posited the theory of medicalization back in the mid-70s. Illich agreed that contemporary medicine had “brought the epoch of natural death to an end”. Death was no longer to be considered, part of life, instead “total war” waged against it, family care and ritual deemed superfluous…”*

This artefact clearly demonstrates the notion of medical power, using the work of Illich *Limits to Medicine* to show that death may be denied. There is a degree of irony here as Illich is talking of natural death, and the treatment imperative denying this, whereas this artefact focuses on the case of Tony Nicklinson and death being at the time of the patient’s choosing, accelerated through assisted dying.

Artefact Sixteen:

Martin D. (2013) Headline – **How I Saved my Father from Care Pathway by Tory MP**. **Daily Mail** (page 6)

Picture – small image of MP and image of headline “Hospitals Bribed to Put Patients on Pathway to Death”.

Daily Mail, Wednesday, January 9, 2013

How I saved my father from Care Pathway, by Tory MP

By **Daniel Martin** and **Jenny Hope**

AN MP told movingly yesterday how she saved her father from the Liverpool Care Pathway, two years after her mother endured an ‘agonising’ death on the system.

Fiona Bruce said she was told ‘almost casually’ by a nurse that doctors had decided to remove life-saving treatment from her 83-year-old father, despite not having consulted relatives.

She moved him into a nursing home where, six months on, he is thriving. Her mother died after she was placed on the controversial system following a brain tumour operation.

Mrs Bruce spoke out during a Parliamentary debate on the pathway, in which MP after MP criticised the way it is being implemented in hospitals.

In a separate development, senior doctors conceded the LCP has become a ‘euphemism for death’, with families ‘frightened’ about their report by the summer, said he had been ‘personally horrified’ by accounts of food and drink being inappropriately withdrawn. It was ‘non-negotiable’ that relatives should always be consulted, he said.

Every year, 130,000 people die on the pathway, under which doctors remove life-saving treatment. In December it emerged that almost half are never told that treatment is being removed.

Mrs Bruce, vice chairman of the parliamentary Dying Well group, said that in her mother’s case ‘it took her weeks to pass away, which was agonising for her, and heart-rending for her family. There was no discussion, no consultation with the daughter.’

Last summer, her father was taken to hospital feeling unwell, she told MPs. Doctors could not diagnose any

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

Mail, October 26, 2012

Not consulted: Fiona Bruce

> *"…Every year 130,000 people die on the pathway, under which doctors remove lifesaving treatment. In December it emerged that almost half are never told that treatment is removed…"*

The medical discourse and end of life care strongly emanated from one specific television artefact. **Dispatches: *Death on the Wards*** is a documentary shown on Channel Four.

This was specifically aimed at the LCP, with the opening sentence being "…is the NHS prescribing backdoor euthanasia?" The implications and discussion will be considered in more detail when presenting the professional apparatus discourse. However, threaded throughout this programme is the medical discourse. Experts for and against the LCP are interviewed throughout, resulting in a contentious and florid debate. The expertise of the doctors is what the programme is hinged upon, with one consultant suggesting people should perhaps not be told of their prognosis:

> ***"There is no data to determine when a patient is reaching the end of life; it is intuition determined by the team at the time. If you say somebody has a poor prognosis then you make it a self-fulfilling prophecy…"***

While the discourse of medical power is well-rehearsed, it should not be oversimplified as being located in one group only; the networks of power in end of life care can be enabling for patients too. The control of the patient is complex; there is a clear interface between medical and institutional power, and other discourses. One such discourse is the economic power discourse that is prevalent in an ever-changing NHS.

7.3.3 Economic Power

> *"…To discipline the body, optimize its capabilities, extort its forces, increase its usefulness and docility, integrate it into systems of efficient and economic controls…"*
>
> (Foucault, 1976 p139)

The economic discourse is prominent throughout the recorded narratives and media artefacts, illuminating a discomfort with the economic influences in end of life care. There is an inextricable link between the institutional discourse, managing scant resources at a Trust level, and rewarding Commissioning for Quality and Innovation (CQUIN) targets from central government. All of these issues, when introduced into end of life care practice, cause difficulties and discomfort:

> *"In terms of beds, we've got a lot of acutely ill patients and we're finding it more and more difficult to allow patients to die on the ward…"* (Participant Six)

> *"There's a number of issues, pressure on beds, pressure on resources and so often when a decision has been made that a patient is for end of life care, emm, that decision usually goes hand in hand with trying to get the patient out of an acute bed."* (Participant Seven)

More obviously, the NHS trusts were rewarded for meeting targets in an attempt to improve end of life care. The targets included professional

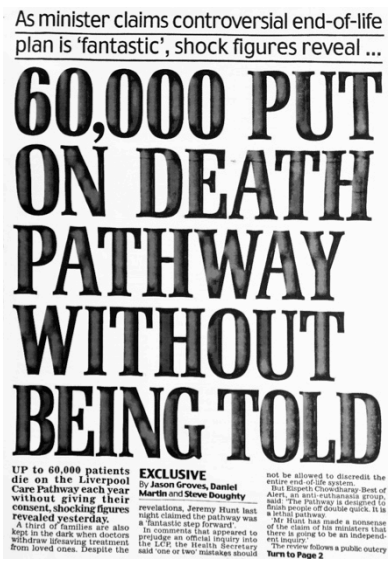
apparatus such as the LCP. Interpretation of this policy driver manifested as discomfort in the recorded narratives:

> *"As the CQUIN target became known and we were encouraging people to use the LCP in order that the Trust should not lose this big chunk of money, I started to become concerned that the… the… the… main the… patient focus had gone and so people were put on the LCP almost pre-emptively… I felt that this CQUIN target was starting to interfere with good, good end of life care…"* (Participant Two)

The participants voiced their concerns about the financial rewards and institutional priorities, feeling that this impacted on decision making in end of life care, their practice being measured through the return of audit which is itself institutional apparatus to control best practice:

> *"…I do find another issue the fact that we are audited on the use of the Liverpool Care Pathway (long pause) somewhat difficult. Obviously the audit of the Liverpool Care Pathway and its implementation at the time of death is a quality measure (emphasised deep breath)… On occasion I have had to (pause) be careful not to (pause) make the desire to fulfil an audit criteria drive the clinical consultation which would clearly be inappropriate…"* (*Participant One*)

The financial incentives associated with end of life care highlighted in the recorded narratives were given a stronger voice in the media, in which the economic discourse was strongly sustained.



As minister claims controversial end-of-life plan is 'fantastic', shock figures reveal ...

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD

UP to 60,000 patients die on the Liverpool Care Pathway each year without giving their consent, shocking figures revealed yesterday.

A third of families are also kept in the dark when doctors withdraw lifesaving treatment from loved ones. Despite the revelations, Jeremy Hunt last night claimed the pathway was a 'fantastic step forward'.

In comments that appeared to prejudge an official inquiry into the LCP, the Health Secretary said 'one or two' mistakes should not be allowed to discredit the entire end-of-life system.

But Elspeth Cuneyhazy, Best of Alert, an anti-euthanasia group, said: 'The Pathway is designed to finish people off double quick. It is a lethal pathway.

Mr Hunt has made a nonsense of the claim of his ministers that there is going to be an independent inquiry.

The review follows a public outcry

EXCLUSIVE By Jason Groves, Daniel Martin and Steve Doughty

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Artefact One: Groves J. (2012) Headline – **60,000 Put on Death Pathway Without Being Told**. **Daily Mail** (Front Page).

"…Clinical judgments are being skewed by incentives for hospitals to use the pathway. Health Trusts are thought to have been rewarded

with around £30 million for putting more patients on the LCP…"

This echoes what was highlighted in the recorded narratives; the use of such apparatus as a quality measure was not highlighted and the article uses the sum of £30 million in order to dramatise the scale of the situation. The economic discourse takes precedence without a counterbalance being given about the intention to improve end of life care underpinning the CQUIN rewards.

Artefact Thirty-Eight:

Doughty S. (2012) Headline – **Hospitals Bribed to Put Patients on Pathway to Death:** Cash Incentive for NHS Trusts that Meet Targets on Liverpool Care Pathway. **Daily Mail** (Front Page).

Cash incentive for NHS trusts that meet targets on Liverpool Care Pathway

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

HOSPITALS are paid millions to hit targets for the number of patients who die on the Liverpool Care Pathway, the Mail can reveal.

The incentives have been paid to hospitals that ensure a set

By **Steve Doughty**
Social Affairs Correspondent

percentage of patients who die on their wards have been put on the controversial regime.

In some cases, hospitals have been set targets that between a third and two thirds of all the deaths should

be on the LCP, which critics say is a way of hastening the end for terminally ill patients.

At least £30million in extra money from taxpayers is estimated to have been handed to hospitals over the past three years to achieve these goals. Critics of the method warned

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> *"…Hospitals are paid millions to hit targets for the number of patients who die on the Liverpool Care Pathway, the Mail can reveal. The incentives have been paid to hospitals that ensure a set percentage of patients who die on their wards have been put on the controversial regime. In some cases hospitals have been set targets that between a third and two*

thirds of all deaths should be on the LCP, which critics say is a way of hastening the deaths of terminally ill patients…"

The economic discourse clearly captures the discomfort around reward-based commissioning and care delivery in end of life care. The media specifically seized on this, capitalising on the growing concerns regarding end of life care and laying the blame for using the LCP as a means to cut costs, save resources and clear beds firmly at the door of the NHS. The reportage oversimplifies the commissioning cycle and underpinning philosophy for journalistic gain, promoting societal concerns. The following section explores *technologies* of the self. Understanding the emerging discourses from this research that can influence the notion of the self is important in order to appreciate the complexities in end of life care.

7.4 *Technologies* of Self

> *"Those practices whereby individuals by their own means or with the help of others, acted on their own bodies, souls, thoughts, conduct and way of being in order to transform themselves and attain a certain state of perfection or happiness to become a sage, immortal and so on …"*
>
> (Foucault, 1982a p4)

Technologies of the self, as Foucault describes above, are a consequence of *technologies* of power, practices that are not of an oppressive nature but in fact are more a relationship cultivated with oneself (Ifotode, 2013). Foucault speaks of the dominant forces that have controlled the individual throughout history, such as the military and the justice system. A decrease in their influence has led to the emergence of biopower as a form of social control and self-discipline (Foucault, 1976). Biopower imposes itself on our bodies, regulating the way we act through self-disciplinary practices and self-surveillance, through which we conform to norms in the way we live and the way we die. At the end of life, such subjugation gives rise to what Foucault

terms ”docile bodies” (Foucault, 2003), which in turn conform to the demanding and controlling gaze of the institution and the doctor. In hospital, the person dying, their carers and sometimes the healthcare professionals undertaking the care fall in line with the expectations of the institution.

The discourses that have arisen from this research in relation to *technologies* of the self, are: personhood, moralistic and religious. These are explored in turn below.

7.4.1 Personhood

Personhood in end of life care has emerged as a discourse. The person, the individual, is not just a body but also has a mind and “soul”. Life in its closing stages forces us to extend our concept of personhood as we look for our legacy, as we look into the eyes of our children and see ourselves reflected, we look into the eyes of patients and see ourselves reflected. Life’s journey comes into sharper focus and now through technology and social media we can be immortalised in time and space:

> *“I feel this role contributes to me as a person. Being able to provide and offer end of life care to our patients is actually quite a very special and privileged thing to be able to do and I have always felt that way…”* (Participant Three)

The personhood discourse was stronger in the media artefacts than the recorded narratives, particularly but not exclusively with reference to strong women.

Artefact Twenty:

Carpenter L. (2013) Headline – **My Very Modern Death**. **Sunday Times** (magazine).

Picture – Double page coloured spread of Kate Grainger in her living room.

> *"Her approach to death brings a new meaning to "modern". Working in tandem with Twitter she has attracted a following to her blog… she recalls how she had been enjoying a lovely supper with her husband and asked him "Would it be fat to have another bun for pudding?" and that he had replied, "Yes but you're dying darling so does it really matter?" "We both then fell about laughing hysterically…"*

This approach to her impending death is projected through Twitter, in which Dr Grainger shared both her living and dying with tens of thousands of followers. She was thus immortalised through social media, leaving a legacy, which has extended for those who follow her the notion of personhood:

> *"Dying gives you a freedom to speak your mind", she says. "I would never have spoken up before about anything really, I was just a normal girl living a normal life, I wasn't involved in any of this but I think the situation I find myself in lets me express what I am feeling in a more clear way…"*

The television media artefacts demonstrate the notion of self in a starkly illustrative manner, using representational metaphor for impact. In **Alive Rankin Faces Death – A Culture Show Special,** Sandra, a lady with metastatic breast cancer says:

> **"…I am considering myself as an Amazonian woman, it symbolizes the inner strength that comes through me, to the bitter end I am not giving up…"**

In addition, another participant in the documentary produced by Rankin, Diana, a woman who is reaching the end of a long and full life, articulates how she integrates death into her life:

> **"…Everybody should take 15 minutes each day thinking about death. That's rather sensible; it seemed to me very quickly to be part of life. Even enormous mountains have a beginning. They come up to their best then they fade away and die. Everything does that; it's the pattern of how life works… It can't be… if it's so completely universal it can't be so bad. It's the most ordinary thing in the world. Why be frightened by it?"**

Personal beliefs and values are manifested throughout the discourse. The individual's philosophy, belief system and enculturation is informed through religion, a bastion of society, that for some has echoes of the past while for others informs and directs their way through care at the end of life.

There is a sharp contrast between the sense of personhood represented in the written media, compared with the television artefacts, particularly the documentary **Alive Rankin Faces Death – A Culture Show Special,** in which people who are dying appear to be in control, dignified and sharing intimate and personal insights through visual representation. This is different from documentaries we see about death and dying which portray the deteriorating body and the distress associated with dying, perhaps following

the institutional imperative associated with the control of death and dying; the how and the where of dying.

One institution that contributes to end of life care is the church. While contingent on history and context, religion contributes to the sense of self in this research.

7.4.2 Religion

The religious undertones in palliative care have been alluded to in this thesis. The notion of penitence and the confessional as a mode of institutional control, exercised over the docile body, is threaded throughout Foucault's works. In palliative care, and specifically at the end of life, the religious undercurrents have long been acknowledged. This was reflected in the recordings and some of the artefacts, which are explored below. Historically, religion has been aligned with palliative care (Howarth, 2007). This can be seen from the recorded narratives extoling the interface with Catholicism:

> *"A patient who is reaching the end of life, whose son is a, erm, Catholic priest and the challenge is around the Catholic church's teaching around, err, around end of life care… still fierce resistance to the LCP and we of course, under those circumstances, we do not use it; we just use the essence of the Liverpool Care Pathway… There has been a fair bit in the, erm, Catholic, erm, publications (long pause to end of the recording).* (Participant 2)

For some, reaching the end of life brings them closer to their beliefs and that has to be respected. The religious discourse appears to have two strands: one critical of end of life care hastening death, as can be seen in these artefacts; and one easing those who have religious beliefs through the dying process. In the media, religion and end of life care often go hand in hand with assisted dying, penitence, pain and suffering.

Artefact 10

Stuart F. (2012) Headline **– Even Losing and Loved One Can Have a Good Ending**. **Sunday Times.**

Picture – Small photo of the author looking into the camera (page 4)

> *"I realised the importance of tradition too. Derek thought of the Church of England as part of the fabric of society… Father Mathew Catterick understood the nature of Derek's relationship with God perfectly…"*

The literature talks of the secularisation of society (Foltyn, 2008; Bishop, 2013). However, this media artefact reflects that for some, religion plays a vital role in helping to ease the dying process. The tradition, history and institutional stature of the church offer strength and comfort for some.

Artefact Twenty Three:

Toynbee P. (2012) Headline – **Would you be Happy to Live Like Tony Nicklinson? Guardian** (page 22).

Colour picture of Polly Toynbee, author of the opinion piece.

> *"…it is not for the courts to make fundamental change but for parliament – even when parliament sentences thousands a year to brutal and pointless suffering… the red benches heavily stacked with the religious, including 26 bishops, saw off the last bills… the palliative care profession has been the most effective opponent because of their wonderful work for the dying. But they are strongly religiously motivated and shameless in their pretence that they can ensure everyone always has a*

pain free end, if eased naturally out of this world…"

This article clearly talks of the institutional power associated with death and dying, the law, government and medicine. Foucault identifies these disciplines as bastions of power and knowledge (1972). For the readers, the language is inflammatory and has overtones that colour the dying process in their eyes *"… the barbarous truth about how badly life ends…"*

End of life care is fraught with moralistic dilemmas and difficulties. The moralistic principles that have emerged through this research are explored in the next section.

7.4.3 Moralistic Principles

The rights and wrongs associated with death and dying are embedded in moral principles, many of which are driven by secular traditions. The law and Christianity have historically exerted influence on how we live and how we die.

In this research, much of the moralistic discourse emerges from the news media, asserting their moral reasoning and principles on the reader through journalistic outputs. It is interesting that despite the recorded narratives offering the participants the opportunity to have a voice in relation to the moral dilemmas faced in practice, the participants chose to highlight different perspectives.

In addition, suffering can often be seen as an existential concept. The emergence of a moralistic discourse captures the complexities and nuances related to the more spiritual and ethereal aspects of end of life care.

Artefact Thirty Two:

Parris M. (2013) Headline – **The Cult of the corpse is Just a Pagan Relic**. **Times** (page 21).

Colour photograph of Matthew Parris, author of the opinion piece.

> *"…In the twenty first century so many educated people should still attach this mysterious reverence to what the bible itself variously calls dust, ashes and grass. So why the remarkable irrational persistence of primitive ideas of the sacrosanct nature of human remains? Why the reverence of dead flesh?"*

The moralistic discourse emerges in this artefact; questioning humanity, questioning how we mourn and grieve for our dead. In addition, it highlights the belief systems that are embedded in society and challenges conventional belief, which is orchestrated through the institutional power of the church and medicine. The institutional control of death and dying is closely aligned to the moralistic discourse, especially when the media extol the rights and wrongs of assisted dying. In the following excerpt, Tony Nicklinson talks of his life trapped in a disabled body, bringing the moral dilemmas related to assisted dying to the forefront of the reader's thoughts.

Artefact Twenty-Eight:

Anonymous. (2012) Headline – **A Fate Worse Than Death**. **Independent** (page 1).

Picture - Colour picture of Tony Nicklinson

> *"He applied to the courts for a doctor to be allowed to kill him. When the court judgment went against him – the judges arguing that such a far-reaching social change was not a matter for the courts, but for a debate in parliament… one of the last things he said to her when he was still able to make*

himself understood by blinking at a perspex letter board to spell out words was 'I am already dead so don't mourn for me'."

This moral dilemma is vividly illustrated in the following artefact, in which the title highlights the pain and distress that Tony is experiencing and also conveys to the reader pain and raw emotion through the imagery used.

A fate worse than death

The moment that Tony Nicklinson, who has suffered from locked-in syndrome for seven years, was told by a judge that he does not have the right to die

Reports **PAGE 8**

In the television artefacts, the moralistic discourse is communicated in an effective and impactful way; the voice of the person is laden with their emotions, which enhances understanding. In addition, the graphic impact of seeing the person sustains the discourse. In **Alive Rankin Faces Death – A Culture Show Special**, Lesley, a woman who is facing her death states:

"For me, once you have died it's all about your soul not your body, they can do what they want with my body. I have gone back to where I belong…"

In the same programme, Lily, an elderly woman who is a holocaust survivor is philosophical about life, describing the amoral experiences she encountered in the concentration camp:

"I have suffered a lot in my life. I have looked death in the eye more than once (camera pans to her

> **Auschwitz number tattoo). Killing was OK; that was the norm; the situation was so bad that in a way you wanted to die…"**

The moralistic discourse arising from the individual's notion of right and wrong, life experience, life enculturation and exposure to dominant discourses is often internalized by individuals, giving rise to self-surveillance in terms of what is right and what is wrong. In end of life care, the societal norms, institutional power and associated discourses posed upon the individual sustain the moralistic discourse. In the media artefacts, this emerges through the voice of the individual and the associated editorial intent and direction.

Foucault's concept of the self is complex, and evolved over the span of both his life and his thinking. The self in terms of end of life care is about living as a whole person or, as Iftode (2013) describes, "living coherently" through regulation and *technologies* of the self. Moralistic priorities, personal beliefs, examination of one's conscience and the religious and spiritual principles through which we conduct our life, all contribute to our sense of self. In addition, the visibility of justice and the representation of how we should and do live our lives, contribute to the discourses that constitute *technologies* of the self in this thesis.

Media is at the centre of this research; the following section explores the technologies of representation that have emerged.

7.5 *Technologies* of Representation

Technologies of representation influence culture and cultural understanding at a given time in history, using language, signs, images and vehicles that represent the subject. While the discipline and associated understanding of representation are complex, for this thesis, representation will be considered through a Foucauldian lens. As such, representation cannot be reduced to an analysis of the words spoken and the pictures published. Where, how and

when we practice, namely the discursive turns, formations, regimes and rules in which the artefacts and recorded narratives are situated, give voice to the discourses that have been uncovered through this research.

7.5.1 Mediatisation of Death and Dying

Media representations echo the prevailing social structures and power frameworks implicit within our society (Orgad, 2012). It is also clear that as we move into a more digital age, where news and commentary are more accessible for all, the media has a huge influence and a critical role in how society views issues related to health, illness and death (Williamson et al., 2011), providing a constant filter for messages regarding health, either explicitly or implicitly (Seale, 2002). The individual's understanding of their world, and health and illness, is moulded through their exposure to mass media, and their personal experiences and lay beliefs (Lupton, 2012). This research found the mediatisation of death to be a prominent discourse heard in the voice of the practitioners and through the media artefacts.

The impact of the media and influence on the understanding of death and dying for those whose loved ones are dying is clear:

> *"…some of the complaints, erm, when you hear the details, makes you feel very sad though, that the consequence of this misreporting and misinformation is that very sad. Grieving people are looking for reasons that their loved one died, never mind that they had an advanced incurable condition and they want to blame somebody…"* (Participant Two).

In addition,

> *"…In terms of family or patient reaction to the Liverpool Care Pathway, I have certainly had families who have said to me: 'oh yes I have*

heard that in the paper I have read about that'. Erm (pause), 'I have seen a newspaper article on that'." (Participant One).

While mediatisation of death and dying does not allow a full picture of understanding perceptions of death and dying, it does illuminate public perceptions of end of life care as a result of the media coverage:

"I don't know if these preconceptions are due to the media or due to previous experience of hospice my thoughts are that it's probably both depending on which patient you are dealing with…" (Participant Five).

The following quote underpins how patients gain understanding from the media; how they interpret media coverage and how it informs and influences the choices they make:

"Patients I have spoken to recently are very media savvy and they're aware of what's going on. I've had the discussion with one lady in particular, emm, a week or so ago, emm, on the initial assessment regarding the LCP and on that occasion she made it very clear that when the time came, she did not want to be put on the LCP as it meant that she would be starved…" (Participant Six).

The media artefacts in this research are an illustration of the mediatisation of death and dying, offering a voice to some, and subverting and silencing the voice of others. Some media artefacts reflect the attempt to offer a more tempered understanding of death and dying. The following artefact offers some balance and insight into positive and supportive end of life care:

Artefact Five:

Mills E. (2012) Headline - **So Tell Me: How Do You Want to Die? Sunday Times** (page 4).

Picture - children picking daffodils on a summer day in a field. Inset: a Marie Curie Nurse. The imagery is positive and engaging

"Birth and death are events that strip the fakeries and trivialities of everyday existence. In them we are revealed naked and whole, bathed in truth…"

In contrast, others wish to justify the sensationalist discourse they have given voice to, when covering such an emotive subject:

Artefact Seven:

Doughty S. (2013) Headline – **Death Pathway Damned: Mail Campaign Vindicated in Devastating Report on Scandal of End of Life Treatment**. **Daily Mail** (page 4)

Picture – Colour photograph of a thin pale young woman with eyes shut and a small child holding her hand.

