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**SUFFERING IN RELATION: AN ETHNOGRAPHIC  
STUDY OF HOSPICE WORK**

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## Abstract

This thesis offers original insights into how suffering unfolds as a relational experience by considering the day-to-day work of hospice staff. In sociology, suffering is understood as a social experience embedded in social and cultural circumstance. The lived experience of suffering is said to threaten an individual's involvement in social life, their relationships and existing roles. However, whilst the existing work on suffering emphasises its social nature in this sense, it largely neglects the relationships between those providing care and the suffering individual. These relationships *emerge through* suffering, while other social relations are threatened and disrupted. The research focuses on how hospice workers negotiate, react to and engage with suffering, in order to examine their relationships with hospice patients. The thesis offers a contribution to several bodies of sociological work: on suffering, emotions, embodiment, the senses, and the social construction of the 'normal'. The study is based on ethnographic research in a hospice aiming to investigate the work of people in a range of occupations. The ethnographic approach involved a sensory focus to illustrate how the hospice workers negotiate their intimate closeness with dying individuals, who are often suffering both physically and socially. The research indicates how the workers' management of the physical body impacts on the social experience of suffering, and how certain relations of the dying person could be maintained through the workers' interactions. In doing so, the work demonstrates how the suffering and dying processes are embedded in socially constructed norms, which are situated within the hospice space and in the everyday actions of the hospice workers. By exploring suffering in this way, the thesis offers an original contribution to existing sociological work. It illustrates how suffering is shaped by, and embedded in, the relationships between hospice workers and patients as a sensory, embodied and relational experience.

**Key words:** Suffering, hospice work, relationality, emotions, sensory, ethnography

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*I, Natalie Richardson, confirm that the Thesis is my own work. I am aware of the University's Guidance on the Use of Unfair Means ([www.sheffield.ac.uk/ssid/unfair-means](http://www.sheffield.ac.uk/ssid/unfair-means)). This work has not been previously been presented for an award at this, or any other, university.*

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# CHAPTER ONE

## Introduction

*'You are making a visual here. But inside something is screaming, 'My God'. But it is time to work. Deal with the rest later.'* - Kevin Carter, quoted in MacLeod (2001)

The above quote from the photojournalist Kevin Carter is taken from a Time magazine (2001) article. Kevin Carter is known for an image that has been referred to as 'the icon of starvation' (Keller 1994: 138). The image depicts a young Sudanese girl, curled up in the fetal position, as she is overlooked by a vulture. The quote, as well as Kleinman and Kleinman's (1996: 5) discussions on the 'moral questions' related to Carter's actions, first stirred my interest in how we witness, react to and engage with suffering. Referring to the article, Kleinman and Kleinman describe how Carter 'adjusted' his camera lens to take the best picture of the girl, staying silent and still, so as not to disturb the large bird. Kleinman and Kleinman (1996: 6) state that it is 'easy to moralize about how Carter's professional success was a result of his failure to act humanely'. Carter was fulfilling the requirements of his job, and was evidently doing his job *well*, as he amassed many accolades and prizes for capturing and later publishing the image. He balanced professionalism, 'making a visual' and needing 'to work', alongside his suppressed reactions to the girl's situation. He describes silently 'screaming, "My God"' while he adjusted his lens and remained perfectly still. An entirely different profession to hospice work, with different aims and responsibilities, this example nonetheless concisely captures the tensions between working as a competent professional, and reacting to, as well as engaging with, suffering '*humanely*' (Kleinman and Kleinman 1996: 6, emphasis added). Furthermore, the example illustrates how suffering unfolds between people, is experienced in different ways, and is shaped by those bearing in the experience. The focus of such debates, which initially captured my interest in the topic, are at the centre of this PhD research. The study takes the focus of hospice workers, whose work is to alleviate suffering, to examine how they negotiate suffering in their day-to-day work, in their intimate relationships with hospice patients. In doing so, the research seeks to provide this alternative perspective on suffering.

## Background to the Study

In sociology, suffering is recognised as a social experience, which unfolds within social and cultural circumstance (Wilkinson and Kleinman 2016). Suffering strips individuals of a sense of self and personhood, as it threatens social relationships and ties to other people (Charmaz 1983; Cassell 1991; Frank 2001). Although suffering can emerge through physical illness or ailments, it is essentially a condition of the self, and what Cassell (2004: 336) refers to as a ‘threat’ to ‘the intactness of the person’. The self is a social phenomenon, and threats to self are ‘at one and at the same time, disruptions of social relationships’ (Bury 1982: 180). The two are interlinked, and suffering is depicted as an ‘affliction of the person, *not the body*’ (Cassell 2004: 336). It unfolds as a social experience in two ways. Firstly, suffering is shaped by the ‘loss’ of (Frank 2001: 355), or disruption to, a person’s social relations with others. Suffering is embedded in the social and cultural constructions of a person as an independent, autonomous being with an able, bounded body (Charmaz 1983; Kleinman 1988; Lawton 1998, 2000). Suffering is often depicted as a ‘negative’ (Wilkinson and Kleinman 2016: 91) experience, as it involves the loss of many different aspects of social life.

Much of this existing sociological work on suffering is based on the first-hand accounts and experiences of suffering individuals, providing valuable insights to the ‘lived flow’ (Kleinman 1992: 174) of suffering to develop an understanding about groups that are often marginalised, and sequestered from society. This thesis situates itself within this existing literature on suffering. However, it offers an original contribution by exploring suffering through the perspectives and experiences of people working with, and bearing witness to, suffering every day. Hospice staff seek to alleviate ‘total pain’ (Saunders 1964: 68) and relieve suffering as a multifaceted experience, which encompasses physical, social, spiritual and emotional pain at the end of life, therefore this research takes this group as the focus to explore how suffering unfolds in their day-to-day working lives. The existing sociological literature outlines the social nature of suffering, by emphasising the ‘loss’ of relationships and the dismantling of social lives. This thesis, by contrast, looks to present the relationships between hospice workers and patients as relationships that *emerge through* and are *brought about by* suffering. By examining hospice workers, I illustrate how they navigate the hospice space and engage with suffering in their day-to-day work. I sought to explore the roles that they play in suffering and end of life experiences. Furthermore, the existing work largely separates the suffering individual and their

experiences from the persons providing physical and emotional care. This thesis seeks to appreciate the narratives, experiences and perspectives of those that bear witness to, and share in, suffering experiences in their day-to-day work. I look to contribute to the existing work by offering the perspectives and accounts of those on the *other side* of this exchange. The existing literature lacks in-depth empirical insight into the roles that these ‘witnesses’ to suffering play in the experiences of suffering individuals and how they are impacted by their work. This thesis is concerned with exploring how the hospice workers interact with as well as experience their relationships with patients and, in turn, examines how the patients’ suffering impacts on the workers. Focusing on hospice workers, this thesis offers an alternative perspective on suffering, which highlights how their reactions to and engagements with suffering shape the experiences within, and the organisation of, the hospice space. The research sought to further a sociological understanding of suffering as a *relational* experience, by focusing on how hospice workers understand, experience and account for their relationships and interactions with patients.

## **The Research**

The perspectives and experience of hospice workers have been largely overlooked in the sociological work on suffering. Where sociology acknowledges the social nature of suffering, the relationships that emerge through and in the context of suffering are largely neglected within sociological thought. The existing literature identifies suffering as grounded in ‘cultural worldviews and social conventions’ (Wilkinson and Kleinman 2016: 17) and this thesis seeks to explore the social and cultural embeddedness of suffering. It asks about the social norms and shared organisational cultures in Broad Lane hospice as well as the everyday practices of hospice staff, their social interactions, actions and shared ideals. It looks at the interplay between shared norms and cultures, and the workers’ everyday routines. In doing so, the thesis seeks to develop a sociological understanding on how hospice workers engage with suffering and how they experience their relationships and interactions with terminally ill patients. The research contributes this alternative perspective to highlight the importance of considering the reactions to and engagements with suffering. The following three research questions were constructed in order to advance an existing understanding of suffering through the experiences of hospice workers:

1. How do hospice workers react to the suffering of patients in the workplace?

2. What kinds of interactions take place between these workers and the patients in the context of suffering, and what is the meaning of these interactions?
3. How do these workers engage with the suffering of terminally ill patients?

The research questions focus on the hospice workers' day-to-day experiences, interactions and their social relationships with colleagues and patients. The study asks questions about the ways in which hospice workers react to and engage with suffering in their work. It considers the social relationships that emerge through instances of suffering and intense pain. Where suffering has been considered a 'loss' (Frank 2001: 355) of sociality, I ask about those relationships and social exchanges that take place in the context of suffering. Such relationships have been overlooked within sociology and in particular, the way in which hospice workers navigate their relationships with people reaching the end of life. By examining their reactions and engagements with suffering, this research sought to appreciate *how* exactly suffering is embedded in social and cultural ideals, practices and norms. By exploring the reactions to and engagements with suffering, we can better understand the ways in which suffering is embedded in social and cultural norms in certain spaces. Therefore, this research sought to expand our understanding of suffering by illustrating the perspectives, experiences and accounts of hospice workers. These groups care for individuals that are reaching the end of life, and I look to examine their roles within experiences of suffering and dying.

The study adopts an ethnographic approach to appreciate the everyday work of the hospice staff and how this unfolds within the hospice space. Observations and interviews were conducted over a period of six months, between April and October 2018. Observations were carried out in the different spaces of the hospice, which, for the purposes of this thesis, I have named Broad Lane Hospice<sup>1</sup>. The observations took place over the two hospice wards in the in-patient unit, the 'day hospice', staff room, reception areas, corridors and in the hospice café. I sought to gather an insight to the behind the scenes work of the hospice staff and so, I often adopted a 'go-along' (Reed and Ellis 2019: 232) approach on the hospice wards to observe moments of intimate, physical care and how the workers interacted with the patients and their colleagues. I was also present in the day hospice for long periods of time, which was an open space and so I would often find myself in the middle of the action and the interaction. The fieldnotes collected offer detailed insights into the everyday work of the staff across the

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<sup>1</sup> Pseudonyms are used to protect the anonymity and confidentiality of both the hospice and the participants.

hospice. The extracts illustrate moments of intimate physical and emotional care on the hospice wards, as well as interactions between day unit staff and patients on the day unit. The extracts also depict moments where I shadowed housekeeping staff on their morning ward rounds and entered into patients' rooms with the nursing staff. The observations adopted a sensory focus, wherein I explore how the hospice space was managed and navigated by the workers. Due to the focus of this study and the ethical confines of the research, this thesis focuses specifically on the hospice workers' experiences of their relationships with hospice patients and their accounts of these interactions<sup>2</sup>. The fieldnotes exclude the hospice patients and therefore this thesis captures the hospice workers' side of interactional exchanges with patients. Eighteen in-depth interviews were also carried out, so as to investigate the emotional work and experiences that take place 'behind the curtains' and behind closed doors (Lawler 1991; Twigg 2006). The interviews also enabled me to explore in detail the hospice workers' understandings, meanings and experiences of their interactions and relationships with both their colleagues and the hospice patients. The research focused on drawing together the experiences of workers in a range of occupations across the hospice, as people working in the kitchen or as housekeepers and support workers are often neglected within the sociological study of healthcare and body work.

### **Structure of the Thesis**

The thesis begins with an overview of the theoretical and empirical literature that has shaped the thesis and many of the debates in the following chapters. The literature review indicates certain knowledge gaps, which the later chapters attempt to address. The chapter is structured into four sections, bringing together literature on suffering, death and dying, emotional labour and the social constructions of 'dirt'. Section one, titled 'Suffering', overviews the theoretical and sociological literature on suffering. This section also outlines the aims of the modern British hospice movement, illustrating how it focuses on alleviating suffering as a multifaceted experience. Section two, titled 'Dirt and Death', considers the management and sequestration of the dying body, which ultimately contributes towards the experience of social suffering. The section highlights how the self is socially constructed, through socially situated notions of 'dirt' and 'normality'. Section three, titled 'The Professionals', turns to the existing literature on how workers in caring professions and 'bodywork' negotiate their emotions, feelings and reactions

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<sup>2</sup> For an in-depth reflection on this, see the 'Ethical Encounters' section in Chapter Three.

in their work. This section also outlines the knowledge gaps in this body of work, bringing these together in the final section of the literature review. Section Four, titled ‘The Relationality of Suffering’, attempts to move beyond the existing concept of ‘emotional labour’ to consider how suffering unfolds as a relational process in interactions and relationships between a multiplicity of persons. The thesis looks to contribute to each of the sociological fields by examining the ways in which hospice workers engage with suffering and interact with patients. This is to develop on a sociological understanding of suffering as a social and *relational* experience.

Chapter Three provides an overview of the methods and ethnographic approach. The methodology chapter explains how the research was designed and the methods implemented in practice, explaining how the research aims align with the ethnographic approach used. The discussion then turns to the practicalities of conducting the ethnographic research in a hospice setting, illustrating the process of conducting the observations, doing the interviews and the thematic analysis. I also provide a detailed description of Broad Lane Hospice to allow the reader to envisage the hospice space whilst reading the extracts and fieldnotes in the later empirical chapters. As the research topic is sensitive, the process of gaining ethical approval and consent from the research participants is discussed in-depth, detailing the ethical issues and encounters in the research. This chapter also describes the day-to-day challenges of researching in a hospice, underlining the embodied aspects of ethnographic research through discussions regarding space, emotions and relationships. Finally, the overlooked process of leaving the field is described: it is demonstrated how relationships are developed with participants over time, and the impacts of doing research, on both the researcher and the researched are emphasised.

From Chapter Four onwards, the findings are presented alongside the existing sociological work in order to develop on an understanding of suffering as a relational experience. Chapter Four considers the sensory aspects of hospice work, demonstrating how the hospice workers react to the patients’ suffering with silence and intimate physical touch, where words and verbal expression were limited. The chapter continues to consider the preparation of food as an act of care, which either sustains or threatens the patients’ sense of agency and control. This expands on our understandings of suffering as an experience that often defies language by exploring how the workers turned to the other senses - touch, silence and taste - to demonstrate

compassion, intimacy and care in their interactions with patients. The chapter emphasises these alternative *sensory* forms of care, which are used to overcome the limits of verbal expression.

Chapter Five continues to highlight the sensory nature of suffering, by examining the ways in which the hospice workers managed certain aspects of the dying process through social constructions of ‘dirt’ and the ‘normal’. The chapter considers the dual nature of dirt: as a social construction and as a material presence. Dirt and dirtiness were experienced by the workers in a physical sense as stains on bed sheets, excretions and offensive odours. Dirt also symbolised disorder, and the chapter illustrates the subtle practices of ‘shutting’ away certain sights, smells and sounds, which disrupted the peaceful, inoffensive social order of the hospice. Finally, this chapter presents a discussion on how the hospice workers reconstructed the ‘normal’ in their interactions with their colleagues, exchanges with the patients and through their use of humour and their *non*-reactions. In doing so, the chapter highlights the malleability and fluidity of the ‘normal’, as continually reconstructed in the day-to-day work of the hospice staff, in order to portray a sense of ordinariness, social order and normality.

Chapter Six continues to illustrate the ways in which suffering unfolds as a relational experience by exploring how the workers’ management of the physical body impacts on the ties to social life. Many of the workers developed intimate relationships with the patients, coming to know them in the contexts of their broader social lives. However, there were exceptions, and some of the workers struggled with pressures from their colleagues to maintain an affective distance. These intimate relationships often resulted in ‘blurred’ boundaries, where the workers needed to maintain professional limits in their interactions with patients. The chapter considers the fluidity of suffering within these intimate relationships, detailing how the workers experienced suffering in relation to the patients, sharing in their experience. Finally, the chapter illustrates the rituals and rites practiced by the workers at the end of a patient’s life. The chapter explores how the workers sustained social life in the moments leading up to, and after, biological death, developing on a sociological understanding that the self is embedded in social relationships and roles. Overall, the three themes in this chapter illustrate the roles the hospice workers play in constructing the patients’ social identities at the end of life and posthumously.

