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Thesis:

Moral Reasoning, Death and the Clinic: The Ethics of End-of-Life Decisions

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Abstract

This thesis explores the ethics of end of life decision making by examining the experiences of family members who were involved with the care of a loved one with terminal cancer. There are two main objectives to this research. The first is to understand the nature of the encounters between clinical care and families, how the dying trajectory affects decision making and how family dynamics impact end of life care. The second objective is to understand the process of moral reasoning and to determine whether the nature of ethical engagement differs for end of life decision making.

Each narrative case study provides a sequence of events from diagnosis to the end of the patient's life. It also includes both patient's and families' engagement with ethical problems which were encountered during the course of the trajectory, an analysis of their moral reasoning and what both patient and families considered to be a good death. Over thirty hours of interviews were conducted with ten participants. Narrative analysis is used to draw on pertinent contextual information along with an assessment of moral reasoning. This is done in two ways. First, it refers to the general rules of moral reasoning (Cohen, 2014) and applies the theories of three moral worlds (Zigon, 2007). Second, through a structural analysis of the narrative, other moral positions and indicators are revealed. Using a phenomenological approach to the data, important factors which proved to have a considerable impact on engagement with ethics included background and intention, the nature of the subject's life-world, and inter-subjectivity. In addition, both temporality and the emotions were given considerable focus to determine the way in which these elements also shaped end of life decision making.

This research responded to the need for more qualitative data for end of life decisions and, by combining both medical and moral anthropology, presents an innovative approach toward understanding both decision making and morality. It reveals that both life-worlds of patients and families are altered by a terminal diagnosis consequently changing the embodied moral worlds of the decision makers. The social and perceptual transformations, the sense of liminality and the power of emotions over their embodied moral worlds changed the nature of their engagement with ethics. Indeed, background experience, inter-subjectivity and emotions sometimes had a greater influence on moral choice than outside powerful social and cultural influences which made up their moral assemblage. My concluding finding is that moral reasoning, when it comes to end of life decision making, should be understood as an exceptional space which alters the parameters of our usual engagement with ethics.

The findings presented in this thesis have practical implications for medical professionals who engage with families and also for social workers and other counselors who assist families involved with end of life care. It also has implications for the study of moral anthropology by showing how death and the accompanying emotions shape our moral perspectives, decisions and worlds.

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Introduction

End of life decision making in the twenty-first century reflects a complex array of issues surrounding quality of life, clinical care and patient autonomy. The clinical management of death and the dying trajectory creates a paradigm whereby the personal, social and political aspects of the human body come into play. Both medical literature and contemporary discourse surrounding health and, by extension, end-of-life care, support patient self-determination and responsibility over decision making (Eliott & Olver, 2008 ; Van Brussel, 2014). In addition, the current ideals of institutional clinical care promote both patient autonomy and advocacy (Diprose, 1995 ; Silvester & Detering, 2011 ; Walker et al., 2015). Relationships of power between doctor and patient are no longer absolute, and unquestioned medical authority regarding decision making is being challenged. It is within this often confusing and unfamiliar domain that patients and families find themselves after a loved one receives a terminal diagnosis.

Transformations in science and technology in the last two hundred years have altered the way we die through biomedical attempts to cure and at least stall death. As Foucault argues, governing health was initially about "the control of the health and the bodies of the needy classes, to make them fit for labour and less dangerous to the wealthy classes"(Foucault, 1994: 155). What evolved from this initial project along with scientific development was a complex system of governance over the health of the population through which expert knowledge and power were inherent to its success. Bodies became objectified by medicine and were perceived as completely removed from all other aspects of the human being (Foucault, 1994). Indeed, medical advancement led to the body becoming politicised via monitoring, supervision and interventions. These forms of control constituted a bio-politics of the population (Foucault, 2008: 139). And, from a physician's point of view, death created a duty to prolong life which consequently resulted in prolonged dying trajectories (Walter, 1994: 49). From the nineteenth century, clinical and pharmacological developments along with the attitude that 'doctor knows best' extended the power and control that professionals had over the body resulting in a period of patient passivity during the twentieth century (Kellehear, 2000: 6; Lyon & Barbalet, 1994: 52). This biomedical view of control over life and death and over bodies ignored the social and individual subject which

even today still reduces the social to the biological (Lock & Scheper-Hughes, 1996: 48). In clinical care, we are a dying body; to the physician, we are a medical unit of analysis (Turner, 1992: 169). For most of the twentieth century, the medicalisation of death and the objectification of bodies as biological entities devoid of personhood meant that to a great extent, dying resulted in surrender into the hands of professionals and the clinic. This decision making was almost exclusively the arena of the physician yet medical interventions and attempts to cure began raising questions regarding patient vulnerability, suffering and autonomous rights.

Two key concerns which began to emerge surrounding medicalised deaths, and which continue to be the cornerstones of care today, are patient autonomy and advocacy. The erosion of the idea of the passive patient and the unquestioned acceptance of the rights of medical authorities began in the 1960's due to medical embarrassments like the thalidomide affair which led to a need for state regulation of medical practice (Weyers, 2006: 808). Also at this time, Dame Cicely Saunders launched the palliative care movement and Kübler-Ross published her study on a patient's psychological journey through the stages of dying. The medicalisation of death in hospitals became a moral question and there was a shift in the focus toward patient's experiences. Both paradigm shifts had as their central concern the comfort and holistic well-being of the patient which in turn, lead to the ideology of the 'good death' (Borbasi et al., 2005 ; McNamara, Waddell & Colvin, 1994). What became clear was that advances in technology and an unquestioned authority of the medical establishment did not always lead to positive outcomes highlighting that medical practice had ethical obligations to the wider community.

One famous case of this emerging ethical concern was the legal battle between the parents of Karen Quinlan and the Supreme Court of New Jersey in the United States in 1977. Karen was in a vegetative state on life support and required constant respiration and artificial hydration and nutrition to stay alive. Initially, the court rejected the parent's plea to remove her life support so she could die. The court's argument was that the medical establishment had a moral and professional duty to keep her alive (Weir, 1977: 272). Although the only thing keeping her alive was technology, it was still considered murder if she was removed from it. However, the court later ruled that they would not be charged for removing her

respirator because she would be dying of 'natural causes' and keeping her alive was inhumane – the decision being supported on the grounds of a patient's right to self-determination (Weir, 1977: 276). This shows that around this time, the patient's right to autonomy started to become recognised as an important consideration for end of life decision making. Further, that where a patient cannot exercise that autonomy, others have the right to advocate on their behalf. Karen's right to die, her right to self-determination, was exercised by proxy through her parents. What this case demonstrated was that keeping people alive at any cost could no longer withstand moral scrutiny. Preserving life was not the greater good because there was no quality of life. Letting nature take its course was not killing, it was relieving her of this inhumanity.

Due to developments such as this case, keeping people alive at any cost is no longer considered the most ethical action. Further, medical intervention time and again has showed that medical treatments at the end of life can increase the suffering for the dying patient (Borbasi et al., 2005: 110; Kastenbaum, 2004 ; Mohammed & Peter, 2009). That is not to say that futile surgeries and attempts to stall death by physicians, patients or families no longer happen; but that longevity at any cost is no longer viewed in itself as a universal good. This concern with suffering and quality of life is manifest in public discourse surrounding the right to die movement, 'death with dignity' groups, and the decriminalisation of physician assisted suicide (Hart, Sainsbury & Short, 1998 ; Van Der Weide, Onwateaka-Philipsen & Van der Wal, 2005 ; Van Wesemael et al., 2009). These political and cultural manifestations demonstrate a desire to further shift the power and governance of biomedicine over the body into the hands of those who are suffering – the patient. It symbolises a challenge to the prolonged and over medicalised death of the past in favour of patient self- determination and autonomous rights.

Patient autonomy and advocacy in the twenty-first century is now highly valued in clinical practice and is prominent, particularly in nursing education (Cole, Wellard & Mummery, 2014 ; Van Brussel, 2014). This principle supports the value that people should have the right to make their own informed decisions about medical treatments they wish, and those they wish to forgo (Silvester & Detering, 2011: 452). Physicians are the harbingers of choice by providing information to the patient with respect to what treatment or interventions are

available to them (Maynard, 2006). Both patients and families' right to choose or reject options leads to a sense of empowerment and reinforces the value of patient autonomy which, in turn, leads to a reduction of subordination to medical hegemony (Waskul & Van der Riet, 2002). As a result, patients are being given more control over medical intervention and challenging the old notion of the passive patient (Ivanović, Büche & Fringer, 2014), even rejecting the clinic altogether and choosing to die at home (Kellehear, 2009b).

This shift in a patient's autonomous rights also supports the value and idea behind advocacy. However, with this empowerment comes responsibility. Current institutional and public discourses promote the idea that the individual is responsible for their own health (Maynard, 2006 ; Price & Cheek, 2007) and from a bio-political point of view, the delimitation of individual freedoms implicates a notion of responsible self-management (McNay, 2009: 61). This power shift regarding patient responsibility is evident in end of life care. One manifestation of this, for example, is the global increase in patients taking up advanced directives and exercising some control over death by requesting do not resuscitate orders (Cherniack, 2002: 303). This is important not just due to the power dynamic between the medical establishment and the patient but because it directly affects what is expected of both patients and families when they engage with clinical care after a terminal diagnosis.

The current political, sociological and cultural conditions surrounding end of life care raise inherently moral questions regarding death and dying. Therefore, there are complex factors impacting moral reasoning, many of which are made explicit through first-hand accounts. Indeed, what needs to be assessed is how families navigate, understand and engage with this terrain.

Some studies have focused on family engagement. Clive Seale has undertaken many studies regarding end of life care and has examined family perceptions of clinical care (Seale, 1991). In these he showed that families were able to explain how the patient responded to care, and he found that they were often more critical of the quality of care than the patients (Seale, 1991: 151). Another more recent quantitative study looked at satisfaction of family members with the care the patient received and found that the institution and location of care was linked to the ability to attain a positive dying experience (Teno et al., 2004). This

work demonstrated that variations in experiences can depend on location and that family members have a vivid recall of the clinical care experience. Families can face problems navigating clinical options and settings, their emotional state is heightened when dealing with death and their life-worlds are transformed by it.

Current research has focused on an array of topics concerned with patient and family experiences of end of life care. From these studies we know that patients may not relate to all the elements considered to be part of a good death, that institutions can shape nurses perspectives of patients and that end of life care should be customised based on individual circumstances (Broom, 2012 ; Broom & Cavenagh, 2010 ; Broom & Kirby, 2013 ; Kellehear, 2008b). Other studies showed that families can have problems with staff, difficulty with doctor's communication, confusion about prognosis, temporal pressures on decision making and face an unpredictability of events (Borbasi et al., 2005 ; Curtis et al., 2002 ; Kastenbaum, 2004 ; Kaufman, 2010b ; McNamara, 2004 ; Russ & Kaufman, 2005). More recently, there has been some focus on families and their perceptions of events (Heyland et al., 2006 ; Quinn et al., 2012 ; Witkamp et al., 2015), problems in clinical settings and family conflict (Abbott et al., 2001 ; Anderson, Kools & Lyndon, 2013), and with making decisions (Eliott & Olver, 2008 ; Radwany et al., 2009).

Although many have documented how families deal with clinical encounters, none explore the existential experiences of families and how this affects decisions not just in clinical settings, but outside this environment. My phenomenological approach allows for this understanding of the different contexts, values and emotions which shape engagement with ethics and thus, end of life care. Many decisions are made from home and further, home deaths, according to my data, are the preferred place of death. Further, none of these studies explore the fact that end of life decision making should be distinguished from all other areas of medical decision making. This is because the moral reasoning which determines ethical choice is not the focus of these studies. Only through an analysis of moral reasoning can we understand the subjective experience and the transformative effects on life-worlds under these conditions. Further, a focus on the care of patients from the time of diagnosis to death provides a bigger picture not only of the impact of families on patient experience, but what events impact moral choice.

Some studies have attempted to focus on the moral questions faced at the end of life. Seale's (2009) recent study explored decision making through a quantitative analysis of doctor's decisions which they thought may have hastened deaths (Seale, 2009). It showed that doctors from different clinical settings, say between a hospital or hospice, reported their decision making differently and those who identified as religious were less likely to admit that their treatment decision might have hastened death (Seale, 2009: 1662). Seale determined that the clinical setting influenced the type of moral concerns which were raised regarding end of life care in relation to the questions of the quality and sanctity of life.

Also from the social sciences, Broom (2012) has researched end of life care and the question of morality. In this study, he claimed to unpack and reveal the moral economy of modern dying practices (Broom, 2012: 297). He interviewed patients and, although he recognised the clinic as a political space, he did not analyse their moral reasoning and largely equated the moral question with religiosity. However, we cannot reduce morality to religious influence. It is but one potential source among many. The strength of these studies was that they highlighted that the type of institution or place of death directly influenced the experience for patient and families. Their weakness is their approach to the moral question. No detail on moral processes are explored which does not allow for an understanding of how patients or families' moral positions are formed.

My research begins with a different premise: that morality is informed by many sources. One cannot hope to understand moral reasoning from a fixed, universal standpoint nor should morality be limited to religious influence. Instead, morality should be understood to be relative to the embodied life-world of the decision maker which is influenced by many moral sources. Therefore, my study is more dynamic in that it seeks to delve further into family experiences by understanding not only the patient and family's response to clinical care, but how and why certain decisions were made and on what moral grounds they were based.

More recently, studies have focused on prognosis, doctor's communication and temporality and their impact on clinical care experiences (Borbasi et al., 2005 ; Goldsteen et al., 2006 ; Kastenbaum, 2004 ; Kaufman, 2010b ; McNamara, 2004 ; Russ & Kaufman, 2005 ; Seale,

2009). Other studies have focused on families in terms of how conflict and dynamics affect decision making (Kramer & Boelk, 2015 ; Kramer, Boelk & Auer, 2006 ; Rothchild, 1994), their perspectives on place of care (Teno et al., 2004) and how they cope emotionally when caring for their loved one (Grbich, Parker & Maddocks, 2001). In this vein, Broom and Kirby (2013) sought to understand the death experience itself and the role that families play at the end of life. They revealed that family dynamics cannot be underestimated and that palliative care clinics should acknowledge the strong influence they have on individual death experiences (Broom & Kirby, 2013: 499). My thesis corroborates the position that families' impacts on patient experiences are significant and pivotal. However, this thesis goes further as narratives outline their involvement from diagnosis to death providing greater qualitative detail on decision making each step of the way. Therefore, it provides a more comprehensive look into family and patient dynamics and a broader understanding before admission to hospices, at which point, important decisions have already been made.

Beyond the clinical experience, some studies have focused more directly on the moral questions raised during end of life care. Some of these revealed that nursing staff experience conflict and contradiction due to clashes between institutional, occupational and personal moral objectives (Borbasi et al., 2005 ; Worthley, 2000). In another study of both doctors and nurses, the moral question is also explored; this time with a philosophical approach (Raus et al., 2014 ; Rys et al., 2013). Raus et al., (2014) reviewed opinion pieces submitted by doctors to medical journals covering a span of several decades. The Rys et al., (2013) study conducted interviews with doctors and nurses about the reasoning process and decision making they undertook. Both these studies were concerned with the medical treatment called Continuous Sedation, probably due to the ambiguity which often surrounds it. In the assessment of opinion pieces, moral responsibility was purported to be linked to the types of terms used for CSD and also, the types of justifications (Rys et al., 2013: 535). In the study which conducted interviews with doctors and nurses, feelings regarding CSD as an end of life decision affected their feelings of moral responsibility by way of four dimensions of 'closeness' between themselves and the patient (Raus et al., 2014: 3).

The significance of the studies was not just that they engaged with the question of morality but that they demonstrate that there are often conflicts between occupational moral

obligations and personal moral worlds. This highlights that there are competing influences on embodied moral worlds which is the position taken in this thesis. However, these studies are not ethnographic and their approach to the moral question and process is limited. Although they focus on moral problems, they do not interrogate the life-world of the decision maker or critically analyse any of the processes of ethical engagement in order to understand each moral position and what constitutes it. There is also a presumption that morality is essentially one universal concept which can be applied to all and in which decision makers occasionally experience conflict.

What is clear from the literature is a comprehensive focus on moral reasoning for end of life care is largely absent. What proves to be important for the objective of this thesis in terms of moral reasoning is the dying trajectory itself, the clinical care experience and family dynamics. What is undisputed in medical anthropology is the impact of temporality on decision making (Borbasi et al., 2005 ; Ivanović, Büche & Fringer, 2014 ; Kaufman, 2010b ; Mohammed & Peter, 2009 ; Russ & Kaufman, 2005 ; Worthley, 2000). And, although hope has also been shown to be significant in its effects (Cellarius, 2008 ; Good et al., 1990 ; Kaufman, 2010b ; Russ, Shim & Kaufman, 2005), I argue that both liminality and empathy play more significant roles in the process of moral reasoning for decision makers. Their role will be explored through the manner in which they transform the space occupied by participants during end of life care. Hence, these two important contextual elements are integral to the understanding of the dynamics of end of life decision making within which moral reasoning takes place. They affect how choices are made, what choices are made and why they are made. They impact both perception and the life-world of my participants who had to cope with difficult end of life decisions. This thesis attends to this neglected area to demonstrate not only how these factors impact medical decision making but how facing terminal illness transforms moral reasoning itself.

What is also clear from all the literature is the importance of being able to achieve a good death. What may seem simple is proven to be very complicated and the potential to achieve this rests on many circumstantial conditions. Decision making by patients and families is done with the aim to achieve this. Patients, families and physician's interactions and the type and quality of clinical care affect not only the experience but ethical engagement. How

these experiences were managed is central to this research. Through narrative accounts, family members articulate their engagement, perception and experiences of caring for their loved one with respect to the clinical encounter, the dying trajectory and whether or not they felt a good death was achieved.

In chapter one, I explore both past and current literature on end of life care to demonstrate the impact of context on medical decision making and the current values in health care. This context is vital if we are to understand the experience of end of life care. First, I look at the dying trajectory and the notion of the 'good death' and outline the evolution of changes and ideologies which have come to shape contemporary end of life care. This is to show how both changes in the health system and social values have impacted on our treatment of dying patients. This brings me to an exploration of the values of the palliative care movement we know today. The objective here is to seek to understand the potential normative behavioural models within institutions and how these can affect both patient and family experiences. In sum, it allows the reader to consider how the public discourses on heath and the intersection between clinic, staff and family can raise moral questions. Finally, I discuss the moral question itself by exploring the dividing line between life and death by elaborating differences between prescriptive moral arguments and practical moral actions.

Chapter two explains what moral anthropology is and how it should be distinguished from moral philosophy. I feel it necessary to explain this distinction in detail because opponents of moral anthropology, I believe, tangle up the objectives of moral philosophy with moral anthropology. It also outlines some normative ethical theories, such as duty and virtue ethics, which have been adopted by anthropologists.

In chapter three, I felt it pertinent to define the objectives of moral anthropology itself. To do this, I outline some approaches and explore concepts that other anthropologists in the field have applied, such as moral reproduction and freedom and the concept of moral economies. What was also important here was to distinguish two main approaches to the moral question. The first lies in whether or not the scholar approaches morality from a universal or relative position; the second focuses on the aspect of morality being analysed. I

situate my own research within these approaches which also serves to justify the theoretical propositions I have adopted. Finally, I engage with the critics of moral anthropology by highlighting both their misconceptions with discipline's objectives and their confusions about morality.

In being clear about my approach to morality and to avoid confusion, chapter three explores in detail the specific differences between moral philosophy and anthropology. I carry forward my exploration of the moral question in anthropology by summarising and critiquing some current ethnographic approaches to the moral question (Fassin, 2008 ; Robbins, 2007, 2009 ; Scheper-Hughes, 1996).

Chapter four and five outlines my phenomenological approach to the data and the points of focus which I will concentrate on in order to understand a participant's engagement with ethics. Within this discussion I introduce what I consider to be the two most important factors impacting end of life decision making, temporality and emotion; but more specifically, liminality and empathy.

Chapter six outlines my research methods and design and provides details of my data collection. Along with the analysis of episodes of moral reasoning, I outline how my approach to narrative analysis can also reveal, through content and structure, other moral indicators, stances and positions.

Chapters seven through eleven contain each case study which are grouped under prominent themes. I introduce these themes and outline their implications with respect to the life-world of the participant and how these themes and specific contexts shape moral reasoning and thus, end of life decision making more generally. Through these case studies, my three research questions are answered.

The first group of case studies examines the themes of Autonomy, Biomedicine and Maintaining Personhood. In this chapter, I examine the limits to both the principle and practice of patient autonomy, the promises of biomedicine and the nature of the biomedical encounter. I also explore how the carer's embodied view of patient debilitation and their

experiences of the biomedical encounter are shaped by their backgrounds and their life-worlds. In this chapter, there is a protective caring response from the participants which serves as a buffer between the biomedical realm and the personal, inter-subjective relationship between patient and carer. This is demonstrated through their moral reasoning which sees the value of autonomy through the maintenance of patient personhood.

Chapter eight is entitled Family Dynamics, Acceptance and a Good Death. This chapter examines what the participant's believe were good deaths experienced by their family members. Central to this achievement, I argue, is the demonstration of acceptance exhibited by the patient, even in the circumstances of biomedical misdiagnosis and lack of care coordination. The significance of the impact of family dynamics on the experience of the dying trajectory for the patient is also central to this chapter. I explain how both family conflict and support affect what decisions are made, the course of the trajectory and the moral reasoning of my participants.

In Bio-Politics, Suffering and Moral Obligation, there are three case studies. These emphasise bio-political aspects of body governance and failings of institutional moral obligations. The first two of my participants express their despair at the suffering of their family member which was particularly drawn out. The first of these is an explicit interplay of power relations where medical knowledge, technologies and a desire to cure is allowed dominance. This leads to an extended dying trajectory and suffering. The second case regards the prolonged institutionalisation of the patient and the failure by the clinic to control pain and implement the necessary care. In the first two of these cases, not only is the patient rendered powerless but so it seems are the family members. Finally, the third case in this chapter concerns a participant who saw breaches in care and actively took actions to counter these breaches as they occurred. Her moral reasoning at the time of the events was clearly translated through action. However, although all are critical of failings within the medical system and their lack of humane treatment of patients with respect to their personhood, each participant had a different perspective or 'moral stance' toward the events that transpired. There were different levels of moral outrage which attested to the differences in background and intention, life-worlds and level of involvement in decision making.

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Chapter ten examines the particular circumstances and moral reasoning which occurs when nurses care for their loved ones. In Nursing the Family: Self, Identity and Moral Worlds, I explore how moral reasoning is affected by concepts of the self and embodied perception. I examine how their role as a nurse affected their experience in caring for their loved one and their ethical engagement with choices. To do this, I use Taylor's (1989, 1992) concept of the self to help illustrate the connection between self, identity, and embodied moral worlds. In essence, this chapter seeks to determine the influences of the institutional moral world of medicine, the cultural construction of the nurse, and the reality of being a family member. I ask what these various sources of morality have on moral reasoning and, as a consequence, on approaches to care.

The final case study entitled Liminality, Transformation and the Moral Assemblage stands apart from the other cases. This chapter is dedicated to one narrative, one case study. It differs due to the fact that the participant and patient always made collective decisions. Due to this reason and the richness of detail, I felt that life-world of the patient could be the focus of examination. This case study is also different in that the patient experiences a three year period of remission. It is for this reason that I explore how the embodied experience of the patient exists in a liminal state. Many paradoxes arise with regard to the biomedical encounter as the patient was himself a healer. The wide variety of competing moral worlds, the 'moral assemblage' (Zigon, 2014), provides an insightful picture of the patient's life-world, embodied perception and in some respect demonstrates the limits of cultural and religious structures which constitute the subject. I attempt to answer some of these paradoxes by demonstrating the considerable affect that background experience and emotions have on the moral reasoning of the subject. I argue that the embodied moral world, filled with emotions and experience, affected by looming death, can give precedence over other social and cultural moral influences.

In general terms, each case study examines the nature of embodied moralities, how they are constituted, impact on and are impacted by biomedicine and death. Without any presumptions regarding motivation of moral actors, I explore each theme and allow the data to reveal the nature of the participant's moral reasoning. These narratives highlight not only

the predominant values which emerge when caring for a dying relative but through the interrogation of moral choices, answers larger questions about how our ethical engagement changes when it comes to death. On a theoretical level, some moral reasoning reflects certain normative ethical theories but I argue that this is less important than the understanding that embodied moralities should be understood as affected by an assemblage of moral worlds and that emotions are vital in shaping moral choices for end of life care.

Finally, chapter twelve serves as both a conclusion and a summary of my findings. In this chapter, The Ethics of End of Life Decisions, I outline the significance of my findings both for moral and medical anthropology, and some practical and political implications for end of life care. I also briefly explain some limitations faced in conducting this research and potential areas of future expansion. Fundamentally, I argue that end of life care engages a nuanced form of moral reasoning and thus should be distinguished in type as a study from other medical and care decision making contexts.

Chapter I – End of Life Decisions in Context

The dying trajectory and the good death

The concept of a 'good death' for palliative patients within institutional settings implies certain accepted norms of behaviour to which the patient is expected to conform – the most important of these being acceptance (Goldsteen et al., 2006 ; McNamara, Waddell & Colvin, 1994 ; Walter, 1994). To make a judgement claim of a death being good or bad is also shaped by broader ideological beliefs generated through public discourse regarding patient autonomy and the values of individualism (Walter, 1994: 63). A patient may or may not naturally conform to this good death model; some patients and families will not always reach a level of acceptance. Irrespective of this, death in an institutional setting still leads to a certain degree of patient passivity due to this normative model and the control over the trajectory by modern medicine and technology (Glaser & Strauss, 1968 ; McNamara, 2004 ; McNamara, Waddell & Colvin, 1995). What is clear is that there are good and bad ways to die and what these are depends on biomedical, institutional, patient and family circumstances.

Before the emergence of palliative care for the dying, death in a hospital setting was common and often led to suffering and isolation for patients who had very little say in the choices made by the clinic (Glaser & Strauss, 1968). Studies by Glaser and Strauss (1965, 1968) were important in defining patient's experiences of death in hospitals and the power relationship between doctor, patient and nurses where patients experienced either good or bad deaths. They explained that dying was a status passage, largely controlled by the doctor, and one in which the patient was expected to conform (Glaser & Strauss, 1965: 49). Good or bad deaths were related to the circumstances of the trajectory, staff and patient communication, and the extent of clinical control over the patient. Similar studies from the field of psychology also reflected concerns regarding the vulnerability of the dying. The book 'On Death and Dying' by Elizabeth Kübler-Ross being a significant example (Kubler-Ross, 1973).

Focusing on the emotional journey of the patient in a hospital setting, Kübler-Ross contrasted the perspective and expectations of the patient with those of the institution. Her main contribution to theory was in identifying the five psychological stages of dying. These were denial, anger, bargaining, depression and acceptance (Kubler-Ross, 1973). These stages defined a common trajectory through which a patient would pass. Like the work of Glaser and Strauss, the positive influence of this study was in bringing to the fore the plight of the patient. Some scholars argue that she brought the notion of the self – the individual, back into focus where treatment of the dying was concerned (Walter, 1994: 30). Developing the stages of grief was a positive step for end of life care in that it enabled institutions to better understand the emotional journey and consequent behaviour of the patient. However, in doing so, it also served to institutionalise new models of expected behaviour which resulted in criticism of her work due to her claims that all patients would follow the five stages and eventually face death with courage and acceptance (Moller, 1996: 53). Further criticisms of her work centred on the implication of arguing that the only acceptable and dignified form of death was that which took place with open awareness, denying different patterns of dying (Moller, 1996: 56).

Whatever the criticisms of her work, what can be said is that her study shifted medical attention and challenged the biomedical 'gaze' and the objectification of the body to the neglect of personhood. Right up until the early 1990's, her work was still recommended in nursing guides (Walter, 1994: 72). Today, it is clear that these stages still have a great influence on shaping institutional discourse and education as many definitions of a good death include similar versions of this behavioural trajectory (Borbasi et al., 2005 ; Broom, 2012 ; McNamara, 2004 ; McNamara, Waddell & Colvin, 1994).

At the same time Kübler-Ross released her book, there was a further change in clinical approaches to dying which resulted in the palliative care movement. Dame Cicely Saunders established the modern hospice in 1967 (Richmond, 2005). Her experience as a nurse, a social worker and physician meant that she was able to obtain a complex and cohesive view of the dying patient and sought to identify inadequacies in care (Kellehear, 2000: 154). Her goal and approach to treating dying patients is still reflected in the objectives and philosophy

adopted by the palliative care movement today. According to the World Health Organisation:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation, 2017)

This form of care for terminal patients incorporates and considers the emotional and psychological well-being of the patient. As Walter speculates; "If medieval and Reformation Christians gazed upon the dying and dead person's soul, if medicine in the Age of Reason gazed upon the body and upon the corpse, whole person medicine today gazes upon the psyche" (Walter, 1994: 37). Palliative care aims to encourage families to be involved and offers support for those dealing with death. This approach to caring for the dying most certainly arose from the problems inherent in the depersonalised, biological approach to patients in hospital care. Kellehear argues that hospice care "was a promising alternative to the 'never-say-die', 'high-tech' impersonal approach increasingly dominant in Western medicine" (Kellehear, 2000: 155). Today, although significant improvements have been made in end of life care, patients and families can still refuse to accept a dying status which can sometimes lead to prolonged and unnecessary suffering.

A recent United States study in health care revealed that inherent problems remain between the medical desire to 'cure' and prolong life, and the desires of the patient. The study found that doctors were still not consulting patients on treatment options nor considering their desires:

> The observational study found that physician-patient communication was unreliable and ineffective. The blunt truth was that physicians often showed little interest in the patients' own preferences and little inclination to honour them. This non-responsiveness to the wishes of seriously and terminally ill patients worked almost exclusively in one direction. If the patient did not want to have CPR used, physicians often continued the plan to use this procedure despite the patient's stated preference (Kastenbaum, 2004: 131).

This study seems to indicate that the shift in consideration for the dying patient is not complete or absolute at least with respect to physician's attitudes. It also lends support to

Kellehear's argument that the institution itself can contribute to greater suffering for the dying patient (Kellehear, 2009c). The in-balance of power and conflicting obligations between staff, institution and patient was highlighted long ago.

Sociologists Barney Glaser and Anselm Strauss were influential in the field of medical anthropology due to their ethnographic research in hospital environments. One important article published in 1965 articulated the dying process in a hospital environment which explained how nurses and staff managed treatment of patients. The dying process, it was argued, is likened to a non-scheduled status passage between life and death. How individuals are treated by the staff was determined by their status within this passage (Glaser & Strauss, 1965). Their particular 'status' is a criterion through which medical personnel identified the temporal process of dying (Glaser & Strauss, 1965: 49). The patient's status influenced levels of communication between staff and patient and dictated the care plan. Identifying the status allowed control over the dying trajectory of the patient to benefit the support systems of care within the hospital. According to Glaser & Strauss, doctors preferred not to tell the patient that they were dying or how long they had to go (Glaser & Strauss, 1965: 53). However, if they suspected that the patient knew, it would be revealed to the patient that they were dying but no time frame would be given (Glaser & Strauss, 1965: 53). Therefore, revealing information about the patient to them or the nursing staff was a means through which doctors could maintain control over the patient. This enabled the doctors and nurses to have more control over the reaction of the patient and by doing so, maintaining the passage:

> Once the patient is told by the doctor that he is dying – and recovers from the shock if the passage is both inevitable and undesirable – he must make the decision either to accept or deny dying. With this disclosure and acceptance or denial, the balance of control over the status passage can shift from the doctor and his staff to the patient (Glaser & Strauss, 1965: 55).

Therefore, if a patient refuses to accept his status as 'dying', he or she removes the control of the process from the staff to themselves. This shift in power upsets the progress of the trajectory which the staff attempt to manage and plan. For example, a patient in denial may affect how much consolidation and planning happened with family in their final days; for the staff it "will frustrate their efforts to relate to him according to how he is supposed to

act...they may give up, leave him alone, and turn to patients they can help" (Glaser & Strauss, 1965: 57).

The works of Glaser & Strauss and Kübler-Ross have provided an important foundation through which we have come to understand institutionalised death. They highlighted patient passivity in institutional settings, the control that experts had over the dying process and what occurs when unexpected things happen to upset the trajectory, like family interference (Glaser & Strauss, 1968: 64). They also highlighted how dissemination of information to the patient was tightly controlled and that there was a common silence between patient and staff about death itself, again in order to maintain control (Glaser & Strauss, 1968: 62). What was lacking in both these studies was phenomenological considerations of the experience of dying from the patient's perspective. Although their observations were a critical step toward understanding and improving end of life care, they still largely ignored issues of patient autonomy and were uncritical of the biomedical ontology which maintained control over the dying trajectory irrespective of the patient's wants and needs. In addition, the influence of families is only regarded with respect to their ability to interfere with the staff's attempt to control the trajectory. Whatever the limitations of these studies, their theories have laid the foundations and provided frameworks for medical anthropology and end of life care – references of their work still appearing in the literature (Borbasi et al., 2005 ; Komaromy, 2004 ; McNamara, 2004 ; McNamara, Waddell & Colvin, 1994).

What is common across these seminal studies is the medical establishment's desire for the patient to exhibit acceptance. There are two important effects of acceptance. For the institution, the clinic has better control over the patient's dying trajectory; for the patient, preparations can help avoid unnecessary and futile surgeries which can result in extended patient suffering (Seale, Addington-Hall & McCarthy, 1997). Hinton argues that although there has been more focus on what each individual perceives and how they cope with pending death, acceptance continues to be a common aim (Hinton, 1999: 21). Broom argues that the 'revivalist' good death, that of acceptance and awareness, may not be in itself problematic, but that "their normative and prescriptive potential is worth considering" (Broom, 2012: 228). This, I believe is understated. The normative model of the good death

which includes acceptance determines the expectations and moral objectives of clinical care. And, since studies including Broom's demonstrate that patients show much diversity in what they consider to be a good death (Broom, 2012 ; Goldsteen et al., 2006 ; Gott et al., 2008 ; Steinhauser et al., 2001), it is a fundamental element in understanding moral choices for end of life care.

A more recent study shows the importance of acceptance and how it affects all parties involved in end of life care. This qualitative study of dying patients with End Stage Heart Failure sought to determine a nurse's perspective of the difference between good and bad deaths by contrasting acute care settings with palliative care settings for ESHF patients (Borbasi et al., 2005). Each institutional setting exhibited major differences in ideologies and thus what was deemed appropriate treatment for the dying patient. One was motivated by cure, the other toward care. Patients who were transported between these two facilities had one approach then another.   Nurses pointed out that in this situation, lack of communication and conflicting objectives between the two facilities increased the risk of a bad death (Borbasi et al., 2005: 105). The author argued that this 'conspiracy of denial' or lack of acceptance from parties involved ultimately leads to bad deaths (Borbasi et al., 2005: 108). This denial, it was argued, can emerge from physicians, families or patients. The author states that sometimes there is a "medical obsession" to attempt to keep people alive and an insistence on "futile" efforts from physicians and families resulting in the extension of suffering for the patient (Borbasi et al., 2005: 110). Paradoxically, although the nurse's idea of a good death involves "the family and patient in decision making" (Borbasi et al., 2005: 107), this involvement, it is argued, can be detrimental if all are in denial. Consequently, family inclusion can lead to bad deaths. Conforming to the 'cure at all costs' ideology of a hospital setting, this study showed that nurses believed there should be a "realistic outlook" toward patients receiving end of life care; that the interdisciplinary team should understand when to "let go" of the dying patient (Borbasi et al., 2005: 111).

Another study which focused on the good death model in palliative care institutions focused on what patients determined to be a good death (Broom, 2012). He researched what effect the religious element of the hospice had on the perspectives of patients and staff. Focusing on the question of euthanasia with patients, he raised the issue of the limits to patient

autonomy as they relate to the moral economy of the religious hospice (Broom, 2012). Although the good death model always includes the elements of acceptance and awareness, acceptance does not always fit within the moral frameworks of the patient's experience. Broom points out that the "idea of a 'natural' ending with closure, acceptance, and dignity did not resonate with their experiences" (Broom, 2012: 231). He found that institutional expectations imposed on the patient seem to connect with desires for euthanasia. When patients indicated that it would be a good thing if they were able to hasten death, it was scoffed at by the hospice staff who considered it a "call for help" (Broom, 2012: 235). Broom explained that any desire for euthanasia or to hasten death within the hospice was not just ignored but was deemed unnatural and considered a sign of the patient's mental or spiritual wavering (Broom, 2012: 235). However, Broom does not explore the moral reasoning of the nurses nor does he analyse the moral claim that hastening one's death is deemed "unnatural" by them. This study assumes that morality is synonymous with religiosity and as such limits itself to illustrating that the religiosity of the hospice provides an additional normative stream in which the patient's behaviour is expected to fit.

Patient's autonomous rights and their acts of self-determination also challenge the good death model (Ivanović, Büche & Fringer, 2014). For example, refusing to eat, refusing pain medications or the preference to die at home are all examples of challenges to the good death normative model. A patient can refuse to be brought back by CPR even if this moral choice is difficult for the family; however, they have a right to make that choice (Elliott & Olver, 2008). Further, efforts at self-determination can also be a reaction to the imposed normative expectations of institutional care and can indicate a desire from the patient to have some control over their own deaths (Ivanović, Büche & Fringer, 2014: 6). Thus, since autonomy is also considered part of the good death model, in principle this means that the patient should have as much control as they wish to die in the manner they wish. Institutional ideals and support for patient autonomy in their philosophy of care may be a progressive mission but can result in all sorts of difficulties in practice.

Clinical institutions such as intensive care units have specific objectives and purposes. An account of daily life in an Australian Intensive Care Unit explains the complexity of the 'cure at all costs' moral position when it conflicts with what the nurses who work there deem

ethical (Worthley, 2000). For example, a father gave his daughter strict instructions that he did not want to be placed on life support should he have another heart attack. However, when he did and was rushed to the ICU, the daughter insisted that they do everything to save his life (Worthley, 2000: 158). Against the patient's wishes, he was placed on life support yet nothing could be done for him. The daughter was then responsible for switching off his life support and hence was ultimately responsible for the timing of his death. Worthley explains that the ideology of the ICU supports this denial of death. Even when individuals are brought into ICU essentially to die, it is not handled in such a way. She said; "nobody seems to die anymore" due to the fact that "critical care medicine has promoted itself as a discipline that can reverse any illness" (Worthley, 2000: 158). Therefore, when families want everything possible done to keep the patient alive, they are obligated to do so even though it goes against their better judgement. Worthley explains that they "go through the motions" of Cardiopulmonary Resuscitation (CPR) hoping the patient will not survive; that this "sham" is an attempt to satisfy relatives, but results in a "prolonged and painful death" which has "no justification" (Worthley, 2000: 159).

Other studies corroborate Worthey's argument by showing that family dynamics and conflict have significant effects on decision making in these settings (Kramer, Boelk & Auer, 2006 ; Rothchild, 1994 ; Su et al., 2014). Other ICU studies found that physician and nursing staff communications with families are central to the decision making process and are vital with respect to family satisfaction with the level of care (Abbott et al., 2001 ; Radwany et al., 2009). Therefore, it is clear that families have a significant influence in these clinical settings which are geared in very different ways to other settings. The orientation and training of ICU professionals is concerned with saving lives rather than helping patients through dying (Curtis et al., 2002: 148). Indeed, any action to save the life of the patient is accepted as the ethical thing to do. Action not only serves to placate the family, it also removes the responsibility for death away from professional staff and the facility (Mohammed & Peter, 2009: 297). One study of ICU's in the United States showed that only 5 percent of patients who entered the ICU were able to make decisions (Radwany et al., 2009: 376). Other studies show that by the time decisions must be made, patients are not able to communicate (Bartels & Faber-Langendoen, 2001 ; Curtis et al., 2002). Therefore, it stands to reason that it is both staff and families who are charged with the decision making in this environment.

Both the Ivanovic et al. (2014) and Worthley (2000) studies demonstrate the interplay and sometimes the conflict between moral positions and ideologies. Acute care settings are about saving lives, but the question of whether the life is worth saving is not really one anyone can answer except perhaps the patient who, as I argued, is often not in a conscious state to do so. Therefore, a 'cure at all costs' mentality could be triggered by the family hoping to keep their loved one alive. The implication as argued by the nurses in these studies is that this can lead to bad deaths. The other consequence of this is that the nurses must carry out actions they consider immoral. This is because they are subject to the institutional moral world of biomedicine and the hospital. Their embodied personal morality comes in conflict with the moral obligations of their role. What this demonstrates is the necessity of identifying the various sources which make up embodied moral positions within any loci. It also demonstrates the strong influence families have on end of life decisions.

Family involvement in the ICU environment demonstrates three important points with respect to the ethics of end-of-life decisions. First, that the place of death and its philosophy of care have a direct affect not just on what decisions are made, but how they are justified. Second, that the dying trajectory is of vital importance to the moral reasoning process as decisions are affected by temporality and three, that emergency end of life decision making sees all medical action as ethical. Indeed, the moral question is neutral with the exception of Not For Resuscitation orders or advanced directives in place which are honoured (Eliott & Olver, 2008: 183). Therefore, what can be determined from this is that moral reasoning for end of life decision making depends on the competing moral objectives of the particular clinical environment, the concept of the good death and the length of the dying trajectory. Indeed, temporality and decision making become fundamentally linked. Where there is no time available to ponder a decision, the decisions lean toward attempts to cure and save the life of the patient (Borbasi et al., 2005 ; McNamara, Waddell & Colvin, 1994 ; Mohammed & Peter, 2009 ; Worthley, 2000). Actions which save lives are easily justified; actions which may hasten death are not.

The dying trajectory and the good death normative model are clearly central in understanding the dynamics involved in end of life care. The type of trajectory and the concept of a good death are fundamental to decision making not just for clinical staff but

also for patient and family. Justifications for choices must always begin with these two important contextual elements. What is clear is that different clinical settings, such as the ICU, can be environments where moral conflict occurs between personal embodied moralities and institutional moral obligation. Therefore, we can see that both the length of the dying trajectory and the institution the patient finds themselves in affects not only the dynamic between staff, doctors and patients but what part the family plays in the process. It becomes an intersection of moral positions but also affects patient experience. Through these considerations we see potential links between temporality and decision making and how this may create moral dilemmas.

Institutional palliative care and patient autonomy

Although the hospice or palliative care institution has a care over cure philosophy, good deaths can be just as difficult to deliver due to attempts to treat the patient (McNamara, Waddell & Colvin, 1995). And, as has been discussed, futile treatments can lead to an increase in suffering for the patient and bad deaths can result when the patient does not fit into the predicted dying trajectory. However, within the philosophy of institutional palliative care, patient autonomy continues to be a central value (World Health Organisation, 2017) even though this autonomy is sometimes incompatible with the normative model of the good death and even with what the patient considers important (Broom, 2012 ; Gott et al., 2008 ; Mo et al., 2012). Autonomy then can be limited by a patient's perspective, condition and family involvement. Hence, the interplay between institutional values of care, patient autonomy and family involvement are a means through which to illustrate how palliative care philosophies impact the ethics of end of life decisions.

Hospice institutions have a clear objective of a care over cure philosophy. As I explained earlier, it was born with the focus on the holistic needs of the patient. Dame Cicely Saunders recognised that patient's pain during their dying went beyond physical pain to the psychological, social and spiritual (Kellehear, 2009c: 390). However, some studies show that there can be a gap between stated philosophy or policy and practical application. McNamara, Waddell & Colvin (1994) demonstrated that even in a hospice environment, the good death can be under threat. The nurses in their study argued that threats came from

the constant encroachment of mainstream medicine which prevented their ability to guide patients through to a 'good death' by doctors who viewed death "as a failure" (McNamara, Waddell & Colvin, 1994: 1505). Other threats to the good death also came from families who would 'not internalise' the philosophy of the hospice and from patients "who refuse to die" (McNamara, Waddell & Colvin, 1994: 1506). Thus, even though palliative care takes a holistic approach, the effectiveness of its delivery is impacted by attitudes of patients, families and doctors.

The McNamara study echoes the studies of the nurses in ICU in that each raised concerns regarding medically futile treatments and the bad deaths which can result. Even though the good death operates as a normative model through which patient care is organised (McNamara et al., 1994), the nurses' perceptions of a good death in the McNamara study demonstrate an interesting anomaly. According to the nurses in this study;

> The elements of patient autonomy and accommodation to individual and family value systems feature as aspects of the Good Death experience…Ultimately, though, the dying person is the central actor, who ideally maintains autonomy throughout the dying trajectory (McNamara, Waddell & Colvin, 1994: 1504).

What this suggests is that palliative ideals of patient autonomy should be at the centre of a good death. However, there is no guarantee that family, patients or doctors will agree.

The Australian National Bioethics Consultative Committee defines autonomy as having the right to make your own life decisions as long as those decisions do not involve harm to others (Diprose, 1995: 203). If patient autonomy is part of the 'good death' ideal, then how do patients exercise this autonomy? If a patient refuses to passively comply with what the institution believes is in their best interest, they have the right to do so. According to Garrard; "…we shouldn't prevent [autonomous] patients from making and acting upon their own autonomous decisions" (Garrard, 2009: 118). True autonomy, it would seem, is actually incompatible with the good death model. If true autonomy is respected, then the good death model could not be maintained. It is for this reason that the definition and negotiation of autonomy within situational contexts is an important part of this research.

Ethnographic accounts from families will articulate these perceptions and experiences of palliative care and autonomy and what effect these elements had on decision making.

An earlier study consulted family members to determine patient's experiences in different clinical care institutions (Seale, 1991). This study found that patient experiences in hospice care were overwhelmingly more positive for the patient than hospital care. These findings also showed that the family were, at the time, more critical of the quality of care than the patients (Seale, 1991: 151). A more recent study also supported the preference for palliative care institutions as place of death over and above a hospital environment (Addington-Hall & O'Callaghan, 2009: 195). These studies suggest that palliative care philosophies toward end of life care were not only preferred but that the experience for the families in these studies was also vivid. Perhaps this is because, as Kellehear argues, dealing with death is "an embodied, moral experience linked to place as political location and experience" (Kellehear, 2009c: 391). This tells us that place of death and philosophy of the institution directly affects not only outcomes for patients but the experience of families. It also demonstrates that different philosophies of care have different moral objectives and positions which can come into conflict.

Studies of moral reasoning for end of life decision making have been given scant focus and attention. There have been some studies which have focused on how emotional investment and involvement in end of life decision making leads individuals to describe events in a way that defends their moral reputations (Seale, 1998). However, this merely points out the moral link between decision making and death. Like the studies I referred to in the introduction which came from the field of nursing and philosophy (Raus et al., 2014 ; Rys et al., 2013), they provide very limited material on the actual moral reasoning process. More recently, a qualitative study regarding CSD treatment interviewed relatives about their loved one's experience of end of life care. They found that overall, relatives believed that sedation allowed for a good death but there were also concerns with whether it was the right choice. These concerns included whether continuous sedation may have shortened the patient's life and that sometimes they witnessed unexpected events, such as the patient regaining consciousness, which was of further concern (Bruinsma et al., 2014: 3247).

What these studies confirm is that different settings and approaches to palliative care directly impact both patient autonomy and experience. Further, they demonstrate how end of life decision making is inherently moral and often leads to dilemmas regarding the right choice to make. The comparison of responses by doctors and nurses regarding CSD reveals that intentions, justifications and terminologies for treatment are carefully worded and explained not only to protect their profession (institutional morality) but also their own moral reputations (embodied moral positions). Hence, ethical justifications for end of life care decisions must be both convincing to others and fit comfortably with the justifier's moral position and view of themselves.

Existing studies which consider morality lack the qualitative detail for a full interrogation of moral reasoning. The strength of each of these studies was that they highlighted that the experience of death and dying for the patient can be greatly affected by the institution. The limitations of these approaches were two-fold. First; the method. Quantitative studies cannot provide details necessary to explain the process of moral reasoning as they lack descriptive detail behind decisions. Second, they approach morality from a universal standpoint as through morality exists in a vacuum. Hence, these approaches are unable to provide a picture of the dynamic nature of decision making because they impart little to no information about the processes involved in moral choice or what informs embodied morality.

This thesis, as a qualitative study, provides the detail necessary to study moral reasoning. It does so by unearthing as much detail as possible provided by families regarding the course of events from diagnosis to death as well as providing detail of patient's responses to end of life clinical care. Through the participant's information, investigation of decisions can be assessed by the justifications which are provided for these decisions. Further, the moral stance of families can also be ascertained through both temporal and causal sequence of events within the narrative in relation to principles of goodness (Ochs, 2004a: 284). Along with whether or not the family member believes the patient had a good or bad death, each care and medical decision will take into account the rules of moral reasoning and the multitude of influences which constitute embodied moral worlds (Cohen, 2004 ; Zigon, 2010). Therefore, beyond current research, this thesis will explain not only what decisions

were made but what broader social and cultural contexts supported these moral positions and inform values. In so doing, it contributes to both medical and moral anthropology and to the broader questions surrounding the human response to death.

The ethics of life and death

It is the justification for action or failure to act which can reveal the values and morals surrounding a dying subject. These justifications emerge within the context of dichotomous concepts such as natural and artificial, care and cure, body and machine and living and dying. A doctor can let a patient die 'naturally', or the family can insist on sustaining treatment. The patient can accept their dying, or they can be determined to fight death until the end. As patient self-determination and rights are given more consideration, it is patients, families and doctors who may express different moral positions when faced with the reality of a terminal illness. These decisions are often conceptualised around issues such as quality of life and conflicts between biomedical and social realities. Decisions to sustain life or to let nature take its course, whether life has ended or if it continues, are difficult terrain to navigate. What is clear is that the details of individual's contexts are vital to determine any moral action. To extrapolate, I will discuss the topic of euthanasia to highlight the theoretical framework necessary to determine how morality of an action is determined. The objective is to show how the human condition and the corresponding ethnographic detail is essential for subjects to not only determine but justify any moral action.

Abrams (1978) argues that the simple distinction between killing and letting die cannot be applied to the euthanasia argument. This is because, she argues, death is always approached as an undesirable or negative outcome (Abrams, 1978: 262). If, however, we begin with the assumption that death is desirable, then the end result may morally justify the action. Therefore, active and passive euthanasia could be viewed as leading to the same, positive result. One could argue that the way in which death is achieved is irrelevant; that passive and active euthanasia are one and the same thing. However, it is not that simple. It is not just the end result that is important with respect to the ethics of a decision; it is, in fact, the *manner* in which it is carried out and how it is justified which is important. This justification must be supported by a cultural and social framework where the justifier

exists which determines whether or not an action is moral. To understand this, we first need to determine the exact difference between active and passive types of euthanasia.

The difference between active and passive euthanasia is that active euthanasia involves the deliberate and active intervention to end someone's life; passive euthanasia is where an individual is 'allowed' to die through an omission of an action (Sanders & Chaloner, 2007: 42). Therefore, active euthanasia requires the intention to hasten death, for example by administering a lethal injection. Passive euthanasia includes decisions such as withholding an action which would sustain life. However, passive euthanasia can also take the form of an action of 'withdrawing' life sustaining treatment. Therefore, omitting or withdrawing treatment could be construed as an action equal to providing a lethal injection. Garrard and Wilkinson define passive euthanasia as withdrawing or withholding treatment to hasten death for the patient where death is considered in their best interest (Garrard & Wilkinson, 2005: 65). So, the justification for 'passive' acts of euthanasia require a moral judgement on the quality of life and the degree of suffering. Although hastening death is the intention in both passive and active cases of euthanasia, in most countries, only one is legal and deemed morally justifiable. So, taking action to end life is always deemed morally wrong, but to omit an action which results in death is morally acceptable. However, passive euthanasia can also be an action of 'withdrawing' treatment – perhaps because it is deemed futile.

So, how is one action viewed as killing whereas the other is not? Beauchamp argues; "Rightness and wrongness in killing depend exclusively on the merit of the justification underlying an act of killing, not the type of action it is" (Beauchamp, 2004: 124). Therefore, even though hastening death is the end result, only passive euthanasia can be justified. This is because passive euthanasia is never framed as an action of killing. Acts of passive euthanasia are often framed in a moral discourse concerning what is natural (good) against what is artificial (bad).

A 'natural' death, of letting *nature* take its course, explains an omission of an action because it opposes treatment or intervention in the 'natural' process of dying. However, a person removed from 'artificial' life sustaining treatment to return to their natural state requires an action to take place. The act of removing the artificial sustenance hastens death. Because

the body is sustained 'artificially', it is easier to justify the action. As Lock argues, "…nature is conceptualised as a domain entirely independent from the moral order. In practice, however, 'nature' continues to serve…as a moral touchstone…when we grapple with assigning the status of life or death…" (Lock, 1996: 577) As with the Quinlan case mentioned in the introduction, the distinction between natural and artificial was used to decide the most ethical action to take (Weir, 1977). Nature won the argument. Indeed, to die naturally is also part of the 'good death' ideal. When treatment is deemed futile or if a patient refuses treatment, the doctor or the patient can allow nature to take its course. This concept was highlighted by Borbasi et al., (2005) who demonstrated that futile interventions were a refusal to 'let go' of the dying patient. Letting go is letting die. These categories of natural and artificial have also arisen in the comparison between early modern deaths and those of high modernity. Early modern death was at home, with people, without medicine and was commonly witnessed (Aries, 1974). Death in high modernity involves medication, is hidden, is prolonged, and involves technology.

The categorical use of natural verses artificial and its relation to passive euthanasia is illustrated in an article by Patrick Hopkins. Hopkins argues that the whole euthanasia debate is not about harms or values but is about finding moral and causal neutrality (Hopkins, 1997: 30). This morally neutral ground is found when we associate acts with nature. He argues; "Passive euthanasia is morally permissible not so much because it is beneficial or right but rather because as a natural death, it is simply the kind of death that occurs when no one is there to cause death"(Hopkins, 1997: 31). According to Hopkins, the moral framework which surrounds the euthanasia debate is concerned with moral neutrality and natural causes. Therefore, medical interventions or machines which keep someone alive are not neutral because they are artificial. Since they are not part of the natural process of life, their removal can be justified. He argues that not only is their removal not considered killing, but that the act of removing or withdrawing treatment "…counts as the annulment of effect and responsibility" (Hopkins, 1997: 33). If we agree with Hopkins, removing life support or withdrawing treatment deemed futile is acceptable because it is viewed as simply resorting back to nature. However, is associating the act with a natural occurrence always an adequate justification? It may contribute to the perception of moral neutrality but not causal neutrality. As Beauchamp argues; "…withholding or withdrawing of a medical

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technology must be *justified*; an unjustified withholding or withdrawing that releases natural conditions is a killing" (Beauchamp, 2004: 119).

One way in which causal neutrality has been achieved with passive euthanasia is by removing the word euthanasia from the equation. For example, it is interesting that a particular treatment, Continuous Sedation until Death, has changed in its description in medical journals over the years. Prior to 2000, the common terms used for CSD included 'terminal sedation' and even 'slow euthanasia' but now the trend in terminology has changed toward the use of the term 'palliative sedation' (Rys et al., 2013: 235). From this we can determine that the medical establishment is becoming particularly sensitive to the moral connotations surrounding the word euthanasia and the word terminal. By changing the description to palliative sedation, they achieve both moral neutrality and causal neutrality. Even though there is clearly an awareness of the consequences of the treatment; the term they use removes any implication that there is. It is obvious why they changed the terms, since euthanasia has a dark past and is always associated with killing.   Its particular association with medical practices during Nazi Germany is embedded in social consciousness.   Anti-euthanasia activists use this as leverage to quash any discussion regarding its viability. As Pollard warns; "What started as an attitude about the disposability of the non-curably sick quickly grew into something more sinister" (Pollard, 1989: 20). Given this link to murder, most of the medical establishment consciously rejects any association with euthanasia – passive or otherwise.   Indeed, it is argued that the term 'passive euthanasia' is avoided because it would result in the erosion of trust between doctor and patient and the medical establishment in general (Garrard & Wilkinson, 2005: 67). So actions which can be justified, like withdrawal of treatment resulting in death, are simply acts which *allow* someone to die. The physician is not the cause of death, but rather the disease (Beauchamp, 2004: 123). Further detail explaining Continuous Sedation will clarify this point further.

In both palliative care institutions and Intensive Care Units, a doctor can make a decision to place a patient under Continuous Sedation until Death. CSD is the act of reducing or removing the consciousness of an incurably ill patient until they die (Rys et al., 2013: 533). This occurs when the patient needs alleviation from pain; but the amount of sedative

required means that the dying individual remains unconscious until death. In one study which analysed moral justifications by doctors regarding this treatment, 52% of the cases stated the treatment came under the description of the Doctrine of Double Effect (Rys et al., 2013: 534). This term is used, often in legal cases, to determine responsibility and ethics of an action. The Doctrine refers to conditions where one is not fully responsible for all the effects of one's actions, but only for those which are intended (Wilkinson, 2009: 144). Therefore, the intended effect may be to alleviate suffering, but the actual effect may be hastened death. Both effects are viewed as possible, but only one intention is behind the action. Therefore, if death results from this treatment, it is viewed as an unfortunate side-effect, not a killing. So, the *moral justification* for this practice is the intention and duty to keep the patient pain free but if death results, no-one is held responsible. This study also revealed that CSD was often carried out without any consultation or consideration for the wishes of the family and that there was little adherence to matters of patient consent (Rys et al., 2013: 539). So even though a patient's right to self-determination is promoted by the medical establishment, where no advanced directive is in place, decisions are made at the doctor's discretion. In fact, in Australia, common and legislative law states that a decision to limit treatment must be made by the doctor who must act in the patient's best interests (Silvester & Detering, 2011: 455). Therefore, authority to make decisions largely rests with whether or not an advanced care plan or directive is in place, whether the patient is comatose and whether or not the family has obtained legal rights to have explicit say in treatment options.

Although the CSD study (Rys et al., 2013) was a content analysis of opinion pieces from medical and nursing journals, it did attempt to answer the way in which moral reasoning operates through the careful use of terms. Justifications for the use of CSD fell into five categories, some more controversial than others (Rys et al., 2013: 537). As I previously mentioned, the Doctrine of Double Effect was used as the justification for treatment (Rys et al., 2013: 536). This suggests that because the Doctrine is recognised as being synonymous with good intentions i.e. the intention to alleviate pain, not the intention to kill; then perhaps it is chosen as the most suitable and satisfactory explanation to avoid any doubt regarding responsibility for hastening death. However, a recent study of Australian Palliative care doctors regarding CSD or terminal sedation demonstrated "…a considerable ambiguity

about their intentions and failed to distinguish consistently between intention and foresight" (Douglas, Kerridge & Ankeny, 2013: 2). This research also pointed out that DDE "…fails to draw a clear line between permissible and impermissible deaths" (Douglas, Kerridge & Ankeny, 2013: 10). It is clear that justifications for treatments that are identified under the Doctrine of Double Effect will continue to remain morally ambiguous but will also continue to play a key role in end of life decision making.