"The inquiry led by Baroness Julia Neuberger – unearthed "distressing" evidence of "desperate people" and vindicates the Daily Mail's persistent highlighting of relatives' concerns last year…"

The media influence on end of life care is seldom acknowledged in the artefacts, with the professional voice being heard through recorded narratives, one such exception is in the following:

Artefact Thirteen:

Pemberton M. (2013) Headline – **The Liverpool Care Pathway to Dignity in Death**. **Telegraph** (page 5).

Picture – Photograph of a pair of young hands and old hands holding each other.

"What really shocked me was the claim… by Dr Bee Wee, who said she had heard that because of recent media reports about the LCP, some patients were now

so afraid of being placed on the pathway that they were reluctant to be admitted to hospital to get the treatment they needed…"

The discourse of mediatisation of death and dying is echoed in the television artefacts. While the drama and indignity of death is integrated into our normal viewing through fiction and the tragedy of world events, the voice of this discourse is clear. In the small number of non-fictional television artefacts specific to end of life care, there appears to be three main perspectives; living with death and dying, assisted dying and the critique of clinical practice in end of life care.

In **Alive Rankin Faces Death – A Culture Show Special**, the photographer, Rankin, very clearly captures his fear of death:

"…Seven years ago my parents died really quickly within 3 weeks of each other… I want to stare death in the face and ask a few questions about it. I want to photograph people who are facing one of the biggest challenges of all; their own death."

The words are powerful; however, the production offers some sense of balance and insight, using restful music and introducing each of the participants through black and white photographs, and in a thoughtful and balanced manner. Rankin uses reflections of the past, through photography, giving the viewer a sense of connection to the person who is in the documentary. He shares the impact this project, the television documentary and the exhibitions, have had on him:

"What I have learned is that you can't help thinking about life and death; these photographs have potency. That's why I have made the title Alive in the Face of Death…"

In contrast, the news media television artefact 1 discusses the concept of assisted dying using the case of Tony Nicklinson. The visual imagery used is very powerful, with contrasting photographs filling the screen of Tony

skydiving and at parties; and then flushed, crying and distressed after his request for assisted dying was denied at the high court. Following this visual montage, the newsreader, using stark perfunctory language, says:

> **"…Tony Nicklinson wanted a doctor to kill him legally last week. His distress was evident when the high court turned down his request… His solicitor read a statement saying he was heartbroken and the fight seemed to go out of him that he could not be killed at a time of his choosing by a doctor…"**

This news article, broadcast at peak time in the evening and using language such as 'killed by a doctor', is likely to fuel the assisted dying debate and places institutional power at the forefront of the viewers mind. The power of medicine; the giving and taking of life; the power of law; the right and the wrong of assisted dying are all manifested in this artefact.

Television artefact 2 **Dispatches: *Death on the Wards*** brings into sharp focus the critique of the LCP. It is critical of end of life care and the control of death and dying specifically in the acute sector; much of the language is sensational in nature. For example, the opening sentence in this documentary sets the tone of the programme:

> **"Is the NHS prescribing back door euthanasia?"**

Throughout the programme, there is a debate between critics of the LCP who are consultants, and consultants in palliative medicine who offer a more balanced perspective. Penny McNamara, a consultant in palliative medicine states:

> **"I think [the LCP] brings consistency; it's a prompt to ensure we review the key issues every few hours. This is a framework to deliver that…"**

Professor Sam Ahmedzai offers a contrasting perspective:

> **"I am concerned about the LCP; what actually happens on busy hospital wards is that the decision is made by basically strangers…"**

The most dominant voice in this artefact is in fact given to Professor Patrick Pullicino, a strong objector to the LCP. Such objections and controversial commentary are delivered through the narrator, who implies this doctor has power and authority:

> **"…A leading consultant who is an expert in his field working in the NHS tells us he wants the LCP banned…"**

In turn the consultant himself articulates his authority in making decisions at the end of life:

> **"There is no data to determine when a patient is reaching the end of life; it is intuition determined by the team at that time. If you say somebody has a poor prognosis then you make it a self-fulfilling prophecy…"**

Some further commentary and narration from this artefact falls into the sensationalist discourse. There is of course an overlap, a convergence and a volume to discourse. While the media offers a lens through which subjects can make sense of the world, it is imbued in a discourse of mediatisation that favours sensationalism. This is explored in the following paragraphs.

7.5.2 Sensationalist Media

For those working in end of life care and living through media storms such as the Harold Shipman case, and the huge amount of coverage regarding the LCP, the sensationalist discourse can be all-consuming. It would be easy to assume that all media coverage is sensationalist. There is a meeting, an intersection, an overlap, with the mediatisation of death and dying.

Commentators have railed against sensationalist media coverage and the impact such a discourse has on the general public, especially those who are dealing with death and dying. David Oliver, a consultant in elderly medicine, frequently talks of the irresponsibility of the media on social media. He states that media does more to ramp up fear than to encourage end of life decisions, influencing patient perceptions with repeated myths about palliative care being aligned to withdrawal of food and fluids at the end of life (2015). This is echoed by Margaret McCartney, a General Practitioner who argues that the Daily Mail campaign related to the LCP and its use of emotive and horrifying language was ignorant and dismissive of the impact it has on patients and carers (2012).

While it must be recognised that the media represents the mundane as a consumable entity, this is achieved through sensationalist coverage. The artefacts examined in this research have highlighted the sensationalist discourse in end of life care, with a plethora of outputs offering jarring headlines and inflammatory and emotive language. The recorded narratives relate the impact of this:

> *"There have been a number of changes of late within the organisation which have really been influenced by bad, emm, or negative media attention, emm, and very much by the recent Neuberger Report where the LCP is now advised should be phased out…"* (Participant Seven).

This illustrates the institutional response to the negative media attention given to the LCP. In addition, the influence on staff, patients and carers is evident through the voices of the practitioners:

> *"The difficulties are with regards to the current media attention as well, you know they've wrongly informed the public about the LCP and I think there are staff, patients and carers who believe what's been said so therefore it's very difficult to start the pathway on these patients, emm, despite education that we, we're able to give and support them. It's very difficult. Emm, the challenges… oh loads of these…"* (Participant Seven).

There is dismay that media attention has undermined the trust and relationship with patients who are reaching the end of their lives, with reference being made to the fact that such sensationalist approaches to media representation profoundly influences the way people think:

> *"The message is going out there that actually there is something intrinsically wrong with The Liverpool Care Pathway when in fact there isn't, so we are being put on the defensive now. We have been using something that is poor quality and in fact dangerous, which clearly is not true and there is a lot of frustration that the, erm, that the media, has manipulated the public to reach this point…"* (Participant Two).

A need to communicate defensively has emerged:

> *"The highlight, the spotlight of the media on the Liverpool Care Pathway and some of the issues that it has raised, has made me feel obliged to say the words 'Liverpool Care Pathway', because I am to a degree concerned that families will come back to us afterwards and say I didn't know my mother was on this, that and the next thing…"* (Participant One).

Good communication with patients and carers as death approaches is the cornerstone of good care. In the previous recorded narrative, the LCP forces an explicit determination that the patient has reached the end of life and that they are told this. The LCP is deemed to be apparatus that flags end of life, not just to healthcare professionals but also to families; the negative connotations causing concern and resistance.

The infiltration of sensationalist media coverage into the hearts and minds of the public and healthcare professionals, sustaining and compounding the discourse, is hardly surprising when the media artefacts are considered:

Artefact One:

Groves J. (2012) Headline – **60,000 put on Death Pathway Without Being Told**. **Daily Mail** (front page).

Picture – No Picture. Headlines are stark and impactful (see p 149)

> *"As Minister claims controversial end-of-life plan is "fantastic", shock figures reveal 60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD…"*

This article offers a sensationalist view of the LCP and the number of patients being put on the pathway at the end of life without being told. The notion of consent is contentious. For many people reaching the end of life, patient consent is not possible, with the medical team exerting their Hippocratic Oath and acting in the patient's best interest to do no harm. It implies that people on the pathway go on to die as a result of the pathway and not that they were dying anyway, with the subtitle on page 2: "Thousands left to Die in Pain", a contradiction in terms; if palliative care professionals were instituting the pathway, pain relief is part of that process. These assertions thus sustain the sensationalist discourse in end of life care, through both imagery and language. This is illustrated in the following artefact; the reader is jolted through the image and headline.

Artefact Thirty-Seven:

Stevens J (2012) Headline – **A Pathway to Euthanasia? Family Revive Father Doctors Ruled wasn't Worth Saving**. **Daily Mail.**

Picture – Patient and his daughter both looking fit and well.

> *"Andy Flanagan was rescued from dying on debated Liverpool Care Pathway… His family gave him drops of water that helped him come round before doctors put him back on a drip… his sister… said the method was 'license to kill'."*

This artefact echoes the sensationalist claims, made through the media, that the LCP was used to free up beds and hasten death. While the article is spoken through the voice of the family of a patient, the language used is

impactful, implying a resistance and reversibility to dying with the patient having been rescued from death.

Artefact Three:

Doughty S. (2012) Headline – **Cancer Expert Brands Care Pathway "the most corrupt practice in British Medicine"** Subtitle – I wouldn't be treated in a hospital here he says. **Daily Mail** (page 4).

Picture – Photograph of a late-middle-aged well-dressed doctor looking sage and statesmanlike, giving the impression of knowledge and of institutional status and authority (see p 142):

> *"Describing the way he believes staff operate to put patients on the pathway he said, the average example is some poor person whose family is absolutely miserable and a nurse comes in, or a very abrupt palliative care doctor, and says they're going on the Liverpool Care Pathway. And then you get the treating doctor, such as myself, rung up by the wife or the daughter in tears saying, 'oh no we didn't want this, we were baffled, we didn't want to do it, we were bullied'."*

This particular article appears to subjugate the voice of palliative care professionals and only paraphrases the voice of the families alluded to, who in turn sound indebted to the consultant. Everything about his dialogue reflects manifestations of power; the treating physician; the females having to call him for help; the disregard he holds for fellow professionals.

The sensationalist discourse in end of life care in the television artefacts takes two themes. One is enabling and captures the patient voice in a way that jolts the viewer into the real world through visual metaphor; the other is critical of the LCP.

Television artefact 2 **Dispatches *Death on the Wards***. Here, the language is inflammatory, at times sensationalising the use of the LCP:

> **Narrator – "A leading consultant in the NHS tells us he wants the most widely used protocol banned (pans to Professor Patrick Pullicino) "does it result in shortening of life? Yes it does and in some cases, quite appreciably… Our daily job is dealing with patients who say 'you wouldn't treat a dog like that'."**

In sharp contrast, the sensational in television artefact 3, **Alive Rankin Faces Death – A Culture Show Special**, is actually graphic; Sandra is presented as an Amazonian woman. This visual is sensational through its graphic interpretation underpinning her thoughts:

> **"I am considering myself as an Amazonian woman. It symbolises the inner strength that comes through me, to the bitter end I am not giving up…"**

Sandra, choosing to manifest her persona as an Amazonian woman, shares threads that weave throughout all of the discourses in relation to metaphor; she is a warrior, she is prepared for war, her fight is with death and dying.

The sensationalist discourse has caused the most debate amongst healthcare professionals, evident through the voices of the participants in this research. The voices of those working in palliative care and end of life care are minimised and the associated concerns and perceptions that have emerged from the media infiltrate into professional practice.

Professional practice is infused with tools, policies and practice drivers that orchestrate the way we deliver care. The next section explores professional apparatus and the influence they have on end of life care.

7.6 Professional Apparatus (*Dispositif*)

Foucault talks of apparatus as institutional and administrative mechanisms, which enhance and maintain power relations within a given context and at a given point in history. George (2014) talks of the emergence of end of life care and its distinction from palliative care. Apparatus in end of life care are the tools that are deemed to be transferable across all care delivery settings, the specifics of which are discussed more fully in chapter four (p52 onwards). The apparatus are closely linked with the control of dying, institutional power and the neoliberal approach to end of life care (discussed more fully on p58). They emanate out of the media artefacts and are heard in the participants' voices, with precedence being given to the LCP for that moment in history.

Some participants voiced concerns about the level of anxiety they felt from the families of dying patients:

> *"Since all the press about the LCP and all the negativity surrounding it, I can't say we haven't felt it on the ward… people are obviously worried that they are using the LCP to kill off relatives and things like that, almost euthanize them to be honest…"* (Participant Six)

The *technologies* of representation have played a part in giving rise to concerns about the LCP, which is held up as the apparatus that has undermined the principles of good care at the end of life:

> *"I think now fear is a factor in starting the LCP and that fear is really driven by negative press and the fear they… they would do more harm than good and that they would perhaps be more exposed to complaints about them starting the LCP, so I think that's… confidence*

has changed. There's still an element of that but I think on the whole, patients and staff are frightened…" (Participant Seven)

Participants take the opportunity to discuss the professional apparatus with particular reference to the LCP; as a means of control of dying. In addition, the notion of auditing its implementation is noted. Auditing indicators of a good death are used as means of surveillance, controlling practice and practitioners using institutional apparatus:

"I think (pause) the fact that we are audited on putting patients onto the Liverpool Care Pathway means that one feels obliged to enter treatment, erm, to enter patients onto that pathway. (Intake of breath) I think (pause) to be honest, that I am not particularly (pause) impressed that the pathway itself improves the quality of a patient's death…" (Participant One)

In contrast, participants commented on the positive use of tools in end of life care; their application and wholesale adoption in practice. The engagement with apparatus as positive contributors to end of life care can bring practitioners into conflict, negotiating the traverse between patients' needs and institutional drivers; these are at times conflicting forces embedded into power networks:

"…It is relatively easy to incorporate such tools into your daily work, erm, and I think, erm, one of the more positive spinoffs of the publicity is that the Trust in a defensive way has wanted, has let us, erm, create an online teaching tool for the Liverpool Care Pathway and made this mandatory training, which is something that we have wanted for some time…" (Participant Two)

While this participant welcomes the mandate to engage with the LCP as an apparatus to enhance quality end of life care, the compulsory nature of the engagement for healthcare professionals within the institutional framework echoes and sustains the discourse of institutional power.

The media artefacts represent the professional apparatus used in practice in a manner that fits their reporting; much of the coverage being sensational. The most blatant and overt criticism is reflected in the artefact below.

Artefact One:

Groves J. (2012) Headline – **60,000 put on Death Pathway Without Being Told**. **Daily Mail** (Front Page).

No picture.

> *"…the pathway involves withdrawal of life-saving treatment, with the sick and sedated usually denied nutrition and fluids. Death typically takes place within 29 hours…"*

The numbers cited in the headline are stark and impactful for the reader. This article goes on to imply that the LCP undermines good symptom control and also increases the number of deaths. The artefact clearly denigrates the role of the nurse in end of life care by implying that not enough is done to deliver care at the end of life. In addition, there is a sense of 'lack of ownership' that echoes throughout this artefact as patients are "put on" the LCP with no engagement; the implication being that they are inscribed as being at the end of life. This is the very antithesis of what the LCP was designed to be; apparatus to enhance end of life care:

> *"Records from 178 hospitals also show that thousands of people on the pathway are left to die in pain because nurses do not do enough to keep them comfortable while drugs are administered. An estimated 130,000 patients are put on the pathway each year…"*

This and other artefacts make reference to the apparatus taking priority over patient care. In the following artefact, the language of "tick box" emerges, as the apparatus is portrayed as being applied without thought across sectors.

Institutional power of government is included; rallying against institutional power of the NHS, levying accusations of poor care and an uncaring approach to end of life care.

Artefact Seven:

Doughty S. (2013) Headline – **Death Pathway Damned: Mail Campaign Vindicated in Devastating Report on Scandal of End of Life Treatment**. **Daily Mail** (page 4)

Picture – Colour photograph of a thin pale young woman with eyes shut and a small child holding her hand.

> *"The Liverpool Care Pathway – once touted as the NHS's way to care for the dying – was yesterday condemned by ministers as "a national disgrace". A devastating inquiry into the system used in hundreds of hospitals also shamed nurses and said their "tick box" treatment of the sick and vulnerable had been uncaring, "rushed and ignorant".*

The sensationalist discourse has informed the perceptions of professional apparatus, using language like *"death pathway damned"* and assumptions that would be deemed to be poor practice in end of life care, such as not communicating with the family being aligned to the LCP alone. The precedence of the apparatus over all else has a voice in this artefact, with reference being made that the LCP overtook the care of patients rather than enhanced it.

Artefact Thirty-Five:

Shipman T. (2012) Headline – **Victory for Care Pathway Families**. **Daily Mail** (front page, continued page 2).

Picture – Black and white photo montage of previous headlines

> *"Putting patients on the death pathway without consulting their families will be outlawed next week… patients have had their feeding tubes withdrawn while their relatives were unaware they had been placed on the pathway. In some cases, relatives have covertly fed their elderly relatives after discovering doctors had given up on them…"*

The apparatus used in end of life care was the subject of one the television artefacts **Dispatches *Death on the Wards***. While the sensationalist discourse is strong, professional apparatus and the influence on practice also emerge. The narrator presents the hospice as the gold standard of care and the person interviewed is negative about end of life care in hospital, using the term "alleviating the dying process" as though it should be sanitised. Dying as part of the business of any hospital is undermined. The interviewee's fears in relation to her mother's death are portrayed as her "worst nightmare":

> **Narrator – "The LCP originated in hospices with the intention of alleviating the dying process. For the dying, hospices are preferable to dying in busy hospitals…" Pans back to daughter whose mother is dying "It would be my absolute nightmare for mum to be on a hospital ward. They don't deliver care; they are too busy…"**

The public perception of the LCP and its application to practice is conveyed vigorously through the tone of voice and visual impact of filming. Choice is implied to be about the LCP (the subject of the documentary) but the narrative could be construed to be about dying. It is difficult when engaging with patients and their families at the end of life to be certain, as emotions run high with many complaints and discomforts about care being in relation to end of life care:

Bereaved daughter and son – "Nothing was explained as to why it was happening. Nobody said anything; there were no choices, no choices, when I asked what the pathway was they said 'oh it's something to make your mum more comfortable'. Narrator – "The family are going to make a complaint; the hospital told them being on the LCP did not change the outcome…"

While the artefacts are emotionally charged and fuelled by sensationalist language, the fact remains that the discomfort regarding the LCP as professional apparatus is clearly reflected through the media. The need for cohesion and commitment to end of life care is clearly heard through the participants' narratives. Particular reference is made, through the professional voices, to the lack of an evidence base, the routinised and over-structured 'tick-box' approach to decision making at the end of life, and the drive to meet individual patients' needs through supportive communication at the end of life. All of these points have emerged through the literature (Hughes and Preston et al., 2013; Seymour and Horne, 2013; Parry and Seymour et al., 2013; Borgstrom, 2015).

7.7 Use of Metaphor

While metaphors can help conversations in terms of simplification of issues and as a means of capturing the lived experience of a challenging situation, the reality for healthcare professionals is that they can also be a way to evade difficult conversations. Some patients may feel metaphor allows understanding and an illustrative recognition of their illness, prognosis and forthcoming death, while others rally against the confusion that the use of metaphor causes as they live with and die from their disease. The use of metaphor emanates through the voices of the healthcare professionals' recorded narratives:

"*From a nurses' point of view, I know how distressing it is for me to watch, feeling somebody who's not related to me but you've got a little*

> *bond with, who you've travelled alongside, looked after all this length of time. So if you've lived with and loved that person for years and years and years and you're watching them – I can't think of anything worse…"* (Participant Three)

The journey metaphor is commonly used by practitioners, while Semino (2015) argues that patients can perceive negative points in relation to the use of metaphor, for healthcare practitioners who use the journey metaphor, it helps to convey the meaning of a beginning, middle and end. In addition, the words *travelling alongside* have connotations of camaraderie, commitment and a sense of presence.

Alongside the journey metaphor, the cancer 'battle' is also evident. This is a metaphor that is well rehearsed in both cancer and palliative care, with little recognition of the negative feelings it can engender for the patient and their family (Grainger, 2014; Gubar, 2015):

> *"There has also been immense pressure on her to fight the cancer, to try all sorts of bizarre alternative therapies and to pray and expect a miracle in order to win the battle."*

The metaphorical language is readily used in the media artefacts for drama and impact. This mirrors the language that has been highlighted in the recorded narratives of journey and battle. The battle metaphor, depicting death as an enemy or not; depicting the fight for rights to life and death as a battle. The metaphors used in the media will have resonance with the reader; they are familiar and commonly used in healthcare, passed on through lay beliefs and conversations. Such familiarity with the metaphors used engages the reader and promotes understanding and belief in the rhetoric.

Artefact Four:

Betts H. (2012) Headline – **Death is Not The Enemy** Subtitle: Medicine's obsession of keeping alive people who are ready to die is inhumane and inhuman. **Guardian** (page 2).

Picture - The article is situated below a picture of Tony Nicklinson, a right to die campaigner, with a banner reading 'Peace at Last'.

> *"She is ready. The medical services, however, are not and are engaged in an aggressive battle to resurrect her. The individual they appear to be fighting is my grandmother herself…"*

'Battle in this excerpt promotes the military metaphor. However, the use of battle and the fight is reversed, with the medical practitioners fighting to defy death when the battle is already lost and the person is ready to die.

Artefact Ten:

Stuart F. (2012) Headline – **Even Losing a Loved One Can have a Good Ending**. **Sunday Times** (page 4).

Picture – Small photograph of the article author.

> *"I learnt that genetics matter. It's not all about prevention and lifestyle and screening. And it certainly isn't a case of just putting up a hard enough fight…"*

The notion of a metaphorical fight voices the helplessness people feel when told by those caring for them to "fight", when fighting is hopeless in terms of outcomes. This gives rise to the feelings of failure and poor self-worth, articulated by Grainger (2014).

Artefact Thirteen:

Pemberton M. (2013) Headline – **The Liverpool Care Pathway to Dignity in Death**. **Telegraph** (page 5).

Picture – Photograph of a pair of young hands and old hands holding each other.

This headline engenders the notion of the LCP as a journey; a concept and use of metaphor that emanates throughout the media artefacts. The journey metaphor is congruent with the voices of the participants.

Artefact Fourteen:

Bingham J (2013) Headline – **Hospitals Treating Liverpool Care Pathway as Just Another Thing to Do**. **Telegraph.**

Picture – Photograph of Dr Bee Wee.

> *"Hospitals are placing patients on the controversial "pathway to death" without proper training for staff or even understanding how it works, some of Britain's leading specialists in care for the dying have acknowledged…"*

Perhaps some of the most visually impactful metaphor emerges from the television artefacts. **Alive Rankin Faces Death - A Culture Show Special** particularly uses imagery to illustrate a warrior mentality and bravery.

The use of metaphor intruded upon my doctoral journey quite unexpectedly through personal experience. For example, when talking to patients, I recall using metaphors aligned to violence, war and the journey in an attempt to vividly portray some sense of meaning to the patient and their family. The public engage with this use of language; professionals use it and the media potentiates its use. We do however need to listen to patients' voices, such as that of Kate Grainger, and temper the use of metaphorical talk when speaking of end of life care.

7.8 Distribution of the Data

The self-recorded narratives and media artefacts produced data that varied across the *technologies* presented in this chapter. Both datasets informed

the evolution of the *technologies* throughout the data analysis process. However, there were tensions and challenges related to data distribution, and these are described below.

It was not unexpected that *technologies* of caring featured heavily when listening to the voices of the healthcare professionals; those caring for people at the end of life. Interestingly, this also featured in the media artefacts. However, the therapeutic imperative was represented in much more negative and often graphic terms in the media; some of the powerful images have been included in this chapter. The volume of data related to the treatment imperative was significant across all media artefacts.