Chapter Seven is the final findings chapter in the thesis. This chapter develops on some of the issues explored in Chapter Six, further underlining the tensions between providing intimate,

holistic hospice care and time-efficient and cost-effective care. Many of the workers described struggling with limited time, scarce resources and bureaucratic regulations, which dictated the type of care they could provide. The chapter also provides an insight into the hospice workers' shared ideal of a 'nice' death, which often conflicted with the patients and their loved ones, as well as with the increasingly medicalised and regulated approaches to care. Overall, the chapter depicts the tensions the hospice workers faced between working in a cost-effective, time-efficient way, and sustaining the patient's autonomy and choice over their death.

The thesis concludes with Chapter Eight. Firstly, I present methodological reflections on the process of doing ethnographic research at Broad Lane. I also discuss the main limitations of the study and I reflect on potential areas for future research based on the emergent findings from this study. The key findings of the research are summarised, and I make clear the original contributions to the sociological literature on suffering, emotions, the body and the sociology of work. The conclusion emphasises, by drawing together three key themes – the sensory, the 'normal' and the social self – how suffering unfolds as a relational, embodied and sensorial experience. I explore the way in which the hospice workers practiced sensory forms of care, as reactions to and engagements with intense suffering. Where verbal articulation was difficult or inappropriate, the findings highlight the use of physical touch and silence as alternative ways of interacting as well as demonstrating care and being intimate with the patients. The staff at Broad Lane played an important role in shaping the sensorial organisation of the hospice space and the experiences of death within it. I consider how the hospice workers shared certain ideas of 'normal' and how they reconstructed these in order to normalise their work and re-normalise the patients' understanding of their situations. The findings tell us of the intimate relationships and interactions between the staff and patients, through the accounts and experiences of the hospice workers. The research illustrates the significant role that hospice workers play in preserving ties to social life at the end of biological life and how their handling of the patients' physical bodies shapes *social* relationships. I draw the thesis to a close by detailing how the staff at Broad Lane shaped the experience and organisation of death and suffering and how, in turn, they were shaped by their emotional engagements with patients in their work. Suffering unfolds in relation to the workers' actions, interactions and engagements, and they experienced suffering *in relation to* their patients.

## CHAPTER TWO

### Literature Review

#### Introduction

Suffering has largely been explored through the perspective of the individual sufferer, and illness narratives have been elicited in order to explore the lived reality of serious, chronic or terminal illnesses (Charmaz 1983; Kleinman 1988; Nettleton et al 2004). This has provided valuable sociological insights into how individuals experience, understand and give meaning to suffering. The perspective of the caregiving professional, as well as how they relate to and engage with suffering, have largely been neglected within sociological thought. Hospice workers seek to relieve social, physical, spiritual and psychological suffering at the end of life or, as it is referred to in hospice care, ‘total pain’ (Saunders 1964: 68). Therefore, the professionals enter into social relationships with suffering patients and often witness instances of intense pain and subsequent death. The ways in which hospice workers react, interact and engage with the suffering of their patients have been overlooked in sociology. Furthermore, their understandings of suffering and their approaches to dealing with their work have been neglected. This thesis and the ethnographic research it centres on seek to explore the hospice workers’ social interactions with their colleagues and the patients. The purpose is to explore the relationality of suffering as well as the manner in which suffering is engaged with and understood by the hospice staff in their day-to-day work.

This chapter is split into four sections which draw together and review the sociological research and theory across the subfields of suffering, emotional labour, and death and dying. Part One begins with outlining the existing understandings of suffering, emphasising the social nature of the experience. In doing so, the section examines the existing understandings of suffering, as embedded in notions of what it *does* to the sufferer or, in this case, the patient. The review will then move on to discuss how suffering can emerge through socially constructed ideals of the ‘bounded’ body and ideas of what constitutes a ‘good death’. This literature is presented in order to highlight the relationality of the suffering experience as a process that is shaped within social settings, interactions and contexts. Turning to the work of professional caregivers, the chapter will then examine the concept of ‘emotional labour’ so as to assess its usefulness in this thesis. The emotional labour concept is often used to explore and appreciate how those in person-facing occupations manage the emotional impacts of their work. Hence, it is useful to

explore this within the framework of this research. This thesis attempts to move beyond the emotional labour framework by contributing an original perspective that examines the relationships and emotional engagements with suffering in hospice work. Therefore, the final section will draw the literature together to begin to explore some of the challenges that caregiving professionals face, such as becoming ‘entangled’ (Dragojlovic and Broom 2018: 23) in suffering and balancing compassion alongside professionalism and routine.

## **Suffering**

### ***Social Suffering***

This research sought to contribute to existing work on suffering that emphasises the social nature of the experience. The existing literature tends to focus upon what the suffering experience ‘does’ to sufferers and how the pain of suffering makes people feel (Wilkinson and Kleinman 2016: 6). This thesis seeks to develop this dialogue by considering the relationality of suffering: suffering as it is experienced by hospice workers in their relationships and interactions with patients. Where the literature on suffering has noted the ways in which it emerges through social and cultural contexts, this research looks to explore the intricacies of these social situations, relationships and interactions, to offer an alternative perspective. It seeks to examine and illustrate the social and cultural embeddedness of suffering, by exploring the norms and notions as shared by the hospice workers at Broad Lane. The relationships between hospice workers and patients emerge through suffering and I seek to examine how hospice workers experience these relationships, with their colleagues and patients, in the context of suffering. Illness narratives and the experiences of those facing forced displacement and poverty have been elicited in order to explore the lived realities of suffering (Das 1997; Kleinman 1988; Bourdieu 1999). Such narratives have been valuable in shaping a sociological understanding and defining an experience that is considered ‘unspeakable’ (Wilkinson 2005: 10). However, such studies have emphasised the social nature of suffering while neglecting the effects of caring for and being present with those experiencing suffering. The caring and the suffering individuals are often separated as two emotionally and physically distinct bodies.

Wilkinson (2005: 83) explains that the typical societal response to suffering is ‘silence’. Studies of social suffering are grounded in developing new ways of ‘*thinking with* the suffering of others’ in order to elucidate it and carry it to the ‘fore of public debate’ (Wilkinson 2005: 82).

In referring to the violence perpetrated towards women during the Partition riots in India and Pakistan, Das (1997) notes how the social sciences have previously reinforced society's silence towards suffering. The denial of the state regarding the abduction and rape of women suggested an indifference towards their suffering, and the women's own silence about their experience was embedded in an inability to articulate the events. As Das (1997: 11) explains, their words 'had the frozen slide quality to them, which showed their burned and numbed relation to life'. The inarticulation of suffering has been shared by sufferers, victims, governments and sociologists. Therefore, many of the emergent studies of suffering attempt to develop an adequate language to understand how suffering impacts on individuals. I look to explore how suffering is engaged with and the types of interactions that take place in the context of suffering to develop an understanding about the 'silences' surrounding suffering. A sensory approach to the research sought to examine the forms of interactions, physical actions and gestures made by the hospice workers.

Due to the subjectivity of the suffering experience, Kleinman and Kleinman (1996: 2) argue that there is 'no single way to suffer', and this subjectivity has contributed to the difficulty to define as well as understand the experience. One element of suffering that we can always be sure, Wilkinson (2005: 17) states, is its inherent tendency to work 'against us' and destroy the aspects of our lives that render us social beings. Cassell (1991) states that physical discomfort can accompany suffering, however suffering is not confined to bodily symptoms. Suffering is experienced as a 'loss' and exists only in the 'absence' of previous social lives, roles and identities (Frank 2001: 355). To suffer is to experience the loss of 'objects, events and relationships' that are important to an individual's sense of self (Cassell 1991: 38). Our 'intactness as persons' (Cassell 1991: 38) comes from our physical being as well as our involvement in social relationships and roles. Therefore, suffering is a social experience, lived 'interpersonally' between people (Kleinman, Das and Lock 1997: ix). However, the existing literature on this topic lacks empirical explorations of how this unfolds in real life and is experienced between people. Hospice workers participate in relationships that *emerge through* and in the context of suffering. Such relationships are largely overlooked when we consider suffering as a 'loss', and this research sought to detail, through the perspectives of hospice staff, the interactions that take place in the midst of suffering. I explore the other side of the 'interpersonal' (Kleinman et al 1997: ix) exchange, to feed into the existing understandings of suffering. Hospice workers enter into the lives of those that are often physically dependent, and I seek to contribute their roles in and experiences of such social interactions. This research

contributes to the existing research by exploring how these care providers develop relationships in the context of suffering and examine how they experience suffering in their work.

Suffering involves an attack on personhood as it is said to threaten our continued existence as social beings with meaningful social ties to others that help sustain our sense of self. In this, suffering leads us to the very edges of existence and to 'the other side of life' (Frank 2001: 355). For Frank, suffering defies definition, as it involves the loss of certain aspects of our lives that are subjectively personal and important to us. It exists in circumstances that we 'cannot come to grips with' (2001: 355) and incorporates a struggle to find meaning during the experience. In this way, suffering appears as the antithesis of rationality, a wholly irrational experience. Frank (2001: 355) states that suffering exists, by definition, on the basis of 'what it is not', defined as a loss of the social aspects of life, which it confronts and dismantles. Therefore, Frank suggests, it is challenging to research, as it cannot be conceptualised. It is characterised by an 'unshareability' (Scarry 1985: 4), destroying words and expressible language. At its most intense, Scarry explains, pain can only be heard through incoherent cries of distress. Extreme suffering has the potential to both threaten and expose the very nature of humanity, social relationships as well as social conditions. Suffering can be understood as a disruption to an individual's sense of self, which exists in relation to personal understandings of social life.

Suffering is described in the existing literature as almost always 'unmaking' (Scarry 1985: 279), both in terms of the impacts on the social world surrounding an individual as well as destructive of an individual's former sense of self. It is a 'product of cultural worldviews and social conventions' embedded in 'historical and material circumstance' (Wilkinson and Kleinman 2016: 17). As a social phenomenon, it is shaped by social and cultural structures, meaning that it is experienced in diverse ways during different periods of time and within different locales (Kleinman 1988; Good et al 1992). Narratives of suffering suggest that it is exacerbated by the loss of social roles, relationships and interactions. Suffering is an existential threat to understandings of self and the 'lived flow' of social life (Kleinman 1992: 174). Much of the sociological work on suffering reaches these same conclusions. However, this existing literature lacks an understanding of how suffering unfolds in relationships and interactions between people. It divides suffering individuals from important personal relationships and overlooks the roles of those caring for suffering individuals in shaping the experience. Furthermore, in focusing on the unshareable and unspeakable nature of suffering, we lack an

understanding of the types of interactions that take place in the context of suffering. This research sought to inform us of the forms of interactions used by those caring for suffering individuals and by adopting a sensory methodology, appreciate the subtle actions, reactions and engagements with suffering.

For Charmaz (1983: 168), chronic illness sufferers experience a 'loss of self'. This emerges as an outcome of the physically debilitating nature of chronic illness as well as the surrounding social norms and stigma directed towards physical bodies bearing chronic conditions, which leads to the disruption and deterioration of existing social relationships. Suffering does not always involve physical pain or illness. Beyond illness, suffering generally emerges through the marginalisation and segregation of groups of poor or forcibly displaced individuals from wider society (Bourdieu 1999; Agier 2002). For Bourdieu (1999), social suffering encapsulates the relationship between economic and social poverty, as well as spiritual suffering. Socially constructed boundaries develop in order to divide normal and abnormal, healthy and unhealthy, visible and invisible, populations. These socially constructed boundaries help to prevent potentially threatening, unhealthy groups from contaminating the 'healthy tissues of wider society' or the existing social order based on a shared sense of safety and security (Bauman 2004: 41). Therefore, suffering is framed around the relational aspects of a person's life and affects the *whole* person as a social being. It comprises of the 'crumbling away of former self-images' (Charmaz 1983: 168) and the disruption of a meaningful social purpose, which is embedded in relationships with others. Suffering emerges with the recognition that a former identity may be completely destroyed, with the incapacity of discovering new, meaningful understandings of the self.

Both Charmaz (1983) and Kleinman (1988) consider chronic illness as involving a multifaceted suffering, which is encompassed by a loss, or a decline, in physical ability and social functioning. Chronic illness sufferers may choose to remain in the confines of the home so as to better manage the unpredictability of their condition, while others fear stigma from a society that favours the physically and socially able. Through this, Charmaz (1983) highlights how suffering is a social experience, exacerbated by the segregation of an individual in their relationships with family and friends as well as their ties to the wider society. Invisible constraints and boundaries, shaped by social and cultural structures of normality and legitimacy, work to segregate groups of people from wider society. Consequently, suffering is devastating of an individual's sense of self, belonging and being. Self is rooted in our

interconnections with others, as ‘meaning’ cannot be ascribed to ‘an isolated human being’ (Elias 1985: 54). The self, and the meanings attached to the self, stem from relationships and interactions with others, and suffering comes about through the loss of and disruption to these relationships. It is a condition of the person and of the self. For Wilkinson and Kleinman (2016: 91), suffering is ‘wholly negative’; embedded in social circumstances, structures, processes and shared ideals, it is an attack on the socially constructed sense of personhood. Understanding suffering in this way, as a ‘negative’ social experience involving certain losses, is helpful to underline the impacts on an individual. However, the sociality of suffering is acknowledged without an understanding of how suffering is negotiated within social relationships between a multiplicity of persons and this view overlooks the relationships that come about *through* suffering.

Reflecting on a number of illness narratives elicited from chronic illness sufferers, Kleinman (1988) highlights that chronicity is not solely a consequence of pathology. Chronicity emerges through illness as well as through experiencing life, social relationships and interactions in restricted circumstances. Others begin to see individuals only for their disability or illness, treating them in terms of ‘unidimensional roles’ (Kleinman 1988: 180). From these relationships with other people, the individual begins to hold ‘negative expectations’ which ‘choke [their] sense of self’ (Kleinman 1988: 180). In this way, Kleinman (1988: 181, emphasis added) highlights the ‘*social* nature’ of chronicity. The individuals inhabited a ‘limbo’ (Kleinman 1988: 181), both socially and emotionally, between two social worlds dependent upon contrasting circumstances of illness and wellness. Suffering with a chronic illness originates from this limbo and emerges through an uncertainty about whether it will ever be possible to re-enter ‘*normal*’ social life. Suffering is exacerbated by such insecurities and uncertainties, ‘assaulting’ (Good et al 1992: 15) the self by threatening what was previously known of an individual’s social life.