There are of course end-of-life decisions falling under passive euthanasia which include extensive consultation with the family, as is the case with patients on life support. Decision making regarding an individual on life support is probably the most complex in terms of justifications and moral reasoning. Dichotomies of natural and artificial and of body and machine become pertinent for making evaluations and distinctions between life and death. The removal of life-support is perhaps the most difficult moral decision for families but reveals much about the moral quandaries of end-of-life decisions. One study showed that consultation with the family is common when a loved one is on life support and that often, the family has control over the timing of the death through the withdrawal of treatment (Curtis et al., 2002: 155). During family conferences regarding decision making, sometimes physicians attempt to alleviate the family's feelings of guilt and responsibility; instead of focusing on this act of passive euthanasia, they focus on the disease or injury which killed them. One physician exclaimed; "So, you don't need to worry at all that if you'd only brought her in a little sooner things would have been different. With this kind of disease, it's just not true" (Curtis et al., 2002: 156).

The way moral actions are managed when people are being artificially kept alive within an Intensive Care Unit reveals the particular way reasons are formed to justify actions to end a life so that they are not viewed as killing. As was the case with Karen Quinlan, the judge ruled that allowing her to die 'naturally' was morally justifiable and more humane than the insistence on keeping her alive. Therefore, the removal of 'artificial' machines was not killing her; it was simply returning her to her natural state. The professional and social responsibility for death is removed. Is it, indeed, the fact that these medical interventions and apparatus are not part of the human body that their removal is acceptable?

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David Shaw argues that this is in fact the central issue. He claims that passive euthanasia is acceptable because of the 'moral distance' that the machines provide (Shaw, 2007: 520). He states that if, for example, technology allowed artificial parts to be integrated into the body, that there would be no distinction between active and passive euthanasia (Shaw, 2007: 520). His main claim is that our bodies can keep us alive against our will. Here, the will represents self-determination or autonomy. So, if a machine is keeping us alive against our will, why is it so different if it is our body? He believes that "from the point of view of the patient's mind and desires, a ventilator, food and the body all have the same status as life-prolonging burdens that should be discontinued" (Shaw, 2007: 520). For someone who wishes to die, this makes sense, but in practice, it becomes difficult and controversial.   There are two reasons for this. First, the patient has family who are socially and emotionally connected to them. Second, a justification for a moral action cannot by the person's 'will', because for a decision to be deemed ethical, it must be supported by reasons outside oneself and be impartial (Cohen, 2004: 15). So, to say that the justification for ending someone's life is because the patient wants it would not be satisfactory. It needs to appeal to a greater good. From the point of view of those responsible for ending the life, there would also be a profound difference if the person was not being kept alive by a machine. It would be even more difficult to find justifications for the decision. Thus even though in principle Shaw's argument may make sense, it is clear that in practice it would be far more difficult to justify.

I have illustrated here how end of life decision making and the context of the biomedical encounter provides a very complex framework within which decisions are made. And, it is clear that prescriptive ethical reasoning in terms of abstraction would not easily translate in practice. This is because death concerns relationships and so inter-subjective considerations must be taken into account. As Rapport has argued, death has a significant impact on our human responses:

> Death is an event that happens to us without our having any possibility of a priori knowledge.   It is absolutely other and with an otherness that we can never transcend: death remains unknowable (Rapport, 2015: 259).

Death also heightens our moral senses, our feelings of moral responsibility and is intrinsically affected by our emotions. As one would expect, a myriad of emotions can be experienced in

caring for a dying relative and can emerge due to the specific circumstances which occur in each case. Hope has been shown to play a central role in end of life care (Cellarius, 2008 ; Good et al., 1990 ; Kaufman, 2010b ; Russ, Shim & Kaufman, 2005). However, empathy, I will argue, is even more central in shaping moral reasoning of carers. This is due to our exposure to the suffering of our loved ones (Nussbaum, 2001: 307).

Just as important as emotions are the temporal factors which impact end of life care. Many studies have shown that temporal conditions are fundamental to understanding the phenomenon of end of life care with respect to decision making (Borbasi et al., 2005 ; Ivanović, Büche & Fringer, 2014 ; Kaufman, 2010b ; Mohammed & Peter, 2009 ; Russ & Kaufman, 2005 ; Worthley, 2000). Hence, these two elements will be influential in the formation of justifications for end of life decisions. Further, responses to end of life care will also reveal the relativity of moral worlds and how embodied moralities affect and are affected by other sources of morality.

I have explained here how context and justification play a central role in determining the ethics of end of life decisions. What might seem justifiable in principle can be very problematic in practice. This is because prescriptive ethics outlining the morality for life and death decisions excludes the contextual factors which in practice would determine the ethics of an action. What this illustrates is that we require qualitative detail of real-life situations to understand satisfactory justifications for moral action. Further, that since bodies are both biological and social, inter-subjective considerations always need to be taken into account (Duranti, 2010 ; Zigon & Throop, 2014). Therefore, without the interrogation of the embodied moral worlds of the participants and what informs them, we would be unable to understand how their justifications are deemed ethical. This is why moral reasoning of participants cannot be understood without consideration for the context in which they are made. Whether we appeal to nature, render the choice neutral or appeal to some universal good, the ethics of end of life decisions must not only consider personal embodied moral worlds but how these are informed by and sometimes conflict with other moral sources and positions.

Chapter II - The Anthropology of Morality

In the previous section, I demonstrated how the ethics of a life and death decision when discussed in philosophical terms is unlikely to be acceptable in practice due to the importance of social, cultural and contextual considerations which impact moral reasoning in real-life situations. What may seem ethical on paper does not always stand up in practice. Further, what may be accepted as moral in context of a live situation may seem irrational or immoral when abstracted from context and isolated in philosophical terms. I used euthanasia as an illustration to show not only the dichotomies which characterise the context of end of life decisions, but how death that is allowed or hastened is justified by staff in clinical environments. This illustration serves as a starting point for understanding the difference between prescriptive ethics or moral philosophy and moral anthropology. I feel it necessary to explain this distinction in detail because opponents of moral anthropology, I believe, tangle up the objectives of moral philosophy with moral anthropology.

Distinguishing moral philosophy and moral anthropology

The first difference between moral anthropology and moral philosophy is the principle objective of the task. Moral philosophy seeks to prescribe moral action i.e. what the right thing to do is. However, moral anthropology seeks to describe moral actions i.e. she thinks X is the right thing to do (Cohen, 2004: 2) Although each is concerned with moral reasoning, moral philosophy uses argument and deductive reasoning to decide what, in a particular situation, would be the right thing to do. Hence, the objective is to debate the ethics of a decision back and forth through postulating certain actions or outcomes.   Moral anthropology, on the other hand, seeks to uncover what the agent thinks is right by attempting to understand their moral world by the way in which they perceive, explain and justify it. Therefore, moral anthropology provides a picture of the agent's moral world and describes that moral world by taking account of the cultural, social and institutional factors which shape it. Thus, moral anthropology describes not only embodied moralities but how they influence and can be influenced by moral sources within society.

Returning to Shaw's (2007) argument, I will illustrate where prescriptive philosophy fails if practically tested to outline the differences in each discipline's objectives. Shaw argued that it makes sense to let people die not just because they are being kept alive artificially, but because they are being kept alive against their *will*. So, for Shaw, ending the person's life is justifiable because they want to die and their body is a burden. This is an argument for the right to autonomy, but disregards anyone else's right to a say. It privileges the patient against other agents and preconceives the world as though in a moral vacuum. Taking this into consideration we must ask if this scenario would withstand scrutiny in real-life. To understand ethical decisions in end of life care is to understand how agents consider opinions of others, the family, professionals and how they respond to the philosophy of care of the clinic itself. Shaw considers none of these things, only what the patient wants. However, justifications for ethical decisions must appeal outside the person doing the justifying to be morally acceptable. Peter Singer claims that;

> …the justification of an ethical principle cannot be in terms of any partial or sectional group. Ethics takes a universal point of view. This does not mean that a particular ethical judgement must be universally applicable…what it does mean is that in making ethical judgements we go beyond our own likes and dislikes (Singer, 1979: 11).

With this in mind, it would be unlikely that Shaw's argument would be accepted in the context of a real life situation because moral reasoning leading to an ethical decision must be justified in a 'universal' way separate from the person doing the justifying. Ethical judgements are universalised only in terms of saying that a particular decision would be the right thing to do in all similar cases (Cohen, 2004: 16). However, they are only partially universal in that they appeal to some agreed, outside 'good'. Further, we are not making an ethical decision when we justify it in terms of only what we, as a subject, individually want. As was evident from the literature, justifications for moral decisions make appeals to what might be considered 'natural', a universal 'good', or their actual moral flavour must be neutralised somehow. The best way I have found to illustrate this is to explain Cohen's theory of moral reasoning which I have adopted as a guide to identify episodes of moral reasoning within my data.

Moral reasoning which supports a moral position always has three features; 1) impartiality, 2) universality and 3) justification (Cohen, 2004: 15). One of the distinguishing features between a moral from an ordinary decision is that the justifications have these specific appeals. Indeed, the fact that we must offer justifications is also relevant. Cohen argues that;

> …the presence of reasons is *integral* to an opinion's being an ethical one, in a way that it isn't with regard to matters of preference…offering an opinion as moral implies that you have reasons for it. Moral opinions *per se* put one into the arena of justification (Cohen, 2004: 19).

This is why the types of justifications offered for moral reasoning are the key to understanding the ethics of end of life decision making. These justifications and appeals demonstrate what moral principle an individual is adopting and what value they are supporting.

Returning to Shaw (2007), I will make a final point. Not only is his argument for switching off the machine not impartial, it fails to take into account that the body on the machine is still a person and a social being endowed with value by family and friends. Thus, no consideration is given for the importance of inter-subjectivity or how others may feel about the decision. Moral choices, in our lived experience, are always made with consideration to our relationships (Zigon, 2014a). Even if the quality of the life is limited, or even if the individual is unconscious, for a justification to be deemed satisfactory, social connection and interaction must be considered. This is why, for example, people find it hard to accept that their loved one is dead when they have been told that they are brain dead. That is because people see death as a transformation which is not completely removed from identity and social relations (Kellehear, 2009a: 139). Families who visit their relative on life-support do not see a shell or a corpse; they see the person that they know and are familiar with (Kellehear, 2008a). Thus, clinical definitions of death do not necessarily resonate with the family. The dying individual remains in a social relationship with other people because "People become attached to others…because of their social relationship to those persons… [the] person is not simply a 'being' but a 'property or quality' given/imposed on someone or something by others" (Kellehear, 2008a: 1538). Thus, accepting the medical diagnosis of brain death will always be difficult because the body is a social being and holds value for the

family. As Lock argues, death and dying can never be stripped of meaning and reduced to a question of biology (Lock, 2002: 106).

The moral question then of whether someone who is in a comatose vegetative state can be considered alive or whether they should be kept alive is not just about the condition of the body, or about the quality of life, but is determined through social bonds of those connected to them and the values they hold. Hence, whatever condition the individual is in, people remain social entities. The example of brain death further demonstrates how different parties can hold different perspectives on end of life decisions due to holding different embodied moral positions. This is also evident in the contrasting perceptions toward the body between biomedicine and families. Lock argues that responses to death are not just social or material, but are also informed by the local categories of knowledge and understanding (Lock, 2001: 483). These local categories of knowledge and understanding inform the way we perceive and what we consider moral. For example, biomedicine itself is grounded on certain ideas and premises toward patients due to the objectification of the body. Further, different clinics have different philosophies toward care and therefore, as was outlined in chapter one, have their own aims and moral objectives in caring for patients. It should now be apparent how important context and inter-subjectivity are to ethical choice and why it is necessary to take an ethnographic approach.

It is clear that moral anthropology and moral philosophy have different aims. Moral philosophy attempts to ascertain the right and good choices based on the presumption that what is moral can be ascertained from a universal, abstract rationale. Indeed, the objective is to argue and prescribe the best moral action in any given situation. Moral anthropology, on the other hand, attempts to identify, describe and understand what counts as morality for the subject in a certain place and time and, with respect to my approach in this thesis, on the premise that morality is not only relative but influenced by many moral sources (Zigon, 2007).

By examining the justifications for ethical decisions, we can understand the core values on which they are based and how they support a specific moral position. What also needs to be considered is that end of life decision making is unlike other decisions in that it is infused

with a particular intensity due to the anticipated and inevitable outcome and all that this emotionally entails. It is a complex phenomenon of dynamic interplay between families, patients, medical professionals and clinical institutions. Through the study of morality and moral reasoning, we can understand the factors which impact choice and how these choices affect end of life care.

Normative ethical theories adopted by moral anthropologists

The principle within normative ethical theories is the standard that the agent is appealing to. For example, to a principle of duty or virtue (Cohen, 2004: 6). In the following section, I will provide a short exposition of normative ethical theories to show how these principles are sometimes applied to explain moral reasoning within ethnographic data. For some scholars, these theories are assumed prior to an analysis of the data. In some respects, this perhaps implies an understanding about moral motivation. Although this is not the position I take, it is one way in which anthropologists have looked at the moral question.

In the anthropological study of morality, Fassin (2014) argues that most common normative ethical theories applied to ethnographic data are deontological (duty), utilitarian (consequentialist) and virtue ethics but the predominant ethical branches are virtue and duty ethics. He tracks duty ethics from Kant to Durkheim and virtue ethics from Aristotle to Foucault (Fassin, 2014: 5). Here, I will outline these two most common approaches and explore what I believe are the connections between ethical theory and social theory, their characteristics and on what principles they are based.

Duty ethics

Deontology (duty ethics) is concerned with the rightness or wrongness of an action and that decisions should be made considering the factors of one's duties and other people's rights (Mastin, 2008: 3). What makes a choice morally right is that it conforms to the 'norm' and what is considered 'right' and what we 'ought' to do (Alexander & Moore, 2012: 1). Thus, due to what is considered moral – the 'right' thing to do – this type of ethics is akin to Divine Command Theory due to the fact that there is reference to an *absolute right* with respect to

the decrees of God (Mastin, 2008: 2). Deontological ethics is also referred to as 'duty' ethics because proponents argue that the motive to be moral stems from a sense of duty. However, even though the term 'duty' says something about the motivation to be moral, it does not explain the complete principles of deontological ethics. What motivates this duty and what are we being dutiful to? Kant believes we have a duty to human reason. Kant does not distinguish between ethics and morality but is concerned particularly with the human ability to reason, our ability to know and the capacities of our rational mind (Kant, 2014). Kant's moral principles take the form of a law in that there are specific rules to be abided by. He is concerned with how we identify a moral act, what makes it a moral act and what motivates us to be moral. It is also prescriptive; as most moral philosophy is, in that it presents what we ought to do and the reasons why (Alexander & Moore, 2012: 1).

For Kant, the notion of 'duty' to act morally is made explicit. He claims that to act morally out of duty and indeed, to act morally at all is to obey moral law above and beyond any personal inclinations (Kant, 2014: 26). Thus here we have the first feature which makes this reasoning moral – impartiality. Moral actions are not 'personal inclinations' but follow a line of duty. That is not duty to the self, but duty to something outside the self. Thus, no self-serving actions can be identified as moral. For Kant, an action cannot be moral at all unless it is done out of duty. Not just out of duty, but from the will to be dutiful. Where the moral motive or urge originates creates the ingredients necessary for morality. Thus, the morality of an action can be found in the principle of the 'will' - it is the volition which is the most important, not the consequences (Kant, 2014: 26). We act out of duty to the law of morality from our 'good will'. Kant qualifies our will as good if it is acting in this manner and for these purposes. That is why he claims that 'good will' is the only thing which can be good in itself – without qualification (Kant, 2002b: 470). So, there is no doubt that Kant was one of the founders of the traditional form of duty ethics.

What is the most obvious aspect of Kant's principles of morality is that he is not concerned with outcomes or consequences of actions. If an act is done from the volition of the 'good will' out of respect for duty for the moral rules or laws, then it will qualify as a moral act. It is, of course, assumed that such an act, by its very nature, will result in consequences of a good and moral quality. We use this volition out of our duty to society and our duty to our

rational mind. Kant states; "Act only on a maxim by which you can will that it, at the same time, should become a general law" (Kant, 2002b: 473). So, for Kant, if you follow his rules of morality, whatever action one carries out either to another or for another, should be such that it would be fair as a general law of society. Here we come to the second feature of moral reasoning – the appeal to universals. A moral action is one that could become law and be 'good' for everyone. To ignore the rules of the general law or maxim is to be irrational. Since actions that could become general laws are objective principles and since they can be good in themselves, this makes them 'imperative' and powerful because we are under this command of reason (Kant, 2002b: 473). Thus, Kant's ethical principles and rule of moral reasoning including good will, duty to moral law, and this appeal to ultimates hence, universality, are collectively called the 'categorical imperative'. Thus, the categorical imperative – with respect to the human will – abided by properly must be an end in itself which, by making it an objective principle, can serve as a general practical law (Kant, 2002b: 474).

Durkheim agrees with Kant on the principle of obligation in that it is one characteristic of the moral rule (Durkheim, 2014: 57). He also agrees on other foundational principles such as duty to society but he explores what consists of a moral fact more explicitly through his justifications, the third rule of moral reasoning. He explains that rules in society are only moral if they contain sanctions. His theory of sanctions stems directly from Kant's theories of analytic and synthetic judgements. According to Kant, 'analytic' judgements are those where the perceived outcome or consequence of an action is covert and hidden within the action; 'synthetic' judgements are those where there are no obvious identifying connections from act to outcome (Kant, 2002a: 380). Thus, to undertake an ordinary action, one may be able to determine, more or less, what will happen. However, to violate a moral rule, the outcome will not be obvious i.e. the outcome has no identifying factors, covert or otherwise, connected with the action. This is why he explains that there is a 'synthetic' link between the act and the consequence which becomes the social sanction. He states;

> It is not the intrinsic nature of my action that produces the sanction which follows, but the fact that the act violates the rule that forbids it (Durkheim, 2014: 60).

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So, we cannot identify something as immoral from the action itself – we only know through the sanctions of society. Thus, Durkheim took Kant's 'universal' theory of the general law and converted this concept into 'sanctions'. He agrees that an act cannot be moral if it serves only an individual's interests, hence it conforms to the first principle of impartiality, but he argues that moral acts are done for the greater good of the group or society (Durkheim, 2014: 58). However, beyond duty to society and obligation to moral rules, he adds the concept of desire to moral acts. He agrees that obligation is one aspect, but for Durkheim, there is more. He states:

> For us to become the agents of an act it must interest our sensibility to a certain extent and appear to us as, in some way, desirable (Durkheim, 2014: 57).

In some respects, one could argue that this mirrors Kant's argument that the volition or 'good will' is a vital component of an act being moral. We can carry out obligation and duty to the moral law of society, but we must do this with 'good will'. So, this weakness in Kant's argument; that our 'good will' or motivation just materialises from thin air is explored further by Durkheim. It is not enough for us to act morally because we are rational beings and have a duty and obligation to society or to God, but we act moral because there must be some element of individual desire involved. We have to see it as 'good', it has to affect our sensibility and has to be meaningful to us (Durkheim, 2014: 60).

Durkheim, instead of emphasising that motivation to be moral is from one's commitment to be rational, says that it is the fear of social sanctions which is our motivation. The second principle; that usually appeals to universals, is for Durkheim, limited to common morals and goals of a group or society. Thus, it is a collective morality instead of a universal one. He sees that we are morally affected by collective group meanings which shape our sensibilities and so we are not only obliged to conform to the rules of the group, but we want to because it is pleasurable. Thus, he is was a moral relativist. Kant, who argues for ultimate 'truths' and ultimate 'causes' to which Durkheim had no interest, saw morality as universal, thus, he was a universalist.

Virtue ethics

Virtue ethics does not consider the action or the consequences, but focuses on the character of the person. Thus, to act morally, one must *be* moral. The main principle with virtue

ethics concerns the whole person; that being virtuous is the most important thing. Aristotelian ethics is a prime example of Virtue ethics. Ethical conduct depends not on the type of action or outcome but inner goodness; the virtues of the subject – the habits and behaviours which make us moral and lead us to the good life (Aristotle, 2004 ; Mastin, 2008 ; Zigon, 2008: 24).

Unlike duty ethics which argues that we conform to our duty and obligations to society to be moral, virtue ethics is concerned not with duty or obligation, but with character. Thus, it focuses on the traits which make up a moral and 'virtuous' person. Virtue ethics does not focus on the consequences of actions or the duty to act, although it takes for granted that these elements are part of the moral reasoning process. Aristotle focused on how we become virtuous and moral, and proclaimed the benefits thereof. Although Foucault is also concerned with individual moral character, he explains morality as a relationship between society and the agent and how ethics functions through the agent's relationship to the self. Virtue ethics is more complex than duty ethics, and its genesis goes further back in history. Thus, beginning with Aristotle, I will explore his main concepts of morality and then determine the similarities and differences between these theories and those of Foucault again using the three principles of moral reasoning.

Morality for Aristotle is all encompassing. To be morally virtuous is not just about behaviours, but about a state of being – this is the goal. Thus, moral virtue is accomplished in a certain way. For example, we might take an action to help someone; this action may be valued by society or be considered 'morally good'. However, consider that this person is carrying out the virtuous deed not for the sake of being virtuous, but for some other reason. People can carry out actions considered virtuous from dishonourable intentions. Thus, we could not count this person as moral from this action. This is why, according to Aristotle, being moral must be measured on the individual's whole disposition:

> But virtuous acts are not done in a just or temperate way merely because *they* have a certain quality, but only if the agent also acts in a certain state, that is (1) if he knows what he is doing, (2) if he chooses it, and chooses it for its own sake, and (3) if he does it from a fixed and permanent position (Aristotle, 2004: 37).

It is important for Aristotle that we are not ignorant about the actions that we take and that we must choose virtuous actions because they are virtuous. This permanent position to which he refers is the stable state of a person whose objective is to attain virtue, not by accident, but through deliberate and purposeful action. Foucault is in agreement. He argues that morality is not just about the action, but about the fact that it establishes moral conduct to which the individual commits to for the future; that it contributes to the certain mode of being an ethical subject (Foucault, 2014: 42).

So, if virtue ethics is about modes of being and the individual's moral response to society, one still has to determine the 'good' and the 'right'. We don't just determine what is good and right by society's rules and laws, we also have subjective responses to these rules. Thus, how do we, as ethical subjects, respond in a virtuous and morally good manner? For Aristotle, because 'good' can pertain to a number of categories i.e. substance, quality, quantity, usefulness, opportunity etc.; there can be no universal good (Aristotle, 2004: 10). Therefore, since what is good is relative and impossible to define, he does not say directly what is good but shows how we can determine what is good. This is solved through the art of balance:

> …but it is in the field of actions and feelings that virtue operates; and in them excess and deficiency are failings whereas the mean is praised and recognised as a success: and these are both marks of virtue. Virtue, then, is a mean condition, inasmuch as it aims at hitting the mean (Aristotle, 2004: 41).

Therefore, when we need to decide on an action in our day to day lives, we should always attempt to hit this 'mean' position. This balance allows us not just to be virtuous, but to live well (Mastin, 2008: 1).

Aristotle makes it clear that it is not simply following this ethical rule which enables us to live well. It takes work. Before one is fully virtuous, it may be difficult to do the right thing, we may struggle to control the desire to do otherwise (Hursthouse & Pettigrove, 2013: 3). Indeed, he argues that although we are 'constituted by nature' to be able to receive moral virtues, their full development only comes through habit (Aristotle, 2004: 31). Therefore, only through practicing these ethical principles can we become habitually virtuous. It is in

this manner which virtue becomes a state of being. Thus, we attain and maintain virtue through habit. Both Aristotle and Foucault follow this line of reasoning.

Foucault also agrees with Aristotle that morality is about dispositions. Indeed it is as much about the self as it is about society. We deliberate over moral choices, for Aristotle – we attempt to find the 'mean'; the ideal position. For Foucault, our ethical engagement is the mode of subjection which refers to how the individual relates to the rule and the reasons one gives oneself for adhering to it (Foucault, 2014: 42). Both scholars agree that the agent has a certain amount of freedom to make their choices and these choices create the ethical self, or the disposition of the agent. For Aristotle, virtue and thus living ethically come through moderation and habit. For Foucault, since his goal is not to prescribe morality, simply says that subjects engage, conform and sometimes challenge moral codes. However, he does take virtue ethics a step further. He suggests that *subjectivation* (the subjects relation to the rule), is relative to the codes of behaviour enforced by society – the stronger emphasis placed on the code, the more subjectivation is carried out in a semi-juridical manner (Foucault, 2014: 43). Thus, the manner in which we undertake moral reasoning or the freedoms and limitations of these are in direct relation to the types of moral codes in society and the manner in which they are enforced. Thus, our engagement with ethics involves relationships of power.

We can see that there are more similarities than differences between the positions of Aristotle and Foucault in their theories of virtue ethics. Those similarities include the focus on the agent and their relationship to self and the moral disposition regarding how they, as subjects, respond to the moral rules of society. Each acknowledges that we do not simply comply with the moral law of society but that we deliberate over this choice. For Aristotle, we should work on ourselves to be moral and become virtuous, thus there is a prescription for morality. For Foucault, we think about what moral codes mean to us and so we also develop over time. Foucault explains ethical engagement; Aristotle tells us how to be ethical.

What I have outlined above is a very brief sketch of the main distinguishing features of each branch of normative ethics. It is obvious, just from this outline, that there would be room

for extensive debate regarding the classification and meaning of terms. For example, what things or qualities can be considered 'good'? And, what things or qualities can be considered 'right'? What is 'right' and 'good' in what situation and for whom? However, debates over these terms are the concern of the moral philosopher, not the anthropologist. Since moral anthropology and this thesis is not concerned with prescribing moral actions; the only thing which is relevant is what the participant or subject considers the most ethical action or choice and how they justify it. If it happens to reflect the principles of normative ethics, this will serve as part of the explanation of their moral reasoning. I do not believe, however, that one should approach the participant with the presumption that they are inherently motivated by any particular normative ethical principle. In sum, the differences between both duty and virtue ethics should now be clear along with the fact that each discipline's objectives are different.

Chapter III - Contemporary Approaches in Moral Anthropology

Now that moral philosophy and anthropology have been differentiated, I will explore the variety of approaches to the moral question current in the discipline. The difference in these approaches can depend on two main positions. The first is whether or not the question of morality will be approached from a universal or relative position; the second depends on the aspect of morality being analysed. Thus, the varieties of approaches to morality are largely dependent on the context of the moral phenomena. Due to these differences in approaches, there is still area for confusion and there are still critics to be answered. Therefore, after exposition of the various approaches, I will very briefly situate my approach before answering some of the criticisms of moral anthropology and explaining the theoretical and methodological approach of this thesis in detail in the subsequent chapter.

Moral reproduction and freedom

Durkheim presupposed that morality was largely reproduced out of duty to conform to moral norms and to avoid social sanctions (Durkheim, 2014: 61). He also made the claim that since morality and religion had been interconnected for so long, it was doubtful whether each could ever be separate from the other (Durkheim, 2014: 62). Joel Robbins is one anthropologist who seems to hold this position, particularly since most of his approaches to the moral question have been in the context of religious principles, and where value conflicts result in systematic cultural change (Robbins, 2007, 2009, 2013). Morality, for Robbins, is best viewed by looking at value hierarchies in culture. Robbins adheres to Dumont's theory of values in that cultures contain a paramount value that structures the relationship between the other values and thus the structure of the culture (Robbins, 2007: 297). In his approach, the value systems are hierarchical. The logic is that stable hierarchical value systems reproduce morality and unstable ones allow freedom or allow challenges to the moral system:

> …a clear understanding of how values operate in culture can help us formulate a model of freedom that does not disregard the force of cultural norms and the routines they produce (Robbins, 2007: 296).

Therefore, value hierarchies which break down can be an avenue or provide an opportunity for individuals to be exposed to choice. Thus, for Robbins, we can understand morality not just through value systems in societies, but through the way in which they break down. Robbins points to pluralist value theory to suggest that when more than one worthy value exists, there is a propensity for more conflict and moral freedom (Robbins, 2013: 100). Utilising his theory, value hierarchies can indicate opportunities for moral reproduction or freedom. When we introduce cultural change; to use one of his examples, such as Christianity to the Urapmin, the conflict in values alters moral rules and therefore permits ethical freedom within the moral reasoning process.

Although Robbins provides a useful example of how competing moral sources can lead to moral freedom, most of his work tends to link moral sources to religiosity which to me suggests that he presumes that they cannot be separated. That, in some respects, by studying the impact of religion on culture we are studying morality. This impression comes from most of his work on morality which explores competing religions, Pentecostal and Islamic deontological ethics, and the argument that in order to approach the moral 'other' in our research, we should adopt some theological methods (Robbins, 2006, 2007, 2010a, 2010b).

Although a clash of religious moral codes provides an obvious example of values conflict, religion is not the only source of a subject's morality. Further, his approach raises some questions. If morality is best analysed through cultural change, does it stand to reason that without this event, reproduction of morality trundles on without challenge or chance of moral freedoms? What other sources of morality are we missing if we restrict ourselves to value conflicts which can arise through competing religious perspectives? How do we explain reproduction and freedom for those in society who do not identify as religious but are obviously still subject to moral codes and make moral choices? Robbins does acknowledge that certain moral freedoms exist in situations of cultural continuity which he calls "stable conflicts." These conflicts do not change the value systems but coexist within the system – the reason for which he admits cannot really be explained (Robbins, 2007: 300). This issue of stable conflicts raises an important problem with his approach which can

only be resolved through acknowledging that there are other sources of morality and other ways in which morality is shaped.

If we are to assume that 'stable conflicts' exist and that they allow for certain moral freedoms, we must also acknowledge then that moral conformity i.e. moral reproduction, is never absolute. This suggests that we conform to moral codes in society but our moral reasoning process provides the potential to challenge it. Moral freedom is always *possible.* Even in situations with stable value hierarchies, we must recognise that the moral worlds which form our total system of morality provide opportunity for contradictions, deviations and even hypocrisies (Zigon, 2009b: 258). Thus what may appear to be a stable moral code under which we live has within it many sources of morality. This is why the example of religious cultural change and the consequential values conflict which emerges is not the only avenue through which we can understand the reproduction and potential freedoms within moral systems. Religion is but one of many moral influences.

Moral economies

Power conflicts in society are rarely separable from larger political issues and often reveal social and cultural inequalities and suffering. The generation and perpetuation of moral economies has garnered passionate engagement by some anthropologists in this field of inquiry. In many respects, ethnographic engagement on the topic has been criticised for tarnishing anthropological research due to the scholar having an ethical agenda.

The theory of moral economies, originating with Thompson, served to explain how angry and violent group responses were not just reactions to economic suffering and food shortages but were a sign of collective action against moral outrages;

> But these grievances operated within a popular consensus as to what were legitimate and what were illegitimate practices in marketing, milling, banking etc. This in turn was grounded upon a consistent traditional view of social norms and obligations, of the proper economic functions of several parties within the community, which, taken together, can be said to constitute the moral economy of the poor (Thompson, 2014: 203).

We can see from the inception of the use of the term moral economy that it referred to expectations of the group based on social norms and obligations and provided an explanation for what occurs when the system, in this case economic, violates what a group perceives to be its ethical obligation. Although Thompson was talking about groups of impoverished people, this theory is translatable to any group. It is not always used simply to explain the dynamics of power conflict between the dominating and the dominated.

Fassin describes a moral economy "as the production, circulation, distribution and use of norms and obligations, values and affects" (Fassin, 2011: 486). Thus, it represents the dynamics of a domain or group's norms and obligations, what they are, how they are formed (and by whom), how they are perpetuated and even, perhaps, how they are challenged. Hence, moral economies have the potential to explain the dynamics of values in society, but are also able to answer the contextual question of how and why they operate as they do. Moral economy theory can explain reproduction and freedom of morality in terms of the social, political, economic and historical power structures and moral codes which contribute to their existence.

The two scholars whom I have grouped in the category concerned with power conflicts are Nancy Scheper-Hughes and Didier Fassin. The focus on the morality of power conflicts suggests that the work is often concerned with political issues since these social elements are almost always linked. Although I would argue that they both take a universal approach to morality, their approaches are not identical. Scheper-Hughes has an overt ethical agenda whereas Didier Fassin is not so explicit. However, both approaches explain the circulation of moral economies and how they often justify deplorable phenomena in culture. Scheper-Hughes makes her objectives obvious. From the position of universal morality, it is the responsibility of the anthropologist to have an ethical agenda:

> If anthropologists deny themselves the power (because it implies a privileged position) to identify an ill or a wrong and choose to ignore (because it is not pretty) the extent to which dominated people sometimes play the role of their own executioners, they collaborate with the relations of power and silence that allow the destruction to continue (Scheper-Hughes, 2014: 318).

Scheper-Hughes' approach to the moral question then is double-sided. We must assess the moral as an object of study, but also ask how, from a universal standpoint, immorality manifests and perpetuates. For Scheper-Hughes, we should not just describe this situation of power conflict, but as ethnographers we also have a moral duty and obligation to expose wrongs. Fassin states his position thus:

> …my intention is to underline how moral issues are profoundly entangled within larger social, historical and political issues which are often missed when one singularises moralities and ethics…reintroducing history and politics is a major reason for my promoting the concept of moral economy (Fassin, 2011: 488).

Scheper-Hughes conforms to this objective too. She incorporates historical and political fact to explain power conflicts in society in terms of how they develop historically and politically and what she describes as the moral economy of violence and poverty in contemporary Brazil (Scheper-Hughes, 1996).

In her article 'Invisible Genocides', she discusses infant mortality and how it is not only normalised but how it is perpetuated (Scheper-Hughes, 1996: 892). The medical, political and religious community were all in on the normalisation, and indeed, justification of this violence:

> Common medical practices such as prescribing powerful tranquillizers to fretful and frightfully hungry babies, Catholic ritual celebrations of the death of 'angel babies', and the bureaucratic indifference in political leaders dispensing free baby coffins but no food to hungry families… (Scheper-Hughes, 1996: 891)

Infant mortality being so common due to poverty leads not only to a lack of emotional response to the death of infants but also to the active assistance in the hastening of their death. Thus, the violence becomes normalised within the moral code of this society. It had become justified. Being justified, this moral economy of infant death is reproduced and reinforced by the wider community – the infants died like Jesus so that their mothers could live (Scheper-Hughes, 1996: 891). The negativity of their death is turned into a positive. This positivity is reinforced by the community in that their death is justified as a spiritual sacrifice for their mothers; that they were doing a service to allow others to live another day. The fact that they are called 'angel-babies' suggests this (Scheper-Hughes, 1996: 891). This label not only helps to naturalise their death but suggests that it is a moral good. A common saying in the community was "Better a baby should die than either you or I" (Scheper-

Hughes, 1996: 892). Angel babies are meant for heaven. They make sacrifices for their mothers like Jesus and therefore, are doing a service by saving their mother's lives. All these justifications not only remove the responsibility from the mother and the community for the baby's death, but reinforce the moral code that infant mortality is normal. We can see how the moral economy of infant mortality perpetuates, reinforces and normalises violence in place and time. Out of necessity or otherwise, deaths are religiously 'celebrated', the government's indifference makes them blind to the irony of providing coffins and the medical community administers tranquillizers to hasten death and silence babies.

Scheper-Hughes provides another example of moral economy in her study regarding homeless street children of Brazil. During Brazil's military state years, homeless street children were regularly rounded up by the police, thrown into reform schools and illegally detained alongside adults in prison (Scheper-Hughes, 1996: 892). Even after democracy and laws passed in an attempt to protect the children, these types of round-ups continued. Police round-ups coupled with vigilante death squads would continue to go around gunning children down (Scheper-Hughes, 1996). Between 1988 and 1990:

> …more than 5000 children and youths were murdered…Very few of these deaths have been investigated, which is hardly surprising when off-duty police officers are often the prime suspects…These attacks are occurring in the noticeable absence of public outrage or widespread collective protest (Scheper-Hughes, 1996: 894).

If there was no public outcry and the reforms did not fundamentally change the system, the question is – how and why did this infringement on the rights of children have been allowed to continue? Just like the 'angel babies', the poor street children of Brazil were not only devalued because they were commonplace, but were demonised by authorities (Scheper-Hughes, 1996: 894). Death was normal for the 'angel babies' because it was they who wanted to die; death was the answer for Brazil's 'criminal' street kids because the community needed to be protected. Power conflicts were directly linked to poverty, economic issues and therefore, politics.

These two examples provide, not just a moral economy of violence, but demonstrate how history, politics and economic factors reinforce power conflicts and perpetuate inequality. They also demonstrate how context and perspective is the key to what is considered a good

and right action and how it can develop into a moral consensus. In terms of power conflicts then, assessing context in terms of a moral economy is vital for an understanding of the perpetuation of beliefs and the moral code in particular groups, domains and societies. What might appear at first glance to be unintelligible soon becomes obvious when each avenue which perpetuates certain moral economies is made apparent. Her study of moral economies then explains how notions of right and wrong are formed, how they can be challenged, who they are formed by and how they are perpetuated.

In Fassin's article 'Scenes from urban life', he also demonstrates how moral economies operate through the demonization of certain groups which leads to justifications for violence by those in power (Fassin, 2013). His exploration of conflicting accounts of events surrounding police violence against youth in an urban housing estate outside of Paris showed many similarities to those accounts of police behaviour described by Scheper-Hughes. Fassin explains how police in training are prepared for their patrols of this area. He states, "At the academy they often hear their professors depict these places as 'a jungle' and their inhabitants as 'savages'…"(Fassin, 2013: 374). Police are then prepared to patrol in an area where the occupants are already 'bad' and devalued and therefore, most probably guilty. In conjunction with this, Fassin argues that the police in training are also persuaded that the magistrates are always too lenient on the suspects arrested which serves to further justify the force behind the blows of violence they inflict (Fassin, 2013: 375).

In this case, the perpetuation of violence is not only seen as called for in the eyes of those in power, the dominating group, but again deemed as necessary. Thus, if we remove the violence from the context of the situation, we would most likely view the violence as bad, destructive and morally wrong. However, the dominated group – the 'urban youth' of the estate – having been demonised as savages, are already bad which in turn justifies and in fact makes violence toward this group morally good and right. Through the demonization of the youth, the public also consent to this normalisation of violence. Fassin argues that the police do this by painting themselves as victims in the media and through exaggerating their injuries sustained in the line of duty against the urban youth (Fassin, 2013: 375). Therefore, the public relations objectives of the police greatly affect public opinion by portraying themselves as the victims to gain sympathy.

I have shown how moral economies are explanatory models for understanding how those in power perpetuate norms, values and moral positions and how these positions are accepted and reproduced. Contextually, the perception of the dominant power asserts the moral good irrespective of whether an action or behaviour would be considered morally good in isolation or in a universal sense. Thus, context, be it economic, social or political is not only relevant to the moral, but is vital in understanding how the moral is created. These examples have also illustrated how moral reproduction and freedoms operate through economic, social and political conflict. I have also shown how ethical agendas of the anthropologist aim to educate and inform others of these moral injustices from a position of universal morality. Moral economies then explain the dynamics of power which perpetuate and reinforce certain moral codes through institutional power and public discourse.

Answering the critics

There are many scholars who object to the study of morality and warn that it may lead to the anthropologist imposing their own agendas onto the societies they study (Caduff, 2011 ; Csordas, 2013 ; Stoczkowski, 2008). As I have just outlined in my explanation of moral economies, injustice and inequalities can be exposed in the process of these ethnographies and the scholar can be transparent regarding their ethical agenda. However, does exposure necessarily mean transformation of this cultural phenomena? Scheper-Hughes believes it is immoral not to transform it based on the obvious injustices uncovered. However, who is to say what is and is not moral? This brings us to the heart of the current heated debate around the study of morality.

Csordas argues that morality cannot be studied as a system without acknowledging the universal existence of evil. This argument is grounded in the confusion that morality must necessarily be tied to religious and the cosmological. He presents the concept of evil as a stumbling block for prospective moral anthropologists. Due to this, there is an insistence on discussing the interchange between the ethics of anthropology and the anthropology of ethics. He claims; "…to elide the question of evil is to dodge the question of morality, for in a sense *if it wasn't for evil morality would be moot*."(Csordas, 2013: 525) Csordas sees the concept of evil as an inherent part of morality – a concept that cannot be ignored if morality

is to be treated as a cultural system. He clarifies the aspect of evil that he will be putting forward by stating:

> Here, I mean the concrete possibility of evil, conceived not only as an emic/indigenous/local category or as an etic/analytic/cross-cultural category, but in an immediate existential sense (Csordas, 2013: 525).

Both statements imply that Csordas endorses a universal view of morality. Since he views evil as universal, one must tackle this evil, this immorality, if one is going to tackle morality. Csordas makes four main arguments. First, that although evil is traditionally connected to mythological, cosmological or religious systems, it can also exist and be treated independent of these concepts. Second, that to ignore the universal and existential existence of evil is to ignore an essential category of analysis. Three, that witchcraft serves as an excellent example of the manifestation of human evil and therefore, serves as loci for morality. Four, the existence of human evil through witchcraft challenges not only cultural relativism, but moral relativism. Since evil is real, adopting moral relativism is wrong and irresponsible. These arguments serve to support his theory that due to the existence of the universal manifestation of evil, morality cannot be studied as a system on its own because this would lead to moralising.

Csordas rejects that the existence of evil should only be viewed in relation to its connection to the cosmological, to the metaphysical or its relevance to Christian concepts (Csordas, 2013: 526). Although these connections are acknowledged, he believes that this connection is less important than the fact that evil exists on a secular level. Thus, he states:

> …to argue that evil be excluded from the study of morality on the grounds that it is necessarily mythological, metaphysical, or religious is to invoke a line of thinking applicable to morality itself…the facility with which evil can be transposed into goodness not only in the mythological primitive but the secularized modern mentality…suggests that a foregrounding of morality and ethics such as that currently proposed in anthropology may already fall under the category of the religious…(Csordas, 2013: 526).

Human evil is real and it can be demonstrated through ethnographic examples of witchcraft (Csordas, 2013: 528). In this exploration of witchcraft, he is concerned with the moral in relation to 'human culpability' (Csordas, 2013: 526). He explores this example of evil as part of the moral system across cultures so that evil can be shown to be a human phenomenon

with structural and social uses independent of myth, cosmology or sorcery. If this is the case, then is logically follows that moral goodness can manifest and be interpreted without any connection to religious or cosmological principles. For example, if we are to accept that evil is human culpability without reference to the supernatural or cosmological, we would have to accept that evil is just an extreme form of badness. However, this proves difficult. Evil acts are not very bad or wrong, but ones that possess a special horrific quality (Garrard, 2002: 321). Perhaps it is not only the origin of the word evil but its use which can demonstrate that it harbours qualities that are distinct from the word bad. In fact, evil and wrongdoing are qualitatively distinct concepts. Calder argues:

> Since an inexcusable intention to bring about, allow, or witness harm is not an essential component of wrongdoing and it is an essential component of evil, evil and wrongdoing do not share all of their essential properties…evil and wrongdoing are qualitatively distinct (Calder, 2013: 190).

So, since we are talking about evil in terms of human culpability, someone who is doing something wrong or even bad is not the same as saying someone is doing something evil. Therefore, it stands to reason that evil derives its special quality from its religious or theological origins. This does not prove, however, that *all morality* is somehow connected with religious concepts, just that the meaning of the word evil is. Evil, for whatever use it finds in culture, is always connected with the non-human, cosmological or religious realm – something which Csordas himself acknowledges (Csordas, 2013: 526).

So, what is at issue for Csordas? Evil as a cross cultural concept may have religious origins but remains part of the secular vernacular. It continues to persist as a descriptive category in the secular Western world for certain kinds of behaviour (Hollander, 2014: 51). Calder argues that there are two essential components which make something evil. The first is significant harm and the second is inexcusable intention to bring about significant harm for an unworthy goal (Calder, 2013: 188). In other words, we could say that it is (morally) inexcusable behaviour which harms someone for inexcusable reasons. Garrard makes a point that it is not just these actions on behalf of an agent which makes an evil-doer evil. An evil torturer understands the pain he is inflicting on his victim and may enjoy it, but what makes the act inhuman is that the evil person is able to psychologically silence the reasoning

process which stops them from doing it (Garrard, 2002: 331). Thus, this perceived cognitive difference is the added element which not only makes the evil doer evil, but makes them frightening and inhuman. This distortion of practical reason makes the evil doer into a monster (Garrard, 2002: 331). Therefore, even the quality of secular evil is connected to elements of the inhuman. This further challenges his argument that witchcraft is a good example of human evil disconnected from the diabolical or otherworldly elements.

Csordas suspects that the foregrounding or morality and ethics in anthropology already falls under the religious since Western society has its moral grounding in theology (Csordas, 2013: 530). He also stated that;

> …an anthropological approach to morality is best served by first attending to evil at the human and inter-subjective level of analysis rather than to cosmological or radial evil. This is not to say that they are unconnected… (Csordas, 2013: 529).

This implies not only that we can never disconnect evil from the cosmological, but that it doesn't matter.

If we agree with Csordas that only through understanding human evil can we understand morality, then we are forced to view morality not only from a universal perspective i.e. that there are absolute truths about right and wrong, but that the moral can never be separate from the religious. This is a mistake. Moral experience is made sense through religion; it is not the source of morality. Religion influences morality "…by providing a conceptual framework within which moral experience makes sense" (Zigon, 2008: 52) Morality may be the reason for the invention of religion, but for us even to understand religious concepts, we must already have moral sensibilities. "Moral understanding is not grounded in a belief in God; just the reverse is the case: an understanding of the religious significance of Jesus and the Scriptures presupposes a moral understanding" (Nielsen, 1978: 156). Thus, the premise that religion is the only source of morality is a fundamental flaw. Jarret Zigon agrees:

> While to some degree it is clear that religion and morality are in fact closely related…it would be a mistake to assume that this is always and everywhere the case…it would seem to be the role of the anthropologist to investigate precisely for whom, when, and how religious conceptions and practice count as moral ones…while religious conceptions and practices can at times and for some have particular moral importance, moral conceptions and practices are in fact much broader than their religious influences (Zigon, 2008: 64).

Hence, even if one can argue for the universal existence of evil, it does not mean that we cannot study all moral sources. Neither does his argument prove that all morality comes from religious sources. Belief that something is good or bad does not equate or necessarily include or incorporate for that matter the notions of evil, nor does this evoke religious notions. If, as Csordas acknowledges, that all forms of evil, human, physical/natural and metaphysical are "all mutually implicated in the problem of theodicy…"(Csordas, 2013: 526), then it is through the anthropology of religion that his approach to the question of evil must be asked. If, however, one disregards the importance of where the concept of evil is derived, but is more concerned with the consequences, then human evil can be tackled through moral anthropology which purports an ethical agenda. Neither of these positions appear to me as problematic.

Csordas' problem with the study of morals then is actually to do with moral relativity. The existence of evil in societies allows for "symbolic violence – not an attribute of any actor but of human imagination itself – and perhaps the most existentially valid ground for a critique of moral relativism"(Csordas, 2013: 534). Evil, which he sees must be addressed, is more than just bad, but must be understood for its "destructiveness"(Csordas, 2013: 535). This perceived problem of moral relativism which makes allowances for evil is taken up by Didier Fassin. He states:

> …how are the intolerable – slavery, torture, sexual abuse, genital mutilation…etc. –
> and the corresponding categories of victims historically produced? To pose this
> question does not imply being morally relativistic in the common sense – suggesting
> that all values are equal – but in a sociological sense – reminding us that the
> supposed eternal and shared values are both construed and debated. From this
> perspective, morality and ethics are not a given, but the result of the action of men
> and women to defend certain values against others (Fassin, 2011: 484).

Csordas believes that the existence of evil not only obligates the anthropologist to take a universal position on morality, but that it is a necessary condition that moral anthropologists have an ethical agenda. This, he feels, is the real stumbling block. This suggests to me that the perceived problem with moral anthropology is not evil, but the conflict between universal and relative moral positions. If, however, ethical or non-ethical agendas are made clear, transparency eradicates such problems.

If one can accept that morality exists in every culture as a system like other cultural systems, studying morality of individuals, groups or societies in any given place and time should not be difficult. And, in disagreement with Csordas, it does not lead to "experience distant" information nor does it "challenge the very definition of morality" (Csordas, 2013: 525). Indeed, it does the opposite. It brings to light moral worlds in more detail above and beyond typical religious categorisation to show the multitude of ways in which moral codes of society are perpetuated and how embodied moralities of our subjects are formed. Further, it does not make ethical agendas a necessity in the study of morality.

The presumption that ethical agendas are obligatory in the study of morality is also shared by Witkor Stoczkowski (Stoczkowski, 2008). He warns against reverting to the mistakes made by Levi Strauss where his ethnographies of primitive cultures were used to impart wisdom to the 'west' in order to develop a new moral order based on reconciling us with Nature (Stoczkowski, 2008: 348). Stoczkowski states that his ethical agenda was to "vilify the faults of modern societies and assign to ethnology the mission of transmitting to the West the lessons of wisdom"(Stoczkowski, 2008: 348). Without doubting that this type of ethical agenda is problematic, it demonstrates more than anything else an anthropologist with distaste for his own society. Once again, moral anthropology simply has morals for its object of study to show how subjects work this out in their everyday life (Fassin, 2008: 334). It does not have to have an ethical agenda. Due to the insistence that it does, Stockowski believes its aim is to "transform" (Stoczkowski, 2008: 351).

The warnings and recommendations of scholars persist with the assumptions that moral anthropology wants to revisit the past, but wrap it up in a different package. It is difficult to debate an anthropological approach when there is such confusion about not only objectives but morality itself. As Fassin argues, their concern has been "that the analysis of moral facts might in fact drag forms of judgement in through the back door"(Fassin, 2014: 3). Hence, Stoczkowski sees moral anthropology as overtly political, to "use its knowledge about society in order to reform society" (Stoczkowski, 2008: 350). He uses Nancy Scheper-Hughes as an example of those having a moral objective to "defend the rights of the oppressed" (Stoczkowski, 2008: 349). This may be true, but she makes her ethical position clear and is overt about her political commitment and her rejection of relativism (Fassin, 2008: 334). In

this respect, Scheper-Hughes should be an example of the unproblematic nature of moral anthropology since ethical agendas are made transparent. If she exposes atrocities which are deemed atrocities by the locals themselves, what is the danger here? Is it really imposing western values to 'transform' a culture? For most moral anthropologists, the objective is to describe and understand morality, not transform it. Those that have an ethical or political agenda are not in the business of hiding it. This raises the final issue complicating the debates in moral anthropology, reflexivity.

Whenever morality is discussed, there is always a concern about anthropological professional obligations. However, there is no need to assume that because the object of study is morality that the anthropologists will abandon their commitment to ethical practice. As Fassin argues, why should it be treated any differently than kinship, ritual or religion as an object of study? (Fassin, 2008: 336). Carlo Caduff argues that the challenge of moral anthropology is "to bring the anthropology of ethics into a productive relationship with the ethics of anthropology" (Caduff, 2011: 466). In other words, due to the presumed 'ethical agenda', it must be most diligent with ethical standards of the practice.

Apart from acknowledging the obvious fears of moralising, Fassin provides a solution. He concludes that this discomfort with morals may have a valuable "heuristic" function for the anthropologist (Fassin, 2008: 342). This implies that reflexivity is just as important as the object of study. Carduff, insisting that all moral anthropology has an ethical agenda, warns that in this process, reflexivity will be lost. Fassin's response to Carduff was as follows:

> …I propose to situate the critic on the threshold of the cave, not in an undecided in-between position, but in one from where it is possible to go inside and outside, alternatively…Linking ethics as an object of inquiry and ethics as a practice involving the subjects of the investigation, the position on the threshold of the cave I suggest as an epistemological stance for critical thinking therefore represents the point of articulation between the anthropology of ethics and the ethics of anthropology, for which Carlo Caduff advocates (Fassin, 2011: 485).

Fassin answers his critics by showing that one does not have to be a pure relativist nor does one have to stand back and view morality from the position of universal absolutes. Moral anthropology can adhere to the ethical not only through reflexivity but when questioning

local ethics. The edge of the cave serves as a metaphor for being critical of one's own understanding of local morality. Therefore, the anthropologist must question and critique their own analysis.

It is clear that the proposed problems with moral anthropology are two-fold. First, that there is danger of moralising and thus transforming cultures and second, a strange insistence that all moral anthropologists take a universal perspective on morality. These have developed not only from a misguided understanding of the objectives of moral anthropology but from their own beliefs in ultimate truths. It is clear that not all moral choices emerge or are connected to religious belief systems and neither is it always necessary for the moral anthropologist to have an ethical agenda. Those that do are as much aware of their professional ethics as other anthropologists hence the transparency of their aims. If their agenda is to transform the lives of the suffering and to bring to light human rights abuses, it hardly stands as justification for fear of the study of morals. The object of study; whether morality or any other object, should not presuppose a neglect of professional ethics.

Chapter IV – The Nature of Embodied Morality

In this chapter, I compare and contrast two phenomenological approaches in moral anthropology, outline my approach to the analysis of narrative and argue why this approach is the most appropriate for understanding the ethics of end of life decisions. Engagement with ethics must be analysed not only in terms of individual moral worlds which can challenge or reproduce moral codes but must also be considered as being influenced by the realms through which these codes emerge – institutions and the public domain. If cultural change explained values conflicts and moral freedoms, and power conflicts can demonstrate the formation and reproduction of moral codes; then embodied morality can show how each sphere of influence affects the subject. Moral dilemmas can be conceptualised for the purposes here as existential conflict. Thus, embodied moral positions must be couched contextually to examine the fields of influence affecting the life-world of the individual and how they tackle ethical problems.

Phenomenological approaches to morality are not simply a description of a lived experience, but take into account context and meaning:

> The field of embodiment, in its lived emotional-cognitive sense, is seen as a mediator between, on the one hand, patterns and structures which can be observed on a societal level and, on the other hand, individual life in its inter-subjective shaping of everyday meaning (Knibbe & Versteeg, 2008: 50).

Understanding how individuals negotiate moral dilemmas and resolve them and how they view or articulate themselves as moral beings in everyday life is a question of relative context between the moral codes of society and the self. Therefore, phenomenology has the ability to illustrate factors which affect and constitute subjective moral experience and how agents engage with ethical choices. To demonstrate this, I will compare and contrast two phenomenological approaches to embodied moralities to explain existential conflict, show the differences in their approach and explain my own.

For Cherryl Mattingly, the moral self is an everyday experiment (Mattingly, 2013). She interrogates moral reasoning from an Aristotelian perspective:

Aristotle also begins with the assumption that the ethical is ontologically basic to all action because in acting we are always oriented toward some telos or good (Mattingly, 2013: 307).

Thus, being moral is what we are every day without consciously engaging with ethical dilemmas. That is not to say that the moral and the social are one, but that from a position of virtue ethics, we assume that personal moral beings are self-aware in their attempts to be virtuous. This is why she compares the everyday moral life of individuals from a virtue ethics perspective as an experiment based on experience (Mattingly, 2013: 311). This means that experience develops our morality but when faced with certain ethical decisions, these deliberations are experimental.

Mattingly claims she supports Aristotle over Foucault because to engage in talk about freedom or un-freedom, we need to bring the individual to the fore in order to understand how people judge what is best in ordinary life and everyday action (Mattingly, 2012: 179). Certainly, to explain embodied morality the subject must be the point of focus. However, we must not confuse everyday action and ordinary decision making with moral reasoning. Indeed, living in a society with rules and moral codes, we are always living as moral beings because we conform to a greater or lesser degree to these. However, our reproduction (in the Foucauldian sense) of moral codes does not necessarily require a conscious engagement with an ethical problem. As has been discussed, engagement with moral reasoning requires a justification, requires reasons for our choices which must be both impartial and sometimes appeal to a universal good (Cohen, 2004: 15). Ordinary reasoning or stating of preferences is not ethical engagement. It is not 'ethical work'. Therefore, Mattingly's everyday morality refers to how we engage with moral choices in everyday life by virtue of attaining some good. She does this by applying an Aristotelian interpretation of morality.

In 'Two virtue ethics and the anthropology of morality', Mattingly explores moral anthropology by explaining the differences between Aristotle and Foucault when applied to the concepts of freedom and agency. For Mattingly, Aristotle espouses a pre-modern humanist virtue ethics and Foucault, a post-structural one (Mattingly, 2012: 164). From her perspective, this means that Aristotle emphasises the first person perspective which more readily helps us understand individual agency and morality on individual terms (Mattingly,

2012: 165). Foucault's post structural position, according to Mattingly, emphasizes the 'oppressive social structures' and gives a prominent place to social structures which shape the moral being (Mattingly, 2012: 175). Although she acknowledges Foucault's theory of the self, she says that his theory of "self-cultivation can be no more than (or less than) practices of normalisation of a particular regime of truth"(Mattingly, 2012: 173). This implies that he only explains normative models of behaviour which reproduce the moral codes of society. In this respect, she prefers Aristotle to explain embodied morality because he has the potential to explain agency. Aristotle argued about the *process* of becoming virtuous and thus about human life and action (Mattingly, 2012: 167). I agree that Aristotelian theory can provide an interpretive framework to explain first person ethical engagement, but I believe that there is more to be gained from Foucault than the view that he simply argues that we reproduce moral codes of society.

Foucault argues that morality is not just about the action we take, but also that this action establishes moral conduct to which the agent commits to for the future (Foucault, 2014: 42). This process involves the individual acting upon himself, monitoring, testing, improving and transforming himself (Foucault, 2014: 43). This suggests that as moral subjects, we develop over time and do not necessary blindly follow what society imposes as a moral code. In this respect, one could say that this is also a *process* of becoming, of cultivating a moral 'self'. His use of *telos* pertained to the type of being that we aspired to be in a moral sense (Foucault, 1997: 265). Therefore, I disagree with Mattingly that his position on self-cultivation is more or less about conforming to the norms of society. It is true that his objectives were not concerned with innate existential questions of primary experience, but he has much to say about the subject's relation to the self within the context of the historical loci in which subjects exist (Foucault, 1997: 34). His theory of the mode of subjection is about this, it is about the self and its relation to the rule; about this interrelationship and the provision of reasons to 'the self' regarding moral choice (Foucault, 2014: 42). Hence, conscious deliberation with the 'self' regarding ethics is a given. Morality is a dialogue with the self. It is not about simply reproducing moral norms but also about the freedoms to challenge moral codes. Along with his theories on power and governmentality, it is for these reasons above that I find Foucault more useful than Mattingly suggests and why I refer to him from time to time throughout this thesis.

Another scholar who takes a phenomenological approach to the moral question is Jarret Zigon. He too believes that individuals work on the self to be moral beings. However, he differs from Mattingly with respect to what he believes to be the best way to discern how an individual's engagement with ethical questions are solved. First, he argues that we develop as moral beings when we are forced to solve moral dilemmas in a conscious way (Zigon, 2007: 138). He believes these moments in time should be the focus of phenomenological study because they show the process through which subjects engage with ethics and how they come to their solutions. It is this process he believes to be the most important and to which he refers as a "moral breakdown" (Zigon, 2007). These moral breakdowns serve to develop our moral self:

> But this return from the ethical moment is never a return to the same unreflective moral dispositions. For the very process of stepping out and responding to the breakdown in various ways alters, even if ever so slightly, the aspect of being-in-the-world that is the unreflective moral dispositions. It is in the moment of breakdown, then, that it can be said that people work on themselves, and in doing so, alter their very way of being-in-the-world (Zigon, 2007: 138).