Similarly, *technologies* of power emerged from both datasets. The self-recorded narratives included notions of medical power that were more focused on the patient and how they are cared for at the end of life. In contrast, the majority of media artefacts articulated medical power in a more controlling sense. The media artefacts articulate economic power in relation to financial reward strategies when caring for people at the end of life. Several media artefacts included this notion; I found it surprising when this emerged in the self-recorded narratives as influencing discursive practice in end of life care.

Media artefacts and self-recorded narratives were both bound to *technologies* of the self; be that the patient or carer voice, or that of the professional. However, the documentary **Alive Rankin Faces Death – A Culture Show Special** contributed significantly to *technologies* of the self. The focus on people who were dying and their positivity and strength was directly opposed to other media artefacts. This offered a counternarrative, a competing discourse to other media artefacts, that focused on the suffering and negative aspects of death and dying.

Technologies of representation were obviously more evident in the media artefacts. However, data in the self-recorded narratives sustained the discourse of both mediatisation of death and dying and sensationalist media.

Professional apparatus emerged from both datasets, sustaining and overlapping with other discourses. The media artefacts heavily contributed to this discourse. As discussed in chapter four, the LCP became a focus of media attention, being held responsible for poor end of life care practice. The media artefacts informed this discourse and the findings reflect the coverage at that time.

The challenge in presenting these findings has been to maintain balance and not become focused on the most emotive and graphic artefacts. In addition, how death and dying is represented in the media could well have been overtaken by a focus on media studies. Maintaining a focus on discourses and *technologies* of power was made more challenging by the emotive language and pictures. Similarly, disentangling myself from reading the narratives as a nurse understanding other healthcare practitioners' experiences was challenging. This is explored in the paragraphs below.

7.9 Reflexivity – Turning the Lens on Oneself

Reflexivity can be defined as the ability to appreciate how one's social position, experience and expertise can shape the way we interpret the world around us (Landy et al., 2016).

In Chapter two, I discussed my personal, professional and conceptual journeys; while this has brought me to where I am today, it has also influenced the lens through which I view the findings of this research. When undertaking qualitative research, there has to be an understanding of how it has been impacted by the experience of the researcher, and how this is managed. Berger (2015) discusses the benefits and challenges to reflexivity, including when the researcher shares experience with the study participants.

In this section, I turn the lens onto myself, looking at the role I play in the creation of knowledge and interpretation of these findings, and considering

the impact of my biases, beliefs and experiences. Sharing experience with participants offers a depth of insight and a degree of sensitisation to the language used. In addition, and importantly for this research, I was able to hear the unsaid, appreciate the position of the participants as practitioners, and understand and explore practice, considering new insights and acknowledging well-rehearsed challenges. The insider knowledge that has influenced interpretation and allowed my insight to contribute to the analysis of the findings is shown on page 171. This participant explores professional apparatus and the impact on practice. The nuances and way in which they communicate shows reticence and reluctance in relation to institutional drivers and apparatus. My familiarity with and insights into practice allowed for a more intuitive interpretation.

Throughout this journey, I have kept copious notes in journals. These have proved to be a valuable tool in facilitating a reflexive approach, allowing me to question my values and preconceptions, providing insight into reasoning, judgements and emotional reactions. Having a shared experience with the research participants, it has been a constant challenge and deliberate effort to understand my biases and their influence on this research, and resist blurring boundaries, making assumptions and imposing values (Drake, 2010).

Inevitably, my voice is evident throughout the findings. I have struggled with the balance of being an expert in palliative care with a strong practitioner background, and being a researcher. I have dipped in and out of both as I progressed through this research and exerted constant and deliberate effort to monitor and recognise my influence. Particularly throughout the analytical process, I needed to constantly strive to think as researcher, looking at data through the lens of a Foucauldian researcher and not focusing on my experience as practitioner, this in itself represented for me a *technologie* of the researcher self.

As a researcher, I have been subjected to competing discourses, evolving across a liminal state between practitioner and researcher. The professional carer with a wealth of experience, finding resonance across the *technologies*,

especially *technologies* of caring, and the Foucauldian researcher whose stance is more detached and distant from experience to emphasise practice and discourses.

Working in the acute sector my entire career, one of the many major challenges when patients are reaching the end of their life is the facilitation of their wishes and choices. Achieving this as a specialist nurse in palliative care is a key driver, and inherently embedded in my personal value system. In contrast, control is in the same respect viewed as negative, the length of my career, and the time I trained and practised this control, was very often orchestrated through medical power and institutionalised practices. Issues of choice, control and wishes are taken-for-granted elements of care at the end of life, where they are understood as existing largely unilaterally. The findings of this research expose a more complex web of power, mediated through a number of competing and overlapping discourses.

The researcher in me appreciates that choice, control and wishes are not inherently ‘good’ or ‘bad’ in terms of end of life care but they are discursive practices. Everything is a discourse, and discursive practice shapes and is shaped by the way we practice. My value judgements have fuelled the internal battle I have had throughout this research; the tensions of viewing this research through the lens of being both a researcher and a practitioner.

This reflexivity will be revisited again in chapter nine to consider broader context and insights.

7.10 Conclusion

The *technologies*, and the discourses that are diffused throughout and within them, illuminate the discursive turns and struggles in end of life care. The voices of healthcare professionals in the recorded narratives echo with the influence of the media.

Technologies of caring explore the multifactorial nature of caring, the cared for and impact on those caring, caring for the carers and also the impact on healthcare professionals of caring for people at the end of their life. Diffused throughout are the *technologies* of power; institutional power in its many guises, medical power, contingent on time and place, and closely aligned and akin to both institutional power and economic power. The latter is an unexpected discourse that found its voice in both the media artefacts and recorded narratives, impacting on both practice and societal perceptions.

Technologies of the self are complex, yet the notions of 'the self' and personhood emerge in a vigorous way at the end of life, uncovering moral, religious and existential dilemmas and reasoning. This is reflected in the data, allowing for understanding, particularly through the media artefacts that provide a lens for us to view dying in an alternative sense.

Technologies of representation emerge though the data, with a strong voice throughout the recorded narratives; the influence of media on end of life care shines through. The media creates, informs and sustains the end of life care narrative through both the mediatisation of death and dying, and journalistic intent and the sensationalist discourse.

The professional apparatus as a form of institutional and professional control is evident throughout the data, with the media particularly sustaining the discourse of power and control in the sensationalist coverage of professional apparatus. Throughout this journey, metaphor has played at the edges of my understanding, sometimes playing a major part in my personal understanding and sometimes subversively offering a sense of understanding, at the margins without being noticed, until I have had the opportunity to reflect. The use of metaphor emerges through the data purposefully for some and unwittingly for others.

The findings from this research will be further explored in the discussion chapter, in which the *technologies* and emerging discourses and their influence on and how they shape discursive practice in end of life care, will be considered.

8 Discussion

This research explores and illuminates the contextual conditions, apparatus and technologies of power in end of life care, including the impact of mainstream media on practice. True to the thoughts of Foucault, the findings do not offer one single truth, but present truth as being a discursive construction of time, space and place, where regimes of knowledge determine what is true and false (Jorgensen and Phillips, 2002). The findings offer a lens through which to view end of life care, where discourses coexist and concurrently shape, and are shaped, in practice. The focus of this chapter is to build on this, to offer a model to appreciate the complexity of discourses in end of life care, which influence, and are influenced by, practice. The chapter will include strengths and limitations of the study and a consideration of the impact of the media for both practice and practitioners.

8.1 The *"Looking Glass"*

The *technologies* and discourses that have emerged in this thesis merge and morph to form and inform understandings in end of life care. This unique contribution to knowledge in end of life care is depicted in Figure 1. The *"Looking Glass"* offers a way to view end of life care; each discourse is in a sense a lens in the *"Looking Glass",* shifting over time. A lens, when held to the light, can change colour, offering us a different way to view end of life care. While each discourse is a lens, they can overlap and shed new light on a situation, rather like a kaleidoscope. As a child, my kaleidoscope changed as I turned the lens; colours faded and emerged. As a researcher, as I look through a different discursive lens, I can see different versions of reality.

The discursive lens through which we view end of life care shifts according to the moment in history, the culture and conditions at play; it cannot be reduced to a "*linear schema"* (Foucault, 1972 p9). In this research, this can be seen in the manner in which the LCP overtook much of the media

exposure at the time of data collection. This will be discussed in more detail later in this chapter (page 207).

This graphic representation of the findings illustrates the interconnectivity of the discourses. The *"Looking Glass"* is a metaphor for how everyday life is exposed in the media. In this research, it demonstrates metaphorically how the media views and represents end of life care, examining the detail of how care is delivered and translating it for public consumption.

I started this journey with an aim to contribute to the understanding of the contextual conditions that inform care delivery at the end of life in the acute setting. This research illuminates the discourses that influence end of life care and highlights how they merge, shape, enable and prohibit practice in this area.

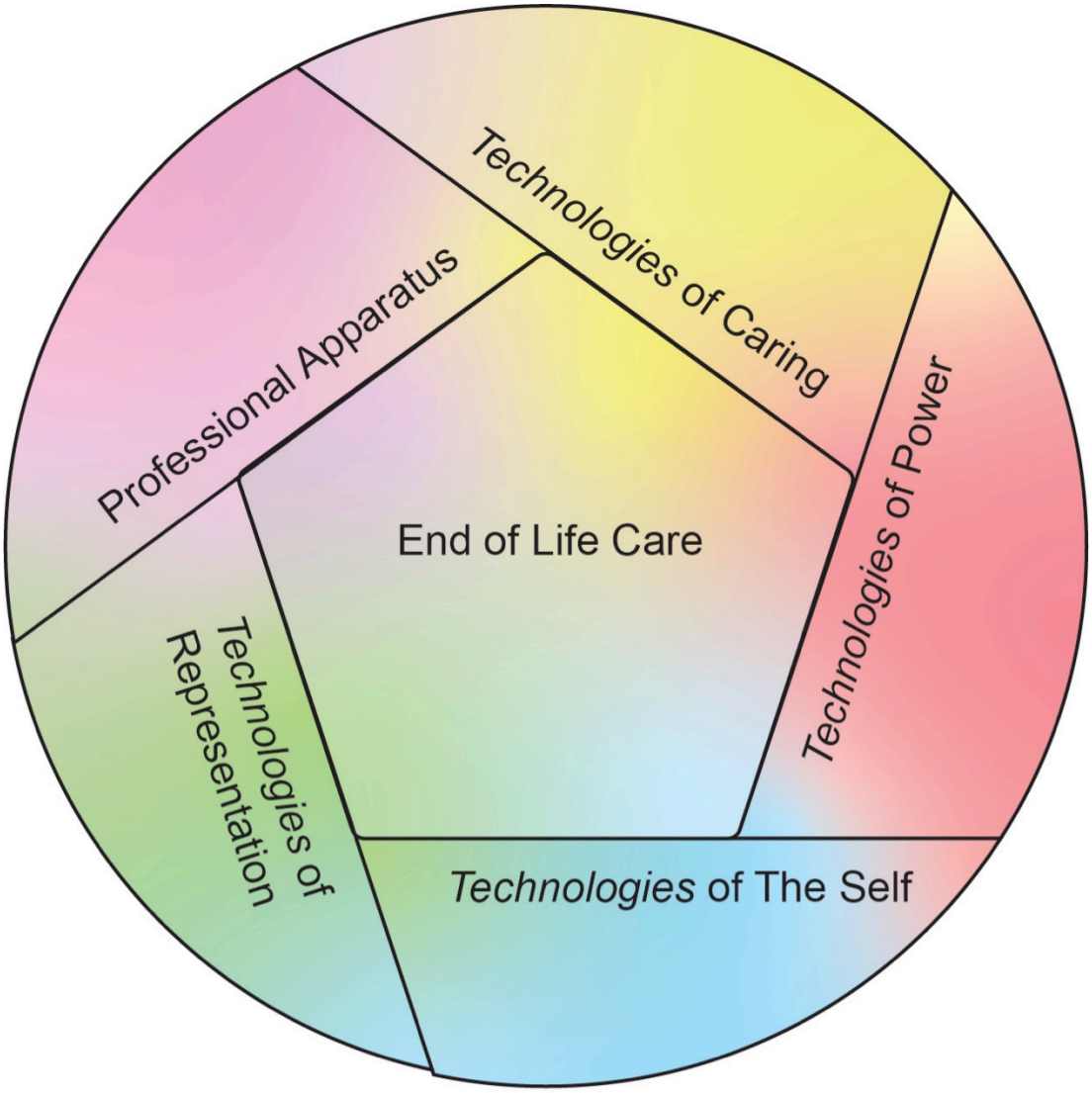


Figure 1 Dying Through "*The Looking Glass*" - A Foucauldian Lens

The *"Looking Glass"* depicts the *technologies* that have arisen from this research; further discussion in relation to these findings follows.

8.2 *Technologies* of Caring

Technologies of caring capture the discursive influences on practice, institutional and organisational apparatus that inform the way people are cared for at the end of life. This gives voice to those who are caring for the dying, through the media and the recorded narratives of healthcare professionals. Healthcare professionals are carers too; the impact of caring for the dying patient and their families who are living with dying is juxtaposed against a therapeutic imperative and this can be challenging. Further discussion of both the therapeutic imperative and living with dying follows.

8.2.1 Therapeutic Imperative

Healthcare professionals in their recorded narratives talk not only about the difficulty of looking after patients at the end of life, but also the challenge of continual treatment; an inability to change gear and recognise dying. In the acute sector, the primacy of treatment has been highlighted extensively. For example, Mannix (2017) talks eloquently of resuscitating people who are dying, doctors feeling helpless and not wanting to stop treatment because they have not had timely conversations with their patients. It would seem therefore that a truly multidisciplinary approach to determining when a person is dying is required (Tuggey et al., 2014). Yet healthcare professionals highlight how the task of communicating this to the dying person and their family is often seen to be the remit of the most senior professionals alone:

> *"Those conversations have to be done by the most senior person, which… that's the difficulty; we can't always get them on board and sometimes it's too late…"* (Participant Seven)

This is despite the fact that the day-to-day personal care and support delivered to the patient is often intimate and promotes deep and meaningful relationships. It is often not administered by the consultant (Page 127).

The good death is considered in chapter four (page 42; onwards), where I highlight how it is challenging to achieve an environment that facilitates a good death within the acute sector (Higginson et al., 2013). In addition, the care hierarchy in the acute setting, including palliative care, can stress the importance of physical care and symptom management (Dahlborg-Lyckhage and Liden, 2010). This can offer a somewhat rigid approach to the uncertainty of death and dying, asserting an apparatus on practitioners which emerges from the knowledge-power nexus, and dictates how people should die and when they should have the benefit of specialist care. The primacy of medical knowledge is evident in both the recorded narratives and media. Foucault (1980, p93) talks of knowledges that are *"disqualified as inadequate to their task"*; while it is acknowledged that the patient has an influence on decision making at the end of life, ultimately the doctor is the authority and holds the hierarchy of knowledge (page 126).

A sense of ownership of the patient comes into play here, as their body is inscribed as dying by the doctor. The care delivered by the senior doctors is that which they have been encultured to deliver; this is the fruit of the discourses they are exposed to while at the same time shaping and informing discourses themselves. Somewhat unfairly, the media seize on this notion of doctors controlling dying, as can be seen on page 127.

Discursive practices allow the therapeutic imperative to take precedence over the acceptance of death and dying. Professional enculturation enables death and dying to be managed in such a way; this is sustained by hospitals' institutional apparatus, and how it is managed, led and structured. In addition, networks of power (Lupton 2012) can mean that patients sometimes dictate that the therapeutic imperative should take precedence; they may insist, despite the best advice of their consultant, that active treatment and interventions continue, despite the impact on quality of life.

This thesis highlights how the media contributes to and shapes the discourse of therapeutic imperative, decrying the care delivered to people who are dying as intrusive and treatment as aggressive. Colourful and sometimes inflammatory language is used to paint a picture of doctors 'fighting to keep people alive', often despite the wishes of the patients and their families. Here, there is a contradiction in terms in the media and the interconnections within and throughout the discourses. On the one hand, we have treatment pursued to the very end of life, eroding quality of life and undermining patient wishes (page 135). On the other, we have the discourse of professional apparatus that condones the theory that treatment is persistently withheld and patients are dying as result of this (pages 142; 145). This is an irony portrayed by the media for journalistic gains (Seale, 2012; Watts, 2013), which contributes to the challenges for practitioners caring for people at the end of life, undermines public confidence in end of life care and contributes to societal concerns.

8.2.2 Living with Dying

The living with dying discourse focuses on the individual and their experiences, with particular reference to the sense of the individual. For healthcare professionals, the burden of caring for people at the end of life and the associated challenges can impact on their wellbeing (Koh et al., 2015). Living with dying impacts on the healthcare professional as an individual – their professional life in turn leaks into personal wellbeing and belief systems. The voices of healthcare professionals in the recorded narratives echoes with emotive language, which illuminates their world of professional practice and the inherent conflicts they work within (pages 131; 132).

The recorded narratives add to the existing body of knowledge in relation to healthcare professionals' perceptions of mortality and the impact on caring for dying patients, when they are often in conflict with the medical mandate (Peters et al., 2013). There appears to be a certain safety and ease in the

medicalisation of death and dying (Clark, 2002), and the sequestering of the dying in the acute setting (Conway, 2008). The development of palliative care units in hospital, and the centralising of specialist and cancer services have to some extent centralised the dying process in the acute setting, making death as invisible as possible (Cottrell and Duggleby, 2016). This controls where patients are cared for when admitted to hospital and is underpinned by the apparatus of institutional policies, procedures and control.

This begs the question: is it death and the fear of death that causes this or is it the fear of the process of dying? Many healthcare professionals see the dying process in its most vivid colours, influencing and informing their fears of mortality (page 132). Such experiences around dying in the acute sector changes perceptions and healthcare professionals can lose perspective that the majority of dying happens in communities (Pollock and Seymour, 2018).

The individual and their journey are clear in this discourse, with an interface and overlap with *technologies* of self, specifically the personhood discourse, or what makes a person who they are. In the media artefacts, suffering is a thread that is cast throughout; pain and helplessness, both for the cared for and the carers, with the media and in turn social media significantly influencing how we perceive end of life care (Williamson and Skinner et al., 2011; Watts, 2013; Seymour and Clark, 2018). This thesis adds to the evidence base, illuminating how the discourse of living with dying is informed by the media.

The resonance of the media is particularly evident in the language used by healthcare professionals, as suffering and metaphors permeate. Imagery and the language used are highly impactful, with the news media becoming vehicles for the production of social knowledge and practices infused within power relations (Hall, Evans and Nixon, 2013). The press focuses on the plight of the person, attracted by the numbers of people affected by their coverage of end of life care (Seale, 2010). This research highlights that the media influences the personal journey of those living with dying, whether that be healthcare professionals or patients and their families (pages 161; 162) This will be explored more fully when considering *technologies* of

representation (page 211). There are some positive influences, shared through personal stories and powerful imagery, especially in the television artefacts. However, while the positive influence is clear, this is not heard in the voices of the healthcare professionals, who are exposed to death in their professional lives.

The language used relating to death and dying is often metaphorical; the language of ‘battle’, ‘fight’ and ‘enemy’ being particularly prevalent. War metaphors are present throughout public discourse, as they are rooted in widely understood schematic knowledge (Flusberg, Matlock and Thibodeau, 2018). Grainger (2014) talks of the term ‘bravery’ implying a choice, and states that being put on a courage pedestal does not help with living. This research has highlighted how metaphor is used in the media for impact, and also facilitates understanding, influencing perceptions of death and dying. Healthcare professionals are exposed to the metaphorical language used in the media and use metaphor to ease understanding. However, this can also provide distraction and detraction from using plain terms, and informing patients of the fact that they are dying.

Technologies of caring highlighted in the context of this research how we care for people who are reaching the end of their life; the discursive influences that both shape and challenge practice, and the influence of the media. The next section will explore *technologies of power.*

8.3 Technologies of Power

Power, in its multiple guises, emanates through the findings in this thesis, particularly institutional power, medical power and economic power. While there are notions of power, and to some extent control, in clinical practice (Kellehear, 2007; Howarth, 2007), Lupton (2012) discusses therapeutic relationships as being rooted in networks of power. Healthcare professionals and patients coexist and communicate and, as in all social relationships, power is evident but not in a repressive sense. This will be explored later in

this section, when considering medical power. This thesis offers a unique contribution to the understanding of these discourses. The Foucauldian lens adopted offers the opportunity to unveil the discursive practices and struggles that are implicit in end of life care, shaping practice and influencing care. Institutional, medical and economic power will be considered in the following sections.

8.3.1 Institutional Power

Foucault talks of institutions as social structures that allow practice to be permeated in the directions required to control and orchestrate care. Institutional power emerges in this thesis, through the hospital (page 140); the policies, procedures, processes, governance and apparatus that permeate end of life care. In addition, the media (page 161), central government (page 149) and the church (pages 139; 158) are institutions that have been highlighted as contributing to the shaping of discourses in this thesis.

The institutional voice of the media will be considered in *technologies* of representation, however, the findings clearly uncover the media giving voice to the institutional power of central government in particular. The policies that govern priorities and key drivers in end of life care are dictated by central government. Policies, such as the enablement of choice for people who are dying, beg the question: to what extent is choice really promoted or is this the manifestation of a neoliberal form of control of choice (Borgstrom, 2015)? The media gives voice to knowledge, control and authority in end of life care. The institutions sustained are not just those of central government but also of the law, the church and medicine.

The voice and power of the church are evident in this thesis, as both the recorded narratives and the media sustain the relevance of the church, its affiliated belief systems and influence on decision making at the end of life. The increase in secularisation in our society (Foltyn, 2008) points to the fact

that the church's relevance for modern day death and dying may indeed be diminished. Bishop (2013) talks of the church being in control of the soul, echoing the words of Foucault when describing the clergy as having *"Power over men's souls"* (2003 p36). The evolution of medicine has enabled the taking control of the body. In addition, in the seminal work of Aries (1981), the shift of the dying person being cared for in the home supported by religious orders and their belief systems rather than being cared for by doctors in the hospital is articulated. Despite it now being a different time and place, this sense of conflict is an undercurrent in this thesis. The church can be at odds with the apparatus used to enhance quality of death and alleviate symptoms (page 139). These conflicts are clear when considering the debates on assisted dying and euthanasia (page 134), where institutional forces are at odds, albeit in a more considered way, as they have been since the evolution of modern medicine.

The institution of law as a means of "policing" rights and wrongs in our society over the life course has a voice in the *technologies* of power. The voice of the lawmakers, and the voice of those who use laws to substantiate their beliefs and values in end of life care, are clearly heard (page 143). Interestingly, there is a sense of irony, certainly within the media artefacts, with the notion of the right to die firmly juxtaposed with the apparatus in practice allegedly hastening death. The right to die movement and the palliative care movement are at the same time similar to and in conflict with one another. Both argue for quality of life and control as key determinants of a good death. However, the right to die movement wrestles with the "when" of dying, as controlled by the law, whereas the palliative care movement is driven by the "how" of dying (van Brussel, 2010).

The essence and identity of the person who is dying is embedded within the institution; be that legal, political, medical or social, which all impact upon the dying process, particularly for those dying in the acute sector. Such an ensemble of institutions facilitates dividing practices; techniques of domination employed and enacted to manage and control the population, in this case, the patient and their families. While this is the case, society equally needs organising institutions and practices. It must be recognised that

although the hospital as an institution controls death and dying, it is a clear necessity for people who have complex needs, require intensive interventions and for whatever reason, cannot die in the community.