The literature presented here illustrates how suffering exists in relation to others and certain cultural norms, and while it often *coexists* with a chronic or terminal disease, it is not necessarily caused by the physical symptoms. It is said to be experienced in relation to other persons, and an individual’s suffering is fashioned by how they experience their social world, relationships and ties to others differently. This research asks about the hospice workers’ roles in shaping experiences of the end of life, their day-to-day practices, shared norms and ideals as well as their ways of interacting and engaging with dying persons. I seek to examine how

suffering is understood by those witnessing it in their work and I hope this will inform our existing comprehension of suffering as an experience that is lived socially. Suffering involves the stripping away of one's former self and sense of social participation, which is entangled in social relationships, roles and interactions. How one 'understands themselves, and how others see them, cannot ... be read in isolation from one another' (Hockey 2008: 348). This thesis seeks to examine how the hospice workers engaged with suffering, to develop an understanding of the interactive and interpersonal processes of dying, death and suffering. The literature largely fails to expand on how suffering unfolds within social relationships and the practices that shape the experience. Reactions to and engagement with another's suffering can evidently exacerbate and influence the experience for the sufferer. However, the work presented here has largely neglected this alternative perspective of the reacting, engaging and interacting individual. While this PhD research does not seek to elicit the experiences of the patients, I explore an alternative perspective on suffering to examine how it unfolds and is experienced by those bearing in and witnessing it. Kleinman (1988) argues that suffering tends to occur when threats to personhood become lasting and a sense of insecurity and uncertainty endures over time. This understanding of social suffering is particularly relevant at the end of life where an individual may experience segregation, loss and a threat to their sense of self.

### *Suffering at the End of Life*

Being cared for, and caring about, engages individuals in interactions and relations with others that are 'saturated with moral meaning ... material practices and symbolic acts' (Wilkinson and Kleinman 2016: 161). However, the experience of suffering has rarely been explored through the perspectives of those caring for the dying and suffering, and especially those caring in a professional context. Focusing on hospice workers enables an insight to the ways in which suffering is engaged with by those that enter into a multiplicity of relationships with terminally ill individuals. The emergence of these new relationships, which are embedded in suffering, as well as the potential impacts of developing relationships *through* suffering have largely been overlooked in the existing literature.

Cicely Saunders is the key figure behind the modern British hospice movement. She sought to develop hospice care that was able to address the holistic nature of suffering at the end of a person's life. Saunders (1976: 1003) established the notion that hospice care should help patients 'to live until [they] die', by alleviating their physical pain and emotional suffering.

Although hospice care operates with the knowledge that the patient cannot be cured, Saunders saw the purpose of hospice workers in making sure that the rest of their patients' lives were as calm and as pain-free as possible. Rather than solely addressing physical pain, hospice care looks to identify and ease 'total pain' (Saunders 1964: 68), and this encompasses mental, physical, emotional and spiritual suffering at the end of life. She explains that this exists in those conditions wherein a patient feels that '*all of me* is wrong' (Saunders 1964: 68). Such a feeling cannot be completely alleviated with only the administering of drugs. Hence, Saunders identified a need for care practices that might engage with the whole person. In founding the modern hospice movement, Saunders (1969) recognised that the suffering related to a terminal diagnosis was often meaningless and lonely. Suffering 'rips apart the social fabric of one's world' (Anderson 2017: 5) and suffering at the end of life is said to be intensified by its endlessness.

Suffering tends to be perceived as a 'loss' (Charmaz 1983) or as 'wholly negative' (Wilkinson and Kleinman 2016: 91) through the dismantling and disruption of relationships. This view often neglects the possibility of hospices as sites of *new* social interactions and relationships at the end of life. Furthermore, there is a lack of sociological literature which explores and appreciates the manner in which *new* relationships and social interactions take place at the end of life. Hockey (1990) notes that the hospice setting seeks to reintegrate dying and living as continuous processes. Hockey's (1990: 155) PhD work adopted an ethnographic approach to exploring the experiences of death across a hospice, residential care home and a bereavement counselling service. She argues that the philosophy of hospice care is focused on developing a 'processual rather than oppositional relationship' (Hockey 1990: 155) between dying and living. She states that entering into a distinct space or institution for dying individuals, such as a residential care home, maintains the societal boundaries and barriers between life and death. For the individual, entering into a place such as a residential care home 'severs connections' and begins the process of 'social death' (Hockey 1990: 157), wherein the individual loses a sense of identity before their physical death. In contrast, hospices seek to 'reintegrate' (Hockey 1990: 155) life with death, and the workers focus on alleviating some of the social suffering that emerges during a terminal illness. She describes hospices as spaces for new forms of social interactions and relationships at a time when individuals feel disjointed from their existing social ties. I seek to draw on the Broad Lane workers' experiences to illustrate the role that they play in and how they experience the concluding days, weeks and months of patients' lives.

The patients' distressful symptoms and their deteriorating relationships with family or friends can be 'transcended' (Hockey 1990: 157) by the hospice's symbolic and spatial features. Hockey refers to the arrangement of the ward space as a shared space, a timetable of certain therapy sessions and activities, as well as the general conduct of hospice staff. She uses the example of the day care centre in the hospice to demonstrate how new social relationships emerge and the patients identified themselves within social circles and engaged in light-hearted interactions with their fellow patients and the staff. For Hockey (1990: 173), hospices were a 'confined space' in which a multiplicity of interactions take place between individuals at varied stages of the end of life. In this sense, hospice care reintegrates life and death and addresses the boundaries between the two in wider society. Hockey's work can challenge the idea of suffering as a 'wholly negative' experience. While patients may be suffering in parts of their life, the hospice space was presented as a site for potential social relationships and interactions. This thesis will contribute to such debates by exploring the tensions between suffering, as a 'loss', and the relationships that come about through the experience of suffering, by focusing on, what Hockey (1990: 196) refers to as the 'uneasy encounters' between hospice staff and patients.

## **Dirt and Death**

### ***'Dirty' Dying***

Following on from Hockey's (1990) argument that hospices address the boundaries between life and death, and that residential care homes reinforce such barriers to life, many other scholars have explored such debates. Lawton (1998, 2000) conducted a similar hospice ethnography and illustrated how hospice patients were often segregated, from both society and the open spaces of the hospice (through the use of side rooms). Her research supports the argument that death and dirt are sequestered from society. Elias (1985: 85) argues that dying individuals have never before been removed so 'noiselessly and hygienically' from society, than in the modern West. Elias (1978 [1939]) also stated that bodily functions, excretions, odours and intimacy are increasingly sheltered from public view and are now understood as private matters, confined to hidden spaces. This thesis situates itself within such debates in exploring the influence of the hospice workers in guiding their patients' sense of social participation - and thus their sense of self. The research aims to contribute to the existing work by adopting a sensory approach to examine how the workers navigate moments that challenge

ideas of normality and of how suffering unfolds in the context of social relationships and interactions between people. I seek to explore the relationships that emerge through suffering from the perspective of the hospice worker and examine how they engage with suffering in their interactions with the patients.

Elias (1985: 74) notes that as people age, they 'are isolated more and more from society' as well as from their social ties to family and friends. For Elias (1985: 74-75), 'emotional isolation' is one of the key elements of ageing and dying in modern social life, and he refers to the many institutions for elderly people as 'deserts of isolation'. Death is often depicted as a 'threat' to rational order. Foote and Frank (1999: 180) note that 'death does threaten a rational controlled world with the chaos of the uncontrollable'. Hospice workers exist and work amidst the 'chaos' of regular death and moments of intense suffering. This thesis takes the focus of hospice workers in order to examine how they navigate suffering and death and to appreciate the everyday practices used to negotiate the processes of dying. Lawton (1998: 121) emphasises that 'unboundedness' and socially constructed *dirtiness* are conditions of death that often result in isolation at the end of life and in old age due to the symbolism of contagion and pollution. Hospices are spaces of intimacy and closeness between the workers and terminally ill patients in moments of feeding, bathing and caring. In these moments, the nature of the work can also be considered to transgress 'the normal boundaries of social life' (Twigg 2000: 45) by 'violating' sensorial experiences of 'touch, smell and sight' (Twigg et al 2011: 172).

Drawing on her ethnographic hospice research, Lawton (1998, 2000) explains that certain deaths were considered too offensive to others and were consequently removed both from wider society and from the view of fellow hospice patients. Lawton refers to such deaths as 'dirty' or 'unbounded' deaths (1998: 121), where an individual loses control over their bodily functions and excretions. These deaths are generally institutionalised, as they threaten the Western ideals of a bounded, sealed, independent body (Elias 1985; Cassell 1991; Lawton 1998, 2000). Lawton adopted a similar ethnographic approach to Hockey; however, she highlights the extent of deterioration and debilitation that hospice patients experience and the segregation that often follows. In doing so, she criticises the hospice ethos and particularly Saunders' (1976) notion that hospice patients are better able to *live* until they die within the hospice space. The ideals of modern Western society are grounded in notions of a bounded, contained body, even in death (Douglas 1966; Elias 1978 [1939], 1985; Lawton 1998, 2000). The isolation of the dying, in particular of those that are experiencing excess excretions,

illustrates a 'denial of a 'bad' death' (Bradbury 2000: 62), which is considered the antithesis of Western ideals of cleanliness, orderliness and peacefulness.

The western notions of self are thought to be reinforced by the institutionalisation of death, dying and dead bodies. The 'dirty' deaths that Lawton is concerned with involved the excretion of potentially offensive odours and substances. These deaths were threatening of healthy society as the experiences involved unfamiliar, and usually bounded, elements of the human body coming into existence. Therefore, these dying individuals were, by Lawton's account, removed from their homes, as their bodies were deemed too repugnant to remain in wider society. Within the hospice space, Lawton (1998: 121) explains that 'unbounded' patients were moved into side rooms, being further marginalised from their fellow patients and hospice visitors. Sequestration happened both from wider society and within the hospice institution. Lawton also suggests that the patients' families began to end their visits when the dying process became 'dirty'. She notes that these deaths seemed to threaten fellow patients, family and hospice staff due to the extremity of suffering on display as well as the smells and sight of the excretions.

Consequently, the 'unbounded' patients experienced a 'social death' long before their physical passing. A 'social death' involves the breakdown of a person's social involvement and relationships with others, in which they become seen as a corpse before their biological and physical death (Glaser and Strauss 1965; Sudnow 1967; Lawton 1998, 2000; Twigg 2006). As the patients in Lawton's study were transferred into side rooms and away from their fellow patients, they experienced a withdrawal from social interaction and sites of possible relationships with others in the hospice, and she relates this to their physical deterioration. Hockey and James (1993) note that the leaking, uncontained body is considered a marker of regression or immaturity and so such norms of behaviour are expected of us from a young age. A failure to manage one's own excretions is looked upon with repulsion in the modern era, as it threatens the social order and shared notions of normality (Douglas 1970). Lawton (1998) states that the unbounded hospice patients offended the hospice staff and patients, which demonstrates the expectations placed on individuals even in the dying process. For Lawton (1998: 138, emphasis added), 'the patients' were looked upon '*as dirt*' needing to be removed, managed and their bodies re-bounded. As bodily excretions came into being, expelled from the body, the patients posed a threat to others with their own 'clearly defined [bodily] boundaries' (Lawton 1998: 137). Social suffering intensifies through the negotiation of the unbounded

body, emphasising how the social and physical states are intertwined. This thesis looks to expand upon this notion by adopting a sensory ethnographic approach to examine how the hospice workers manage the excretions of the physical body, to appreciate how suffering can emerge from, or be alleviated through, such interactions.

Douglas's (1966) work on the social construction of dirt emphasises the way in which our perceptions of normality and cleanliness are formed in social situ as well as through our relationships and interactions with others. Drawing on her immersive anthropological research with the 'Lele' tribe of the Congo and the 'Coorgs' of South India, Douglas (1966: 2) states that 'dirt is disorder' which 'exists only in the eye of the beholder'. For Douglas (1966: 37), things are not dirty in and of themselves, they become dirty when they are displaced; for example, 'food is not dirty in itself, but it is dirty to leave cooking utensils in the bedroom'. Dirt emerges through reactions, which are ultimately grounded in our understandings of normality and appropriateness in a certain situation. Dirt constitutes that which threatens the constructed social order of the society which we inhabit. Our definition of dirt differs between different times, spaces and places. However, dirt exists, symbolically, as 'matter out of place' (Douglas 1966: 41) in all times and places, as defined by the reactions towards the 'matter' at hand.

Recent empirical research exploring the social construction of dirt has developed on the theories of Douglas, by examining how proximity to dirt positions individuals within a social order. Hughes et al (2017: 114-119) conducted an ethnographic study of refuse collectors to show how proximity to waste 'positions individuals' as lower in the hierarchical social structure and challenges the ideals of Western 'normality and acceptability'. This research will incorporate a sensory approach to exploring the work of hospice staff in a manner that appreciates the work of those in different occupations, working across different parts of the hospice. Much of the existing research on caregiving and hospice work neglects the work of those in support work, housekeeping, cleaning, or cooking roles, thereby undervaluing their involvement in the patients' dying and suffering experiences. This research will seek to contribute to existing work by exploring the perspectives of a multiplicity of hospice workers in those roles that are typically neglected in sociological thought.

Eliminating dirt is an attempt to reinstate a sense of order, which has been disrupted and dismantled by the presence of dirty 'matter'. For example, bodily fluids *become* 'dirt' when

they are seen, displaced into a social or public situation. This understanding of dirt as matter out of place constructs the handling of dirt as crucial within the ‘symbolic reproduction of order’ (Shove 2003: 83). Following this line of thought, dirt is a typically *social* matter, and reorganising a dirty environment is to once again bring about symbolic, social order. The symbolism attached to dirt and death as ‘matter out of place’ in public and social life illuminates the socially constructed threats they pose to modern society. The ideals of modern Western society are grounded in notions of a bounded, contained body (Douglas 1966; Elias 1978 [1939], 1985) and Lawton (1998, 2000) argues that this remains so even in death. This research sought to examine the workers’ interactions and engagements with, as well as their actions and reactions to, the patients’ experiences, which ultimately shape the experiences of death and a socially embedded sense of self. Developing this existing literature, the research adopts a sensory approach to examine how the workers negotiate the sensorial aspects of their work and the intimate embodied relations with patients. I sought to explore their reactions to and formulations of the ‘*dirty*’ parts of their work. This thesis intends to illustrate the workers’ engagements with the physical body and the social lives of the patients.

### ***A ‘Good’ Death?***

The sociological conception of dirt and death emphasises the notions of normality and abnormality, which are socially constructed as part of a social order. Bodily boundedness is tied up with notions of (ab)normality, which, from the perspective of Foucault (1991), are both internalised and imposed on the individual through different social regulations. He notes that the ‘judges of normality are present everywhere ... the judge, the doctor-judge, the educator-judge’ and each individual ‘subjects it to his body, his gestures, his behaviours’ (Foucault 1991: 304). Foucault (1991: 304) named this the ‘normalizing power’. He identified the body as an important site of power and an instrument to be managed through the ‘normalising gaze’ (1991: 184), which is both internalised and imposed by external others. Boundedness and cleanliness have been normalised within the modern West, while dirt and death have been relegated as abnormal. Disciplinary power is upheld through the ‘founding and legitimising’ (Foucault 2003 [1974-5]: 50) of certain norms, which determine what is normal and what is not. Through the ‘normalising gaze’, individuals and social groups are brought under control in the regulation of behaviour in order to ensure conformity and prevent resistance to the prevailing social norms. The normalising gaze is a means of exerting control over the actions of individuals and whole social groups, which operates through structural, institutional and

internalised regulation. Such regulation renders persons as ‘docile bodies’ which may be ‘subjected, used, transformed and improved’ (Foucault 1991: 136), and behaviour, ‘corrected’ (Foucault 1991: 200) towards *the* normal. Power is exercised, produced and reproduced through norms, which define behaviour as acceptable and normal, or unacceptable and abnormal.