For Zigon, we also develop as moral beings over time through this process. However, our everyday reproduction of moral being in the world is not the way to understand it. The way to understand embodied moral work is through the conscious engagement with explicit ethical problems, not through our "unreflective moral positions." Zigon's focus on morality then is where the subject engages with moral dilemmas and/or existential crises. The process that we go through to resolve it and return to our normal moral being is not only a process of development, but for Zigon, the best way to understand embodied moral reasoning. Mattingly, on the other hand, believes that the subjective moral experience can be best understood during the everyday mode of being moral, our everyday quest to attain 'the good' because we are motivated by virtue.

Mattingly forms a bridge between the notions of reproduction and freedom of morality by specifying that the moral self develops during every day experiences or living. In Aristotelian terms, the agent is always in a process of becoming; virtue is acquired through a lifetime of habit (Aristotle, 2004: 31). Mattingly believes that we have freedoms to act in the way we believe is morally right, but we do not always know what the right decision is and further, that we can be challenged by others within the same moral world with respect to what is

considered 'good' (Mattingly, 2013: 307). Therefore, the everyday moral life that Mattingly describes is not identical to Zigon's unconscious moral life where, by and large, morality or moral choice is done without much effort or conscious awareness. Mattingly's moralities are processes of deliberation and doubt through everyday experience of deciding the moral 'good'. She argues that people:

> …frequently find themselves befuddled about 'the good' or about who they should become, morally speaking and continue over time to revise and critique their future hopes in light of the things that have happened to them (Mattingly, 2013: 309).

Mattingly, adopting Aristotle, is arguing that we are in a constant state of development due to experience and the process of "becoming" in order to achieve the goal of virtue. However, although she believes that we debate the moral in our everyday experiences, to truly understand individual moral worlds, we need another ingredient – the journey. She states: "It is within this image that the narrative qualities of moral experiments become apparent as temporal moments and spaces in larger narrative trajectories" (Mattingly, 2013: 317). This suggests that moral experiments can be identified by temporal shifts which have a certain quality in the stories we tell about our lives.

One way to illustrate her approach is to describe one of her ethnographic accounts which concerns an African American mother, Dotty, and her chronically ill daughter. Mattingly explains that Dotty embodied a super strong stereotype, but that her constant focus on the health of her child led to conflicting moral positions:

> "She must be like Rambo, but also be able to see her daughter as a normal child who has problems or cries not because she is in pain, but because she will miss her mother"(Mattingly, 2014: 131).

Through this example, Mattingly shows how one good (strong medically astute mother) chosen over another good (everyday loving mother) can leave the agent in a quandary. She argues that one good can subvert another – that of just being a caring mother sensitive to the usual emotions of a child. Dotty often has to choose between two competing 'goods' and Mattingly explains; agents "…may find themselves in dilemmas where pursuing one good can subvert or prevent the pursuit of another equally cherished good" (Mattingly,

2014: 129). She highlights the difficulties in finding the 'best good' in a situation and implies that although we may do our best to be 'virtuous' and 'moral' individuals, it is sometimes quite complicated. Hence, she refers to the mother's morality as experimental because each medical situation builds on the previous one to find the best good in each situation. For example, in attempting to find a better 'good', Dotty goes against the doctor's advice and pushes for transplant surgery knowing the risks but takes this path in order to end the constant struggle (Mattingly, 2014: 132). To be morally virtuous, she must find a greater good where good choices are hard to define and so the surgery is seen as a way to solve the problem permanently.

Taking Mattingly's example, I agree that good solutions are still sought where none seem apparent to the subject. In end of life care, when death is certain and time is limited, the subject often still attempts to find a moral solution, a good solution to the inescapable problem of pending death. Often, family members who cannot accept that there is nothing that can be done may insist on futile surgeries even against doctor's advice and sometimes even against patient's wishes (Borbasi et al., 2005 ; Kastenbaum, 2004 ; Kellehear, 2009c ; Mohammed & Peter, 2009 ; Worthley, 2000). However, do desperate attempts to deal with pending death, grief and negative realities mean that all subjects seek a virtuous life? Does it mean that moral virtue is the principle on which all moral reasoning is based?

If we are adopt Aristotle, we not only aim over time to be moral through virtue, we aim to attain it by hitting the 'mean' position between deficiency and excess (Aristotle, 2004: 41) This means moderate action leads to an ethical life. However, was Dotty's push for risky surgery a show of moderation? Undoubtedly it shows an extreme position, a position of excess which does not comply with the principles of virtue ethics espoused by Aristotle. There is, I believe, two problems with this approach. The first is, should we approach our interlocutors with the presumption that they seek to be moral people through the principles of virtue? Second, if seeking of 'the good' through our "moral experiments" in everyday occurrences, how are we to distinguish these moral experiments finding the good from the everyday moral being of conforming to the general moral code? Is this the same process as engagement with conscious ethical problems in a situated dilemma? She states:

> …investigating the formation of personal moral experience, and the exercising of moral judgement in the singularities of circumstances offers another way to explore the ethical as a social as well as personal matter. To capture the complexity of moral experience, moral self-making and the embeddedness of the moral in everyday practical action, one needs a different inaugural scene that brings the moral ordinary into full view (Mattingly, 2013: 306).

Although Mattingly may not go as far as to suggest the moral is simply part of the social (in a Durkheimian sense), she argues that the moral "ordinary" is where we discover the development of the moral self in its quest for virtue. She also suggests that we just need certain events to make them apparent. However, how are we to decipher everyday seeking of 'the good' from simply preferences instead of real engagement with ethics? Preferences, as I have argued, are not an engagement with ethics. Stating a preference does not need to be justified in an impartial way. This is why it is important to follow rules which identify moral reasoning leaving little doubt between everyday good preferences from a conscious engagement with an ethical problem.

It is clear that there are certain problems associated with applying one normative ethical theory to all subjects and that there is debate over where and when we engage with ethics. However, I think I have made plain the difference between seeking good choices and moral reasoning. That is not to say that ethnographic material will never follow certain patterns which reflect normative ethical theories, just that these presumptions about the nature of the subject should not be assumed beforehand. A further problem with focusing on the "moral ordinary" is the danger of blurring the lines between the personal, social, religious and moral instead of distinguishing them which I believe is the purpose of moral anthropology.

Zigon argues the moral and ethical dimensions in social worlds should not assume that we are dealing with a "neo-Aristotelian" actor, but should offer a framework for making sense of the diverse and contradictory claims that locally count as morality; "…we do not arrive already knowing that a properly understood moral actor, for example, aims at 'the good' or attempts 'to do right' by acting 'responsibly'"(Zigon, 2014b: 17). Zigon believes that we can decipher the engagement with ethics during what he calls 'moral breakdowns' which are conscious ethical engagements by the agent seeking solutions to moral problems (Zigon,

2007). These breakdowns take into account the full cultural and social contexts of the interlocutors (Zigon, 2007: 143). His approach is particularly useful as it does not presume that agents are morally motivated a certain way a priori. An example to illustrate his approach is his account of a Russian woman, Aleksandra, and her recollection of a moral dilemma. Zigon provides his own interpretation, but I shall use the data to discuss what I believe is the practical usefulness of his approach.

Aleksandra is a 51 year old woman separated from her husband for ten years but not divorced. She is university educated and lives with her adult son. She is also a devout Orthodox Christian. She was in a hurry to catch a train and there was a long line for tickets. She knew if she lined up, she would miss the train. She boarded the train without a ticket knowing that if an inspector was on the train, she would have to pay a fine and face embarrassment. Waiting on the train, this is how she described her dilemma:

> And, I prayed to the Lord to help me. And then I also thought that if no inspector comes by, then I will give the money that I saved to some charity or something. But I didn't want to feel embarrassed. And then no-one came, so I took the money and gave it to someone, some beggar or church or something. Because I thought that this was not my money anymore, this is how I solved it for myself (Zigon, 2007: 144).

Aleksandra's morality is rationalised through her connection to God. There is also an indication that her ethical breakdown was resolved by not allowing herself to keep the money that she should have spent. Keeping that money would be morally wrong for her because, perhaps, it was like stealing. It was also breaking the law. The situation is intense for her because she has guilt that what she did was wrong in the eyes of her Lord. She imagined how embarrassed she would be if she got caught. Since there was no inspector, she had to absolve her sins by doing some 'good' – giving the money to charity. Zigon acknowledges that such an act would not seem like an ethical dilemma or be that morally important to some people (Zigon, 2007: 144). Yet, it is clear that religiosity contributes to this intensity and assists her moral compass. This is evident from the following justification that she made for her actions; "But I knew, because God disciplines me, I knew that if I didn't give the money to someone and just saved it I would be punished"(Zigon, 2007: 144).

Another example, also to do with money, is recounted by Aleksandra. Her ex-husband called her and asked to borrow money. He had a good job and she indicated that he did not provide for their son, further, she had been hurt by him. Therefore, she was furious that he had the audacity to ask for it. Against all her emotional instincts she still gave him the money. She explains the dilemma in this way:

> He never gave any money for the son. So why should I? And he works. So why should I give him the money? It was only because the Bible said so, this is the only reason, that is for sure…It says, give to the one who asks for it. And he was my husband officially for quite a long time and he needed money (Zigon, 2007: 146).

Aleksandra's ethical work here justifies her decision again with reference to her duty as a Christian. Even all immediate emotional and rational responses against giving her ex-husband the money are subordinated to her religious duty. Once again, her moral self greatly identifies with her faith and thus, her emotions and instincts are repressed in order to carry out what she believes is the right moral action in this situation. She stated; "…I knew the holy fathers say you should overcome yourself, and this was overcoming myself; my emotions" (Zigon, 2007: 147).

Zigon's examples, according to him, describe the subject in their moments of "moral breakdown". For Aleksandra, her embodied moral world is almost a duality. She must debate with herself over the right thing to do. When she refers to her background experience, to the circumstance and her emotions, she feels one way. However, her solution comes from God. Her personal idea of what is right, guided by emotion and experience is subordinated to the institutional moral dogma of the Church. Indeed, the more intense the dilemma, i.e. whether to loan money to her ex-husband, the more that she must refer to the Bible to solve the quandary. Although she may not be happy with what is, in the end, what God considers 'right', she at least is able to return to her everyday moral being-in-the-world. The more difficult the decision, the more she had to 'overcome herself', not allowing anger or resentment to decide for her.

People who identify as religious are an interesting example of embodied morality and the contradictions which can be faced during a moral breakdown. However, if we approached this data based on the fact that she is religious with deontological normative theory, we

might understand the final decision but not the process through which it was made. Further, could we assume that all her moral dilemmas are solved by referring to Christian principles? No. We can see through her explanation of her deliberation within the dilemma that emotions played a big part in how she felt about these moral problems, yet, she suppressed them. That is not to say that she would never solve an ethical problem emotionally. However, in these cases, Aleksandra's decisions did not reflect what she wanted or what her emotions were telling her was the right choice. She appealed to God.

Both Zigon and Mattingly's phenomenological approach to morality differ in a number of ways. Mattingly seeks to assess the moral in the everyday, whereas Zigon believes that we need to differentiate between everyday moral being and conscious ethical work which he calls a 'moral breakdown'. An agent explaining the solution to a particular moral dilemma is an illustration of this ethical work. Hence, it is a window through which the development or work on the moral self is articulated. Mattingly, however, interprets the everyday search for 'the good' as a moral development journey loyal to Aristotle's virtue ethics and the human subject's desire to become more virtuous. Zigon's approach respects all possible influences which contextualise moral choice in the moments of ethical breakdown whereas Mattingly's subjects, through every-day "experiments", choose good over bad, based on experience to develop their moral virtue. Zigon makes no assumptions about motivation or whether morality can ever be defined as a fixed influence. It is for all these reasons that my approach to the moral question within this thesis will be based on Zigon's perspective on the nature of embodied morality. That is not to say that his theory of the moral breakdown will be used exclusively, but in particular his phenomenological approach:

> …a phenomenological anthropology must take into account the constant interrelationship between…cultural domains, as well as social institutions, various discourses *and* individual persons. It is for this reason then, that I contend that phenomenology is not concerned with describing the experience of individuals, but rather with the description of processes of interrelationships (Zigon, 2009a: 287).

Jarret Zigon believes that the moral process is best understood if we view morality as three distinct but interrelated aspects of society; the institutional, public discourse and embodied moral dispositions (Zigon, 2009b: 258). Any institution which is a formal social organisation like a council, government or religion will have its own code of morality. Indeed, it is a formal pre-requisite to adhere (at least publically) to the institutional morality to which you

are a part (Zigon, 2009b: 258). This was exemplified in the literature when nurses who are obligated to conform to the moralities of their institutions faced a moral quandary between duty to their institution and duty to themselves or their own embodied moral worlds (Worthley, 2000). Second, he describes public discourse morality as manifest through public opinion, media, art and the site of everyday dialogical interactions between persons (Zigon, 2009b: 259). Moral exchange and influence of this type could be evident in an increase in the euthanasia debate in the media or dialogue between members of a family. Third is our everyday embodied morality, our moral being. He argues that our ability to non-consciously be moral is what allows us to be social beings (Zigon, 2009b: 260). We are not conscious of what moral being we are until we must make ethical choices.   Therefore, there is no confusion between everyday moral being and engaging with an ethical problem. With respect to end of life decisions, there are always a multitude of influences impacting moral choice such as biomedical rhetoric, institutional objectives, family influence, background experience and other cultural and social influences. It is for this reason that Zigon provides the most useful framework through which we can understand the nature of moral reasoning.

Finally, Zigon treats morality as a dynamic concept which is more fluid than fixed because there are many elements which make up the moral 'assemblages' of the subject (Zigon, 2010).   These are "diverse de-territorialized aspectual traces of discourses and practices within which a unique range of ethical practices emerge in moments of breakdown"(Zigon, 2014b: 18). This approach, he argues, is beneficial since it does not assume the existence of moral totality and explains the often contradictory moral milieu which emerges from any "…singular social location, situation or experience" (Zigon, 2014b: 18). Therefore, it is the interrelationship of all these parts which affects embodied experience. Indeed, Zigon gives equal credence to all avenues which shape embodied morality. The inclusiveness of his approach, I believe, is its strength.

There were, however, some limitations in applying his theory of the moral breakdown in every case. In some instances, the participant's explanation of moral deliberation could be deciphered with respect to his moral breakdown theory.   As it was in the ethnographic example of his that I provided, the subject was able to explain their moral dilemma and

articulate how they solved it. However, in some cases, participants could not articulate decisions in such a way.

What I found during the course of my research, and what I will later argue contributes to one of my findings, is that deliberations and reasons for our moral choices are not always articulated as neatly as is shown in Zigon's ethnographic example. Further, in some of my cases, my research shows that opposite to what Zigon's Aleksandra did – they allowed their emotions to inform their moral reasoning instead of repressing them. Some people even described their choices as instinctive. Further, if we want a participant's moral opinion of a decision not made by them, moral breakdown theory cannot really be applied. However, this did not mean that they did not have a moral view on the decision. Indeed, it can be through opposition to a moral choice and during moral outrage that clear articulations of moral reasoning are expressed in the narrative. Further, I used other means such as narrative plot and structure, articulations of values and evidence of purported breaches of moral canons to elucidate moral positons and reasoning.

Perhaps the reason that deliberations for moral choices regarding end of life decision making do not always fit neatly with this approach can be found in another one of his arguments. Zigon states that the main motivation for responding to the ethical demand is to get out of this 'breakdown'. He argues:

> That is what is important in the moment of moral breakdown is not 'to be good' or 'to be a good __' but to get back to the unreflective moral dispositions of everyday life. It is having accomplished this return that is considered good, not the act itself (Zigon, 2007: 140).

Hence, he argues that the return to the everyday moral being-in-the-world is the goal. The 'good' in the process is that we have solved a problem and can then go back to our daily business. In most instances of moral reasoning, this may indeed be the case. However, when dealing with a dying relative and all that this entails, would returning to our everyday moral world after making a decision have the sense of satisfaction he suggests? Indeed, the existential shift experienced when one discovers a loved one is dying transforms the life-world of the subject in such a way that there is no returning to the usual, everydayness that he describes. No decisions made will actually solve the problem of death, nor do

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participants or patients exist in their usual world prior to terminal diagnosis. I will argue in my findings that those caring for a loved one going through a dying trajectory experience dramatic shifts in their life-worlds and remain in a liminal state until the death of their loved one. Hence, both for dying patients and for those who care for them, the motivation he describes is unlikely to fit this phenomenon. I will show that due to temporality, emotions and pending death, moral reasoning itself is transformed.

I have shown through the elaboration of the theories of two influential scholars in moral anthropology their theoretical approach to explaining embodied moralities. I have also explained the approach which I prefer based on its inclusive nature and its consideration to all the factors which affect moral choice. I have also attempted to show the limitations of each approach and some of the problems which can arise when normative ethical theories are applied a priori to participants. Moral reasoning, or periods of existential conflict during moral dilemmas, can be articulated quite clearly by subjects most of the time which allows for an understanding of the various factors impacting the choice. However, the limitations of Zigons' theory of the moral breakdown for the analysis of end of life decisions lay in the very nature of the phenomenon itself and how it affects the life-world of the participant. This finding, as you will see, was more revealing than limiting and helped to show that end of life decision making stands apart from other forms of moral reasoning which not only helps us understand the human response to suffering and death, but how reasoning itself is transformed by the experience.

Chapter V – Phenomenology, Inter-subjectivity and Life-world

I have spent the last chapter outlining two different phenomenological approaches to embodied morality to show that even within the same proposed methodology; interpretation and analysis can differ substantially. This was due to the theoretical grounding on which the approach is built. I have also shown the usefulness of Zigon's approach to morality for the phenomenon of end of life decision making and some of its limitations. The benefit of his approach, however, lay in his treatment of the moral subject and the fact that he does not restrict himself to normative ethical theories which presuppose an agent's moral motivations. In this chapter, I will explain why Husserl's phenomenology is useful for understanding the foundations of human experience and embodied perception and explain why some of his important key concepts are helpful for the analysis of moral reasoning. Csordas builds on the work of Husserl, and in some respects, provides a broader paradigm within which we should, for the present purposes, consider perception, inter-subjectivity and life-worlds. Finally, I will address some of the criticisms of phenomenology itself by explaining how the method goes much further than simply describing subjective experience.

Husserl's study of human consciousness forms the basis of phenomenological methodology by emphasising that consciousness is always conscious of (Knibbe & Versteeg, 2008: 56). Hence, far from attempting to grasp the meaning of subjective experience as if it were isolated in space and time, every subject is subject *to* another. This means our experience, thoughts and by extension, choices in life are carried out with due consideration to other people in our lives. Thus, inter-subjectivity is one of the key concepts of the phenomenological approach as experience always includes the presence of another object or being. For Husserl, "…inter-subjectivity is the most basic quality of human existence which is constitutive of the subject and of the very notion of an objective world" (Duranti, 2010: 16). Hence, to understand or describe the meaning of subjective experience for a particular phenomenon and further, to understand the values underpinning moral choice, one must start from the understanding that experience is always inter-subjective and interactional. It is interactional with respect to the presence of other human subjects and

with regard to the society we live in. Our perceptions include interactions not just with other subjects and objects but with public, cultural, social and institutional domains. It is these interactions which further serve to form our moral self. Therefore, the concept of inter-subjectivity challenges some of the claims about the methodology's limitations.

Desjarlais and Throop argue that the criticisms of phenomenology rest on assumptions that it is purely descriptive and subjective, too detailed and dynamic and lacks a broader consideration to political and social processes (Desjarlais & Throop, 2011: 95). To address the first and second point, one has to ask again, what is subjectivity? And, the answer provided by Husserl is that the subject's experiences are always interactional. Hence, the experience of the subject is never born of the subject in isolation, but is always created through the reality of inter-subjectivity. And, a focus on inter-subjectivity shows us moral life as it is experienced (Zigon & Throop, 2014: 7). However, if the very foundations of phenomenology rest on the ontological reality that our experience is always social and always interactional, then this methodology is not simply describing subjective experience but is itself describing a dynamic social process of relating. Csordas advances Husserl's position on subjectivity in useful ways. If we are to explain subjective perception, we must not demarcate mind from body but understand that "with the lived world of perceptual phenomena, our bodies are not objects to us…they are an integral part of the perceiving subject" (Csordas, 1990: 36).

The Husserlian concept of inter-subjectivity which is important for the purpose of understanding engagement with ethics is the idea that the self is always in relationship with an 'other' whether or not this 'other' is present (Duranti, 2010: 16) Existentially, we do not exist in isolation but always think and act in relation to our objective world. This world of other people and social and cultural norms informs and is informed by our responses to it. Thus, our identification with the 'self', our identity, is ever evolving. The very nature of inter-subjectivity means that we respond to the world around us, reflect on our values and in turn, on our moral positions. It stands to reason then that moral choices, inter-subjectively affected, are not made in isolation but always with consideration to others, to our relationships and thus are always inter-subjective (Foucault, 1997 ; Taylor, 1989, 1992 ; Zigon, 2014a). Further, this relationship is not only to others but to society. Thus, it must

take into account all cultural and social processes which affect values and perceptions and in turn, a moral position. Particularly when the object of study is morality, it is exactly these elements which need to be considered to understand what shapes it. As I explained in chapter three, the varieties of approaches to morality are largely dependent on the context of the phenomenon in question and the objective of the anthropologist. Hence, far from just describing one person's subjective position, our existential self is formed and functions in relationship with others and also in relation to our past experience, present concerns and future objectives.

Inter-subjectivity is a necessary part of experience and perception and is central to Husserl's concept of life-world (Husserl, 1981). The life-world is another important concept which is relevant to this thesis. Husserl's life-world refers to the unquestioned, practical, historically conditioned, familiar world of our everyday life which is a dynamic and shifting inter-subjective reality (Desjarlais & Throop, 2011: 92). It is the existential reality of the subject or individual. Further, it is not just situated and subject to place and structure, but experience (Knibbe & Versteeg, 2008: 49). Hence, the life-world is the all-encompassing world of the subject.   One important quality of this concept of the life-world is the fact that it is unquestioned and familiar and is closely connected to another concept; Husserl's 'natural attitude' (Desjarlais & Throop, 2011: 91).   If the natural attitude is familiar and unquestioned, perhaps we could say unchallenged and unreflective? Indeed, Csordas argues that "we must start with the pre-reflective if we hope sensibly to pose questions about appearance and reality" (Csordas, 1990: 38).

As part of understanding the life-world of another, there is another concept important to address; Husserl's term *phenomenological epoché*. This term refers to a 'bracketing', distancing or setting aside of taken for granted positions and unexamined assumptions (Desjarlais & Throop, 2011: 88). Thus, the life-world of another can be understood by leaving aside what is culturally or socially taken for granted by the researcher themselves; the assumptions that come from their own cultural conditioning (Desjarlais & Throop, 2011: 89). We can see the influence that Husserl's phenomenology has had on anthropological method itself, not just within the realm of phenomenology. In ethnographic methods, we aim to be reflexive in our approach to the lives of others meaning that we do not impress

our own bias and prejudices on our interpretation of the life-world of another or their reality. This bracketing off our 'natural attitude' is supposed to allow us to see things as they are without imposing our pre-existing theoretical understanding or assumptions which are a priori part of our consciousness (Knibbe & Versteeg, 2008: 56). Bracketing plays an important role in phenomenology because views on reality are not evaluated for their truth but are:

> …understood as experiences of reality that arise out of the daily life and practical concerns of people, without reducing them to socio-economic conditions or principals external to the situation itself (Knibbe & Versteeg, 2008: 49).

Therefore, understanding and explaining the life-worlds of our participants requires a heavy reliance on contextual as well as subjective information that they provide. The context of their perception and experience should not only focus on external political, cultural or social conditions but also existential conditions of their life-world which make up their subjective experience.

Criticism that phenomenology simply describes subjective experience without reference to social or political processes, is false. Far from just describing subjective experience, all relevant social, cultural and political impacts and influences are taken into consideration as morality is shaped by these processes. One must consider all factors which shape experience; selfhood, sociality, agency and morality (Desjarlais & Throop, 2011: 93). This is another reason that Zigon's approach to moral anthropology has been adopted in this thesis. Another criticism of phenomenology is that it is reductive. Thus:

> In phenomenology reality is comprehended through embodied experience…phenomenological analysts seek to capture the meaning and common features, or essences, of an experience or event (Starks & Trinidad, 2007: 1374).

Meaning and common features or themes of an event are important, but so is that which shapes them. And, one cannot simply describe subjective experience without interpreting how that subjective experience is informed. Inter-subjectivity means relationships with not just other people but social and cultural exchanges. These are what inform moral being (Zigon, 2009a: 287). Instead of just understanding the moral code as a social normative prescription of behaviour, by breaking it down into moral worlds; institutional, public discourse and embodied, we can begin to understand the dynamics through which our

morality is formed, reproduced and challenged. We don't just follow the moral code blindly, we consider what it means to us – to the self (Foucault, 2014: 42). That which shapes our perception and values shapes our morality and therefore, our end of life decisions.

Phenomenology and particularly the concepts of inter-subjectivity and life-world are an important part of being able to explain the existential worlds of participants. Far from simply describing subjective experience and identifying common themes or "essences" of a phenomenon, phenomenology goes so much further in its potential to explain the dynamic nature of being-in-the-world, how it shapes us and how we shape it. So, to understand embodied perception which shapes moral worlds, and the relationship between subjectivity, objectivity and life-worlds, Csordas puts it another way:

> Objectivity is not a view from nowhere but a view from everywhere that the body can take up its position, and in relation to the perspectives of "other myselves"…it is not true that contemporary phenomenology denies an "irreducible objective reality"…phenomenology insists on an indeterminate objective reality (Csordas, 1990: 38)

Now that I have covered the key elements which will ground analysis of the data, there are two other influences which are particularly pertinent to not only medical decision making, but with regard to end of life care. These are temporality and emotions. In the following section, I will explain why these two elements will be given special attention in the analysis of my data and how these will be utilised in conjunction with the other theoretical approaches and grounding that I have already explored.

The vital role of temporality and emotions

In terms of important features which impact end of life decision making, I argue here that the two most significant impacts come from temporality and emotions. Temporality has been shown to be one of the most important elements affecting end of life care (Borbasi et al., 2005 ; Ivanovic, Buche & Fringer, 2014 ; Kaufman, 2010b ; Mohammed & Peter, 2009 ; Russ, Shim & Kaufman, 2005 ; Worthley, 2000). In one respect, it influences the impact of prognosis in terms of what treatments are offered what value time pays (Kaufman, 2010b: 231). Patients must often weigh the value of the proposed time left with considerations

regarding quality of life (Shim, Russ & Kaufman, 2007: 248). It is at this junction that temporality and hope can be linked.

Hope, as an emotion, has been the focus of studies in medical decision making and doctor's communication in terms of how it is encouraged and through the belief that it is therapeutic for the patient (Cellarius, 2008 ; Good, 1994 ; Good et al., 1990) Hope is also said to mitigate the sense of powerless in the face of death (Doka, 2005: 87). However, hope is not the only important emotion impacting end of life care. This thesis will explain that along with hope, empathy plays an equally important role in moral reasoning and therefore, in end of life decisions.

Temporality

Temporality and death are intrinsically linked not only in end of life care but in the narrative itself. After a terminal prognosis, both patients and doctors must deal not only with the illness, but impending death. This temporal pressure is central to end of life care due to its impact on clinical staff communication, prognosis, types of 'care', and is sometimes behind risky attempts to 'cure' (Borbasi et al., 2005 ; Ivanovic, Buche & Fringer, 2014 ; Kaufman, 2010b ; Mohammed & Peter, 2009 ; Russ, Shim & Kaufman, 2005 ; Worthley, 2000). It is also central to physician communication. One study suggests that physicians within oncology create time horizons which do not focus on the end, but stay open ended and focus on the present, discussing only current treatment or management of treatment (Good et al., 1994: 857). Although many studies regarding physician communication in dealing with terminal patients focuses on their objective of maintaining hope (Cellarius, 2008 ; Good et al., 1990 ; Kaufman, 2010b ; Russ & Kaufman, 2005) data from my research will show that this is not always apparent, explicit or a conscious objective of the physician. As Good (1994) explains, they do engage the patient in the realm of the present – current symptoms, current concerns. However, I will show that for patients and carers, a liminality or timelessness may be more of an accurate description of existential states.

Hence, temporality impacts the clinical management of dying as well in at least two ways. The first and perhaps the most obvious is the fact that terminal prognosis guarantees the

patient a finite amount of time left. Hence, from prognosis, the clock is ticking. This feeds into a sense of urgency for patients and families. Decisions made revolve around both the question of the quantity of time left and the quality of life (Kaufman, 2010b ; Russ & Kaufman, 2005). However, it has been shown that prognosis itself is not accurate or even considered that important for physicians. Christakis and Lamont's large cohort study of 365 doctors showed that from a sample of 504 patients, only 20% of estimates proved accurate (Christakis & Lamont, 2000: 469). This study also stated that prognoses were not considered an important part of doctor training nor literature. This is concomitant with the findings in this thesis with only three of the ten cases receiving an accurate prognosis and only two doctors in these narratives actively promoted a sense of hope. Unlike day to day moral choice or moral dilemmas, the ethics of end of life decisions are obviously subject to time limits and a sense of urgency even if the time provided is not accurate.

The second way that temporality impacts both clinical decisions and end of life care in particular is what Cunningham describes as a state of suspended animation. She writes:

> Prognosis time is confusing, for it suspends us between poles of certain events (having cancer or not, dying or not dying) even as it retains the uncertainty of either. We thus cycle between various combinations of mourning and anticipation, as we unconsciously remain suspended in these imagined possibilities, the chances of something horrible happening, hope and thus anticipation, potential loss and despair…a temporality which suspends one in time both before and after an event, a nonlinear time in which it becomes impossible either to anticipate a certain future or mourn a clearly delineated 'past' (Cunningham, 2014: 463).

Patients and families, along with having their life-world transformed, must not only think of time left, or hope for more time but are uncertain about either. Therefore, unlike decisions made for other illnesses, we can see how the impact of temporality for terminal illness differs. The clinical care experience, the uncertainty and ambiguity of information, makes temporality a much more intense and complex affect for terminal illness than for non-terminal health issues.

Temporality for end of life decisions then impacts end of life care in many ways. We may infer from this the ways it affects both patients and participant's life-worlds through propositions. One may infer that 'time left' as a temporal concept may mean that the

shorter the trajectory, the higher the urgency and the more likely that risky treatments will be considered. Likewise, the longer the estimated time left, the less intense the level of urgency and more time for decisions to be considered. However, since liminality is also an important feature of terminal illness, the following four questions should be raised. Does the length of the trajectory directly impact the decision to take up or refuse treatments? What part does quality of life play in decision making with respect to time left? How does liminality make end of life care different from other medical decision making and, finally, in what circumstances does the end not come soon enough? It is from these questions that we can see the many ways that temporality can shape end of life decision making. It plays a significant role in the participant's and patient's experience, in the process of decision making and in their moral justifications.

Emotions

How can we talk about death and dying without talking about emotions? Emotions go beyond feelings. They are a way in which we interact with our world – they are a complex mix of beliefs, judgements and feelings (Simpson, 2004: 431). Therefore, they impact not only our existential experience of life, but they also influence our judgement and reasoning behind decisions we make. They accompany experience and are vital to our inter-subjective relationships. In sum, they affect both perceptions and choices. Hope is one emotion prolific throughout the literature and within the data in this thesis. However, the other important emotion is empathy. Nussbaum argues that empathy and compassion are themselves a certain type of reasoning (Nussbaum, 1996: 28). Thus, emotions such as hope and empathy not only contribute to the intensity of the experience but they are fundamental in their impact on decision making. Throughout the narratives in this thesis, it is clear that exposure to death and dying triggered emotional responses in both patients and participants which affected both their existential experience and their moral reasoning.

Emotions, such as hope and empathy, inform the reasoning process a great deal when it comes to suffering and death. I have discussed the impact of hope and how it plays a role in decision making during clinical care. Hope is an emotion which links both thought and feeling. Hope is an emotional state and an emotional attitude (Cellarius, 2008 ; Simpson,

2004). The second relevant quality of hope is that it is linked directly to temporality. To have hope is to think about the future, a positive future. Nussbaum describes hope as the thought that one's future good is not fully under one's control (Nussbaum, 1995: 57). Hence, hope is for a desired future event and thus is linked to our values. When time cannot be imagined, there is an ambiguity; the temporal state becomes liminal.   Hence, hope is an emotional response to certain circumstances or situations in the present in relation to what we wish for the future.

Cellarius argues that hope has three elements. First, that it is an active emotional experience; second, hope flees the bad and aspires to the good; and third, hope has effects (Cellarius, 2008: 113).   Throughout my data, hope emerges in patients and families in response to prognosis, from the interpretation of physician information and in potentialities in courses of action. It is not, however, always a choice of 'being' in response to 'medical facts' regarding possibilities for recovery. Hope can be present whether or not the physician encourages it. What became apparent is that even where there is an explicit lack of hope coming from health practitioners; hope can either remain or emerge in the patient, family members or both spontaneously. This demonstrates clearly that hope is a blend of emotion and cognition.   Thus, it is, as Lazarus argues, a coping resource (Lazarus, 1999). It emerges from a need. It is something which is chosen because of its required effect in response to a negative and undesirable present. Above all, hope is a future orientated emotion regarding what we value and what outcomes we desire. Lazarus puts it succinctly:

> …To hope is to believe that something positive, which does not presently apply to one's life, could still materialize, and so we yearn for it. Although desire (or motivation) is an essential feature, hope is much more than this because it requires the belief in the possibility of a favourable outcome, which gives hope a cognitive aspect and distinguishes it from the concept of motivation… (Lazarus, 1999: 653)

As will be shown, hope can exist without encouragement or support from others. When a terminal prognosis is delivered, those that insist on having hope are viewed by those that do not as being in denial. But, isn't denial only hope that is not shared by others? Some of us need hope to keep going even if it defies 'reason'. In this way, emotions become reasons.

Emotions are a type of reasoning as they go beyond impulses; they require both thought and belief (Nussbaum, 1996: 31). Mamo agrees stating that "…our emotions go beyond the mere 'feel' or 'feeling' of that emotion (the physiological manifestations); emotions are a way in which we interact with our world and many or most of our emotions are a complex mix of beliefs, judgments, and feelings" (Mamo, 1999: 431). Death and dying are arguably one of the biggest triggers of emotions for those dealing with these difficult experiences. Participant's emotional reactions are prolific throughout the narratives in their recall of how they felt about events, through their choice of words, through the tears that they shed but most importantly, through the way in which they impacted moral choice. Mamo argues:

> …the emotions in death and dying for patients and family members provide a link between feelings and cognitions, mind and body, and individual and society. Death and dying are human events seething with emotion (Mamo, 1999: 34).

Therefore, it is clear that the emotions are an important and often neglected avenue through which we can understand moral reasoning – particularly for end of life decision making. To demonstrate how emotion impacts end of life decision making, I will now explain empathy and compassion.

Nussbaum argues that that witnessing suffering and the evoking of empathy and compassion concerns our values in that it "involves the recognition that the situation matters for the flourishing of the person in question" (Nussbaum, 2001: 307). The situation, a dying relative, could not affect the flourishing of a subject any more. Thus, our morality makes compassion with respect to dying inevitable since it destroys a value we all share – life. Not just any life, but the life of someone one loves.

Aristotle spoke of how compassion operated through what he termed the judgment of similar possibilities (Aristotle, 2004). Nussbaum challenges Aristotle's *judgement of similar possibilities* by saying that these are not necessary conditions for compassion to exist. She states:

> Compassion then, has three cognitive elements: the judgment of *size* (a serious bad event has befallen someone); the judgment of *nondesert* (this person did not bring the suffering on himself or herself); and the *eudaimonistic* judgment (this person, or creature, is a significant element in my scheme of goals and projects, an end whose

good is to be promoted). The Aristotelian *judgement of similar possibilities* is an epistemological aid to forming the *eudaimonistic judgment* – not necessary, but usually very important (Nussbaum, 2001: 321).

Thus, Nussbaum is arguing here that the *eudaimonistic judgement* will exist whether or not the other elements are present. However, I argue that each of these three cognitive elements are present in the compassion for a dying relative. With regard to size, death couldn't be larger. With respect to being undeserving of the situation, even if there is a link say between smoking and lung cancer, family are not going to see the suffering as being self-induced and therefore, show no compassion. The final one, the *eudaimonistic* judgement, is already there when we are discussing a family member. Therefore, compassion in relation to a dying family member has the power of all three of Aristotle's conditions. Hence, although Nussbaum is right to say that the first two may not necessarily be present for compassion to exist, I argue that each of these impact compassion for the dying family member. What is clear is that each cognitive element of compassion highlights the power, intensity and importance of empathy when we are witnessing suffering. It also shows how emotions and thought work together to impact moral reasoning.

Compassion for the suffering of a loved one was a prominent theme running throughout the narratives in this thesis. Suffering of the dying evokes great empathy and compassion, particularly for a family member. Death is not just misfortune, loss or illness, but includes the impending end of personhood (Mamo, 1999: 14). Thus, witnessing suffering of a loved one through the dying process is not like exposure to some random misfortune – it is the witnessing of the fate of us all. We can feel compassion for others for misfortunes that we may envision befalling us, but with death it does not require this imagination. We do not ask ourselves if it will ever happen to us. We can see then how compassion and all other emotions play a great part in the experience of caring for a dying family member and the choices which go along with this. This gives credence to my proposition that both temporal and emotional influences make moral reasoning for end of life decisions different from all other forms of moral reasoning.

It is clear that when it comes to death, emotions play a large role in the affect that experiences have on participants. They emerge in the content of the narrative, in the re-

telling of the story. Our compassion and hope are not just stirred by our social bonds to loved ones but because we all have the potential to suffer in the same way – we are all mortal. Hope plays an equally important role in its links to temporality and also with respect to its blend of emotion and cognition. Hope emerges to escape negative future events by providing positivity in the present. It promises a future. Hence, emotions play an enormous role in end of life decision making. They are often the reasons for sharing a story, they shape the events that transpired and they impact the moral reasoning process in significant ways.

In this discussion of the impact of both temporality and emotions, I have attempted to show why these elements are particularly important for understanding end of life care. Dying patients occupy a different realm to those who can be cured. Both patients and carer's life-worlds are transformed by this, by the emotions involved and sometimes, through the ambiguity and liminal space which is occupied by the experience. One cannot speak of the link between inter-subjectivity on perception and choice without acknowledging that integral to the sustaining of these relationships include both social and emotional considerations. Whether decisions are being made by the patient, the family or as a collective exercise, temporality, hope and empathy inform and intensify both the moral significance of the situation, the course of events and the way in which choices are deliberated.

Chapter VI – Research Design, Methods and Analysis

I have outlined the phenomenological methodology which served as the foundation for this research and explained why this approach was most suitable when the object of study is morality. Within this, I identified the important concepts which will serve as points of focus, such as life-worlds and inter-subjectivity, with regard to this research. I also explained why both temporality and emotions have considerable impact on end of life decision making and how these two elements will be given particular consideration in the data analysis. In this section, I will explain in detail my research design and methods and the reasons for choosing this approach. In addition, I will go into detail to explain what key aspects of narrative analysis are important with regard to identifying moral reasoning and moral positions. This entails a discussion of both content and structure of narrative and the ways in which we can identify aspects of life-world, inter-subjectivity and background and intention which inform moral positions. Finally, I will present the details of my data collection and participants and outline the initial identification of themes.

The narrative case study

As I have argued, understanding the moral reasoning of end of life decision making requires a thorough understanding of the context of each individual participant's experience. Along with my phenomenological grounding, I adopted the method of data collection in the style of the narrative case study (Brandell & Varkas, 2010). It resembles both a narrative ethnographic approach and a traditional case study with respect for the fact that I began my research with a set of theoretical propositions. These were formed after an extensive study of the relevant literature from the field of medicine, medical and moral anthropology, and sociology. Theoretical propositions strengthen the research in that they ensure that only the relevant information regarding the unit of analysis is gathered (Yin, 2009: 29). These propositions guided key questions in the initial interview. Each case, therefore, provided details of the clinical care experience, the dying trajectory and the decision making processes undertaken by family members and patients. Common themes were identified from the narratives which mapped the end of life care experience from terminal diagnosis to death within which the moral reasoning was analysed. This data served to answer my first two

research questions and provided examples of both moral reasoning and general moral positions.

The following list details the five theoretical propositions which preceded the data collection. These guided the data collection and analysis (Yin, 1994: 27):

1. In line with Jarret Zigon's theories there are three main sources of morality; institutional, public discourse and individual and that these can overlap but can also be challenged (Zigon, 2009: 258).
2. That the dying trajectory has a direct relationship to the way moral reasoning in end of life care is carried out.
3. That emphasis on the 'good death' as a normative behavioural model in clinical settings has a direct relationship to acts of self-determination by the patient.
4. That the justifications for end of life decisions are either neutralised, appeal to 'nature' or what might be considered a 'universal' value.
5. That moral reasoning relating to end of life care is different from everyday moral reasoning.

These propositions resulted in defining the three main research questions as well as aided in the formulation of the questions which were asked in the initial interview. The three research questions were:

1. How did the patient and family respond to the philosophy of care provided by the clinic?
2. How did the dying trajectory affect decision making and how were these decisions justified?
3. How does exposure to death and suffering alter the agent's normal moral reasoning process?

Thus, question one covered propositions regarding the 'good death' biomedical model and its relationship to both the patient's and participant's concepts of a good death. Question two covered the proposition that the type of dying trajectory has a direct effect on the way in which moral reasoning is carried out with regard to length and type of illness. This question also covered the decision making and thus specifically focused on the justifications for care choices. It was proposed that these would fall into the three categories; neutral, natural or universal. Finally, the third question looked at the phenomenological experience of suffering and death and how this alters the ordinary moral reasoning process. Thus, in linking the propositions with the questions, my approach ensured that the right data were

obtained and the right questions were asked in interviews. The development of these questions from this process allowed for each case to be asked the same set of questions in the initial interview. Analysis of the first transcript allowed for the development of more specific questions relevant to each case. Once again, the second group of questions were designed to hone in on the object of inquiry, morality, but also to further illuminate the specifics of each case i.e. clinical experience, interpretation of events and the moral position of the participant in relation to their experience.

The details obtained from the narratives included participants and their loved ones' lived experience from the diagnosis to death, their response to and experience of clinical care, the length of time spent within facilities, the place of death, medical and other care decisions, how they were made and how they were justified. Particular attention was given to the impact of temporality and emotions. Common themes and structural impacts on decision making emerged highlighting the importance of these which included family dynamics, suffering, autonomy, advocacy, personhood and good deaths.

In terms of units of analysis, there were two to consider. The first unit of analysis was the experience of the individual, the second unit of analysis was their moral reasoning. This unit was the object of my study and could not be understood without reference to the first. Thus, existential moral conflict (moral dilemmas and quandaries) of the participant with regard to end of life care shaped the meaning of the lived experience for the subject. I began with the understanding, as Zigon argues, that there are multiple sources of morality which have the potential to inform the embodied moral world of the decision maker (Zigon, 2007).

Both the patient's and participant's reaction to clinical care differed in various ways depending on the context of the experience. These variations, it was identified, were due to prior exposure to cancer, background experience influencing decisions, the type of cancer the patient suffered, the length and type of dying trajectory and the amount of family involvement and support. Thus, it was through this that cases could be compared and contrasted and patterns identified. Further interrogation of the specifics of each case allowed for grouping of cases into specific chapters. Although these groupings shared

common themes, they were more specifically grouped according to parallels in the data with reference to the first two research questions.

Background and intention

Along with the focus and due consideration given to life-world and inter-subjectivity, both background knowledge and intention were also important. These aspects contributed further details which were relevant to the shaping of the participant's moral world. Why my participants took part in this study was a good starting point. Some participants provided reasons up front; at other times these reasons were buried within the content of the narrative or sub-narrative. Hence, both relevant background knowledge and past experiences were important for an existential understanding of the participant's life-world. One cannot expect to understand the entire life-world of each participant but enough to contextualise the subjective experience of end of life care as it relates to their moral reasoning.

Bruner argues that the first issue of narrative is intention – why the story is told and how and when it is interpreted as it is (Bruner, 1991: 10). He also argues for a tale to be worth telling it must be about how an implicit canonical script has been breached, violated or deviated from (Bruner, 1991: 11). It gives the story 'tellability' due to its significance as an event (Ochs, 2004a: 284). Within this breach – the experience of death – there can be further breaches which take place based on the participant's expectations and standards. This is why both the reasons why the participant takes part as well as their background knowledge are important. Each of these elements can be either implicit or explicit. There were participants who told me before the story began why they wanted to take part and there were others that did not reveal any reason. This also applied to background knowledge. Sometimes the participant would impart some personal background knowledge up front before telling the story or they revealed it in the midst of the telling. Relevant background knowledge included prior exposure to death, cancer, medicine, and clinical care institutions. Indeed, this information was often imparted to support the moral position of the story teller.

One of my central objectives was to determine how narrators made sense of personal experience in relation to cultural discourses; how the narrator responded to and sometimes disrupted the hegemonic perceptions in society (Chase, 2013: 57). For example, two of my participants had experiences which served to shape their moral reasoning with respect to death. One participant worked in the field of neuropsychology and the other was themselves a cancer survivor. These factors were important in understanding the moral reasoning process in terms of their expectations and understanding of clinical care and biomedical culture. Hence, background knowledge and experience significantly informed their moral responses.

As far as intention is concerned, some of the plots within my case studies included medical transgressions, misdiagnoses and a general disappointment with the quality of clinical care received. This also revealed some motivation for sharing their story. Through death, the canonical script is breached; through transgression, it is breached again. The trauma of death, already infused with grief, is further exacerbated by anger and frustration.

Thus, irrespective of whether or not the participant overtly stated reasons for taking part, these reasons emerged from within the narrative or through the message within the central plot. As is clear, there are many ways to interpret background and intention of the participants through what is shared and how it is shared. Although sharing of background knowledge is helpful to establish existential values and aspects of identity, it is not always through this that we can understand intention. The following three examples show that the participants had similar background knowledge of nursing but had completely different reasons for telling their story.

Jill took part in my study because she saw my notice calling for volunteers as a sign from her mother "beyond the grave" telling her to take part. Being a nurse, she had exposure to death and dying. She also believed that my study was important because death wasn't talked about enough and her mother experienced a painful death even though she thought morphine could knock out any pain. She also believed that everyone should have advanced care directives. She was very close to her mother and she had said that sometimes at home, she could smell her mother's favourite perfume.

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Jenny had been a nurse for 48 years. She was currently writing a book about widowhood. Two things that surprised her about the caring of her husband during his dying months was the emotional affect it had on her and the type of illness he contracted. She had nursed her mother and sister in their palliative care stage and obviously had been exposed to death and dying throughout her long career. However, she found that the experience with her husband was completely different. It was extremely intense and emotional for her and it was also a shock for her that he died of a brain tumour even though he had a family history of heart problems.

Denise used to be an auxiliary nurse in her early working life but she had had many professional jobs over time. I didn't find out about the nursing straight away, it came up half-way through the narrative in the first interview. She also told me that she had experience in community care for the elderly back in England. Although she never said why she wanted to take part, her experience with her father's death left her appalled at the level of care provided the elderly in the hospitals. Indeed, she believed that, in part, it was the reason that he gave up the fight. She believed that the elderly are at risk and that there is no proper care for them as there used to be when she was nursing. She said she wanted to become a patient's advocate to ensure that vulnerable patients are looked after properly.

From these three cases it is clear that although each participant had a nursing background, all their reasons and intentions for taking part differed. It was not so much because of nursing knowledge, but because the events somehow breached canonical expectations. Jill found out that morphine wasn't the miracle pain killer she thought, Jenny never expected her husband would die of a brain tumour and Denise was appalled at the hospital system's lack of proper care. As will be shown in the in depth exploration of each case, we will see that these unexpected events sometimes become the driving theme of the story. This does not necessarily link with intention, but it can. What they do all have in common is that their end of life care experience was linked to current concerns – to their present sense of self. Jill still smells her mother's perfume, Jenny was still dealing with the grief of the loss of her husband and was writing a book about it, and Denise was compelled to become a patient's advocate to protect the elderly.

Narrative environments, practice and morality

The analysis of the narratives was carried out in a number of ways. With respect to the phenomenological approach I adopted, the focus of analysis was first centred on understanding the life-world of the participant and how inter-subjectivity affected moral perception of events. This focus on inter-subjectivity here is not concerned with the inter-subjectivity between the participant and the interviewer but was concerned with how inter-subjectivity shaped perception at the time of the event, and by extension, moral reasoning. In this regard, the concept of the narrative environment was less important than narrative practice, content and structure. I have already explained the importance of background and intention to analysis. In this section, I will explore narrative practice, content and moral reasoning and how my approach to analysis was chosen due to its usefulness in revealing moral positions.

Interviews are a shared exercise of social interaction couched in a purpose. Therefore, narratives elicited from interviews need to be considered with respect to the where, how and who; where the interview takes place, who is doing the telling and who is doing the listening (Gubrium & Hostein, 2008: 249). Hence, an important part of understanding the data was to begin by remembering that the volunteer for the research understood where the interview would take place, how the interview would be carried out, and who would be doing the listening. This can be referred to as the circumstances of production and reception or *narrative environments* (Gubrium & Hostein, 2008: 252). As I argued earlier, the most important aspect of the narrative environment for this study was the background and intention in each case. In this regard, the context for each case began with the question of 'why' they were taking part. Since the volunteer already had all the information regarding the objectives of the research, the 'why' of the research, one could say the question of why the experience is shared was important in this study as it provided another moral indicator.

The narrative environment does not determine the story but conditions the storytelling (Gubrium & Hostein, 2008). It is concerned with the local reality of the circumstances where, why and for whom the story is being told (Chase, 2013: 59). These stories were volunteered with the participants' understanding of the objectives and scope of the

research. Thus, since these stories were volunteered for a very specific purpose, the background and intention of the story teller was more important than the narrative environment in which the interviews took place. Thus, I do not disagree that sharing a story is a social process and a form of social action (Gemignani, 2014: 134), but that the observed environment and behaviour were not relevant or useful as were the intention, background and discourse itself for the purposes of this research. This is due to the fact that the participants, in understanding the research objectives, knew why they wanted to respond to the call for volunteers. This circumstance makes it significantly different to other ethnographic interviews which occur in an ongoing basis and usually much more informally during the course of certain types of ethnographic field work. Further, due to the sensitive nature of the topic, there was no doubt that the sharing of these stories had a special reason and purpose for the participant. In some narratives, this was obvious, in others, more subtle. Thus, what I saw as important in the narrative analysis for the purposes of understanding moral reasoning required a key focus on the practice of the telling and the content of the story itself – not the environment.

Thus, through narrative 'practice' i.e. the word content, personal expression, linguistic particulars and narrative structure, an analysis of moral reasoning can be achieved. The practice includes certain linguistic elements and inflections such as word choice, pitch, laughter, tears, hesitation, whispering and so on which were analysed along with the content. The content analysis includes the way the content was organised, how it was assembled and how it was received (Gubrium & Hostein, 2008: 247). Based on my theoretical propositions, six key words/themes were identified in the narratives and given codes. These included references to autonomy, good death, the dying trajectory, self-determination, medical futility and family dynamics. At the same time, evidence of moral reasoning was also identified. On completion of the interviews and transcriptions, cases were grouped according to similarities in clinical care experience, dying trajectory and moral stance. As analysis progressed, the significance of temporality, emotions and family dynamics became apparent.

The consensus in many disciplines is that narratives of personal experiences revolve around an unexpected or troubling turn of events (Ochs & Capps, 1996: 27). Death of a loved one

can be both of these things. Additional 'troubling' events within this experience can contribute to the emotional impact of the events. This was shown to be a motivation for sharing in at least half of my participants. Evidence of this came from the expressions of anger and the displays of grief both physiologically present during the course of the interview and with regard to the language used when stories included medical transgressions, misdiagnosis or wasted time. Hence, even though dying can be considered bad in itself, there are negative events which made the dying trajectory worse. Sandman argues that we can say death is bad in relation to what it deprives us of yet it can be considered good if one is in an overall bad situation (Sandman, 2005: 24). This moral position was evident in some of the case studies presented in this thesis. Death can be welcomed, particularly if the dying trajectory has been drawn out or if existential or physical suffering had been extensive and unmanageable.

It would be a mistake to pigeonhole these stories as simply 'illness narratives'. Illness narratives are about a "patient's illness experience and illness world as a social reality apart from the conception and definition of illness as formulated by biomedicine" (Hyden, 1997: 52). Hence, they usually centre on first-hand accounts of the patient's experience of their illness and suffering. This approach to illness was championed by Arthur Kleinman and others to help physicians focus more closely and further understand illness from the patient's point of view (Bauer, Singer & Susser: 1997, 16). The concept of illness narratives emerged from patient's accounts to serve as interpretations of the illness experience with respect to suffering and identity (Hyden, 1997: 51). Thus, although the narratives presented here contain within them these stories – including the clash between biomedicine and patient's experiences – they are not first person narrative accounts of this. They are the family's moral reaction to the patient's illness based on a shared experience but within this paradigm. Therefore, instead of illness narratives, they are narratives about illness (Hyden, 1997: 54).

Another reason why they are not specifically or exclusively just about illness is that terminal prognoses promises no recovery. Hence, they may describe an illness experience but the certainty of death makes the emotional impact for everyone involved much more intense and places emotion in a much more prominent position in terms of its impact on moral

reasoning. Thus, these cases are both an illness experience and a response to death and dying. Death and morality are intrinsically linked particularly with respect to end of life care (Raus et al., 2014 ; Rys et al., 2013 ; Seale, 1998). Further, the *object* of my study is ethics and morality, hence, analysis of familial responses to end of life decisions means that the *subject* may be illness but the object is morality. Not morality of the patient, but of the family member who shared their story. It is their moral world which is shared in these personal accounts. However, in cases of shared decision making, the moral reasoning of the patient will also be considered where these details are provided. Indeed, most of these narratives involve breaches, violations and deviations from canonical scripts. As such, participants are surely providing their moral position with respect to their experience.

It has been argued that story telling not only conveys an image of the self but that narrative and self are really inseparable (Hyden, 1997 ; Ochs & Capps, 1996). Narrative is a dynamic vehicle through which participants reveal their existential self by reflection and scrutiny of the moral codes of society which illustrates their values and responses to the norms and expectations of our social world. Hence with moral reasoning:

> There is no specific moral action that does not refer to a unified moral conduct; no moral conduct that does not call for the forming of oneself as an ethical subject; and no forming of the ethical subject without 'modes of subjectivation' and an 'ascetics' or 'practices of the self' that support them. Moral action is indissociable from these forms of self-activity and they do not differ any less from one morality to another than do the systems of values, rules, and interdictions (Foucault, 2014: 43).

As I argued in chapter two, there are two important aspects of the moral reasoning process. The first is our mode of subjection or the way we relate to rules and second is the reasons one gives oneself for adhering to them (Foucault, 2014: 42). Further, to reiterate, moral reasoning follows certain rules in order for the choice to be deemed moral. These include impartiality, universality and justification (Cohen, 2004: 15). Therefore, along with what the content revealed about morality and moral positions, incidences of moral reasoning were also analysed. These instances could be identified and easily distinguished from other choices and preferences which were not moral in nature. This is important because in order to comply to or challenge a rule, we have to be able to justify our moral position – we have to offer *reasons.* These reasons as justifications emerged from ethical deliberations within

the narrative with the participant either reflecting on their decision at the time of the event or offering a moral position of the choices made for end of life care in hindsight. All instances of direct moral deliberation were given codes and identified throughout each narrative transcript serving as a framework around which the case study was articulated.

Narrative structure

I have explored the relevant aspects of narrative analysis which have been adopted in this thesis and explained how they provide information on life-worlds, meanings, perceptions and moral positions. Now I will delve into the important elements of structure to explain how temporality within narrative provides further data to understand moralities. The narrative structure of the plot, tense changes and references to the past and future reveal existential meanings, concepts of self and life-worlds. Indeed, language and by extension the creation of a narrative itself is just one of many symbolic ways in which our identity is not just expressed but shaped (Bucholtz & Hall, 2004: 370). The structure of the narrative is another way in which we can further understand context, meaning and morality.

The point of view of the participant can be implicitly assessed through the structuring of their narrative plots (Ochs & Capps, 1996: 26). Although most of my case studies followed a standard, linear trajectory, each contained tense changes and references to past, present and future events, selves, objectives or information which interrupted the temporal flow of the narrative. Beyond the manner in which the story is expressed, it is a "practice of constructing meaningful selves, identities and realities" (Chase, 2013: 57). A shift to present tense or reference to their present life revealed the meaning of these events for them and how they were conceptualised in relation to their current perceptions of the 'self'. Reflecting on a past event involves reconstituting that event, in telling about the past we are formulating it and reconstructing it in relation to the present and the future (Gemignani, 2014: 129). Hence, the protagonist sharing the story is also constructing who they are in the present in relation to their past experience with respect to what they want or see themselves to be in the future. Shifting to present tense can also show how the protagonists evaluate the experience which can provide meaningful context as well as answer why the story is worth telling (Bruner, 2001: 29). Interestingly, eight out of ten of my participants

referred to a present state of affairs in their life which, in one way or another, had intrinsic links to their experience of end of life care. Ochs and Capps argue that:

> Interlocutors tell personal narratives about the past primarily to understand and cope with their current concerns. Thus narratives are often launched in response to current worries, complaints and conflicts (Ochs & Capps, 1996: 25).

Although these narratives regarding illness and death are not entirely spontaneous since they have been shared in response to my research project, it's clear from the data that present concerns were linked with their past experience. The word 'concern' here should not necessarily refer to anything negative but to what was a current conscious objective in their life-world at the time of the interview. Therefore, tense changes within the narrative revealed not only the meaning of the events for the participants, but how they see themselves.

Another element of narrative structure which emerged and became an analytical tool was the identification of a story within a story. I have assigned these stories the term, *moral codas*. These *moral codas* were stories unrelated to the central plot but served to further a point, provide more meaning or further justify a moral position within the central narrative. These *codas* also seemed to provide more context with regard to the meaning that the experience had for the participants. Other past experiences which were important in the narrative but had nothing to do with death, cancer or biomedicine were only deemed significant through their location within the narrative structure and whether or not they were used to clarify or reinforce other events.

Narrative structure then provides important symbolic indicators with respect to the meaning of the experience for the participant. Temporal shifts are just as important in the interpretation of the data as the content. Indeed, the meaning of the narrative can only be understood in relation to the functions of its constituent parts (Bruner, 1991: 8). Elinor Ochs argues:

> Narrating personal experience allows us to reconcile how we (and others) behaved in the past and how we project ourselves (and others) in an as-yet-unrealised future with current self-understandings. That is, narrating experiences is a way of fashioning a sense of continuity of self (Ochs, 2004a: 285).