In *Discipline and Punish* (1991), Foucault details his teaching on institutions and surveillance. He talks of the *Panopticon,* invented by Bentham, in order to observe and modify the behaviour of prisoners in their cells. It allowed for the continuous observation of inmates, enabling behaviour modification through self-surveillance and isolation from others. This allowed for an impersonal and anonymous relationship with power. Prisoners are unsure if they are being watched or not (Downing, 2008) and cannot learn from those around them (Nettleton, 2013). *Techniques, apparatus,* policies and procedures can all be seen to feed into the principles of the *Panopticon* in the hospital setting, as these are institutional tools that impact upon the delivery of care in the hospital. Foucault does not intend for the *Panopticon* to reflect an oppressive power (Downing, 2008). Indeed, we see what Lupton (2012), determines as networks of power at play, yet still for patients at the end of life, there is an expectation of behaviour; of how they should die in the hospital. The complexity of the how, when and where of dying emerges from the findings of this thesis (pages 124-127); some people are taking back control of their dying (page 153), some are accepting how they should, and indeed are dying (page 137) and some, despite their best attempts, are having their dying controlled through the disciplinary forces at play (page 158).

The choices faced and the challenges of dying in the acute sector are conveyed through the recorded narratives offering professional perspectives of the patients' care. The media artefacts also contribute, with their vivid reportage of dying, which will be explored more fully on page 212.

Disciplinary mechanisms, surveillance and institutional apparatus, and the associated technologies in end of life care give rise to complexity, opening up a space whereby resistance thrives, and transformation and the emergence of new practices occurs. For professionals, it is this exposure to discourse that both shapes and allows the shaping of their practice in end of life care.

One such example is in the withdrawal of the LCP; how it emerged and the associated changes to practice that occurred (Sleeman and Koffman et al., 2015; Twigger and Yardley, 2016; Seymour and Clark, 2018) are reflected in the voices of healthcare professionals and media artefacts (chapter 7 p172).

The disciplining of the dying patient through institutional power and surveillance in the hospital is indicative of diffuse power relationships, not attributable to one sole source. This is reflected in the second half of Foucault's corpus and contrasts with his work in *Birth of the Clinic*, in which he discussed the *medical gaze* and the dominant power that the doctor holds over the patient. This is reflected in both the media artefacts and the recorded narratives through the discourse of medical power. The next section explores the findings in relation to medical power in more detail.

8.3.2 Medical Power

While institutional power focuses on power that permeates end of life care through organisation, apparatus, policies and procedures, in this time and culture, we still see the predominance of medical power. While power is not negative and coercive but productive and positive (Foucault, 1991), it does control the population's life events, such as births, deaths, sickness and disease (Foucault, 1976). A key part of such control is through *"le regard"*, the gaze; the medical gaze.

The findings in this thesis illustrate the perceived predominance of medical power in this space and time. The recorded narratives and media artefacts place the dying patient in the hands of the doctor in terms of decision-making at the end of life. The self-recorded narratives (pages 126; 145) talk of the nature of decisions made at the end of life and the doctor's role, while the media artefacts represent in vivid terms how the consultant should have control of managing care at the end of life (page 145). While Foucault talks of "docile bodies", ready and willing to be sculpted and inscribed upon, using the mechanisms of power (Downing, 2008), in end of life care, medical power

includes confrontations, struggles, contradictions and inequalities as they exist within and as a result of all power struggles.

Understanding power in end of life care is less about how it is exercised and more about why it takes place; what networks facilitate such power networks (McHoul and Grace, 1993; Powers, 2007)? It is less about the doctor as the power broker, and more about the enablers and prohibitors that contribute to power.

In end of life care, the inextricable relationship between power and knowledge, which puts power in the hands of the doctor, is an oversimplification. Discourses emerge and clash, form patients and professionals and are formed by us. This is an important point to consider when discussing the implications for practice (page 226).

Foucault clearly states:

> *"Power must be analysed as something that circulates… it is never in anyone's hands; never appropriated as a commodity or piece of wealth. Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads; they are always in the position of simultaneously undergoing and exercising power. In other words, individuals are the vehicles of power, not its points of application…"*
>
> *(Foucault, 1980 p98)*

Despite this, in both the recorded narratives and the media artefacts, the power of the medical discourse is used as a means to depict a sense of ownership of the dying patient. This appears to be an oversimplification, yet one which is represented in its broadest sense, certainly through the media. Examples of this are peppered throughout the media artefacts; one consultant suggesting patients should not be told they are dying:

> "...*if you say somebody has a poor prognosis then you make it a self-fulfilling prophecy…"* (Page 147)

And another suggesting that doctors are not allowing a grandmother to die:

"…Medical services… engaged in an aggressive battle to resurrect her…" (Page 129)

The prevalent discourses highlighted in this thesis illuminate the patient subjectified as a dying person; a consequence of power relations and the discursive practices that are part of care delivery in end of life care. Dividing practices include exposure to the therapeutic imperative, being allocated where they are going to die (often segregated from others in a cubicle) and being subject to a 'dying' classification, both socially and 'scientifically'. This is illustrated in the contribution of Kate Grainger, who spent her time discussing dying, wanting to be remembered for her positive impact and not being labelled as a dying person (pages 66; 135). Despite such classification, death is deemed to be something that should be medically prevented at all costs and controlled through medical science (Howarth, 2013). We must however, recognise that death can seem to be everywhere for doctors and is painful; living everyday with the friability of life, doctors often hide behind their "fence of knowledge" (Guglani, 2018). Death can take them into uncharted territory. Some doctors embrace the challenge of working in new ways, collaborating, communicating and delivering good end of life care, while others feel ill-equipped and use institutional apparatus as blunt instruments, reverting to the therapeutic imperative.

This dichotomy, the doctor delivering care and the human struggling to cope, is expressed in the recorded narratives, most overtly in the therapeutic imperative (page 123). The media on the whole maintains the simplistic notion of medicine having a stranglehold on patient care. It is an oversimplification to consider the doctor as being in sole charge of the dying patient; there is a multidisciplinary team, and the patient and their family who may find it easier to maintain the principle of the all-seeing doctor making decisions. While there are notions of seniority emerging from the findings, aligned to control and the ability to make decisions (pages 123-126), the watched, the dying person can take control in an insidious or proactive way and use the watcher to their own ends, to facilitate the death they want.

The voices heard through the media sustain the institution of medicine as consultants or senior clinicians who are deemed to be experts in their field. The media uses the medical discourse to both reinforce and undermine the very medicine they represent; those clinicians are often quoted as criticising and condemning differing specialist areas of care, offering insights into the discursive practices in end of life care in relation to professional hierarchy and power.

Medical power is overtly represented to be the controlling factor in end of life care by the media. The press uses tools and tactics, which will be further discussed in *technologies* of representation, to give voice to the broader end of life care debate (Seale, 2010). While this echoed some of the concerns raised in the professional clinical press (Seymour and Clark, 2018), the impact of such coverage and the inflammatory language used fuelled public outrage and anxiety leading to moral panic regarding end of life care.

8.3.3 Economic Power

Following a long career in end of life care, I had assumed that the media artefacts in particular would make use of the economic power discourse in end of life care. My assumptions have been challenged and the findings in this thesis offer a novel perspective into how economic drivers operate as discursive mechanisms within an institutional framework.

Throughout the recorded narratives and the media artefacts, reference is made to the scarcity of beds in the NHS (pages 148-151). This has been interpreted as the rationale for undertaking reward mechanisms for tools, policies and procedures that orchestrate patient care. The Commissioning for Quality and Innovation (CQUIN) reward scheme was applied through central government. ostensibly as a way of improving end of life care, ensuring that the tools and triggers that enhance care delivery were both recognised and utilised. Such a scheme is orchestrated through the mechanisms of institutional power, with recognition of the financial reward being explicit in the findings. While apparatus is a natural focus of organisational and

institutional priorities, it is, in and of itself, an insufficient guarantor of good end of life care (Borgstrom, 2015). This issue is particularly resonant in the recorded narratives, which display a palpable discomfort about audit and targets (page 149).

This calls into question the organisation of care, decentralising the control of care and focusing on the health economy as resources in the NHS become scarcer. Despite the fact that a great deal of work within palliative care can be governed by routines and rituals (Dahlborg-Lyckhage and Liden, 2010), my perceptions regarding the CQUIN reward scheme have been transformed, as I have developed an appreciation of the discursive practices circulating within the economic discourse.

The media is driven by neoliberal imperatives and economic viability; in order to remain viable entities, they may have little choice but to initiate coverage that might fuel a scandal. However, there is a degree of irony when considering the power of the economic discourse in the media, where the medical power over death and dying is clearly voiced, with comments such as the therapeutic imperative, not allowing people to die. This is juxtaposed against the institutional control exerted through central government, with tools and audits to enforce a structured approach to death and dying.

Technologies of power are embedded in the discursive machinery that is clinical practice. Foucault talks of time, space and context; discourse is not representative of a single truth and, as such, we exist in practice with myriad discourses which, rather like the *"Looking Glass"*, emerge, strengthen and compete at different nodal points in practice, dependant on that specific space and time, shaping how we deliver care.

8.4 Technologies of the Self

Technologies of power are external to the individual and reflect the mechanisms that regulate and produce the subject – the person – confining, constraining and enabling them (Schirato et al., 2012).

> *"…technologies of the self, which permit individuals to effect by their own means or with the help of others a certain number of operations on their own bodies and souls, thoughts, conduct, and way of being, so as to transform themselves in order to attain a certain state of happiness, purity, wisdom, perfection, or immortality…"*
>
> *(Foucault, 1982a p4)*

Technologies of power in this thesis illustrate the subtle and ever-present formation of the dying person as a subject, while the networks of power offer insights into the medical and institutional discourse. Considering this alone does not allow for an understanding the subversion and resistance that occurs from the person's relationship with the self, internal conflicts, techniques applied to their bodies, and their attitudes (Zamora and Behrent, 2016).

As we look at dying through the *"Looking Glass"* in this thesis we can see the *technologies* that have emerged from the findings. *Technologies* are blurring boundaries and "through discursive techniques", bringing the self to the fore (Rose, 2001 p10). *Technologies* of the self are used to self-regulate, to confine, constrain and enable as internalised mechanisms of power (Schirato et al., 2012). Discussing the self in the biomedical context, Rose (2001) asserts that the notion of medical dominance in healthcare is an oversimplification. Rather like the conflicts seen in some of the narratives and artefacts, *technologies* of the self are edging out the medical discourse:

> *"I think our culture and society has lots of different demands on an individual when they are dying (tuts) and seeing my friend respond to all of these external demands has been both, erm, very upsetting but also caused me to reflect on the palliative care, inverted commas, right way of being."* (Participant Two – Consultant in Palliative Medicine)

> **"…I am considering myself as an Amazonian woman; it symbolizes the inner strength that comes through me,**

to the bitter end I am not giving up…" **Alive Rankin Faces Death – A Culture Show Special,** Sandra.

For the healthcare professional, the sense of identity as a carer, as a professional and as a person is also influenced by technologies of the self, which both confine and transform practice. Such internalised mechanisms of self-regulation and conflict are described in this thesis under the guises of personhood discourse, moralistic discourse and religious discourse.

8.4.1 Personhood

It is living our lives as a whole person, being driven by our conscience, morals, justice and spiritual principles, that determines conduct in everyday life (Schirato et al., 2012). The person, their beliefs, values and the very essence of the individual, come into sharper focus as the end of life is reached. Life's achievements and failures come into sharper focus and there is a drive to search for meaning, be that of life, the past or the future. End of life care professionals are in turn exposed to surveillance from their patient, the family, the institution through apparatus and governance, and in addition, by the media. The complexity of therapeutic relationships is described by Rose (2001, p19) as a series of entanglements; these include experts, apparatus, the patient, the wider family, immediate carers and indeed the media.

The recorded narratives do not have a strong sense of personhood emerging from them. While healthcare professionals recognise the privilege of caring for the dying patient, the professional persona takes precedence over the sense of self. There are however glimpses of the person, as can be seen in the excerpt from the recorded narrative above, where the participant clearly articulates the tensions at play. Given that the institutional priorities of the hospital are focused on outcomes and throughput, the healthcare professional is a vehicle and an asset; the essence of being a person coming secondary in the professional context. The person who is dying can be

invigorated like Sandra in the quote above (page 202), or lose some sense of being an individual, reverting to the docile body sculpted into the dying mould by the institutional mechanism, constructs and contexts (Downing, 2008).

The media artefacts powerfully represent a sense of personhood; the strength of the representation is evident through both the images and the words. *Technologies* of the self represent an attempt to create order in an uncertain and chaotic world as death approaches (Van Brussel, 2010). The media artefacts illustrate this concept, for example, with the coverage of those who are searching for meaning and an assisted death. Gott (2008) considers social death as being like a shell; here, the media portrays biological death being denied through the institutional power of the law, government and medicine. In addition, the law, medicine, clergy and government appear to compete for primacy, depending on the representation of the given voices through the media.

While the notion of quality of life is clearly represented as the ability to be actively engaged, to communicate effectively and function at the highest level, there is an interesting conundrum highlighted through the media representation of Kate Grainger. Her story as she was dying was one of using social media to demystify the process. She promoted her legacy throughout the dying process, and through social media has left an eternal footprint. This gives a sense of the person being present, offering a memory, a trigger, which denies the sense of being lost. Digitisation and the internet preserve the identity of the individual and maintain a social presence for the dead (Walter et al., 2011).

8.4.2 Religious Discourse

The religious discourse emanates from the findings of this thesis; the recorded narratives do not show this particularly strongly, however the media artefacts do; with echoes of the past, the present for some and potential future challenges in end of life care. How death is viewed in society has

changed over the centuries, emerging from the sole remit of the clergy and associated religions, to firmly within the grip of medical control as the secularisation of society has grown (Lupton, 2012). Historically, illness and death are closely linked with religion and purity; for some, the notion of illness as a punishment endures (Turner, 2008). The evolution of palliative care and, as such, the discipline of end of life care has a strong link with religious orders (Bishop, 2013). While the secular shift in society has disrupted the discursive machinery that has enabled peace and dignity at the end of life, keeping the patient at the centre of care delivery, while listening to multiple voices, is at the heart of good end of life care.

The religious discourse emanating from the findings reflects the conflicted challenges seen in practice. Spirituality encompasses religion, including the need for reconciliation, divine forgiveness, religious rites and sacraments and interface with the clergy, which may or may not be included (Kellehear, 2000). These findings talk little of the notions of spirituality and more about the power of religion, with particular reference to the critique of assisted dying and the role of the church. Additionally, and in contrast, the role of religion in easing the dying process also emerges from the findings.

Foucault, in *The Will to Knowledge – The History of Sexuality: 1* (1976) talks of the techniques of examination by a priest or a doctor; both observe and interpret what they learn from the person in the confessional or therapeutic relationship. They alone define what is 'the truth' and reconstruct it accordingly. This is important when considering the openness and exposure that is communicated at the end of life. While the confessional has shifted as society has become more secular, we can still consider the notion of the confessional as a means of not admitting sins but weakness; a form of institutional control that influences how people die. The exposure of the person to such institutional control, which includes the church, is reflected in the findings (pages 155-158). However, the intertwining of discourse described earlier highlights that it is an oversimplification to consider institutional power, as the self emerges as a force in its own entity. McNay (2002) states that rather than needing the expertise of the priest or the doctor to mould the self, individuals have the power to do so; to take control of their

dying. Indeed, Rose (2001) argues that advancement in biomedicine and the associated institutions, apparatus and *technologies* have given strength to, and become “deeply intertwined”, with *technologies* of the self (Rose, 2001 p2).

8.4.3 Moralistic Principles

Determining and exploring moral dilemmas is difficult, especially at the end of life. There are no formulae for determining the correct stance in relation to moral dilemmas (Earle et al., 2009). It is contingent on contextual conditions; the people, the circumstances and the point in history. What we do have in contemporary healthcare is a code of medical ethics, upheld by moral principles, which are: beneficence, non-maleficence, respect for autonomy and justice (Beauchamp and Childress, 2001). While Foucault takes an anti-universalistic stance to morals (Faubion, 2014), the medical ethical code is regulated through the presence of each point of the code, with none taking priority.

With this in mind, the findings in this thesis, primarily through the media artefacts, call into question our value system in terms of moral conduct in end of life care. Journalistic intentions and drivers in the media take priority, and the moral discourse is captured through the concepts of institutional power, namely medical power denying death, the law denying assisted dying, and the church driven by the sanctity of life (page 158).

It is interesting that the moralistic discourse does not emerge strongly from the recorded narratives, although specific reference is made to ethical challenges in relation to institutional power. In end of life care, moral and ethical dilemmas are part of the everyday; we see the challenge of this in the self-recorded narratives in relation to the therapeutic imperative (page 123). Moral values are infused within the medical encounter, an example being the rights and wrongs of assisted dying, which come through strongly in the media artefacts. It is such moral judgements, some from carers and some

from commentators that influence discursive practice through the newspaper artefacts, particularly in relation to assisted dying, where dying is portrayed as ‘the worst fate’ (page 159).

In contrast, the moral values and judgements portrayed in the television artefacts highlight the notion of the lived experience of death and dying, the notion of humanity and the sense of the person. It enables the viewer to appreciate life’s experience and promotes a greater understanding of living with dying without prioritising the biological death. The media as an institution is influenced by the moralistic discourse as much as it shapes it. The influence of the media on end of life care practice across all of the *technologies* is visible, which begs the question: does the media have a moral imperative to present a more balanced debate?

Foucault’s earlier works detail the political subjugation of docile bodies in the grip of disciplinary power (Besley, 2005), exposed to competing discourses. In turn, healthcare professionals are docile bodies, subjugated through the demands of the institution which determines how they should and do practice. *Technologies* of the self are constructed and reconstructed through self-surveillance and internalisation of desired behaviours, influencing the social construction of the person as an individual (Faubion, 2014). For the dying person exposed to the discursive mechanisms at play in end of life care, this impacts on their sense of self. For the healthcare professional too, discursive practices influence their sense of self, personhood and professional values and judgements. The following section will consider the professional apparatus that controls and regulates end of life care.

8.5 Professional Apparatus

Foucault focuses on apparatus in terms of the power-knowledge nexus, and as a means of providing surveillance, categorising, and regulating populations (Schirato, 2012). Discursive and historical drivers give rise to the need for apparatus to control and regulate. In end of life care, the apparatus

are: policies and guidelines developed by central government, and procedures and tools cascaded through the institutional mechanisms of the hospital. These may be national or local, often generated from pockets of good practice seized upon and scaled up to be transferable. Tools facilitate and homogenise practice, however, they can also be used to dictate the delivery of care at the end of life.

While the literature associated with policies, practice drivers and the associated tools is plentiful, this thesis contributes a novel perspective, offering a Foucauldian lens to understanding the contextual conditions that impact upon practice in relation to apparatus.

The recorded narratives echo with the disquiet of practitioners who are dealing with anger, upset and dismay from families of those who are dying, in relation to their grief, the dying process, their beliefs and for some their understanding that has been shaped, in part, by the media. Discourse is contingent on a moment in time; historical and cultural conditions. For this moment in time the findings in my research focus on the LCP. This moment in time aligned with the data collection phase of this research; the volume of reportage related to the LCP took me aback. While this provided artefacts that clearly demonstrated the influence of media on end of life care practice, it also made other apparatus fade in to the background. This is hardly surprising as the media coverage and professional debate at the time focused on the LCP as a signifier for the state of end of life care (Seymour and Clark, 2018).

The impact on practice and insights into the application, utilisation and withdrawal of the LCP is well evidenced in the literature (Stocker and Close, 2013; Currow and Abernethy, 2014; Seymour and Horne, 2015; Di Leo and Romoli et al., 2015; Sleeman and Koffman et al., 2015; Twigger and Yardley, 2016; Seymour and Clark, 2018). The findings of this research provide an insight into the impact that the media and associated professional disquiet, debate and conflict has on those delivering care for people at the end of life, when the contextual conditions are toxic and heavily laden with criticism. The LCP emerged from end of life care in the hospice setting, scaled to offer

guidance in all sectors. The wholesale adoption of the LCP as apparatus influenced discursive practice in end of life care. The institutional discourse manoeuvred the apparatus in an attempt to normalise and standardise the management of patients at the end of life, diffusing with the moralistic and religious discourses and informed by medical power.

Journalists are conduits for the institutional apparatus of the media, which are inextricably bound to the complicated power-knowledge nexus (Hall et al., 2013). Discursive practices emerge through this influence of the media on the patient and their family, with explicit reference being made to the fact that they are afraid, feeling that their relatives who are dying may be killed (page 172). The language used instils fear with the sensationalist, medical power and moralistic discourses diffusing through the media artefacts. Moral panic emanates out of the voices of both the participants and the families through the participants, which in turn contributes to the shaping of the discourse. In addition, defensive practice and a reduction in confidence is evident when caring for patients at the end of life, which is ironic given that such tools are designed to offer choice to patients and enhance care delivery (Regnard, 2014).

Institutional control over apparatus also emerges in the findings. The application of tools in practice is mandated firstly though central government, monitored and rewarded through the CQUIN targets, and secondly through the hospital where audit is used as surveillance to determine compliance with the utilisation of the given tools. Thus, the tools become bureaucratic; audit takes away choice of compliance and can fuel a tick-box economy in care delivery (Borgstrom and Walter, 2015). The economic and institutional discourses both merge and collide at this juncture; reward and institutional imperatives are juxtaposed against the medical power discourse firmly embedded within the institutional framework. For the practitioners in their discursive practice, we hear the challenge of focusing on the individual while being cognisant of the institutional demands.

The media artefacts compound the perception discussed above, however the use of sensationalist language in the reportage related to the apparatus in

end of life care, specifically the LCP, is inflammatory. Such media coverage influences the evolution of professional discursive practices in end of life care, instilling disquiet and contributing to the caution surrounding care delivery in end of life care. There appears to be two layers to the way that the media report the end of life care "crisis". One is through glaring headlines and controversial headings of articles; the second is the inflammatory language which is infused throughout the artefacts, compounding and sustaining the sensationalist discourse. Both approaches are informed by the journalist's discursive way of seeing, which influences their representation. In turn, this influences discursive practices in end of life care. The apparatus, which is bound with the power of the institution, becomes tainted through the sensationalist discourse. There is a push and pull in the discursive practice of healthcare professionals; on the one hand, an awareness that the apparatus when applied properly offers quality end of life, and on the other, the tensions that occur as patients, families and other healthcare professionals are critical of the apparatus.

Institutional power is being exerted through the use of apparatus, and while such power can be coercive (e.g. CQUIN targets), the use of apparatus is unavoidable if society is to operate. Discursive practice in end of life care has both shaped and been shaped by media; in turn the apparatus we work within are constructed in response to a crisis or a problem. The crisis in end of life care, viewed through the *"Looking Glass"*, has led to moral panic and a space for change, and as a result we see emergence of new apparatus. The LCP was deconstructed following the Neuberger review (DH, 2013) yet in its place, we have the five priorities of care, which similarly control how we manage care for those at the end of life. Having a degree of longevity to my career, I have seen familiar issues and approaches to care rising and falling, according to the demand of the social structures, discursive practice, context and culture.

The role of the media in the portrayal of apparatus and influences on end of life care will be explored further in the *technologies* of representation.

8.6 *Technologies* of Representation

This research offers new perspectives and a unique contribution to understanding how the media impacts on discursive practices in end of life care, informing and shaping discourse while also being influenced by it.

To develop an appreciation of the sociocultural constructs that contribute to public understanding of health and illness, it is important to recognise the role of the media (Bunton and Crawshaw, 2006). People are consumers of mass media; they construct their sense of reality from, and understand the world through, the media, their personal experiences or those of their family, and in their discussions with others. For many, the media will be their first exposure to significant health and medical issues (Lupton, 2012). The media is a social institution presenting culture, social life and politics, both moulding and reporting how these are expressed, contributing to societal understanding and constructs (Bell and Garrett, 1998), and sustaining and reproducing the dominant frameworks of understanding and power networks in society (Orgad, 2014).

For Foucault, the power associated with media representation exists through the way in which they legitimise some discursive regimes and tactics but not others. The media affords certain people and social entities a voice, visibility, legitimacy and authority, while others are deemed to be invisible, voiceless or illegitimate (Orgad, 2014). The findings in this thesis demonstrate that this is in fact more complex; the media is more than a window into our society. Discourses surround and define the events being represented; they are material results of a discursive practice. There is no representation of a single truth, as the surrounding discourses inform and are being informed by the media (Hall et al., 2013). We see this when looking at the media artefacts in which the medical, economic, therapeutic imperative, moral and personhood discourses are both represented drawn upon.