Ideas of what constitutes ‘normal’ also seep into ideals of death and what is meant by a ‘*good* death’. Mellor and Shilling (1993: 423) argued that modern Western societies are ‘bereft of a communally acknowledged model of a good death’, however, there are often certain, common ideals of the dying process, which are sought by the dying person and those around them. These relate to the prevailing socialised notions of normality/abnormality surrounding death and disorder. The suppression of the dead and dying (Elias 1985) from the public sphere shapes the construction of an idealised ‘good death’, which is often a process that involves ‘falling peacefully asleep’ and ‘quietly slipping away’ (McNamara et al 1994: 1504-6) from social and physical life. Good deaths in Western societies are often depicted as events that unfold with a certain degree of control over physical symptoms, pain and leakages (Bloch and Parry 1982; Lawton 1998; McNamara 2004). Furthermore, death should ‘serve’ (Kearl 1996: 345) the needs of the dying, the loved ones and all those surrounding the dying person. Death can be considered *good* when it aligns with the needs of those persons, and the broader ‘social orders’ (Kearl 1996: 345) in which the people are positioned.

Bradbury (1999) conducted a study which looked at representations of death amongst medical staff, death work professionals and the bereaved in London. She found that the majority subscribed to the ideal of a medicalised good death, in which the individual is ‘unconscious and free of pain’ (Bradbury 2000: 61) and the professionals are in control of the situation. The funeral directors in her study described ‘hiding any evidence of violent, or bad deaths’ (Bradbury 2000: 62). They would clean bodily leakages and disguise physical cuts or bruises as well as hide any noticeable signs of distress. This practice was to ‘create the illusion’ for the loved ones that ‘the deceased had died a good death’ (Bradbury 2000: 62). For Bradbury, this represents a denial of a ‘bad’ death, as a process people struggle to deal with, as opposed to a denial of death in its entirety. Like the construction of ‘dirt’ as defined within social groups, norms and cultural contexts, the understandings of a ‘good’ or a ‘bad death’ are constructed in certain times, spaces and places. Experiences of suffering are embedded within social and cultural ‘worldviews’ (Wilkinson and Kleinman 2016: 2-17) about ideas of normality,

acceptability and a 'good' death. The knowledge of such ideals shifts within different societies and for various groups of people. Broad Lane exists within a certain locale, and I seek to explore the workers' shared notions of death and explore the socially constructed norms that influence their work practices, interactions and actions.

In this, a 'good death' can be considered a 'relational' process, as a death can be identified as relatively 'good' when it 'serves not only the needs of the dying but also those of the survivors and of the broader social orders as well' (Kearl 1996: 345). McNamara's (2004) ethnographic study examined Australian palliative care work and incorporated the accounts of those working in various different occupations. She argues that the majority of the workers in her study actively tried to ease their patients towards achieving their own shared ideal of the 'good death'. She demonstrates the tensions between the palliative care workers helping the patients to, what they believed was, a good death and the patient's own autonomy and control over the manner in which they died. The occurrence of a good death supports and upholds the 'philosophies and goals' of the hospice institution and facilitates a 'smooth running of the organisations' (McNamara et al 1994: 1504). This PhD research looks to develop our understanding of the socially constructed ideals of dying and the normalised notions of a 'good' death. The research adopts the focus of hospice workers to examine the construction of ideals and norms within the hospice space, which are said to influence experiences of dying and suffering.

## **The Professionals**

### ***Emotional Work***

This literature review will now examine the work on caregiving professionals in order to explore the existing understanding of how professionals negotiate physical pain, unboundedness and social suffering. Wilkinson and Kleinman (2016: 162) explain that caregiving comprises of 'heavy lifting, physical support and hard work', with the work exacting a substantial emotional and physical burden on the workers. The work challenges notions of normality and confronts the workers with situations that are usually private. Hockey describes the interactions between hospice workers and patients as particularly 'uneasy encounters' (Hockey 1990: 196), as hospice workers seek to ease another's emotional distress, whilst managing and dealing with their own feelings of grief. Therefore, workers often employ certain practices to distance themselves from the tasks at hand. According to Hochschild's

(1979) definition, emotional labour is the management of emotional responses: firstly, the emotional management of others to bring about a desirable emotional state, and secondly, the manipulation of one's own emotions in order to continue to fulfil one's professional requirements in a work setting. Emotional labour equates to a 'management of feeling', which is performed in order to create a 'publicly observable facial and bodily display' for the setting (Hochschild 2003: 7). This thesis looks to move beyond the concept and framework of emotional labour by highlighting the relationality of suffering and the complexity of relationships between patients and hospice staff. However, in order to move beyond the concepts, an outline of the existing work is required.

In her early work, Hochschild (1983) focused specifically on professionals working in the airline industry, but the theoretical bases of her work can be applied in alternative professional contexts. Applying Marx's (1975) alienation theory, Hochschild argued that workers are alienated from their work as their emotions are commodified. In spheres of work that involve dealings with members of the public, professionals have to accept 'uneven exchanges...[,] disrespect or anger' (Hochschild 1983: 85-6). For Hochschild, the workers are required to disregard their own frustration in these circumstances, hiding their authentic reactions. Rules regarding how professionals should act or feel are imposed by organisations on the workers. Beyond their outer display of emotions, professionals, Hochschild argues, further attempt to alter their inner feelings. In this way, their performance goes far beyond the 'public' self. Hochschild claims that this equates to confusion between public and private selves, with workers unable to comprehend how they truly feel. Their emotions are commodified, and their feelings are governed by the rules present in the organisations they are employed by.

Hochschild's emotional labour concept has faced critique with regards to the degree of control workers possess over their emotions as well as the extent to which emotions are commodified in the workplace. For Bolton (2000), workers possess some degree of control over their affective expression. Parsons (1951) explained that professionals are expected to perform tasks in a detached, unemotional manner, however this becomes challenging when the nature of bodywork and extreme work occupations are taken into consideration. Some of the sights, smells and sensations involved are unsettling, challenging notions of bodily boundedness and intimacy with the body of another person (Twigg et al 2011). Body work involves the handling, monitoring and directing of the body of another person (Twigg et al 2011) and therefore, can provoke the need for emotional management practices. Referring to sex workers, Sanders

(2004) states that they employ humour to emotionally disengage from their clients or certain situations. Although the workers describe some of the sights, smells and the conversations they engage in as 'disgusting', there is an unspoken expectation on behalf of the client that they will meet a 'happy hooker' (Sanders 2004: 282). Therefore, the workers feel it is necessary to divide their innermost feelings from their outer displays of emotion. Disguising these personal emotions maintains professionalism as well as preserves the boundaries between their personal and public feelings. The workers in Sanders' study described how they would laugh with their clients and with their colleagues to make light of the circumstances. Emotional labour is an internalised process and an example of 'deep acting', in which the worker is 'evoking or shaping as well as suppressing' certain emotions (Hochschild 1979: 561). While the workers in Sanders' study may wish to display feelings of repulsion or horror, they displayed the image of a competent professional. Being detached, clinical and rational helps to evade personal or emotional distresses and change the situation for those involved. In contrast to Hochschild, their emotions were not fully commodified; they managed both their inner and outer feelings in order to operate competently as a professional.

Through her interviews and observations with hospice workers, Cain (2012) describes how their front stage behaviour comprised of compassionate, calm and sensitive expression. In contrast, backstage behaviours consisted of morbid humour, efficient planning and strategizing. The participants maintained that both were genuine representations of a professional self and were important in managing the strains of their work. Their proximity to death and dying disrupted any social norms in regard to talking about death. To the workers, death was a natural and celebratory time of life, rather than an event to be sequestered or marginalised. Through talking and joking about death they were better able to understand the dying process as well as perform tasks in the front stage. For Cain, one set of behaviours is subordinated in either the public or private sphere, and both are equally important. While the front stage presentation of self meets the organisational aims of a hospice, the backstage behaviour helped the professional to fulfil their aims in the front stage. Backstage behaviours also helped to create a bond between co-workers as well as manage the stresses of their work. The separation of emotions into 'front' and 'backstage' regions highlights a manipulation of feeling, which supports binary notions of the worker as a care provider and the patient as sufferer. This work on emotional labour neglects the complexities of the relationships between workers and patients by constructing a barrier between backstage and front stage work.

Through adopting these emotional labour practices in the workplace Boyle (2005) argues that healthcare workers may lose sight of the humanity of their patients. In a study of paramedics in Australia, Boyle (2005: 48) describes the added role of managing emotions in the front and backstage as 'emotional process work'. Emotional process work is an additional task, which enables the paramedics to maintain a professionally stable appearance. In using humour to cope with the witnessed suffering and to redirect emotions, the paramedics used similar performance methods as Cain's (2012) hospice workers. However, in doing so they would act with professionalism in front of patients. Many of the paramedics felt that they had become desensitised, due to the frequency with which they experienced - second-hand - death and dying. By contrast, Cain's hospice workers felt an exaggerated compassionate response in the front stage. They remained sensitive to the experiences of their patients, while the paramedics in Boyle's study adopted certain practices to distance themselves from their patients. This tells us of some of the wider differences between medical professions and hospices, where the latter are usually a space of compassion and caring at the end-of-life, rather than curing or extending life (Cain 2012). By contrast, paramedic work is usually concerned with preserving life and working in a time efficient manner to do so (Boyle 2005). In both occupations, the workers engage in a complex on-going negotiation, which involves balancing compassion alongside efficiency and professionalism.

The workers in both studies negotiated compassion in the face of suffering whilst also operating within their professional boundaries. To demonstrate this, Lewis (2005) draws on observational findings of neonatal nurses and found that they performed emotion work by managing their own emotions as well as attempting to negotiate the emotions of the parents. In this way, they would balance professionalism with emotional support while maintaining a suitable distance. Although they demonstrated empathy and feeling by helping the bereaved parents create memory books, they believed that demonstrating too much emotion might jeopardise their professionalism. The nurses negotiated the expectations assigned to their role by acting emotionally and supportively as well as in a detached and professional manner. Lewis describes how emotion and professionalism are not necessarily in direct opposition within caregiving professions, however tensions can arise through 'going *too far*', if interactions and relationships 'veer too much into non-professional territory' (Lewis 2005: 575). Therefore, the nurses were highly skilled in employing various strategies to manage emotions with, and alongside, professionalism, moving between the different forms of emotion management (Lewis 2005: 568). At times, they go beyond their professional duties of care in providing 'gifts' to the

patients and their families (Lewis 2005: 574), through making memorabilia with bereaved families or by offering them time and space to grieve. Essentially, caregiving professionals actively engage in careful decision-making processes, and act accordingly, negotiating the boundaries of professionalism and compassion.

McCreight (2005) draws on narrative interviews with nurses handling miscarriages in hospital and explains that the nurses in the study would develop their own meanings in regard to death. Rather than death resulting in a greater need for efficiency and professionalism, the nurses saw emotion as valuable and appropriate in the situation. Empathy was both a ‘valid and necessary component of decision-making’ (McCreight 2005: 446). In this way, emotion was a way of dealing with the situation and developing relationships with the families by enabling rather than hindering professional efficiency. The care that the nurses provided was holistic, and they would often share a tear with the grieving families. Walter (2017) states that medical professionals care for people with sympathetic concern and an element of vulnerability, approaching patients as human beings first and foremost. However, with increasing rationalisation of medicine and health care, the nurses in Lewis’ (2005: 573) study describe the pressures they faced in being able to provide compassionate care, especially from doctors, who usually embedded their work in ‘prescriptive’ aspects of the situation.

Much of this existing sociological research and literature focuses on the work of nursing staff, who, Reed and Ellis (2020: 313) emphasise, are particularly well represented in studies on the topic. They argue that more research is necessary to explore how those in “‘hidden’” and “‘taboo’” work ‘articulate and manage their emotions in sensitive settings’ (Reed and Ellis 2020: 313). Their ethnographic research on post-mortem work illustrates the, often hidden, emotional work of those in a range of occupations, which has so far been overlooked within sociology. This PhD research sought to explore how those working in various occupations across the hospice handle the sensitive and emotional nature of their work and examine how different groups engage in emotional work ‘regardless of profession, status position or even gender’ (Reed and Ellis 2020: 324). Therefore, the ethnographic research will seek the experiences of those in ‘hidden’ positions, such as housekeeping, support work and cooking. I also seek to develop on understandings of emotions in hospice work, to explore how the hospice staff at Broad Lane experienced their relationships with patients through the different spaces of the hospice.

### *Divisions of Emotional Labour*

The existing literature on emotional labour raises the issues of gender and hierarchy. Reed and Ellis (2020: 324) argue that existing research tends to focus on the ‘marginalisation and feminisation’ of emotional work, with a ‘limited’ focus on particular occupations. Therefore, the existing literature explores the ways in which emotional work is gendered, undervalued and often carried out by nursing staff. Doctors and other clinicians that are considered as at the top of the medical hierarchy tend to distance themselves from the humanity of their patients. As Twigg (2000) explains, doctors are skilled in separating the person from the body and often use certain distancing techniques to do so. For Kleinman (1988: 91), doctors often adopt a ‘dehumanizing’ and ‘narrow vision’ of medical treatment, which is concerned mostly with physical symptoms and divides the body from the social or emotional aspects of illness. The profession is organised so as to disengage with emotion and remove personal involvement or attachment from the role (Kleinman 1988). By contrast, ‘dirty work’ (Twigg et al 2011: 174), which involves intense and intimate dealings with the body of another and often challenges the norms of bodily contact, is considered unskilled, low status and largely female work. For James (1992), doctors are perceived to be highly professional characters, detached emotionally and physically from their patients. Isaksen (2002) argues that the ideals of masculinity encompass ideas of the body in a bounded state, which contributes to the male fearfulness of engaging in the intimacy of ‘bodywork’, or ‘dirty work’. Therefore, the nature and practice of the medical profession is embedded in gendered stereotypes.

The caring professions are usually described as underpaid, their importance underrecognised, and the professions classed as low status roles. James (1989) argues that this lack of recognition for caring work and bodywork is reflective of the low status of supposedly ‘female’ responsibilities within the home. Emotional work is largely invisible, as opposed to physical care, which is visible and easily recorded (McNamara 2004). The work involves ‘anticipation, planning, pacing, timetabling and troubleshooting’ (James 1992: 261). However, the work is undermined as unskilled, devalued and a taken for granted aspect of care work. Medical professionals in lower paid, undervalued roles tend to engage more with the emotions and personhood of their patients. In contrast to doctors and consultants, who interact with patients at key points of their lives, Erickson (2017: 647) argues that nurses and nursing assistants engage with patients in everyday contexts and get to know them ‘well’. This research will attempt to move beyond the existing notions of emotional labour, by emphasising the

relationality of suffering. However, the research will also contribute to the existing literature by exploring the work of those in lower paid, and typically undervalued, positions in the hospice. Therefore I seek to contribute to the currently 'limited' (Reed and Ellis 2020: 324) focus in this field, by adopting an approach that incorporates the perspectives and experiences of those in 'hidden' professions.

### ***Emotions and Death Work***

Referring to palliative care workers as 'escorts through the dying process', Erickson (2017: 650) highlights how higher status workers hold a contextual competence based on training, while lower status workers develop an *intimate* competence in coming to know their patients well over time. Nursing assistants learn about death through sustained, daily exposure to the dying body, rather than through official training. They come to know the person as an individual and are able to provide them with personalised care, as lower status medical professionals are often said to be more approachable and tend to keep patients calm, or simply listen to their traumas (Kessler et al 2015). This research looks to expand on these ideas by documenting the day-to-day work of hospice staff working in a range of occupations. In particular, the research hopes to illustrate the work of those in close day-to-day contact with patients that are largely overlooked in the existing research on hospice care, and health care in general, such as cooks and housekeepers.