These temporal elements within the narrative are indicators not only of what is important to the narrator but provide chances to contextualise the material, emphasise a point or further justify a moral position. As Duranti argues the temporality of our inner life is expressed through narrative and shows this reflexive aspect of our nature (Duranti, 2009: 15). Temporal shifts in narrative structure compliment the obvious points of moral reasoning within the content and their accompanying justifications. Therefore, the way the narrative is constructed by the participant reveals a construction of their existential reality (Bruner, 1991: 6).   This is how temporality plays a role not just in the experience itself, but in elucidating the participant's view of events.

Narrative structure adds to an understanding of the meaning of the experience for the participant along with revealing aspects of the self and life-world. Through shifts in tenses in the narrative and other temporal changes, a further layer of analysis can be explored. The structure can also reveal which aspects of the events had greater impact and meaning for the participant through causal links. *Moral codas;* stories within stories, reinforce a moral justification or position by providing further detail regarding the value system and beliefs upon which their moral reasoning is based. They also allowed for a further contextualisation of the events by revealing further meanings the events had for the participant and therefore, provided another avenue through which morality could be understood.

Data collection

Obtaining participants for my research was heavily restricted. Hence, my data collection was limited to staff, students and alumni of James Cook University due to the Human Research Ethics Committee's view that the project was considered high risk. Approval for research was granted by the Committee in May, 2015 (H6133) and I concluded my data collection in August, 2016. I sourced potential participants for my study by advertising in the student bulletins which were distributed via the internet to staff, students and Alumni. I also posted flyers on noticeboards throughout the university. One participant was sourced from an outside party after an amendment request was approved by the Committee.

The call for volunteers displayed the title of my thesis, the objective of the research, inclusion and exclusion criteria and the confidentiality process in compliance with the National Health and Medical Research Council's "National Statement on Ethical Conduct in Human Research" (2007). Exclusion criteria specified that no patient be under the age of eighteen at the time of the event and no participant be under the age of eighteen at the time of the interview. Thus, no narratives were regarding loved ones under the age of eighteen. Potential participants were also told that taking part was voluntary and that they could withdraw from the research at any time without explanation or consequence.

The call for volunteers included my James Cook University email which was provided to make initial contact. Those who met the selection criteria were interviewed by myself and were recorded on a digital recording device. A list of core questions were asked in the initial interview but it was carried out in a semi-structured manner. That is, I allowed the participant to share their story without interruption. I found that both first and second interview questions were covered in the initial interview which was beneficial in that questions of detail specific to their case could be developed in full for the subsequent meeting.

All participants were provided with 'care packs' which included details of access to free counselling through James Cook University as well as other flyers and cards for help-lines across Australia should they feel distressed in any way from the interview process. All participants were interviewed twice with an approximately four to six week gap in-between interviews. Interviews ranged between one to three hours each. Out of the ten participants, only one participant withdrew after the first interview.

Participants

Participants who volunteered for my research were interviewed twice and over thirty five hours of narrative was transcribed by myself verbatim. Besides identifying moral stance and positions from within the content and structure of the narrative, each episode of moral reasoning required its own analysis. I utilised Cohen's (2004) rules of moral reasoning as a guide. My completed data set consists of ten individuals who volunteered to be part of this

study. My participant's experiences related to events which took place between eighteen months to twelve years prior to the interview, five of which were accounts from five years prior. In the case where the experience was twelve years prior, two stories were provided, the second more recent within the last three years. Seven of these interviews were conducted face to face in a closed meeting room; the other three were conducted via Skype. These made up the ten narrative accounts.

All case studies referred to a family member who received a terminal diagnosis of cancer. Not all initial diagnoses were followed up immediately with a terminal prognosis. When, however, prognosis was provided, five were given between zero and two months to live, two were given between three to six months and three more than six months. In three out of the ten cases, this prognosis was accurate. Although age of both participant and the deceased was not relevant to the objectives of this research, it is interesting to note that the ages of the deceased ranged widely between fifty four to eighty three years. Age factors into care decisions in various ways from considering treatments to the emotional impact of prognosis on patient and family. Although all received clinical care, outpatient consultations and referrals to specialists, place of death was evenly divided with five dying at home and five in a clinical setting. All participants had close involvement with the patient during their dying trajectory and/or were responsible for the direct care of the dying patient.

I identified three levels of involvement in end of life decision making which emerged from the ten cases. There were participants with direct medical decision making, some who shared decision making with the patient and those who made non-medical end of life care decisions. Four participants fall into the first group and the other six are a combination of shared, direct and other care decisions. Of course, some cases had elements of each level and four case studies came exclusively under level three. Moral analysis of these care decisions was identical to the others except they included the participant's moral reaction to certain decisions which they did not make or where out of their control. Even though these participants did not make or take part in making medical decisions, they were still present during physician and patient interactions, made other care decisions and were witness to the clinical care process during the patient's dying trajectory.

It is important to point this out because the manner in which the moral position or actual moral reasoning is shaped depends the participant's level of involvement in end of life care. For example, they may assert a moral position in response to decisions or events or they may actually share how they came to certain decisions. In whichever the case, the same rules of moral reasoning apply in that their moral positions must be impartial, appeal to some outside 'good' and provide a justification. Thus, what will be evident is that in cases where the participant was directly involved in the decision making, their explanation of their moral reasoning will be described as it happened first hand.

The first two broad primary contextual elements of importance in understanding and positioning the moral reasoning of each participant were to assess how they defined their experience of clinical care encounters and the manner in which the dying trajectory played out. In all cases, the narratives provided include the participant's recollection of events including both the patient's and the participant's response to clinical care and advice they received. Initially, these were grouped more broadly into positive, negative and mixed responses to clinical care and whether or not they considered the patient had a good death. With respect to the dying trajectory, the series of events and the type of dying trajectory experienced by the patient was also important. By 'type', I mean four aspects which were present within the data which proved prominent with respect to the manner in which the trajectory played out and how this affected moral reasoning. The first of these is the level of choice and control that the patient was able to maintain which I will call in short, *patient autonomy*. The second was the level of *physical and existential suffering* either expressed by the patient and/or perceived by the participant during the course of the trajectory. The third was the part which *temporality* played in the participant's view and the fourth was the impact of *family dynamics.* These four themes, to a greater or lesser degree in each case, shaped and characterised the participant's experience of the dying trajectory.

The major values which emerged which classified a good death were the value of patient autonomy, advocacy, quality of life and freedom from suffering. Within these broad themes emerged sub-themes such as dignity, empowerment, identity and personhood. As I have mentioned, disappointment and even anger at the standard of clinical care was evident in many cases. Medical misdiagnosis, medical transgressions and the resulting time wasted

impacted not only on the perceived quality of care in a pragmatic sense but resulted in intensified emotional trauma for patient and family through exacerbated suffering, frustration and the elimination of hope. The impact of these events and how they were dealt with and/or perceived reveals the existential point of view of the narrator, their moral position, objectives, intentions and the values which support their justifications. Hence, an ethics of their end of life decision making.

All my interviews were digitally recorded and transcribed verbatim by myself to ensure accuracy and reflexivity with the data. All the names were allocated pseudonyms to protect the identities of participants and patients and the names of cities (where applicable) and hospitals were also de-identified. This was due to the sensitive nature of events and the detail of some of the negative experiences. De-identification was also important due to the regional location where this research took place and due to its classification by the ethics committee that the nature of this study was considered high-risk.

Chapter VII – Autonomy, Biomedicine and Maintaining Personhood

The challenge to the normative idea of the passive patient is concomitant with the rise of patient autonomy as a valued ideal in end of life care (Diprose, 1995 ; McNamara, 2004 ; Silvester & Detering, 2011). This autonomy traditionally refers to patient's maintaining independence and self-determination. This implies freedom of choice and control over decision making. However, self-determination as an expression of patient autonomy from a biomedical view does not always accord with the value it has for both patients and carers. Research shows that the meaning of the term is contingent on many factors and that autonomy as rational individual decision maker is too reductive (Eliott & Olver, 2008 ; Van Brussel, 2014). In line with this view, the cases in this chapter will attest that the value of patient autonomy is less about decision making and more about the preservation of personhood.

What is clear throughout this thesis is that even though patient autonomy can be heralded as progressive in both biomedical and palliative care practice, the manifestation of autonomy as self-determined actions is obviously limited to both the level of debilitation of the patient and the level of family support. Therefore, the principle value of autonomy for families and for health care may not have the same meaning. There are two reasons for this. One, the variability of the value of autonomy and two, the ability to exercise this autonomy:

> Although individual autonomy is the dominant principle informing bioethical theory and medical practice in most of Europe, North America, and Australia, some have claimed that the current dominant concept of autonomy ignores relational ties, emotional pressures, culturally determined values, and contextual variables that also shape patients' decision-making (Eliott & Olver, 2008: 181)

The cases in this chapter show that consideration for inter-subjectivity is vital to understanding not only what autonomy means but also how it can be achieved. Terminal patients rarely journey the path to death alone and so family members are part of the process, accompanying dying patients in their clinical encounters throughout their trajectory. However, biomedical encounters in the clinical setting focus only on the symptoms and problems with the physical body (Lock & Scheper-Hughes, 1996 ; Turner,

1992). This first affects personhood by bringing the body to the forefront to the neglect of other aspects of personal being; and culturally, by situating the patient outside the cultural ideal of health and wellness (Maynard, 2006: 214). This Cartesian mind-body approach by the medical establishment toward sick bodies can find "social realisation through this mechanics of power" (Leder, 2005: 112). In the biomedical encounter, the shift for the patient therefore is both personal and social. Hence, although the diseased body becomes the point of focus for biomedicine, the family and patient's inter-subjective reality and personal relationships continue. Therefore, there is tension between the universalising categories and practices of doctors and the relational meanings and practices of biographical persons (Monks, 2000: 28). This is one of the reasons that autonomy can have different meanings.

What is clear is that the biographical component, the person, who can be neglected in biomedical encounters, is the very thing which needs protecting for the families and patients in this chapter. It is also the key to achieving a good death:

> More and more, dying 'well' means dying in accord with the individual's personal way of living; joyfully, beautifully, with dignity, autonomously. The concern with *my* death is enshrined in the fierce debates among medical professionals, ethicists, politicians and lawyers, as well as amongst the general population, on the permissibility of human intervention in dying (Van Brussel, 2014: 175).

Selves that once mastered their body, through cancer, become enslaved by it (Waskul & Van der Riet, 2002: 487). Maintaining this self above and beyond the deterioration of the body becomes the autonomous objective. Perhaps it is a reaction to this sense of enslavement which leads to a rejection of intervention since offers of intervention can further serve to reinforce a sense of powerlessness (Waskul & Van der Riet, 2002: 492).

The rejection of clinical intervention in the following cases not only allows for more 'natural' deaths according to the perspective of the participants. These are justified in the maintenance of personhood. Medical intervention is not sought; there is a desire to die at home, and a determination to fight the deconstruction of self that often accompanies dying and debilitation. The participant's moral views support the patient's rights to reject treatments, exploratory surgeries and helped keep the involvement of clinical care in the

patient's life to a minimum. Each participant spent a great deal of time with the patient in their dying trajectory and support for their autonomy was protected by them, understanding their loved ones and their desire to maintain a sense of self. In both cases, this was conceptualised through a critical perception of reductive biomedical values which neglect inter-subjective considerations, emotions and personalities of patients. These participant's moral positions, therefore, confirmed that protection of the patient's personhood invariably leads to a good death.

April

April's story is about her father, Doug. Although she made no direct medical decisions for her father, she did drive interstate to be with him as much as possible during his final months and provided emotional support for him and their family. She was also responsible for taking him to hospital and outpatient's check-ups from which I was able to get a better understanding about their experience of their clinical encounters. April didn't claim to have relevant knowledge or exposure to end of life care but her intention in taking part seemed to be linked to current objectives in her life. When she first expressed interest in the study she said that her "father died in the manner he chose". This indicated to me that her father was able to maintain autonomy. April's narrative not only highlighted her moral stance on biomedical threats to personhood but is a commentary on the dissociation between the objectives of the health system and the holistic needs of the patient.

April's mother and father had been married for fifty years when her father received a terminal diagnosis of pancreatic cancer. At the age of seventy-six, he was given three months to live. Initially, they offered chemotherapy and there was talk of a potential operation. Doug declined this offer stating that all it would do would make him sick and he was already sick (Int. 2016: 15). In the second interview, April elaborated on the reasons why refusing treatment was the right way to go. She said it was not worth it if it just extended his life a couple of weeks. Further, that it would not have been worth the impact it would have had on his quality of life. He would also have had to make a plane trip and when telling me this explained the contrast between biomedical objectives to those of the family. She said;

So, now they are going to put a sick old man on a plane to *****, for no reason….because they are about the sanctity of life and stuff and lengthening…So, well, really? Can we not start looking at what that does to a person's quality of life toward the end and the family? (Int. 2, 2016: 10).

Besides refusing treatment, as April put it, "his big thing was to die at home". This is in line with recent trends with patients refusing to be placed in clinical settings and thus expressing their moral right to die as and where they wish (Kellehear, 2009b). This wish was supported by his General Practitioner and, due to family support, he was able to do so with the occasional progress visit to the hospital and home visit from palliative care nurses. April explained how the care of her father played out:

I'm the second eldest. So, I can say thankfully, or…I mean it took a bit of pressure off me because my sister stepped up but she actually took over most of the care. Talking to…every day to like the nurses and the morphine and all this. She was a psychologist, you know and she…she works at ****** University. She knows how to work systems and she knows how to talk to people across the board so. And, not only that I think, I just took it really hard, um, emotionally. Where, she was able to sort of hold it together more… (Int. 1, 2016: 6)

April saw her role as emotional support and company for her father. She says that; "…I was actually sort of just…be engaged in a relationship with dad…it was…It taught me a lot about myself. And, it taught me a lot about my father…towards the end…" (Int. 2016: 6). Some of this reflexivity reveals how she saw herself in relation to her siblings which the experience brought to the fore in those final months with her father. Her father's death and her experience in caring for him was a transformative event for her. She saw it as a definitive change in her personal life – a change in her sense of self. April said; "I had…I had just kind of been wandering around and…I was a teacher's aide and I've done all sorts of things" (Int. 1, 2016: 10). She said that once her father died, she went into a big depression. When she came through that, she made decisions to give her life direction; "I was not going to be my father sitting in that chair thinking about what I hadn't done" (Int. 1, 2016: 10).

It is obvious throughout the narrative that not only was the experience very emotional for her but that it brought a new level of self-awareness:

Because I KNEW that he had the potential to do a lot more things and I've been thinking MY WHOLE LIFE well I've got a sister who's a psychologist, I have a brother

who is a high school teacher, I'm in the middle well I don't need to do anything, I'll just plod along because I don't really have to because I always saw myself as being…you know…the not so bright one between these two bright stars. But I think that one thing that it kind of brought home was, you can be great in your own way, in your own area (Int. 1, 2016: 10).

April saw the time she spent with her father in his dying days as a learning experience for her. She learned a lot about her father and about herself. She listened to him tell stories of his childhood and he spoke about their family history. Often, he would also sing songs to her. These songs had meaning for April as she said that the words would describe experiences that they had shared together. She said that he only did that with her. It was April who was closer to her father growing up; he used take her fishing on the boat which he didn't do with her sister (Int.1, 2016: 20). She also said that he told her she was different to the other children because she was a good listener. April says that this surprise compliment was very "powerful" for her.

With regard to her father's dying trajectory, she shared a particular instance where he couldn't eat. She said her mother and the nurses were concerned about this, that he might starve to death, so they put him in hospital "and they tried to force feed him" (Int. 1, 2016: 3). She also said that they put him in a ward where people were dying which was really upsetting for him:

> …they wanted to get his strength up and everything but the thing is he had cancer and they didn't…he couldn't eat! He just couldn't eat! And so, it was a matter of, he couldn't eat therefore he couldn't go to the toilet. You know? So, therefore, like, we have got to get him to go to the toilet because that is part of the health thing, so we have got to get him to eat. But, his CANCER stopped him from eating. So, to me it was like, well, you are forcing a person to do something that their body is just shutting down, it's just going; 'I don't want to do this.' So, you know… (Int. 1, 2016: 3)

This example illustrates April's view of biomedical intervention and body objectification which can occur at the expense of personhood. April saw this process as futile and even unnatural. She understood why both the nurses and her mother encouraged it, but clearly saw it as unnecessary and morally wrong. In addition, she knew that attempting to do so was pointless. In her view, he couldn't eat because the cancer prevented it and so it was the natural progress of the disease. There was even a certain cruelty in making him do so,

particularly when he was put into a ward with dying patients who were "screaming." Doug refused to stay there and left the following day.

April's moral position on the cruelty and pointlessness of some treatments was evident from another example. Here, she again sympathised with his experience of the process, and emphasised the potential for his existential suffering. In relation to the affront to his dignity and personhood, she mentions this treatment:

> And they used to, you know, they'd give him enemas and all sorts of bloody STUFF. But it's like well, he's not eating and if you're not eating, you're not bloody, you know? It just, it just seemed to be this whole thing of well, you know, we are going through these steps. But, who is the person in the middle and what is he experiencing the person in the middle? (Int. 1, 2016: 9).

Clearly April understood that the medical establishment need to carry out their responsibilities but she also saw the futility and the cruelty in it.

April told me in the first minutes of the interview that the family were all with her father at the end. She said; "I was with him, we were all with him when he passed away. Because he was at home coz that's what he chose to do and we all respected that…" (Int. 1, 2016: 4). Telling me this early in the interview showed its level of importance particularly since the intention to take part seemed to be connected to the fact that her father "died in the manner he chose." Doug's ability to die at home was possible due to his family's support which allowed him to maintain a certain amount of autonomy. He not only had control over where he would die, but had more control over the course of the trajectory. Doka argues that decision making provides a sense of control for the patient at an uncontrollable time but also mitigates the sense of powerlessness felt in the face of death (Doka, 2005: 87). Dying at home is a refusal of an over medicalised, clinical death and at the same time, allows the patient to remain in familiar surrounds with family where their sense of self as a whole person is able to be, to a degree, maintained.

April made several comments throughout both interviews which indicated that she believed that her father had the best death possible. His pain was managed, he had family around him and he had little medical intervention. Her sister who was a psychologist took time out

from work to stay with them and was responsible for administering his morphine. April was glad that her sister had the strength to do this as she doubted that she could have done so. However, she still saw her involvement as just as vital. She said; "…just being there and listening, in my own way, I was doing as much for him as what my sister was popping morphine into him…" (Int.1, 2016: 22). It is clear throughout the narrative that Doug's sharing of stories from his childhood and family life with April was revered by her. Sharing his life experiences in many respects is a reinforcement of one's personhood. Focusing on this aspect of self was a symbolic homage to his life on the one hand and a renunciation for his failing body on the other.

Clinical interactions and conversations with doctors recounted by April were described by her as both necessary and threatening. She described a sense of protection she felt for her father against potential interventions. She said; "you know, we didn't let any…medical stuff, anybody interfere…when it came to things that he was really sort of strong about" (Int. 1, 2016: 11). The family become Doug's protector against any threats of medical intervention. Although he was terminal and he was dying, he was still allowed to be Doug. He was in death as he was in life:

> …dad is, or was a strong man who always had control over his own life. And, I don't think he wanted to lose that toward the end. And, I think that's one thing…family…at least we can kind of say well, we did everything we could to ensure that that's the way dad's life ended the same way he lived it, you know? Making choices for himself, and having people around him. And, having as little medical intervention as possible (Int. 2, 2016: 15).

For April's father, it was no intervention and no clinics.   When she talked about her father's wishes, she contrasted these with the health system. To a degree, she understood their obligations. She said that her father "played the game…he did what the medical profession REQUIRED of him to do" (Int. 1, 2016: 7). His General Practitioner would come and visit Doug at their home who April described as being helpful and supportive of his wish to die there. He still had to make occasional hospital visits for blood tests to which they complied. Thus, clinical visits and encounters were kept to a minimum, to those which were mandatory, those that were "required". At one point in his dying trajectory, the suggestion of a palliative care institution was raised by doctors which Doug flatly refused.

April kept coming back to the central value of personhood in terms of her sympathy for her father's existential experience. She shifted into the present tense and reflected back to his night in the hospital where people were dying around him:

> I don't for a moment even try to think of how he might have been feeling. Lying there, you know…with death all around him…You know, they are trying to force feed him because he doesn't eat. And, knowing, you know, that he has this disease that is actually going to kill him in X amount of weeks. You know I mean, to me, on one level I suppose you know it's a scenario that I think the health department have to play out, I mean the hospital has to. I mean, they're about…giving care and when life exists to preserve it…but you know what I mean? But this is why I'm now kind of, see both sides of the whole. When people get to a certain stage, do we really want to prolong someone's life? Especially having been in that situation with dad… (Int. 1, 2016: 9).

April's empathy for her father's feelings and existential suffering was the core of her concern. That is because we do not see bodies as simply objects, we perceive them as another 'myself' (Csordas, 1990: 37). She understood that the hospital were obliged to try everything but also knew that this could lead to needless suffering. As April saw it, when people get to a certain 'stage' – when their bodies are at a stage of dying – attempts to prolong it are both cruel and unnatural. In fact, attempts to preserve life artificially impact on its quality and so for April, there is no point. She knew that it is the hospital's moral obligation, but her view was that it wasn't right. Here; she challenges and questions biomedicine. April understood that the health system are obliged to "preserve" life, and yet believed that this action is not worth the compromise that the patient has to endure. She questioned the ethics of a complete disregard for these impacts on the person in the process. For April, patients are much more than dying bodies. In the second interview, I asked about this supposed clash between the objectives of the health department and the objectives and the wishes of patients. She said; "…I think they have got to start treating the whole person, not just the disease" (Int. 2, 2016: 10).

Although Doug was able to die at home, April said that not everyone would be able to do this due to the emotional stress involved. She did, however, emphasise that family can provide what clinics lack:

> …it's walking that line of making these moral choices that remained for dad towards the end there. And, they were left up to people, who, I mean, we're not medical people at all. But, we do have the emotional…attachment to the person concerned.

And, I think in that regard, it's a lot more humane. Because, instead of having a doctor make a decision about a person under his care based on symptoms and whatever else, this was made by people who loved him and it was a very hard decision and it was a very hard process to go through. But, it's about knowing the person and knowing how he wanted to finish you know? (Int. 2, 2016: 15).

Again, end of life care should not just be made by doctors attending to bodily symptoms, but should include a holistic approach to the patient which can only really be achieved by loved ones. Palliative care emerged due to the recognition of this need and indeed today, these aspects of end of life care are viewed as essential to a good death (Black & Csikai, 2015: 32). However, it raises the question: Can patient autonomy as maintenance of personhood ever be achieved in an institutional setting? From a biomedical perspective, autonomy may be promoted in terms of decision making, but for April, this is not its true value. April's view suggests that protection of the patient's personhood is the most important value of autonomy and this can only ever be achieved by those who know the patient personally, who have an emotional connection to them.

Doug's family, being those closest to him, ensured that he was treated as the person he always was before. For April, the only way to make true moral decisions was by recognising and honouring this.   For her, this is the "humane" approach to care. An affront to this perspective was highlighted when she shared with me an incident at the oncologist's office. She said; "…my father was like a few weeks away from passing away, the doctor would say silly things like; 'How are you today Mr. Smith?' And, my father would say; 'Well, how do you think I bloody am? I'm dying!"(Int. 2, 2016: 1). To both Doug and April, this question came across as insensitive. However, in terms of the language of oncology, where no hope remains, doctors tend to communicate with a focus on the present (Good et al., 1994: 857). Once hope is gone, the future is not discussed. It is also telling in another way. Doug's reaction is due to the nature of the question. It was not a question about his body, he was asked how 'he' was – the person, the self. Clearly, dying is existentially confronting which is why he answered with such anger and emotion. In many respects, he is critical of their perception which makes plain their artificial separation between mind and body, reason and emotion from which biomedicine operates (Mamo, 1999: 14).

Knowing that Doug had received palliative care in the home, I asked April if she had been given any special aides to assist in looking after her father, like shower chairs or a special bed. She said that they had organised a special mattress for him but he had real problems lying flat and so he ended up living and sleeping in his favourite armchair. It was at this point that April told me about other problems with the health system that they encountered. She said these added to the stress of the situation:

> Oh, yeah…but the system was so slow that it was like (rolls eyes)…By the time we would get it, he wasn't with us anymore and you know? We also found that being in the system, it was just REALLY HARD to get things in a timely manner when you'd say you know, my father has TWO MONTHS, we need something now. "Oh, we are sorry but we just can't help for another month or so." Well, what good is that for me? It's like getting the disabled parking. I wanted to get disabled parking from them so we could take him to hospital and we could PARK and get him in. No, no. We had to go through this whole process of getting him in, you know, which took weeks! I'm like, "He doesn't have weeks!" So, we had to park all the way down there or drop him off with mum or whatever, sit him down and I'd have to go and park, come back, find him a wheelchair and get him in. So, then we would have him sitting outside, in a public place, you know? (Int.1, 2016: 17)

April's moral stance throughout the narrative demonstrated an understanding of the moral obligations of the health system but also pointed out their failings. The urgency of looking after her father and, indeed, the temporal pressures which go with looking after any dying patient seem to run counter to the system's abilities to provide an efficient service. As a consequence, further indignities are endured by the patient, like having to sit out in a public place because they were unable to get a suitable car parking spot.

April discussed the details of her father's pain management. She said that the nurses gave them much more morphine than they needed and explained that her sister and her father had control over the intake. April took this oversupply of drugs as a symbolic gesture. She said that the nurses were not explicit but were "implicit" in this way. She said; "…I use the word euthanasia debate, I think it's hap….it's used a LOT, it's just used in more of a, a subtle sort of way"(Int. 1, 2016: 6). She expressed that there was a moral dilemma between providing enough pain management and the possibility that they might be hastening his death. This dilemma, as I have discussed, is referred to in the medical profession as the Doctrine of Double Effect. That is, the concern with the possibility that pain medication may

alleviate pain but may hasten the death of the patient (Rys et al., 2013). She told me that her mother was really worried about this issue after Doug passed away. However, April said they were all able to reconcile this by knowing that he was not in pain and that they were relieving his suffering. She told me that her mother thought "we helped your father" but "we had to let him go and it's what he wanted" (Int.2, 2016:7). April told me that "it was better than the alternative of maybe having him go on for another week or so? And, there was NO benefit to that at all you know?"(Int.2, 2016: 7).

The reasoning and values expressed by April with regard to her father's avoidance of medical intervention and what role they played in "not letting any medical stuff interfere" raises a paradox. "Helping" their father was not only viewed as ethical but in some respects natural and led to a good death. This reflects Gandsman's argument that medically assisted deaths, in the rationalisation of right to die activists, are constructed as natural deaths (Gandsman, 2018b: 333). The paradox being that "if a medically assisted death is premised on the rejection of biomedical interventions, it is simultaneously a biomedical intervention" (Gandsman, 2018b: 334).

Doug died one evening after the last of his children had come to visit. She said that just before his death, he made a strange sound which brought everyone to his side. They all gathered around and spoke reassuring words to him. They held his hand and told him he could go. April told me that if one's family are able, dying at home is the best way to go because you are surrounded by people who love you, know you and understand what you want. She said;

> ...it's a much more human way of dealing with death too. You know? Coz to me death just becomes this...let's shunt him over here, you know? I don't think there would be anything worse than ending your days in a cold clinical nursing home or palliative care ROOM...Just waiting for somebody to turn up to visit me every now and then (Int.2, 2016: 5).

Clearly a good death is one at home with family, not in a lonely "cold" clinic. Once again, contrasts appear between clinical care and family care. The first is cold and unnatural, the second; warm and comforting.

April told me that her father died, her family fell apart. She said they all "fragmented". In explaining the details to me of why some of her family members do not speak anymore, she again returned and reiterated the differences between herself and her sister. In describing her ability to play nurse and her ability to remain emotionally in control, she said:

> I was too sympathetic and I was too…emotional and I think that's why I've gone into social work because I really do plug into people's um, you know, grief and stuff…I really can plug into…BUT, when it comes to really personal stuff like dad, it really did…but my sister was able to distance herself a little bit from that (Int. 1, 2016: 13).

Here April shows that her current life-world has been directly shaped by the experience of her father's death. It has helped her learn that she was "a good listener" and that she is an empathetic person. She indicates that as long as it isn't a close family member, she can put these traits to good use. Thus, her narrative and her experience directly affected her current life-world in terms of her choice of career as well as her moral position. She linked the transformative experience of caring for her father to her present view of herself, her current concerns and her future objectives to become a social worker.

Discussion

Doug's death was an emotional and transformative experience for April. At the time of the interviews, it was clear that her life-world and current concerns directly linked to this experience with regard to her career objectives and how she viewed herself. There was her life before her father became ill, and her life after. April never provided evidence that she had any extensive background experience with death, cancer or the health system and yet she had very definite opinions from her experience with her father with respect to proper end of life care decisions. The biomedical objectification of bodies is criticised and contrasted with the loving and supportive understanding of the family. Even though she acknowledged the moral obligations of the health system, she sees that their failures are in their neglect toward the holistic needs of the patient. Therefore, most of April's moral reasoning appeals to nature. The biomedical approach is artificial, the holistic approach which the family can provide is natural. Bad deaths occur in cold, clinical environments whereas good deaths can occur where family can help the patient maintain their sense of

self and autonomy at home. And, autonomy is less about self-determination and more about the preservation of personhood.

According to April, the institutional foundations of biomedicine and its approach to dying patients focus too much on the disease and objectify the body at the expense of the person. Due to this, medical intervention is dangerous not just in its capacity to create physical suffering, but due to its neglect for the person and their capacity for existential suffering. Therefore, preserving quality of life is not just about preventing debilitation or further debilitation through surgery but about maintaining the familiar. It is about preserving the patient's ability to be themselves and rise above the incapacities of their body. Force feeding was not only unnatural but cruel and futile, the chemotherapy would only make him sicker and the oncologist's words were insensitive. Again, the moral problem remains the consideration of the body at the expense of the rest of the person and their emotional state. Any treatment which may only add weeks to a life is not worth the suffering which would be endured. For these reasons, she rejects the idea that dying bodies should take up any intervention that is offered and sympathised with her father's views on surgeries and chemotherapy. Overwhelmingly, the value of autonomy for April did not mean self-determination or freedom of choice, but what came from this freedom of choice. And, this was the maintenance of normalcy and personhood through the rejection of clinical intervention, prevention of extended suffering and the emotional comfort of dying at home.

Broom and Kirby's study on family involvement at the end of life found that family tensions were most commonly situated within a dialectic between the patient wanting a quicker death and the family desiring to keep them around (Broom & Kirby, 2013: 508). This is contrary to April's moral position. First of all, her criticisms of the health system and biomedical approaches in general lay in their inability to treat "the whole person, not just the disease". Holistic treatment, which is another association with completeness, with nature, is what end of life care should be. Biomedicine, on the other hand, is unnatural because it focuses on the body exclusively to the detriment of the person. Bodies which, due to the cancer, cannot take in food should not be forced to do so. This is again unnatural, even cruel. She understands biomedical obligations to "preserve life where it exists" but points out where this objective is morally questionable. If intervention reduces quality of

life, it cannot be justified. A good and "humane" death should also occur with family since they are emotionally connected enough to know the patient, to know what they want and to not let "…any…medical stuff, anybody interfere…" in the dying trajectory. Therefore, support for the patient's rights to die when and how they wished was not in contention.

It is clear that, fundamentally, the central values underpinning April's moral position concern suffering and quality of life. And, although this is expressed from her own opinion and embodied moral world, she also garners support or is informed by public discourse morality. In particular, public discourse which underpin the principles of the 'Right to Die' movement and Death with Dignity groups (Van Brussel, 2014). In the example she provided where her mother was concerned that the pain medication could have hastened Doug's death, the moral question is reconciled in two ways. First, she appeals to public discourse morality by stating that although euthanasia is not talked about much, from her experience, it still goes on in an "implicit" way. This was reinforced by the fact that the nurses gave them more morphine than they needed and due to the fact that both her sister and her father were given some control over this. Thus, the dilemma is reconciled first by stating that the practice "goes on", thereby making it impartial. Second, to alleviate suffering, one has to provide pain medication which may, as is the case with DDE cases, have an unintentional effect. However, for April, where all quality of life is absent, this effect is not negative. Alleviating suffering is a positive effect and therefore, if it does speed up the process, it is not necessarily a bad outcome.

April's moral reasoning also reveals that holistic considerations rely on the emotional connection that family provides which requires a personal understanding of the patient's personality and of what they want. Further, she argued that it is more humane to die at home with non-medical people making decisions because they have an understanding of the person and the patient can achieve a better death because it. The quality of life left rests on allowing the person to maintain familiar surroundings and allowing them to die as their wish around family. April's argument is that this emotional relationship with the person allows the patient to maintain a sense of personhood which reduces the patient's potential for existential suffering. The sterile clinical "room" and being in his "favourite chair" also highlight this juxtaposition. The clinic is lonely, home is comforting and familiar. Hence, a

good death was achieved by her father because the family, who had an emotional understanding of the patient, were able to keep him pain free, protect and preserve his wish to die at home and reduce the potential for extending suffering through medical interference.

Aprils moral stance toward end of life care is the more natural the death that can be achieved the better it is for the patient. Care is better than attempts to cure, prolong or 'force' the patient to live longer. Purely biomedical approaches toward dying patients neglect the person which, for April, is the most important and most threatening thing for patients. Focusing solely on the body and attempting to keep it alive or attempts to prolong life are not moral due to the consequences for the person. Dying at home with loved ones who are emotionally connected to you can help you maintain a sense of self and achieve a good death. And, a good death is a natural death, with minimal medical intervention, taking place at home surrounded by family.

Alex

Alex had had many experiences with cancer and death which affected her life-world and thus her moral perspective of end of life care. She had lost her father, her mother and her husband within at ten year period at the time of the interviews. As a child, she had also survived cancer. Although the narrative focuses on her mother's dying trajectory, she often refers to her husband's death throughout the story to reinforce her clear moral position that there are inexcusable failings within the health system. Alex shared in many care decisions for her mother and also undertook other end of life care decision making. Like April, her story argues for the value of patient autonomy with respect to maintaining personhood. Alex makes it clear upfront that advocating for her mother was her duty as a daughter and she supported many of her mother's choices even when they went against her better judgement. She believed that this does not matter because patient choice is paramount. Alex criticised and rejected the institutional and public discourse surrounding cancer based on her past experiences which have informed her embodied moral world. Like April, Alex also explained throughout the narrative how family are the only ones in a real position to understand the patient and help them achieve a good death.

Alex's mother died in 2007 and her husband in 2013. She told me that if anyone she knew had cancer she would tell them to fly interstate to a major city to get treated; that one should never get treated here (Int. 1, 2016: 4). With her experience with her husband's death, she now knows that this is not always possible. She said that in the time elapsed between her mother's and husband's death, "nothing had changed" in clinical care. Not only is patient autonomy neglected, she argued, but she believed that there was too much ambiguity with information surrounding cancer and major inadequacies in biomedical approaches to care. These inadequacies were pointed out when she discussed her husband's death in hospital. She believed he suffered terribly due to inadequate pain relief and sub-standard care. Alex's wealth of experience with cancer, her extensive exposure to death and interactions with the health system seemed to be her motivation for sharing. It was clear that the medical transgressions which her family endured didn't just add to the emotional trauma of the experience but resulted in moral outrage.

Alex's mother, Carol, was diagnosed with adrenal cancer in 2005 and given six months to live. Alex found out about her mother's diagnosis through a letter. They lived in different states when she found out, her father's death taking place only a couple of years before. Initially, Carol was offered exploratory surgery to get a better idea of the stage and size of the cancer but she refused. She was also offered oral cancer medications and morphine. She took the cancer medications but not the morphine because Alex claimed she wanted to be "compos mentis". Alex was an only child and she admitted that her relationship with her mother was a bit combative and strained but she took this in her stride. She said that her mother was angry after the death of her father and this anger was directed at her. She was not surprised by this and did not take offence because she knew her mother and told me that she also knew that she was loved by her parents. Minutes into the interview, I asked if she has any brothers or sisters:

> No, I'm an only child. SO. In some ways you could probably say...How did you go through with your mum and dad's final things? It's my decision. And, I know their words so we don't have to suddenly work on oh well, is mum having a bad day? Or, she doesn't know what she's talking about or she's got dementia. Or, anything like this. Is, I did have medical staff question my integrity. Um, but you know? We made a decision to come up... (Int. 1, 2016: 2).

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Alex and her husband moved interstate so that they could care for her mother. Here, she also indicates that knowing her mother's personality was essential to knowing how to look after her. Being the only child, she had no other family involved in the care. Alex felt that due to this, it was her responsibility and duty. However, having sole responsibility makes you subject to scrutiny.

Alex explained this scrutiny to me. She said that the nursing staff would make home visits to her mother's house where they were living. On one occasion, they had asked Alex why she was letting her mother smoke. Alex replied; "She is going to die anyway, she may as well enjoy it!"(Int.1, 2016: 7). Alex said that she could not see the point in telling her mother how she should behave. Further, she wasn't going to take this from a nurse who often went outside to smoke herself. She didn't like the hypocrisy. She said; "if you want to talk the talk, then walk the walk" (Int.2, 2016: 11). Further, Alex knew that respecting her autonomy meant letting her mother behave how she normally does – to continue to be herself.

This incident shows a clash between biomedical perceptions of care and family perceptions. Once again, the biomedical approach tends to focus on bodily health exclusively and relegates other aspects of the patient's well-being, like maintaining personhood, into the background. The nurses expected Alex to curb her mother's unhealthy habits; to conform to the biomedical model of patient care where the sick are expected to adapt to their role and manage their illness as part of the new 'normal' (Lupton, 2003: 98). The differences in patient perception placed Alex at odds with the nursing staff and yet she did not express that she felt in any way obliged to comply. Alex was demonstrating what Rapport terms "cosmopolitan politesse":

> …a 'caring' and 'affective' recognition of the individual Other that might amount to a kind of inaction…to endeavour to occupy a middle ground between 'how people wish to live' and 'how others want them to live'"(Rapport, 2018: 251)

Clearly, the institutional moral objectives of biomedicine did not fit with what Alex believed was the right course of action. In addition to this scrutiny, Alex felt that there were also social expectations of her based on gender. She said; "the assumption is that you give up work" (Int. 2, 2016: 10). She believes that women in particular are subjected to normative

roles because you are expected to be the "carers, the nurturers, she's your mother, you should be there twenty-four seven" (Int. 2, 2016: 10).

For Alex, true patient autonomy can be supported only through a shared understanding between the family member and the dying relative. Only family can know with confidence the patient's personality and what they want. Alex knew that her mother did not want to be fussed over and that the more fuss that was made, the more she would be made to feel infirm and helpless. According to Alex, those on the outside – whether they are health professionals or not – do not know what is best for the patient because it is not just about the body or some 'ideal' that the family give up everything during the caring process:

> …for the patient, we talk about mindfulness and we talk about you know, you need lots of people around you caring and supporting you. But if the PATIENT doesn't like the nurse, doesn't like the doctor, doesn't like what you're doing, then there's no point being there (Int. 1, 2016: 6).

Alex demonstrates here that even if they had the power to implement this behavioural model on her mother, it wouldn't work. Indeed, the patient has control, with support from family, over what happens to them. Alex knew this and was not about to try and change her. She knew that the best she could do was let her be herself, "enjoy herself", and continue to make her own choices.

Alex explained that when her father was dying, she had made flights up to visit. With respect to her mother, she knew she had to make a permanent move to be with her. When I asked her how she came to this decision, she said "because she was alone." Hence, Alex had her sense of duty to care for her mother, but forcing her mother to relinquish her normal life was not going to benefit anyone. Indeed, Alex believed that it simply doesn't work that way. She said they take control of the choices; "They CHOOSE what they want to eat, they choose what they want to drink" (Int. 1, 2016: 7). Carol also made the choice to die at home. She told me that this wish was central in determining everything else. After she discussed her relationship with her mother, she told me about her background knowledge of cancer:

> Her doc…It was a very strange thing and I think different doctors treat cancer in very different ways. You, maybe I should take a step back. I know a bit about cancer

because I have had cancer myself. My mum's had cancer, my dad's had cancer and even as a kid, so…I know the stigmas and I believe they still continue today. I know we have the Jane McGrath Foundation and everybody wears pink and we think; "Oh well, everybody gets over it." You know, like it's just a cold or appendicitis…but there are a lot of stigmas out there on…how you treat, or how you deal with the person… (Int.1, 2016: 3).

This part of the narrative shows that her exposure to cancer and the health system is extensive. When she said 'dealing with the person', she is again critical of the biomedical neglect toward personhood. As Mattingly argues, it is biomedicine's rationality to disguise the role of human relations and push the social and the cultural to the margins (Mattingly, 1998: 276). Like April, neglect of personhood is the main problem. She also believed that modern medicine did not consider the whole body in terms of the effect of diet, hormones, food and drugs on one's physiological well-being. It is clear that she had definite opinions of the insufficiencies in care not only toward patients but the families who care for them.

Throughout the narrative there were references to her husband's experience and how much he suffered during his dying trajectory. One of the examples she shared was when her husband began bleeding to death, she rushed him to the cancer centre where his specialist worked and where all his records were kept. The centre told her that she should have gone to the hospital and that they were just a holding centre.   Meanwhile, she said to me, her husband was dying. According to Alex, a further transgression happened when he was dying in hospital and he was having spasms due to the level of pain that he was in. She had told me that she would stay there all day, around eighteen hours. During these events, she said that she had tried to get the nurses to provide more pain relief but that they would not comply. When she was refused help, she said she was so upset by witnessing her husband this way that she cried and begged for them to provide more pain relief. Their response, according to Alex, was that they had raised his morphine as high as it could go and that when he needs more, he is given it. They also said that they were checking his condition every four hours. Alex knew that this wasn't happening because she was spending all day and most of the night with him. This made her angry because she said that she knew they were lying. In Alex's view, their failures in care were compounding her husband's suffering. This experience, as part of her life-world, had coloured Alex's perception of nurses. She said the belief that nurses work really hard is "bullshit":

…when you can't get the basics of facility management in care, in patient care, there is a problem. So, in my experiences, there were no four hourly lobs. Most of the time, unless I asked for it, the bed wasn't changed. And, as I said, of a morning, you know…'Oh, you want me to change the bed?' (*pulls a face*) (Int. 1, 2016: 17)

The final blow in her husband's dying trajectory was when he had developed a huge haematoma in his leg which kept growing. Her husband had expressed to Alex while he was still alert that he wanted no surgical intervention. Alex said that the surgical team were proposing to cut him open and that she had made it quite clear to them that this was against her and her husband's wishes. She said she could overhear some of the phone calls to the head of surgery and felt as though she was being ignored because there was a real threat that they would try to carry it out. She said they were using him like "a piece of meat" and that it was a frightening experience to have to fight against this decision. The following day, he died.

Alex has not just experienced many disappointments with the health system, but she contrasted these with the public perception and discourse surrounding cancer awareness. As she said with the Jane McGrath foundation, she believes that this type of public discourse provides false hope. She said the perception is that there is a down time but people get over it. Alex knows that this is far from the truth. You can wear pink all you like she said, but people will continue to suffer and die. She took this a step further and said that there was even evidence that in our culture, cancer has become a fashion statement. She said; "…we don't associate with cancer, we associate what's with the cancer. And, that is, raising money and we are being seen and we are popular and it's a nice colour and we are hearing all the good things" (Int. 2, 2016: 29). It might be fashionable to be seen supporting cancer awareness, but it doesn't provide people with the real picture. Alex says the reality is it makes people really sick, it's painful and it's ugly.

Returning to the story of her mother, there were three occasions of interactions with clinical staff and shifts in the dying trajectory which were of significance with regard Alex's moral position. The first of these occurred because, along with the adrenal cancer, her mother had developed a growth in her stomach. Alex explained the interaction with the doctor:

We went to this specialist and she said we can do an exploratory thing and see how big it is. And, I said; "So what is that going to mean for her in quality of life?" Like, I never spoke to my mum like she was not there, it was just that I knew that sometimes she was a bit deaf? Or selective? And, I said; "What does that mean? You are talking to me now and I said…I've dealt with cancer a lot. So, I'm not one of these you know, relatives that you can push aside and sort of say well you need to speak to someone who has got more authority. Um, I'm not completely stupid"…And, she said; "Well, we don't really know, but she could have a life." I said; "What kind of life? I said; "At the moment, she sits at home…and unless we take her out she doesn't go out." And, I said; "And, if she had a colostomy bag; that would absolutely…she'd die. So, what are you suggesting this is? Give it to me straight." And, she said "we don't know" (Int. 1, 2016: 5).

You can see that this interaction demonstrates the ambiguity that Alex says exists in the treatment of cancer. It also shows that Alex's focus is on quality of life which not only means considering the physical effects of intervention but how these will affect personhood. Clearly, the surgeons were offering to open her up to find out more, offering choices. This is quite a common clinical approach to dying patients, offering choices to the family and patient is preferred over offering nothing (Maynard, 2006 ; Mohammed & Peter, 2009). However, they were already weary of this when she told me that initially, her mother refused to be opened up because of her "medico-legal" background. Alex explained that this was how she knew it was risky. But now, the risk here for Alex was how the physical results of intervention would affect her sense of self; how it would affect her existentially. The doctor in this interaction couldn't provide them with answers and for Alex, this was the very information they need. As was the case with April, Alex felt that family are much more qualified to judge how intervention will affect patients due to their close relationship. Further, Alex said that she didn't even need to discuss these things with her mother as she already knew what she wanted. And, she said that was, "I'm not being cut open, and I'm not going there, and I'm not doing this – end of story. Okay? And, so it's all about; 'What do we do to make you feel better?'"(Int. 1, 2016: 10).

Carol lived passed the six months given at prognosis and was still being cared for at home. Alex told me that a little while after this, there was a terrible turn of events. She said; "And, then she had a change of mindset. And, this is probably the most HORRIFFIC…she suddenly wanted to be alive! But, we are talking twelve months down the track" (Int. 1, 2016: 7). Carol had a change of heart and had decided to go back to the doctor who had suggested

exploratory surgery. When she got there, she was given a referral to specialists who were interstate. Alex, true to supporting what her mother wanted, did not argue with her about this but had a feeling it was not going to turn out well:

> And, so, I went down on the plane with her (*long pause*). And, was…I mean, I think in some things you have to be realistic. I mean, I'm seeing this thing growing, and I'm seeing her cantankerous and I'm seeing her tired in a way but fighting which is a bit different to other people that I've seen that have just…given up. And, but, on this trip, you can see – she thinks she is going to Nirvana (Int. 1, 2016: 7).

When they arrived at the hospital, there was a lot of waiting around. She said that her mother was full of hope. Before they did the tests, the doctor had come in and spoken to them. He said there might be something they could do about her quality of life but Alex said they weren't given false hope. She underwent a multitude of tests to be assessed by a team of specialists. Once they had drawn their conclusions, the oncologist came back to speak with Alex. She said he came toward her and he had tears in his eyes. Alex told me that before he had a chance to say anything, she knew what the answer was. He told Alex that they couldn't do anything and he told her he was sorry:

> …But, once they had checked the ultra-sounds and once they'd got all the guys together and he said; "I'm just sorry." And, he said; "Do you want me to tell her?" And, I said; "No, I better." Like, at the end of the day, it's got to be you because ah, that's not somebody else's responsibility. I mean, it was hard enough for him to tell me. It was hard enough for me to hear and there was also the thought that I was like…We have got to get back on that plane that night (Int.1, 2016: 8).

Alex clearly saw informing her mother of the bad news as her responsibility, her duty. Just as it was her duty to care for her mother because she was alone, it was the same with the disclosure of bad news. She said to me in the second interview that you should care for your parents as they cared for you. It is this sense of duty within her moral reasoning where it becomes apparent that there is a significant difference between treating a sick patient and treating a terminal one. Pending death affects not only what options one takes up, but also what is valuable. And for Alex, that is quality of life in the preservation of personhood. She said to me if it were a case of a broken arm or another illness, it wouldn't have mattered who imparted the news. But, with respect to the gravity of the news, it should be the family. We can see that death changes moral reasoning in this way and thus, what can be considered moral in particular situations. This includes the views of patients and families.

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Indeed, emotions play a large role in this. Irrespective of clinical information or any promise from oncologists, her mother suddenly decided to have hope that she would survive. This emotional coping shifted the dynamic, changed the course of the trajectory and what actions were considered moral and worthy.

After the devastating news during their visit to the team of specialists, Alex said that she got her mother, Carol, a couple of wines on the flight back. Further, she said to her mother that the focus now was going to be on her quality of life. She said that she said something to the effect of; "I don't need a witch doctor, that's it! We are now about we are going to make you comfy and what you can do and what you can't do and so we are not going there and I'm not having any funny people put funny things in your head"(Int. 1, 2016:9). Alex's mother lived another year which was well beyond any estimates provided initially by the oncologists. She was able to remain at home until the last two weeks of her life at which point she was moved into palliative care.

Alex doesn't characterise her mother's experience as a bad death, but she highlights in her story all the threats which can lead to a person's suffering during their dying trajectory. It is clear, however, that she considers her husband's death as bad and indeed, traumatic. With regard to her perception of biomedicine and clinical care, she made another comment which suggested why they often fail in delivering adequate care.

In both interviews, she indicated that professional staff often see the family as a problem because they need someone to blame when the patient deteriorates. She believed that this happens because they don't have the answers themselves. Clinical staff also see you as an obstruction in amidst the chaos:

> And, then you have the matron. And then it's like, she's had an argument with the specialist and she's arguing with flossy that's gone off to the toilet again. And, the last thing she wants is another patient and another problem and another relative. And, you are seen as the problem (Int. 2, 2016: 15).

For Alex, as I had mentioned in the beginning, the standard of clinical care had not changed between her mother and her husband's death. The 'system' failed to consider personhood as vital to quality of life. This is not only a problem for the patient, but also for the family

member. The failure to see the worth in the relationship which supports this value and a failure to understand what effect medical interventions are going to have.

To conclude, there was a *moral coda* in Alex's narrative which emerged during the first interview. It is a comment about death, families and responsibility. It is also a comment about herself:

> I actually know of an Aunt and Uncle of a friend of mine and they were still arguing about Nona's grave, you know, ten years down the track! Who's paying for it? Those kind of concepts are totally alien to me. It's just like, neither of you can claim to be a good child. I don't claim to be a good child, but I'm not pretending otherwise. Whereas, you're claiming that I loved her very much and I want the grand mausoleum. And, I loved her very much and I'm prepared to pay $20,000 you know? And, it's like, you know what? You are just selfish buggers and you just wanted to know what was in the will (Int.1, 2016: 10).

It is appropriate to show this piece of the narrative because it provides further conceptual illustration regarding death and morality and about Alex's life-world. It suggests that caring for your parents isn't about attempting to show love through spending the most at the grave site, it's about showing that love through support while they are still alive. And, that love means protecting who they are and respecting their right to maintain their sense of self when the body fails. She also didn't claim to be a 'good' child, but she did indicate that she undertook her duty as a daughter by putting her mother's well-being first. Indeed, she also never pretended to have an amicable relationship with her mother, but this, for her, doesn't change the sense of duty an only child has to her parents.

Discussion

There are two important aspects of Alex's life-world which shape her moral reasoning. There are also two ways in which we could interpret her engagement with ethics. Hence, in this discussion, I will explore these ways by first considering the impact background experience had on her moral reasoning and second, consider how inter-subjectivity and relationships shape the same.   We can assess these impacts through not only her justifications and reasons for her moral position or decisions but in her response to biomedicine and the value she placed on the protection of personhood. In so doing, I will engage with Zigon's argument that traditional moral philosophies are inadequate to

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illustrate engagement with ethics because they pre-suppose an individual, rational, non-relational being (Zigon, 2014a: 21). Although I agree that ontologically, we always exist and perceive inter-subjectively, I reject the notion that reasons which might reflect traditional moral philosophic principle are without value. That is not to say that these philosophies, which presuppose a rational, isolated individual attaining the good should be adopted a priori, but that evidence of these normative philosophical positions should not be ignored. In sum, this discussion will demonstrate the degree to which Alex's moral reasoning was shaped by inter-subjectivity and to what degree it reflected a Kantian duty ethics.

 Alex's life-world consisted of extensive background experience with cancer and death. Life-world's are not just situated and subject to place and structure, but experience (Knibbe & Versteeg, 2008: 49). These experiences affected her view of the medical establishment. There were problems with the biomedical approach to terminal patients, problems in the administration and coordination of clinical care and problems with how professionals treat families. At the early stage of the first interview, she made it clear to me that between her husband's death and her mother dying; "nothing had changed." Alex's experiences included many breaches, violations and deviations from the canonical script which provides motivation for telling one's story (Bruner, 1991: 11). Both with her husband and with her mother and to some extent, herself, Alex's experiences with death, cancer and the health system have resulted in an overall negative view of clinical care. Like April, she sees that biomedical approaches to dying patients tend to disregard the whole person and focus only bodily symptoms. Indeed, sometimes they can't even get this right. She had to ask staff to change her husband's bed, they could not control his pain, and the threat of surgery was traumatic and unjustifiable. Due to this, she said that he was treated "like a piece of meat". The symbolism here is clear, a physical body devoid of the person inside. Hence, it is those experiences prior to her mother's death which led to a total mistrust of the medical establishment due to their moral failures.

These experiences shaped Alex's life-world and morality in two ways. They formulated qualitative distinctions which shaped her perception and informed her decision making (Taylor, 1989: 25). Our past, to a degree, educates us and influences us and our perception of events that we encounter. These experiences are also justification for the value she

places on personhood. Autonomy is an unquestioned value for Alex, but protection of personhood is the goal. For Alex, patients will exercise their autonomy, as she said with reference to her mother; "they choose what they want to eat, they choose what they want to drink". One could interpret the value of personhood as a reaction to the reductionist, bodily focus of biomedical interactions. Not only does an exclusively biomedical approach neglect patient personhood, but it can threaten not only physical but existential quality of life. Through biomedicine's failures experienced in her past and the biomedical encounters she experienced with her mother, such as their recommendations for Alex to impose behavioural changes on her, would affect her quality of life and so were rejected. Further, the encounter where exploratory surgery is suggested is also rejected because as Alex had said; "…if she had a colostomy bag; that would absolutely…she'd die." The existential suffering is worse than the obvious potential for physical suffering which would accompany a procedure.

If we refer to personhood as meaning an expression of the self, the individual, of those qualities specific to that person, then this feeds into the question of relationships. One has to know the person to protect their right to personhood. And, this is where the value of personhood is connected to inter-subjectivity and relationships. Alex made it clear throughout the narrative that she understood her mother. She told me from the outset that she didn't need to figure out her mother, "she knows her words" and she didn't have to interpret her behaviour as "having a bad day". Alex saw that enforcing any rules of behaviour on her mother would infringe on who she was and thus on her quality of life. If Alex had imposed the regime the nurses expected, it would have affected not only her mother but their relationship.

And, thus in this respect, it attests to the view that moral choice is largely about the maintenance of relationships (Zigon & Throop, 2014: 9). This has limits, however. There is no question that the ontology of being necessitates inter-subjectivity. It is a necessary part of experience and perception and is central to Husserl's concept of life-world (Husserl, 1981). For Husserl, "…inter-subjectivity is the most basic quality of human existence which is constitutive of the subject and of the very notion of an objective world" (Duranti, 2010: 16). Thus our being, our perception is always interactional:

> …humans as such are essentially relational beings who by their very nature are always beings-in-relationships and are always in the world first and foremost as affective beings rather than thinking and contemplative ones (Zigon, 2014a: 21).

I believe equal credence should be given to the power of embodied moral positions informed by background experience. That is not to say that we exist as a disconnected "rational" being, but that embodied positions, supported by background experience, can take precedence in influencing our ethical engagement. What I would say is that foregrounding inter-subjectivity as the foundation for perception is fine but that, like the "rational" agent approach that Zigon criticizes, we cannot reduce the study of morality to the study of sociality. If moral action is only seen as maintenance of relationships at the expense of any notion that we may be evaluating and judging on other terms, it can confuse the social with the moral. I agree with his point that one should avoid approaching a subject as though they are neo-Aristotelian actors, but his position might reinforce this point too far the other way. Hence, beside the maintenance of relationships, moral reasoning can sometimes fit traditional moral philosophical theory. In this case at least, one could argue that besides relationships, Alex was predominantly influenced by her own embodied moral world.

As I have argued in my methods chapter, the foundations of my analysis took into consideration Zigon's theory of moral worlds which include; embodied, public discourse and institutional moral forms (Zigon, 2007). Alex's embodied moral position is given prominence in her moral reasoning. It is largely informed by her qualitative distinctions – her experience (Taylor, 1989). Alex's life-world was greatly influenced by her prior exposure to cancer, death and the health system, and we know from her moral position that this shaped her perspectives as well as her sense of duty to relationships. Alex rejects both institutional and public discourse morality in favour of her own embodied moral world. She is confident to trust her own embodied position. She was critical of staff failing to do their duty and of the doctor's inability to answer questions regarding how their actions would affect her mother's quality of life. The nurses she had encountered did not sway her approach to end of life decisions and actually reinforced her convictions due to their failings and even hypocrisy. Indeed, the volition of doctors and nurses is also questionable since they only see bodies,

not the person inside, and cannot provide answers to important questions which are clearly about quality of life.

Alex also rejected public discourse morality with regard to perceptions toward cancer when she criticised cancer support groups like the McGrath foundation. Not only is their message unrealistic, that people come through it, but that those in the groups are not engaging in it for the right reasons, but for fashion. Their volition is false because they are carrying it out for the wrong reasons, they are doing it "to be seen" to be doing something. Indeed, volition is vital for what qualifies as a moral action for Alex which I will now demonstrate.

Due to Alex's sense of duty with respect to her mother's care, her moral reasoning reflects a type of Kantian duty ethics.   It does so in the following way. Alex was not concerned with the consequences of letting her mother smoke or what happens if she didn't eat but on maintaining her duty to allow her mother to do what she liked. Kant says that an action based on duty without good will behind it is not moral at all (Kant, 2014: 26). Alex criticizes both the will of the surgeons who treated her husband like a piece of meat and the volition of the people joining the McGrath foundation. And, for Kant, it is the volition which makes a moral action, not the consequence (Kant, 2014). If good deeds are achieved for immoral purposes, then the action is not ethical. This is clearly patterned in Alex's moral reasoning. Duty is not determined by reference to consequences but by reference to consistency and the requirements of rationality (Cohen, 2004: 41). When her mother suddenly wanted to live, it is described by Alex as a "terrible turn of events" because Alex knew there was no hope. However, due to her duty to her mother, she did not try and talk her mother out of it. She allowed her to do what she wanted regardless of what the consequences would be. This again was allowing her to maintain her personhood but overall, she had a duty to her mother to support her autonomous decisions. She was the one responsible for breaking the bad news when they saw the specialist and she also had a duty to protect her husband from unnecessary, dangerous and futile surgery. This protection of her mother's personhood was paramount not only for her quality of life but was based on an understanding of her mother and their relationship.