For this thesis, the delivery of end of life care at this given moment in time becomes at odds with societal expectations, fuelled by the media through the construction of narratives and images. There is a shift in perceptions,

completely divergent from what should be expected, filtering what we can and do see, while informing understanding (Seale, 2002). We are entering a new world where virtual influences and social media use and shape discursive practice, with bodies of understanding and communities of practice proving influential in end of life care. The influence and power of the media is clear; the media exerts influence on the individual, be that a patient or professional, through the exchange of information that shapes knowledge. Despite the media not being technocratic, it is through this influence that the media has changed the way that healthcare professionals and their long-held institutionalised apparatus operate in end of life care.

Technologies of representation are complex. They are contextual entities, emerging at a given time, fuelled by discursive practice in end of life care while also concurrently shaping them through the privileging of some voices over others. At the outset of this research, my understanding and appreciation of the power of the media was quite one-dimensional; my views as a healthcare professional working in end of life care focused only on the sensational nature of the reportage. The findings presented in this thesis illustrate that this is an oversimplification and there is a discourse mediatisation of death and dying and a sensationalist discourse.

8.6.1 Mediatisation of Death and Dying

The media influences and informs the voices of the participants in this research, but there is also a certain disquiet expressed by healthcare professionals regarding how people who are dying and their families are influenced by media reports. The negative media coverage and the dearth of positive reporting cause uncertainty and fear, for both the general public and the healthcare professionals caring for them (Watts, 2013). Such emotions and societal perceptions impact significantly on distress in end of life care, fuelling anger and a blame culture. This is particularly evident in the critique of the LCP levied by the press, which has influenced both the way care is

perceived by patients and the way it is delivered by healthcare professionals, and has emerged strongly in the findings (pages 161-162).

Power dynamics are implicit throughout the media artefacts; patients are deemed as being inherently powerless, with doctors, lawmakers and politicians being all-powerful, firmly rooted in the institutional power of medicine and the state. The media artefacts reproduce this long-held power dynamic as it is so normatively embedded in society (Fowler, 2007). This is juxtaposed against the subjugated voice of those working within the specialism of end of life care; doctors and other healthcare professionals seldom being given a voice.

However, other disciplines within medicine are afforded a voice, attributed with expertise, implying a hierarchy of knowledge in medicine itself. This may indeed be related to the history of palliative care, how it emerged and how and when it was recognised as a medical speciality in its own right. The power dynamic does of course include the institution of the media, who hold greater influence than ever before due to the increasingly technological age we live in; in its broadest sense the media includes written, digital and social media. In turn, the digitisation of media and social media has changed the very nature of the gaze, as the apparatus used for dissemination and surveillance are more proliferative.

Foucault emphasises the institutional dimensions of discourse and specific institutional practices (Nixon, 2013) represented in the media. For end of life care, such practices and tactics are related to the apparatus, policies and procedures under scrutiny. The infusion of the power of the institution, medicine, the media and the state mirrors the *"Looking Glass"* in which we can see the complexity of power in terms of enabling and controlling end of life care.

A point worth noting is the fact that in addition to the critique of end of life care and assisted dying, the notion of living with dying emerges from the media artefacts. In the small number of television artefacts, living with dying has strong representation and can be seen through images and words, particularly in **Alive Rankin Faces Death – A Culture Show Special**. This

counters the more sensational images of death and distress seen in some of the news media; the power of such images and their influence on societal perceptions related to the construct of end of life care cannot be denied (Nixon, 2013). The sensitive use of imagery, music and words is juxtaposed against the news coverage on assisted dying; the same media, with institutional power of medicine and the law overtly controlling dying and the right to die. Such media coverage influences discursive practice in end of life care as it mitigates against the more sensationalist reportage, offering a sense of balance, and influencing and informing the viewer through a different lens.

There is a degree of overlap and interplay between the mediatisation of death and dying and the sensationalist discourse; the mediatisation discourse offers a different lens, which illuminates the discursive formations that influence societal understanding and clinical practice.

8.6.2 Sensationalist Discourse

The sensationalist discourse in relation to end of life care perpetrated in the media undermined decision making for patients, their families and healthcare professionals alike, at a time when people most need support. The voice of the healthcare professional is heard in the recorded narratives; there is clearly distress and difficulties in practice in relation to end of life care as a result of the media campaign, a point noted by Seymour and Clark (2018). While initially the LCP was criticised in multiple media outputs, as highlighted in contemporary literature (Seale, 2010; Watts 2012; Watts, 2013; Seymour and Clarke, 2018), in the recorded narratives the undermining of therapeutic relationships with patients is challenging, with practitioners torn between discursive formations, institutional demands and expectations, the therapeutic imperative and *technologies* of caring.

One participant clearly articulates that the media campaign is purposefully manipulative, using sensationalist tactics in order to malign end of life care

(pages 167-168). Healthcare professionals talk of families denying their loved one being on the LCP and of being told of the LCP. Such denials can be likened to the denial of death; if the LCP is viewed as being an instrument of death then, as Zimmerman (2004) argues, denial of death can be a consequence of poor care. Such sensationalist coverage fuels the taboo of death and dying and contradicts the principles that constitute a “good death” (page 42). When death is viewed in the context of the sensationalist reportage, it also undermines the cornerstone of good end of life care and communication. Without this, wishes, choices, feelings and expectations cannot be explored (Mannix, 2017).

The sensationalist discourse is just one of the discourses that inform mass media and in turn, media representation, which is more than a simplistic view from a window into reality. The media is itself an institution with its own discursive contexts and practices; the journalistic code of balance, objectivity and the public interest is in turn a discourse (Hall et al., 2013). Journalists interpret news or current affairs through a particular discursive way of seeing. Through challenging norms and offering different ways of seeing through oppositional narratives, the media engage in disruption; this leads to resistance and the time and space for change.

Gellie (2014) talks of dramatised dying in terms of media coverage; the sensationalist and dramatic reportage of the LCP and end of life care produced jarring and impactful headlines, and images that conveyed messages of distress, lack of dignity and examples where death was hastened through the use of the LCP. The language used in such coverage implies that death is the worst fate and, as such instils fear in the masses for themselves and those they care for.

The media artefacts use statistics, numbers, CQUIN targets and audit of the LCP as state apparatus to sustain the institutional discourse; these are used in a sensationalist context, however, they are still driven by the professional apparatus of the institutions. Some such artefacts are also laden with irony, for example, healthcare professionals can interpret statements related to the

large number of patients on the LCP who die, but for other readers, these have the potential to instil fear and trepidation.

Foucault's thoughts on the disciplinary society; the hospital, the prison etc. lead to thinking of the mass media as a means of surveillance and self-surveillance, implying self-regulation, monitoring and regulation of the self and others (Schirato et al., 2012). He acknowledges the changing face of disciplinarity in his work, *The Birth of Biopolitics;*

> *"…To what extent is the dominance of neo-liberal and capitalist imperatives, values, discourses and logics in the west likely to inflect or even transform practices or regimes of disciplinarity, normalisation and biopower?"*
>
> *(Foucault, 2008 p134)*

For end of life care and the benefit of this thesis, we have insight into how the media has influenced the public as potential recipients of care. The public has socially constructed expectations, which impact on not only their view of end of life care but on how they perceive those delivering the care. The media is used as a vehicle to share the story with the intention of changing practice through surveillance and networks of power. Power emanates from the media artefacts. Driven by the discourses that exist within end of life care and the discursive practices that circulate within the hospital culture – whether that be between doctors and patients or within hospital teams – the media portray and exploit the conflicts that exist when delivering care in the hospital setting.

Language in the media artefacts sustains the sensationalist discourse, which is particularly evident in the television artefact, **Dispatches: Death on the Wards.** The sensationalist language built on previous news publications and was deemed inflammatory, causing distress and difficulty for all involved (Seymour and Clark, 2018). The programme was rooted in the institutional power of medicine, with sole authority being given to the medical voice. Such sensationalist language pervades many of the media artefacts, which are driven by the desire to connect with consumers regarding contemporary

concerns (Richardson, 2007) and increase readership/viewing figures. Some newspapers offer themselves as having a ‘duty’ to highlight difficult issues so countering open criticism. Sensationalist coverage of this nature demonstrates a discursive imbalance, which offers a space for conflict to develop.

In truth, if the media sees that the campaign and coverage around anything attracts readership and profile, they will ensure it gathers pace and takes priority (Seale, 2010), driven by economic and neoliberal imperatives. It is such a gathering of pace that allowed for the scope, volume and intensity of media outputs to increase. The media plays an important role in affecting policy change (Lloyd and Banerjee et al., 2013) and in addition functions as a means of constructing social and moral pictures and situations that help people understand the complexity of the world. This unleashes great political potential, mobilising energy through discursive tactics (Dahlberg and Phelan, 2013). It is the extent of the reportage in terms of volume and content; this energy and the broader discourses, economic, institutional, political and cultural structures (Waisbord, 2014), that converts fear into moral panic.

8.7 Moral Panic

The concept of moral panic emerged from the work of Stan Cohen in the 1970s, which examined the impact of youth subcultures, such as mods and rockers. The term has since been used in relation to an exaggerated reaction or response from the media, the state or wider public to a defined social group or structure.

Cohen’s (2002) definition of moral panic connects with the furore in the media regarding end of life care. He talks of the trigger for moral panic being a person or group of persons who threaten the moral fibre of society through the undermining of societal values and interests, which is then stylised by the mass media. Cohen (2002) highlights the notion of “moral barricades”, which are controlled by the state, the church and the media as an institution. Part of

the cycle of moral panic is to harness expertise, to pronounce what the solutions should be, or could be, applied to the issue under examination. Society then finds ways of coping with the crisis. When a moral panic has been experienced, the panic sometimes passes over and is forgotten, remembered only through a collective memory. More serious moral panics have a longer-lasting effect, impacting on change in legal or social policy (Critcher, 2006).

Key dynamics need to be in existence to fuel moral panic:

1. The mass media – seizing an opportunity, orchestrate the early stage of reaction through exaggeration and distortion, predicting the serious nature of the dilemmas at play, using inflammatory language and symbolisation for impact. Media focuses on blame, what behaviour is at fault and who is responsible.
2. Moral entrepreneurs – particular individuals or groups on a crusade to eradicate or change the behaviour under scrutiny; underlying motivation and tactics will be at play.
3. Societal control – institutional power, law, the church, the state, central government; all contributing to the evidence and solutions associated with moral panic.
4. All of the above is undertaken in the name of public opinion to address the moral panic and offer solutions.

(Critcher, 2008)

The moral panic that has been experienced in end of life care can clearly be mapped against the theoretical models posited by Cohen (2002) and Critcher (2008). The mass media seized on an article written in the Daily Telegraph in 2009 by concerned healthcare professionals – not “scaremongers” (Mackintosh, 2015), which garnered a significant response and flagged the professional and public disquiet, specifically in relation to the LCP, which opened the door for the mass media (Seymour and Clark, 2018). Moral entrepreneurs seized on this opportunity to exacerbate the sense of scandal, which significantly impacted on end of life care (Borgstrom and Walter, 2015), and lobby groups, religious groups, healthcare professionals from a

wide variety of specialisms and especially and sadly, grieving families, were touched by this. This is largely because while the media can exert their editorial influence, in turn, interest groups and lobbyists exercise their power and use the opportunity to have a voice (Seale, 2010).

The mass media campaign grew as newspaper headlines warned of the threat that will undermine moral fibre, followed by television sustaining this through sensationalist documentaries (Thompson, 1999). The impact on end of life care was significant; fabrication of myths, and the ramping up of fear through the use of graphic language and inadequate or incomplete empirical evidence (Hanusch, 2013) was evident. However, there was no denying that in addition to this, some examples of poor care were highlighted (McCartney, 2012; Oliver, 2015).

Interestingly, and with reference to the institutional power discussed in the findings, societal control of the end of life care campaign was evident, with power-laden institutions of the media, medicine, law and the church at odds, and fighting for moral supremacy. In the same vein, the “moral barricades” silenced the voice of reason.

Palliative and end of life care is a specialism that spread-eagles across institutions. Relationships between institutions and discursive practices are never easy or simple; complexity is the nature of any fluid relationship (Fairclough, 1995). The discourses that have emerged from this research disrupt some of the discursive tactics employed in the discipline. In palliative and end of life care, there is tendency to not speak out in the face of mounting criticism; the disruption that results from emerging discourses creates space for resistance, through which change can happen. That change needs to give greater voice to the discipline, to recognise the *technologies* at play and, working with and through, institutional apparatus, ensure that we respond to the challenges posed in a timely and determined manner.

While discussions were plentiful in the professional domains in which we exist, this did not emanate into the public consciousness with sufficient

gravity and conviction. The cycle of moral panic in end of life care is represented in Figure 2.

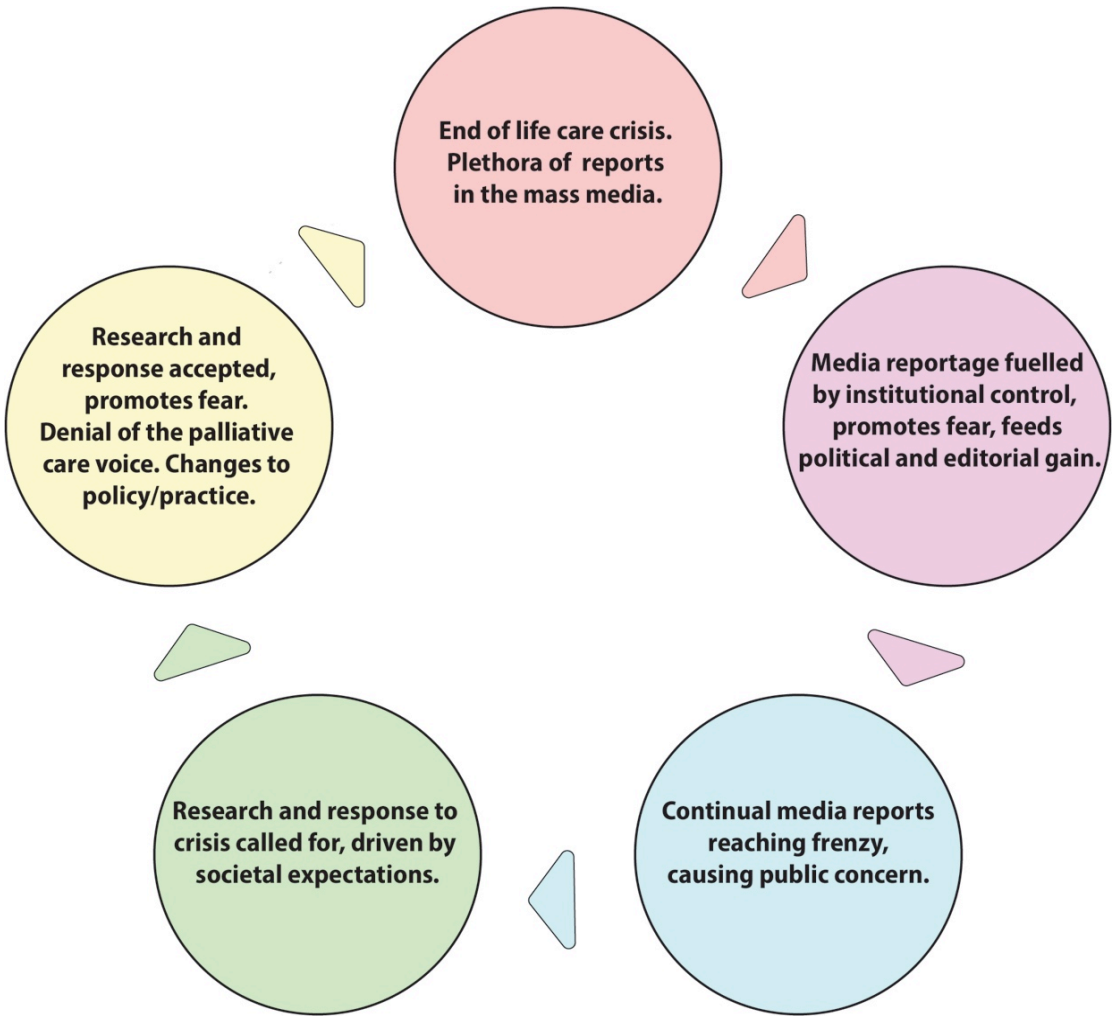


Figure 2 Moral Panic in End of Life Care

Moral panic should not be viewed as something that exists only because the public has been whipped up into a state of frenzy. It is in fact in existence as a moral panic because it has been exaggerated in terms of its extent and significance in comparison with the knowledge and evidence available (Cohen, 2000).

8.8 A Different Space and Time

The history of palliative care offers insight into the evolution of a relatively new discipline, an emerging discourse; putting personhood at the centre of therapeutic intentions ahead of the curative drive in medicine, disrupting and challenging the notion that the patient is a subject in need of repair. Such challenges and resistance to the institutional order and power cause a degree of chaos, and shifting and emerging discourses offer the opportunity for change. While this is challenging, we must grasp the opportunity, despite the disarray caused in practice. The media plays its part in this process, influencing and being influenced by societal shifts and discursive turns. The dismantling of the LCP and the challenge for practice is an example of this; change is everywhere, there is no constant or single truth, and we must be watchful and responsive.

Crticher (2006) talks of the severity of moral panics, how they may disappear and how they stay in the consciousness of the public. In this thesis, *dying through the "Looking Glass"*, I shed light on how *technologies* and discourse inform practice and public understanding with particular reference to the influence that mainstream media has on the understanding of discursive practice and contextual conditions that influence end of life care. This is true for that time in history; as Foucault says: understanding and discourse is contingent on cultural understanding at a given space and time. The repercussions from the fallout of the moral panic in end of life care are still felt within the palliative care discipline. In fact the legacy re-emerged in 2018 in the media, demonstrating that the fear instilled through moral panic is just below the surface; the discursive formations emerging again to speak about the end of life care, with the media seizing on the opportunity and privileging the critical voice.

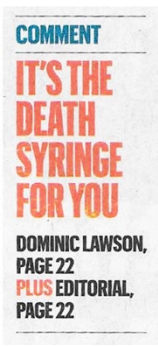
The Gosport War Memorial Hospital scandal emerged following many years of criticism in relation to the use of opioids at the end of life. Relatives and nursing staff had for many years complained and made professional representations to the organisation and professional regulatory bodies, only

to be ignored. An independent panel was set up by the House of Commons and a report published, which found that around 600 patients had their lives shortened through the inappropriate prescription of opioids. This was indeed a scandal, with the report clearly stating:

> *"…What has to be recognised by those who head up our public institutions is how difficult it is for ordinary people to challenge the closing ranks of those who hold power…"*
>
> (Gosport Independent Panel, 2018)

The previous critique of end of life care came flooding back; the media campaign was relentless, as can be seen in the images below. The sensationalist coverage was misleading, while also undermining the confidence of both doctors and nurses (Gallagher and Gannon, 2018), and largely focused on the medical control of death and dying rather than the organisational (Darbyshire, 2018) and institutional power and apparatus that allowed this to happen.

While the repercussions and learning from this report are still at the forefront of our professional consciousness, we need to be mindful that the disarray caused by prolific media campaigns reopens old wounds and is never far away. Here are some examples of the media coverage in August 2018.



8.9 Implications for Practice

The aim of this thesis is to contribute to professional understanding of the contextual conditions necessary for optimal end of life care. The findings

uncover and explore the emerging and competing discourses that influence end of life care and offer a different lens, a *"Looking Glass"* through which to view dying.

Throughout this journey I have talked of the transformation that has occurred in my thinking. My professional, academic and researcher identities have evolved and I have been subjected to competing discourses that have shaped my thinking, practice and understanding. This brings to the fore a particular challenge, around communicating my thoughts and disseminating this research to those professionals who influence end of life care. I have included just some of the presentations I have undertaken so far, which have been positively received (**Appendices 8, 9 and 10**).

While it comes relatively easily to me to present these findings in an engaging way, it is important that this should not prevent professionals' own expanding understanding of the complexity of the discourses at play in practice at any given time. In addition, healthcare professionals need to become more aware of the constraining and enhancing potentials of power, and thus develop an understanding that goes beyond a simplistic binary view. A deeper appreciation of power networks at play and the enabling nature of power is important. It should not be viewed as sitting solely within a hierarchy, as it can constitute a productive force. There thus needs to be an understanding of power and its relationship with knowledge and discourse, and their impact on, and relevance for, practice. Healthcare professionals need to develop an appreciation of the fact that power is not exercised only by doctors or managers but also by those who resist. It is through resistance that we generate change, and this can be a creative and constructive process. This research will make a difference, particularly in the acute sector, where services and the way we deliver care are structured around seniority and hierarchy. By disseminating this research, I will highlight the productive and constructive nature of power, alongside the potential for change and the impact this can have on end of life care.

The complexity of end of life care echoes through this thesis. The mainstream media influences discursive practice in end of life care and as

such, professionals need to understand this, and appreciate how they might deal with the challenges and opportunities posed. The impact of the media emerges strongly from this research, providing a novel insight into its influence on practice in end of life care. While the media exerts influence on the individual and their perceptions, it must be recognised that this in turn impacts on decision-making. It has an influence on healthcare professionals, increasing their workload and impacting on their therapeutic relationship with the patient and their family, as they have to explain, explore and address the tensions arising from media exposure. In turn, the media exposure can undermine confidence in the issue being covered. We can see in the cycle of Moral Panic (page 220) how this can spiral, influence institutional drivers, public perception and change the apparatus in end of life care.

There may also be opportunities through which we can make a difference to practice using the media. A perfect example of using such opportunities to influence practice is portrayed through the work of Kate Grainger. She used her professional knowledge and profile to capitalise on an opportunity, to harness the power of the press and social media, to make a difference while living with dying herself. Her resistance to the way she was managed while dying brought about real change. For example, the “Hello My Name Is…” campaign was launched through her work. The challenge she posed to professionals was to be a person with the patient and dismantle the barriers associated with a label and a role.

We do need leaders to appreciate the dynamic between media, power and practice at all levels (policy to the bedside). If we don’t ensure that leaders understand the influence of the media, then we can’t in turn take a whole-system workforce development approach to develop such an understanding. Qualified healthcare professionals need to develop media literacy and engage in developing a sense of the impact media has on practice. Supported by their organisations, education should thus be made available. Taking a whole-system approach to developing the workforce may enable an understanding of the influences of the media and enable all voices to be valued and have currency.

In addition, when preparing healthcare professionals for practice, in pre-registration health programmes and medical schools, we need to integrate media awareness and media impacts on practice into the curriculum, using a case study approach, so learning is real and lessons are learned.

There are well-rehearsed debates in palliative and end of life care regarding burnout, compassion fatigue and building resilience (Peters et al., 2012; Koh et al., 2015; Hill et al., 2016). While discussion and debate continue, and guidance is issued to help build resilience and safeguard staff (Hospice UK, 2016), we can hear in the voices of the professionals working in the acute sector the challenges of caring for people who are reaching the end of their life. The *technologies* of end of life care, the discursive formations and contextual conditions illustrate the complexity and challenge of delivering good quality end of life care in hospital. We need to endeavour to offer support to healthcare professionals who need it and recognise that while in the hospice setting there is often supervision and support for staff working with palliative care patients, this doesn't often translate into the acute sector.

The *"Looking Glass"* and the kaleidoscopic nature of the discursive lens through which we view end of life care offers the opportunity for healthcare professionals to view practice differently; developing an understanding that the contextual conditions of practice are contingent on culture, history and that moment in time, can result in changes to institutional apparatus. We see this portrayed vividly with the demise of the LCP.