Erickson (2017) states that palliative nursing assistants tend to become familiar with their patients' idiosyncrasies and how they can help them die more comfortably. These relationships are key to alleviating forms of 'total pain' (Saunders 1964: 68) and social suffering. Being with the patient through their suffering and getting to 'know them well' (Erickson 2017: 647) has the potential to emotionally burden the professional caregiver. However, the emotionality of the work of those in 'hidden' (Reed and Ellis 2020: 313) occupations is neglected within the existing sociological work. These consequences of such work tend to be neglected both within the academic sphere and within the workplace. Hospice workers witness death, distress and suffering daily, and Funk et al (2017) highlight how they often feel time constrained in their ability to process and express the emotions related to their work. They refer to organisational demands for efficiency, quick rates of patient turnover and strategies for self-preservation as restricting the worker's space for emotional expression. The workers in Funk and colleagues' study engaged in a balancing act, managing compassionate feelings alongside a professional

identity. Crying or displaying emotion were perceived as signs of weakness and a lack of ability to fulfil the professional duties of the role. Therefore, grief and feelings of loss were often suppressed and pushed aside.

Professionalism, efficiency and compassion exist in tension in occupations that are potentially distressing. In hospice care and other healthcare settings, the lack of provisions, time and space for workers to process their feelings is a financial as well as political issue (Borgstrom and Walter 2015). Furthermore, being with the patient to fulfil the aims of end-of-life care is not usually contracted or paid for. Therefore, professionals are rarely able to take time to reflect on the experiences of their work. For Kleinman (1988: 211), therapists and professionals providing physical or emotional care can become 'wounded healers', traumatised by witnessing the suffering of another. However, the characteristics of this relational suffering have not been captured in much detail thus far.

There tends to be a lack of organisational support for professionals undertaking emotional and intimate work. Sorenson and Iedema (2009) draw on their findings from a study at an Intensive Care Unit in Sydney, to demonstrate how the emotional aspects of the clinicians' work deeply affected the quality of care they were able to provide as well as their well being. Performing emotional labour was necessary in order to 'survive the assaults of their work' (Sorenson and Iedema 2009: 6), and the organisation would neglect the stresses of the work placed on the workers. Sorenson and Iedema recommend that the staff acknowledge and discuss the trauma that they experience in order to overcome the emotional challenges. The study also highlights the gendered divisions of labour in regard to the emotional management of patients. Nurses were predominantly female and engaged more with the humanity of their patients and the compassionate side of care. In comparison, doctors were usually male, and they would attempt to separate the emotional being from the dying body. As 'women's and nurses work' (Sorenson and Iedema 2009: 19), emotional labour faces subordination and marginalisation. Emotional labour was intrinsic to the work and helped to maintain the social and emotional well being of the patient, as well as the employees. Despite the need for such emotional work, both of self and others, in caregiving work, there tends to be little recognition of its challenging, complex and time-consuming nature.

Emotional labour and emotion work are inevitably core elements of caregiving work in a hospice setting. This literature illustrates the skill and complexity of navigating emotions while

working in a ‘frontline’ or patient-facing context. Emotional labour, as it is presented here, is the act of manipulating and managing emotions as well as performing appropriately in the workplace in accordance with expectations and requirements. It often involves displaying certain emotions in the front stage and acting otherwise in the backstage (Hochschild 1983; James 1989, 1992; Funk et al 2017). However, this body of literature tends to overlook the relationality and fluidity of emotions and suffering. The literature on emotional labour in the workplace fails to fully explore the ways in which caregiving professionals *engage* with patient suffering in intimate relationships, where suffering unfolds between those involved. The research questions, which are outlined at the start of the next chapter, have been developed with these knowledge gaps in mind and seek an appreciation of how suffering is engaged with and reacted to, as well as the workers’ accounts of the social interactions that take place between them, their colleagues and the patients. This thesis adopts a new perspective, which moves beyond the binary definitions of the patient as sufferer and the hospice worker as a detached caregiver, to explore how suffering unfolds in relationships and social interactions.

## **The Relationality of Suffering**

### ***‘Entangled’ in Suffering: Thinking Beyond Emotional Labour***

As I have demonstrated in this chapter, suffering is said to involve a loss of relationships, social roles and ties to social life. It is often described as a ‘loss of self’, or personhood, which is based on previous ‘self-images’ (Charmaz 1983: 191). Personhood and self are relational concepts (Jenkins 2004; Cassell 2004; Hockey 2008). Hockey (2008: 348) notes that how an ‘individual understands themselves, and how others see them, cannot ... be read in isolation from one another’. She argues that a sense of personhood emerges through interactive processes between how an individual understands themselves, and how others perceive them. The loss of a socially embedded sense of self that occurs in suffering is related to the disruption to and deterioration of relationships, which ultimately help to sustain a person’s identity and self. The meaning of the self is continually ‘developed and maintained’ over the life course through ‘networks of social relationships’ (Charmaz 1983: 170). Correspondingly, through terminal and chronic illnesses, the disruption to and deterioration of relationships causes a ‘*loss of self*’ (Charmaz 1983: 176) and the conditions for suffering. As individuals become more physically dependent and ‘desire...intimate social contact’, which preserves both their ‘self-images’ and their ‘images in others’ eyes’, they also become ‘less capable of maintaining

relationships' (Charmaz 1983: 191). This is a paradoxical condition, wherein social dependency often coincides with feelings of social isolation, and this can exacerbate *social* suffering. This thesis seeks to explore how hospice workers engage and interact with patients in these particular moments of physical and social dependency.

Although suffering is largely understood as a social condition, sociological thought has neglected how suffering impacts and emotionally affects care providers and those in the caring relationships past the point of diagnosis. Broom, Kenny and Kirby's (2020) study, which involved interviewing individuals living with cancer and their nominated carer, illustrated the relational and temporal aspects of living with, and anticipating dying of, cancer. They refer to the 'temporal dislocation' of living with the disease, wherein the 'former self haunts the future and the present' (Broom et al 2020: 1014) through the knowledge and memories of what once was. In the study, cancer was observed as a 'disruption' to the notion of 'who they are/were/will be within time' (Broom et al 2020: 1014). The authors refer to this as a 'renegotiation' of personhood, and a 'rethreading of time' in the ongoing processes of 'becoming' after a cancer diagnosis (Broom et al 2020: 1018). Illness impacts one's sense of self, which is constructed through the disruption of previous, present and future relationships, and the process illustrates the 'temporal and affective entanglements of social life' (Broom et al 2020: 1019). This research aims to explore these 'entanglements' (Dragojlovic and Broom 2018: 23) and in particular to understand how the Broad Lane staff seek to alleviate another's suffering and may become affectively involved in the process. According to Dragojlovic and Broom (2018: 23), the suffering experience unfolds as an 'interpersonal entanglement' of 'affective assemblages' (2018: 3) between persons. While it has been widely acknowledged that suffering is a social experience for the suffering subject, they argue that the other actors are often unappreciated within this 'relational assemblage' (Dragojlovic and Broom 2018: 22). This study sought to explore how hospice workers share in, and shape, the patients' end of life experiences, examining the reciprocity and relationality of the conditions of suffering. By examining suffering through the hospice workers' experiences, I look to study the cultural and social embeddedness in their everyday practices and actions.

This relational nature of suffering, in which suffering unfolds as an 'entanglement ... across' (Dragojlovic and Broom 2018: 23) and between the dying persons, their loved ones and carers, is often overlooked. Much of the existing literature assumes a unidirectional flow of care and a one-sided experience of suffering, however Dragojlovic and Broom (2018: 22-23) challenge

this with their concepts of ‘assemblages’ and ‘entanglements’ of suffering. For Dragojlovic and Broom, caring occurs as a ‘connectivity’ between persons and bodies, through practices of caregiving, which, rather than being ‘delivered’ as an ‘action’, are *shared* between the dying individual and the carer. I hope to explore through this research how suffering can be experienced by the workers ‘*in relation to*’ (Simmel 1992: 60, emphasis added) the dying individual, as they become ‘entangled’ (Dragojlovic and Broom 2018: 23) in the affective process, in a ‘continuity of gain and loss, of flux and of reflux’ (Simmel 1992: 60). This research sought to examine how this reciprocal flow of emotion and suffering unfolds in the hospice workers’ day-to-day work, to continue to challenge the binary notions of suffering and caregiving, as well as to move beyond the distinctions previously made between a ‘frontstage’ and ‘backstage’ experience of work.

For Dragojlovic and Broom (2018), suffering unfolds between a multiplicity of persons in a multidirectional flow. They challenge the ways in which the medical sphere has observed dying as an individualised process and separated the professional from the patient as well as from the suffering ‘of the *other*’ (Dragojlovic and Broom 2018: 25). The binary notions, which separate and distinguish between ‘cared for/caring; caring/suffering’ (Dragojlovic and Broom 2018: 37), neglect the possibility for collective and relational suffering, such as the suffering of professionals *with* their patients, bearing and feeling some of the weight of the experience in the dying process. Notions of ‘compassion fatigue’ (see Alkema et al 2008, Boyle 2011), burnout (see Katsounari 2015), and, I would argue, that much of the existing literature on emotional labour fail to account for these ‘*entanglements*’ of emotional affect ‘across’ persons (Dragojlovic and Broom 2018: 23). Such concepts succumb to assumptions of ‘unilateral’ (Dragojlovic and Broom 2018: 23) compassion and suffering, wherein suffering affects the patient, and the professional feels a compassionate response in turn. The ethnographic research will adopt a focus on how relationships unfold every day in the hospice, to examine how suffering is embedded in social interactions and engagements between patients and workers. Furthermore, the research will adopt a sensory approach to examine the ways in which socially situated notions of ‘dirt’ and ‘normality’ shaped the experiences within and the organisation of the hospice.

The emotional labour literature largely neglects this sociality of emotions and of the suffering experience, wherein the professional or caregiver shares in their dying process. Hospice work is potentially ‘self-dissolving’ (Russ 2005: 129), as it often encompasses a sense of emotional

depletion and deficiency, as the professional gives *of* themselves and becomes emotionally involved in the other person's dying process. The impacts of experiencing another person's suffering in their day-to-day work are embedded in the expectations placed upon the workers, which Russ (2005: 141) describes as 'performing the impossible'. Based on her observations recorded in a hospice primarily serving AIDS patients, Russ (2005: 141) explains that hospice workers are called upon to 'give completely, yet never lose – as pure vessels of compassion, to provide an endless supply of generic love'. The exact complexity of the work and the extent of negotiation of emotions emerge in the need to continually strike a balance between empathy, understanding and care, as well as fulfilling tasks and keeping a professional stance.

Russ (2005: 129) refers to the two, often conflicting, 'economies' of hospice care. She explains that hospices operate at the 'interstices' between 'an ethic of pure gift, sacrifice, and charity' as well as 'by standards of efficiency and discipline, cost containment, and profit making' (Russ 2005: 129). The workers in her study negotiated these two economies in their day-to-day work, through caring, yet remaining at a distance, giving, 'but not giving all', and 'giving everything but one's self' (Russ 2005: 138). She describes the impossible task of giving to patients while not losing one's self and the tensions between being caring yet remaining at a distance so as not to overstep the boundaries in their relationships with patients or lose one's self. Russ describes the workers' collection of grief and loss and the need to practice ritualistic processes of 'cleaning' away the 'accumulation of spirits' (Russ 2005: 148). This demonstrates the fatigue, feelings of 'receiving too much – too much suffering and too much loss' (Russ 2005: 148) - in hospice work. Experiencing the day-to-day loss of patients often leads to a need for limit setting and maintenance of boundaries. Similarly to Dragojlovic and Broom (2018), Russ (2005) describes that the hospice workers found it necessary to maintain some detachment at times, in order to avoid becoming overwhelmed with feeling and bearing in the patients' suffering, which helped them to carry on doing their work.

### ***Rationality and Routine***

Following on from Russ's (2005: 129) 'two' contrasting 'economies' of hospice care, there is a large sociological body of work that examines the tensions between professionalism and compassion. Sudnow (1967) published one of the most influential texts in the sociological study of death and dying in the American hospital setting. His research adopted an ethnographic approach, in which he sought to study the 'daily routinised interactions within an

organisational milieu' (Sudnow 1967: 8) by looking at the social organisation of 'death work' and focusing on the routines, procedures and tasks related to death and dying. Sudnow's ethnographic detail explored the act of pronouncing a person 'dead', tending to bodies after death and examining them, as well as the processes of speaking about death. From his observations, he concluded death to be a 'routine, daily event' (Sudnow 1967: 34) on many of the hospital wards. The hospital was, for Sudnow, a site of bureaucratic control and organisation, meaning that the event of death slipped into oblivion.

Hart et al (1998: 67) describe Sudnow's work as demonstrating the ways in which 'the value of organisational efficiency [is] held far higher than that of human dignity'. Sudnow refers to tasks such as collating files and forms together before a patient's death, in readily prepared 'death packages' (Sudnow 1967: 35), as administrative tasks to help the work of the hospital staff unfold with ease, and a sense of mundanity. Sudnow (1967: 35) states that the preparation of these forms in advance of death informs us how death was regarded as 'an event in a class along with all those matters that are the recurrent daily happenings of ward life'. The hospital operated as an 'efficient administrative organisation' (Sudnow 1967: 35), where death was approached, and was managed, in such a manner that minimised any disruption and disorder. Sudnow's ethnographic detail, about the mundanity of death within the hospital space, reflected on the practices and processes of the workers to make death less noticeable and obvious to others in the hospital. The workers negotiated death with the same regularity as any other day-to-day task, due to its frequent occurrence and need to be hidden. This thesis will adopt a similar approach by appreciating the day-to-day practices of hospice workers, in order to explore how they negotiated death and its frequent occurrence within the hospice.

Moving from Sudnow's hospital, back to the hospice space and palliative care work, there has been much discussion regarding an increasing medicalisation, routinisation and bureaucratisation of its practice (James and Field 1992; Clark 1993; McNamara 2001; Borgstrom and Walter 2015). James and Field (1992: 1368) largely attribute this to hospice care's absorption into mainstream medical models and health systems in the UK, this had led to hospice care being governed by rules and bureaucracy. In the past, and in the emerging stages of hospice care, hospice organisations were 'effective' at 'breaking the "informal" rules of care' (James and Field 1992: 1369) by challenging typical medicalised approaches to death and dying. However, James and Field note a rising trend of auditing hospice services. In this, the ideals of hospice care, of providing 'total care' to dying patients, are dismantled. Instead,

the services are evaluated in terms of ‘quality and cost-effectiveness’ (James and Field 1992: 1370). They emphasise how such measures are at odds with the hospice’s practice and aims, which focus on compassion and demonstrating empathy through the use of communication. Hospice staff work at the intersections of caring, compassion, and being efficient, and this research will seek to examine how the principles of the hospice ethos (to alleviate total pain) are negotiated alongside demands for cost-efficiency and time-effectiveness. Furthermore, the workers’ relational and emotional experiences of suffering will be considered alongside these institutional pressures and demands.

The ethos and guiding aims of hospice care are not driven by the same concerns of those that audit, evaluate and monitor the service. Walter (1994: 167) explains that audits are a ‘growing aspect of hospices’, and it is far easier to demonstrate ‘effective pain control, high bed occupancy and financial cost per patient’ than to emphasise the satisfaction of the hospice patient as well as the workers’ listening and communication skills. The audits tend to focus on the ‘measurable’ aspects (Walter 1994: 168), and the methods to evaluate care are usually quantitative, which tend to overlook the experiences of death and dying in a hospice context. Measures for cost-effectiveness within hospices place ‘emphasis on bed occupancy’ (James and Field 1992: 1371), leading to the dismantling of old traditions, such as leaving a bed empty for a period after a patient’s death. The tensions between such ‘caring’ activity’ and cost-saving tactics (James and Field 1992: 1371) emerge as hospice care becomes more heavily routinised, bureaucratised and regulated through the rational principles of medical systems. For Walter (1994: 166), hospices are ‘caught between a clinical world’, focused on the needs of patients and alleviating symptoms, as well as a ‘financial world’ concentrated on distributing scarce resources. Thus, a ‘hierarchy of care’ emerges (McNamara 1994: 936), which tends to prioritise physical symptoms as aspects of terminal illnesses that are easier to control.