Duty ethics is also reflected in her *moral coda*. Her anecdote regarding people arguing about spending money on lavish tombstones points out again her moral position by highlighting their lack of duty of care and the in-authenticity of their volition. Their choices or actions are not coming from good will or love but from selfishness and ego. They want to appear to show love though spending money but she claimed that the purpose of this posturing was to access the Will. She said that she doesn't claim to be a good child, but she knew that her duty of care for her mother came from the right place.

For Alex, families are not the problem, they are the solution. Family members know the patient and should protect their autonomy and personhood. Biomedical approaches fail in this area. Her moral reasoning is justified both by her background experience which has shaped her life-world and by her understanding and relationship that she had with her mother. Clearly, the maintenance of the relationship with her mother throughout her dying trajectory was important, but also was her sense of duty which must come from the right volition. This meant allowing her mother to remain who she had always been in the best way that this could be achieved. Even against her better judgement, she allowed her mother to see specialists because for Alex, that is what you do not only if you really care about the person, but if you carry out what is your duty as a family member.

Chapter VIII – Family Dynamics, Acceptance and a Good Death

One of the most important dispositions considered for patients to achieve a good death is acceptance (Goldsteen et al., 2006 ; McNamara, Waddell & Colvin, 1994). It is considered good for clinical care staff, the patient and the family. Acceptance is said to remove the danger of the patient being subject to futile surgeries and allows for patients to manage their personal affairs (Borbasi et al., 2005 ; McNamara, 2004). However, not much is known about the function of acceptance when the patient spends most of their dying trajectory outside the clinical setting. In this chapter, I will explore the link between awareness and acceptance when families are the carers and how they view acceptance and its relationship to good deaths. Therefore, both the context of family dynamics and emotions will be explored to illustrate what role these play in the emergence or repression of patient acceptance and how this affects their moral reasoning.

It is widely acknowledged that the work of Glaser and Strauss and Kübler-Ross had a significant influence over palliative care approaches (Sandman, 2005: 68). Until the 1970's, non-disclosure to terminally ill patients about their status was an accepted code of conduct for physicians who tended to focus on hope (Lokker et al., 2012: 1227). This habit of non-disclosure of their condition and the withholding of information in institutional settings revealed both patient powerlessness and physician's control (Glaser & Strauss, 1965). In the past, patient's awareness of their dying status was seen as a dynamic power shift in circumstances which would, from the physician's point of view, require the patient to accept their fate (Glaser & Strauss, 1965: 55). This suggests that, at least in the recent past, patient acceptance was a good thing for staff, but not necessarily the patient.

However, Kübler-Ross's psychological study argued that acceptance was good for the patient (Kubler-Ross, 1973). The central idea for Kübler-Ross was that "dying people progress through identifiable stages as they approach their dying and death, with each of the stages characterised by observable behaviours and emotions" (Hart, Sainsbury & Short, 1998: 68). The psychological stage that a dying patient reaches (or is expected to reach) is that of

acceptance. Out of all the other 'stages' toward death, acceptance is still expected and considered the central goal in the journey to death:

> Since the 1970's, attention has been more focused on how each individual perceives, understands and copes with approaching death. The eclectic use of psychological and social concepts, which are open to flexible interpretation, has generally been preferred to any universal maxim, although peaceful acceptance has remained the seldom questioned common aim (Hinton, 1999: 21).

The result of this expectation means that patients who for whatever reason do not pass through these stages are viewed as non-compliant patients - deviations from this normative model (Hart, Sainsbury & Short, 1998: 69). It seems that acceptance is not only expected to emerge in the patient but that it is considered a good result for everybody concerned with their care. However, what role does acceptance play if the patient is not confined to a clinical setting?

For acceptance to be possible, there has to be open awareness to the facts. An extensive comparative study of over four hundred patients and carers showed that the presence of open awareness enabled the patient to have more control over the place of death and that they were less likely to die alone (Seale, Addington-Hall & McCarthy, 1997: 483). This suggests that awareness allows for more planning (which suggests acceptance) and thus empowers the patient to have some form of control over the events during their dying trajectory. A more recent study of dying patients showed that they not only understood the expectations regarding awareness and acceptance, but saw that embracing these was a realistic and sensible approach to dying (Goldsteen et al., 2006: 381). This suggests that acceptance is seen as a good and 'sensible' thing for patients too. However, what all these studies also indicate is that there is a clear link between awareness and acceptance and that in effect, one facilitates the other.

In this chapter, I argue that there is not such a clear defined link between information, awareness and acceptance. I suggest that acceptance does not have to be linked to medical facts at all. This is the case for three reasons. One, acceptance is an emotional state and demands the relinquishing of another emotional state, hope. Two, families who are carers

also have to battle their own emotional responses to events and hearing a terminal diagnosis is rarely the end of emotional and moral deliberation. And, finally, even where doctor's communication is not ambiguous but very direct and clear and patient and family are 'aware' of the situation, it can still have little effect on the elimination of hope in the mind of patient, family members or both. Our emotional responses to death help explain why the provision of clear medical knowledge does not automatically translate into full comprehension of the life threatening nature of the illness (Mamo, 1999: 32). Hence, even if the patient has full awareness of pending death and has reached acceptance, their dying trajectory can be hijacked by a member of the family who does not want to give up hope for a cure. This attests to the reasons why we need to understand what acceptance means for families who are carers and how it impacts their moral reasoning.

The following two stories included patients who suffered negative events such as medical misdiagnosis and lack of care coordination leading up to their terminal diagnosis. The context of these complicating factors and the impact on my participant's life-world will be explored as well as the part that acceptance played in moral reasoning and in achieving a good death. In one case, acceptance came from prior brushes with cancer and having an old and infirm husband whom the family thought would die long before. In the other case, there was no background exposure to cancer and patient acceptance seemed to emerge miraculously in the patient but not without opposition from a family member. In both cases the patient's illness was initially overlooked or misdiagnosed which contributed to a sense of frustration and temporal intensity since there was a sense that time had been wasted. In both cases, my participants were actively engaged with the care of the patient and with decision making. Also in both cases, the patients died at home surrounded by family.

Carrie

Carrie's story is about her mother Fay who lived overseas with Carrie's father who was himself very infirm. At the time of the terminal diagnosis, her mother was seventy-four and her father was ninety. She said her father was "dying for years" and needed to be cared for which made things difficult for the family when her mother became ill. Being in different countries, Carrie was not present when her mother received the diagnosis. At the time of

the interview, she had lost both her parents and was no longer married to her partner whom she was with at the time of the experience. Her mother's death brought about big changes in her life in a short period of time. It is clear that she had a thorough understanding of clinical care and cancer due to her prior experiences. At the time of her mother's diagnosis, she had just had her first baby and took all the leave she could to help her family out. On top of the family dynamics which directly affected decision making and coordination of care, Fay's cancer had gone undetected for some time and therefore was in the late stages of development.

Carrie began to cry just minutes into the interview. When I told her we could resume the interview another time, she told me that she would cry anyway. She knew that it would be an inevitable response to sharing her story. She began by telling me that her mother had been visiting the doctors quite frequently because she felt unwell. Her father, being much older, had been in and out of hospital for years. Since her mother was responsible for caring for her father, it was a particularly difficult circumstance to navigate when the news came back that Fay had cervical cancer. It was October 2010 when Carrie found out. At the time, she was on maternity leave having just had her first baby. Carrie used as much leave as possible to be with her mother and made the trip to New Zealand in December, 2010. Living in another country made it particularly stressful for Carrie to coordinate her time to be with her mother. On top of this, she had a new baby to care for. However, due to her dependent father, her mother needed help at that critical time.

When her mother received the terminal diagnosis, surgery was offered. However, Carrie believed that once the size of the tumour was established, surgery was no longer considered an option. What the physician did offer was radiotherapy which her mother agreed to. The doctor had told her that treatments were to slow the spreading of the cancer which had already reached her bone, lungs and liver. The late discovery of the cancer limited what could be done. Due to her father being so old and infirm, her uncle took her mother to her appointments before Carrie could reach New Zealand. Even though her mother endured the radiotherapy, she was initially reluctant "…she was asking questions at the time essentially about is it worth doing this even?"(Int. 1, 2016: 5).

Carrie made it clear early in the interview that the dynamic with her parents added to the difficulty of the situation:

> …(*sigh*) Now, with the dynamic between my parents. My father was obviously quite a bit older and she had to do a lot of looking after him. So, she was grumpy with the GP in that she had known that something was wrong and the thing when they found it was twelve centimetres in diameter. So, it had…she was a little bit angry that the GP hadn't been a little bit more um…alert. So, she would have had trouble with it. I mean, a thing that size… (Int. 1, 2016: 4).

Her mother, now extremely sick herself had to continue to nurse her husband. Carrie said he was almost deaf, had very bad eyesight and "he had lost himself" at least two years before he died which was not long after her mother passed away. He had been in and out of hospital at times for various things like broken bones from falling over. She explained that due to his condition, he didn't quite understand what was going on with his wife which was hard on all of them. Carrie said that since he was quite oblivious to the situation, her mother had to say "I'm sicker than you are!"

Since Carrie could not be with her mother the entire time, home care nurses visited the house not just for her mother but to also care for her father. Carrie gave me the nursing log books and one can see from these the extensive care that was required around the clock with each patient needing specific routines and attention. This home care included cooking, cleaning and the dispensing of medications but it also detailed descriptions of their bodily functions, their sleep and eating patterns and any issues which arose. It also detailed the times when Carrie was involved in carrying out care.

Carrie's mother's late diagnosis of cancer meant that it was already at stage four and had metastasised into other organs. Although she was angry that the doctor had not discovered it earlier, most interactions with doctors and nurses were described by Carrie as "mostly great" and "absolutely wonderful", particularly the oncology specialists. Carrie's mother only agreed to the radiotherapy because she was told it would ease the pain and help prevent her bones from breaking. When Carrie talked about the radiation therapy, she said that the surgeons had a different attitude to the oncologists:

> …when we talked to the bone surgeons, the bone specialists, I said to them about the surgery, "She doesn't want to spend the rest of her life recovering from this, you know? Coz, they didn't seem all that…The oncology doctor was lovely and was

obviously good at dealing with people, the bone surgeons, not so much (Int. 1, 2016: 9)

Carrie and her mother knew from the experience they had had with her father how difficult broken bones were to manage when you are older. So, Carrie was suspicious about having surgery, but they were happy to continue with radiation if it was going to prevent such a scenario. Carrie said that even with all her mother's difficulties with having to manage her father and her late diagnosis that she still expressed a level of acceptance:

> …When she was in her dying phase, I made the mistake of telling her that she was coping wonderfully. And she said; "What choice do I have?" So, she had accepted that she was dying and had accepted that from the time I got back in December. (*sigh*) We'd talked to the vicar and we had talked about the funeral. So, she was across all this (Int.1, 2016: 8).

Although Carrie had this discussion in the later stages of her mother's dying trajectory, she told me that she regretted saying it because of her mother's response. She also added that they never spoke about death in a direct way. Carrie said that attending the oncology visits with her mother and the visits to the bone specialists made her "confident enough that I was putting it together reasonably accurately from observation" (Int. 1, 2016: 9). Both Carrie and her mother were present at the appointments, they both had the same information and thus the implication was a shared awareness of the stage of her condition. This awareness meant that discussing death itself seemed unnecessary. However, her mother had met with the vicar and had prepared funeral arrangements without actually talking about death itself. Above all, her mother had accepted her fate. Carrie told me right at the beginning of the interview that when her mother told her about the cancer, "she was quite clear that she was dying". The only thing that her mother really wanted was to die at home.

Past experiences seemed to play a big part in her mother's ability to accept her fate, even though she expressed anger at the doctors for the late diagnosis. Fay had survived breast cancer in 2002, and Carrie made a point of telling me this at the outset. Carrie believed that "her earlier brush with cancer" had an influence on her being able to accept that she was dying. She said that she and her mother realised that this was different, that it was not going to be a matter of cutting it out. With her breast cancer, it was caught early and she had successful surgery to remove it. However, Carrie explained that her mother had "survivor guilt" because when she had the breast cancer, another relative also had it but didn't

survive. With her cervical cancer, it was much further developed and they both knew there would be no cure.

There were a few occasions where Carrie took charge of the decision making during visits to the hospital and during Fay's care at home. When Carrie and her mother went to visit the bone specialists, they recommended getting a scan of her hip bone. Carrie said "that tuned into probably the worst bit of the whole process" (Int. 1, 2016: 6). They had told her that she would have to be admitted into hospital for the night in order for her to be in line for the machine. Even though her mother did not want to stay in hospital, Carrie felt that they were not given a choice. Consequently, she left her there and went home to look after her father and her baby and returned the following afternoon:

> …I took my baby and the push chair in…I was there and I waited for her while she had the scan and she came back and nobody seemed to be making any great…great efforts to get her discharged. She had had what she had been in there for, but there was a risk that she was going to have to spend another night in hospital. Of course, we had the pressure of needing to get home to look after my father. And, in the end we just walked out. I said, "You have had the scan, let's go." And, I busted her out of hospital (Int. 1, 2016: 7).

Carrie's background experience motivated her actions. First, they had lots of experience with hospitals due to her father's illnesses and age. Her mother by this time had already had to endure "horrible" radioactive rod treatment early in her illness, had the chemotherapy cream which her mother was scared to use and had to endure radiotherapy to ensure that her bone did not break. When I asked Carrie if she would usually 'bust someone out' of hospital she said; "no, normally we are pretty obedient when it comes to that stuff" (Int. 2, 2016: 2). She said that the experiences with her father and the fact that they were angry and frustrated contributed to her decision. She said her mother was shocked that they did it, but delighted and pleased that her daughter had done this for her. She said it made her mother happy.

Taking on the role of carer confers a unique intensity to decisions, values and interactions (Totman et al., 2015: 505). The intensity for Carrie was family dynamics and emotions. Her anger and frustration as well as past experiences clearly influenced Carrie's life-world and thus her moral reasoning. Carrie's mother was angry at the late diagnosis from the doctor

and they had both had years of experience dealing with hospitals due to her mother's previous cancer and her father's infirmity. This is why Carrie advocated for her mother to ensure that she came home even if it meant breaking the rules. In contemplating the rules, she rejected them because from her standpoint, they were not moral. Carrie, in busting her mother out, refused to let her mother to be subjugated into the cultural role of the passive patient. The hospital was a metaphor for a prison from which you must escape. It is also seen as 'risky' if you are trapped there. Hence, Carrie's ethical work considered these social and cultural expectations not just with respect to herself but with consideration of how they would impinge on her mother. Further, family dynamics affected these decisions since both her father and her baby also needed her care. Carrie's prior and "usual" obedience to the rules of the hospital is overturned because it is superseded by a greater value and moral good – her family. Instead of waiting patiently for a discharge which was taking too long, she took it into her own hands to do what was right for them. Her usual behaviour is to conform to the rules, but limited time, family dynamics and prior experience demanded a different approach.

Busting her mother out of hospital resulted in a new problem. He mother still had the cannula in her arm. At first, Carrie called the hospital and they had insisted that they come back to have it removed. Carrie did not want to go back to the hospital and neither did Fay. Carrie sought an alternative. They called her brother-in-law who was a medical professional and he agreed to drop in on his way home and remove it for them. He said she could have bled to death had it not been removed properly. When Carrie explained to him what had happened, he argued that there was no good reason that Fay needed to stay in hospital overnight just to have a scan. This piece of information reinforced Carrie's conviction that she had done the right thing taking her mother home.

Another two events which highlight Carrie's moral reasoning occurred when Carrie's mother was close to her dying phase at home. Carrie had been responsible for administering the morphine and saline into the cannula in her mother's arm. Although they received regular visits from the palliative care nurses, she had been given the drugs so that she could carry out this task herself. Carrie shared two stories regarding conversations she had with the nurses:

…the district nurse had a talk to me about that one coz she came around in my mother's dying phase while I'm still doing the injecting of the pain relief. And, she obviously thought that it might be disturbing me a bit coz she had a little chat with me…She'd been told not to worry whether this and any particular administration of medicine could be the end or could cause death. You treat the pain and you don't worry about the fact that the pain relief might in fact bring on death. And she told me this and I actually hadn't been worried about that, I'd been worried that I hadn't been bumping up the pain medication enough. And, that maybe I should have been bringing on death a bit faster. So, that was interesting. I think that's why we went to the pain pump. So, there wasn't any temptation or to make sure that I didn't feel guilty (Int. 2, 2016: 4).

Again, the Doctrine of Double Effect is raised by professional staff highlighting the pertinence of this moral dilemma in health care (Douglas, Kerridge & Ankeny, 2013). However, with regard to Carrie's life-world, this was not a concern. Her compassion for her mother's suffering was more of a concern than whether or not she might be hastening death. This example shows the differences in each subject's moral worlds.

Another interaction Carrie had with a nurse was an interesting interplay between public discourse morality, institutional morality and embodied moral worlds. During her mother's dying phase, Fay said to Carrie that perhaps it was time that she went to the hospice. Carrie knew that this was not really what her mother wanted; she believed she said this because she didn't want to be a burden. Carrie's response was that it would be more trouble for her to be in a hospice than at home where everyone was there and they had beds to sleep in and so forth. She said that;

As she was going into her dying phase, she did say something like, you know, maybe it's time to go to the hospice. Because she didn't…again you know…you can't get her view on this….because she didn't want to be any trouble. And, I said to her that it was better that she stayed at home, that it would be more trouble at the hospice because we would have to get there to visit whereas at home, we have beds, we can sleep. We didn't have to get there…But, I don't think her heart was in the suggestion. If I had thought that she had genuinely wanted to go into the hospice, I would have got her there. But, I didn't think she did. I think she was trying to be, to make things easy for us. And, it didn't seem to me that it was necessary. If I had thought that she genuinely wanted to go into the hospice, I would have got her there. But, I didn't think she did. I think she was trying to be, to make things easy for us. And, it didn't seem to me that it was necessary (Int. 1, 2016: 10).

It is not uncommon for palliative care stage patients to feel they are a burden to the family and often make the choice to enter institutions to resolve this (Broom & Kirby, 2013: 505).

Carrie knew that being at home was best for her and everyone else. When she told me about this, she then said that she told one of the home visiting nurses. The nurse told her a story from her life. She said that when her husband was dying, he was transferred to a hospice toward the end. She said that it was a move that she regretted. Although Carrie didn't provide any more details of this story, it was information within the narrative which provided support for Carrie's moral position. Any question that it might have been the wrong choice is eliminated by confirmation from an outside source.

Discussion

Acceptance was exhibited by both Fay and Carrie early after the diagnosis. Although Fay was angry that her doctor did not detect the tumour until it was too late, she still accepted that she was dying. Carrie showed acceptance immediately by taking leave, flying over and helping the coordination of care for her mother and helping her die at home. She was also able to advocate for her mother and protect her from possible negative scenarios, like staying in hospital or being subjected to any unnecessary intervention. Family dynamics also played a central role in Carrie's life-world and impacted moral choice. She had a new baby to look after, her father was very old and infirm and so certain choices were based on these existential considerations. Nowhere in the narrative did Carrie say that she could not accept her mother's fate and nowhere in the narrative does Fay attempt treatments or investigate treatments due being hopeful. Acceptance allowed Fay to carry out such things as meet with her vicar and organise funeral arrangements. Carrie believed that her mother's acceptance was probably due having survived cancer before.

Background experience and family dynamics which impacted on the life-world of both Fay and Carrie influenced their ability to accept that she was dying and also, influenced decision making. Indeed, her mother had "survivor's guilt" due to another family member dying where she survived, and they had dealt with hospitals for years since her father was very old and infirm and had spent a lot of time in and out of clinics. This attests to the significance of background experience in shaping life-worlds and in turn, both emotional responses and moral reasoning. Indeed, so much so that Fay even saw acceptance as inevitable, a

disposition which she believed was the only one she could have. Even though Fay was angry and frustrated because of the delay in diagnosis, acceptance still emerged spontaneously.

One of the rules of moral reasoning is that for a choice to be considered moral, it must be impartial (Cohen, 2004: 15). In the three situations discussed, Carrie's moral reasoning always includes an outside party which serves to uphold or validate her moral position. Her decisions are also fuelled by temporality and emotions. When she busts her mother out of hospital and has to get the cannula out of her arm, her relative says to her that she shouldn't have needed to stay the night in there anyway. Carrie didn't want to wait around and waste time. Again, when she was injecting the pain medication, the nurse wanted to put her mind at ease about the potential of hastening her death. However, Carrie was not concerned about this since alleviating suffering was the greater good and if this was the outcome, she was not worried about it. Finally, with respect to her response to her mother suggesting she go to the hospice, she said she knew her mother just didn't want to be a burden. Again, keeping her out of clinical institutions was seen as the right choice. This is further validated by an outside, impartial source when the nurse told Carrie she regretted sending her husband to the hospice. In each case, her choice is further validated by an outside party and so her emotionally driven decisions become justified because they are impartial. Thus, her embodied moral position, the choices she considered morally right, were reinforced and validated throughout the narrative by public discourse morality; through the conversations and the sharing of experiences with others.   Further, the sources which did validate her decisions, the relative and the two nurses, were medical professionals.

Carrie's moral reasoning also reflects a utilitarian position. Utilitarian's moral choices rest on the consequences of the action, not the action itself. Thus, an action is right if it results in the greatest outcome (Mastin, 2008: 2). Further if the consequences concern more than one person, the right action is the greatest outcome for the greatest number (Cohen, 2004: 37). In all three cases of Carrie's moral reasoning, she is not concerned with the action itself, but what results from the action. In busting her mother out of the hospital, she is not concerned with breaking the rules, she is concerned that her mother may be at risk of staying there. The consequences; getting her mother home safe, is the moral objective and the greatest outcome. Hence, breaking the rules is justified. Further, with respect to injecting pain relief

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medication, she was not concerned with whether she may inadvertently be injecting too much and potentially hastening death, quite the opposite. She was worried that her mother may not be getting enough and that her suffering may be dragging out. For Carrie, if the medications did hasten death; that would be a better outcome than prolonged suffering. Again, the outcome is what is important, not the action. And finally, the decision to keep her mother at home when she suggested the hospice was not only based on the fact that Carrie knew that her mother's heart wasn't in it, but due to the fact that it would be better for everyone concerned for her to remain at home. There were places to sleep and people didn't have to travel to go and see her. So in this case, the moral reasoning rested not only on the consequences but achieving the greatest good for the greatest number of people.

Sally

Sally's story concerns her ex-husband Philip whom she helped care for when he was diagnosed with bone cancer. It is also a story about the frustration and time wasted due to clinical misdiagnosis. This makes temporality a central contextual factor impacting decision making as well as emotions of anger and frustration felt due to clinical failings. Like Carrie, family dynamics played a vital part in the course of events and the patient, Phillip, readily exhibited acceptance despite this. Sally had a lot of involvement in Philip's care including making medical decisions. Being a medical professional herself, she took advantage of the access she had to other professionals in the hospital system to gain advice, palliative care aides and other help she saw necessary in order for Philip to have the best death possible. Also unique to this case was the relatively recent past in which these events took place which was eighteen months prior to the interview. Sally didn't express to me directly why she wanted to take part but like the previous story, a canonical breach takes place; a biomedical failure to identify an illness. By the time Phillip was diagnosed, he only had six weeks to live.

Sally is astonished at her ex-husband's ability to accept his fate considering that the doctors failed him and also due to the disorganisation in clinical care which followed. She said he never complained and was able to have a good death because of this calm acceptance. This acceptance is juxtaposed with his mother, Kate, and her reaction to the news which was to

maintain hope for a cure. Kate's inability to accept his dying became an antagonism for Sally and the rest of the family involved with his care. Sally said it made a difficult situation more stressful because Kate insisted on finding a cure when there was none. After Philip's death, Sally told me that her family no longer have anything to do with her.

Sally said that at the time of the terminal prognosis, she was separated from her husband. It had been a year that they had been apart when she was told that he was ill. Philip was diagnosed with bone cancer. At the time, he was living with his mother as he had become so ill, he had to give up his job. Sally said that Philip had been going to the doctors with all his symptoms and they didn't seem to be sure what was wrong with him. Nothing he was given was making him better. Sally told me minutes into the interview how the misdiagnosis happened:

> …he just had been becoming quite unwell for some time and going back…you know the repea…the revolving door with the doctors. I'm not well, I'm getting tired. That went on for a LONG time and then they started treating him for what they call Costo-Gregitis which was an inflammation of the bone. They said you've got inflammation here, gave him some whatever, steroids or whatever…Unfortunately, it wasn't bone inflammation it was secondary bone cancer and it was only when he went to see (a specialist) because one of the doctors suddenly went, 'no this is not right, send him off there.'(Int. 1, 2016: 1)

When Philip went to the specialist he received an MRI which revealed cancer throughout his body. His mother rang Sally to let her know. Sally said that the doctors "didn't join the dots enough." During that time, Sally tried to organise an Enduring Power of Attorney while he was in the regional hospital. This was also cause for frustration for Sally because the hospital refused saying "wait until he is home and better." Sally insisted to them that he was deteriorating every day and she expressed this urgency to them. At one point, he came home briefly and it was then that they were able to organise it.

After Philip received the diagnosis, he was situated in a regional hospital which didn't specialise in oncology. Sally said that they were not able to manage him because they had to call oncology at another clinic to ask them what to do. Sally tried to get him admitted to the city hospital oncology ward, but they refused to admit him until his appointment which was a further two weeks away. She said that oncology had the referral, but they wouldn't take him straight away because he wasn't technically their patient yet. She said that this was so

frustrating because he needed that specialist care and they wanted to get him stabilised as he was very ill. The hospital staff where he was were unable to manage his special needs. Sally said that it all contributed to the stress of the situation saying that it was like "feeling him slip away". She also could not understand why an oncologist couldn't consult at the regional hospital. With the misdiagnosis, delays and lack of continuity she said; "That's not good clinical care" (Int. 1, 2016: 15).

Sally utilised her position in the hospital system to find out more about his diagnosis. Straight after she found out, she spoke to a clinical nurse in oncology to see what could be done for him. She found out then that it was "too far gone" and that his treatment would be palliative. Sally said that she knew this information before his oncology appointment but she kept it to herself. After two weeks, Philip had his oncology appointment at the city hospital. He was extremely ill and due to the cancer in his bones, he couldn't walk and needed a wheelchair. When he was asked by the doctor if he could get up and walk, he said he couldn't. Once they saw this, they told him that there was nothing more they could do. During this consultation, all the family were present including his adult children, Sally and his mother, Kate. Everyone knew that he had the cancer long before the terminal prognosis was provided but now it was made clear that they would not be able to offer anything. Philip's mother flatly refused to accept that there was nothing oncology could do. Sally said that she started protesting, abusing them and telling them they had it wrong. Even with Philip's shock and disappointment, Sally said it brought out the best in him; with her mother-in-law, it bought out the worst. She said that her mother-in-law "…attacked this poor oncologist…not physically, but verbally and emotionally…" because they could offer no treatment.

One recent extensive ethnographic study revealed that "medical encounters early in the diagnostic process served as a defining trust-building or distrust-building experience" for patients and families (Schaepe, 2011: 918). The same study showed that patients take longer to process the news whereas families tend to feel the weight of the news more readily and feel overwhelmed by the thought of losing their loved one (Schaepe, 2011: 916). With Philip's prolonged illness, misdiagnosis and delays in proper care, trust had already eroded before this event. Philip's mother not only refused to accept the news, but argued

that their diagnosis was wrong. Even though Sally also expressed her disappointment and frustration with the failures in clinical care he received, she was still able to reach a level of acceptance of the situation.

One study demonstrates that prognosis is received differently by different people. This is because patients and carers "face different threats…relatives have the caring role and will have to cope with the realities of bereavement" (Hinton, 1999: 32). While talking about the prognosis event, Sally said of the oncologists:

> They're humans too and they're feeling the helplessness of us coming in…and they've got this wash of emotion…our emotions…There was a lot of emotion in the room obviously, my daughter was in there too so it was the three generations (Int. 1, 2016: 7).

Although all the family were overwhelmed by the news, Philip's mother's reaction was different to everybody else. Although they both had a caring role to play, Sally invested her time and contacts pragmatically to organise advanced directives and a palliative care team so that he could die at home. Indeed, throughout the dying trajectory, Sally's actions reflect this pragmatism which demonstrated her level of acceptance.   Sally was trying to make the most of time left; the mother-in-law was searching for avenues through which she could gain more time. Sally interprets Philip's mother's behaviour by saying; "...what do you do when your child is dying? You just want to do everything you can but it just made it harder for everyone else" (Int. 1, 2016: 7).

Sally believes that due to the mother-in-law's reaction, the oncologists offer a treatment which was for liver cancer. Sally claimed that it did not sound beneficial and that the side-effects included the skin peeling off the hands. They also did not claim that it would make a difference; they just told Sally that it was something they could try. Sally held the Enduring Power of Attorney and told the doctors that it wasn't worth it. She had questioned the point of doing it when it was not going to "cure him". Further, it would increase his suffering in the short time he had left. The doctors agreed with her. Sally believed that they were only reacting to the emotional response from the family and felt obligated to do something. The only other treatment Philip received was one target dose of radiation for the lump in his chest under the objective of improving the quality of his remaining life. This radiation was

administered just days before his death. However, Sally claimed that; "One treatment and he just got sicker" (Int. 1, 2016: 7).

After Phillip's terminal prognosis, he remained in the hospital to be stabilised. The following day while Sally was there a doctor came around to discuss the advanced care directive. Sally explained how difficult this process was:

> And, I think they nominated some lowly, poor intern or registrar or someone had the bad job of doing it because when they went through it, they're talking about CPR. And, it's like; "Now, do you want to be revived?" And, of course you go "Yes!" And they go; "But, we can't do it for you because you have cancer in your chest and if we do it, we will break all your bones in your chest and you will bleed to death" (*laughs*). It's like, great! (Int. 1, 2016: 16).

When the doctor left, Phillip had said to her that that it was "confronting." Sally said that this part was difficult and horrendous. Just the day before he had been told there was no treatment and now they told him that his life would not be saved.

At this point in the narrative, Sally shifts to the present tense which showed how this past experience related to her current life-world. It also shows how temporality and emotions mix together when dealing with end of life care. Sally told me that she currently works with older people and she tells them that they should do advanced directives while they are well. She believes that this type of talk when you are dying could be avoided by being prepared. She said even she has one as the reality is one can die at any time. She said to me that she tells people; "Do them NOW!" Her reasoning for this is because it is not as emotionally confronting while you are well. Having it organised means that you will not have to endure the trauma of having to experience this confronting process when you are dying. Indeed, it is all about reducing the emotional impact of the realities of death.

Sally said that even when you are very accepting of the circumstances, no-one wants to talk about death:

> …I tell everybody get your health directive in place BEFORE you are in a situation where it's right at that end of life. Because, nobody would ever want to go through that. I'd much rather be doing it on a theoretical level, than a practical level of…you are going to

crush my…basically, you are telling me I'm going to die. (*laughs*) NOW. Not down the track, NOW. Hmmm. It's awful… (Int. 1, 2016: 17).

Sally said to me that at the time a family has been told of a terminal prognosis, they don't accept it straight away. For this reason, she said the family are still trying to stay positive and having a discussion about a DNR order before the family have had time to accept it just adds to the trauma. In Philip's case, his dying trajectory was short, a matter of six weeks. Thus, there was not much time for the family to process what was happening. With respect to discussing death with him she said; "There was always that, putting on the face for…you know…nobody talked about the fact that he was going to die." (Int. 1, 2016: 6) She said "none of us were going near it." That was why she said she was relieved when a psychologist who was a friend of the family had the talk with him in private, as she described it – "the death talk."

Accepting that her son was dying was too difficult to accept for Kate. She continued to search for a cure right up until the end. Unlike Sally and the rest of the family who were, however reluctantly, accepting the situation, the mother-in-law could not seem to. Seeking alternatives fits with a 'free market' approach to services provided by health care. The patient, or by proxy the mother, reacts to the service as any other consumer and thus is inclined to 'shop around' if they are not satisfied (Lupton, 1997: 373). It has been argued that the health system like any other institution in a neoliberal framework can be viewed in economic terms and thus can be treated as, or consumed, like any other commodity on the market (Kenny, 2015: 13). Kate's actions exhibited this perspective. She claimed that not only did "oncology have it wrong", they failed in the diagnosis and so they had up until that point failed to provide good service.

Besides Kate's drive to seek an alternative, she also conceptualised the medical inability to cure her son in terms of conspiracy. According to Kate, there were problems with the whole medical establishment. Sally said that Kate believed that the cure for cancer was out there but being withheld. Sally explained what had happened after the prognosis in the hospital;

> Yeah. She wanted us to sequence his DNA and send it off to America. She was going on about there being these conspiracies with big pharma not giving the drugs, the

drugs are out there, we've just got to cash in all his Super and find them and…Then she was going down the alternative route and sour sop will cure him…wants me to drive to Mission Beach to get sour sop and juice it all up (*laughs*) (Int. 1, 2016: 7).

I asked Sally what that was. She replied; "It's a fruit!" and began laughing again. She said that her mother-in-law did get the fruit and fed it to Phillip until he insisted he didn't want it anymore. She also spent the following six weeks printing articles off the internet of alternative therapies which they could try.

Pending death "represents no future in a culture orientated to futures" (Maynard, 2006: 230). One study showed that carers who sought alternative therapies for their loved ones did so to maintain a future orientated approach and to maintain a sense of control (Olson, 2011: 908). This sense of control is couched in bio-politics because it is concerned with the politicisation of bodies, the cultural expectations over controlling them and how we deal with the social expectations around body status. Maynard argues;

> When health is spoken of as a virtue, people who lack it are made to feel inadequate. Modern Western medicine reinforces our cultural myth that the body can be controlled. Physicians and researchers focus their (and our) attention on the potential for imminent cures realized through successful medical intervention (Maynard, 2006: 219)

The destiny of our life through our body is no longer fixed but can be manipulated and enhanced through biomedical options which rests on the cultural expectation of choice (Kaufman & Lynn, 2005: 330). Kate's motives and moral position reflected this cultural expectation that the body can be controlled and since modern medicine failed, control could be found in alternative therapies. The anxiety of limited time, the temporality of the events leading up to prognosis and the fear of losing her son all contributed to her drive for a cure and to her wanting to maintain hope.

Unlike Philip's mother, Sally not only disagreed with the conspiracy theories, she said it was cruel to say that there was a cure as it gives people false hope. She viewed this false hope as reflection of a whole industry who feed off people with cancer and she saw her mother-in-law taken in by it all. She said "they" hold things in front of you regarding cures like experimental treatments, clinical trials and those stories of individuals who have cured

themselves miraculously. She said that this implies that "you all must be failing" if you are not curing your cancer. This is why she said it's wrong and cruel. This reflects current bio-political rhetoric regarding health and the body which is no longer simply about governance over the body, it is equally about self-governance over one's body (Kenny, 2015). Thus, a failure to be healthy, to cure one's cancer, becomes a personal failing.

Sally understood Kate's anxieties, but she said that since she never relented throughout his dying trajectory, it made things extremely difficult. Not just because she didn't agree, but because it impacted on Phillip for all the reasons above. Sally justified her annoyance and opposition to Kate's view by explaining, once again in the present tense, her experience working in health care:

> It's just crazy because if you look at how busy the um, I've just been through the cancer centre to see the psychologist there about something for work. PACKED waiting room. There's people everywhere, there's people outside. It's like, they are full strapped. If somebody had the cure, they would be making millions out of it. So, they are not going to be hiding it. It does your head in when you keep hearing this stuff when you've got a sick person; it's awful (Int.1, 2016: 8).

Although in some respects Sally understood Kate's need to cling to hope, she also claimed that it was a source of discomfort during the process of caring for her ex-husband. She felt it was unfair on herself and on him. She said that he and others around him benefited from his "calm acceptance" as it helped him get what he needed in the limited time available. According to Sally, he had a good death because of it. Sally said that the whole experience of caring for Philip brought the family closer together except for the mother-in-law, who they now have nothing to do with.

Due to Sally and Philip's acceptance, they were able to focus on making most of the present. Sally was very surprised at this considering that the doctors had failed him. Even though nothing could be done for him except pain management, she said the day after the DNR order "he just went for the ride" without complaining which she described as "amazing." In fact, Sally attributes his ability to have a good death to the level of acceptance and peace that he seemed to have. She said; "…he did show a very good death that way. And, it was a very good death for him in that journey because he seemed to be more at peace than the rest of us" (Int. 2, 2016: 1).

Philip wanted to die at home and Sally made sure that she did all she could to make this happen. They had been together for thirty years before they parted. I asked her whether they had had any "heart to heart" conversations during those final weeks together. She explained it this way:

> It was um, for him coming back, there was not a problem but we weren't in that very, close…stage that you would have been as a husband and wife to be able to really dig down into that…Though, he did ask as soon as he was back on the scene; "So, are we back together again?" "Let's just see how this goes first" (*laughs loudly*) (Int.1, 2016: 6).

Sally knew people in palliative care so she organised all the equipment they needed for him to stay at home. The palliative care nurses came in and administered the drugs and showed the family what to do. His General Practitioner made home visits too. Sally believed that his helpfulness may have been due to the guilt he felt for his failure to diagnose him earlier. In whichever case, he did all he could to help facilitate his home death. Philip's family ensured that he would get to see all his friends in his final weeks which is what transpired. People flew from interstate to see him and many relatives either stayed in the house or visited frequently.

Sally described this time at home helping care for Philip as both confronting and happy. In contrast to the time leading up to prognosis, the clinical care provided by the nurses and GP at their home was described as "brilliant." In the four weeks he was home she said he went from "sitting outside and eating a little breakfast with me and talking (*whispers*) and within a week he would be in the palliative care bed"(Int.1, 2016: 13). If terminal illness leads to a loss of personhood, Philip's family attempted to help him maintain a sense of this. Sally explained;

> We opened up the house and we just had everybody come round and we had a big, living, wake sort of party. And, invited all his work colleagues around and all his friends and we had another football party (*laughs*) when the footy was on. You know, basically it was just visitors coming from interstate, family coming from inter-state…he had a ball. Because, we sat him in the lounge room and all these people came (*laughs*). So, he was enjoying things…but of course he was sick, yeah (Int.1, 2016: 8).

Sally expressed that these final weeks were as good as they could make it for him. His children who were young adults helped him out and many people took turns in the night to

ensure that he was comfortable. Sally said that some people in the extended family thought it was odd that there was a party atmosphere. She said that some people were 'horrified', notably her mother-in-law's husband, at the way in which everyone was carrying on. She said there was an expectation that everyone should be sitting around, solemn and sad. Sally said that those who were 'horrified' were told that this was the way that he wanted it. Sally said; "…this is a typical Aussie larrikin type of nut…we are going to go out screaming and laughing (*laughs*)" (Int. 1, 2016: 14).

Discussion

Family dynamics and a short dying trajectory impacted Sally's moral reasoning during Philip's end of life care. Sally clearly saw acceptance as a necessary disposition leading to a good death for Philip and she exhibited this early on. In contrast, hope in this narrative plays a negative role due its impact on the family and its "cruel" implications for the patient. Although Sally understood Kate's emotions, she rejected her ideas not only because she saw acceptance as sensible, but because it implies not only that others have given up, but that the patient has somehow failed. Alternative cures and conspiracies are morally wrong because they obligate the patient to remain in a state of hope and lead to an expectation that they should be looking for cures. Acceptance, on the other hand, is sensible since it allows the patient to make the most of the time left and does not hold out false hope. Exhibiting acceptance allows for a good death because time is spent on comfort and family in the present, instead of wasting time hoping for a non-existent future.

In the instances of Sally's moral reasoning, she not only adopted the position of patient's advocate, but she sympathised with the institutional world of biomedicine of which she is a part. Even though she overtly acknowledged their failings, she did not lose her sympathetic understanding of their expertise or their role. Sally also flatly rejects public discourse on health and alternative cures which are not worth pursuing because they are laughable and because they are cruel for the patient by offering false hope. Sally categorises Kate's refusal to accept Philip's fate and her insistence on cures as being indicative of a broader problem in the public discourse around cancer. Public discourse on health in contemporary society is increasingly putting the responsibility on the patient to cure themselves (Lupton, 2003).

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And, it is this idea that Sally rejects. The thought that potential miracle cures are "out there" but are being withheld are as outrageous for her as the idea that patients can cure their cancer with healthy eating or will-power. Sally laughed when she spoke of these potential cures because she believed that they were scams. She said "they would be making millions out of it" if there was a cure.

Much of Sally's moral reasoning also reflected a virtue ethics position. Certain moral actions may be considered good by the subject, but they are only good if they are done from a state of being from which one is able to attain virtue:

> But virtuous acts are not done in a just or temperate way merely because *they* have a certain quality, but only if the agent also acts in a certain state, that is (1) if he knows what he is doing, (2) if he chooses it, and chooses it for its own sake, and (3) if he does it from a fixed and permanent position (Aristotle, 2004: 37).

In all cases of Sally's moral reasoning, she does so from a fixed moral position. She is always pragmatic, she doesn't believe in the extreme views from public discourse on alternative health or conspiracies and works tirelessly to have the best care for Philip through acceptance and a focus on his comfort. Even though clinical care failed him in some respects, this does not shift her conviction that it is the most sensible route to take. This is evident when she calls the hospital to try to bring the appointment forward, when she requests to organise the Enduring Power of Attorney, when she gets information from the oncology nurse before his appointment. Further, when the doctor felt she had to offer something to Philip, Sally doesn't just reject it because it would cause him more suffering; she rejects it because she knows that they were only offering it because the family was shocked and emotional. She knows that they feel they need to offer something. And, finally, she rallies her contacts to make sure that he has all the palliative care equipment he needed at her home. Hence, Sally undertook what she considered the moral action, the virtuous action, not by accident, but through deliberation and purposeful action:

> But it is in the field of actions and feelings that virtue operates; and in them excess and deficiency are failings whereas the mean is praised and recognised as a success: and these are both marks of virtue. Virtue, then, is a mean condition, inasmuch as it aims at hitting the mean (Aristotle, 2004: 41).

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Excesses of any kind are not considered moral for Sally nor would they have led to any good outcomes. The conspiracy theories were extreme positions and so were the claims regarding natural cures. Since they are not part of mainstream medicine and are on the fringes, they are too extreme, to "excessive". Further they are not just wrong because of this, but because they are harmful to the patient by imposing false hope and responsibility. Sally saw these ideas as taking advantage of vulnerable people who are desperate, and their claims are laughable. Further, she even doubted who Kate was doing it for. Thus, she questioned her virtue. She insisted there was a cure, demanded DNA sequencing and fed Philip blended fruit called "sour sop" perhaps as a way to cope. However, although it can be considered good for those maintaining it, hope can also have the potential to cause vulnerability and harm (Cellarius, 2008: 113). Sally clearly saw her mother-in-law's hope, or lack of acceptance, as harmful.

Sally empathises with the institutional moral world of biomedicine, rejects most public discourses on health and alternative cures and thus conducted herself in a balanced way from a position of virtue. Although she acknowledged the failures in clinical care, she accepted the terminal diagnosis and focused on the present and what could be accomplished in the limited time available. Philip also exhibited acceptance, Sally describing his fate as "bringing the best out in him". This is juxtaposed against the mother-in-law and her insistence on hope for a cure and a focus on the future for Philip. Her actions were "cruel" because of their impact on the patient and may have been good for her coping, but not for him and so were without virtue. Acceptance also provided positive things for Philip like the organising of his living wake party. Philip's "calm acceptance" meant that he could "go for the ride" and let Sally organise all these things for him. Accepting the prognosis led to organising the Enduring Power of Attorney, rejecting unnecessary treatments, organising palliative care and family and friends to visit. In this regard, acceptance allowed actions to take place which may not have occurred as quickly if the family remained in a state of hope. Due to this, Sally was able to organise a home death, which was his wish. She did not chose this because it was easy to organise, but because it was what she saw as the most sensible and virtuous thing to do.

Chapter IX – Bio-politics, Suffering and Moral Obligation

In the section on background and intention, I explained that the breaching of a canonical script contributes to the desire to share events through narrative. Death is always a breach of life, but when it is compounded by further breaches in clinical care, patient well-being is sacrificed and replaced by both physical and existential suffering. In the previous chapter, the participants exhibited acceptance early in the terminal diagnosis even though they expressed clear frustrations with biomedical failures such as misdiagnosis and lack of coordination of care. However, these failures did not result in a total lack of control over the dying trajectory or bad deaths. In this chapter, failures in patient care are more palpable and the pain, suffering and alienation of dying is compounded. This is evident from the narratives of the participants who bore witness to this and hence their stories are imbued with more anger and emotion. Both empathy and moral outrage accompany their criticism of biomedicine's attempts to cure, their failures to manage pain and through a lack of humanity and respect shown for patient dignity. In this regard, these cases reveal how bio-politics can create the potential for suffering when their obligations over body governance, control and power fails.

To understand how a moral obligation has been breached, we must understand the usual rules of engagement between patients and institutions. For Foucault, we must analyse institutions from the standpoint of power relations and not vice versa as the understanding is to be found outside them (Foucault, 1994: 343). What he means is that we cannot understand relationships of power by simply looking at what goes on at the institutional level. We must look 'outside' this to understand the ideologies and knowledge which sustain this power relationship and form the foundations of the institution. As Lock argues, all medical practices are the products of ideologies and include unquestioned assumptions (Lock, 2001: 479). And, it is these assumptions or 'truths' which inform the purpose of the governance, which objectify the patient and, in many respects, constitute the subject. For example, truth claims about science which form the foundations of biomedical knowledge create a power structure which operates in the clinical encounter between doctor and patient.

Van Brussel argues, "…the dying patient is increasingly regarded as a competent individual, capable of making their own (end of life) decisions, rather than passively at the mercy of the medical professional" (Van Brussel, 2014: 175). The manifestation of this ideal of patient autonomy in reality, however, raises a paradoxical issue. In order for this level of patient independence to become a reality, patient dependence must be successful. What this means is that body governance and control by biomedicine and the institutions through which they operate need to maintain power over the deterioration of the body. This is their political objective and their moral obligation. In this respect, patients cannot exhibit this ideal of competent decision maker when these objectives fail. This is why even though autonomy may be touted as a central value in contemporary end of life care, cancer patients can still experience complete subordination to medical hegemony (Waskul & Van der Riet, 2002: 493).

The nature of the power relationship and its effects on subjectivity are important to recognise in order to grasp the significance of its failure. Foucault argues that "Every relationship of power puts into operation differences that are, at the same time, its conditions and its results" (Foucault, 1994: 344). These are the systems of differentiation that he refers to (Foucault, 1994). Therefore, the normal conditions and results of these differences between the patient and the clinic result in a moral obligation to maintain control over the patient's body. When this obligation is not carried out, it is not only a failure for the patient, but it is a complete failure of the conditions of the power relationship. This failure in their moral obligation to those who are subject to them is explicit for the participants in this chapter. Foucault argues:

> There are two meanings of the word 'subject': subject to someone else by control and dependence, and tied to his own identity by a conscience or self-knowledge. Both meanings suggest a form of power that subjugates and makes subject to (Foucault, 1994: 331).

Many bad deaths result from an inability to control the dying process (Waskul & Van der Riet, 2002: 488). Issues of subjectivity, power and control over the course of events then occupy the realm of this bio-political process. One way in which clinical care can fail in its moral obligation is through a failure to control not only the trajectory but the outcomes

which result from this failure. Therefore, the patients who are subject to this failing experience both a defiance of the expectations of the relationship but as a result, an increase in their vulnerability.

For the patient, there are two levels of assault going on. If 'we', the self or the subject, as embodied perception, "are our bodies" as Leder would have it, then pain and suffering has already led to a disassociation with the self. We are both alienated from others and ourselves; the body becomes another 'other' (Leder, 2016: 453). The second assault arises not just in the inability to manage this pain and suffering but where the institution's actions and inactions intensify this experience for the patient:

> The body is out of control and assumes a form whose mere presence poses a threat to the self, the scene of interaction, and those who must interact with 'it' (Waskul & Van der Riet, 2002: 488)

If one of the top priorities for families in quality end of life care is physical comfort and emotional support for patients (Teno et al., 2004: 88), then the absence of this means more physical and existential suffering for the patient and often, moral outrage for families. Kellehear argues that "most of a person's distress lies outside of them, in the realm of power, loss of control and a sense of disintegration at the hands of 'others' "(Kellehear, 2009c: 392). The following cases epitomise this statement where breaches in the relationships of power and therefore, what is expected from their clinical obligation, leads to additional patient suffering.

In the following three case studies, the first two participants expressed their despair at the suffering of their family member which was particularly drawn out. The first case is an explicit interplay of power relations where medical knowledge and a desire to cure is allowed dominance. Indeed, it is the most extreme case of medical futility found in all my case studies. The second case regards the prolonged institutionalisation of the patient and the failure by the clinic to control pain and implement the necessary care. In each of these cases, not only is the patient rendered powerless but so are the family members. However, although all acknowledge suffering, each had a different perspective or 'moral stance' toward the events that transpired. This is largely due to the differences in their background,

intention and family dynamics. Finally, the third case in this chapter concerns a participant who saw breaches in care and actively took actions to counter these breaches as they occurred. Her moral reasoning at the time of the events was clearly translated through action. Although all the families in this chapter witnessed patient suffering and expressed what they perceived as failures, there were different levels of moral outrage which simply attests to the differences in background and intention, life-worlds and level of involvement in decision making.

Kevin

Kevin lost his mother to brain cancer in 2009 and spent as much of her final year with her as was possible even though he lived interstate. He is married with two children and is a mature age student. He also made a point of telling me that he was adopted. He was interested in being part of this study because he believed that death was not talked about enough and believes the "Western" tendency to conceal death does not help us face it. From the time of her prognosis to his mother's death was a year. Due to the promise of a cure, she underwent both chemotherapy and several brain surgeries which resulted in extended suffering, her emotional withdrawal and poor quality of life. Although Kevin's story articulates an extreme in-balance in power over the patient by biomedical attempts to cure and he acknowledges her pain and suffering, he still manages to gain something of value from the experience. Kevin confessed that he always had a fear of death and that witnessing his mother's death helped him alleviate his fears about his own mortality.

His mother was seventy nine when she was diagnosed with brain cancer. When I asked about the decision making process, he explained that his family were not an "emotional" family and said that there were lots of troubles in the past. His father made all the medical decisions during her dying trajectory because his father "wore the pants" in his family. Throughout the narrative it was particularly obvious that his mother's 'voice' was absent. At the time that these interviews were conducted, he had also lost his father who had suffered from Alzheimer's in his final years. He told me the circumstances surrounding his death, but the focus of this case is the story of his mother. Kevin and his sister had no part in the

decision making but Kevin attempted to spend as much time as possible with his mother in her final year.

Kevin's father was present when the doctors had told his mother that she had a brain tumour and that her condition was serious. The doctor advised immediate surgery not just to delay death, but as a cure. Kevin said that they basically implied "If you don't do it, you will die!" Where biomedical advice emphasises the sense of urgency, patients have little time for choice or for the weighing of risks (Shim, Russ & Kaufman, 2007: 248) According to Kevin, his father had great faith in modern medicine:

> I think it was respect for the medical profession. And, you know, as I said, he was a professor, not just a doctor. And, I think that my father just had a strong belief in the medical profession. And, they had cured my mum many years ago when she had a brain tumour. Yes, yeah (Int. 1, 2015: 3).

Hence, the dynamic at the initial stage of the decision making was a strong faith in medicine backed by a history of a prior cure. Kevin's mother had a brain tumour removed when she was forty and the surgery had been successful so there was confidence that this could be achieved again. However, taking no action was not recommended and so the initial surgery was agreed to. Not much is mentioned about his mother's views throughout the narrative but his father's faith in medicine is made explicit.

Throughout her final year of life, Kevin's mother, who at that time was eighty, endured a total of three brain surgeries with follow up chemotherapy each time. Kevin told me that she suffered a great deal and yet his father never questioned the medical advice or the necessity of further surgeries. Issues such as risks and recovery from these procedures were never discussed. As Kaufman argues, risks of surgeries are often not discussed in an attempt to maintain control or they are displaced by hope (Kaufman, 2010b: 235). This was the case with Kevin's mother. The doctors maintained control over the situation and instilled hope in the family that she would be cured. Kevin said that "the medical model doesn't allow you the sort of time or space…to mull it over" (Int.4, 2016: 12). In Kevin's mother's situation, the decision for surgeries was made at the beginning and then there was no re-assessment of the situation. There was no pause to question whether the surgeries were worth continuing

and, even when I prompted Kevin for her views, he said that his mother never voiced her opinion.

It is abundantly clear that the final year of Kevin's mother's life was dominated by the biomedical desire for governance over the body, for control over the patient in the objective to cure. Kevin's mother epitomised the role of the passive patient, with no mention of her exercising autonomy or of her expressing an opinion of what was happening to her. Kevin believes that her suffering made her withdraw and he made the point that these surgeries on someone her age were just too much. Kevin said; "…if they're eighty, just getting over the operation has got to be a huge hurdle" (Int. 2, 2015: 2). Being always in a state of recovery, her dying trajectory was made extremely difficult. He said it was "…operation, hope, operation, no hope…" (Int. 2, 2015: 8). After the second surgery, Kevin said that she withdrew into herself; he believed she had given up. From Kevin's point of view, the surgeries were not worthwhile because they destroyed the quality of her remaining life.

Kevin's mother, after two surgeries and follow up chemotherapy, endured a third and final surgery. After this, the doctors abruptly told the family that there was nothing more they could do and she was admitted to a palliative care ward for the remaining two months of her life. Even though Kevin thought the surgeries destroyed his mother's remaining life, he does not lay the blame with any one party. With respect to his mother's situation, he mentions that "it must be natural, musn't [sic] it? For human beings to clutch at…the family and doctor sort of both play a part in…clutching at straws, hoping for the best. And I guess in our little world it's not acceptable to say…Oh well, crudely, just, that's it" (Int. 2, 2015: 1). Although he doesn't enjoy the analogy, he says it's like when you go to the vet, you ask them what they think and the vet tells the person it is up to them. However, "when it comes to people we are more (deep breath)…we put the decision making onto the medical profession" (Int. 2, 2015: 3). From this it is clear that Kevin believed that it was natural to allow the doctors to make the decisions for his mother and he also believed that it is natural for families to remain in a state of hope. The systems of differentiation between medical knowledge and the family resulted in a total reliance on medicine to control the situation and provide hope. This is why he saw the desire for a cure as a unified objective.

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When he told me that they announced abruptly after the third surgery that there was no more hope, he said;

> No, well some people are very cynical about the Western medicine and the way that it approaches things. But, I don't think we can just blame medicine, we've got to look at ourselves as well. We're the ones who, you know, how can I put it? We, we dance with the medicine, we dance with the doctors. So, yeah…when I did sociology, they're so anti-medicine it's you know…Western medicine…they're out to make money and fame and fortune and…I don't think that's totally true (Int.2, 2015: 2).

Kevin clearly rejects the economic determinism proposed by some theorists that medicine is all about monetary transaction. In his case, his father went along with the medical promise but clearly at the expense of his wife. We can see that systems of differentiation are all in play which created a power differential with very little resistance. Indeed, in this medical encounter, the patient is not only subject to the power of medicine but also to her husband who had total confidence in their ability to control the body. It was a situation whereby the jurisdiction over the body is completely given up to the doctor (Lupton, 2003: 26) Supporting this in-balance of power was Kevin's father's faith in medicine and the status of the doctor who was imparting the advice. He was a professor and henceforth his knowledge, education and professional standing gave him the upper hand (Lupton, 2003: 119).

Two of the values of a good death, patient autonomy and quality of life, were sacrificed not only by the belief that medicine's governance over bodies is absolute, but due to the families need to maintain hope. As a result, patient vulnerability and suffering were the inevitable result. His mother's final year "was not good quality you know?...most of the time was spent recovering from surgery…" (Int.1, 2015: 2). Kevin said that after the second surgery, his mother had "switched off emotionally" and that she had a "terrible time." He said by the time she was in palliative care, "…all the operations and the sickness and that had just worn her down, she'd just had enough" (Int.1, 2015: 5).

Interestingly, during the second interview, he told me that he had an Advanced Directive drawn up and that he had nominated his son as Power of Attorney. Even with this in place, he expressed some guilt for putting this responsibility onto his son. Kevin believed that there

are good and bad ways to die. He doesn't want to live if he is a "vegetable" just for the sake of living. Since Advanced Directives are about empowering the patient, I asked him what the notion of patient autonomy meant to him. He said it was about choice:

> Oh, well to me it means that the patient has the choice to, to accept or refuse or amend any treatment they have. Even if it goes against the medical prediction or whatever you call it. So, it means the patient has the full freedom over their treatment, environment, all that… (Int. 4, 2016: 9).

Freedom of choice here seems to equate with control and choice over treatments and place of death. Clearly, this is something that his mother did not have. This could also point to his experience with his father (which he also shared with me). There is little autonomy or dignity when he described his mother's experience, and with his father who suffered from Alzheimer's, the loss of power was also marked. When he described his father's final months, he said that he was glad he spent time with him. He said even though he held a grudge for some of the things that had happened in the past, he still wanted to spend time with him and talk to him even though he knew that his father was not responsive and perhaps did not recognise him. He said just talking to him and being with him helped him resolve some of his own issues.

It was clear that Kevin's current perspective and life-world had been directly influenced by the experience of his mother's death. With the recent drawing up of his Advanced Directive and with autonomy being equated with choice, Kevin seems to seek to prevent the same scenario for himself. The medical team, Kevin said, are "trying their best…lose respect for the individual and their dignity…they are just looking at the physical model…you know, the heart needs this, without looking at the whole, whole person" (Int. 4, 2016: 10). And, in his mother's case, the medical decisions did not include this consideration and instead epitomised a complete objectification of the body at the expense of the person. Indeed, she withdrew emotionally under the strain before the final surgery was carried out. Kevin told me that she never complained and that she remained "stoic" but also contextualised this by letting me know that they (the family) were "under the thumb" of the father. Hence, although Kevin clearly recognised how much suffering his mother endured, he did not lay the moral blame on any one party. His moral stance is ambivalent. He believed that it was the 'natural' joint desire to maintain hope and have faith in doctors for a cure that results in

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what happened to his mother. In this respect, even the cultural objectives of medicine are viewed as natural.

When his mother was admitted into a palliative care ward, Kevin was present most of the time along with his sister. Kevin told me that he was annoyed that his father kept saying that there was no need for them to be there. It distressed him so much he sought out a social worker in hope that she would explain to his father that they wanted to be present. Kevin doesn't think the social worker ever confronted his father nor does he think it would have been any use anyway. He said at least it allowed him to "vent" his feelings. Apart from this, he described the facility and staff as being "excellent", but again that his mother was really withdrawn. He told me that they allowed cats in the ward which gave the place a "homely" feeling. But, by then; "…she'd gone…her…not her soul but you know what I mean? Her essence had gone and it was just this physical body just winding down" (Int.2, 2015: 6)

When I asked Kevin if he got to share any moments with his mother while she was in palliative care he looked away and became upset. He said he thanked her for some things, and then he said he also apologised to her about certain things that he had said and done in the past. He gave me an example of a fight they had when he was young and when he had said to her; "You are not my mother!" When I asked what her reply was, he said that she was pretty unresponsive by then. Kevin wasn't sure if she even heard, but he felt better for saying it.