Only through stepping out of the schema in which they have been encultured, as I have, can healthcare professionals develop critical insights and understanding. While it can be a frightening place to be, this allows for the development of novel insights and opportunities. Clear recommendations for practice follow.

8.10 Recommendations for Practice

Throughout this thesis I have talked of the challenges of being an educator, practitioner and researcher. Recommendations follow for each of these domains:

8.10.1 Recommendations for Education

- Within pre-registration nurse education, we include the importance of empowerment (a problematic term, of course) for both nurses and patients. It is recommended that the importance of power is embedded within the curriculum, so that an understanding of the productive nature of power is appreciated and used to the best advantage.
- Media literacy should be included in the curriculum across all multi-professional healthcare education, including workforce development. This is important, to ensure the impact of the media is appreciated, and to enable healthcare professionals to appreciate they too are influenced and can be part of the discourse and inform the media.

8.10.2 Recommendation for Clinical Practice

- Implementation of end of life care apparatus should include an explicit consideration of the potential power and influence of the media on practice. Practitioners could then become more proactive at engaging in media communications around their area of expertise, thus more proactively shaping its discourses.

8.10.3 Recommendations for Future Research

- I will be using a participatory approach and workshops with professionals to explore how the findings from this research could pragmatically impact on practice.
- Further research could build on these findings to explore the influence of contemporary social media sources on end of life practice.
- The findings from this research could also inform further research into the impact of the media on other spheres of practice, such as obesity and dementia.

8.11 Strengths, Limitations and Opportunities

At the outset of this research, I discussed the major leap it was for me to contest the way I was trained and to engage so wholeheartedly in a different way of thinking. In the same vein, while Foucauldian discourse analysis challenges thinking in clinical practice and its associated taken-for-granted assumptions (Cheek and Porter, 1997), Foucault does not speak naturally to some practitioners. We need to break down these barriers and encourage healthcare professionals to step out of their schema in order understand the relevance of this research. This may seem problematic in terms of engaging with healthcare practitioners and disseminating this research, however, my experience is the opposite; it has been received with great interest and provoked curiosity. As a known professional in the field, I am hoping my doctorate will act as a catalyst for others to step out of their comfort zone, embracing difference and enquiring, as I have, and will continue to do.

This research offers different perspectives and understanding; a different lens, revealing an unspoken and under-acknowledged view of the landscape in end of life care. The clear and coherent connection with the theories and philosophies of Michel Foucault is implicit throughout this thesis. This is important, as critics comment that some Foucauldian discourse analysis only pays lip service to Foucault, so undermining the research itself (Hook, 2001).

One of the opportunities arising from this research is the chance to open up new ways of thinking for healthcare professionals in end of life care; understanding power as a more dynamic concept and the opportunity this holds for changing practice.

Foucault's thinking and its impact on this research are considered in chapter five, which discusses the concepts of archaeology and genealogy, and the notion that the way we understand and think in a given time is contingent on the discourse and knowledge of the day (Hook, 2001). This *"Looking Glass"* is contingent on the time and space in which the research was conducted, and thus will be a foundation for further learning and future research.

9 Conclusion

This research offers a new lens through which we can view end of life care, particularly in acute settings. The *"Looking Glass"* provides a kaleidoscopic view of the discourses at play in end of life care that have emerged from this research; discourses that emerge, clash and overlap, forming and informing how we practice. The aim of this research was:

To contribute to the professional understanding of the contextual conditions necessary for the delivery of end of life care in the acute sector.

The participants were recruited from the hospital setting or significantly contributed to end of life care in hospital. The narratives they provided yielded rich data about end of life care in hospital and the influence of the media on care delivery. In addition, media artefacts contributed to understanding the rhetoric associated with end of life care.

The discourses arising from this research illuminate the contextual conditions and the complexity involved in end of life care at that moment in time, allowing a view of practice outside of existing boundaries, while shaping and being shaped by practice. The challenge that emerged at the same time as this research was the media campaign in relation to the LCP, which significantly increased the volume of reportage that could be used in this research. In addition, the type of media coverage and the sensationalist lens significantly shifted the emphasis for this research. While media artefacts about end of life care practice were plentiful, the impact was on end of life care for all sectors, although care in hospital had significant coverage.

This research has highlighted that the application of Foucauldian thought to palliative care can be productive. Exposing dying and the discursive formations that hold true in this thesis offers a novel view; insights into how healthcare professionals are not immune to, but part of, the influences that mediate how care is delivered at the end of life. How indeed the media can have such a strong influence on perceptions, understanding and practice.

The media is a powerful force with a clear impact on institutional practice. In the acute sector the focus is on cure; the notion of death can be viewed as a failure. The biomedical model that underpins care delivery in hospital makes it a challenge to deliver holistic care. These challenges can be seen in the recorded narratives (*technologies* of caring) and in the media (*technologies* of representation).

This research shows that the media is important in shaping how people think, speak and practice in end of life care. This creates a complex field of competing and converging discursive practices which at any one time can present productive possibilities.

9.1 Personal Reflections

I hope the reader can see the personal, professional and philosophical journey I have been on. This is not only a doctoral journey but also a journey of confidence, which some say may be one and the same. At the start of my journey, my perceptions of Foucault's notion of power were naïve, probably as a result of the way I was educated and practised in my formative years, where you stood to attention when a qualified or more senior nurse walked into the room and never questioned the doctor. Times have changed of course, as has my understanding and appreciation.

There is no doubt that being so close to both the participants and the subject has been a major challenge throughout this research. My experience and perspective has influenced the interpretation of the data and the findings. I am firmly embedded in end of life care and care deeply about this sphere of practice. As a result, and as discussed earlier (page 182), it is not easy to separate myself from my clinical background; indeed, this closeness was the reason for this research to see the light of day. My supervisory team, who do not have the same clinical background, have kept me on the straight and narrow, highlighting presumptions and ensuring analytical rigour. While being close to the clinical field of end of life care is a challenge, it has also been a

great benefit to this research. Being known has engendered trust and confidence with the participants, and has provided me with unique insights and access to participants through my existing relationships.

Earlier in this thesis, I talked of stepping in and out of my comfort zone, as the research developed. In doing so, the parameters of my understanding changed. My appreciation of the research process and the philosophical changes I have undergone have been seismic. As I have progressed through this journey, I have stepped in and out of the researcher, practitioner / educator ways of thinking. At this point in my journey, I have noticed that I no longer swap and change; I seem to have emerged as a hybrid of the different domains. It is from this point that I will further my research intentions.

10 Journey's End

I started this thesis by outlining my professional and personal journey. I would like to complete that here and move on. This doctoral journey was very nearly not completed because of my personal exposure to death and dying. While so many people are touched by cancer and advanced disease, professionally and personally everybody copes differently; everybody has different ways of caring and everybody has different responsibilities.

When I wrote about my personal experience, it was heartfelt and in the moment. My father had chronic disease, which rendered him significantly disabled. At the beginning of this journey, listening to him and walking alongside him changed my thinking. It altered what I perceived was important and what was not important. We lived in the moment. On his diamond wedding anniversary, my father gave my mother her diamond necklace, said he loved her, and soon after had a brainstem stroke. This was unexpected in the scheme of things. What happened afterwards undermined the way I think of end of life care. We knew he was dying; he had articulated his wishes and wanted to die at home. His General Practitioner called immediately and was supportive. However, the rest of the services fell short, we were instructed to call an ambulance and take him to hospital, and it was only our determination to make it happen, and nursing knowledge, and a brilliant GP that kept him at home. My father died comfortably in his own bed four days later, with his wife and family by his side.

The literature I have considered in this thesis talks of enabling choice and having conversations, so we know what people's wishes are at the end of life. The reality is sometimes very different. We need to be cognisant of that and make sure choice means exactly that; integrate and invest in services to make this a reality.

On a much happier note, my younger sister is well, and living an active and very full life following her intensive treatment for breast cancer. Living with

dying is part of everyone's life. As Mannix (2017) talks of the inevitably of death, so should we make this part of life for everyone. As for my journey, and the decisions I made to care and support the people I love, I wouldn't change a thing except for perhaps to turn back time.

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12 Appendix One – Information Sheet

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Information Sheet for Participants

I would like to invite you to be involved in a research study which aims to explore understanding related to the cultural, social and professional conditions necessary to deliver quality end of life care.

I have provided this information sheet to help you understand why the study is being carried out and what it will involve for you before you decide whether to take part or not.

This will take about five minutes to read. I would like you to read the information carefully and discuss it with other people if you wish. You are very welcome to speak to the researcher, if you would like additional explanations or more information.

What is the study about?

The purpose of this research is to contribute to professional understanding of the contextual conditions necessary for the delivery of high quality end of life care in the acute setting. The study will explore how end of life care is shaped and how tools such as the Liverpool Care Pathway and Preferred Priorities for Care used in end of life care emerge and become embedded in practice. It is hoped that the study will provide insight into practice challenges such as achieving choice, comfort, holistic care and dignity.

The study will also provide original insights into the influence that mainstream media have on those delivering care.

The research is being undertaken as part of a professional doctorate.

Why I have been asked to take part in the research?

As a doctor or nurse caring for patients at the end of life and working within Newcastle upon Tyne Hospitals NHS Foundation Trust I would like to invite you to take part in this study. Your name has been nominated to be invited by Carol Richardson, Matron, NCCC this is because you would have particularly relevant insight into the challenges of delivering end of life care in the acute sector.

What is involved and what am I being asked to do?

As a doctor or nurse caring for patients at the end of life you will be asked to carry a voice recorder for the period of one week, with some flexibility built in should you have difficulty with this timeframe. Two doctors and three nurses working in both specialist palliative care and generalist settings in secondary care in Newcastle upon Tyne Hospitals NHS Foundation Trust will be invited to participate. You will be invited to record your views of positive or negatives thoughts, feelings and experiences related to caring for patients at the end of life. This will not record data from actual patient episodes, it is important that patient confidentiality is upheld. The researcher will meet with each participant prior to commencement of the recording to discuss the study and discuss any issues related to the process of data collection, the study itself or any other queries participants may have, and again at the end of the week – the latter meeting will give you an opportunity to reflect on the process of taking part in this study.

You may wish to draw on episodes or specific challenges in your current practice or experiences in the past (it would be helpful if you could tell us which it is). In particular, if you decide to participate, you will be asked to comment on the following (you may wish to answer some questions at lengths and not others – these are only suggestions rather than a questionnaire):

How do you feel about caring for people at the end of their life?
In your daily practice, is there a drive to incorporate end of life care tools when caring for dying patients?
Which are these drivers?
How do you feel about them?
What is most easy / difficult about incorporating such tools in your daily work? Why?
What are the challenges?

It is envisaged that the recordings will be very much up to the individual health care professional as to how you wish to capture your views and experience. You can phone the researcher at any point during the data collection process if you feel the need to talk things through with someone professional contact numbers are stated below.

We would hope for the recordings to last between 30 minutes and an hour, but the exact length, and whether it is recorded in one or several episodes is entirely up to you. This is designed so that the research is little disruption to your working life, while enabling you to reflect on end of life care and get back to recording as and when you feel is most convenient and adequate. Recordings should take place in a private and confidential environment. The recordings will be anonymous – only the researcher will know who has agreed to take part and therefore has a recording. Please don't state your name or profession on the recording, but even if you do, this will be removed from any written document as will any other identifiable information that has been included in error. At the end of the recordings you will be asked if you agree for the researcher to contact you in case they have any questions they wish to ask.

If you would like to take part in this study, please complete the reply slip and return to Joanne Atkinson using the prepaid reply envelope or e-mail address provided.

If you agree to take part the researcher will contact you to first review this information sheet with you and answer any questions you may have.

What happens if I do not want to participate?

Participation is completely voluntary. It is entirely up to you to decide if you would like to take part.

What would happen if I agree and then change my mind?

You are under no obligation to take part and if you do decide to take part, you are free to withdraw at any time if you change your mind without giving a reason. However, the data collected from the interview will still be used in the research with all personal identifiable information removed. It will not be possible to withdraw the data at this stage. Not taking part or withdrawing at any stage will not affect your employment or future education in any way.

Will my participation in the research be kept confidential?

The information gathered by the researcher (i.e. recorded in depth accounts) will be anonymised (i.e. all names will be removed). The researcher will ensure confidentiality
is maintained unless there is disclosure of professional misconduct or harm to any individual in which case the researcher will inform the relevant person or body of this disclosure.

What will happen to the information that is gathered?

The researcher will type up the recordings with names and any other identifiable information removed. Only the researcher will have access to this information. The information from all of the people involved will then be analysed and used to complete the final report. Any direct quotations or comments that are used in the final report or any subsequent publications or presentations will be anonymised. Names and details of participants will not appear in any printed document. The voice recorders will be picked up by the researcher at the end of the recording period and following a meeting to discuss your experience will be transported back to the university.

The recordings will be stored securely in a locked cabinet at the Northumbria University and destroyed a year after the end of the research. The transcripts will be kept for three years and then destroyed.

What will happen to all the information collected for the research and how will the research report be disseminated?

All the information collected will be looked at and analysed in order to identify participants' thoughts and views about delivering end of life care. These will then be used to produce a final report. As in your normal practice, please DO NOT share any patient's personal details

A summary of the research finding will be sent to all the participants and the full report can be requested by the participants after the final report has been produced. Findings may also be used in subsequent publications and presentations, meetings and conferences.

What if I feel I need to talk to someone confidentially once I have completed my recording?

If you need to talk to somebody confidentially or have any issue when undertaking the research, you can contact Joanne Atkinson or Monique Lhussier on the numbers below.

Who do I contact if I want to ask more questions about the study?

Please feel free to contact the researcher, Joanne Atkinson, if you need further information.

Joanne Atkinson
Principal Lecturer
Coach Lane Campus East
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NE7 7XA

Telephone No: 0191 2156112
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Dr Monique Lhussier
Senior Lecturer
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Coach Lane
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Newcastle upon Tyne
NE7 7XA

Telephone No: 0191 2156036
Email: Monique.lhussier@northumbria.ac.uk

13 Appendix Two – Consent Form

CONSENT FORM: Healthcare professionals

Research Title: From Philosophy to Apparatus How Do We Improve Care at The End of Life?

Research Aim: To enhance professional understanding of the cultural / social and professional conditions necessary for the improvement of care at the end of life.

Researcher: Joanne Atkinson

	Yes (please initial)	No (please initial)
I have read and understand the Information Sheet and have had the opportunity to ask questions which have been answered to my satisfaction.		
I understand that I do not have to take part. If I do take part I may withdraw at any time, without giving a reason.		
I agree to participate in an unstructured narrative / interview. I understand that these will be recorded. I give permission to the researcher to have access to this information for analysis.		
I understand that the information I have given in this study may be used in the future as part of further work on this subject.		
I understand that my interview / narrative will be analysed, transcripts and results from the study will be anonymised and that my name and details will not appear in any printed documents.		
I agree to take part in this study		
I would like to receive a summary of the results of the study		
I understand that data collected during the study may be looked at by individuals from regulatory authorities. I give permission for these individuals to have access to the data.		

_____ _____ _____

Name of Participant **Date** **Signature**

Name of Researcher **Date** **Signature**

14 Appendix Three – Example of Recorded Narrative

Recorded Narrative Transcript - 03

OK I'm going to start about how I feel about caring for people at the end of their life *emm* basically from student to newly qualified nurse I found the prospect quite daunting actually *emm* I think it's probably because dealing with death is not obviously a regular occurrence. *Emm noticeable intake of breath* and when you join the medical or nursing profession you don't know what to expect. You've never see it before. I relied quite heavily on senior members of staff to guide me through the process so I've learnt a lot from them. *Emm swallowing* Tools such as the Liverpool Care Pathway *emm* are enormously beneficial for newly qualified and *Emm noticeable intake of breath* student nurses to act as a guidance I suppose. To guide them through the process of death. Not that it is a typically *emm* straight forward process – everybody's different – all the types of patients that you look after are different *noticeable intake of breath* but it's there to act as a guide and support people through the process *emm* and guide them I suppose.

054

I can still recall the first ever patient *emm* that I looked after who was dying. I was on *err emm* in the third year of my training *emm* I was frightened, *emm* I didn't know what to expect, *emm* very much relied heavily on the guidance of the junior sister at the time who took me in, or prior to to taking me into the room of this patient who had actually died, we were going to lay this gentleman out *noticeable intake of breath* and she talked me through everything before we even went in there. She, she told me what I should, should have expected *emm* explained that it, you know, you don't always

expect the same things from the same patients when they've died. *Noticeable intake of breath* emm from how they would look. She told me *emm* particularly when *swallowing* we rolled them possibly that they might *emm* release what seems like a breath and not to be frightened by that. She talked me through the whole process so in actual fact when we went into that room to lay that gentleman out it wasn't scary. It was emm a moment to give the final cares *emm* to that patient to – you know – there was – she heavily promoted dignity and *emm* respect of that patient even though they were no longer there. *noticeable intake of breath emm* she was really important to me and a very good role model that junior sister *emm* because without that I didn't know what to expect and that stayed with me throughout the whole of my training and the years since I've qualified really *emm* and I try to do the same for other junior members of staff and any student nurses that I have. *Noticeable intake of breath* I still remember how I felt at that time *emm* the fear of the unknown I suppose *emm* the stigma attached with, with dying. It's sometimes a horrible thing and it's not. It's a very natural thing and it was made out to me to be a very natural thing from the description that the junior sister gave me about it emm and *yeh* I carry that through *emm* when I now look after patients that are dying, when I lay patients out *noticeable intake of breath emm* that's followed through.

056

As a junior member of staff *emm* I often found that communicating with patients that were dying and communication with their families and friends quite difficult. *Emm* I always worried about saying the wrong thing or saying something that was inappropriate or that they felt was inappropriate *emm*

because I felt nervous *emm* you don't want to upset people and you certainly don't want to say the wrong thing *swallow.* I spent a lot of time watching how senior members of staff *emm* communicated with patients that were dying and communicated with patients families *noticeable intake of breath* and friends and I learnt a lot from those people *emm*. I think there's a lot to be said for experience when it comes to end of life care – I don't think it's something that *emm* you can automatically *emm* or that's automatically built into you as a person – to be able to deal with that *emm* especially when you're really, really young *emm* and I'm not saying that *emm swallow* young people can't cope with death and dying and can't communicate appropriately – that's not what I'm saying at all – *noticeable intake of breath emm* it's just that with experience you learn how to *emm* families are going to potentially react, you learn how patients can sometimes *emm* some patients are absolutely 100% ready to die. They would be frightened, some of them, but some of them have accepted it *emm* but some, some haven't accepted it, some don't accept it and, and that's extremely difficult to deal with and that side of communication *noticeable intake of breath* when you're communicating with families, friend *emm* relatives *emm swallow* and the patient themselves is often difficult.

057

What I have actually learned through experience is that sometimes there isn't the right thing to say *emm* and that's when listening becomes extremely important. *emm* some people just feel ten times better *emm* just to get the feeling off their chest and that can be patients, families, friends *emm* just somebody to talk to, to tell them how they're feeling. Somebody who'll listen

to them, who'll give them a hug *emm* they not, you know, some some people aren't looking for answers, they're just looking for somebody to off load to because they don't want to have to burden their families or their friends with, with that.

058

What I find most difficult about looking after patients *emm* who at the end of their life swallow *emm* these days, even with the experience that I have, it's the sheer volume of patients that we seem to have *emm* coming to the ward now. *emm* I suppose in the last ten years *emm* there's been a lot more *emm* research done and people are more aware *emm* of cancer. There's, it's come a long. Long way and with that *emm* you know it's more and more people being diagnosed and we're only a small unit. We cater for *emm swallow* a small – relatively small – amount of patients when you compare it with a general medical ward *emm* that has probably an extra ten beds to us. *emm* the sheer volume of patients and it's so acute now. *emm* We, we look after a lot of patients who undergo bone marrow transplant and *emm swallow* so when it comes to patients, looking after patients who are at the end of their life *emm* in terms of beds we've got a lot of acutely ill patients *emm* and we're finding it more and more difficult *emm* to allow patients to die on the ward but they choose that they want to die on. Some patients want to die at home and that's great. We provide an excellent service to do that. *emm* but the ward is still very acute so even when you've got a dying patient on the ward *emm* who demands a hell of a lot of *emm* of care and attention, it's not just the patient that you're looking after you've also got their family and friends *emm* as well as your acutely ill patients *emm swallow* and it's a lot.

And when I think back to when I was *emm* at the beginning of my career *swallow emm* we had the time *emm* to look after patients properly without feeling that you were neglecting any of your other patients. *emm* we did have the time. We seem to have spent a lot of time with patients that were dying. You were in there all the time *emm* patient's and family's felt your presence all the time and these days *emm* I'm finding myself conscious of the fact that I need to go in and check this – families alright , that the patient's comfortable *noticeable intake of breath* but I'm also aware that I've got other patients that require my attention as well and it's just sometimes a little bit *emm* too much and you end up feeling guilty because you want to be able to provide everybody with the exact care that you would want to provide for your own family and friends *emm* and you've got to juggle your time very, very *emm* well, you've got to juggle it very well *emm*.

059

I think one of the hardest things to deal with in practice is actually deciding when somebody is *emm* palliative I suppose. *Noticeable intake of breath emm* not just palliative but sort of end of life care. We get a lot of patients *emm* that come in who've undergone a hell of a lot of treatment *swallow* and they're tired, they're, they're fed up *emm* we're pumping them full of drugs *emm* to try and, and help to make them better and it's who actually makes that decision that enough is enough. *emm* the patient has a massive influence on that *emm* but as well it's the, the Doctors. Trying to get a Doctor make a decision – what generally happens on our ward and it happens a lot *noticeable intake of breath* is that the Doctors will write in the notes not *emm* for escalation of care e.g. 'Not for ITU but for all ward based kind of care'. So

that would mean basically there's no DNAR in place but you know that patient's not going to get any better but you're expected, because there's no DNAR in place, to resuscitate that patient should anything happen to them. There is no clear guidance *noticeable intake of breath emm* it's almost like we have to pin somebody down to actually make a decision. *emm* You know you say to a Doctor you've said that this patients not for ITU but what happens if they go off on the ward you've got no DNAR in place. We would have to resuscitate and we're not going to get anywhere with that patient but probably, more than likely, cause them some, you know, a lot of trauma *emm* and are you actually going to get them back *emm* and if you know that's not the case , if you know that's not going to happen *noticeable intake of breath* then you need some, some sort of a decision has to be made and *emm* and when eventually, you know, a decision is made its usually to go towards the Liverpool Care Pathway. *emm* And then that, that again, once that decisions been made that needs to be discussed with the family and what I find is that 9 times out of 10 on the ward that discussion takes place with the family and friends but it's not very often a nurse is present. There, there's a certain number of consultants and Registrars that will ask for a nurse to be present when a discussion takes place *noticeable intake of breath* but it doesn't happen all the time so you don't know what's been discussed with the family and the friends. *emm* You know you've got some' you know, a Doctor comes up to you and says 'we've started this patient on LCP' and that's the first you're informed of it.