Such ruptures and tensions within the hospice ideals are evident in Broom and Cavenagh’s (2011) study, set in an Australian hospice. They apply James and Field’s notions of a creeping institutionalisation of hospice care by examining the ‘social disruption of the self’, experienced by end-of-life patients (Broom and Cavenagh 2011: 107). The emotional management and efforts to maintain detachment are evident in the interactions between the hospice workers and the patients, where ‘there was a sense of chat, but not conversation’; the patients referred to such interactions as ‘performative, or perhaps fleeting’ (Broom and Cavenagh 2011: 107). The workers attempted to dissociate themselves from the patient’s grief and despair, and the authors

questioned the ‘authenticity’ (Broom and Cavenagh 2011: 109) of the interactions and relationships between the workers and the patients. The effects were observed through the loss of self and the sense of social liminality the patients experienced, as the workers managed the emotional state of the hospice and of themselves through inauthentic ‘hope and cheer’, which ‘dislocated’ (Broom and Cavenagh 2011: 109) many of the patients from the gravity of their situation. Again, the practices of workers impact the experiences of the patients, emphasising the relationality of the dying process in a different sense. The approach adopted in this research intends to build upon these ideas, by contributing the perspectives and experiences of the hospice workers, to explore how they negotiated these tensions between compassion, caring, efficiency and maintaining an affective distance from patients.

## **Conclusions**

This literature review has emphasised the knowledge gaps in the sociological work on suffering. Sociology has largely failed to explore how suffering unfolds in a relational sense between workers and patients. The existing literature on suffering highlights it as a social experience, grounded in social, historical and cultural circumstance, impacting the sufferer’s participation in social relationships, and the emotional labour literature explores the negotiation of emotions and feeling alongside professionalism. The two subfields have often been treated as distinct areas of research, where the professional is neglected in the sociological study of suffering, and the complex relationality of suffering is neglected in the emotional labour and emotional work fields. The existing work falls short of viewing suffering as an ‘*entanglement*’ of affective feeling (Dragojlovic and Broom 2018: 23) shared between workers and patients. I seek to combine these areas of research and theory within this thesis, to emphasise the current limitations and knowledge gaps of both. In the research methodology, I integrate a sensory approach to examine how the physical, dying body is negotiated by the hospice workers alongside their social suffering as two intertwined aspects of the dying process. By conducting an immersive ethnographic study to appreciate the everyday intricacies of hospice work, this research will develop an understanding of how the workers experience and negotiate the physical and social suffering they engage with in their day-to-day work. Therefore, this research sought to develop an understanding of suffering as emerging through relationships and, in turn, to explore those relationships that emerge in the context of suffering.

Drawing on the literature presented here, the research will illustrate the sensory, temporal and relational aspects of dying, death and suffering, through an ethnographic approach that looks to highlight the corporeal and emotional aspects of hospice work. In this, the thesis and the research position itself at the intersection of work concerned with death, dying, suffering, and the socialised notions of (ab)normality and dirt. The work adopts an original perspective by positioning itself between these, usually distinct, sociological fields of thought. Suffering is said to be embedded in ‘cultural worldviews’ and ‘social conventions’ (Wilkinson and Kleinman 2016: 2-17). This research sought to appreciate the social constructions of notions of normality, dirt and dirtiness within the hospice space to examine how suffering and death are shaped by the workers in Broad Lane. Where the existing literature and theoretical discussions on suffering elicit its social nature, I look to detail the everyday practices, actions and interactions of hospice staff that shape the social organisation of Broad Lane hospice and the experiences of those within it. With this focus and conceptual approach in mind, I now move on to outline the research methodology. The research questions have been developed with these literature and knowledge gaps in mind, seeking to explore suffering as a relational and social experience, by emphasising the hospice workers’ reactions and engagements with the patients’ suffering. As this literature review has highlighted, reactions to suffering and dying may help to alleviate or heighten feelings of social suffering. Adopting a sensory methodological approach that sought to appreciate how the hospice workers react to and engage with suffering in their interactions with patients will contribute to this understanding of it as a *relational* process.

## CHAPTER THREE

### Methodology

*'What is special about ethnography ... is the practice it realizes ... The ethnographer's angle of exposure places her so uncomfortably between distinctive moral worlds and local and global ethical discourse and, what is more, creates such a destabilizing tension between them that she is forced to become ... self-reflexively critical of her own positioning as well as attentive to the new and unexpected possibilities that can (and so often do in real life) emerge.'*

*Kleinman 1999: 414-5*

#### Introduction

A number of scholars have emphasised the challenges posed by conducting empirical research on suffering (Kleinman 1991, 1999; Frank 2001; Wilkinson 2004). Wilkinson (2004: 115) argues that in conducting empirical research, 'language always seems to fall short of expressing a substantial part of what suffering *does* to people'. This often leads researchers to question their 'conventional frameworks of analysis and inquiry' (Wilkinson 2004: 115). Kleinman (1999: 414-5) highlights the importance of ethnographic research to study suffering, as a form of inquiry that exposes the researcher to unfamiliar 'moral worlds' and brings about a self-reflexive mode of critical analysis. However, efforts to understand and present a conceptual framework for suffering also have the potential to amplify distress and pain (Frank 2001). The same inexpressibility of suffering is shared by researchers seeking to understand suffering, and Wilkinson (2004: 118) argues that they are plagued by the failure of social science to create an adequate language, in the form of empirical research and analysis, that conveys 'the existential reality of pain and violence'. Suffering has been portrayed as an unspeakable, inexpressible lived experience, which contributes to the difficulties of researchers to empirically study suffering. In the context of these challenges, it is important to reflect on the processes of *doing* this ethnographic research, which is focused on engaging with suffering through the experiences of hospice workers.

In constructing this chapter, I hope to explore the mundane, everyday processes of doing ethnographic research in a hospice setting. Furthermore, I place importance on the aspects of ethnographic fieldwork that are often overlooked, and this includes elucidating the processes

of entering as well as ‘getting out’ of the field (Iverson 2009: 9). I hope to explore these as key moments in the overall process of *doing* ethnographic research. I will consider my negotiations with gatekeepers to enter the field, awkwardly moving about spatially in the hospice and finally deciding how as well as *when* to leave the field. In this chapter I attempt to incorporate a reflexive account of the methodological decisions and ethical challenges of being a researcher. As England (1994: 85 emphasis added) states, ‘the researcher cannot conveniently tuck away the personal behind the professional, because fieldwork *is* personal’.

## **Research Aims and Questions**

Informed by the literature, as presented in Chapter Two, the research sought to illustrate the day-to-day work of hospice staff and, in particular, the way in which they negotiated suffering as a relational experience. In order to meet this aim, the research questions were constructed as follows:

1. How do hospice workers react to the suffering of patients in the workplace?
2. What kinds of interactions take place between these workers and the patients in the context of suffering, and what is the meaning of these interactions?
3. How do these workers engage with the suffering of terminally ill patients?

To appreciate the everyday lives of hospice workers, an ethnographic approach was adopted, and fieldwork conducted in a hospice over a six month period. Eighteen in-depth interviews were also conducted with staff members working in a range of different roles in the hospice. I spent a total of 150 hours in the hospice conducting observations in different areas of the hospice, such as the in-patient ward, day hospice, café and staffroom. The experiences of terminally and chronically ill individuals have been studied greatly, whereas there is a lack of understanding of the perspectives and experiences of those caring for these groups. This research sought to examine how hospice workers engage with suffering in their day-to-day work, contributing an alternative perspective to further develop an overall sociological understanding of suffering. Consequently, the study incorporated only the narratives and experiences of hospice workers, excluding hospice patients from the study and narrowing the focus to only the staff in the hospice. This approach presented unique methodological and

ethical challenges, which I will reflect on later in this chapter<sup>3</sup>. I was often present during interactions and exchanges between the hospice workers and patients, but noted only the words, gestures and actions of the hospice staff. *Interactions* unfold between a multiplicity of people, however this thesis looks to explore how the hospice workers' experience these exchanges, to elicit an alternative perspective on suffering. My decision to exclude hospice patients was further supported by a need to obtain NHS ethical approval. As Reed (2007) highlights, this can be a very complicated and time-consuming process and is often very difficult to achieve within the time limits and confines of a PhD. Consequently, the fieldnotes were recorded in a manner that excluded any quotes from patients, and the interactions were described in a way that only portrayed the workers' words, actions and gestures. The aims of the study are embedded in developing an understanding of the 'dynamic nature of [hospice] work life' (Smith 2001: 225 emphasis added), and I was able to gather an in-depth, original insight into suffering as a relational process through examining the day-to-day experiences of the workers.

### ***Positioning of the Researcher***

The research aims and questions focus on eliciting the 'meanings, functions and consequences of human actions' as they develop in everyday life (Hammersley and Atkinson 1995: 3). Consequently, the research was grounded in a constructionist philosophical positioning and interpretivist epistemology. The combination of observations with traditional interviews reveals the 'complexities' (Atkinson 2015: 22) and intricacies of working life in a hospice. Conducting the research over a period of six months provided insights into 'the mundane [and] the routine' (Hammersley and Atkinson 2007: 5) aspects of the participants working lives, and being present in the hospice offered an understanding of the 'ordinary, ordered ways' (Neyland 2008: 88) in which hospice professionals go about their work on a day-to-day basis. Interviews then sought to gather 'insider accounts' (Hammersley and Atkinson 2007: 52) from those working in the hospice and I was able to ask about their understandings of interactions, events and circumstances. This combination of observations and interviews was particularly fitting in the hospice setting, as there were some elements of the work that could not be observed and took place behind closed doors. Some of the intimate physical care that took place in patient's rooms, such as bathing or dressing, as well as care that took place in patients' homes was out of bounds in my observations. At times, I was able to join the ward staff on 'go-along's' (Reed

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<sup>3</sup> See the 'Ethical Encounters' section on page 65.

and Ellis 2019: 232) to observe ‘board rounds’<sup>4</sup>, experience ‘ward rounds’<sup>5</sup> and enter into the patients’ rooms with the workers.

### **Preliminary Fieldwork**

Before the fieldwork began, there was a period of negotiation and discussion with key gatekeepers at the hospice. Throughout this time, research relationships, some of which had existed previously after a small undergraduate study (Richardson 2016)<sup>6</sup> with staff at the hospice, were redeveloped and sustained, in order to gain access to the hospice. The research project also went through some processes of renegotiation, wherein the gatekeepers suggested I rephrase the wording of the information sheets and consent forms. Prior to receiving ethical approval, I made contact with Eileen, the day unit Sister, who acted as a key gatekeeper to accessing the hospice. At this point, I sent Eileen a short summary of the research proposal, which she passed on to the Director of Clinical Services. In the meantime, I applied for ethical approval through the University’s ethical application process, which was granted in late February 2018.

Eileen was then able to arrange a meeting with Mary, the Director of Clinical Services and Diane, the Sister on the in-patient unit. Eileen played a significant part in the preliminary stages of the fieldwork, arranging meetings and introducing me to key contacts at the hospice, making the negotiations of access much easier than anticipated. Eileen had been working in the hospice since it had first opened, just over twenty years ago, and so she was seen as a trusted individual, who could ‘vouch’ (Reeves 2010: 318) for my intentions as a researcher. Prior to the meeting, Eileen, Mary and Diane were provided with copies of the information sheets, consent forms and a proposed poster that I planned to put up around the hospice to show that a research study was being conducted there. In the meeting, Diane offered advice, especially on the wording of the information sheets. Diane explained that my use of the word ‘shadowing’, to inform the workers of how I wished to observe them, was inappropriate. In her reasoning, she noted that as medical professionals, her staff might feel as if they were going to be inspected, almost as if they were being audited, which might make them reluctant to participate in the research.

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<sup>4</sup> ‘Board rounds’ took place in the mornings on the wards and before patients arrived in the day hospice. A multidisciplinary team would review and discuss the patients’ needs and their current symptoms.

<sup>5</sup> ‘Ward rounds’ usually took place after ‘board rounds’ and involved a multidisciplinary team entering into the patients’ rooms to talk with them and assess their symptoms.

<sup>6</sup> I carried out 12 interviews with hospice staff in 2016 as part of an undergraduate dissertation.

Most of all, she wanted verbal assurance that I would not be physically ‘following’ the workers wherever they went.

My initial intention in planning the fieldwork was to enter the hospice with a hybrid volunteer/researcher role. However, in the preliminary meeting, the gatekeepers decided that it was best that I did not adopt a volunteer role. Organisational ethnographers tend to adopt certain roles in the field in order to develop relationships with those being studied and gain deeper insight into the organisation (Hammersley and Atkinson 2007). However, my role as a non-participant observer was agreed in the preliminary meeting with key gatekeepers, where they agreed that I should not adopt the role of a volunteer to avoid ‘over-rapport’ (Ballinger 2008: 590) and potential deception. For Neyland (2008: 81), ethnographers must participate in a balancing act in order to avoid ‘going native’. I adopted an ‘insider-outsider’ (Lofland and Lofland 1995: 97) role, not becoming too integrated in the hospice set-up in order to avoid over rapport and deception as well as to engage with the hospice as an unfamiliar site. Lawton (2000: 27) describes wearing ‘two hats simultaneously’ by adopting a volunteer role during her hospice ethnography, as a potential challenge wherein the participants were unsure whether they were talking with the ‘volunteer’ or the ‘researcher’. However, she also explains that acting as a volunteer meant that she was present in scenarios where it would have been too ‘awkward or obtrusive’ (Lawton 2000: 31) for a researcher to be present, such as after a death on the ward. As a researcher, I found myself in a tentative position, in comparison to the gatekeepers who could ‘control, mediate and support access’ (Caine et al 2009: 493) to Broad Lane. Therefore, in line with the gatekeepers’ wishes, I opted for the role of a non-participant observer. As I was not able to adopt a volunteer role, I sometimes experienced the awkwardness of feeling out of place, or too still amongst the busyness of the ward. However, I soon learnt how to navigate and embrace such awkwardness, finding it more ethical and appropriate to move to another space when necessary.

The senior nurse, Diane, was also interested to know whether I would be making notes about the patients, which I assured her I was not. I had made the decision not to pursue the NHS ethical process and therefore was not able to make notes about the patients’ actions or anything they said in exchanges with workers. This decision was made for several reasons. It was made in light of the hospice being a charitable trust, which was funded by various sources and only partly by the NHS. My research aims also focused on exploring the day-to-day experiences of

the hospice workers, rather than those of the patients. Most of all, the time limitations of doing PhD research meant that pursuing NHS ethical approval would have been difficult. The NHS ethical process is often viewed as ‘difficult, time consuming or simply impossible’, especially for an NHS ‘outsider’ (Reed 2007). Featherstone and Northcott (2020: xiv) describe the NHS ethical process as a source of ‘‘mock terror’ in the corridors of Universities across the UK’. On reflection, receiving NHS ethical approval would have made my research findings more inclusive, in terms of providing a fuller picture of the interactions between the workers and the patients. I was only able to record the one-sided interactions of the hospice workers, as opposed to the patients’ reciprocal interactions and exchanges with them. However, the research focused on the hospice workers’ understandings and their engagements with their work. I was able to concentrate my observations on the workers’ actions, their phrases and movements, as well as their day-to-day work practices, to attend to the gaps in knowledge. Conducting the interviews alongside the observations meant that I was able to ask the hospice staff about the meanings they assigned to their interactions with patients. Ultimately, the feasibility of gaining NHS ethical approval within the timeframe of a PhD was a major deciding factor.