Beyond personal reconciliations, Kevin believed that spending time with his mother in her final months alleviated his fear of death. I didn't realise the extent of this fear until he described it as "immense" and he put it in context by describing himself as a "fully practised hypochondriac (*laughs*)." He said that watching his mother go through the dying process helped him accept his own mortality. He said there are "yucky bits" about dying but people don't "run around the room screaming." He said it's a lot more peaceful than he thought even though he didn't think peaceful was the right word. He attempted to conceptualise what he meant by bringing up the topic of euthanasia. He believes that there is value in letting nature take its course during a dying trajectory and in the reconciliation and closure which can be achieved through witnessing death. With regards to pain and suffering, he

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believed it is a part of life. Essentially, he believed that facing death was good for both patient and family and that if this process was cut short through euthanasia, these benefits would be lost.

In another interview, we discussed the social worker incident again. Kevin jumped straight into present tense regarding a documentary he had just seen the previous evening. He asked me if I saw it, I hadn't. Then, he told me what it was about:

> There was one on TV last night…A new documentary. And, the girl was adopted and her adoptive mother told her when she was dying that she was adopted. And, then she went through all this stuff to find her mother and she found her and she was arranging to meet her and her birth mother died…So, sometimes events can sort of…you know you haven't got forever to do things you know? Yeah… (Int.4, 2016: 8).

This *moral coda* feeds into the value Kevin placed on witnessing death which included union and reconciliation. It links to my question about his reference to seeing a social worker because his father did not seem to understand his children's needs or emotions. The sense of missed opportunity in the documentary points to his own belief in the value of reconciliation before death. This was true of his mother, but also his father's death. When his father was dying, he told me that he had to forgive and forget all the issues that he had with him.

Another *moral coda* which was present in the narrative is a story about his past. Kevin had just finished talking about his father's death and how he was able to forgive his dad because "he was a human being like all of us." Then, he shared a very personal story. Kevin told me that when he was nineteen, he spent time in a psychiatric hospital:

> And, there was a, one of the lady patients in there. She was mentally ill, and, um. I don't know if they even called it Alzheimer's then, but I forget what they…but she was a bit off the planet. And, she was dying and it was on the Christmas Day…that the, sort of the nurses knew that she was going to die and somehow the old lady got out that she wanted to see her kids, her teenage children.
>
> So, the nurses rounded up about four, three or four of us younger ones and we went in and visited her. And, you know, she thought that we were her…kids. And then, and then it was all kisses and all this and that. And then, she died that afternoon. But, those nurses, when I look back I think, 'How wise were they to sort of put up that?'…That's what she wanted to do before…Well, she would have died anyway; you

know what I mean? It's similar like I was just saying with my father. People say, 'people want to see something or somebody and then they're free to, to die if you like…I always have a warm gooey spot in my heart for that! (*laughs*) (Int., 3, 2015: 11)

Again, this *moral coda* touches on the dying process and how something of value can be gained from it. He respected the nurses in showing this patient some dignity in death and in providing her with some comfort before she passed. It is again about reconciliation and closure, two of the positive aspects which he believed could be gained from witnessing death. Irrespective of all his mother's suffering and powerlessness which he clearly recognised, death is seen as an opportunity for family members to gain something positive from the experience.

Discussion

Kevin's story regarding his mother shows the dynamic interplay of Foucault's systems of governance. In particular, the differentiation between biomedical perception and knowledge of the body, and a lay-person's understanding. Indeed, these differentials provided both the conditions of the power relationship and the results (Foucault, 1994: 344). The conditions were complete faith in medicine which resulted in an unhampered pursuit for a cure at the expense of the patient's autonomy and quality of life. Out of all my case studies, this example is the most extreme picture of patient vulnerability and powerlessness due to both biomedical domination and family dynamics. There was no negotiation or time allowed for considering or even discussing the risks of surgery and recovery. The hope for a cure is supported by the father and the doctors over and above any consideration for what his mother thought or might endure. However, instead of regret and outrage, Kevin's moral stance is not to lay blame on one party in the process but to justify the decisions which were made as 'natural' and even inevitable. Although he reflected on her dying trajectory with regret for both her physical and existential suffering, he blames this on the human need for hope which works in unison with the broader cultural push for cures.

Kevin believed that the justification for taking up the initial surgery was based on the fact that she had been 'cured' of a brain tumour before when she was forty. This provided confidence in the surgery being successful. However, even though Kevin thinks age should

be a consideration, studies show that surgeries are offered regardless of age (Kaufman, 2010b ; Shim, Russ & Kaufman, 2007). As Kevin pointed out, it takes a lot to recover from an operation when you are eighty compared to when you are forty. This was true of his mother's experience. During this process she was unable to regain any quality in her remaining life.

The other important influence on her end of life care was of course family dynamics. No-one in the family questioned or challenged the decisions made at the time by the father and the doctors. Kevin's view is that quality of life has more value than attempting to gain more time. He was clear that whatever time may have been gained from the surgeries was not worth it. His mother didn't just physically suffer from the surgeries, but she withdrew emotionally. She experienced both physical and existential suffering. She had "given up". From a Foucauldian perspective, if degrees of rationalisation are adjusted to the circumstances in question, then this power relationship responded and adjusted to the faith and encouragement of his father in the drive for a cure which was unhampered because the rest of the family were "under the thumb."

There are consequences of the cultural milieu of medicine which stresses longevity by any means and at any cost (Kaufman, 2010b: 226). Even though Kevin does not place the blame on any one party for his mother's painful dying trajectory, he clearly does not want to experience the same level of powerlessness. This was evident in his belief that autonomy is about choice, and when he told me about his Advanced Directive. This directive seemed to be about having control and choice with regards to treatments regardless of what the "doctor's prediction" is. It symbolises a preference for a natural death over an overly medicalised one. He wants the rights and controls that his mother never had, he wants a say, a voice. Highly medicalised deaths characterised by a prolonged dying process incapacitates the patient from engaging in their own decision making (Black & Csikai, 2015: 33). He clearly wants a say in decisions and preferably a natural death where the body, if it's a "vegetable", should not be kept alive by machines. Clearly, Kevin doesn't want to experience the sense of powerlessness and vulnerability that his mother had. Kevin wants to have choices and control. This shows a rejection of the total body governance and power that medicine had over his mother.

Kevin's moral positions appeal directly to nature in several ways. First, he does not lay the blame with what happened to his mother on either medicine or his father but believes that both parties were responsible. He said it was "natural isn't it?" to "clutch at straws" – to hope or share in the belief that a cure can be found. Second, even though he had a "phobic" fear of death, he believed that the process for him made him accept the death of his parents and accept his own mortality. Confronting as it might be it, he saw that it had both social and emotional benefits. Third, it seemed that the experience had influenced his life-world in the sense that for himself, he does not want an over medicalised death and wants control over decisions which are made about his body.

Contemporary culture places little value on the dying process itself (Cottrell & Duggleby, 2016). Kaufman reinforces this by arguing that biomedicine only recognises the transition between life and death in the most perfunctory way (Kaufman, 1999: 77). This is not the case with Kevin. He challenges the view that the dying process has no value. This is evident when he talks about his opposition to euthanasia. Kevin believed that artificially brining on death should not be allowed because there is value not only in dying naturally but for the family to witness death. Interestingly, Doka argues that the very lack of recognition of this value in dying is one of the reasons that euthanasia emerged (Doka, 2005: 87). In opposition to the biomedical view, Kevin's "natural" view is that this is the reason euthanasia is considered good. Even with his mother's extended physical and existential suffering and even though he wished she would die sooner, he did not believe that life should be cut short artificially. He emphasised what was valuable for him within the experience; and that this would be lost if euthanasia was legal. In rejecting euthanasia, he did not reject it on the grounds of the argument that patients will be left more vulnerable and medicine will wield more power. His argument is not about slippery slopes. Kevin's moral position favours 'natural' deaths. For Kevin, death is a natural part of life, if we kill ourselves prematurely we will not only deny this natural process but may also miss out on the potential for family connections and reconciliation. This also applies to being kept alive artificially by machines if you are a "vegetable" which is clearly wrong. Instead, one should be "letting nature take its course". Both Kevin's *moral codas* solidify the values that can be gained from a natural death over and above a highly medicalised dying process or worse, a pre-planned medicalised death.

Becky

Becky is in her late thirties and is a nursing student with an objective to work in mental health. She lost her mother in 2009 from kidney and bone cancer. She wanted to be part of this study because she believed that death is not discussed enough but also because she felt that people are not allowed a proper grieving process. She hoped that studies like mine might help change this. Although Becky was not part of the medical decision making, she made many other decisions with regard to her care. After her mother's terminal diagnosis, she moved back in with her father so that she could be with and support her mother. Out of all my participants, Becky's mother spent the most time in hospital which is where lack of communication, ineffective pain management and loss of dignity were just some of the transgressions which left Becky and her father angry.

Unlike Kevin's story, there is no hope offered for a cure after the initial diagnosis and there are no attempts to extend life. Therefore, even though Becky's mother refused any surgery, the last year of her life was still filled with suffering. The hospital where she spent ten of her remaining twelve months couldn't get her medication right and were not able to manage her pain. Also frustrating for the family was that the visiting oncologist and other staff were very scant in their communication which led to anger, confusion and frustration for Becky. Becky also pointed out that her mother lost her sense of dignity in hospital. Indeed, the sense of vulnerability and powerlessness experienced by the patient and to a certain degree, the family, was highlighted throughout her narrative. It is a story filled with emotions of empathy and grief for her mother and still now, anger for the breaches in clinical care. The only small consolation for her mother was the relief that she was able to experience when she was moved into a palliative care ward in her final two months where she described the staff as wonderful and able to manage her pain.

As narrative theory suggests, often stories are told in response to current concerns (Ochs & Capps, 1996: 25). During both interviews, Becky was still visibly upset and told me she still had nightmares and flashbacks about her mother's death. She said while in the hospital, they could not manage her pain nor did they treat her with dignity or respect. Becky was in the middle of getting her nursing degree which she said was bringing all the issues back up

for her. She told me the past two years had brought back memory after memory of what happened with her mother but particularly bad memories with respect to the nursing she received. Not only was Becky studying to be a nurse, but her mother was also a nurse her entire life. So, in addition to this background information, her intention for taking part is explained by her in this way:

> That's why I wanna do this. I mean, I'm so grateful that you are out there trying to change stuff I mean that's amazing. I mean, death just isn't talked about is it? And, the dying process and everything it's…it's so…you've got a cut off point for death, you know? Okay, you can grieve for a year, and then you're done! (*laughs*) And, you can never talk about it again, you know? It's ridiculous (Int. 1, 2016: 17).

Throughout the narrative plot, there are clear violations of norms and expectations of clinical care which compromised her mother's ability to maintain some degree of autonomy and dignity. On top of the physical suffering she witnessed her mother go through she also described her existential suffering. One example she provided was when her mother had bouts of diarrhoea. Becky, spending everyday with her mother in hospital, had to shower her. That was when she said with regard to dignity that "…I watched it disappear from her" (Int. 1, 2016: 8).

Right at the beginning of the first interview when I asked about the quality of clinical care she received she said that the hospital could not cater for her mother's needs even though she was supposed to have had the best oncologist in the area. Becky said, "He just couldn't contain her pain. AT ALL! It was horrific to watch! She was screaming in agony, screaming…the house down!" (Int. 1, 2016: 2).

Before her mum got a terminal diagnosis, she had often suffered with back and leg problems. When I asked about the details of the initial diagnosis, she was unsure but she knew that her mother was told she had cancer in her kidney and bone and that she had twelve months to live. This timeframe proved to be accurate. The first decision making that Becky was aware of was after the initial news that her condition was terminal. This was surgery to remove one of her kidneys, but Becky says that she refused this:

…oh, there was talk about um, taking a kidney out at one point. Um, but…yeah, no. Mum decided not to do that. But I think when they talked about that they didn't realise how bad it was (Int. 1, 2016: 4).

Becky said that she didn't know why her mother opted not to have surgery. She did, however, agree to the targeted radiation therapy for her kidneys. She qualified this by explaining that although she and her mother were really close, after her mother was given the terminal diagnosis, she said that she "withdrew" a lot and that this initial decision was not discussed. She said that her mother "went into herself" when she knew that she was dying. Becky said that perhaps because her mother was a nurse, she "knew what was coming" and perhaps she was frightened by that.

Becky provided a summary of the series of events which led to her mother being admitted to hospital:

> The timeline, it just…everything went wrong. She got diagnosed, she had radiation…So, she was sort of in and out of hospital for that. And then, we decided, while she was still well enough. Coz, mum and I were very close, we decided to go to Kangaroo Island for a little holiday. It was horrific. She ended up breaking her neck. Um, and so, we literally went from hopping, almost, to Kangaroo Island – how ironic – to all these different hospitals on the way home in the ambulance? Um, they didn't know that she'd broken her neck. I mean, she should have been air-lifted. I don't know why? That was a failure in the very beginning. Coz, we finally got back to Ballarat and she got whisked away in the ambulance and she went straight to Melbourne to get all her neck fused. Um. They basically said that she shouldn't be walking. So, that was insane. So, from that moment on it all just went downhill. She sort of never came out of hospital from that moment (Int. 1, 2016: 5).

This was just the beginning of the trauma for the family. When I asked Becky if the doctors had advised against her mother walking or going on a holiday she said "no". So, the shock of being told that after the injury occurred was extremely frustrating for the family. This proved to be the beginning of a whole series of communication and care issues between the hospital, patient and family.

Mattingly points out that part of our moral obligation to take care of the 'self' requires us to call upon expert care (Mattingly, 2012: 172). In this expert care, we give up control and independence (Scott, 1999: 145). As I argued in the introduction to this chapter, our dependence means that this relationship comes with expectations. These expectations are

about the nature of the relationship. Not just with reference to the differentials in power due to knowledge differences and being institutionalised, but what the patient should expect from this relationship. The institution's failure to carry out their obligation evidenced by several failures to which Becky attests are in effect breaches of this relationship which result in reinforcing patient vulnerability and powerlessness. This is why these failures lead to anger and moral outrage.

Becky and her father took shifts in being with her mother at the hospital. She said someone was with her all the time. Becky slept at the hospital too and was staying with her father so that she could do this. With the hospital's inability to get the medication dosages right she said she was either "too drugged out" to communicate or in "total agony." She said that the medications were also making her frightened and made her hallucinate which left her fearful of being alone at night. Becky said that when her mother could communicate, she was critical of what the nurses and doctors were doing around her. Becky said it would "upset her" if she was being treated the wrong way or if they didn't do something correctly. She said that this was part of her mother's character and laughed about that. She said that since she was a "perfectionist" in her nursing career, she was going to be critical of what was going on.

Along with the clinic being unable to manage her mother's pain, she also had a fall and broke her arm while in hospital. Becky said the hospital just put a temporary blow-up cast on her arm which she believed should have been proper plaster. She said it was put on and then taken off without discussion or explanation with the family. Becky explained that this experience was "bad enough as it is, you know, let alone having to put that stuff on top of it….see mum suffer more and more and more and more. You know, it was horrific. And, unwarranted" (Int. 2, 2016: 5). Further, Becky pointed out that they were left alone "a lot!"

These examples show that there were breaches of the normative expectations of clinical care through bad pain management and a further violation of care expectations when her mother got injured while in hospital. These events all contributed to the sense of powerlessness and vulnerability experienced by the patient and suffering witnessed by the family. Hence, although the differentials in power contribute to the relationship between

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biomedicine and patient, patients are not passive recipients in a one-sided power relationship between the institution and themselves but "are active participants in the ongoing processes of social interaction" (Waskul & Van der Riet, 2002: 495). Even though Becky described her mother as being in either agony or being drugged out, there were occasions where she had some lucidity. It was during these times that she questioned the staff about what they were doing or let them know if they had done something wrong. Becky's mother, having been a nurse her whole life, felt she had authority to question the staff. This demonstrated her attempts to exercise autonomy and challenge the dynamic of this interchange even in the most terrible of circumstances.

Becky told me that out of the entire experience of her mother's stay at the hospital, their attempt to take her home one day was an the event which makes her the most angry. The hospital allowed it, but set up no palliative care provisions such as a bed, living aides or nursing visits. They were discharged with a tub of drugs and given no advice. Consequently, her mother was in too much pain, didn't have the proper bed and ended up returning back to the hospital via ambulance that evening in agony. When I told Becky I understood that you can't place a bone cancer patient in a normal bed she explained the experience reflexively in relation to her current circumstances and knowledge of nursing:

> NO! And, we did! And, this is the thing you know, looking back now and especially me doing nursing now, it's just horrendous how little we knew and how little we were informed. But, how could you send someone with that late stage cancer home with NOTHING? We didn't really know anything about her drugs, you know, I was administering ah…morphine orally to her…before the ambulance came because she just couldn't…she was just screaming! You know? And, the ambulance is like 'we can't give you any more drugs.' It was horrendous. But then, she just went back to the hospital and that was it. So that, that's where we get really angry (Int. 1, 2016: 12).

The family's attempts to give her mother some comfort and familiar surroundings failed because they were not given proper advice or provisions. Once again, the hospital failed to ensure that her mother was given proper care. This failure was consistent with the lack of communication Becky said they received from both the visiting oncologist and the nursing staff. Aside from the obvious anger in response to this failure, these events further eroded not just her mother's existential and emotional state but those of the family.

I asked Becky if a social worker was ever provided for the family during the ten months of her mother's stay. She said they never saw a social worker. She said at one point, she was unsure about her mother's condition and tried to question the staff but their responses were "confusing" and "rushed". She said that looking back she just remembers the confusion and fear. She said it "still shocks her" how little they were supported by the nurses in the hospital. An example of this was when the nurses believed that her mother was going to die and they asked the family to prepare. Becky was scared about witnessing the dying process and so she asked the nurse what to expect. This was where she described the conversation as "rushed". In another event which Becky described as "sad" was when her mother indicated that she wanted someone to talk to besides the family. Although there was no social worker, there was a chaplain. In the early part of her mother's stay, the chaplain would often come around but at that time, her mother shooed her away. Becky told me that her mother was not religious at all. However, after some time, her mother decided she wanted to talk to her. Becky said it was sad because every time the chaplain came, her mother was "too out of it" to speak with her. In the end, neither her mother nor the family were provided any counsel during the ten month period.

The Glaser & Strauss studies revealed that patients who conformed to normative behaviours were favoured and those who became difficult, such as those refusing to accept death, would be avoided (Glaser & Strauss, 1968). This is relevant not because Becky's mother refused to accept death but because the management of her dying process was obviously difficult for the staff. In Becky's words, "they could not cater AT ALL!" Not only has the good death normative model of patient behaviour been observed and studied over and over (Broom, 2012 ; Goldsteen et al., 2006 ; McNamara, Waddell & Colvin, 1994), but challenges to this model from patients have also been documented (Broom & Kirby, 2013 ; Ivanovic, Buche & Fringer, 2014). These studies show that certain patients are avoided if they do not fit the normative model of behaviour in some way. Further to this, there is evidence that staff morally evaluate patients based on their responses to care and behaviour while in the clinic (Lupton, 2003 ; Sarah & Arber, 2006). What this suggests is that even though the transgressions are in no way the fault of the patient or family, it is the patient who is consequently morally judged and avoided. Lupton argues that such moral categorisation of

patients "transfers the fault for the lack of progress from the doctor to the patient" (Lupton, 2003: 134).

During the interviews, the breaches and violations of care are put within the context of the background knowledge and experience that the family had with nursing. Becky's mother was a career nurse. When she wasn't suffering, she would question the staff and let them know when they were doing the wrong thing. In addition, the interviews took place while Becky undertook her nursing degree. Hence, the reflexivity of the participant in their moral assessment of the situation is explained in knowledge differentials. Becky's current life-world at the time of the interviews demonstrated a sense of a self that was 'back then' – a layman's perspective of events. Now, she had much more knowledge which she used to further assess and understand what went wrong with her mother's care. In many respects, this knowledge imbued the events with an even more tragic tone because the extent of the clinical care failures were more readily understood.

Becky talked about what she was doing now and what she was learning in her nursing degree. She looked into the future toward her goal to work in mental health; as she put it – those that were most "vulnerable". Her current life-world and sense of self is highlighted when she brings up a story from the present which reinforces her moral position:

> I look at when I was on placement you know? I think there were three or four people that had died whilst I was on placement…It was horrible! And that was at *******, just horrible. They just leave them in a room, and nothing. Just the way, you know…the treatment was not great…We walked into a room and there was a woman that actually was, actually reminded me of mum which was quite difficult. But, this nurse and I walked in to change her and she had, you know, adult nappy thing on. She was really confused and everything with all her drugs. And, this woman just literally just grabbed her and like pulled her and she's screaming and she's saying "I'm falling, I'm going to fall!" And, I remember mum did exactly the same thing and this woman just didn't warn her, didn't talk to her. You know, that's still going on today. And, I was just shocked. I mean, I walked out of there and I was really upset…I was the student nurse telling her "It's okay, we have you. Don't worry…we're doing this, we are doing that" you know? The other nurse just couldn't care, just didn't care at all (Int. 1, 2016: 16).

There are several points to make about this *moral coda*. Not only does it reinforce her moral position that the treatment that her mother received in the hospital was appalling, but it

provides evidence that this is not an isolated incident. In this scenario, she describes the nurses carrying out their task with focus on the body without consideration for the person. Having a terminal, diseased and 'abject' body leads to the experience of powerlessness for the patient because the 'self' is caught between the body and the institution managing it (Waskul & Van der Riet, 2002: 491). Instead of trying to counter this reality for the patient through an expression of respect and dignity for the person, this type of treatment reinforces their vulnerability and sense of powerlessness felt by them. Even though the patient was frightened, the patient's body was the focus, not the emotions of the person inhabiting it. Along with all the types of physical and existential suffering that a cancer patient can endure, reinforcing this suffering by a lack of consideration for the whole person is a further transgression of their moral obligations to the patient.

The Institute of Medicine regards quality end of life care as including respect for the holistic needs of the patient, management of pain and symptoms, counselling of patient and family and revision of care plans (Black & Csikai, 2015: 32). In Becky's case, the hospital and staff failed in all these elements vital for end of life care. However, when the clinic fails in its obligations to the patient in the basics of bodily management, we can then see that the moral breach is more than simply the result of systems of differentiation, but may actually boarder on neglect. It had reinforced the sense of indignity and powerlessness for the patient far beyond what would already be experienced by being institutionalised. The lack of control over the body and the powerlessness which ensued for Becky's mother is recognised in nursing journals:

> By failing to see the distinction between the disempowering effects of the institution and its approach to patient care on the one hand, and the disempowering effects of disease on the other, nurses and other healthcare practitioners are in grave danger at best of doing a disservice to many of their patients and at worst of causing irreparable distress (Scott, 1999: 145).

Neither the staff, patient or family seemed to be able to garner control over the circumstances. Through this lack of control, the patient becomes 'difficult' to manage and is avoided. Becky's mother experienced this through a mismanagement of medications, lack of communication, by being discharged without proper provisions and through general abandonment.

Becky compares the experience of the hospital to that the palliative care facility as "night and day." Once her mother was in palliative care, they controlled her pain and her mother was a lot more comfortable. She said; "We saw little sparks of what mum was before" (Int. 1, 2016: 11). They were also better communicators and allowed for and provided emotional support. They took time to explain all the medications to the family and Becky said that they brought the "humanity" back into the situation. By this she means that they afforded her mother dignity and respect. She said they would get her up on a bed and shower her and do her hair and that they "tried." The nursing staff were making an active, conscious effort to respect her as a person. This was in opposition to the seemingly careless approach afforded her by the nursing staff at the hospital.

Her mother's extended dying trajectory and all her suffering had taken a toll. Even though Becky was thankful for the manner in which she was treated in palliative care, she told me that a week before her death her mother said to her "I want to die". Becky said:

> And, that was the first time ever that I'd heard anything like that from her. And, she just broke down and cried and cried and cried and cried. So, that was difficult. That was a really tough moment. Because, if…honestly, if I had of had um, morphine on hand, I would have given it to her. You know? She was DONE. She was over it (Int. 2, 2016: 6).

Becky had been on that long and painful journey with her mother and had watched her suffer. The emotions which come with witnessing the suffering of a loved one have a great effect on moral reasoning. We can see how empathy deeply affected the nature of her experience and how it led to moral outrage. Toward the end of the second interview, Becky talks about that very topic.

As she shared in the *moral coda* her nursing placement experience, she also discussed some of the subjects she was currently studying. This highlighted her values and reasoning with respect to the breaches in care which happened to her mother and her approach to undertaking a nursing degree. She reflected on the incident with the frightened woman again and the nurse's rough and careless handling of her. Becky was "shocked" that there are still nurses like that. Then, she talked about her course:

> Well, we do, we do 'ethics'. We do, 'the human person and something', um, and I'm doing a subject right now on human dignity. So, it's kind of, you know, it's kind of

nailed into us. But, I think you have either got it or you don't. To be honest. I don't know that you can be…teach empathy! (Int. 2, 2016: 7).

From Becky's experience in caring for her mother and through her experience in work placement, she is certain that empathy does not come naturally. She even suggested to me that nurses like the one she worked with during her placement should work in the emergency room where patients are unconscious. Although she was joking, her point was that at least the patient would not be aware of the treatment they were receiving. Becky's moral argument is that not only should the patient be treated holistically, but that the carer has to want to do so – they have to embody this caring attribute. Without this virtue, they cannot do what is right and that is to act out of a place of compassion. The moral breach in their duty as nurses was not only in their biomedical and personal care failures but in their disposition.

Discussion

In Becky's account of her mother's experience, we can see the nature of the relationship between the institution and the patient when the obligations within this relationship are unfulfilled. Dependency implies power differences, but when dependency turns to neglect, there seems to be a fine line between moral failings and malpractice. What results is increased patient vulnerability and powerlessness and an increase in suffering. The usual biomedical governance does focus on the body sometimes at the expense of the person. However, Becky's mother's experience takes this dynamic to the next level. In her case, even the body is neglected. Therefore, Becky's story is not only about failures in clinical care, but moral failures since it was an overt neglect of the expected relationship between staff and patient. For Becky, they not only failed in fulfilling their role, they reinforced and added to powerlessness and suffering. Indeed, they were even abandoned. The sense is that her physical and existential suffering could have been avoided if the clinic and the staff responsible for care did things properly; i.e., show they cared. Therefore, the breach of the moral canon here is the failure in both professional and moral obligations of the clinic toward the patient but also in the character dispositions of the staff. It is this innate character flaw which Becky sees as the worst problem and one which can be further conceptualised by way of virtue ethics.

One extensive study in 2009-2010 in Irish hospitals found that caring tasks for nurses which patients most valued were those that were most likely to be compromised. Talking to patients, educating families and updating of care plans were important to patients but were aspects neglected due to under-staffing, time constraints and nurse burn-out (Scott, Matthews & Kirwan, 2013: 29). Hence, although it may be documented that these are the reasons that these failures occur, we can see that beyond systems of differentiation which create the power relationship, the location of the patient can also increase their suffering:

> …we are unable to understand the role of *place* in creating suffering if we do not link place with styles of dying…[or recognise how place] might actually contribute to the suffering of the dying, is to sanitize dying from its relationship to place when place itself is recognized to play this important role in creating suffering (Kellehear, 2009c: 392).

Becky had witnessed her mother's loss of dignity, her emotional withdrawal, her physical suffering and her fear. When her mother could, she questioned the staff. When in agony, she screamed. The clinic's inability to manage Becky's mother's condition may have resulted in stigma and labelling her as a difficult patient and therefore, being abandoned. The consequences of this were that the family had to take responsibility for showering and helping her with toileting. They also had to make sure she wasn't left alone and thus took shifts to ensure that someone was always with her. It was not just for company, she was genuinely "scared" at night.

The Royal College of Nursing currently describes the role of the nurse as, "…the provision of care to enable people to improve, maintain or recover health, to cope with health problems, and to achieve the best possible quality of life, whatever their disease or disability until death (Scott, Matthews & Kirwan, 2013: 25). Throughout the narrative, Becky's response to what the nurses and doctors did and didn't do indicates what was expected of them, what they 'should' have done. They failed in their moral obligations but also reinforced the sense of powerlessness felt by both the patient and family. They did not appear to be controlling her pain, or helping the patient and the family "cope". Indeed, in the whole ten months of her stay, not even a social worker is offered.

Shifts in her narrative showed Becky's reflexivity and what knowledge she didn't have back then compared to now. This aspect of her life-world influenced not only her understanding of the situation but her moral reasoning. Her new knowledge of the role of nurses and clinical care compounded her grief for her mother since now she knows what is supposed to happen. As a result, failures in moral obligations become more profound.

Good argues that our idealised vision of medicine includes 'caring' as the central moral value and that indeed, medicine is the central site of most of the important value issues in contemporary society today (Good, 1994: 87). Internationally, the nursing literature over the past decade emphasises the importance of 'care' and 'caring' in nursing practice which includes psychosocial support and recognition of the patient as a whole person (Scott, Matthews & Kirwan, 2013: 25). Hence, Becky's current understanding of the institutional moral objectives of medicine and specifically, what is expected of nursing, was not evident in the hospital where her mother spent most of the time. What occurred runs counter to these values. In her *moral coda*, she expressed that the nurses dispositions and conduct toward the patient "upset" and "shocked" her because it was devoid of these values of caring and respect for personhood. She can't believe that "this is still going on today".

The juxtaposition to these moral failures is presented in the narrative when Becky described her mother's last two months of life in palliative care. She acknowledged that within palliative care, they not only communicated, but they treated her mother as a whole person. They controlled her pain as well as showered her and did her hair. For Becky, they "tried". Her mother was able to regain some calm and semblance of her 'self' and that little "sparks" of her mother's personality came back. She said that the nurses in palliative care brought the "humanity" back into the situation. And, this is where we can understand the full aspect of Becky's moral position in relation to all these events. Certainly, it centres on the obligations of nurses and of biomedical practice in general, but the moral lacking here is really about inner attributes, feelings and motivation toward care.

Due to this, we can view Becky's moral reasoning as a reflection of the principles of virtue ethics. Aristotle says that for an action to be moral, (1) the agent must act from a certain state (2) he must know what he is doing (3) he chooses it for its own sake and (4) he does it

from a fixed and permanent position (Aristotle, 2004: 37). Becky believed there are virtues or attributes that nurses should have to do their job. She was taught about patient care in her course, but her experience with her mother and during her placement showed these attributes lacking. She told me she is taught about ethics and dignity in college, but "you have either got it or you don't…you can't teach empathy!"(Int. 2, 2016: 7). Thus, even though the moral expectations are clearly laid out for nurses, one must be conscious of and purposefully act from compassion and empathy for fellow humans. Further, it cannot be taught, this virtue must be in your character for your actions to truly be moral or, in effect, for you to even be in that profession. Indeed, nurses must care, they must have certain virtues to carry out their job and they must do this because it is virtuous – they must "choose it for its own sake."

Virtue ethics is also evident by Becky's value placed on intention. For Becky, it is not enough to recognise what is required of nursing, one's intention, "to act from a certain state", must also be honourable. Otherwise, you should not be in nursing. And, this is reflected in the value of empathy. Hence, although the quality of the act; to treat the patient as a whole person instead of just a diseased body is a valuable thing in itself, it is the intention behind the act that is important. The intention must come from virtue of your empathy for another human being who is suffering. Hence, a nurse can treat the patient as a whole person but it must be done authentically. This is why Becky says it can't be taught. "Compassion, like other major emotions, is concerned with value; it involves the recognition that the situation matters for the flourishing of the person in question" (Nussbaum, 2001: 307). If one cannot recognise what would be good and right in the treatment of another, then one can neither empathise nor feel compassion for another. Indeed in this respect, they may not have the natural empathy required to be a nurse. Lack of empathy led to moral infringements which were inhumane and immoral.

Denise

Denise's father's case was different from other accounts within this thesis in a number of ways. His dying trajectory was very short and he had been an active senior right up until prognosis. He was also only one of two patients who died in the hospital setting. His

trajectory was a mere thirteen days between diagnoses to death. Denise had extensive involvement with her father's care decisions and medical decision making during this time. Where she saw failures in the moral obligations of the institution toward her father, she confronted staff or took control of the situation herself. She did this because she already believed elderly patients are particularly at risk in institutions. Patient vulnerability and powerlessness is highlighted within the narrative along with anger at the lack of consideration for patient dignity. Denise was very sure that problems with the health system were prolific which is why she believed that patients need advocates. Her view is that without a family member to advocate for patients, suffering and bad deaths will result. There is no question about her moral outrage, much of which was directed at what she considered to be incompetent nurses.

Denise had very clear opinions about end of life care and expressed her concern about elder abuses going on in Britain and Australia. From the moment of the first interview it was obvious she believed, perhaps more than any other participant, that the health system was not only flawed but that the elderly in particular were at risk. They were not at risk due to the practical constraints of the clinic and overworked staff; they were at risk due to pure laziness, deliberate neglect and even criminality. What is important is that she held these views prior to her father's death and this served to motivate her to act on his behalf. Her view that we should "take on the system" was suggestive of why she wanted to take part in this research. Further, she said in the first interview that she wanted to start an advocacy programme so that vulnerable patients are no longer subjected to the neglect in care that she believes is wide spread.

Denise emigrated from England to Australia sixteen years ago and has had many jobs in her professional career. One of those relevant to her background understanding of end of life care was her time as an auxiliary nurse and as a community care worker in England. She told me that this was "proper care". She said that patients were assisted with bathing, showering, toileting and feeding and that the basics of hygiene and nutrition were monitored. This information was not revealed to me straight away, but throughout the narrative she reflected on her past experience to compare it to the standard of care today.

She made it clear that her view was not just based just on her father's experience, but other experiences that she had heard and read about from clinical settings everywhere.

Denise's father was suffering from what they thought was bronchitis while Denise was on holiday. While away, she received contact from her brother who lived in the same city as her father that he had been admitted to hospital. At that time, they had thought he had a heart attack. Denise spoke to her father on the phone and during this conversation, the doctor said that he wished to speak with her. He told her that his condition was serious – he had lung cancer. Denise did not want the doctor to tell her father this news while he was on his own, so she made sure that her brother was there when they told him. He was told he had six to eight weeks to live. They said that all they could do was to offer chemotherapy. However, they told him "it could kill you as well as help you" (Int. 1, 2016: 3). Denise said that her father took the news pretty well and had initially said that there was no need for her to rush back from her holiday. The hospital wanted to detain him until they had done a biopsy which took several days. Denise said that during this time, he had to fast and her father was getting frustrated that it was taking so long. When they did discharge him, he was sent home with a nebuliser for breathing and his medications.

While Denise was away, she called him at home each day to make sure he was okay. At first, he was glad to be home because he had been fasting in the hospital before the biopsy and was happy to be able to eat again. However, a couple of days later, things changed. Her brother went to visit him on a Saturday morning and realised that his condition was poor. Since Denise had been talking to him every day, she believed that something must have happened to him Friday night. She also said that perhaps he hadn't been taking his medications. So, her brother called Denise to ask what to do and she suggested getting hold of a wheelchair so that he could get him into the car and back to the hospital. The following morning, Denise called to see how he was and she said:

> He sounded REALLY, REALLY bad. And, I rang my brother and I said; "is he eating is he drinking, is he doing this is he doing that?" "No. None of that's happening, none of that's happening."…My brother wanted him to make a Will. This is where me and my brother fell out…I'd worked out that he wasn't drinking, he wasn't eating and there was no-one there to advocate for him…Coz my brother was kind of like Mr Accountant…sort of like, "Oh, I've done my bit, you know…and I want him to write a

Will" and I'm saying; "He doesn't need to write a Will, I'm not going to force him. Leave him be." So, I then got myself a flight back from the Whitsundays… (Int. 1, 2016: 5).

Denise told me that she was closer to her father than her brother was. She also said that after what transpired at the time of her father's death, her relationship with her brother has never been the same.

Ochs argues that often the teller can pitch themselves as the protagonist who took the moral high ground over others in the incident (Ochs, 2004a: 284). In Denise's case, it is herself against her brother. As has often been the case throughout this research, family dynamics plays its part in end of life care choices and moral reasoning. Old conflicts or differences in opinion can arise during the process of caring for the patient which has an impact on the course of events and the relationships themselves (Broom & Kirby, 2013 ; King & Quill, 2006 ; Kramer, Boelk & Auer, 2006). In Denise's case, however, family dynamics has to do with moral virtue. She said it took her a couple of years to forgive her brother due to the fact that from her father's hospitalisation to his funeral, he seemed more interested in counting the money from her father's estate than mourning his loss.

Denise told me when she returned from holiday, she stayed at her brother's house which was closer to the hospital. She arrived late on a Monday night and the first thing on Tuesday morning, she went to see him. She said she wanted to "nurse him" and make sure he was eating and comfortable. It wasn't until the end of the first interview that she told me why she thought he had stopped eating and drinking. I was interested in this as there is evidence that patients can refuse to eat or drink to have control over their deaths (Curtis et al., 2002; Ivanovic, Buche & Fringer, 2014). According to Denise, this was not the case. She explained that she had asked her brother what had happened with the food at the hospital and he had told her they brought the food, left it for a while and took it away again. Denise was outraged because she knew that many patients need help to eat. She told me that was when she said; "Right! I've gotta get there…You know, dad…they're not even feeding him now, you know, it's ridiculous. I said; 'He's gonna die of thirst and starvation let alone the cancer!'"(*laughs*) (Int. 1, 2016: 20).

When Denise went in on the Tuesday morning, she did all she could to help her dad with eating and drinking. She said she brought his favourite thick-shake and she said he "couldn't get it quick enough" but that unfortunately, he was having trouble keeping it down. It was on this day that she shared with me an event which she said was indicative of what is happening in hospitals. After explaining that her father suffered from Crone's disease, she said:

> And, there's an aside to that as well. When I first got to the hospital, he was wearing one of those adult nappies. And, I said to the nurse; "Oh, how long has he been double incontinent for?" And she said; "Oh, since we re-admitted him." And, on that Tuesday when I was with him all day, dad said; "Oh, can I have the bottle, I need to wee." So, he undid the nappy and weed fine. Later on in the day he said; "Oh, I need a bed pan, I need a bed pan." So, I went charging around the ward looking for a nurse…anyway, because of the Crone's disease, we hadn't got the bed pan in time. And, when the nurse finally came in to see him she goes; "Oh, you know, you're wearing such and such, you can just do it in your diaper thing." And I said; "How would you like to shit in your knickers?" (Int. 1, 2016: 7)

Denise told me that this was happening in hospitals all the time now. She said to me that they put the nappy on the patient whether or not they are incontinent "expecting them to mess themselves and then they'll pick that up in about four hours' time…" (Int. 1, 2016: 7). Bruner argues narrative does not just involve a story about the past, but shifts to the present tense brings the protagonist into a present 'evaluation' of the incident which can provide meaningful context as well as answer why the story is worth telling (Bruner, 2001: 29). Here, Denise's shift to present tense reveals just that. She expressed that this event was linked to her current concerns, which were to advocate for patients and to fight against and expose elder abuses. It also contextualised the meaning of the event in terms of her moral reasoning. Patients are suffering and their dignity is not respected because the nurses would rather put a diaper on a patient than help them go to the bathroom or provide a bed-pan.

When Denise was told by her brother that they had brought a tray of food, just to take it away again, she knew he was not getting the care he required:

> And, that made me realise that that's where the breach was because as soon as he said that, it added up to what I already knew was happening in England…I hadn't expected it in Australia quite so suddenly but there it was, bare-faced. And, all my previous experience just showed me what the absence of proper nursing was…It

used to be SRN's…and then there was auxiliary. So we had all their tiered nursing system…So, it was all about sort of patient care and everything was geared toward patient care in its totality when I was nursing…Not only did the auxiliaries wash but also the SEN's washed if we were really struggling…we all washed patients (Int. 2, 2016: 9).

Denise was intrigued to the reason why the system had changed so much and why the nurses didn't seem to care about the basics of care or the dignity of their patients. She wondered what was going on in nursing education now to; "know what has been put in their head and why they had this kind of approach." Denise also brought up the issue of dignity by sharing a recent discussion she had with some people who worked in social services. She said that some of them claimed that the problem with lack of care in nursing was that nurses do not get paid enough. Denise's response was; "Dignity costs nothing. You know, if you can't provide dignity you shouldn't be in care" (Int. 1, 2016: 12).

There are studies which show that families are much less likely to be satisfied with the level of care received from doctors and nurses in hospitals than in the hospice setting (Addington-Hall & O'Callaghan, 2009 ; Seale, 1991). Further that the dissatisfaction with hospital care was due to; "…patients being 'devalued' or 'dehumanised' often due to a lack of adequate personal care and dignity…"(Addington-Hall & O'Callaghan, 2009: 195). Denise's grievances reflect these studies. She presented two moral arguments regarding the quality of care of patients in hospitals. The first was that nursing education and the structures within the clinical institutions were resulting in patient neglect compared to the previous system. Second, that the nurses are careless, lazy and lack compassion. Denise had also told me that during her stay in hospital with her father, the nurses were "noticeably absent". She said; "They didn't come to see him on a regular basis at all" (Int. 2, 2016: 3).

Denise spent most of her time on Tuesday by her father's bedside making sure he was getting looked after. She didn't like to think what it would have been like for him if she wasn't there. She told me that the disregard for his dignity and other failures in care in the hospital directly contributed to her father's change in attitude. At first, when the doctor told him he could have chemotherapy, Denise said he was all for it. She said that he was in "fight mode" and she was happy to support his desire to fight the cancer. The doctor hadn't given them any guarantees but they wanted to try it anyway. So, at first, there was a general

optimism from her father even though the doctor was not optimistic about the efficacy of treatment and even warned of its potential harm. Denise said that on that Tuesday, he still wanted to undertake chemotherapy which was scheduled for the next day.   When she arrived on Wednesday morning to get him ready for the treatment, he no longer wanted to go. She said that it would have been directly related to the lack of dignity with which he was treated. When she asked if he was sure and whether he understood what that now meant, he said he knew. She said because she knew her father, being "messed about" as well as the indignities would have really "pissed him off big time." She said;

> To be honest, I think that probably the health system accelerated that decision. You know the fact that he was in a nappy, the fact that they wouldn't bring him bed pans, the fact he couldn't hold food down and they weren't helping him with that, the fact that if I wasn't there to mop him up when he was sick, he wouldn't have got anything at all. The fact that I, his daughter, had to put his willie in the bottle for him to wee, DIDN'T REALLY HELP THINGS AT ALL! (Int. 1, 2016: 17).

According to Denise, his treatment in the hospital had eroded his desire to fight the cancer. She said she didn't know what happened to him on that Tuesday night, but she believed something had changed his attitude dramatically. She also surmised that it had to do with how difficult it was just to get the chemotherapy. She said; "He didn't want to put clothes on and get in an ambulance and then drive the best part of an hour…to get him to another place, to get this chemo…You know, when you're pretty much on death's door, it's a big…big…big…big…job"(Int. 1, 2016: 7).

Denise believed he had resigned himself to the fact that he was going to die. She felt the need to stay by her father's bedside from that time on because she did not feel comfortable leaving him. She said that when she arrived on the Wednesday morning, his call button was out of his reach. She said that that would never have happened when she was nursing – it was a big "no, no!" She added; "…like, if he woke up in the middle of the night, he would be waiting in pain and no button because they put it out beyond his reach as you do for a quiet life on night shift!"(*laughs*) (Int.1, 2016: 17).

As with all the cases within this chapter, the actual death itself is not necessarily described by the participant as bad. In fact, in all cases, it is the dying trajectory leading up to death where all the suffering and transgressions occur. Denise said her father had a good death

because "I made sure of it" and said; "…he went quickly with relatively little discomfort." According to Denise, it is these failures in the basics of care which lead people to contemplate alternative paths to death:

> He slept all the way through and that was my intention. To make sure that he had the most painless death possible…I mean, hospitals can't provide dignity, they can't provide you pain relief, there's no guarantees at that point and that is the time that you haven't got the strength to advocate for yourself. So that's why I think people are starting to look at euthanasia as being an okay thing, because they are losing their dignity and they are in pain and it's not being managed. Unless you can do those things, I think euthanasia will actually…get more momentum coz nobody wants to see their family die. You know, to die is one thing but in pain and suffering all the way to the door… (Int. 2, 2016: 19).

The failures that Denise pointed out which happened to her father were further reinforced by introducing impartiality to her moral argument. She explained that the quality of nursing did not just fail in her father's case, but that these kind of incidents are happening throughout the world. She told me of a newspaper headline in England which read "Too Posh to Wash." She said this was a story which explained why nurses now refuse to do the basics of patient care. She said that nurses do not want to carry out the basics of hygiene for their patients anymore because they believe they are above it. Her theory is that there is a problem in the way they are educated. They have degrees now and they don't want to have to wash somebody.

Throughout the narrative, Denise refers to her past as an auxiliary nurse to show that the duties she used to do are neglected in the current hospital system. Indeed, beyond their education or a lack of staff, the reason for the neglect comes down to laziness and even criminality on their part. She justifies and contextualises this view by sharing some horror stories that she had read and heard about. She told me that the treatment of the elderly is "criminal" in nature. She said due to what she had read in the press in England, she knows that abuses are happening in residential care centres and hospitals alike. She said part of her objective and passion to advocate for the elderly led her to call a group based in ******. She said that the coordinator at this group was very "aggressive" and disgruntled by the lack of support in Australia to help prevent elder abuse. She said that the woman told her some terrible stories about what had happened to people in nursing homes, how they were mocked when they were naked and had things thrown at them. She said; "she's got the full

monty about horrible stories about the elderly which is why I stayed with my dad. As soon as I realised that the nursing care wasn't as it was when I was a nurse" (Int. 1, 2016: 12). Hence, it is clear that Denise views the problem to be beyond education or staff shortage, but the nurses themselves.

Clearly Denise's current passion and concern for elderly patients is part of her life-world. This is supported by her research into elder abuse and end of life care in general. She said to her husband that when it comes to the end, she will be by his side in the hospital and she hopes that he will do that for her. This is to ensure that they each receive the right treatment and care and that there is someone to advocate for them. She said; "I would even do it for my brother!"

When it was clear that her father wanted to give up the fight on the Wednesday morning, Denise did all she could to keep him comfortable. Her description of events in the last two days before his death also indicated, as was evident throughout the narrative, a lack of coordination of care. In response to this, Denise took charge of the situation:

> I went and saw…the doctor on duty…And, I said; 'Okay, what's your palliative care plan?' 'We don't have one, we don't normally get this'. And I said; 'Well, you better get one, coz my dad's going to be passing away shortly…coz I don't want him to be in PAIN, I don't want him to know he is SUFFERING…I know he probably will suffer…but I don't want him to…I don't want anything that's going to make his…agony any longer…you know, nothing to sustain life, just to like, let him go'. And, they kind of like, went sort of like scratching their heads and…you know…conference…huddle, huddle, huddle and all this kind of stuff (Int. 1, 2016: 8).

Forty-five minutes later they had organised a plan for his pain management. As soon as he had the first dose, Denise said that was it; that he was fast asleep and didn't wake up again. So he was not conscious from the time that he received the pain killers on Wednesday to the time of his death on Thursday afternoon at four o'clock. She said it was only on Thursday that he showed signs of struggling and then he was given another dose of medication. She said not long after that, he passed away.

Discussion

Becky and Denise experienced similar issues in their experience of hospital care. At first glance we may consider that their moral reasoning and position in relation to their parents' deaths is identical. The 'system' failed in the basics of care, the nursing staff remained scarce and as a result of the various failings, an increase in suffering and indignities were endured by the patient. However, the differences in both life-world and family dynamics resulted in different outcomes. Becky didn't feel that she could get any changes to happen even when she attempted to find out more and ask questions. Denise, however, demanded change. The differences in the life-world of the participant affected perception and agency with regard to their expectations of care. Denise knew and was suspicious of end of life care before her father was diagnosed with a terminal illness. In a sense, she was prepared to see transgressions. Becky on the other hand was not prepared – she was "shocked". What they did share was anger at the moral failings of the hospital and both described this failure in terms of the nurse's character and attributes.

Foucault argues that between relationships of power, there is always 'freedom' and the possibility of resistance, otherwise, there would be no power relationship (Foucault, 1997: 292). However, as I have argued previously, if the institution fails in their part of the relationship, then more vulnerability and powerlessness ensure. If the institution where this form of governance took place changes the parameters of this relationship, it excludes any possibility of 'freedoms'. Patient autonomy and choice become simply ideals which cannot be fulfilled. Denise essentially argues that due to this imbalance of power, advocates are needed. It is through neglect, failures in the basics of care and being "mucked around" that the patient loses the will to fight for their life. Even though I have shown how autonomy as an ideal is prolific in both medicine and nursing, the cases in this chapter show that this is far from the case. The level of powerlessness which results ensures that autonomy remains out of their reach. Due to a flaw in this unspoken power relationship between clinic and patient, dependency leads to neglect. Thus, the institute fails in their moral obligation. An obligation implies that a special relationship exists between parties which is either based on obligation or is a result of it (Cohen, 2004: 46). This special relationship between patient and staff failed and resulted in an extreme state of in-balance where the hospital's lack of care

had to be taken up by Denise. In her view, the clinic not only failed in their moral obligation to carry out their professional responsibilities but in actually caring and having empathy for their patients. This lacking was contextualised by emphasising what "proper care" is, through her description of the "horror stories" and tales of criminal neglect. This strengthened her moral positions by offering further evidence that it is not confined to her personal experience, but pervasive around the world.

Even though Denise's concern and criticism with the nursing staff was centred on character, it does not necessarily reflect an Aristotelian virtue ethics. Denise's moral reasoning and her justifications reflect a much broader, much older form of virtue ethics – the Golden Rule. The Golden Rule goes as far back as the written word and variations of it have served as guidance for moral conduct throughout countless religions and philosophies (Duxbury, 2009 ; Guseinov, 2014). The rule states; 'Do unto others as you would have them do unto you' (Gould, 1983: 76).   When we make a moral judgement, we must justify it with reasons. These reasons rest on a basic principle (Cohen, 2004: 35). The Golden Rule has a unique characteristic in that it is both a principle on which moral reasoning is justified; we could say its logic, and also prescribes a rule for moral conduct. For Aristotle, morality comes from virtue and moderation and so is concerned with character which is the way to a good life. The universal 'good' of happiness is achieved this way. However, the Golden Rule, at first glance, does not seem to be appealing to universals. It does assume, however, virtue within subjects. It not only assumes that virtue must be within to be moral, but the rule itself shows a virtuous individual how to find a moral solution to a problem (Guseinov, 2014: 92). Aristotle doesn't provide one rule for all moral problems, just guidance on how to hit the 'mean' as this will lead to a moral and virtuous existence. The difference with the Golden Rule is that it asks the virtuous person who seeks moral solutions to carry out an imaginative task. It asks them to imagine themselves in another person's place (Fiala, 2009). Thus, it requires us to empathise with others. It also expects that people can be interchangeable as subjects and that they are individually responsible for their conduct (Guseinov, 2014: 91). So, one can see how the Golden Rule requires the innate characteristic of virtue and empathy first which suggests that the consequence of all people being treated with respect would be the natural consequence of having these attributes.

Virtue ethics is about one's character, how we perceive something, how we reason about it and how we behave (Cohen, 2004: 53). To explore Denise's moral position then is to say that hers is based on virtue as a principle, with the Golden Rule to justify the ethical principle. It is clear that character is central to morality for her. When she comments on the nursing, it is their character that she criticises. Indeed, it is character that is the fault of the criminal element who abuse the elderly in retirement homes and it is due to laziness that nursing staff fail in their obligations. When she was nursing, the nurse was "geared toward the patient." Now, nurses are geared toward what is easy for themselves "for a quiet life on night shift." Thus, the failures in their tasks come from their neglect to care about what is best for the patient. According to Denise, their 'attitude' has changed; their character has changed. They have degrees now, they are above doing the dirty work, the basics of patient bodily care. They are now "too posh to wash".

Another character problem she perceives is laziness. Instead of taking the patient to the bathroom because they are too lazy, they put adult nappies on them whether or not they need it. This results in increased suffering and indignities for the patient. As Denise said; "If you can't provide dignity, you shouldn't be in care." Indeed, she tells the nurse; "How would you like to shit in your knickers?" Denise is saying, put yourself in my dad's shoes. But, she is also calling the nurse out on her lack of character, indeed, her lack of virtue. The Golden rule requires that you are able, by virtue of character, to put yourself in another's place. If you carry this out, your behaviour will be moral. If everyone followed this rule, it makes for a society where individuals consider others. Nurses have a professional obligation to have this trait, to 'care' for those who are vulnerable, sick and in the cases throughout this thesis, dying. If we can imagine, as a nurse, what would increase our suffering and indignities if we were the patient, then we should do everything in our power to ensure that those circumstances do not occur. For Denise, if you do not have this virtue – if you cannot treat others as you would like to be treated, then you should not be nursing.

In all these cases, the systems of differentiation which underlie the power relationship between biomedicine and patients cannot fully answer the failures in moral obligations. Beyond patient dependency and reliance on expert care, the relationships of power in this dynamic are completely out of balance. Patient autonomy, a well touted value in end of life

care in these cases seems like an impossible dream. As a result, increases in vulnerability, physical and existential suffering is the result. The imbalance in power is taken to the extreme where indignities are suffered and it seems to the participants, a lack of empathy is shown.

In every case outlined here, the patient withdrew under duress, for Kevin and Becky, due to long term physical and existential suffering. For Denise, due to incompetence, laziness and a lack of empathy from staff. According to all the participants in this chapter, biomedicine failed in the cultural expectations of their role and for Becky and Denise, nursing staff lacked virtue of character which resulted in patient suffering and neglect. In all these cases, the power differentials were compounded further by failures in attending to and considering patient suffering which was witnessed by the family and, at least with regards to both Becky and Denise, resulted in moral outrage.

Chapter X – Nursing the family: Self, Identity and Moral Worlds

This chapter will explore the dynamics of moral reasoning from the perspectives of two nurses who cared for their loved one during their terminal illness. I will examine how their role as a nurse affected their experience in caring for their loved one and their ethical engagement with choices. To do this, I will use Taylor's concept of the self to help illustrate the connection between self, identity, and embodied moral worlds. The intention is to determine the impact which both the institutional moral world of medicine and the cultural construction of the nurse has on their identity, sense of self and moral reasoning.

The institution of biomedicine and its approaches to cure have been explored at length. And, in the previous chapter, I explained how background knowledge affects values and life-worlds of participants in such a way that it shapes their expectations and perceptions of clinical care and thus their moral stance. In this chapter, the focus will shift to explore more closely the experiences of nurses when they care for a terminal relative. To do this, I will explore the juxtaposition between their specialised biomedical knowledge, their professional role and their personal role as a family member to determine how this dual role is negotiated. This analysis of the interplay between embodied and institutional moral worlds and dual identities will explain how nurses as family members approached the care of their relative to determine what factors affect role identification and its manifestation into an ethics of care.

The centrality of the role of care and caring form the foundations of the cultural and social perceptions of nursing (Good, 1994 ; Scott, Matthews & Kirwan, 2013). Lupton argues the role of the nurse is linked with values which are innately feminine such as altruism, caring, gentleness, nurturance and empathy (Lupton, 2003: 133).   And, what we can see in a majority of these attributes is that the cultural construction of the nurse is predominantly concerned with, depends on and values the *character* of the nurse.   Many nurses see an important part of the their professional role to be the patient's advocate (Cole, Wellard & Mummery, 2014).   Indeed, none of these qualities could be expressed unless patient advocacy was made a priority. Advocacy is also a core value which features prominently for

the two nurses in the case studies in this chapter. With consideration of both character and advocacy in mind, one objective here is to determine both the internalisation of these traits as a part of their role and whether or not nursing a family member leads to simply exercising these traits. A further objective is to ascertain whether or not the nature of their relationship with the patient alters their approaches to care.

In the previous chapter, I explained the reaction of the participants when the character of the nurses they encountered was lacking which spoke to the salience of this cultural construction and public perception of their role. Even though there may be practical reasons for failing to fulfil this role, it served to demonstrate how important these attributes are by the moral outrage felt when breached. What this clearly suggests is that nurses are expected to not only care for the physical body of the patient but care and give due consideration to personhood. To care for the person, one has to have the character to do so, the inner virtue – the empathy.

Much of the literature on the topic of good deaths provides valuable perspectives from nursing staff who express perceptions of their roles. The trend in education and expectations of nursing staff is shifting toward holistic aspects of care which actually mirrors many of the ideologies and institutional values which formed the foundations of the palliative care movement viewing psychological, social and spiritual care to be equal in importance as symptom management (Black & Csikai, 2015 ; Borbasi et al., 2005 ; McNamara, 2004 ; McNamara, Waddell & Colvin, 1994 ; McNamara, Waddell & Colvin, 1995). The gap then between the contemporary cultural expectation of the nurse and what occurs in actual practice affects the already understood, be it implicit, power relationship. If nurse's roles are reduced to symptom management without the empathetic care for patients, this further disempowers the patient regardless of whether ideals of patient advocacy are held (Cole, Wellard & Mummery, 2014: 577). Hence, even though there may be real, practical difficulties for nurses attempting to fulfil the cultural expectations of their role, it is also clear that the emotional component of their role, compassion and empathy, are at least of equal importance as their medical expertise. With this in mind, it is important to illustrate that their institutional role within the health system differs greatly from that of a physician.

Good argues that training to become a physician is a retraining of perception. He explains:

> Within the life-world of medicine, the body is newly constituted as a medical body, quite distinct from the bodies with which we interact in everyday life, and the intimacy with that body reflects a distinctive perspective, an organised set of perceptions and emotional responses that emerge with the emergence of the body as the site of medical knowledge (Good, 1994: 72).

Anatomy training then is not just about learning a science, but about learning to perceive the body in a different way than before. To re-train their ordinary gaze into a physician's 'gaze'. Good also implies that the process of the reconstruction of perceptions involves cultural work – the cultural reconstruction of the body from a person to an object (Good, 1994: 73). Hence, although nurses receive medical training, their role is grounded in the 'caring' attributes which require a focus on the body as a person. If nurses were culturally conditioned through their education to objectify the patient; to reduce bodies of patients to simply the 'site of medical knowledge', nurses would fail to carry out their role. Teaching a nurse detachment and objectivity is not suitable as it flies in the face of their professional and moral obligations to patients (Viens, 1995: 278).

It is clear that the role and obligations of nurses is two-fold. Along with symptom management and medical expertise, the personal care expected includes empathy and compassion. I have discussed how compassion is the result of being able to sympathise fully with another. Further, as we have seen from the previous chapter, the ability for compassion centres on one's "personal characteristics" (Scott, 1997: 47). Nussbaum agrees when she argues that empathy and compassion are qualities which rely on innate attributes of the subject (Nussbaum, 2001). Therefore, we can conclude that cultural expectation of nurses places equal credence on medical knowledge and character disposition. This suggests that nurses do not just have to be personally willing and able to exhibit compassion and empathy, they have to have the *capacity* to do this. As my participant and nurse in training Becky said; "You can't teach empathy" and auxiliary nurse, Denise, argued; "If you can't provide dignity, you should not be in care." It is clear then that the extraordinary expectations of nurses and the two-fold nature of their role includes a vast array of qualities

from professional expertise to the personal capacity to demonstrate emotional support and empathy.