060

I think in terms of *emm* informing patients or discussing with patients about the possibility of starting the Liverpool Care Pathway it, it rarely happens. I suppose because of the acute nature of the diseases that we deal with. *emm* patients can become *emm* very poorly very quickly and, and often *emm* slip into a deep sleep and when it happens as quickly like that as it usually does *noticeable intake of breath* you miss that window of opportunity to discuss with the patient *emm* you know, what the LCP entails. It's usually a discussion that occurs with *emm* the family and friends rather than with the patient *swallow* but in terms of its use I've always found it really beneficial. As I said earlier *emm* for particularly qualified and junior members of staff its, its, it acts as a guide *emm* you it tells you who to inform, which discussions should take place, what drugs should be prescribed, the criteria for putting somebody on an LCP. But what I've struggled with lately particularly *emm* since the report *emm* came out of, you know, bad examples or bad practice *noticeable intake of breath emm* with *emm* using the LCP is that nobody kind of knows what to do. It's like we're treading on eggshells *emm swallow* you know do we, do we still use the paperwork, do we not. And we have had communications from senior members of staff who, who've obviously said the LCP will phase out because of bad practice and it will eventually be replaced by something else and that we should continue to. To use it *emm* until something, until it's replaced with something else. But then we've had *noticeable intake of breath emm* I looked after a lady recently who was end of life care and whose family really, really struggled to come to terms with the fact that their, their mother was dying *emm swallow* and that they felt that we were withholding fluids from her *noticeable intake of breath emm* but the fact

of the matter was the lady could not, she had no gag, she would have choked on the fluids and you explain and that to the family *emm* is all well and good. You almost feel as if *emm* in providing the usual end of life care for a patient that you would normally provide to any other patient but I felt like I was doing something wrong and I acted no differently to the way that I had always acted with patients' and I knew that giving this lady a drink would cause her more distress than not. And we provided mouth care packs etc. but from the family's point of view we were withholding fluids and therefore that was *emm* you know torturous to their mother. *emm* and in that instance I *emm* utilised the Palliative Care Team. They're a fantastic resource not just for symptom control *emm* you know they've got the time sometimes that we don't to discuss in-depth *emm* information with families and friends and stuff. But in this instance *emm* I called them to come and have a discussion with this family and they did and they listened to the family *emm* you know they, they realised that they were getting more distressed at the thought that their mother was being dehydrated *emm* and we started sub cutaneous fluids *emm* Its about getting that balance you know, you don't want your patients' to suffer but you don't at the same time want their family and friends to suffer either. It's, it's a difficult one and sometimes I think at the minute in particular everybody feels like they're treading on egg shells but what, what do we do? Nobody wants to be accused of neglect and you know *noticeable intake of breath* in certain circumstances that is exactly how, you know, you know, how the public feel that the LCP works and I've had so many positive experiences from using the LCP with patients' from *emm* it guiding me through the process of *emm swallow* of what to expect and who to inform

emm and from my patients' as well who *emm* received excellent care and it terms of the documentation *noticeable intake of breath emm* there's so much that's going on with the family and with the patient *emm* and your documentation is a key part and with the LCP everything is just so easy to document. Its set out in a way that's *emm* you don't feel like you're missing anything out. You can document when the patient is agitated, how you've already dealt with that agitation, whether they've had pain *noticeable intake of breath emm* everything that you could possibly think of and there's sections to *emm* document extra bits that you come across when looking after that patient.

061

Another complex issue when looking after patients who are dying is *emm* pain relief. *emm* When I was first starting out in my career we used to have *emm*, in particular on a night shift, one Doctor for the ward *emm swallow* and these days we have one Doctor for an entire Directorate on night shift and when you're titrating analgesia for a patient who is quite clearly in pain and is dying and you got distraught family members who are having to witness this and struggling to get a hold of a Doctor because they're dealing with some acute emergency elsewhere, *swallow* is really, really difficult. *swallow* and *emm* it's, it's happening more and more often. *emm* You know we've got the drugs prescribed but they're only prescribed every four hours and it's only been an hour since they last had it. The patient's still in pain and you're making that phone call and you know, through no fault of their own the Doctor as soon as they, they can get there they will change the prescription *emm* and they're only working alongside one other Nurse Practitioner.

noticeable intake of breath so there's two of them for to look after say four wards all with acutely ill patients and *emm* ultimately they have to prioritize their time and for me my priority is that dying patient and for them it could be another patient on another ward who's acutely ill who's, you know, having a cardiac arrest *emm* and so there lies the problem. So a lot of the complaints that we've had *emm* over recent years have been from families who've, who've felt that *emm* the needs of their loved one weren't dealt with as quickly as they should have been. *swallow emm* A lot of the time the patients who complain about that do not complain about the, the care of their loved ones *emm* it's the sheer, sheer amount of time it takes to get those drugs *emm* sw prescribed again. I mean they're already prescribed but you know, to get them more frequent, more frequent *emm* as a prescription. I recently had a very young *emm* a very young man who was in *emm* palliative phase of life and *emm* he had excruciating pain and you know, we would give him analgesia, it would work for a little bit and then it would wear off and then it would happen again. And the comment that was made by his mother to me was "I've got 12 dogs and I wouldn't allow a single one of them *emm* to put up with pain like this". And I mean this was during the day and I knew, no matter what, that I had to get this young lad comfortable before the night shift came in because you're then even left with even less staff to deal with *swallow* with problems and you know, should his pain continue to get worse and he didn't have the analgesia *noticeable intake of breath emm* that he needed then, then that patient would suffer and you know, that, that's not fair. *emm* And to give them their due, I mean our team pull together and we you know, we worked together as a team to get this young man settled and

comfortable and pain free *swallow* which in turn made his family feel more at ease because he was no longer suffering. *emm* And I had to take myself off after that incident into a quiet room and I absolutely broke my heart because all I wanted to do in my career is look after people and when you can't control somebody's pain through, you know, no fault of your own because it's out of your hands *emm* then that, that becomes something that you struggle with *emm* and it's hard to come to terms with. You don't feel like you're doing a good job for that patient and you cannot reassure that patient or their family and make them feel *emm* secure and comfortable and well looked after if you don't have the tools at hand to do that.

062

I think one of the things that we do well is as a team *emm* that we work really well together. We work well to recognise *emm* when members of staff are feeling out of their depth *emm* which is particularly important with junior members of staff. I always remember in the early stages of my career having senior nurses *emm* ask me whether I feel comfortable enough to look after that patient *noticeable intake of breath* and I'm happy to say that that's continued throughout my career. That's something that's never changed and it's one thing that I always try to do with junior members of staff now *swallow emm* Because at the end of the day the ward is extremely acute *emm* these days, there's no other way about it – the ward is acute, it's very, very busy. *emm* We now work with less, less number of staff per shift than we, than we used to *emm* which means you can't as a senior member of staff be you know, in one place at one time, you have to be, you have to be around *emm swallow* and be there to support other members of staff and that can

sometimes be quite hard when you know, *emm* as the, as the years go on we, we're experiencing *emm* a faster turnover of staff. People are going elsewhere looking for jobs. We've got people approaching retirement. We've got a lot of junior staff *emm* on the ward which is *emm* unusual *emm* it, it's – I've certainly never known the ward like this and you've got, you've got to, as a senior nurse, be more aware of that *emm* because the minute you leave that person *emm* feeling out of their depth *emm* the, the more negative they could feel potentially about end of life care. If they haven't got their support there then, then how are they expected to cope and how are they expected to learn. *swallow* I for one seriously learnt by *emm* experience, learnt by watching. *emm* I definitely wasn't thrown in at the deep end *emm* and I was very, very grateful for that because *emm* death and dying is a complex *emm* it's a complex area of care *emm* and there's a lot of *emm* sensitivity required *emm* so for me that's highly important and I'm fortunate to work in a team of people that still *emm* appreciate that. *emm* I think we're extremely good at supporting *emm* junior members of staff *emm* I think the Trust provides an excellent teaching system *emm swallow* you know, to guide people through the Liverpool Care Pathway. *emm* I remember when I was first starting to use it I was, actually had somebody, *emm* somebody there, a person who actually came to the ward to teach us how to use the LCP appropriately *emm* and I think it's a shame these days more and more frequently *emm* these training systems are now kind of put onto the Intranet system for you to *err swallow* to watch a video or to, you know, PowerPoint Presentation that you're supposed to watch and then answer questions at the end and sometimes it's not about being able to answer questions. Sometimes it's

being about being you know, able to ask questions yourself. *emm* We're all different at the end of the day. We've all had different experiences *emm* we all feel differently about different things and sometimes having the appropriate person there to ask those questions to *emm* feel comfortable to ask those questions to is really, really important *swallow* and I think without the close knit team *emm* that I work with I certainly wouldn't feel *emm* as confident and as I suppose at ease *emm* at dealing with death and dying as I do now. *emm* Its almost become *emm* I wouldn't say second nature because that would make it sound as if you know, I was a little harder by the fact of dealing with death and dying – it's not that at all it's just – it does become easier to talk to patients, to relatives, to *emm* other members of staff even about it.

063

I feel that overall *emm* as an individual I feel that I look after end of life patients really well. I think the team that I work with look after patients in end of life *emm* really, really well *noticeable intake of breath* And unfortunately yes we've got less, less staff *emm* more acutely ill patients *emm* as well as dying patients *noticeable intake of breath* to look after *emm* and sometimes it's hard, shifts are hard and *emm* its just really important to me to know that I'm working with a team of people who are on the same wavelength as me. We all want one common goal and I think sometimes it's, it's sometimes easy to kinda think 'Oh God' it's just you don't feel like you're doing a good job because you don't do things like you use to do and I've come to the realization that no we can't do things the way we used to do them *emm* for one way, for one reason or another but it's important to look at ways that we

can draw together as a team to, to do things. *emm* It's different, you haven't got the, you haven't got the same number of staff. You're dealing with *emm* acutely ill patients at the same time, it's constantly finding that you have to prioritize your time whereas in the past you were allocated a dying patient and that was your, your patient for the entire day. You had the time. It's not like that now and you know, trying to be a positive as I can *emm* in the respect that you know, things have changed *emm* the NHS has changed and rather than focus on the negative *emm* aspects we need to be focusing on the positive aspects. Things that we do well *swallow* and you know, we have to learn to adapt and *emm* deal with situations as there're occurring at the time. *emm* I find it very stressful at times to *emm* you know, when I spoke earlier about titrating patients analgesia *emm* things like that, but as long as I know that I've got a strong team behind me, which I always do, *emm* and that we achieve the goal at the end and I can hand on heart say that I've never sw not achieved a goal in the end. We've struggled along the way but you know, in all *emm* years of my career so far *emm* I've certainly *emm* not had *emm* such a negative *emm* experience with end of life care that would, that would make me *emm* completely criticise the entire system because I can't do that, because my experience is 'we get there in the end these days'. *emm* We just need *emm* a bit more stability. I suppose now that the LCP is under scrutiny emm that's, that's the next step forward. *emm* You know, as a professional dealing with death and dying *noticeable intake of breath* I *emm* it's such a taboo subject in the, in the public eye *emm* we're not a nation of people who deal with death very easily at all *swallow* and what the LCP provided was just some sort of guidance of how to deal with it and you know,

my worry is that we've got you know, newly qualified staff starting on the ward who, who are started at such an unpredictable time *emm* in terms of end of life care and it's something that they're having to deal with and it's hard as a professional that they look up to *emm* to provide guidance because I don't know what kind of guidance I should be providing. All I know is that I have a dying patient that *emm* needs to be kept comfortable and *emm* you know, as free from anxiety and discomfort as possible and I know how to achieve that *swallow* with or without the LCP but what it does provide is a guidance and you know, that is, that's just so important. That combined with an actual person, somebody you can look to as a role model *emm* I think it's the perfect combination. It was for me and it's made me *emm* view death and dying in a totally different way that I did when I was first starting out in my career *emm* it's no longer a daunting prospect.

03 Discursive Formations

Therapeutic

Tools such as the Liverpool Care Pathway are enormously beneficial for newly qualified and student nurses to act as a guidance I suppose. To guide them through the process of death. Not that it is a typically straightforward process – everybody's different – all the types of patients that you look after are different.

Professional Apparatus

She (a junior sister) heavily promoted dignity and respect of that patient even though they were no longer there. She was really important to me and a very good role model that junior sister because without that I didn't know what to expect and that stayed with me throughout the whole of my training and the years since I've qualified really and I try to do the same for other junior members of staff (importance of professional support – Thinking that the unsaid is that this is scary and a lonely road for the patient and the nurse support and guidance is really important)

The stigma attached with, with dying. It's sometimes a horrible thing and it's not.

From student to newly qualified nurse I found the prospect quite daunting actually I think it's probably because dealing with death is not obviously a regular occurrence (is it not an inevitable occurrence is this because we are focused on health and see death as a failure?)

I had to take myself off after that incident into a quiet room and I absolutely broke my heart because all I wanted to do in my career is look after people and when you can't control somebody's pain through, you know, no fault of your own because it's out of your hands then that, that becomes something that you struggle with and it's hard to come to terms with (emotional burden – living with dying)

Because the minute you leave that person feeling out of their depth the, the more negative they could feel potentially about end of life care (support how does this fit with the discourses of palliative care do they fuel this perception that we are not doing enough, when is enough enough? Living with dying)

Experiencing Dying

With experience you learn how to families are going to potentially react, you learn how patients can sometimes some patients are absolutely 100% ready to die. They would be frightened, some of them, but some of them have accepted it but some, some haven't accepted it, some don't accept it and, and that's extremely difficult to deal with.

Patients can become very poorly very quickly and, and often slip into a deep sleep and when it happens as quickly like that as it usually does you miss that window of opportunity to discuss with the patient you know, what the LCP entails. It's usually a discussion that occurs with the family and friends rather than with the patient but in terms of its use I've always found it really beneficial.

But what I've struggled with lately particularly since the report came out of, you know, bad examples or bad practice with using the LCP is that nobody kind of knows what to do. It's like we're treading on eggshells you know do we, do we still use the paperwork, do we not (left with no steer does this link with some of the media artefacts defensive medicine and treatment decisions confused and inconsistent?)

Giving this lady a drink would cause her more distress than not. And we provided mouth care packs etc. but from the family's point of view we were withholding fluids and therefore that was you know torturous to their mother and in that instance I utilised the Palliative Care Team.

All I know is that I have a dying patient that needs to be kept comfortable and you know, as free from anxiety and discomfort as possible and I know how to achieve that with or without the LCP but what it does provide is a guidance and you know, that is, that's just so important.

Economic

In terms of beds we've got a lot of acutely ill patients and we're finding it more and more difficult to allow patients to die on the ward.

I'm finding myself conscious of the fact that I need to go in and check this – families alright, that the patient's comfortable but I'm also aware that I've got other patients that require my attention as well and it's just sometimes a little bit too much and you end up feeling guilty because you want to be able to provide everybody with the exact care that you would want to provide for your own family and friends and you've got to juggle your time very, very well, you've got to juggle it very well (Resource issue, acute area where they care for dying patients resources very tight impacting on patient care)

Medical

Trying to get a Doctor make a decision – what generally happens on our ward and it happens a lot is that the Doctors will write in the notes not for escalation of care e.g. 'Not for ITU but for all ward based kind of care'. So that would mean basically there's no DNAR in place (are doctors afraid too this is death denying, is death a failure?)

A Doctor comes up to you and says 'we've started this patient on LCP' and that's the first you're informed of it (sense of team need for team communication control and medical power I and only I make these decisions)

Mediatisation of Death and Dying

Like we're treading on egg shells but what, what do we do? Nobody wants to be accused of neglect and you know in certain circumstances that is exactly how, you know, you know, how the public feel that the LCP works and I've had so many positive experiences from using the LCP (impact of media in EOLC and the change in approach to delivering care in order to defend against any critical levy)

It's such a taboo subject in the, in the public eye we're not a nation of people who deal with death very easily at all and what the LCP provided was just some sort of guidance of how to deal with it (Death as a taboo)

Sensationalist

He had excruciating pain and you know, we would give him analgesia, it would work for a little bit and then it would wear off and then it would happen again. And the comment that was made by his mother to me was “I’ve got 12 dogs and I wouldn’t allow a single one of them to put up with pain like this”. Language metaphor

Institutional

You had the time. It’s not like that now and you know, trying to be a positive as I can in the respect that you know, things have changed the NHS has changed and rather than focus on the negative aspects we need to be focusing on the positive aspects (changing NHS architecture is this commitment to end of life care rhetoric no resources to make it a reality, targets and audit institutional power ? voice)

15 Appendix Four – Newspaper Artefact and Initial Analysis

Newspaper Artefact One

As minister claims controversial end-of-life plan is 'fantastic', shock figures reveal ...

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD

UP to 60,000 patients die on the Liverpool Care Pathway each year without giving their consent, shocking figures revealed yesterday.

A third of families are also kept in the dark when doctors withdraw lifesaving treatment from loved ones. Despite the

EXCLUSIVE

By **Jason Groves, Daniel Martin** and **Steve Doughty**

revelations, Jeremy Hunt last night claimed the pathway was a 'fantastic step forward'.

In comments that appeared to prejudge an official inquiry into the LCP, the Health Secretary said 'one or two' mistakes should not be allowed to discredit the entire end-of-life system.

But Elspeth Chowdharay-Best of Alert, an anti-euthanasia group, said: "The Pathway is designed to finish people off double quick. It is a lethal pathway.

'Mr Hunt has made a nonsense of the claim of his ministers that there is going to be an independent inquiry.'

The review follows a public outcry

Turn to Page 2

Artefact 1.

Daily Mail December 2012

Monday (New Years Eve) – signal of intent – sensationalist

Headline article

Front Page

General consumption / circulation – mainstream media

Headline

Numbers 60 000 Death Pathway Without being told – Headline

Main Body

60 000 patients

Die on the Liverpool care pathway

Without giving their consent (giving consent when dying – planning for death)

Shocking figures (sensationalist mediatisation)

Kept in the dark (death analogy?)

Doctors withdrawing lifesaving treatment from loved ones (mediaclisation sensationalist)

Jeremy Hunt claimed pathway a fantastic step forward (political) Prejudge an official enquiry into the LCP (political institutional discourse the law)

Hunt - One or two mistakes should not be allowed to discredit the entire end of life system (unsaid yet it does – reticence to be explicit institutional and mediatisation)

Anti Euthanasia group – pathway is designed to finish people off double quick (economic and moralistic - language final and perfunctory)

It is a lethal pathway (Death inevitable it is an end of life pathway mm)

Mr Hunt has made a nonsense of the independent enquiry (control legal power governmentality institutional discourse)

String of disturbing cases highlighted by this paper (media control overt mediatisation)

Pathway involves withdrawal of lifesaving treatment (professional apparatus and control implied, sensationalist people are dying Life Death paradox)

Sick are sedated usually denied nutrition and fluids (experiencing the dying)

Death takes place in 29 hours (said short time, implied should be longer, reality how do we prognose death contrary to what has been said undermines the thrust of people not dying put on pathway experiencing the dying and professional apparatus)

60 000 from MCCC and RCP (just numbers who have used the LCP used by the DM as interpretation of number dying unnecessarily – manipulation mediatisation)

Patients not consulted despite being conscious

Records from 178 hospitals thousands of people left to die in pain (sensationalist having pain and being left in pain mediatisation)

Nurses do not do enough to keep them confortable (professional power and control blame – the voiceless with least authority?)

Clinical judgment being skewed by financial incentives (echoes RQ comments re financial incentives, interesting considering the papers political stance and the fact that the Tory government brought these incentives in economic)

£30 million to put people on LCP (sensationalist figures again mediatisation and economic)

Critics say it is a self-fulfilling prophecy no scientific method for predicting death (undermines the consultation issues here medicalization of death and dying)

Many cases of families not being consulted (Norman Lamb – care services minister, balance no palliative care input in article, silenced unsilenced - experiencing the dying)

Hospice style care to terminally ill people in hospital (Jeremy Hunt – underpins the above comment where is the palliative care voice institutional in terms of the organisations where people die)

Hunt give people dignity in their final hours (cos he is an expert NOT – institutional and experiencing the dying)

Patients and families should be fully in the loop (what does this mean?)

Figures were scaled up from MCCC and 44% of cases conscious patient no record of the decision (Scaled up or made up! mediatisation)

One in three families did not receive a leaflet to explain the process (new development professional apparaus)

LCP system spread across the NHS in the past four years review due to report in the new year (Published new years eve testimony to the agenda of this paper? Unsaid)

16 Appendix Five – Television Artefact Initial Analysis

Dispatches Death on the Wards – Channel 4 Documentary 5th March 2013

Opening sentence is the NHS prescribing backdoor euthanasia? (powerful opening sentence setting the scene for the documentary)

Woman states I asked why is my dad like this and the doctor said your dad is dying (this is symbolic of the death denial that permeated through society)

Narrator a leading consultant in the NHS tells us he wants the most widely used protocol banned (pans to Professor Patrick Pullicino triangulates with written media)……does it result in shortening of life – yes it does and in some cases quite appreciably (technologies of power the doctor as the oracle he says therefore it is) another female doctor … our daily job is dealing with patients who say you wouldn't treat a dog like this and implicate euthanasia (relevance of gender?? Edited to actually support the previous statement? Technologies of representation the power of manipulation)

(Patient in wheelchair with terminal lung cancer admitted to St John's hospice for pain relief pictures of her in a wheelchair in he snow with daughter)

…. Her busy life was brought to a standstill when she was diagnosed… I have loved life and I have give lots as well as taken lots, ts been a wonderful life, at the moment I am going through that awful grieving process of understanding my body (technologies of caring – a rare glimpse of how it feels to be inside a dying body)

Here (St John's) the have a plan for the dying patient its called the Liverpool care pathway and it starts when a doctor judges a patent as being close to death (doctors judgment technologies of power, professional apparatus)

(Dr Penny Macnamara consultant in palliative medicine) Shows a patient consultation narrator says she is a strong advocate of the LCP…. I think it brings consistency it's a prompt to ensure we review the key issues every few hours, this is a framework to deliver that.

(Narrator) The LCP originated in hospices with the intention of alleviating the dying process and for the dying hospices are preferable to dying in busy hospices (pans back to daughter) it would be my absolute nightmare for mum to be on a hospital ward they don't deliver the care they are too busy (technologies of caring demonstrates the challenges and the desperation of carers) Like most of us Connie would like to die at home (?)

Colin –terminally ill with MND he too trust Dr Penny McNamarra with his care ….its really important you develop relationships with good palliative care

doctors before it is too late (technologies of caring – understanding the experiencing dying)

Narrator – a key principle of the LCP is to stop treating a patients underlying disease if the treatment is deemed to be futile (triangulates with GJ interview the word futile used all of the time technologies of power and professional apparatus) The LCP may have begun in the hospice movement but now it is part of something much much bigger the palliative care strategy. You may not be aware of this but by and large hospitals and hospices have an approved framework for dying patients and by far the most common is the LCP (professional apparatus made real for the consumer) The aim is to standardize care some doctors remember care before the LCP.

(PM) I remember walking into wards where patients are distressed and agitated in their last days of life, I think that is a horrible thing to experience and a horrible thing for relatives to witness (technologies of caring what is unsaid is the horro the numbers the history of eolc in hospital)

(N) It is estimated that around 90 00 people die a yaer when on the LCP (! Triangulates with media artefacts the surprise that people on the care of the dying pathway die) it was designed for cancer patients but now people with all types of diseases are put on the pathway their average age is 82

(N) description given of LCP ….but this is when it gets controversial medication to treat the underlying disease is stopped and even food and drink is stopped (delivered in a sensationalist manner – technologies of representation)

Pans to a picture of LCP documentation …. Relatives claim their loved ones have been starved and dehydrated…. Lurid media headlines have claimed that the LCP is close to legalized euthanasia, and that doctors are killing off patients who have months if not years left to live to save money (pictures of headlines - technologies of representation, sensationalist narrative)

(PP)There is no data to determine when a patient is reaching the end of life it is intuition determined by the team at that time. If you say somebody has a poor prognosis then you make it a self-fulfilling prophecy (technologies of power medical opinion being the authority)

(PP Patient strokes and dementia daughter being interviewed) I said my dad isn't a number (N) why did you say that (Daughter) because I didn't want them to kill my dad off (technologies of representation language is stark – sensationalist) PP came back for a weekend away stopped pathway – narrator with notes – show that there was serious disagreement between PP and the other doctors and nurses regarding this patient (this is an example of

medical power one doctor and the ownership of patients Lupton networks of power) Daughter – went home and lived for another 14 months he had his ups and downs.