Both Mary and Diane sought reassurances that I would feed the findings back to them and the other staff after the fieldwork had ended. It was agreed that I would return after my analysis to present my findings, which I did in late 2019. The preliminary meeting was a formal process of ‘renegotiation’ (Hammersley and Atkinson 2007: 3) of access to the hospice, coming to agreement about my presence there over the following six months. It was agreed in the meeting that I would conduct observations on the in-patient unit first, as some changes were taking place in the day unit and the number of days that the service was provided were being reduced. I was somewhat reluctant to agree to this, as Eileen, the gatekeeper, worked as the Sister on the day unit. I was going to be ‘going it alone’ so to speak. However, as a researcher, and meeting key individuals in the hospice for the first time, I had rather tentative attachments to the hospice, and my access was granted by this group of gatekeepers. Consequently, I agreed to start my observations on the in-patient unit.

### **Doing Hospice Ethnography**

Ethnographic studies in medical and healthcare settings have a well established history. My research was grounded in some of this existing literature and influenced by some of the

approaches that had been adopted previously in medical settings, such as Hockey's (1990) anthropological account of the experiences of death, Glaser and Strauss' (1965) study on the awareness of death and dying in hospitals as well as Atkinson's (1975) ethnography in an Edinburgh Medical School. I attempted to illustrate the mundane practices and routines of the hospice workers, adopting a similar approach to Sudnow (1967: 8) in his classic hospital ethnography, by examining the 'daily routinised interactions within an organisational milieu'. I attempted to explore the micro actions, jotting down situations that, at the time, felt ordinary or routine or, simply, quite dull. As Tipper (2020: 138) illustrates, ethnographic research offers a way of 'attending closely to people's ordinary, lived experience', and by adopting this method I was able to experience the hospice workers' everyday routines and practices as their days unfolded. Furthermore, I sought to examine the interplay between embodied everyday interactions and the organisational cultures and norms of Broad Lane hospice. Featherstone and Northcott (2020: xi) draw on their recent ethnography of British hospital wards to note that an ethnographic approach enables an insight to the 'unspoken and tacitly understood' as well as the broader 'social world' of the hospice, which allows us to explore the day-to-day work of hospice staff as well as the institutional characteristics that shape such care.

The hospice space was an unfamiliar site. However, I entered into the everyday that belonged to the hospice workers, and so I was able to pay 'detailed attention' to the 'ordinary practices and local understandings of mundane life' (Tipper 2020: 138). Adopting this ethnographic approach in the field meant that I was able to 'enter into and to share the everyday lives' of hospice workers (Atkinson 2015: 3), examining their routines, everyday practices and the taken for granted aspects of their work. Conducting observations over an extended period of time enables immersion into the workers' ordinary working lives, eliciting a 'vivid, dynamic and processual portrayal of lived experience' (Smith 2001: 232) as it unfolds in real time. I was able to record the workers' movements about the hospice space, their gestures and interactions, as well as the sensory experiences of being and working in a hospice. I sought to explore how the hospice workers managed their emotions and engaged with patient suffering both away from and with patients. Consequently, observations were carried out in different areas of Broad Lane hospice. I observed across the in-patient unit, day unit, the staff room, café and reception areas over the six month period. The gatekeeper, Eileen, gave me a tour of the hospice on my first day of observations and assured me that I could access all areas in my research. I will now provide a detailed description of these spaces within Broad Lane hospice, to illustrate the setting before the later empirical chapters in the thesis.

### ***Broad Lane Hospice: The in-patient unit and day hospice***

Broad Lane hospice provided in-patient and day care to adults with palliative needs in the local area. It is situated in a town in the North of England, and the town has a relatively small, majority white, working class population with a small ‘Black and minority ethnic’<sup>7</sup> population in comparison to the national demographic (ONS 2011; ONS 2019<sup>8</sup>). Originally, when it opened at the end of the 1990s, the hospice held four single en-suite patient rooms and one same-sex communal ward. It was renovated around ten years ago, when the ward space was converted into fourteen single, en-suite patient rooms. The hospice could therefore currently hold up to fourteen patients at a time, and each patient had their own contained facilities. Some rooms had spacious balconies that overlooked the fields below the hospice.

The in-patient unit, which the staff members often referred to as the ‘IPU’, could be found a short walk away from the main reception, down a short corridor. Leading off from the corridor to the IPU were some ‘quiet rooms’, which were designed for patient and family use. There was also an administrative office, guest bathrooms, two clinical rooms and a stairway that could only be accessed by staff members (the staff room, community team and management offices could be found downstairs). Before entering the IPU, there is a set of double doors. The doors usually remained open and were only closed when a patient’s body was being removed, out of sight of those in the reception. The in-patient unit was split into two wards. A side exit and a ‘breakout space’ could be found in the middle of the two wards. The ‘breakout space’ held a small kitchen and a set of sofa chairs. The space was designed for the use of patients, volunteers and staff, but the hospice volunteers mostly congregated in there. The side exit near the ‘breakout space’ was used by the ambulance service to bring in new patients and the funeral directors to wheel the bodies out discreetly, without having to use the main entrance.

While on the in-patient unit, I would usually try to get to the hospice for around 8:30am, in time for the ‘board round’ in the doctor’s office. The board round took place each morning and was attended by the senior nurse, doctors and consultants as well as the ward clerk. The staff would gather around a whiteboard to review each of the patients currently on the hospice wards.

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<sup>7</sup> I use this term in quotation marks to reflect its use in the original source. I recognise the problematic and ‘highly contested’ nature of this term (Gunaratnam 2003: 17).

<sup>8</sup> References omitted from the reference list to preserve the anonymity of the hospice and participants.

A 'ward round' followed the board round meeting, where the staff would visit the patients in their rooms. I attended this meeting on a few occasions, and I found that it enabled me to join the staff as they moved about the wards and entered the patients' rooms. I was able to observe the workers' actions and interactions with patients as well as their embodied ways of caring, moving the body and handling medical equipment by going along with them on the ward rounds, which made the 'hidden' (Reed and Ellis 2020: 312) work much more accessible. The busyness on the in-patient unit would fluctuate at different times. Mornings were usually the busiest time of the day, when nurses would be administering medicines, health care support workers bathing patients and the housekeepers changing bed sheets or cleaning patients' rooms. In comparison, the afternoons were quiet, so the nurses would take the opportunity to write their notes, the doctors would usually be in the office and the health care support workers would wait around listening out for patients needing their help. However, in the afternoon there was often opportunity to talk with some of the workers, as they were stationary for longer periods of time.

I began observations in the day unit after around two months. The day unit held four sessions a week on three different days. Just before I began my fieldwork in the hospice, the days that the day hospice services were offered had been cut down from four to three due to funding. In our interview, Eileen discussed the '*finite*' amount of money the board of commissioners had available to them, which often resulted in decisions such as those to cut day hospice services and prioritise the physical, which I will discuss further in Chapter Seven. At the time of writing, Broad Lane hospice is an independent charity, reliant on substantial amounts of charitable donations and fundraising each year. In the last year, the hospice received nearly sixty percent of their income from the NHS, and the other forty percent was raised through charitable donations and fundraising events. They need to raise at least two million pounds of voluntary income each year to continue providing their services and maintain the hospice site. A board of trustees were responsible for the strategic governance of the hospice and for overseeing the work carried out by the hospice staff. They also rely on over four hundred volunteers to help care for patients across the wards and the day hospice.

On the days it was open, the day hospice hosted around fifteen patients. Due to the recent changes, two groups would attend on a Thursday and the day would be split into a morning and an afternoon session. Patients would need to be referred by their GP, over the age of 18 and have palliative care needs to attend. They could only attend the day hospice for a limited

time, namely until their symptoms became stable enough to be discharged back to the GP or until they passed away. The day hospice sister, Eileen, handled the referrals and discharges, and she would admit to me on numerous occasions that discharging patients was one of the most challenging aspects of her job. In comparison to the in-patient unit, the day hospice had more of a homely feel. There were mismatched comfy reclining sofa chairs in the conservatory, where patients could relax and chat. There was also a large table for craft making where the patients could do ‘memory work’ (see image 1 and 2). The ‘memory work’ was supported by the health care support workers and the volunteers, who would prepare the table with crafts before the patients arrived. The day hospice cupboards were well stocked with different crafts and the patients could paint picture frames, design memory boxes, write letters or cards and make silk scarves for their loved ones. The crafts table was a place of both laughter and sadness. The craftwork had very emotional undertones, with the patients making things that could be left behind after they died. The crafts represented the ways in which ‘the materiality of things is... more permanent than the materiality of the body’ (Gibson 2008: 1), as the patients designed objects that they intended to leave behind for loved ones after they died.



*Image 1: The entrance to the day unit, the tea-making station and the crafts table.*



*Image 2: The crafts table in the day unit, set up ready for patients to arrive. In the background is the lounge area, where the patients often relaxed on the 'comfy' chairs.*

My role in the wards shifted from a researcher sitting on the sidelines, watching and waiting for interaction and dialogue, to an active participant in the day unit, taking part in games and (*often reluctantly*) gentle exercise classes. In the in-patient unit, I often adopted what Van Maanen (2011: 2) refers to as the position of the 'self-reliant loner', watching from a chair in the middle of the ward and talking with the workers whenever they had a moment to spare. My role shifted and adapted as a fluid position in the hospice throughout the fieldwork process. This was in stark contrast to my vague role as an active member of the day hospice, where I would take part in activities, play games and engage in light-hearted interaction between patients and staff. As Charmaz (2006: 21) notes, the ethnographic researcher might become 'more involved in the scene than anticipated', with little time to jot down fieldnotes and a pressure to become involved in the day-to-day happenings in the setting. This occurred much more often in the day unit, and I often had to scribble notes from memory in my car once leaving the hospice at the end of the day.

### ***Writing the Fieldnotes***

Ethnographic analysis is a continuous process, which occurs both in and out of the field (Hammersley and Atkinson 2007). Emerson et al (2011: xv) describe the process of writing

fieldnotes as a largely ‘hidden and mysterious’ practise in ethnographic research. Therefore, I will reflect here on this ‘hidden’ process, to elucidate the embodied and methodological challenges of writing fieldnotes whilst in the field. I kept a field diary in order to enable me to reflect on ‘ideas and hunches’ throughout the fieldwork (LeCompte and Schensul 2010: 214). The majority of the fieldnotes serve as ‘imperfect’ (Atkinson 1992: 468) records and reconstructions of the settings as well as what I considered to be key events and interactions that took place during the six-month fieldwork period. Tipper (2020: 139) highlights that fieldnotes incorporate the experiences, reflections and perspectives of the researcher, and so the researcher often shapes what is considered important and unimportant. Sometimes, I relied on memory when it was inconvenient to carry the notepad with me. In such instances, I would type notes into my phone or write them down shortly after the event. I would develop my fieldnotes at home, adding in the extra detail or moments that I may have missed from earlier that day.

Although I was able to record detailed fieldnotes about my time in the hospice, in certain moments it was much more challenging to record in-depth notes and intricate details. On the ward, taking notes might have been seen as quite ordinary, as much of the nurses’ work involved jotting things down on paper. However, the challenges of note taking were particularly apparent in the day hospice, where I became much more of a participating observer as part of my fluid role as a researcher (Charmaz 2006). Recording details would mean withdrawal from the activity and segregating myself as a researcher. I was in effect, ‘participating-to-write’ and ultimately developing relationships with the workers to form better quality fieldnotes (Emerson et al 2011: 24). I would often be the subject of flippant remarks from staff members during my time in the hospice. In one instance, one of the health care support workers asked me whether I was ‘writing nice things about us in [the field diary]’. At a different time, another member of staff asked me where she could ‘get a job where [she could] just sit around all day’. Jotting down notes in my field diary in the presence of the workers often resulted in inquisitive remarks and reminded them of my presence. I would often find it easier to disappear for a few moments, either to the toilet or to sit at a table in the café, to write my fieldnotes. I opted mostly to record my notes in private, away from the sight of the staff in the hospice. Crang and Cook (2007: 57) refer to the phenomenon of ‘ethnographer’s bladder’, where it is often necessary to make several, frequent toilet trips to quickly jot down notes in private, away from the eyes of staff members. This also helped to avoid disruption to my ‘roles

and relationships' (Crang and Cook 2007: 57) with the hospice workers, who were much less aware of my note taking when I did it in private.

The fieldnotes replicate an account and a portrayal of the important, ordinary and routine aspects of working life in Broad Lane hospice. As Van Maanen (1988: 1) points out, ethnographic notes are 'written representations of a culture (or selected aspects of a culture)'. Atkinson (1992) explains that fieldnotes reflect the researcher's interpretations of events as well as their decisions to omit certain aspects of the field. Inevitably, analysis began at the very beginning of the fieldwork, where I decided what to include and to omit in my writing about the hospice. Fieldnotes are interpretations of what is classed as important by the researcher, and the omissions from the fieldnotes are based on decisions made by the researcher whilst in and out of the field. The omitted moments are never recorded and are never seen by anyone other than the researcher, as details and moments of interaction and dialogue that are insignificant in the eyes of the ethnographer. Emerson et al (2011: 9) explain that fieldnotes are not 'facts' collected about situations which occurred in the research setting, they are descriptions, which 'select and emphasise' certain aspects of the field while 'ignoring and marginalising others'. Fieldnotes are an interpretive process, which requires much self-reflection (Emerson et al 2011). As an example, my focus in doing the research quickly became focused on the sensory experience of being and working in a hospice as a place that was embodied by the smells, sights, sounds and physical relationships of those within it. The fieldnotes helped to develop my focus for the later interviews, which took place after a lengthy fieldwork period. As I will explain later, from the fieldnotes I was able to construct themes, which guided the interviews.

### ***Thinking about the Sensory: A Methodological Turn***

In adopting an approach to studying the everyday work of hospice workers, I was able 'to become part of the human encounter with death' and bear witness to some of the same 'sights, sounds, social encounters' as hospice professionals (Hockey 1990: 20, 166). Soon after beginning the fieldwork in the hospice I became focused on the 'multisensoriality' of the hospice experience and that of the hospice workers (Pink 2009: 1). Spaces of care and caregiving are 'permeated' with 'sensory experiences and emotional reactions' (Edvardsson and Street 2007: 25). For example, Lawton (2000: vii) described the hospice in which she conducted fieldwork as a place that contained 'visible signs of bodily decay, the stench of

incontinence, the lethargy and despondency of patients'. Researchers doing similar fieldwork have previously taken an approach that accounts for the senses and the day-to-day sensory experiences of being in a hospice or other medical setting more narrowly conceived (see Lawton 1998, 2000; Gunaratnam 2009; Featherstone and Northcott 2020). As Mason and Davies (2009: 587) note, the sensory is 'in ordinary and everyday ways' part of our experience of human life and our social relationships with others, and so we cannot 'filter that reality out of our social scientific ways of knowing the world'.