From this we could assume that nurses who internalise this cultural construction of their role that their moral reasoning would reflect this and their choices would largely be influenced by the institution of the nursing fraternity. The question to ask is under what conditions does the nurse identify and adopt the perspective, attributes and value of their professional role in caring for their family and what part does their sense of self and identity play in both the shaping and exercising of their embodied moral positions?

Taylor's theory of self and identity may be useful in the following way. Like Husserl, the self exists always in relation to another; that human action takes place with consideration to how the agent constitutes themselves as an integral part of some 'we' (Taylor, 1992: 176). Thus, the self is inter-subjective. Further, that our identity is constituted in four ways: 1) our notions of the good, 2) our understanding of self, 3) the kinds of narratives in which we make sense of our lives, 4) conceptions of society i.e., what it means to be an agent among other agents (Taylor, 1989: 105). We must ask what contextual factors affect this duality and therefore, what part does identity play in the shaping of embodied morality?

Taylor and Husserl's theory of perception complement each other and thus are useful tools for understanding the dual role of the nurse and the interplay of embodied and institutional moral worlds. Husserl gives an example of perception. He sees a table, but at the same time is reminded of another table which was once in its place. Even though one can think of both tables at once, they remain separate vis., there is unity in the sense that they appear within one intuitive presence (Husserl, 1981: 295). Therefore, memory is:

> …a unity of temporal duration. It is a unity, not only in relation to the extraction and thematic contemplation of a perceived individual thing or event, but in relation to the unitary phenomenon of the 'impression' which founds this activity, a phenomenon in which a unity of objectivity…is sensuously pre-given to us, is already passively there for us (Husserl, 1981: 296).

Thus, background experience provides memories which colour and constitute a current event or experience. They are both symbolic and emotive and thus affect perceptions.

These experiences then play a part in forming the self and allow us to make qualitative distinctions which give us the ability to be able to choose one thing over another (Taylor, 1989: 25). Hence, our identification with the self in relation to the good is shaped by past experiences. As Husserl argues; "…every perception as a consciousness intending an actual objectivity, has its horizon of before and after"(Husserl, 1981: 297).

Considering the dual role of the nurse along with their dual role as nurse and family member, the following two case studies will explore the degree to which the internalisation of this role impacts moral reasoning. The cases also share several similarities. Both were women who were full time nurses by occupation. Both cared for a loved one who had a terminal illness and each patient had a dying trajectory of four months. Also in both cases, the patient had a brain related terminal illness. One was described as brain cancer the other, a tumour. As you would expect from their occupations, each had prior exposure to death and dying. The differences were that the younger of the two women had less time as a nurse, approximately ten years or so. The older participant who told me she was sixty-five had been nursing for forty-eight of those years and had never had another occupation. Indeed, she is the most experienced nurse I interviewed. She was also the most experienced when it came to end of life care as she had nursed her mother and sister in their palliative care stage in their homes only months before her husband was diagnosed with a tumour.

Jenny

Jenny is sixty-five and has been nursing for forty-eight years. Out of all my participants, she had had the most exposure to death and end of life care not just due to her occupation, but due to the fact that she had already nursed two family members who died before her husband, Gary, was diagnosed with a brain tumour. In a matter of twelve months she had lost her mother, sister and husband. Therefore, it would be difficult to find another participant who had more experience as a nurse or more experience caring for dying relatives. Her involvement with her husband's care was extensive and unrelenting and many of her choices seemed to reflect an intense internalisation of her nursing role. Jenny was also one of the more emotional participants I interviewed and her intention was linked to issues in her current life-world. Five years on, she still found her loss difficult and she had

since been inspired to write a book about it. What baffles her most is that even with all her years nursing and nursing both her mother and sister, the experience in caring for her husband was the most difficult and much harder to reconcile.

Jenny and Gary had been married for twenty-eight years when he was given a terminal prognosis. They both had two children from previous marriages and had a child of their own. The children were part of the narrative, but not involved in medical or other care decisions. It was Jenny who took control of the course of events during Gary's illness where she had an unshifting determination to advocate her husband. It was clear that her life as a nurse had a great impact on her sense of self and identity, because the first thing she explained was her career and the various roles she has had from operating theatres to working with indigenous patients. In all her clinical care encounters when caring for Gary, she utilised her nursing expertise to the full, advocated for him and actively engaged in every step of the process throughout his dying trajectory. Like some of my other participants, she had her share of frustrations with the health system which Jenny dealt with by confronting each issue as it arose.

Jenny described Gary as being reasonably fit at the time of prognosis for the age of seventy-two apart from being on small doses of medications for his heart. However, Jenny had noticed that her husband had been having strange medical episodes. During these episodes which she called "A typical TIA's" (Transient Ischaemic Attacks), he would go grey around the mouth and had a bit of tightening of the chest but no pain:

> So, when these things were happening, I initially thought it was just the heart. Um, unrelieved by 'Angenine' but then he didn't have any pain so you know? And, but he, during the worst of them, he couldn't talk. And, that was what alerted me to the fact that it was neurological not cardiac. And, he went into hospital here, at ****. And, no-one would listen to me (Int. 1, 2016: 2).

Gary had been admitted with a supposed heart problem but Jenny knew it was more than that. When she returned to see him the following evening, she expected to have an answer but he had been told by the renal physician that he was being discharged after a small change in his medications. Jenny was not happy with this and confronted the staff. She told them to put it on the record that she was a registered nurse and that she understood that

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his condition was not cardiac, but something else. At that time, she wasn't sure. He was still sent home but they returned the following evening when Gary had another episode.

In a recent study of nurses who took care of terminal family members, the data showed that the participant's 'nurse self' not only required accurate information for them to have confidence in staff, but they would also actively seek out colleagues who could help them interpret what was happening (Salmond, 2011: 16). This was the case with Jenny. The following day, Jenny spoke to another doctor where she was working to ask if she could see Gary. She described the symptoms to her and had told her how many attacks he had had that morning alone. The doctor insisted on seeing him straight away. Jenny attempted to contact her husband at home to arrange this meeting. She tried him twice on the phone but no-one answered. Eventually when he answered, he was saying things that didn't make sense. Jenny knew she had to go home straight away and she organised a nursing colleague to go with her. When they arrived, they found that he had had another seizure and so they took him straight to the emergency room. It was from that time on that he began calling Jenny, Maggie, which was his first wife's name.

Jenny waited for five hours in emergency before anyone came to see him. She was really annoyed by the lack of care shown. She said he was in a state called *post-ictal*, which means a sleeping state that patients fall into after having a seizure. Once he was finally seen, they kept him in overnight. When Jenny returned the following morning, she confronted the original doctor who had discharged him with a presumed cardiac episode. Jenny said she stood at the end of the bed and when the doctor came in she said to her; "I told you so!" The doctor responded; "Oh, well, we've got to try and get him an MRI." And, Jenny said; "Yes, absolutely. I want an MRI and I want it done today." The doctor had said that she didn't think it was possible to have it done that day, but Jenny insisted that they do. She complied.

When the results came back, the doctor indicated that in looking at the MRI, it could be a number of things from a clot to a tumour. Jenny said the doctor was vague. When she talked about the condition Gary had and how vague the information was at the start, she described her advocacy this way:

> …at the time they take a seizure, from it…from the tumour, it's probably too late to be telling him that he's got a tumour….And, so it was me then. It was up to me to know what was going on and I wasn't happy with the fact that they weren't forthcoming with the information (Int. 1, 2016: 18).

Jenny wanted to fly to another city to see a neurosurgeon straight away which is what they did. She was very happy with the neurosurgeon there even though he was to deliver the worst of news. She said the tumour went from 'astrocytoma' to 'glioblastoma' – which is the worst kind of tumour you can have. She said; "…he was already at grade 16, he was gone!"   Jenny appreciated the information and honesty which the Radiation Oncologist provided for them at that hospital. She told me that she remembered exactly where she was sitting and exactly word for word what was said when the terminal prognosis was given:

> He looked at me, he looked at Gary and then he said; "I'm Malcolm Cartright; Radiation Oncologist. Glioblastoma Multi-Forming. Your age is against you – three to six months (Int. 1, 2016: 4)

Jenny said this was exactly how he said it, straight to the point. She said; "…he became my best friend because he was the only person in the whole process who actually told the truth…who, well, who would actually tell it to you straight" (Int. 1, 2016: 5). Although the fits and the tumour itself were affecting Gary's cognitive abilities, Gary had expressed to Jenny that he wanted everything done that could be done as treatment. So, when they expressed this to the oncologist, he had said "Irrespective of anything we do for you, you've still only got three to six months" (Int. 1, 2016: 5). What is interesting is that this was close to Gary's birthday and Jenny arranged for people to send birthday greetings to him, a care decision made as a wife, an example of her embodied moral reasoning.

Whether or not the doctor believes treatment will help, it is clear that patients and families can take it up anyway. This doctor did not make any promises to Jenny and Gary, nor did he provide false hope. Yet, Gary received targeted radiation and oral chemotherapy five times a week. As I have shown throughout these case studies, not all sources of hope grow or dissipate in relation to medical advice or information. Instead, it is sometimes just an existential position that the patient or family member adopts for their own coping reasons. Gary wanted the treatment and Jenny advocated for it, supporting his right to autonomous decisions. Thus, Jenny's approach to caring for her husband was holistic in that allowed him

to make choices that he felt comfortable with as it maintained hope. Jenny told me that they never talked directly about death and so the topic of him dying was never discussed. She fully supported him in making sure he got what he wanted, medically and emotionally. She said; "…And, the fact that he was holding on with every slither of hope that he could that they were wrong. And, while I suppose I hoped they were wrong, I knew they were right" (Int. 1, 2016: 5).

When they returned home from interstate, they had quite a wait throughout Christmas and the New Year before he could start intensive treatment. She said that they made the most of this time to be together. They swam in the pool and relaxed and enjoyed each other's company. He didn't receive his first treatment of radiation until five weeks later. After just two sessions in the first week the treatment was delayed as the city was going to be hit by a category five cyclone. This was when Jenny made a decision which seemed to be purely from empathy and compassion. Not as a nurse, but a personal decision as his wife.

The cyclone was predicted to hit an island which their daughter, a chef, was working on. This created a lot of stress for them due to the fact that she was stranded out there. Gary was overwhelmed with grief at this news and Jenny told me that it was a difficult moment for her:

> And, he was saying to me…this broke me…this absolutely broke me up. "You'll have to save her ashes and scatter them with mine" is what he said to me that day. And then, he was crying because his own son had died at 31 years old in 2000 and he said; "No man should lose (*whisper*) two children in his lifetime." And, ah, he was crying. (*Whisper*)…It was really, really, really hard to take. Just coz I couldn't let him see how upset I was (Int. 1, 2016: 7).

Luckily, their daughter had survived the cyclone unharmed and was back on the main land. When they found this out, Jenny said that it was imperative that they fly up and see her. Unfortunately, they couldn't get a direct flight which made the journey worse. In Gary's condition, this was very risky for his health. However, she said Gary had to see his daughter and so did she. When I asked whether she considered these dangers at the time, she said that this did not even enter her mind. She said she did not discuss it with a doctor, that the decision was just "instinct…it was reactionary." She said that only in hindsight did she consider the dangers of it. The priority was to be reunited with their daughter. Now,

looking back she says; "It was the worst thing that we could possibly have done. You know, I probably killed him...with that because the cabin pressure on the brain...but he wanted to SEE HIS DAUGHTER" (Int. 1, 2016: 7).

What was clear throughout her narrative and during the interviews themselves was that her emotions were still raw. However, at the time of these events, part of maintaining control and exhibiting hope meant she repressed her personal feelings as a wife. She kept her emotions from Gary, she said she couldn't let him see how upset she was. She said; "It was important for him to know that I was the strong one. I had to be the strong one." This is indicative of keeping up a professional front and being in control of the situation – exhibiting a strong, stoic professional stance. A recent extensive study regarding nurses dual roles showed that their own anxieties and fears are often repressed when the patient is a loved one due to the need to appear calm and in control for family members and the patient (Giles & Hall, 2014: 1458). It is clear that this happened throughout his dying trajectory as whatever negative, grief stricken and fearful emotions Jenny had about his condition and his dying were kept to herself.

After the family reunited for the weekend, Jenny and Gary returned to their city and recommenced the radiation treatment on the Monday. Jenny said it was that night that he started missing words and had trouble speaking. His brain tumour was resulting in a condition called *expressive and receptive dysphasia* which meant that how he was receiving information was impaired as was his ability to speak and convey what he wanted. The tumour also began to affect his ability to walk. His next trip to the hospital required a wheelchair. This time, the staff determined that the swelling of the brain was causing his symptoms so he had to stay in hospital for three days and be administered cortisone. Jenny later insisted on a further dose of cortisone to improve his quality of life to which the doctors agreed. After this, he came home again, but they maintained the routine of radiation five times a week.

In all their admissions to hospital, Jenny had a couple of complaints. On one occasion, when he was first admitted for a biopsy, she said she was left completely alone. On top of this, she said he was a neurological patient in a cardiac ward. Jenny knew that the nurses in that

ward were not equipped to deal with a neurological patient. She said to me that they would ask how he was and he'd say he was fine but Jenny knew that he wasn't. Not only was he calling her Maggie, but prior to that admission, he was seen putting his teabag in his soup and wearing his best leather shoes in the shower. She described her wait in the hospital when she was by his side:

> Three days I was there before anybody even spoke to me in the hospital...Unbelievable! UNBELIEVABLE! And then the nurse unit manager came on the morning he was going to theatre and she said "I'm so and so." I forget what her name was and she said; "Are you his wife?" and I said; "Yes, I'm Jenny." She said, "Well, I'm going to take him down to theatre now, would you like to accompany us?" And, I burst into tears! And, she went, "Are you alright?" And, I said "Yes", and she said; "It's okay." I said; "You're the first person who has spoken to me in THREE DAYS! (Int. 1, 2016: 10).

This experience that she had with her husband affected her perception of her role as a nurse. Indeed, she later explained to me that it was this incident that made her more conscious of families, particularly those with dying relatives. In the narrative, she shifted to present tense and told me that now; "I make a point of going to them and asking them what sort of support they've got at home…do they have any questions? And, make sure they know where to get me, what shifts I'm working so that I can actually tell them" (Int. 2, 2016: 12).

As I have argued, background and intention of the participants is an important indicator of their current concerns in their life-world (Ochs & Capps, 1996: 25). Shifting to present tense provides an indication of the protagonist's evaluation of the situation (Bruner, 2001: 29) as well as revealing present concerns in a participants life-world. Through this shift, they reveal how they make sense of these events in relation to how they see themselves as an agent in society (Taylor, 1989: 15). Jenny's participation in this research related to her current concerns of writing a book but also because she was still nursing, her experience affected her current role as a nurse. It led to a shift in perception toward families with dying relatives and a renewed empathy for their situation.

Another revealing aspect of negotiating her professional and personal role as carer was when she told me how difficult the process was. Indeed, Jenny had told me at the beginning, she couldn't believe how different it was to nurse her husband compared to her

sister and mother. She had managed to nurse them at home, but it was too difficult to manage this with her husband due to his condition. In addition to this, she did not expect that he would get a brain tumour; she always thought it would be heart related due to his family history. So, it was the unexpected illness but also the emotional intensity of the experience for her. She believed with all her experience, she should have been able to control the emotional aspect of caring. While her husband was in hospital for brain swelling for a few days, she said the best thing happened to her:

> The social workers called a morning tea for carers of people with cancer. And, ah, I saw it on the notice board on the ward where he was and I hummed and harred; Will I? Won't I? Will I? Won't I? And, the next morning I rang and said; 'Is it too late to put my name down to come to the morning tea?' 'No, no, no…please come.' And, I met two women there who have remained staunch, loyal friends. They both lost their husbands that same year. And, we got one another through it. Yeah, and people that I've never met before, but will remain friends for a long time…And, my big difficulty as came out in that very first session, I sobbed and sobbed and sobbed…was that…I'm a nurse. I've been nursing for forty three years, I should be able to cope with this. And, the social workers were fantastic in convincing me that it's far different when it's… (*whisper*)…your spouse. This is different all together (Int. 1, 2016: 8).

Jenny was battling the fact that it was taking such an emotional toll. As she had told me, she never talked to Gary about his death and did not show emotion in front of him. She played the nurse, made decisions for him and not just medical decisions, but personal ones based on her understanding of what her husband wanted. She was her patient's advocate. Thus, her own personal suffering needed to be kept hidden. She said there were times when she would talk to her cousin on the phone, but have to hide in the bathroom so that she could have a cry. She actually told me that she felt that she had done most of the grieving before his death.

Jenny clearly sees her nursing role as epitomising a strong, medical decision maker and patient's advocate, but did not account for what she would feel as his wife. She didn't expect the personal emotions to be as hard to contain as they were which were obviously always just bubbling beneath the surface.

Jenny's battle with her dual role as wife and nurse was not lost on her children. Gary was getting regular chemotherapy and radiation even though the doctor had said that it would not slow down the progression of the tumour. However, being the advocate, Jenny made sure he got the treatment regularly. One day, the children confronted her on the issue of his treatments. She told me that what they said was similar to what they had said when she was nursing her dying sister. She told me that during that time, they had said; "Mum, stop being a nurse and start being a sister." Now, with reference to their father, they said; "Why are you letting him go through all this mum; it's hopeless?" She told me her reply was; "Yes, but it's his choice." Gary had said from the outset that he wanted everything to be done that could be done. So, Jenny's value for patient advocacy and her role as a nurse was clearly influential in most of her decisions which was also pointed out by the children who noticed this attribute once before.

On one of the last visits to the hospital for radiation, the social workers came in to see Jenny with the Do Not Resuscitate Order (DNR) and it was then that Jenny had told them that he was not for resuscitation and that his treatment should be "comfort measures only", pain relief. She told them that if there was anything else she thought necessary, she would ask for it. She told me that she didn't want anything extra given to him and that this choice was "purely from my own um, experience and knowledge you know um, medical knowledge" (Int. 2, 2016: 5). Hence, it is clear that Jenny's 'medical knowledge' and experience in the hospital and understanding his condition was that any attempt to resuscitate would only cause more suffering.

While the social worker was there, she asked them to organise a referral for palliative care. The nurse on duty said to her that he wasn't in need of that yet but Jenny insisted. She said; "I wanted him on their radar, because I could see what was happening." Also at this time, she asked for a copy of the MRI which she had not seen yet. When she saw it, she could see that there were three major arteries wrapped around the tumour. She had said to me that if she had seen this earlier, she would have had a better understanding of his symptoms and would have been able to piece together what was happening. Now she had seen the MRI, she predicted that he would have a bleed. She called her children to warn them that this was imminent so that they could arrange to come and see him, which they did. This was two

weeks before his death. The next admission to hospital was when he had the bleed that Jenny predicted. When she went in to see him, he was paralysed down one side. She asked him to give her a smile, to which he responded the best he could. She said that that was the last time he acknowledged that she was there. Jenny stayed with him and he died four days later.

Jenny explained to me how she saw herself with reference to her experience:

> I'm a realist, I'm a realist. We are born to die. That's all there is to it from the moment you take your first breath there's one day you're going to take your last breath. Doesn't mean I'm not a caring person. I mean, I wouldn't have lasted forty-seven years in nursing if I wasn't a caring person…When I married a man that was fourteen years older than me, I suppose deep down in the back recesses of my brain I knew that the likelihood is, with women outliving men, the likelihood is that one day I'd be a widow. I just never expected it the way it happened. He had a heart condition, his older brother had…a heart attack…his younger brother had died of congested cardiac failure…I would never have expected he'd have a brain tumour. Never, never, never… (Int.1, 2016: 17).

This statement shows that Jenny saw herself as a practical and rational type of person. It also showed that the caring aspect of her role as a nurse is recognised. As I have discussed, the cultural construction and expectation of nurses comes under the banner of 'caring' but includes advocacy and empathy.

Jenny surmised that perhaps it is the support from others and the nature of the relationship that makes the difference in one's ability to cope with palliative care. She said with her mother and sister, she had some type of emotional support and so others shared some of the burden. She said; "Well, with mum, I had Tracey and Jen there backing me up on every decision I made. With Tracey, I had Jen and Gary there backing me up on every decision I made. With Gary, I was SOLO!" (Int.2, 2016: 12). Thus, the pressure of not having another family member to support her decisions made a great deal of difference. But, she believed there was more to it. She thinks it has to do with relationships:

> …as much as you love your mother, after your umbilical cord is cut, you really are two separate people. Whereas a husband and wife are, literally joined at the hip for life. If it's a good marriage and that sort of thing, you are one (Int. 2, 2016: 11).

This emotional closeness not only made the impact of the experience more intense, but made the need to remain in control and repress these feelings all the more difficult. With her decades of experience as a nurse and her direct experiences with her sister and mother, she expected it to be the same. As Husserl argues, past experience colours perceptions of current experience (Husserl, 1981: 295). This is reinforced here in the way in which she thought, based on the past, that this process would be the same. However, she did not count on the new emotions that she would experience. Hence, regardless of her palliative care experience with family in the past, her emotional reaction to events changed the nature of the experience.

The experience with her husband also directly contributed to changes in her professional approach to families. Thus, the experience with her husband affected her life-world. This was evident in a *moral coda* which reflected her renewed empathy for families dealing with death:

> …relatives have NO IDEA, they have NO IDEA at all. And, that's why I spent time with a young lad just down there because nobody had told him that this room was the palliative care room…he'd always had a bad relationship with his father and was told his father was, you know, didn't have all that long to live. I just said to him; 'We are expecting him to go in the next twenty-four hours' and the boy had said; 'But, he was talking a little while ago.' And, I said; 'Yes, they do. The often talk.' And, he said; 'Well, my brother's arriving this evening. Will he last that long?' And, I said; 'Well, yes, he will. But he will go very quickly after your brother arrives because he'll have then seen everybody he wants to see.' (*Whispering*) It happens every time…nurses are much better at telling patients and relatives than doctors are (Int.1, 2016: 20).

Jenny shifting her narrative to present tense reveals a lot about the values which Jenny holds and the meaning she took from her experience. The problem is that relatives are not informed, they have 'no idea' what is going on. She aims to rectify this problem by providing them information. Not only this, but she believes nurses are much better equipped to do so than doctors are. This again reaffirms the internalisation of the cultural construction of the nurse, one that includes both medical knowledge and compassion. It shows that personal care and attention, indeed empathy, is as important to their role as expertise. It is part of their moral obligation to families which Jenny clearly recognises.

Discussion

It is clear that Jenny internalised the cultural construction of the nurse in terms of how she identified with the situation and what she expected of herself in caring for her husband. Her extensive experience nursing and her previous decisions to nurse family members also demonstrated this. She favoured her nursing role which was predominant throughout Gary's dying trajectory distinguished by her insistence on accurate and direct information, her appreciation for honesty, her consulting with colleagues and her recommendations for his care. She also expressed a recognition of the qualities of the dual role including care, empathy and advocacy which were recognised by Jenny as important as medical expertise. Her role as a wife and family member was to a large degree repressed in order to maintain control of the situation and in order to support and give strength to the patient. Her emotions had to be released in private and she even had difficulty reconciling how emotional she was when she thought, based on her history, she should have been stronger. It is clear that the emotional toll attested to the existential conflict between her role as a nurse and as a wife.

Taylor argues that one of the influences on our morality is our respect for and obligation to others, and the dignity or attitudinal respect that we think we command from others with regard to our character (Taylor, 1989: 15). In tune with Husserl's theory, both perceptions and self-understanding develop not only from past experience but from inter-subjectivity. Therefore, along with background knowledge shaping our life-world through the creation of qualitative distinctions (Taylor, 1989: 27), our self-perception also plays a part in our moral choices. Therefore, when we consider how others see us, our character, it would be in the context of our place in the world and how we fit into this world. Jenny, by internalising the cultural construction of the nurse but at the same time being a wife and family member, experienced emotional conflicts due to the suppression of her wife role. This was recognised by her children who asked her why she was letting Gary go through all the treatments which they considered hopeless. She justified it by saying that it was his choice and therefore, exhibited the advocacy for patient's choices as nurses do.

Zigon argues that our embodied morality is influenced by the institutions with which we are connected to, in that there is a certain adherence to their moral principles (Zigon, 2008: 162). The institutional moral world of nursing and biomedicine affects the embodied moral worlds of those who are part of that world. The more acculturated to that world, one would presume, the more influence that moral world has over decision making. In addition, each moral world which influences our decisions has the ability to either support or subvert our moral position (Zigon, 2009b: 259). In Jenny's case, identification as a nurse and the influence of this institutional moral world governed most of the important care decisions for her husband and subverted her role as wife. Indeed, Jenny identified as a nurse first, and wife second. Put another way, the institutional moral world of biomedicine took precedence over decision making subverting her embodied moral position. On first meeting, I learned about her extensive experience as a nurse and the details of her career. Jenny strongly identified with her role and all the experience which came with it. This impacted her sense of self, identity and moral choice. Hence, most of her moral reasoning was from a nurse's perspective due to the internalisation, identification and embodiment of this role.

As a nurse, Jenny's medical expertise was utilised to the full as she monitored symptoms to assess Gary's condition, let staff know of her experience and demanded information and action when this was vague or inadequate. She insisted on clarification from the clinics, pointed out some inadequacies in clinical care and gained a new perspective and empathy for relatives. This in turn affected her professional life and current life-world. Her personal empathy as a wife had to be suppressed to a degree in order for her to maintain control over the situation as a professional which gave prominence to institutional morality and showed an internalisation of the cultural construction of the nurse. Her negative experiences of events, like being left for three days without being spoken to, gave her a greater perspective on the needs of family members. This influenced her life-world as a nurse in that she now ensures that families are well informed where she can because she knows that the families often have "no idea" what is going on. This attests to the view that our morality continually develops over time. The empathy for the suffering of families had been reinforced through her experience with Gary which has influenced how she now applies herself as a professional.

Advocacy, as part of the cultural construction of nursing, also played a large role in her moral objectives. Besides organising his care throughout the dying trajectory, she advocated for her husband by facilitating what he wanted irrespective of what she thought. She knew that there was no hope and so did the doctors yet she supported him through his radiation treatments five days a week and did not discuss the topic of death. Indeed, her need to maintain control both over her emotions and the practicalities of nursing her husband fore-grounded her institutional morality over and above her embodied moral world. By maintaining control as a nurse, she allowed Gary to maintain control over his destiny by fulfilling his wishes and supporting his autonomy. Thus, the 'good' choices were those that supported his autonomy irrespective of what she may have thought of these choices as a wife. As patient's advocate, and as a nurse, she supported Gary in his hope of getting better by refusing to talk about death and in his decision to do 'everything' possible for his condition which was to continue radiation.

As a wife and family member, Jenny's embodied moral world took over when she made the instinctive decision to get him on the plane to see his daughter. He was dying, he had lost a son and they almost lost their daughter. Thus, the decision to fly to be reunited with their daughter was based on empathy, emotion and instinct. She said she did not think about it, that it was reactionary. Describing her reasoning as 'instinct' we could say it reflected an appeal to nature. It was a natural, instinctive choice that needed no deliberation. Thus, the empathy for her husband and family governed this moral choice, regardless of her medical knowledge and understanding that flying would be detrimental to his condition. She said it was something she "had to" do because he was in despair. The nurse in her knew the dangers, but the wife made the decisions. She reconciles this decision she made for him by saying:

> For me, I would not have been changing the destination I was only changing the journey…probably if anything I shortened it a little bit…he was going to die…but, maybe he died two weeks earlier because of it, I don't know… (Int. 2, 2016: 7).

As I argued earlier, compassion is the ability to empathise. In this scenario, we can see that empathy plays a great part in moral reasoning in two ways. First, as her role as a caring nurse, empathy is part of carrying out the holistic approach to caring for the patient, advocating for and support their emotional well-being and their treatment choices. Second,

empathy is also part of the personal experience of caring for her husband and is also central to her personal experience of events. Her role as a caring wife and mother won over any medical considerations regarding this decision. She didn't get advice on the flight, she just arranged it. Not only were family ties more important, but her moral position was that the quality of his remaining life was more important than any affect this decision had over the quantity of time he had left. This was also evident when she insisted on "comfort measures only" and her decision regarding the DNR.

What she was not expecting, and one of the reasons for her sharing her story, was how difficult it was for her to care for her dying husband. One can interpret that throughout the narrative, her identification as a wife was the emotional part of her experience but not necessarily the moral world from which she made decisions regarding his care. The dynamic between the influence of institutional and embodied moral worlds was epitomised in her decision to attend the morning tea for people caring for loved ones with cancer. The pressure of maintaining the emotional control and advocating for him as a nurse was revealed when she said she couldn't stop crying at the meeting. When this occurred, she could not understand why, with all her experience, that she would be so emotional. She felt she "should" be able to cope with it after forty-three years of nursing and after having done it two previous times for other family members. Therefore, how she thinks others see her also plays a role in her moral reasoning here. A nurse 'should' be strong and be able to handle such experiences and she had done it before. Hence, Jenny really internalised the nursing role since she was puzzled by her overwhelming personal emotions. This internalisation had become a fundamental part of her identification with self. During his trajectory, she hid her emotions from Gary, she didn't discuss death, she knew she had to be the strong one and had to hide herself away so that she didn't cry in front of him.

For Jenny, putting patient advocacy first involved both medical expertise and emotional support and empathy. This directed the majority of her decision making. Therefore, she was predominantly influenced by the institutional morality of nursing. However, her sense of self with regard to her character and this link to morality also reinforced this. This is evident by the surprise she felt at how emotional she was looking after her husband when, as a nurse, she 'should' be able to handle it. During his dying trajectory, she maintained

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control by utilising her skills as a nurse and by tempering her emotional feelings as a wife. This was not just so that she could apply herself to the task, but also with full consideration of her husband's emotional state. Therefore, as always, inter-subjective considerations play a part in moral reasoning. The children knew this when they told her that she should *act* as a wife, not a nurse. She played patient's advocate in getting the treatment he wanted even though it was considered "hopeless" by the children. She didn't think there was a point either, but she believed she was providing what he wanted. This indicates that to a great extent, Jenny's sense of self and identity internalised the cultural construction of the nurse due to her extensive experience in this role. This is reinforced with regard to how she believes others see her. In turn, her moral reasoning was influenced more by institutional morality than her embodied moral world.

Jill

Jill is a mother, nurse and student in her mid-forties. She had around a decade experience as a nurse and was very direct in her reasons why she wanted to take part in my study. She told me that when she saw the call for volunteers notice she felt as though it was a sign from her mother "beyond the grave" telling her to take part. Being a nurse, she had exposure to death and dying but the experience of losing her mother in 2007 was very difficult for her. Her mother was diagnosed with brain cancer and had a short dying trajectory of four months. Like Jenny, she spent much of this time caring for her mother but unlike Jenny, she did not have full control as a nurse due to family dynamics. Her father being a dominating figure in the family refused to accept his wife, Betty's, terminal diagnosis which impacted on the quality of her end of life care.

Jill and Betty were very close, but her mother experienced much suffering and in some respects, experienced a bad death. As with Jenny's narrative, advocacy is a central theme and indeed, Jill directly referred to herself as "patient's advocate." However, due to family dynamics, this advocacy to a great degree was blocked by her father whom Jill described as always abusive and controlling. She told me that this experience lead to her organising advanced directives for her and her husband because she feels that this is the best way to allow the patient the treatment and care that they want. It is clear from the interview that

Jill believes in an afterlife although we never discussed religion. She said that oftentimes, she can smell her mother's favourite perfume which she feels is confirmation that she is still around.

Like many of my participants, the sub-narrative of the topic of euthanasia runs through Jill's story. In the first minutes of the interview, she said that even before her mother knew she was dying, she had discussed the topic of euthanasia with her and from this she established that her mother believed it should be legal. It is interesting that the beginning of the narrative starts this way perhaps because the reality of her mother's death was filled with prolonged suffering. It is also a key memory which shaped Jill's life-world. The mention of this became more significant to me when it is again mentioned several times throughout her story. Jill said she wished she could have ended her mother's life sooner even though she didn't think she would have the courage even if it *was* legal. Jill also told me at the outset that her mother's death was traumatic while it was occurring and traumatised her long after she passed away. She said she felt lost and she also told me that she no longer speaks to her father. In many respects, the central plot of her narrative is about her desire to advocate as a nurse for her mother but this was blacked by her father. Due to this, her embodied morality as a daughter took precedence in her decision making.

Studies show that "families have different levels of relational ability, based on their history of shared experiences, as well as the strengths and vulnerabilities of individual family members" (King & Quill, 2006). In Jill's family, she saw herself as her mother's protector but at the same time, knew her place in the family. Although her mother made the initial decision to take up treatments, the rest of the medical decision making was left to Jill's father. However, Jill provided both emotional and personal care at home and in the hospital throughout Betty's dying trajectory.

When her mother was told she had a terminal illness, Jill immediately took on the nursing role, particularly after her mother first had radiation therapy. Like Jenny, Jill was not only a patient's advocate because she was a nurse, but she was already her mother's advocate within the family unit. The inter-subjectivity both in terms of perception and life-world was intrinsically linked to her mother which was confirmed by the fact that she described their

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relationship as "co-dependent." Indeed, on many occasions the reflexivity in Jill's narrative expressed what she *would* have done had she been allowed. George, her father, refused to listen to the advice of his daughter or the clinical care team's advice while Betty was in the hospital. Consequently, he controlled the situation not only because he usually did in the family unit, but due to the fact that he didn't want to believe the truth that his wife was terminal. Jill never challenged her father as she believed it would make things worse for her mother who was suffering enough.

Before Jill provided me with the circumstances of her mother's illness, she summarised how her father affected her mother's care:

> My father was quite an abusive man both physically and mentally so from the earliest stage I can remember, I protected her and she protected me. And, then even in the death process and the diagnosis…he was very much in denial…He didn't even want mum to go on the PCA equipment, you know, the continuous morphine and dazlame infusion? I was fighting against that, the system, what mum wanted and I put personal stuff aside because I was thinking about what she needed, what she wanted and then I had to deal with myself later (Int. 1, 2015: 1).

There is an important point to make here regarding the narrative sequence and organisation and what it reveals about Jill's moral world. Her mother's belief in euthanasia revealed spontaneously at the outset of the interview followed by an explicit explanation of her father's character highlights not just the two important themes relevant to the story but also reveals Jill's sense of self and identity. In the first respect, their temporal order implicates a form of derivative and causal relation (Ochs, 2004b: 271). This is what linguists often refer to as indexicality. One event or situation links to another indicating the participant's perception that the two incidences are causally linked. It also articulates her moral position. In addition, the father is the moral antagonist and the narrative sets the scene for an account of personal experience where the events ran counter to what the participant assumed *should* have unfolded (Ochs, 2004b: 271). Thus, within the first few minutes of the interview, it was clear that Jill's perception of her experience was negative overall and that these themes impacted the meaning that she drew from the experience and hence her moral position.

Jill's mother was getting headaches for eighteen months before she was admitted to emergency at the local hospital. Jill received a phone call from her father that afternoon once they had done a computerized axial tomography (CAT) scan on her brain and found seven metastases. It was secondary brain cancer. When the doctor gave the prognosis, Jill said the physicians were very honest. Three weeks after the initial diagnosis, Betty was given a very specific time frame with respect to how long she had to live. He said; "Look, this is not curable. There's no operation that we can do. The parts of the brain that it's in…" And, he had also said; "Most people do not last longer than four months…You're probably looking at this stage, from what was going on in the scan, half of that without radiation"(Int. 1, 2015: 15). Jill recalled that the "…doctor was as direct as he could be without being awful. But the problem was that my dad would then come in and say 'But you never know, miracles can happen.'" The doctor then responded; "No, that's true George, miracles can happen" (Int. 1, 2015: 15). Hence although the doctor was attempting to be clear regarding prognosis, he was prepared to provide hope and believe in miracles for the sake of the father.

Her mother made the initial decision to have the radiation as it was going to give her twice the time. Betty thought that doubling her time left was worth it so that she could spend more time with her grandchildren. So, Jill took her to her appointments and helped her at home. One thing which her mother was sure of was that she didn't want to die in hospital. Jill was confident that she could look after her mother and provide palliative care at home. Jill was happy that her work allowed her to take leave so that she could look after her:

> Yep, and I actually cared for her. Coz, what happened actually, my dad had his prostate operation six weeks before mum got sick. And, um, also, before mum got to the palliative stage. So, she toddled along, she ended up in a wheelchair coz she lost the ability to use her legs because of course it was in the brain so it was affecting her speech and her ability to walk and use her arms… And, I went and cared for mum because my dad ended up back in hospital hemorrhaging from his bladder. And, so I had him in the hospital and I'm caring for mum pretty full on at home, cooking and toileting was very hard because she got quite heavy and I'm not a big person, so, my brother and I went and got her a shower chair, a toilet chair. Um, now even when dad came home, he went off at us for bringing in, what would you call it, 'living aids' at home because it was like this um, um, you know…us basically saying that this is how sick mum's getting (Int. 1, 2015: 4).

Betty and Jill had both demonstrated acceptance that time was limited. The only person in the family unwilling to accept it was her father. When Betty was diagnosed, Jill tried to talk to her father about home palliative care but she said that her dad "switched off from me at that point and I didn't really push the issue" (Int. 1, 2015: 2). She explained to me not only that he was in denial, but that she thought that perhaps he refused because the hospital were suggesting to send her mum to the same palliative care unit where her Auntie was sent. She said;

> My Auntie passed away at the *** one and I think that's why dad wouldn't let his wife go there. It was very strange because it's a beautiful facility and I was just so distraught and I'm like; 'They know what they are doing there dad, this is their specialty. You know, this is their gig, this is what they do'…And, no, I actually stayed in the hospital with mum for twenty-four seven for three weeks… (Int. 1, 2015: 4).

Jill told me that she left the rest of the decision making to her father because she "knew that in order for him to cope, he had to make the decisions." Ironically, giving him the power may have conformed to the usual dynamic of the family, but it did lead to periods of distress and suffering for Betty and the clinical care staff. While Jill, being patient's advocate, was attempting to empower her mother, George was working in the opposite direction and from a completely different existential position.

During her radiation and as her condition worsened, his denial began to impact on Betty's quality of life both in terms of physical and existential suffering. Personally, some members of Betty's family and friends never got to say goodbye to her and never had a chance to visit her before she passed away. This was because after terminal prognosis, Jill rang family members and friends to tell them that her mother had less than four months to live. Her father also made phone calls but did not tell anyone that her condition was terminal. Those that spoke to Jill came to see Betty; those who spoke to George did not. It was not until after her mother's funeral did she find out how angry people were that they were not informed that she was dying. Jill explained that this was why people are still angry with her father all these years later and do not want to have anything to do with him.

This lack of acceptance and insistence on maintaining hope serves to maintain a future orientated approach and sense of control (Olson, 2011: 908). It was clear from the beginning that her father wanted to maintain hope regardless of the information he was

provided or what the other family members thought. His existential position, his need to cling to hope, was not based on fact but emotion. Again, this shows the significance of emotions and how they impact moral reasoning when medical facts show otherwise. We are subjects embodied in the context of our life-world, we are subject to external and objective events, but can be carried away by internal emotional states. This is because emotions are a significant source and guide to our sociality – to our agency (Lyon & Barbalet, 1994: 49). For Jill, her father who lacked the ability to accept the prognosis did have control over events. Thus, Jill's father's attitude directly affected Betty's provision of appropriate care. Interestingly, even though Jill was a nurse and very close to her mother, she was accepting of her mother's diagnosis and did what she could to care for her in the time she had left. In her acceptance she was able to advocate for her mother all she could within the limitations imposed by her father.

Jill said while her mother was in hospital, the staff came to her to get her permission for her mother's care but she would tell them that they had to consult her father. Jill's narrative and sense of self really came through with regard to this in her reflexive speech. Through certain incidents during her mother's dying trajectory, she told me what she would have done as opposed to what happened. Our reflexive speech is not simply an account of the past, but is a critical moral evaluation of events (Duranti, 2009: 14). There were three main occasions where Jill explained events and told me if she had the choices, what those choices would be. However, even though she was a nurse, the family dynamic was a more powerful social structure for this participant and had greater impact on her ability to carry out her moral objectives. Thus, like Jenny, Jill had nursing advocacy as her core value for patient care, but caring for her mother was largely driven by her embodied moral world. When she told me what she would have done, it was as a nurse and as a patient's advocate. She wanted the freedom to advocate for her mother but was limited by her father and his dominant presence in the family. Hence, the context of Jill's life-world differed greatly from Jenny's. Jill had the moral objective of being patient's advocate, but only within the confines of what her father would allow. Hence, for the most part, her father was in control of medical decision making. However, initially, she had relative freedom to carry out home care for her mother while her father was in hospital. After he returned, she had to step back. It was not

long before her mother's condition worsened resulting in a seizure one evening. This event showed the true extent of her father's hope which became problematic at the hospital.

Sometimes, within the clinical setting, families can oppose recommendations by the treatment team and the patient, and old grievances and rivalries can rise to the surface (Rothchild, 1994: 251). When her mother took a seizure, she was rushed to the emergency department. During that time, the staff wanted to admit Betty to a palliative care facility. Her father flatly refused. There was a debate back and forth between the staff and her father but he stood his ground. Jill said that her mother lost her ability to speak and she looked as though she had had a stroke. After George refused, they put her in a ward but the staff were not confident she would last the night through. Jill was prepared and ready to accept this. However, her mother recovered. The clinical care team couldn't explain it but her mother was able to speak again. From that point on, Jill ensured that she spent every moment with her mother. She knew that not being in the right facility, she would need all the help and support she could provide. As a nurse, Jill was well aware of the situation. Jill gave me an example of an incident which occurred during her mother's stay in hospital:

> She had lost the ability to use the whole left side of her body. One morning, they came in to give her a sponge. And, they're busy and I know what it's like on a medical ward, I've worked there myself and they really just didn't have the time and this is what I was trying to explain to dad…they have four to eight patients and mum is special needs…They came in to wash her one morning and they said; "Jill, why don't you go downstairs and have your fag and your coffee and have a break?" And, so, I went down and did that. Came back and she was still waiting. And, she was half naked. And, she said; "Don't leave me again". So, I couldn't. And, I took over that part of her care. So basically, I didn't tell them to, but they really…they stayed away from us a lot and I think it was coz they were scared of my dad which meant that mum missed out (Int. 1, 2015: 5).

There are several interesting aspects to this excerpt. The breach in care on behalf of the staff does not lead to moral outrage for Jill. Being a nurse, she understands the difficulties inherent in the situation. Further, she knew that the facility would not be able to cater for her needs. And, unlike Denise and Becky, she is more understanding of transgressions from staff. They were busy, she was not in the correct facility and her father was making it difficult for everyone. He not only refused to listen to their advice, at one point he was aggressive toward the staff and they had to call security. So, Jill is almost apologetic in her

understanding and sees the reasons for their failings. She said; "They understood what was happening and…they were marvellous…but the female nurses in particular were really frightened to approach him…So, I was mum's advocate"(Int. 1, 2015: 5). Jill seems to be prepared to make the best of the situation within the limits of their family dynamics and the limitations of being in the wrong facility. Since she was clearly influenced by the institutional moral world of nursing, she forgives their shortcomings and does not get angry. She simply carries on and makes sure she can help as a daughter.   Again, her personal embodied morality takes precedence over choices.

Another incident occurred when medical staff wanted to put her mother on a syringe driver to control her intense pain. Jill says that she, her mother, and the staff wanted it, but it took four days to convince her father. During that time, her mother was in a lot of pain. The whole medical team including the oncologist and social worker had approached them and insisted on a family meeting. After the first one, Jill did not want to be part of it. She said this was because; "I knew he looked at me as the enemy." Jill explains the moment when her father finally agreed to it;

> …So it took them another four days of pretty tough family meetings minus me after the first day. And then finally he came in and when he did say yes he burst into tears then collapsed as if he'd sent her to the gallows (Int. 1, 2015: 7).

George's reaction to having to relinquish control demonstrates that his "hope bubble", as Jill described it, could no longer be sustained. His hope for a 'miracle' is crushed when forced to share the moral objectives of others and to accept the reality of the situation. During the four days where he refused, her mother continued to suffer. Once the syringe driver was put on, they had better control over Betty's pain but her mother still had difficulty communicating. However, Jill was always there to help her in any way she could. When I asked whether she ever challenged her father, she said that this was the only way to manage the situation because it would lessen family conflict and her mother's suffering. She said; "Maybe because he would have yelled at her and told her off for getting the syringe driver put on? Coz, he was always an abusive type person, it was another point in her life where

she had to get him to make the decisions so that she didn't suffer, on top of suffer!"(Int. 1, 2015: 14).

As Betty deteriorated, her pain was not always managed and this not only created anxiety for Jill, but came as a surprise. The shock for her was that some suffering cannot be alleviated regardless of medication:

> Do you know there were sometimes when she was so bad I wish I could have gave her an injection on the spot and not even thought about it. I couldn't do it, physically. But, it was in my brain. The thought was there. I thought "Oh, for God's sake, just go now mum, it's just dragging on too long. You are in too much pain, this is bullshit." Yep. There were definitely points where the treatment wasn't, or the medicine wasn't good enough. And yet, I thought morphine was magic! But, when you see that it's actually not working on someone, I was absolutely blown away. I didn't realize that would ever happen (Int. 1, 2015: 17).

Not only was Jill surprised that some suffering could not be alleviated with medications, it was difficult for her to watch. She knew how her mum felt and she knew that the pain and indignity was extreme for her. Like Becky, her empathy for her mother's suffering leads to thoughts of ending it for her. This shows again the power that emotions, such as empathy, have on our moral reasoning when exposed to death and suffering.   The experience transforms our life-world in such a way, it can lead us to consider things we would never in any other circumstance, like ending someone's life.

Jill told me that her mother was a very proud woman. However, now she had lost her hair and the seizures had damaged her body and ability to speak. When Betty lost the ability to use one side of her body, Jill said; "…she was ready to go nigh nighs…"   Jill's wish that it would be over for her mother was also reinforced by her mother's wish:

> She said to me, these were her direct words and she didn't say it just once. So, she wasn't just saying it in times of need or extreme pain. She said, 'If I had a bloody tablet!' And then she said to me when she was in extreme pain and distress, 'Can you just go and get me something off the shelf and pop it in my bloody veins love, you know, knock me off for good?' (Int. 1, 2015: 20)

Of course, Jill told Betty there was no way she could do that but it just added to her anxiety knowing that, without a doubt, all her mother wanted to do was die. Jill said to me she never wanted to get to that point and yet she had to watch her mother endure the kind of bad death that she had seen her sister go through.

The *moral coda* which is part of Jill's narrative conceptualizes her moral stance with respect to her mother's experience. Again, it linked directly to concerns about prolonged suffering, bad deaths and the topic of euthanasia. She told me that her Auntie, her mother's sister, was diagnosed with breast cancer, had her breast removed and had radiation. Six years later, she received the all clear from her specialist and continued to get her blood checked and have scans every two years. One day, she had pain in her back which turned out to be secondary cancer – the cancer was in her spine. Jill told me that from the spine, it made its way up to the brain. The parallels between her Auntie and her mother were that the source of her mother's brain cancer was in her lung, so it was also secondary. Further, it was also a commentary on the horrible symptoms of patients who are dying with brain cancer. She made it clear to me that her mother already believed in euthanasia and witnessing what her sister went through reinforced this belief. Jill said that her mum "saw her sister and she was horrified." She said that her Auntie was unable to communicate, had spasticity and was in a fetal position; "…like the visions of an old asylum person." Further, she had no conscious orientation and was described as being like a vegetable. Her mother being witness to her sister's fate saw this as pure cruelty and confirmed her feelings that there needed to be provisions in place for patients so that people can die without suffering like that.

Clearly the experience of being caught between wanting to have control as a nurse and being limited in that control as a daughter was both frustrating and traumatic for Jill. The experience of her mother's death had a direct impact on Jill's life-world and her current circumstances. She told me that this was the reason that she arranged Advanced Directives for her and her husband. She said it was unfair to leave it to the family and that "…It all should be written down." She also said; "I would have preferred to have never had to make a decision with mum's care. I would have preferred that everything was written down…" (Int. 1, 2015: 17). Not long after that she says that "I need the piece of paper to say it for me! I think that takes the stress off your loved ones" (Int. 1, 2015: 18). Perhaps this is a solution to what she went through to ensure that the patient has as much control over the circumstances as possible. That way, family cannot interfere, create conflict and as a result, prolong suffering for the dying patient.

We can see that Jill attempted to carry out her role as a nurse but was blocked in this endeavor by her father. She internalized the values of nursing in her insistence on being a "patient's advocate." However, clearly, due to her qualitative distinctions from background experience as a family member, her embodied moral world took precedence in her moral reasoning. She took leave from work and provided her mother support in the hospital, but stood back from the decision making. All the reasoning behind this was justified by the fact that she had her "abusive" father and what conflict and suffering would ensue should she challenge him. In many respects, her emotions played a role in her decision to allow her father control because she felt she had to protect her mother. Even where the staff were not providing the greatest of care, she is not critical. On the one hand, this is due to her identification as a nurse, but on the other hand, this is because it was her father's fault. He had made all decisions difficult, including the refusal to put her in the correct facility. Therefore, we can determine that her moral reasoning, although influenced by the institutional world of nursing, was predominantly influenced by her embodied moral world and her sense of self as a daughter.

Discussion

Jill's account of her mother's death shows that she identified with the cultural construction of the nurse in her emphasis on patient advocacy, her sympathy with the staff and in the way in which she attempted to carry out care for her mother in the initial stages of her illness. Although she identified as a nurse, we can see that her sense of self and identity as a daughter was the overwhelming influence in this case. The emotions of her family life which informed her qualitative distinctions were much more pronounced and thus took precedence over and above any internalization of her role as a nurse. However, that is not to say that she did not identify with these cultural attributes such as advocacy and compassion, but that her moral reasoning centered on inter-subjective concerns. These were to do with their history as a family, her knowledge of her father and her need to protect her mother. Thus, her innate, unhampered moral reasoning reflected the internalization, understanding and identification as a nurse, but it was her qualitative distinctions based on family dynamics which informed her moral reasoning.

One of the ways our identity is shaped is through our conception of society and what it means for us to be an agent among other agents (Taylor, 1989: 105). Jill identified as a nurse and through identification with this role understood what had to be done with her mother's care. These included the living aids at home, being in the correct facility, being on the syringe driver, acceptance of the diagnosis and through informing other family members. However, her mother experienced unnecessary suffering because her father had control over decisions. His hope, in many respects, led to more suffering for Jill's mother. However, challenging, ignoring or attempting to override her father was not an option even though it may have allowed her mother the right care. Jill identified herself in her relationship with others in terms of understanding her place as an 'agent among other agents'. Her place in the family, which informed her embodied moral world, was the self through which she felt she was able to make decisions. Thus, predominantly, her moral reasoning was informed by both her background experience and inter-subjective considerations.

First, prior experience informed Jill which position was better than the other (Taylor, 1989: 72). And, it is clear these qualitative distinctions had strong emotive effects which impacted her choices. She described her father as abusive and dominating throughout her life and he was this way to both herself and her mother. Therefore, these emotions from the past overrode her volition as a nurse/decision maker. She knew that conflict with her father would make things worse for her mother and so to keep this suffering at a minimum, she had to allow him control. Hence, even though within society Jill was a nurse, it was overridden by her place in the family which is why it had the greatest impact on her embodied moral world.

Both Husserl and Taylor agree that perception and conception of self includes consideration for others and Zigon agrees that moral reasoning is heavily influenced by relationships (Husserl, 1981 ; Taylor, 1989 ; Zigon, 2009a). Due to her relationship with both her mother and father, she identified with a certain role within that dynamic culture of the family. With regard to her mother, she described their relationship as "co-dependent" and said that "they protected each other" for as long as she can remember from her father. She knew from background experience that it would be better for everyone if her father was allowed to remain in control. Even though both Betty and Jill exhibited acceptance early on, her

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father's denial resulted in a sense of helplessness when watching her mother suffer which lead to the wish from both parties that death come sooner. Further, even though the staff in the hospital had in some respects failed her mother, instead of moral outrage, she sympathized with them because she knew that her mother was in the wrong facility and that they had to deal with her difficult and aggressive father.

Jill made decisions from her qualitative distinctions, her embodied moral world and from considerations for inter-subjectivity. Her sense of self and identity within the family unit was more powerful for her than her identification as a nurse. One can clearly see that she acknowledges the institutional morality of the nursing fraternity by the fact that she knew what 'should' have transpired for her mother and the way that she sympathized with the staff. She said she was always the "patient's advocate" which is embedded in nursing philosophical traditions, is reinforced in nursing education and is an important nursing function (Cole, Wellard & Mummery, 2014 ; Ezeonwu, 2015 ; Walker et al., 2015). However, she could only advocate for her mother within the confines of her role as a daughter. Due to the nature of Jill's life-world and sense of identity, qualitative distinctions and inter-subjectivity had the overriding influence over moral choice. Avoiding conflict to reduce the potential suffering for her mother was really fixed in her understanding of self, identity and family.

Chapter XI – Liminality, Transformation and the Moral Assemblage

It is clear that bio-technologies offered to control the disease and disintegration of bodies can have a powerful influence on subjectivity by promising hope. With a terminal illness, one's body not only fails but is socially and culturally pushed to the margins falling outside the normative health paradigm reinforced through biomedicine and public discourse (Maynard, 2006: 230). Therefore, diseased bodies not only transform the subject through loss of control, but through stigmatization (Waskul & Van der Riet, 2002: 489). This stigma not only alters the patient's sense of self but, along with the fear of death, can alter their life-world. Hope a very powerful emotional experience which has effects (Cellarius, 2008: 113), but we have seen how empathy also has significant power over moral choice. What is apparent in this chapter is that emotions play a large role in decision making than other moral influences which make up the subject's assemblage. Biotechnologies, although they can bring hope, can never completely reinstate the subject back to their prior self. A cancer diagnosis not only brings death into the present, but transforms the life-world of the patient. This transformation, I argue, remains even with patients in remission. This transformation in bodily and subjective status along with the ambiguity surrounding time can be understood as a liminal space where the body and self of the past cannot be reinstated completely nor can a future healthy self be guaranteed.

The following case study stands apart from all the others in several ways. First, it is a story where a multitude of moral influences impact the patient's life-world and yet the decision making seems to contradict usual beliefs, practices and value systems. This anomaly can be explained in terms of not only the transformative effect of diagnosis and remission, but through the power of the embodied moral world when emotions essentially guide moral choice. This story also stands apart as it includes a period of remission and relapse. I will argue that one way to understand these contradictions is to delve further into the constitution of embodied moralities and how they operate as an assemblage. A moral assemblage includes all cultural and social particularities unique to the subject including all the public and institutional moral worlds which make up the subject's moral constitution (Zigon, 2010). Taking into account these influences, the liminal space and the power of

emotions, we can better understand moral reasoning where choices do not seem to coincide with the life-world of the patient. Zigon explains assemblages in this way:

> Because a singular social location or situation cannot be understood as constituted by any one totalizing moral discourse, it must instead be understood as an assemblage of diverse deterritorialized aspectual traces of discourses and practices within which a unique range of ethical practices emerge…because these assemblages are a unique conglomeration of various aspects of diverse and often contradictory discourses, as well as diverse and sometimes incompatible embodied moral dispositions, each assemblage is unique and singular on its own…Thus, it provides a way for us to understand the fact that oftentimes seemingly incompatible moral discourses and dispositions exist rather comfortably in the same situation or location (Zigon, 2014a: 19)

Zigon's assemblage theory makes clear that the subject is not instrumentally influenced by separate channels; one, then the other. It shows that due to these over-lapping influences each subject has a multitude of moral sources in their life-world.   But, the provision of justifications for certain moral choices are not always articulated clearly. Zigon argues that engaging with ethics is "a moment of freedom, creativity and emergence" (Zigon, 2010: 9). This is because each engagement with ethics draws on different aspects of the assemblage but also involves dialogue with the self. And, since the self is transformed and remains in a liminal space, it stands to reason that our engagement with the self and moral choices arising in these circumstances are also affected in a particular way.

Medicine is "perhaps the oldest site where one can observe the play of truth, power and ethics in relation to the subject, and to the possibilities of a good, or as the Greeks would have it, a flourishing life" (Rabinow & Rose, 2006: 200). The application of medicine and healing uses technologies which are supported by certain presumptions which affect subjectivity. It is governed in "…a domain of strategic relations focusing on the behavior of…others, and employing various procedures and techniques according to the case…" (Foucault, 1997: 88). And, since a cancer diagnosis places the subject outside normative ideas of health; biotechnologies provide hope to bring them back. Patients are "…engaged by the pull of the normal…to minimize the disruption of their disease, to be fully functional and able – able in daily life and enabled to plan for a future" (Maynard, 2006: 217).

With a cancer diagnosis, however, the space occupied by the patient is substantially different to that occupied by a patient suffering any other disease. Cancer violates biological and normative boundaries which directly affects the social and personal sense of self (Waskul & Van der Riet, 2002: 487). This is due to both the terminal threat and also the stigmatization. Thus, this new space occupied does not promise a return to the past or absolutely guarantee a healthy future, even if the patient enters years of remission. This is where the concept of liminality is useful.

In Turner's theory of rite of passage, the liminal period that he describes refers to a transitional space occupied between past and future social and cultural statuses that the initiate occupies (Turner, 1967). This space is ambiguous and is both symbolically and culturally removed from everyday norms under which usual life is governed (Turner, 1967: 94). The initiates are structurally invisible and ritually polluting and are secluded physically and symbolically from the realm of culturally defined and ordered states and statuses (Turner, 1967: 98). They remain in this state until they are reintroduced into society with a new "clearly defined structural type" along with an understanding of the norms and obligations which go with these (Turner, 1967: 94). Therefore, a liminal space is transformative to both sense of self and social status.

Some argue that the first stage of cancer diagnosis puts the person into an acute phase of liminality (Little et al., 1998: 1490). Others have claimed that the state of remission is akin to a liminal space that the patient's occupy (Bruce et al., 2014). I argue that both are correct and indeed, that the liminality experienced by remission is only a slight shift in status and hope but is never a complete return to subjectivity before or after diagnosis. Remission is not a re-entering back into society with a new status, or reclaiming one's old status, even though it may be viewed as a positive event. It never returns the subject completely back into the health paradigm. Therefore, since the subject does not return completely to their prior state nor do they completely enter a new one, they continue to occupy a liminal space. Liminality is created from the initial shock and shift of status which impacts the life-world and existential state of the patient in a transformative way. If both body and self are transformed by this new space that the patient occupies, then one's moral assemblage must also transform. Therefore, the usual influences within the subject's moral reasoning will also

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be affected. As I have argued elsewhere, terminal illness and end of life decision making must be viewed as an exceptional space unlike any other health related decision making which patients occupy. For this reason, ethical engagement in this space is unique.