(PP) I don't think that doctors would people on the pathway to make them die I don't believe that is true really don't (adds balance)

Another case described by narrator woman elderly cervical cancer diagnosed two weeks before in casualty brought in unconscious – family describe a consultant tapping the patient on the shoulder calling her name a few times then turning to the family and saying she was hours or days from death (this kind of practice is what has brought the media storm about and caused the LCP to be held in disrepute technologies of caring and power juxtaposed against each other) Husband – this was the first time he had seen my wife she had been seen by other doctors he just said your wife's dying and it were shock I couldn't believe it

(she was transferred to a hospice) placed on a syringe driver that administers drugs, the family recall being told that she did not require food or fluids. Daughter – I believe in dying naturally not numbing the senses and starving people (stark language could this be avoided with good communication, technologies of caring and maybe power, impact on the family for the rest of their lives)

(Connie transferred home to die interviewed earlier in the programme daughters as carer) I feel I am waiting for a bus (blunt use of language experiencing dying technologies of self though)

(Narrator) one of the harshest criticisms of the LCP is that it is not properly explained to patients or their families

(bereaved daughter and son) nothing was explained as to why it was happening nobody said anything there were no choices, no choices (carer burden leaving with guilt at not being a string advocate technologies o caring – what is unsaid is what was said) (daughter) when I asked what the pathway was they said oh its something to make your mum more comfortable. The family are going to make a complaint the hospital told then being on the LCP did not change the outcome – (yes but the communication was poor institutional control, technologies of power)

Professor Sam Ahmedzai is one of the country's leading palliative care consultants (associated with medical power technologies of power he is therefore an authority) concerned about the LCP what actually happens on busy hospital wards is that the decision is made by basically strangers (trying

to remain true to the philosophy of palliative care but critical of the operationalization professional apparatus)

For some doctors this can be a box ticking exercise without intense decision making (professional apparatus) if it is not de-humanizing then it is certainly automatic and that is not good when dealing with a dying patient.

Junior doctor working in elderly care when the LCP is explained properly then I have not had a family that have had a problem conversely when it is not explained correctly great problems occur (need to recognize the strength of the therapeutic relationship technologies of caring)

Narrator – the accusations against the LCP are so serious that the government has ordered a review (institutional control technologies of power governmentality) we surveyed 3000 doctors of the 573 that replied 57% said the pathway was being used less because of negative press coverage (technologies of representation)

Kate Granger I have always thought of the LCP as a good quality toll that enhances care at the end of life and I haven't changed that opinion since being diagnosed terminally ill. (very powerful professional knowledge and self disclosure technologies of self) widespread criticism has impacted on its use.

(Narrator) this is an issue pitting doctor against doctor one doctor told me the LCP had no place within medicine (technologies of power, hierarchies within medicine perhaps).

17 Appendix Six - Northumbria University Ethics Approval

Professor Kathleen McCourt CBE FRCN
Dean

This matter is being dealt with by:
Professor Olivier Sparaganc
Associate Dean
Faculty of Health and Life Sciences
Research & Innovation Office
Room H007
Coach Lane Campus East
Newcastle upon Tyne, NE7 7XA

Tel: 0191 2156480
Fax: 0191 2156083
Email: *julie.blackwell@northumbria.ac.uk*

Joanne Atkinson
Northumbria University
Faculty of Health & Life Sciences
Coach Lane Campus
Newcastle upon Tyne
NE7 7XA

3rd December 2012

Dear Joanne

Faculty of Health and Life Sciences Research Ethics Review Panel
Title: From Philosophy to Apparatus How Do We Improve Care at the End of Life?

Following independent peer review of the above proposal, I am pleased to inform you that University approval has been granted on the basis of this proposal and subject to compliance with the University policies on ethics and consent and any other policies applicable to your individual research. You should also have recent CRB and occupational health clearance if your research involves working with children and/or vulnerable adults.

The University's Policies and Procedures are available from the following web link:
http://www.northumbria.ac.uk/researchandconsultancy/sa/ethgov/policies/?view=Standard

You may now also proceed with your application (if applicable) to:

- NHS R&D organisations for approval. Please check with the NHS Trust whether you require a Research Passport, Letter(s) of Access or Honorary contract(s).
- Research Ethics Committee (REC). [They will require a copy of this letter plus the ethics panel comments and your response to those comments]. If your research is subject to external REC approval, a 'favourable opinion' must be obtained prior to commencing your research. You must notify the University of the date of that favourable opinion.

You must not commence your research until you have obtained all necessary external approvals.

Both the University and NRES strongly advise that the supervisor accompany the student when attending an external REC.

All researchers must also notify this office of the following:

- Commencement of the study;
- Actual completion date of the study;
- Any significant changes to the study design;
- Any incidents which have an adverse effect on participants, researchers or study outcomes;
- Any suspension or abandonment of the study;
- All funding, awards and grants pertaining to this study, whether commercial or non-commercial;
- All publications and/or conference presentations of the findings of the study.

We wish you well in your research endeavours.

Yours sincerely

Professor Mima Cattan
Faculty Research Ethics Review Panel

18 Appendix Seven – Trust R and D Approval

The Newcastle upon Tyne Hospitals NHS
NHS Foundation Trust

Royal Victoria Infirmary
Queen Victoria Road
Newcastle upon Tyne
NE1 4LP

Tel: 0191 233 6161
Fax: 0191 201 0155
www.newcastle-hospitals.nhs.uk

SS/MC

27th February 2013

Ms Michelle Muir
Lead Nurse Palliative Care
Cancer Services
Freeman Hospital

Dear Ms Muir

Trust R&D Project:	**6485**
Title of Project:	***From Philosophy to Apparatus How Do We Improve Care at the End of Life?***
Principal Investigator:	**Ms Michelle Muir**
Number of patients:	**10**
Funder (proposed):	**No funds**
Sponsor (proposed):	**University of Northumbria**

Having carried out the necessary risk and site assessment for the above research project, Newcastle upon Tyne Hospitals NHS Foundation Trust grants NHS Permission for this research to take place at this Trust dependent upon:

(i) you, as Principal Investigator, agreeing to comply with the Department of Health's Research Governance Framework for Health and Social Care, and confirming your understanding of the responsibilities and duties of Principal Investigators by signing the Investigator Responsibilities Document. A copy of this document will be kept on file within the Joint Research Office.

(ii) you, as Principal Investigator, ensuring compliance of the project with all other legislation and guidelines including Caldicott Guardian approvals and compliance with the Data Protection Act 1998, Health and Safety at Work Act 1974, any requirements of the MHRA (*eg* CTA, EudraCT registration), and any other relevant UK/European guidelines or legislation (*eg* reporting of suspected adverse incidents).

(iii) where applicable, you, as Principal Investigator, should also adhere to the GMC supplementary guidance *Good practice in research* and *Consent to research* which sets out the good practice principles that doctors are expected to understand and follow if they are involved in research – see http://www.gmc-uk.org/guidance/ethical_guidance/5991.asp

NHS Permission applies to the research described in the protocol and related documentation, the following versions of the key documents are approved:

Document	Version	Date
Protocol	3	25th February 2013
Participant Information Sheet	2	25th February 2013
Participant Consent Form	2	25th February 2013

Any changes to these documents, or any other amendments to the study must be submitted to the Research Ethics Committee and MHRA (if relevant) for review – see http://www.nres.npsa.nhs.uk/applications/after-ethical-review/amendments/ for guidance). All amendments must be submitted to the R&D office for review in parallel with ethical and regulatory review so that implications of the amendment can be assessed. You must send a copy of all amendment documents to the R&D office and if the changes or amendments to the study have implications for costs or use of resources, you must also submit details of these changes.

19 Appendix Eight – Palliative Care Conference

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The media – influencing care

Joanne Atkinson

Director of Programmes: Department of Public Health and Well Being,
2nd April 2016

1

The Story So Far…….

- My Story
- The Research Story
- The End of Life Care Story

2

Illuminating the Discourses

- Mainstream media
  - Journalistic press only
  - Terrestrial factual outputs (postmodern life is saturated by dramatised death – Gellie et al 2014)
  - Collection and analysis of artefacts
- Tape recorded narratives
  - Specialist palliative care teams (consultants and CNS)
  - Consultant medical staff – cancer centre
  - Specialist cancer nurses
  - Cancer ward nurses

3

Emerging Discourses

- Moralistic
- Professional Apparatus
- Institutional
- Medical
- Technologies of caring (consumerism)
- Economic
- Mediatisation

SENSATIONALIST

4

5

6

plan is 'fantastic', shock figures reveal ...

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD

UP to 60,000 patients die on the Liverpool Care Pathway each year without giving their consent, shocking figures revealed yesterday.

EXCLUSIVE by Jason Groves, Daniel Martin and Steve Doughty

revelations, Jeremy Hunt last night claimed the pathway was a fantastic step forward

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How I saved my father from Care Pathway, by Tory MP

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

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8

targets on Liverpool Care Pathway

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

HOSPITALS are paid millions to hit targets for the number of patients who die on the Liverpool Care Pathway, the Mail

by Steve Doughty Social Affairs Correspondent

northumbria UNIVERSITY NEWCASTLE

9

More Examples

DAILY EXPRESS

RISE OF UKIP AND NATION'S UTTER DESPAIR OVER MASS IMMIGRATION

FREE DAMBUSTERS DVD

SHOCKING CARE OF DEMENTIA PATIENTS

Fillings at 90% of homes and hospitals

Why I'm happy if I look

FREE PRIDE & PREJUDICE BOOK

SUNDAY EXPRESS

FREE INSIDE YOUR GUIDE TO SAVING MONEY

100 ways to save £1000s

FAMILIES TOLD TO NURSE PATIENTS

Relatives should wash, feed and care for their loved ones in hospital

Dead BA pilots 'victims of toxic cabin fumes'

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10

ADHD and why we working mums need to look in the mirror

NOW GPs CHARGE TO VISIT CARE HOMES

NHS probes doctors' cash demands

Race-day Zara leaves

Why words look blurred when you read in bed

Can wearing high heels SAVE you from falls?

Dangers of cutting back on milk

GP SURGERIES: 1 IN 6 IS FAILING

1,200 practices may be putting patients at risk, warns watchdog

Quality of services can be checked online for first time

Taxman's celebrity blunder that has cost YOU millions

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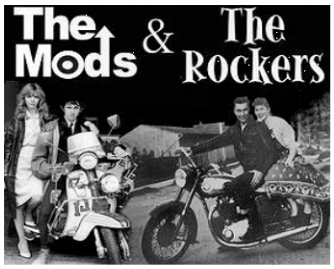
11

Moral Panic (Cohen 2002)



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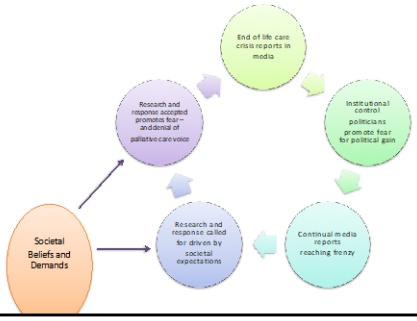
The Cycle of Moral Panic in End of Life Care



13

The Professional Voice

- The spotlight of the media on the LCP and some of the issues highlighted families are saying "oh yes I have read that in the paper" (Consultant)
- People are obviously worried that we're using the LCP to kill off relatives and things like that (Senior Cancer Nurse)
- I once picked up a Daily Telegraph and on one page was the LCP and how it was a tool for killing people off to shorten lives and save money for the NHS. On the very next page was an article about physician assisted suicide – a contradiction indeed (Consultant in Palliative Medicine)
- There a a lot of conflicting messages coming form the media that are impacting on practice (Clinical Nurse Specialist in Palliative Care)

14

Final Thoughts

- Resonance for all areas of practice – examples?
- Being heard versus being silenced
- People first…..
- Recognising influence
- Networks of power (Lupton, 2012)

- And finally burn the Daily Mail!!!

15

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Cohen S. (2002) *Folk Devils and Moral Panic* London. Routledge

Gellie A. Mills A. Levinson M et al (2014) Death a Foe to Be Conquered Questioning the Paradigm. *Age and Ageing 0 : 1-4*

Lupton D. (2012) *Medicine as Culture, Illness Disease and the Body*. London Sage

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16

20 Appendix Nine – Research Conference

Northumbria University NEWCASTLE

Discourse, Death and Fake News

Joanne Atkinson

North East Regional Palliative Care Research Symposium

March 20th 2018

#TakeOnTomorrow

1

The Story So Far…….

- My Story
- The Research Story
- The End of Life Care Story

#TakeOnTomorrow

2

The Research

- *From philosophy to apparatus how do we improve care at the end of life*
- Foucauldian spectacles!
- Critical discourse analysis
  - An opportunity to consider many perspectives without seeing the correctness of any (O'Connor and Payne 2006)
  - Discourse as a tool, a way of thinking of a culture revealing truths and power and the links to politics and the social world
  - The push and the pull can illuminate – silenced and unsilenced, the voice and the voiceless
  - Reflective open ended, the connection of texts (and voices) to historical and social contexts, practitioners and their practice

3

Research Aims

- Aim – To contribute to the professional understanding of the contextual conditions necessary for optimal end of life care.
- To explore what are the emerging, competing and overlapping discourse
- To consider the influence and impact of mainstream media on discursive practice in end of life care
- To explore how these discourse shape end of life care practice

4

Capturing the Voices

- Mainstream media
  - Journalistic press only
  - Terrestrial factual outputs (postmodern life is saturated by dramatised death – Gellie et al 2014)
  - Collection and analysis of artefacts
- Tape recorded narratives
  - Specialist palliative care teams (consultants and CNS)
  - Consultant medical staff – cancer centre
  - Specialist cancer nurses
  - Cancer ward nurses

5

Illuminating the Discourses

- Analytic framework adapted from Parker (1992) allowing exploration of the imposition and distribution of power through language and the reinforcement or undermining of institutions through discourse.
- Phase 1 – initial detailed descriptive analysis
- Phase 2 – emergence of broad categories, use of language, news representation, sources and subjects (Van Dijk, 2009)
- Phase 3 – explored in the broader context, landscapes and drivers, voices and the voiceless.

6

Emerging Discourses

- Professional Apparatus – tools, policy and practice drivers
- Technologies of Caring – therapeutic relationships, consumerist and experience of dying
- Technologies of Self – personhood, moralistic and ethical codes
- Technologies of Power – institutional and professional
- Technologies of Representation -

SENSATIONALIST

Northumbria University NEWCASTLE

7

Fake News – The Power of Representation

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As minister claims controversial end-of-life plan is 'fantastic', shock figures reveal ...

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD

UP to 60,000 patients die on the Liverpool Care Pathway each year without giving their consent, shocking figures revealed yesterday.

A third of families who also kept in the dark when doctors

EXCLUSIVE by Jason Groves, Daniel Martin and Steve Doughty

revealing, Jeremy Hunt last night claimed the system was a 'fantastic step forward'.

In comments that appeared to apologise for Jeremy Hunt's comments

not be allowed to discuss the dying patient's care.

But Rupert Chamberlain-Best of Alert, an anti-euthanasia group, said the pathway is designed to hasten the death of frailer people in a blind pathway.

Mr Hunt has made a numerous of the pathway's shortcomings that there is going to be an independent

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cash incentive for NHS trusts that meet targets on Liverpool Care Pathway

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

HOSPITALS are paid millions to hit targets for the number of patients who die on the Liverpool Care Pathway, the Mail can reveal.

By Steve Doughty Social Affairs Correspondent

percentage of patients who die on the pathway, and are the controversial regime.

In some cases, hospitals have been set targets that believe a third each

be on the LCP which critics say is a way of hastening the end for terminally ill patients.

Alistair Kilmartin, a cancer survivor from Surgeon is estimated to have been handed to hospitals over the past three years to achieve these goals. Chief of the national wanted

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A fate worse than death

The moment that Tony Nicklinson, who has suffered from locked-in syndrome for seven years, was told by a judge that he does not have the right to die

Reports PAGE 8

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11

Page 4 Daily Mail, Monday, November 5, 2012

Cancer expert brands Care Pathway 'the most corrupt practice in British medicine'

I wouldn't be treated in a hospital here, he says

Critic: Professor Mark Glaser

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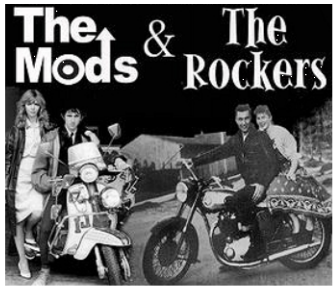
12

14

Moral Panic (Cohen, 2002)



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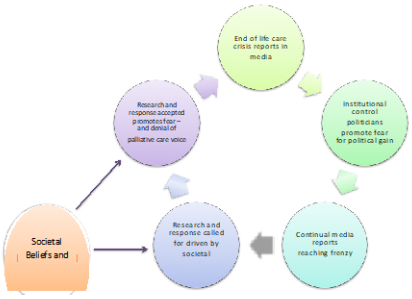
The Cycle of Moral Panic in End of Life Care



16

Final Thoughts

- Overlapping discourses
- Being heard versus being silenced
- People first …..
- Recognising influence
- Networks of power (Lupton, 2012)

- …….and finally burn the Daily Mail.

17

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21 Appendix Ten – Palliative Care Congress

End of Life Care Provision

Influences of Broader Discursive Formations

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Background

This study examines the discursive formations impacting on end of life care practice in the hospital setting. Practice is influenced by two major and sometimes conflicting issues.

Firstly, the demands of policy and practice drivers to apply tools (apparatus) across differing care settings make little reference to the broader cultural influences on delivery. Secondly, recent years have seen unprecedented media interest in end of life care, and the emergence of powerful discourses that influence health care professionals delivering care.

This work focusses on the tensions, challenges and possibilities that emerge from this intersection.

Aim

To explore the influence and impact of emerging, competing and overlapping discourses on end of life care practice in hospitals.

Methodology

Discourse analysis is a collection of methodological approaches, which attempt to link linguistic, socio-cultural and historical aspects of a field of study. Analysing discourses provides a route to better understanding the challenges and philosophy of care at the end of life.

Methods

Collection and analysis of artefacts from journalistic press and terrestrial television (factual outputs) was undertaken.

Narratives from four consultants and six clinical nurse specialists working in palliative care, and a cancer centre were digitally recorded, over a two-week period. Guidance was given regarding the aim of the study and length of narratives varied from ten minutes to two hours.

Media Artefacts

Cash incentive for NHS trusts that meet targets on Liverpool Care Pathway

HOSPITALS BRIBED TO PUT PATIENTS ON PATHWAY TO DEATH

HOSPITALS are paid millions to hit targets for the number of patients who die on the Liverpool Care Pathway, the Mail can reveal.

By Steve Doughty
Social Affairs Correspondent

"The incentives have been paid to hospitals that ensure a set

be on the LCP which critics say is a way of hastening the end for terminally ill patients.

At least £50million in extra money from taxpayers is estimated to have been paid to hospitals over the past three years to achieve these goals. Critics of the method warned

percentage of patients who die on their wards have been put on the controversial regime.

In some cases, hospitals have been set targets that between a third and two thirds of all the deaths should

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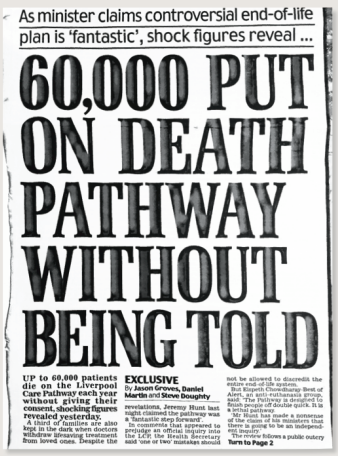
Daily Mail 31/12/12


As minister claims controversial end-of-life plan is 'fantastic', shock figures reveal ...

60,000 PUT ON DEATH PATHWAY WITHOUT BEING TOLD

UP to 60,000 patients die on the Liverpool Care Pathway each year without giving their consent, shocking figures revealed yesterday.

A third of families are also kept in the dark when doctors withdraw life-saving treatment from loved ones. Despite the

EXCLUSIVE
By Jason Groves, Daniel Martin and Steve Doughty

revelations, Jeremy Hunt last night claimed the policy was a 'fantastic step forward'.

In comments that appeared to preclude an official inquiry into the LCP, the Health Secretary said 'one or two' mistakes should

not be allowed to discredit the entire end-of-life system.

But Rispeth Chowdharay-Best of Alert, an anti-euthanasia group, said: 'It is clear that the aim is to finish people off doubly quick. It is a lethal pathway

'The Mail has made a nonsense of the claim of ministers that there is going to be an independent inquiry.

The review follows a public outcry

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Daily Mail 25/10/12

Illuminating the Discourses

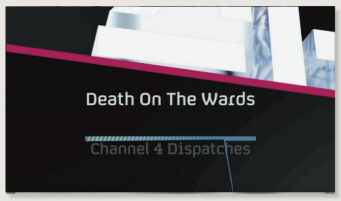
An analytic framework was adapted from the work of Parker (1992) and utilised to analyse the recorded narratives allowing exploration of the imposition, distribution and operation of power through language and the reinforcement or undermining of institutions through discourse (Foucault, 1972).

The media artefacts were analysed utilising a three-phase approach.

- ***Phase 1 was an initial detailed descriptive analysis.***
- ***Phase 2 saw the emergence of broad categories allowing for textual analysis and a more detailed analysis included the use of language, tone of the article, visual imagery and its impact, how the news was represented, sources quoted and subjects captured (Van Dijk, 2009).***
- ***Phase 3 in which the news articles were explored in their broader context, the landscape the media exists in, how they are read, what are the drivers, who has a voice or not, and who are worthy of reporting (Van Dijk, 2009).***

Media Artefacts

Alive in the Face of Death – Culture Show BBC2, 13/07/13



Death on the Wards – Dispatches Channel 4, 05/03/13

The Professional Voice

There are lots of conflicting messages coming from the media that are impacting on practice (Clinical Nurse Specialist in Palliative Care)

I once picked up a Daily Telegraph and on one page was the LCP and how it was a tool for killing people off to shorten lives and save money for the NHS. On the very next page was an article about physician-assisted suicide – a contradiction indeed (Consultant in Palliative Medicine)

The spotlight of the media on the LCP [Liverpool Care Pathway] and some of the issues highlighted families are saying "oh yes I have read that in the paper" (Consultant)

People are obviously worried that we're using the LCP to kill off relatives and things like that (Senior Cancer Nurse)

Findings

The media artefacts and narratives have reaffirmed the metaphorical language utilised when discussing end of life care, and highlighted the impact that the sensationalisation of end of life care has on practice, instilling a moral panic that both disables and fuels the need for change.

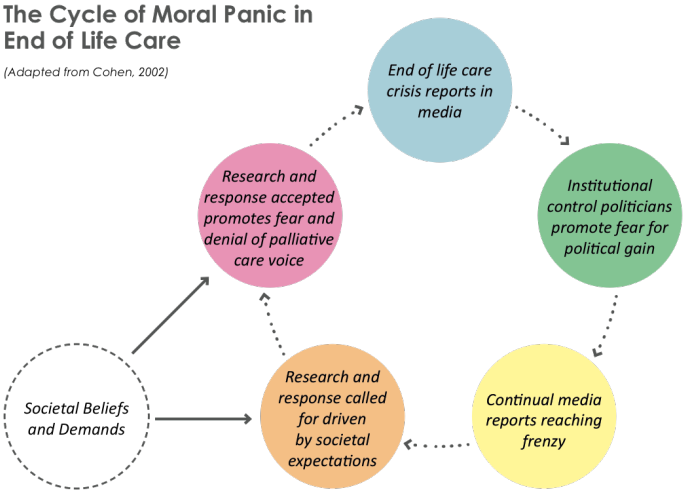
Prominent discursive formations include:

- ***Professional Apparatus***
- ***Technologies of Caring***
- ***Technologies of Self***
- ***Technologies of Power***
- ***Technologies of Representation***

The tensions, challenges and possibilities that emerge from this intersection influence practice in terms of how we orchestrate and perceive end of life care, how networks of power infiltrate care delivery and finally how media influences the care we deliver at the end of life.

The Cycle of Moral Panic in End of Life Care

(Adapted from Cohen, 2002)



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