It is clear that the appeal of biotechnologies to cure the body and rectify this shift in social status, are powerful. However, the lure of biotechnologies to reinstate the self can only in part explain some of the reasons behind moral choice. In this case study, there exists not only competing methods of healing in the subjects life-world, but also competing cultural and religious structures which constitute the subject. It is for this reason that I argue that the transformation created by liminality foregrounds emotions and memory which, in turn, empowers embodied moral positions over and above outside moral influences.

Both the participant in this study and her father, Bill, made decisions as a collective exercise. Due to this fact and the richness of the information I was provided, I was able to focus on the life-world of the patient and their moral reasoning. In this respect, it differs from the other case studies in this thesis. This chapter involves Bill, a Christian deacon, who was diagnosed with terminal stomach cancer and took up chemotherapy treatment. Aside from Bill's religious role in the community, he also practiced traditional Samoan medicine at home. He healed broken bones, sprains and helped babies suffering colic. Both the patient and participant, Nadine, wholly identified as practicing Christians. The contradictions arise when this traditional medicine is not adopted by the patient the first time or even after the cancer returns. Further, Bill keeps his condition secret and shares his diagnosis only with immediate family which goes against usual cultural practice of sharing with extended family. Even though Nadine, my participant, said that Bill was the most traditional out of both her parents, many of his moral choices contradict this. Hence, although there are many cultural and religious influences constituting his moral assemblage, his transformation after the diagnosis creates such an existential shift that emotions predominantly inform moral choice.

Nadine

Nadine comes from a large Samoan family who were residing in New Zealand at the time her father became ill. Bill, her father, was a Christian Deacon of the local church. He also had

the 'gift' of traditional cultural healing practices which he would carry out from time to time when requested. Nadine told me that there were seven siblings in the family, four biological siblings and three adopted. The adopted siblings were no longer living at home. Nadine and another sister who were the oldest living at home were directly involved with her father's care and were part of the decision making process throughout his dying trajectory.

There are essentially two parts to Bill's story. The first is Bill's diagnosis of terminal cancer, treatment and then his remission. The second part explores the cancer returning and the decisions arising from this. Nadine's family were already exposed to death as they had lost their mother suddenly a mere three months before her father first became ill. Biomedicine and Christianity are the institutions which seem to have the most impact on the life-world of the patient even though Samoan tradition and medicine also features prominently in this moral assemblage. Nadine conceptualises her father's response to cancer and his subsequent treatment choices in terms of biomedical optimism, background experience and religiosity.

Nadine told me that her father was always a smoker and that even as a child she remembers he had a habit of coughing. Her father was fifty eight at the time that he received a diagnosis of cancer. Nadine said that her father began having trouble keeping food down, he was lethargic and he was also coughing a lot more than usual. When I asked her if she and her sister encouraged him to see a doctor she tells me that her mother had died:

> Yeah. Well, quite early on, quite early on…Well, he wasn't so reluctant because we had lost our mother. He didn't want to kind of run the possibility of him leaving us as well. So, we was really onto it. Um, just around…he was a man of faith so he didn't really want to think that there was anything wrong with him or anything so he…It wasn't until he kind of personally saw the differences and the way energy levels and things that he was ready to go to the doctors (Int. 1, 2016: 2).

Just three months before, their mother was at the local doctors when she collapsed and died suddenly. Nadine indicated that since they had already experienced the loss of their mother; her father would not be complacent about his health. Thus, his background experience was a motivating factor in his response.

When Bill went to the General Practitioner, they did blood tests and Nadine explained that she and her sister were there. She also said they did exploration by a video tube down his oesophagus, an endoscope, which was when the diagnosis of stomach cancer came through. Nadine said that when her father was told, he took it quite well. She said that his attitude was; "No, I've got faith that this is going to be…he was just full of hope that this, that this isn't the end of me" (Int. 1, 2016: 3). Nadine believed that both faith in God and his faith in medical promise were the groundings for his decisions. She said;

> The doctors were so…there was some hope. There was a glimmer…there was a possibility of different treatments that were given to him. And, then he just clung onto that and just amplified it (*laughs*). Yeah, the positive spin on things…there wasn't any possibility of him misunderstanding that there was a possibility of recovery (Int. 1, 2016: 1).

Biomedicine defines the body in terms of measures – the promise of success of intervention and more than ever health is conceptualised in terms of numbers (Kaufman, 2010a: 409). At the time of the diagnosis, they were told that the cancer was stage two, but it was "growing" and "spreading", working its way from his stomach up to his oesophagus. They didn't tell him how much time he would have left if he had treatment, but he was told that he would only have about eight months if he did nothing. Bill was lucky that he was only at stage two; however, it was still a diagnosis of cancer. Thus, both the transformation of his life-world from diagnosis along with the emotion of recently losing his wife gave the biomedical promise power to provide him with hope.

While they were at the clinic, there was a Samoan translator there for Bill as English was his second language. Nadine recalled lots of "big words being thrown around" as she put it. The translation went well and she said that they explained everything carefully to her father. They had said that he could have an operation, have chemotherapy or radiotherapy, but the choice was up to him. The family had time after returning home to discuss the options together. When I asked her how they came to their decision on the type of treatment they would go for, she contextualised it by saying "whatever treatment that would give him the best options of staying with us" (Int. 1, 2016:4).

Here we can see the effect of biomedical promise of a cure. The doctors were not only providing many treatment options, but they were full of optimism that he would recover.

Biomedical language insists that "science and technology consist of a set of knowable truths that are materially applied in the interest of improving human health" (McGibbon, 2008: 1153). Contemporary health initiatives are premised on the view that disease is preventable, that death is avoidable if the subject conforms to certain behaviours (Price & Cheek, 2007: 398). Self-responsibility within 'health' covertly implicates a moral judgement if one is not well suggesting that proper steps of 'self-care' have not been taken (Powell & Biggs, 2004: 20). The subject's status is already changed as a cancer sufferer, but is further impinged on by these additional normative expectations and stigmas based on these biomedical 'truths' and the public discourse surrounding health and well-being. The sick person, already in a state of being deprived their usual status is given the further charge of depravation (Leder, 2018: 115). The cancer sufferer has the added shame that their condition may have been brought about themselves. This is why we cannot explain decision making by simply stating that biomedical promise is overwhelmingly powerful. The power only comes from the promise not of reinstating the prior self that has been stolen through cancer, but by the promise of removing the stigma and even shame of not being healthy. In addition, hope may have been the only conceivable option under the conditions of recently losing his wife. Nadine points out that anything would be done as long as it meant "staying with us." Thus, any further threats to the family had to be dealt with swiftly.

Toward the end of the first interview, Nadine told me that her father practiced traditional Samoan medicine. She explained this with regard to the opposition her father received both from family and from a traditional healer about his moral choices which I will return to shortly. What is important to explore first is the fact that, in both interviews, she used the word "doubt" to explain why her father did not, from the outset, consider traditional medicine for himself. Overwhelmingly, it seemed that biomedical technologies and the hope that they promised won over. Nadine said; "…he had more information around the Western medicine than he did the traditional medicine" and in the second interview, she said that it had to do with information again; "they'd show the diagrams and this and that and actual video cameras going down" (Int. 2, 2016: 7). She also said that he was "OVERWHELMED by all this other info…and he had never seen the inside of his stomach…" (Int.2, 2016:8). Visually showing him the cancer and the multitude of options he was given to reverse it gave him hope of recovery. The promotion of diagnostic capacities and scientific technologies

within the parameters of risk awareness and reduction become the ethical good (Kaufman, 2010a: 411). But, does that completely explain his moral reasoning? The urgent and emotional need for him to survive for his family along with his transformed self must have also had a great impact.

The family sat down to discuss the various options Bill could take up for treatment. Nadine said that they decided on chemotherapy. When I asked how they came to that decision, she said:

> Ahh, because the other ones were quite um, abrasive compared…So, the chemo one was presented as the least um, physically…I think the other ones they would have to operate and everything. Like, it was really extreme, yeah…The chemo was presented to him…he doesn't need to be in hospital (Int. 2, 2016: 1).

She said it was a slow release chemotherapy where the patient wears what she described as a 'bum bag' around the waist, and the chemotherapy is in a balloon which releases the medicine into the blood stream. Nurses came every other day to clean the entry way and he would have to go in once a week to change the balloon.   Nadine said he could wear a shirt over it and you couldn't see it and that her father was well and mobile enough to continue with his church responsibilities.

Bill's choice of the least invasive, least restrictive and indeed, least obvious treatment meant that he could hide the fact that he even had cancer. He could continue with his usual life even though he had been transformed into this state of liminality. On the outside, he could maintain his social and bodily status. If he did not experience any shift in his sense of self, or any transformation from being diagnosed, there would be no reason to need to hide his condition.

Once a week, Bill had to get regular check-ups at the doctor to monitor his status. At one of these check-ups, after just two months treatment, he was told he was in remission. Nadine said after he received this news, he had a new lease on life. Previously, he only socialised with church goers. Now, he not only broadened his social circle, but his political interests and was taking part in rallies. Nadine said that these were things he never did before. Throughout the period of remission, which lasted three years, not only did her father engage

in new activities he also changed the unhealthy behaviours he once had like smoking and drinking. Nadine told me about her father's change in behaviour:

> …he was an occasional drinker and like the cigarette use was obviously daily but he'd stopped all of that for three years…he was committed to getting better. He was always active, he was a physically fit person, didn't overeat or anything…he had no issues around obesity or anything like that so he was just really, really fit… (Int. 1, 2016: 6).

Here we can see through the narrative the understanding that the subject themselves is responsible for their health. This reflects public discourses which imply that chronic disease and prevention of it is dependent on the subject, and since this implicates responsibility – comes with a sense of shame (Price & Cheek, 2007: 398). Being in remission meant that he no longer had to hide the fact he had cancer and his enthusiasm for life was given a significant boost. However, it did not mean that he was transformed back to his prior self and his state of liminality had disappeared. His new lease on life could be interpreted as an attempt not only to reinstate his status as healthy through his "commitment to getting better" but as a way to throw off this liminality by engaging in new activities; an attempt to adopt a new status.

It is clear that Bill's transformation in behaviours and habits shows that he internalised both institutional and public discourses surrounding health, particularly with regard to responsibility. He imposed on himself new ways of being and eliminated previous negative or bad habits in order to fight against the threat of the cancer returning. When Nadine reflected on the remission period, she not only asserted her father's commitment to his own health but the health of others. She said; "…he took every possible opportunity he had to tell everyone that he knew that was smoking to stop smoking because of what he was going through…he would go around and say 'See? This is what happens'" (Int. 2, 2016: 3). I asked Nadine what it was like when they discovered he was in remission:

> Yeah, yeah. It was awesome. It was…So, they had explained to him but also explained to him that they would need to keep checking because they didn't know how long this remission would last for the rest of his life or you know? It needs to be checked. Um. So, yeah, so he still had that dark cloud of you know, could possibly come back? (Int. 1, 2016: 6)

What is clear here is that even in remission, the person still lives with the imminent threat of death. The new lease on life does not remove the fact that the life-world and sense of self of

the patient is forever transformed. The cancer patient still lives in a state of liminality, with no recourse to their previous state and with a constant threat of cancer returning. One can never return to prior cancer status and neither can they, with certainty after treatment, re-enter society as a healthy individual who will never have cancer. This is reinforced through regular check-ups at the doctor and hence the spectre of death remains a continual threat from diagnosis on.

The three years Bill spent living his new life-style always had the potential for relapse. Unfortunately, this came one day when Bill noticed he was becoming fatigued again just before he went for his regular check-up. He was told that the cancer returned and, as Nadine put it, "with a vengeance." The disease is anthropomorphised; it had personality, agency and a motivation. The weak grip on hope of being free of cancer is destroyed for good. This was clear in his attitude to the news. Nadine's sister was with their father for the check-up, but when they came home she said:

> …he had come back and he was just…It wasn't so much um, 'we're going to fight this, I am determined to stick around', the talk was; 'look, they have told me they can give me this operation and it will prolong my life for, you know, a couple of months…he had accepted that he had a few months. So, those few months that he has with us is going to be about making sure that when he does leave that we are all set…that little talk was hard…you could just see the strength in there as well but he, he had accepted that he only had a few months (Int. 1, 2016: 7).

The doctors were clear that this surgery, which involved removing half of his stomach and laser treatment, would give Bill another few months with his family. As was the case with Carrie's mother who had survived cancer once before; she could somehow more readily accept her fate since "she had dodged a bullet" the first time. Surviving cancer then, just like being in remission, can never truly remove the transformation and stigma which occurs in the patient's life-world. In Bill's case, acceptance replaces hope. His new disposition allowed for him to organise and plan with his family with regard to assets, funeral arrangements, and his last Will and Testament. He also, with the care and assistance from his family, managed a home death.

Before Bill went in for the surgery, the family had met with the professional team at the hospital. I asked Nadine if she thought that the clinical care throughout the process of her

father's cancer was adequate and whether or not their experiences were positive. She said that the clinical care team were wonderful, the communication was excellent and even the palliative care nurses who visited their house regularly became friends. Nadine said; "…we had such good people that were in there, that understood that we had lost our mother suddenly as well so the health professionals knowing how much support we would need as a family and us being quite young…"(Int. 1, 2016: 9). This background experience of their mother's death is again emphasized as being a significant part of their life-world and context in which decisions were made.

The professional staff knew that the children needed more than the usual emotional support under those circumstances. Once they explained that he was out of remission, Nadine said they took them all (the children) into a room and they had grief counsellors there not only for emotional support, but to ensure the children clearly understood the circumstances surrounding their father's condition. At this time, the doctor suggested that post-surgery, Bill could enter a hospice. Nadine told me that at first, she thought that this would be good for him. Bill had said no to this on the basis that if there was nothing more they could do for him, he wanted to die at home. Nadine remembers this event:

> I was in two minds about that because I was still in the hopeful space that something can be done. So, I'm thinking, well, hospice care is where he can be looked after by professionals that could help him along the way you know? And, then there may be a possibility of getting better from this is what I thought. Um, until somebody explained hospice care to me! (*laughs*) Like, okay, so they are not about doing any kind of intervention? Ah, okay!"(Int. 1, 2016: 9)

Nadine had said that her father was "gung-ho" about being at home with family. So, it was arranged that hospice care would be provided at home. The carers came around every other day and provided all the living aides that he would need to manage at home. Nadine had quit her job and postponed her degree so that she could look after her father and the younger children at home. In his final months, Nadine cared for Bill full-time. Clearly, it is not only the patient but also the family members that are thrown from their usual lives into a liminal space. Lives are altered and emotions and stressors become part of their life-world. This is corroborated by a recent study (Jordan, Price & Prior, 2015) which found carers of children with a terminal illness also experience major shifts. Their accounts make

explicit a sense of moving away from a state that was known and understood, to one of flux, uncertainty and vulnerability. Suspended in this way, participants knew themselves as altered in terms of their former, and unfinished in terms of their future selves (Jordan, Price & Prior, 2015: 850).

Biomedical approaches to treatment worked for Bill for three years. He also took responsibility and adopted 'self-care' behaviours to avoid the possible return of the cancer. This demonstrates not only the power of biomedical rhetoric and public discourses regarding health but attests to how the threat of death leads to transformation of the self. Biomedicine fulfilled its promise giving him years of remission but what of traditional Samoan medicine and his religious influences? Nadine indicated that his faith in God played some role when I asked her to clarify the following:

> …he was a man of faith, and so he didn't want to think that there was something wrong with him…coz he wanted to stay alive…so his faith was that God would keep him alive because we would be with no parents if he wasn't here…so his faith was that God would keep him alive to be with us (Int. 2, 2016: 1).

God would not take a father from his children who had recently lost their mother. God being such a big part of their lives, and being their guide to moral goodness provides hope through faith. These two institutional moral worlds, of biomedicine and Christianity, make up part of his assemblage which impacted his moral reasoning. It reinforced hope and confidence that he would continue to live well into the future.

One study which explored the relationship between religiosity and trust in biotechnologies showed that the only impact it has on choice has to do with the belief in a personal God:

> A personal God that hears prayers is likely to be a personal God that answers prayers, or at least considers answering them. As a result, one can be optimistic about biotechnology because if it looks as if it might produce negative results, it is possible that God can and will help correct or prevent such outcomes (Scheitle, 2005: 853).

Hence, it is possible here that faith gave him extra hope and confidence that he would be looked after, that the treatment would work because his family needed him. However, although Christianity was a very important part of Bill's moral assemblage, it did not

necessarily guide moral choice but his faith simply reinforced his hope. Although one might assume it played a significant role since his occupation was as a Deacon, there is really no evidence within the narrative to suggest that it played any further role in moral reasoning other than as another source of hope. Religious dogma from the Bible, prayer or other religious rituals are never directly referred to as playing any part in his justification for choices or with reference to what action he should take.

There is evidence, however, that both background experience and emotions had power over moral choices and in this respect reinforced his own embodied moral position. To explore this, I will now elaborate further on some anomalies. Bill chose biomedicine due to the promise of a cure and due to the information they provided. However, he was a traditional practicing Samoan healer. Like his Christianity, it was a big part of his life but it was not adopted as a healing method for himself. Since his moral reasoning seems to defy the social, religious and cultural structures which make up his assemblage, an understanding of his choices can be obtained through the nature of his past experience and memory. Nadine referred to past experiences influencing his decisions such as her mother's death and other situations to which I will now turn.

Taylor argues that our qualitative distinctions which are part of our identity are formed from past experiences and they always play a role in our moral assessment (Taylor, 1989: 25). Taking this approach, we can better understand the choices that Bill made. In one example, Nadine told me of a situation which occurred just after her mother's death. She said that after her mother died, there was a lot of interference from the extended family over the issue of traditional Samoan burial rites. This issue arose because of her mother's tendency to shun traditional ways. Nadine described her mother as a "trend setter"; that her father was the serious one and her mother was the "comedian." Again, that her father was very traditional yet her mother "fought against being traditional." Nadine said that her mother was always "morbid" because she discussed her death and funeral arrangements with the children even though she wasn't even sick. Nadine thought it strange that she was really specific about what she wanted, who was allowed to attend the funeral and so forth. When her mother died suddenly, they discovered that she had already had all the arrangements planned with her friend who was a funeral director. Nadine knew this, but it took Bill by

surprise. It became humorous for Bill and the family when Bill realised that he had signed a paper confirming these arrangements and yet had no idea that he had done so. He thought it funny that his wife had her way even in death.

Nadine told me that her mother wanted to be cremated, which is against Samoan tradition, and she wanted her ashes to be placed on the mantel piece in a Paua shell box to be buried with Bill after he died. Both Bill and the children respected these wishes. However, the rest of the family strongly opposed these actions:

> Yeah, because he, he didn't want to hear everyone else's…And, because…my mother had just passed away. She had gone against ALL cultural um norms, we had her ashes and we had so much of our family's input on how we were living because my mum had passed away and her ashes were still in the house and…So, we had family, we had family members make special trips to New Zealand. Um, to tell us how wrong it was to have death in the house (laughs), with the ashes there. And, trying, you know? Yeah. So, my father was just like, nup, me…and my children…that's why no-one was to know about him either or any…having a say in his treatment or anything that is happening so that's…yeah. So, all that prep, so everything that's…all this learning from my mum's passing came into play and helped my father's stuff as well. So, he only really let in, the Reverend and everything. So, that was it. Just the Reverend and his wife knew about what was going on and even that, it was only ENOUGH information around when the op was or anything like that but not around the details or the possibility of this treatment or this treatment. It was, that was all decisions that were made between um…It was all the decisions made by my father but after consultation between me and my siblings (Int. 1, 2016: 20).

Hence, when Bill received a terminal diagnosis, the family members who had interfered before were not informed on his condition. This is also unusual in Samoan culture. A major study of Samoan health choices showed that in almost all cases presented, that family members had a significant say in treatments and could easily persuade and individual on which course of action to take (Norris et al., 2009). Bill's secrecy in keeping his condition to his immediate family is clearly from this prior experience. What Nadine indicates here is that prior to his condition, it seems they felt they had the right, or even duty, to tell Bill that he was insulting Samoan tradition. We can determine from this that these qualitative distinctions which made up his identity informed his moral choices above and beyond Samoan social and cultural traditions.

When Bill's cancer returned, he agreed to treatment which involved surgery to remove part of his stomach. Nadine said that this was done to give him a little more time to make sure all affairs were in order for the children. Bill's only concern about the surgery was that they sewed his body back up correctly making sure that his tattoo would not be affected. Nadine said that this was very important to him. When I asked Nadine if she thought that this final surgery was worth it, she said not really "because it meant that the rest of his days were in pain." What had transpired was in addition to the surgery and subsequent hospital stay, he had contracted a post-operative infection which meant more pain and more time spent in the clinic. Nadine said to me that "that's when the decline came."

When Bill returned home, clinical care employed hospice staff who made regular visits. Nadine said that by this stage her father was so thin, he looked like "Skeletor." She described this as "heartbreaking." Although the hospice staff provided everything that Bill needed, he refused to wear incontinence pads and toward the end, even refused pain medications. Hence, he had to be showered and taken to the toilet by Nadine's brother as he wouldn't use the special toilet they had provided him either. Nadine believed it was because he was too proud. She said he was very good at pretending he was fine when the hospice ladies visited. Nadine said the house was always full of laughter. Nadine would walk them to their car when they were leaving which is when they would ask her how he was *really* doing. Nadine couldn't be happier with their service and told me that even on days they did not visit, they would always call to see how they were doing.

It is this discussion around the topic of pain and suffering after the surgeries which prompts Nadine to explain traditional Samoan healing. Nadine said; "being Christian, and he was a traditional healer as well? So, there was a mix. He does see both sides." I said that I wanted to know more about this healing and she explained to me how one is "blessed" with the "gift" of healing. The actual practice which her father carried out involved massaging. Indigenous Samoan healers are known as *fofo*; some treat internal and external conditions with herbal medicine and massage and others treat bones and muscles through massage, manipulation and setting (Shiraz, Hess & Luce, 2003: 65). She said he had healed people with sprained ankles, broken bones, dislocated shoulders and babies with colic. She said it was all word of mouth; healers are only identified through asking family and friends. Nadine

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explained how treatments work by recalling sessions where she watched her father treat a baby. The parents had taken the child to the General Practitioner but it was not getting better. Nadine said that it is called *Nau* – translated into English means 'broken'. She said her dad's name came up, people gave the couple their address and she said they just arrived on the door step with no warning. She explained how the healing works. She said that with the baby, in the first massage session it was really upset. However, when they returned for the second and third session, the baby is clearly much better and happier. Nadine went in detail in the second interview about these practices that her father carried out and more specifics were given with respect to the way one becomes a healer. She told me of broken bones that were healed through manipulation and that sometimes the screaming from the patients could be heard by the neighbours!

Toward the end of Bill's dying trajectory, there is evidence that perhaps word had got around about his illness. Nadine had said that family members at that point tried to persuade her father to take up traditional healing but he refused. However, when Bill became really weak and close to death, an Auntie suggested to bring in a traditional healer and this time, Bill agreed. Nadine said; "…even when he did accept letting the healer in…you could see that it was just out of hopelessness. It was out of that hopelessness. He was looking for a miracle…this was another kind of like, a possibility of some hope" (Int. 1, 2016: 17). Again, his choices are justified through emotion. He had lost his hope of surviving but this provided an opportunity. The suggestion here is not that there is belief that traditional healing will work, but that it provided hope out of the hopeless situation. This is similar to how his faith worked with hope in that God may intervene with a "miracle."

Some further aspects about traditional healing need to be clarified. Nadine told me that the healer had said that Bill had what is known as *lipi* which she said translates in Samoan as inflammation of the thyroid. Nadine said that her father knew it was cancer and not thyroid due to the information he received from oncologists. Nadine told me that; "…there's no word for cancer…" in Samoan healing. We might surmise that this may have been why traditional healing was not adopted. When the healer arrived the first time for Bill's treatment, Nadine said that the healer spoke to Bill and told him that he should have sought traditional medicine sooner:

> Sooner, before the ops. Yeah. Before the ops. Because the healer was just saying 'right it's gone…you know, they have performed these things on you and everything and it's that that's caused this'…you know, where it never…but it started from it being the thyroid (Int.1, 2016: 16).

Bill talked to the healer and said that he had to have the operation because it was in his stomach. The healer rejected this. Nadine said of her father that she "saw the look on his face when he thought that he had made a mistake." The healer indicated that he shouldn't be treating him but he still agreed to do it. Nadine was there when the healer first came:

> And, the man was just going to my father THE WHOLE TIME; 'You left it too late, why did you go Western medicine? And, my dad said; 'I know! But, I have faith in God to know that this is going to help, this will help me now' (Int. 1, 2016: 13).

It is interesting in both quotations that it was Bill's belief in God, not in traditional medicine that he was relying on. He hopes for a "miracle" and he has "faith in God" that whatever the healer does will help him. What is also apparent is that Western medicine taints the efficacy of traditional Samoan medicine. Even the diagnosis of cancer was denied and conceptualised as a thyroid problem. As far as the healer was concerned, Bill's taking up biomedical treatments was the reason he didn't get better. Norris et al. (2009) found that Samoan's distinguish between their illnesses and *palagi*; Western illnesses. They argue that the type of illness can only be identified by the efficacy of treatment. Their study suggested that if illnesses responded to western medicines, they were understood by Samoans as *palagi* illnesses, if they responded to traditional treatment, they were understood to be Samoan illnesses (Norris et al., 2009: 1473). Hence, the identification of the illness comes from success of treatment, not the other way around. The traditional healer was arguing that Western medicine failed because their diagnosis was wrong and not through a biomedical understanding that cancer has no cure. However, this does imply that those who diagnose also cure and those that cure, diagnose.

Bill's reluctance to try his own methods of healing is also paradoxical with regards to another situation from her father's past that she mentions. We were discussing the thyroid and she said that traditional healing had worked for her father before when Western treatments failed. Nadine recalls when her father had an inflammation of the thyroid;

> …a few years earlier he had gone to Samoa and came back and he had a swollen, swollen thyroid gland. And, it was SO massive. He had gone to the doctors and

everything. And, I think it was THAT and he didn't, and he didn't…he knew that THAT was the thyroid thing. And, THAT worked. So, the traditional stuff worked. Coz, he also sought European, so he went to the doctors and everything, they drew tests off it, they did all of this stuff and gave him medication and stuff. Um, but it only got larger. So, then he sought traditional… (Int. 2, 2016: 7).

Even in this instance, traditional medicine cured his thyroid problems yet he did not try this first. When he did, it was successful. However, this prior success with traditional treatment did not seem to influence his decision making when he was told he had cancer. This is probably because a terminal diagnosis is different to a diagnosis of any other kind. The transformation which occurs for the patient is substantial. Further, since he had thyroid problems before he was diagnosed with cancer, he knew that the symptoms were different. Therefore, we can surmise that may be why he accepted the biomedical diagnosis. Once again, background experience impacted his moral reasoning over and above other sources of morality within his moral assemblage.

One may surmise from this that perhaps traditional medicine is sought as a back-up treatment when biomedicine is ineffective (as was the case with the baby). However, Bill's decision making when he was diagnosed with cancer shows otherwise. Nadine's description of the history of healing that her father carried out suggests that some patients sought traditional medicine first and were return customers. She told me that her father had several generations of the one family seeking treatment. Further, Bill had treated patients with broken legs and dislocated shoulders which were cured over a number of visits. This also suggests that they sought traditional healing over and above biomedical approaches.

On the day the traditional healer came, Nadine was responsible for collecting the vine leaves needed for the treatment which grew in their garden. She pounded them up and mixed them with oil before his arrival each day. The healer covered Bill's body in this ointment which turned his body green. And, like Bill's methods for his patients, the therapy consisted of several successive sessions. The treatment was to be done for four days in this case, but Bill only survived to receive three sessions from the healer. Nadine explained:

So, the man had come around for three days and covered my dad head to toe in um, this medicine. So, we had to collect the leaves and they get grounded down and get

added to oil and then he had to be massaged from head to toes. And, the man prayed over him and everything. And, then um, then a knife is needed! (*laughs*) Then a knife is brought into the room…and he's basically speaking to the thyroid…threatening it with the knife…so he did that for three days (Int. 1, 2016: 13).

One can see the different approaches to healing and understanding of illness in this excerpt. The illness is not treated as a purely biological problem but perhaps a spiritual one. Worsley argues that the bio-mechanistic framework of 'western' medicine where the objectified body is a 'case' is in contrast with traditional medicine and healing approaches throughout the world. He claims that symptoms of physical illness in traditional medicines are explained:

> …not within a bio-mechanistic framework which separates nature from the supernatural, the social world from the world of Nature, and the physical individual from his or her social matrix, but which precisely postulates an interdependence of all four: Nature, super-nature, society and person…Physical illness is therefore always approached within a framework that is not naturalistic, but cosmic (Worsley, 1982: 317).

Thus, this holistic approach to treating illness doesn't reduce the body to a biological entity, a 'case', but operates within a framework which is inclusive of social, cultural and cosmic realms which can impact on a person's health. The assumptions or 'truth claims' within this indigenous medicine are that illness can be spoken to, that medicine is only one aspect of healing; the other aspect is spiritual and cosmic. Instead of rigorous aggressive biotechnologies, the rigor required here is an effective threat with a knife.

The most intense sequence of events that Nadine shared with me was her father's last day. Prior to this, when they sat as a family and made preparations for his Will and funeral, her father let the children know that he had signed a Do Not Resuscitate order. Nadine indicated that it was very important to them;

> …one of the preps that my dad had put in place was a non-resuscitation order? Which was REALLY important for us. He would stress that over and over again. And so the day he passed away, my dad…We had no pre-warning or anything but my dad had said; "Go and get your sister from work" (Int. 1, 2016: 19).

Nadine knew that it was a sign that he didn't have long to go. She also said she knew the DNR order was going to be a source of conflict due to her cousin's religious views. Her cousin, Kerry, was a nurse who was staying with them at the time. Although part of the

institution of biomedicine, she didn't express the often proclaimed 'patient's advocacy' asserted by so many nurses. She saw illness in spiritual terms. She told Nadine and the family that her father's condition was worsening because their faith was not strong enough and that they needed to be praying more. Nadine said that there's "the belief that the cancer is a demonic being that you can cancel out with the name of Jesus kind of thing" (Int. 2, 2016: 10). Nadine said that although they were both Christians, they were "not in the same headspace." Although Nadine stressed to her cousin several times how important the DNR order was for her father, Kerry refused to listen and said that if he stopped breathing, she would be resuscitating him.

After Bill told Nadine to pick her sister up from work, Nadine had a feeling he didn't have long to go. She said she drove as fast as she could, picked up her sister, and on their return, they noticed an ambulance going in the same direction. Nadine knew it was going to their place, but her sister said she was being silly. She followed the ambulance all the way to their home and it did pull up in their driveway. Nadine said she knew that her cousin would be trying to revive her father so she ran in the house, cutting the paramedic off on the way to get to him. At the same time, she was yelling out that he had a DNR order. As she predicted, she saw her cousin with her father on the floor pumping at his chest. The paramedics explained the order to her cousin and she stepped away. Not only was the DNR order important to her father, Nadine conceptualised this in spiritual terms:

> And, there was MY…See, I told you! You know, there was my, yeah, you shouldn't have even tried because God came to take him because he needs to rest. And, yet you just think in your stubbornness, to have you know? In your stubbornness you are going to you know, keep him, you are going to try and keep him alive and keep him in this pain kind of. You know, that kind of, you don't know what God you are praying to! (*laugh*) That kind of thing, that was going on so…In her…When I shouted out to her to stop, she knew to stop. You know? She backed away and just started weeping but…it was that whole, yeah. It was a battle of the faiths. (*laugh*). Whose faith? Like, I know that God you know, I know you know? We have a lot of faith and we also have faith that everything happens for a reason. And, he had to go. Um, and that God needed him to rest. And came and put him to rest kind of thing (Int. 2, 2016: 11).

Nadine not only took this action to advocate for her father, his death is conceptualised in terms of being free from suffering. She did describe his final weeks as "heartbreaking"

because he was always in pain. Thus a 'natural' death is the way one should pass and God determines when that time comes. In the second interview, she said to me "Because, at the end of the day, God is the only healer" (Int. 2, 2016: 8).

Discussion

It is a testament to the transformative nature of a cancer diagnosis on the sense of self that the choices that Bill made regarding his treatment seem to ignore what might be considered the most prominent influences making up his moral assemblage. The transformation of self and the occupation of this liminal space becomes so powerful that it prioritises qualitative distinctions and emotions in moral choice. Biomedicine takes priority over traditional healing, family members are kept in the dark and faith in God simply boosted his need for hope. His years of remission attest to his struggle to shake the stigma and be returned back into a status of health adopting healthy habits and embracing a more expansive approach to life. However, it is clear that remission never removes a sense of liminality when the threat of the cancer's return is merely a check-up away. This case demonstrates, in particular, the considerable shifts which occur to subjectivity, identity and life-worlds of the cancer sufferer when the threat of death is forever present. This transformation also shifts the usual parameters of moral reasoning which is evident from many of the end of life decisions which were made in this case. Many of the parts of Bill's moral assemblage were ignored and his reasoning becomes more insular. It was more in line with an embodied moral world informed by experience and emotions than one would expect with so many competing social, cultural and spiritual influences.

A recent study of patients in remission explained that they continue to feel like they are in-between. They say things like; "I have cancer and I don't" (Bruce et al., 2014: 41). Thus, even though remission can bring hope and even a life more thoroughly enjoyed, it is never a complete return back into the society of the healthy. This suggests that the transformation of self is permanent. Bill's body and its potential failure alter his life-world and perception of self indefinitely. Therefore, we should understand that remission may give people renewed hope, but it does not enable the initiate to cross the threshold to the other side – back into the status of the healthy. This ambiguity and transformation clearly alters perception and in turn, one's embodied moral world.

Bill's background experience of his wife's death, previous family interference, and worry regarding the potential of leaving his children orphans informed his moral reasoning. They were past events which made up his qualitative distinctions, but also brought with them emotional affects. Memory and experience, like Husserl's table, bring both symbolic and emotional aspects into present perceptions (Husserl, 1981: 295). Therefore, his qualitative distinctions had greater impact than his usual sources of morality. In this respect, emotions played a role in Bill's moral reasoning in two ways. First he had recently lost his wife and second, he had been previously judged by his extended family. Further, he was convinced of the biomedical optimism which was provided him when he was first diagnosed and therefore, hope played a large role at the beginning. Emotions:

> ...have their reasons, and are not limited to instinctive traits selected by evolution that triggers basic and urgent reactions. They also guide deliberations based on the relation between past learning and anticipations (Kirman, Livet & Teschl, 2010: 216).

The acute liminality experienced after the diagnosis, which is not eliminated by remission, shows that the sense of self is affected and transformed in such a way as to impact moral reasoning. Bill's actions during remission show that he attempted to shift his status away from being a cancer sufferer, and he clearly internalised the message that one is responsible for one's health. The construction of a healthy life-style is, after all, associated with positive self-identity (Powell & Biggs, 2004: 24). The habits he changed attested to his attempts to recover a sense of self that he had before; to shift out of his liminal space and be reintegrated back into the normative health paradigm:

> The worry about immortality can now all be forgotten in the daily bustle about health. Mortality generates *Angst*, disease is pregnant only with *anxiety*. Illness can be conquered, and so anxiety (unlike the *Angst*) does not paralyze, but spurs into action. If immortality cannot be made into a realistic goal, health can (Bauman, 1992: 19).

It is clear that as much as cancer is a constant physical threat, the existential threat is just as powerful and one which Bill was clearly living with. Bill internalized the health message during remission through, as Nadine stated, his "commitment to getting better." Bauman argues, death has causes (Bauman, 1992: 5). We are not dying because we are mortal; we are dying because we have cancer. The implication here is that death can be avoided.

Although we cannot escape death, we can at the very least insure ourselves against its causes by pursuing health. Bill's pursuit of health during remission reinforces this denial of death and shows that remission is not like coming out of a state of liminality. Remission is not a re-birth or "incorporation" back into society with a new status because the patient remains neither ill nor well, they remain symbolically neutral (Turner, 1970: 99).

Even though strong cultural tradition, healing practices and Christianity made up Bill's moral assemblage, we can begin to understand why he made the choices he did. His transformation was permanent and so was the liminal space that he occupied. When we make decisions, we "compare potential alternatives with emotions and feelings from similar past situations" (Markič, 2009: 58). Due to this, his qualitative distinctions became more powerful due to the emotions which arose from them and from the need to protect both himself and his children. His sense of secrecy about his cancer and indeed, his conscious attempt to avoid certain moral influences i.e. from family, attest to the shift in his existential state. The existential threat to self proves to be as significant and important to moral reasoning as the physical threat of death:

> To be in liminality is to be in limbo, on the threshold of between here and there, without social-cultural classification or a medical diagnosis of where 'there' is, will be, or if the ritual subjects ever make it there (Kelly, 2008: 336).

Zigon argues that embodied morality is about being existentially comfortable in one's world and that our engagement ethics is about cultivating this existential comfort (Zigon, 2010: 5). Bill's life-world, with its many social, cultural and spiritual influences could not provide him the comfort that his existential state required. He needed to make choices which were emotionally comforting based on experience and immediate family needs. The liminal space occupied when terminal also affects the life-world in this way. Therefore, in situations such as Bill's, we can clearly see that not only is there a permanent transformation of the self but that this existential shift alters the normal parameters of his moral reasoning. Bill clearly made choices that would make him comfortable, not choices which were true to Samoan tradition and culture. In such extraordinary circumstances, no other moral influence had the power when he engaged with ethics.

We can see that Bill's choices were an attempt to protect and reinstate his existential comfort, although due to the transformation which occurs with a cancer diagnosis, can never truly be attained again. Being terminal is not only a liminal state between life and death, or a liminal state because we fall outside the health paradigm. It is both a state which transforms our status in society, and a state which transforms the self. It does so in such a way that it alters our embodied moral world and in so doing, the nature of our engagement with ethics.

Chapter XII – The Ethics of End of Life Decisions

This phenomenological study of families' engaging with end of life decision making utilised the context of both the dying trajectory and the clinical care experience as groundings. Unlike other studies in end of life care, this research focused on morality as the object of study. Through these narrative case studies, an analysis of the life-world of the participant and their care decisions provided intimate detail into the experiences of terminal patients and the moral world of the carer. Using Cohen's (2004) rules of moral reasoning and Zigon's (2014) theory of moral worlds, I began with the premise that embodied moral worlds are influenced by various sources. Instead of asking what motivates moral actors, I demonstrated how their morality was constituted. This novel approach toward understanding care decisions moved beyond current understandings of the impact and significance of family members in patient outcomes and of temporalities which affect decision making. My findings suggest that terminal patients and carers occupy a unique space where emotions are pivotal in the shaping of moral reasoning for end of life care. This contributes new knowledge to the field of moral and medical anthropology with regard to the nature of our embodied moral worlds and how ethical engagement is affected by death. These findings point to paradoxes which have broader political implications for end of life care which will be illustrated through the concept of autonomy and relationships of power. These raise new questions regarding biomedicine and the human response to death which are conceptualised below by a discussion of the desires for euthanasia which was a recurring theme throughout these narratives.

First and foremost, this thesis contributes to new understandings of the significant role that families play in end of life care. Family experiences and their roles in the clinical care of patients have been the focus of several studies (Abbott et al., 2001 ; Curtis et al., 2002 ; Heyland et al., 2006 ; Radwany et al., 2009 ; Russ & Kaufman, 2005). The impact of family dynamics on end of life care has also been explored, but only within the domain of palliative care wards (Broom & Kirby, 2013). The closest parallel to my study was another by Broom (2016) which explained how informal carers caring for loved ones in the last weeks of their life was a morally ambiguous social practice which mixed ideas of duty, gift and virtue with

feelings of failure, shame and suffering (Broom et al., 2016). In line with this study, my research shows that family dynamics have a significant impact on patient experiences within clinical care settings and that the social practice is inherently moral. However, my research included experiences outside these settings and did not simply report how the family felt, but how these feelings translated into engagement with ethical problems. This is important if we wish to understand the reasons behind decisions. And, since this thesis mapped decision making from diagnosis to death, it provided a timeline of events which these families responded to and engaged with providing a more dynamic picture of how they navigate and coordinate care.

What is evident from this research is that a focus on moral reasoning allowed for insights other studies could not achieve. At the date of writing this thesis, there was no *end of life care* research in this field which focused on morality as the object of study. Although Cheryl Mattingly (Mattingly, 1994, 1998, 2006, 2012, 2013, 2014) is prolific in medical anthropology and has focused on moral reasoning, she has not focused specifically on end of life care. And, as I argued in the introduction, she applies an a priori virtue ethics to the manner in which actors aspire to 'the good' choices. I think I have demonstrated that this can be methodologically reductive. Allowing moral actors to reveal how they ethically engage led me to the discoveries which I will, in due course, extrapolate. Further, this thesis also contributes new understandings to the field of moral anthropology in general. To begin with, it is the first of its kind at the time of writing this thesis to use Zigon's theory (2014) of embodied moral worlds to explain end of life decision making. His theory was useful in understanding and illuminating the impacts of public discourse and institutional moral worlds on embodied moral worlds. His concept of assemblages was also helpful in explaining certain contradictory aspects between the life-world of participant and their choices. However, some limitations of his theory were discovered when the prominence and effect of emotions was found to have a significant impact in the shaping of moral reasoning. Background experience proved influential in informing emotional states as well, which is where Taylor's (1989, 1992) theories of qualitative distinctions helped to explain certain justifications and moral constitutions where Zigon's (2007) moral breakdown theory could not. The patterns he argues participant's follow in solving ethical problems were not consistently identifiable in this research. This is because, I believe, terminal illness elicits an

extraordinary space when families must confront the death of a loved one. Under these conditions, some choices based on emotions were heavily loaded with empathetic sentiment often supported by an impartial source. This finding supported my theory that moral reasoning, when it comes to death, differs from all other forms. The influence of emotions and the social and perceptual shifts transforming their moral worlds affected the nature of their usual engagement with ethics.

So, in what way did emotions affect moral reasoning? Main and his colleagues argue that empathy is both inter-personal and relational and more emphasis should be placed in understanding its function, not its form (Main et al., 2017: 364). The function of empathy and its grounding in inter-subjectivity between patient and carer proved to have a significant effect on engagement with ethics. It gave emotions and feelings priority in decision making but also influenced moral deliberation in other ways. Particularly in instances of prolonged and unrelieved suffering where there were perceived assaults on the dignities of the patient, families made decisions which were so dominated by empathy that other moral influences were relegated to the background and usual compliant adherences to 'moral codes' were challenged. This is because "empathy is both affective and cognitive in its aims. That is, emotional resonance with another serves the goal of attempting to imagine and understand what it is like to be another person" (Main et al., 2017: 362). The more intense the empathy the family member experienced through the caring process, the more powerful their personal embodied moral worlds were over any other moral influences. Public discourse, institutional moralities and other social influences in the subject's assemblage were weakened against the power of emotional, empathetic considerations.

According to many of the families in this study, only *they* knew the person and so understood what was best for their care. Evidence of this was found in expressions of advocacy for the patient by the participant, justifications for rejecting treatments, breaking the rules of the clinical encounter, allowing a continuity of personhood (such as smoking), ensuring provision of a home death and choosing to conduct a living wake. It is clear from my research that empathetic considerations of families were not simply emotional responses, a by-product of witnessing suffering, but attested to both the inter-subjective nature of moral reasoning and the centrality of emotions in shaping it.

This has significant practical implications for several reasons. First, clinical institutions and nursing staff who purport the holistic care approach often proved lacking in practice. This had a detrimental effect on both patients and carers because the family member felt they had to physically substitute themselves in the hands-on care for the patient. And, second, since empathy was central to their life-world and perspective of events, the apparent lack of empathy shown by staff resulted in judgements of character which stifled communications and created tension between staff, families and patients. Indeed, when care and caring form the foundations of cultural and social expectations of nursing (Good, 1994 ; Scott, Matthews & Kirwan, 2013) along with altruism and empathy (Lupton, 2003: 133); their lacking proves to be a major moral transgression. The extent of these transgressions seemed to be directly related to the level of patient debilitation, the level of family support and the efficiencies of the clinic. Thus, these considerations regarding empathy need to be acknowledged and taken seriously within institutions because they directly affect comfort and care outcomes for extremely vulnerable patients. One is not implying that nurses be expected to demonstrate a complete *knowing* of the person as the family does, but as one of my participant's argued, apply the Golden Rule. Acknowledgement of the pertinence of these implications would translate into better communication with families regarding treatment decisions, less patient and family distress and better end of life care.

Returning to other findings in the area of temporality, medical anthropology has done significant research into how it affects clinical care decisions and patient experience (Borbasi et al., 2005 ; Ivanovic, Buche & Fringer, 2014 ; Kaufman, 2010b ; Kaufman & Fjord, 2011 ; Mohammed & Peter, 2009 ; Russ, Shim & Kaufman, 2005 ; Worthley, 2000). Many of these studies have focused on the connection between time and medical decision making. However, what has been made apparent from this research and is that end of life care needs to be distinguished from other medical decision making contexts for two reasons. The first relates to the existential position of the patient and the carer. Terminal illness alters life-worlds where perspectives differ substantially to other illness contexts. Facing death is dramatically different to being ill. This is important to acknowledge for future research in end of life care because, as I have shown, it directly affects engagement with ethical problems and medical decision making.

The second reason end of life care must be distinguished from other contexts is that the life-world and clinical experiences of families and patients are affected by a sense of timelessness. This timeless and unusual space, this liminality, which is occupied by both patient and family, is a concept which has found a resurgence in popularity through its use in explaining the nature of illness experiences for patients in breast cancer remission (Trusson, Pilnick & Roy, 2016) roles and thresholds in mental health education (Evans & Kevern, 2015), patients newly diagnosed with Multiple Sclerosis (Strickland, Worth & Kennedy, 2017) and for explaining the experiences of heart patients on Ventricular assist devices (Standing et al., 2017). In this regard, my research brings this concept to end of life care not simply by way of acknowledging how it makes both patients and carers feel, but how this feeling informs moral reasoning which results in practical outcomes in medical decision making. Just as Good argued decades ago that doctor's communication focuses on present treatment and concerns (Good et al., 1994: 857), I argue in a similar fashion that the present, not the time left, better illustrates temporal effects on decision making for end of life care. Once again, pending death creates a contextually unique space.

There is a final point to make about liminality. When entering this liminal space, as Turner argued, participants loose status and structure and exist on the margins of society, unclassified (Turner, 1967: 98). It separates the individual from their earlier fixed socio-cultural structure into a state of ambiguity which is unlike the past (Carter, 2017: 297). We know that such social transformations already occur for patients, but I must argue that it is just as significant for families. Some recent studies support this argument based on the fact that families close to the patient experience distress, ambiguity and uncertainty due to the inter-subjective nature of the experience (Adorno, 2015: 117). Further, Carter argues that for carers who are family members, the future of their loved one is limited and in turn, their future is also changed (Carter, 2017: 299). My findings support this transformation by proxy particularly since carers who are family members are emotionally engaged with the person. Indeed, the ambiguity of this space, this confrontation with death, reveals certain paradoxes regarding care which I will now explore through the concept of patient autonomy and within relationships of power.

I argued in the introduction of this thesis that true autonomy was not compatible with the good death normative model espoused by institutions because autonomy understood as self-determination would not conform with what institutions believed led to a good death. And, in agreement with other studies, the meaning of autonomy as rational individual decision maker is too reductive (Eliott & Olver, 2008 ; Van Brussel, 2014) and there is tension between the universalising categories and practices of doctors and the relational meanings and practices of biographical persons (Monks, 2000: 28). This research illustrated this tension by making salient the realities of embodied perceptions of patients and families and how they defined autonomy. Overwhelmingly, autonomy did not mean decision making for my participants but had to do with control, control in the preservation of self; to protect personhood. We know that dying affects personhood by bringing the body to the forefront of focus to the neglect of other aspects of personal being (Maynard, 2006: 214). Further, that terminal patients can feel complete subordination to medical hegemony (Waskul & Van der Riet, 2002). These assaults on 'self' corroborate with other studies which showed that families' dissatisfaction with the level of care received in hospitals was due to; "…patients being 'devalued' or 'dehumanised' often due to a lack of adequate personal care and dignity…"(Addington-Hall & O'Callaghan, 2009: 195). However, my research shows that it was not simply the objectification of bodies that was at issue or subordination to medical hegemony. The definitions of autonomy provided by my participants and the manner in which they sought to both protect and preserve these values raises broader political questions regarding relationships of power and systems of control when it comes to end of life care.

As discussed in the thesis, Foucault's systems of differentiation and the instrumental modes are two of the five systems which make up his theory of governmentality (Foucault, 1994: 155). These two are pertinent here as the ideologies and knowledge which form the foundations of any biomedical institution and biomedical rhetoric in general are manifest through the instrumental modes – legitimised practices of intervention (Rabinow & Rose, 2006: 197). Thus, these systems, this governance, creates the relationships of power which allow modern medicine to work on bodies (Foucault, 1994: 345). Taking these two systems, we can determine the dynamic of power between biomedicine and patient and the cultural and social expectations of negotiating this relationship. Kaufman argues that control over

the timing of our death reflects the contemporary biomedical model and expectation in end of life care (Kaufman, 2010b). Further, the ideal promoted in health care to counter this loss of control (through dying) is the promotion of the idea that the patient can assert some control over the way they die (Doka, 2005: 87). Thus, medicine promotes the idea that the governance of bodies is controlled and certain. As is evident from this research, biomedicine can often fail in such areas as misdiagnoses resulting in incurable, advanced stages of disease. Lack of care coordination limited access to appropriate treatment and an inability to control patient's pain. This not only puts into question this system of governance but also leads to moral outrage for families and suffering for patients.

When we focus on the other parties in this relationship, the patients and families, we will uncover what seems to be a paradox in terms of control and responsibility. For Foucault, there is no power without the possibility to freedom:

> ...there is not a face-to-face confrontation of power and freedom as mutually exclusive facts (freedom disappearing everywhere power is exercised) but a much more complicated interplay...freedom may well appear as the condition for the exercise of power...The power relationship and freedom's refusal to submit cannot therefore be separated...At the very heart of the power relationship, and constantly provoking it, are the recalcitrance of the will and the intransigence of freedom (Foucault, 1994: 342).

Foucault focused on the subject's relation to the 'self' within the historical loci in which they exist (Foucault, 1997: 34). Current Western systems of bio-political governance, these relationships of power, serve to make subject to; and empower. Our mode of subjection within this contemporary environment refers to how the 'self' responds to the rule; how individuals are brought to work on themselves (Rabinow & Rose, 2006: 197). Therefore, it does not just concern governance over bodies, but concerns self-governance (Kenny, 2015: 13). Current institutional and public discourses promote the idea that the individual is responsible for their own health (Maynard, 2006 ; Price & Cheek, 2007) and from a bio-political point of view, the delimitation of individual freedoms implicates a notion of responsible self-management (McNay, 2009: 61).

The point I am making is this. The scientific micromanagement of bodies has informed an individualism which has manifested into the micromanagement of self. Power and responsibility over the governance of bodies has shifted from the halls of medicine into the hands and moral choices of humans. We are now responsible, on many levels, for the health of our own bodies. As Rose argues;

> "...the ethos of human existence – the sentiments, moral nature of guiding beliefs of persons, groups or institutions – have come to provide the 'medium' within which self-government of the autonomous individual can be connected up with the imperatives of good government" (Rose, 2001: 18).

The public discourse on health is an implicit form of governance in the guise of empowerment. Indeed, if "...individual autonomy is not is not an obstacle or limit to social control but one of its central technologies..." (McNay, 2009: 63), then it is through this concept that the contradictions in these relationships of power will become apparent.

This quasi 'empowerment', this self-surveillance, promotes notions of human freedom and control over our own bodies, but how does that translate into the realm of end of life care? The paradox in this contemporary system of governance with regard to these relationships of power is made salient when it comes to caring for the dying subject. In the in the process of dying, a society that insists individuals take control over their bodies, when dying, allows no such control. The messages of self-management and responsibility are made redundant. All the promotion of patient autonomy provides little comfort when there are very specific limits to this control. The families in this thesis articulated this understanding of power and responsibility through their moral reasoning, through the manner in which patients responded to their diagnosis, and in responses to systems of care – particularly under the conditions where they were perceived to fail. Under these conditions, it seemed for the families that neither party in this relationship had control.

If we look at the well promoted value of patient autonomy then, we can see an impasse. Autonomy for my participants was about control to preserve the 'self', to preserve personhood. Within this is an attempt to ensure control against failing bodies and an attempt to manage that failure. The paradox is that this autonomy, control and preservation

of self, relies on giving up control. For a level of patient independence in the form of control to become a reality, patient dependence must be successful. Patient dependence can only be successful if medicine has the patient's body under control. A body in control means less existential and physical suffering.   Only biomedical techniques and their successful dissemination can facilitate such autonomous realities as they relate to control and the preservation of self.   Put simply, patient autonomy is only possible where the body and person are managed properly. For the families in this thesis, there was no hope in exercising any form of autonomy when the patient's pain was not managed; autonomy meant nothing unless dignity and personhood, the patient's 'self', was protected.   This protection manifested in some families, as I have said earlier, through advocating – to maintain the person in their 'usual' state as much as possible.

In some cases in this research, dying at home provided some protection against this loss of control. Families who were willing and able to care for their loved one at home expressed less distress regarding their and the patient's experience.   Dying at home facilitated a continuation of self, a rejection of this bodily governance, an attempt at grasping authentic autonomy and of managing these relationships of power. Indeed, those that died at home were said by the families to have had a good death.   Home, which can be the means to preserve personhood, is also a metaphor for the self. Rapport argues that:

> To be 'at home' is to find oneself comfortably open to one's environment, and not wary of colonisation and fearful of the need for closure: one is at home when one has the most expansive sense of oneself (Rapport, 2018: 256).

Thus, we can see that the value of autonomy for families in the preservation of self is about attempting to garner control or protection of 'selves'. But what of those that were unable to have any form of protection of self? The moral reasoning of these families expressed dismay at these assaults on personhood. These were three-fold. Unmanaged bodies, lack of care and empathy and prolonged existential suffering. It manifested in patient behaviour in either complete emotional withdrawal or an outright request to die. Attesting to the inter-subjective nature of moral reasoning and the power of empathy once again, families shared this wish.   Witnessing this subversion of failed promises of autonomy and a lack of biomedical management resulted in both physical existential suffering. This led families to

attempt to grasp some semblance of control that this 'self-responsibility', this autonomous freedom, promised.

The desire for euthanasia, a common recurring theme from the interlocutors in this thesis, is born from this promised right of control over one's body. As I discussed at length in this thesis, the unspoken rule of the Doctrine of Double Effect protects professionals from potential associations with euthanasia by focussing on intent, not outcomes. As one would expect, those dealing with dying patients in palliative care are less likely to support the legalisation of euthanasia (Ezekiel, 2000 ; Lee et al., 2009). Indeed, many doctors who oppose euthanasia believe that better palliative care will eradicate any desire for such practices (Pollard, 1989 ; Wilkinson, 1990). Dr Richard Fenigsen, who has written extensively against the practice of euthanasia, stated:

> Patients suffering from trigeminal neuralgia, who in the past sometimes committed suicide out of fear of a new attack, never do so now thanks to effective medical treatment. I will go as far to say that there is currently no reason for pain, in and of itself, to bring a sick person to despair (Fenigsen, 2011: 245).

Along with this view that medical science can always control bodies is the view that desires for euthanasia are just about pain. We have seen from this thesis that these desires are considerably more complex. They are as much about an inability to suffer further deterioration of selves as they are about bodies. However it promotes itself, we know that modern medicine does not always have full control over the body. Indeed, the need for the DDE suggests that neither dying trajectories nor effect of medicines can be predicted with certainty. These desires, for some of the patients and families in this thesis, for medically assisted deaths are at once an extension of biomedical power and recognition of its limits (Gandsman, 2018b: 334). As Rose argues, we increasingly understand ourselves in somatic terms; human rights have a biological dimension whereby these rights exist just by virtue of our existence (Rose, 2001: 21).

The other point regarding desires for hastened death was that these desires by the patient were often shared by the carers. This attests to the findings herein that for end of life care, emotional affect over moral reasoning is prominent. At no other time would family members wish death upon their loved ones. In this way, empathetic engagement manifests

in shared goals expressed as the right to die. Indeed, I believe the wish for the right to die is not about biomedical control or the lack of it, but is the born from the very self-surveillance messages, the 'techniques of the self', emanating from these systems of governance who insist we have sovereignty over our bodies. This is the central paradox and I believe, one that is not lost on those who are dying. Perhaps this is why right to die activists construct this want for control over death, which requires medical intervention, as a 'natural' way to die (Gandsman, 2018b: 334). A recent ethnography showed that once right to die activists gain the means of this control over their death; it gives them more reason to live. Gandsman argues they "can feel more comfortable with whatever time that remains knowing that they are not trapped by their present circumstance...but by choosing to live, both liberates them and gives their life meaning" (Gandsman, 2018a: 218). Perhaps in some respects, this attests to the liminal spaces occupied by the dying; death solves the problem of existing in this constant state of ambiguity.

To my final point, the findings of this thesis have extensive potential for development. The sensitive nature of death and dying and determinations of 'high risk' research is not denied here as being important and should not be underestimated. However, the findings I have just outlined point to obvious areas of expansion for further research which should include all parties involved with the patient. An expanded ethnography would enable an incorporation of life-worlds which were unreachable within the confines of this study revealing a greater understanding of interlocutors within these systems of power and governance. This would be beneficial not only in furthering our understanding regarding the significance of families for end of life care, but would enable an illustration of the dynamic of clinical institutions, professional staff and the public at the point of interaction. Investigating dying trajectories and clinical encounters from the perspectives of all parties would allow for a much greater understanding of moral reasoning for end of life care and how these interactions and relationships directly affect engagement with ethics. Further, since 'self' preservation in the face of death proved to be a central value for families and for their conceptualisations of autonomy, further work could be done in this area within the paradigm of the anthropology of the self. More application of Taylor's (1989, 1992) theories may prove useful in this area. Indeed, a better understanding of the desires for euthanasia could have potential for expansion through this approach. Recently, there has been a call

for "a more rigorous body of anthropological work on the issue of dying...Investigation of dying has, by and large, a richer pedigree in other disciplines, such as sociology..." (Goodwin-Hawkins & Dawson, 2018: 270). I hope that as an early researcher, and within the restrictions I have outlined, I have countered some of the lack of representation of dying within the field of anthropology and have encouraged and inspired others to pursue the topic further.

Through the lens of the moral reasoning process, I have shown not only how important and significant families are in outcomes for patients during dying trajectories but also have highlighted some practical and political implications of my findings for end of life care. The extraordinary nature of the space occupied during dying trajectories, which affects both patient and carer, demonstrates not only how morality is inherently inter-subjective, but also how important emotions are in engagement with ethics. In this regard, some common assumptions about temporality and decision making have been challenged and the importance of empathy has been uncovered. Through these findings, new understandings in the field of moral and medical anthropology have been unearthed and paradoxes have been indicated which demonstrate that end of life care should be distinguished from all other medical decision making contexts. The prominence of emotions and the liminality of these spaces demonstrate that moral reasoning, when it comes to death, differs from all other forms.

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