The sensory became an integral aspect of the data collection, where I focused on the sights, smells and noises within the hospice space to develop an understanding of the physical space, as well as the ordinary and everyday work of the hospice staff. As day-to-day life unfolded in the hospice, I was able to experience the 'sensory routines and rhythms of life' (Pink 2009: 65) as well as the 'unspoken and tacitly understood' (Featherstone and Northcott 2020: xi). Back (2007: 8) argues that researching with a 'democracy of the senses' means that, we, as researchers, are more likely to 'notice more and ask different questions of the world'. He describes the importance of sociological listening as embedded in an 'openness to others that needs to be crafted' and that which listens to 'the background and the half muted' (Back 2007: 80). As so much that researchers attempt to understand 'about other people's lives is unlikely to be noticed by them or easily put into words' (Crang and Cook 2007: 77). I was able to appreciate the subtleties of interaction, the unsaid and the 'intangible' (Perkins and McLean 2020: 156). In adopting this approach, I sought to examine the ways that the hospice staff interacted and acted in embodied ways, to examine and understand the 'silences' (Wilkinson 2005: 83) of suffering. The fieldnotes detail the complexities of working life as it is lived, felt and experienced within the hospice and appreciate the mundane as well as the ordinariness of hospice work. Furthermore, I paid close attention to the work of those who are often hidden within sociological research on healthcare and emotional work as '*background*' workers. The experiences and perspectives of cooks, housekeepers and support working staff are relatively unheard in comparison to doctors and nurses (Reed and Ellis 2020) and the fieldnotes documented their roles in the hospice space. A focus on their work also developed my sensory methodological emphasis, as their work involved preparing food, managing the cleanliness of the space and physically and intimately caring for the patients.

This sensory approach was adopted quickly after entering the hospice for the fieldwork and later went on to form an important part of the findings. For example, Chapter Four illustrates

the significance of physical touch and the importance of silence and food work as sensory forms of care. Chapters Five and Six illustrate how certain sensory emissions, such as noises and smells were managed by the workers, to explore the social, symbolic order within the hospice, shared by the workers. Whilst I was in the hospice, I noticed the sounds which were considered normal and those that were considered less so. The singing and joking of the housekeeping assistants could be heard throughout the wards, while patients' doors were shut, and grieving families were ushered into 'quiet rooms'. Lavender air freshener would cloud the shared spaces, while any smells of urine and faeces would be kept contained by a shut door. Reflecting on these sensory experiences within the hospice can help to 'vividly' illustrate the setting for the reader, provoking 'auditory ... [and] olfactory images' which offer more of a 'complete description' (Emerson et al 2011: 58). In the context of this research, adopting this sensory focus engages with the day-to-day work of hospice staff, in examining the way they negotiated the smells, sights and sounds of death, dying and grief.

As Pink (2009: 60) reflects, 'through our own emplaced experiences we can gain better insights into those of others'. Sensory reflections often take a very self-reflective tone, as they are indications of how the researcher interprets their own experiences within the field setting. Taking the opportunity to walk and move about the hospice with the workers enabled me to 'live and move as [the workers] do' (Lee and Ingold 2006: 69). For example, in the following extract from my fieldnotes I have joined the ward cleaners on their morning rounds to clean each of the patients' rooms:

On to the next room, the door is open for staff or visitors to walk in and out of, but there are no family members in this room and the patient is asleep, so I decide to stand outside the door again. Just as the cleaners start their work in this room, a health care support worker stops them "I keep smelling something", "well it's not us!". Yvonne, one of the cleaners, goes into the room and she dims the bright lights while telling me that she does this as she feels it is more "relaxing for the patient... they don't need those bright lights on them". Yvonne then goes over to the patient and gently covers up their arms with the blanket. She stands at the end of the bed and looks at the patient with a smile "aww, the other day she was sat right up in that chair"; she points to a chair next to the bed.

Moving about the spaces of the hospice provided me with insight into the up-close intimate care occurring in the patients' rooms and on the day hospice, especially the work of those that have often been overlooked as carers of the dying in previous sociological research. Reed and Ellis (2019: 210) highlight how adopting a 'go-along method' in ethnographic research exposes some of the 'hidden aspects' of work practices that are often 'shrouded in secrecy'. They adopted this method of walking with post-mortem workers and conducting interviews on the move in their study to demonstrate how the 'boundaries' of the work are 'fluid' and are 'rarely tied to one location' (Reed and Ellis 2019: 212). The method helped to 'demystify' (Reed and Ellis 2019: 219) some of the work that often takes place behind closed doors, and I found that by 'going along' with members of staff, wherever possible, I was able to highlight some of the work that is often neglected within sociological research. For example, the extract from fieldnotes presented above illustrate the housekeeping assistants as they tend to a patient, dimming a light whilst the patient is asleep and covering them up with a blanket. Such intimate acts, carried out by housekeeping staff, were exposed by drawing on this method and moving about with them through the wards during their 'rounds'. Moreover, moving about the wards with the hospice staff allowed for an insight into the sensory interactions and moments of physical touch, as well as the opportunity to experience the emotions and relationships involved in doing hospice work.

I also reflected on my own feelings of awkwardness of moving about with the workers, deliberating where and how to stand while they busily moved about. Often, the richest and most detailed fieldnotes were recorded from these moments of moving with the workers, joining them in their day-to-day rhythms of work in the hospice. I could observe the physical closeness of the workers with the patients and their interactions, as they unfolded as an embodied and lived experience. However, as I will explore further in this chapter, moving about *with* the workers was not always feasible, and doing the fieldwork often involved a lot of inactivity and sitting with the movement going on around me.

### **Doing the Interviews**

Caregiving professionals are considered difficult to observe at times, since the majority of care work tends to take place behind curtains, closed doors or within patients' homes to preserve the dignity of the patients and the professional (Lawler 1991; Twigg 2006). Interviews enable an insight into the aspects of social life that take place 'behind closed doors', where Miller

(2001: 3) argues, 'most of what matters to people is happening'. In conducting interviews, I was able to talk with a number of workers that worked in the community and in patients' homes. Gaining ethical approval from the NHS would have been necessary to enter into the patients' homes to observe the community staff as they worked. Therefore, carrying out interviews with hospice staff that worked in the community provided an insight into their work. Such work, that takes place in indoor spaces, such as the home, is often 'hidden' (Reed and Ellis 2019: 210) and where I was not able to physically go-along with these staff, I was able to engage in in-depth conversations with them in our interviews. I approached members of staff working in different roles, in order to gather a range of different experiences<sup>9</sup>. I interviewed eighteen hospice staff working as consultants, doctors, nurses, health care support workers, physiotherapists, a therapist, a bereavement support worker and a cook. The interviews usually took place during their working day and so, they were often difficult to arrange or took place on an impromptu basis when the participants had some time available. The interviews covered the elements of the participants' working lives that took place out of sight as well as the meanings the workers assigned to their work practices. These 'insider accounts' (Hammersley and Atkinson 2007: 52) built upon the data that had already come out of the observations. The interview guide and overall focus of the interviews developed over a prior fieldwork period of four months in the hospice. During these months of fieldwork, I began to observe and construct some important key themes, such as the importance of physical touch and humour in authentic relationships between workers and patients, as well as the tactics to contain death or distress.

The interviews allowed for reflection on certain meaningful incidents, relationships and interactions that had occurred in the hospice during my time there as well as a chance to seek clarification on my interpretation of these events. I began conducting the interviews towards the end of the fieldwork, which meant that I was able to organise the interview schedule<sup>10</sup> around the key themes from my observations in the hospice. The interview schedule consisted of open-ended, broad questions, framed around key themes, such as relationships, forms of sensory interactions, emotions and suffering. I would start each of the interviews by explaining the contents of the information sheet and consent form and asking for their consent to record the interviews. Each of the participants agreed to the interviews being recorded, and I often took notes during the conversation.

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<sup>9</sup> Participant profiles can be found in Appendix 1.

<sup>10</sup> The interview schedule can be found in Appendix 2.

I began the interviews by asking a set of introductory questions about their employment history and asking, *'what drew you to hospice work?'*. I organised the interview schedule in a manner that progressed towards the questions that I anticipated might be more difficult and emotional to talk about. After the set of introductory questions, I asked the workers how their work *'made them feel'*. The questions on emotions were followed by questions on the different forms of interaction that I had noticed during the observations, such as the use of humour and physical touch. Then I would ask, *'what does 'suffering' mean to you?'*, as well as ask whether they felt they experienced suffering in doing their work. The final sets of questions considered their relationships with colleagues and patients as well as how they managed their emotions.

I would try to end each of the interviews on a positive note, especially when the interviews had felt particularly emotional. The final question I posed to the participants was *'how has your work changed you?'*, which they often engaged with very thoughtfully. After conducting a few interviews, I found that my confidence as a qualitative researcher developed, and I did not need to rely on the interview schedule. Although the interviews were purposefully open-ended, I steered the conversations in a way that felt informal, while keeping to the key themes and topics. Where my observations focused on how the workers carried out their day-to-day work, the interviews sought to appreciate the *'meaning of actions and events'* (Spradley 1979: 5, emphasis added). I was able to explore the findings from my fieldnotes in detail in order to elicit the hospice workers' understandings of certain events. I could also ask questions that were particular to the individual participant. For example, there was a particular situation during my observations where one of the nurses on the in-patient unit had directed a grieving relative into one of the hospice's 'quiet rooms', and so I asked about this situation in my interview with this particular staff member. I was able to check my understanding, to understand their 'meanings' and experiences (Spradley 1979: 5) of certain events and circumstances.

### **Thematic Analysis**

As I have already touched upon, analysis was an evolving process, occurring both while I was in the field and once I left the hospice. In the fieldwork period, I was somewhat engaged in thinking about the data and developing my initial ideas about the potential themes. After each day at the hospice doing fieldwork, I would type up my fieldnotes and reflect upon the events

of that day. Throughout the fieldwork period, my key ideas about the study were already beginning to be shaped by the emergent data. I familiarised myself with the fieldnotes to develop an interview guide with certain themes that I wanted to ask my interview participant's about. At this point, I had a clear idea about some of the important themes, which inevitably led the focus of my remaining observations and shaped the interviews. These early themes in the fieldwork period centred on the importance of touch, the use of humour, authentic relationships and keeping a certain social order of events, interactions and the sensory in the hospice.

Upon leaving the hospice and finishing the six month fieldwork period, I entered into a more focused and structured analysis phase, building my thinking about the data further than the preliminary analysis. Firstly, I transcribed all of the interviews and ensured that all of my fieldnotes were typed up. After a period of transcription, I worked with the data, reading and re-reading interview transcripts, fieldnotes and scribbles to discover and construct key themes. I would mark certain sections of the interview and observation data, colour coding it to separate it in different, yet inherently interconnected, themes. The interview and observation data seemed to correlate with each other, with the interviews echoing the findings from the fieldnotes. The interviews often offered further detail, where the fieldnotes lacked some depth of meaning. My approach to analysis was largely thematic, which involved 'identifying, analysing and reporting patterns' from reading the fieldnotes and interviews (Braun and Clarke 2006: 83). This approach meant that I adopted an active role in coding the data and the themes were constructed through my 'thinking about [the] data' (Ely et al 1997: 206) as well as how I interpreted the participants' accounts.

The fieldnotes and interview transcripts were read systematically and repeatedly in order to become familiar with the data. This approach helps to create detailed interpretations and develop the findings 'beyond the obvious meanings in the data', whilst preserving the narrative accounts and lived experiences of the participants (Clarke and Braun 2013: 121). Drawing on Braun and Clarke's understanding of thematic analysis, the process involved appreciating the 'events, realities, meanings [and] experiences' (Braun and Clarke 2006: 86) that I encountered in the hospice during the fieldwork and interviews with staff members. In order to further interpret the themes, I revisited the existing literature and my theoretical frameworks after identifying certain patterns within my data.

## **Ethical Encounters**

Suffering is an inevitably sensitive research topic. Focusing on the experiences and accounts of hospice workers presented particular ethical and methodological issues, and there was a potential for emotional distress. The existing literature suggests that caregiving professionals can experience second-hand suffering in managing the pain of another person and emphasises the difficulty of speaking about experiences of suffering (Kleinman 1988; Frank 2001). It was necessary then, to adopt a sensitive and self-reflexive approach to conducting the fieldwork in the hospice. I followed the appropriate procedures to gain ethical approval from the University of Sheffield. I also familiarised myself with the British Sociological Association's (2017) most recent statement of ethical practice to ensure the research abided by their guidelines. In doing so, I made certain adjustments and decisions to ensure the safety and anonymity of the participants throughout. The participants were given pseudonyms and I refer to the hospice as 'Broad Lane' to ensure its anonymity. These principles of confidentiality and privacy will remain in any future publications to come out of this research. In conducting the research, I began to develop an understanding of ethical issues and processes as on-going matters, to be handled and engaged with throughout the entire research process. Here, I consider ethics as a fluidly evolving process, which requires flexibility, reflexivity and thoughtful decision making throughout the research: before, during and after the fieldwork. In this section, I reflect on the ethical issues I encountered over the course of the fieldwork and how I navigated these.

Patients were excluded from the data collection and this decision was made in light of my research aims as well as the difficulty involved in obtaining NHS ethical approval (Reed 2007; Featherstone and Northcott 2020). Furthermore, my institution strongly discourages students, where possible, from doing research that involves engaging with the NHS ethical process. The study sought to explore the hospice workers' accounts and *their* experiences of interactions and relationships with patients. In light of the research focus and the difficulties in obtaining NHS ethical approval, I described the *interactions* between hospice staff and patients in the fieldnotes through noting only the words, gestures and actions of the staff. This often presented methodological and ethical challenges, where I was sometimes present during an interaction between hospice staff and patients, but I was only able to document one side of the exchange. The research findings elicit the important perspective of the hospice worker and I explore how suffering is reacted to, engaged with and the forms of interactions used by the workers. However, *interactions* take place between a multiplicity of people. So, it is necessary to note

that the research findings and fieldnotes would have, at times, been strengthened by the voices and actions of the hospice patients in the interactions.

I described and detailed the interactions between staff and patients very carefully in my fieldnotes, making sure to exclude any specific details about the hospice patients. I detailed the workers' actions, words and subtle gestures, which usually occurred *in response to* the patients and certain situations. Ahmed (2004: 4) draws on the interactivity of emotions to suggest that 'all actions are reactions, in the sense that what we do is shaped by the contact we have with others'. For example, I described hospice workers touching a patient's hand and noted their actions and use of words, while omitting the patient's response, and this tells us about how the hospice workers react to distress, suffering and pain. The fieldnotes illustrate one side of an exchange by describing the workers' *reactions* and actions, which usually emerged from moments of social interaction and social exchange. My core focus was to explore how the hospice workers at Broad Lane navigate the emotional challenges of their work and examine how they engage with patient suffering. I was able to pay particular attention to and illustrate their movements, handling of the patients' bodies as well as their choice and delivery of words and other forms of sensory care. The research also explores how the hospice staff interact with their colleagues and navigate these relationships at work. Due to the exclusion of hospice patients, the reflections in this thesis on the interactions and relationships *between* the hospice staff and patients are largely based on the workers' experiences, accounts and their understanding of these. The ethnographic fieldnotes depict the hospice workers' side of a social exchange, by appreciating their reactions, physical movements and words. In the interviews, I was able to ask the workers about the events I had witnessed as well as ask about their understandings of and the '*meanings*' (Spradley 1979: 5) they attach to their relationships with patients. Here, they were often able to talk in-depth about specific relationships and interactions with patients and colleagues. By focusing on the hospice workers, we can see how *they* experience their everyday work and their relationships with hospice patients.

A key ethical issue throughout the fieldwork was attempting to ensure informed consent during the fieldwork period. The observations were conducted in an overt manner, with the hospice visitors, patients and members of staff continuously made aware of the on-going research project. The issue of consent was negotiated in the preliminary meeting, where we agreed that posters would be placed in prominent places in the hospice and information sheets left in convenient spots. During the fieldwork, I would hand out information sheets to staff members

whenever I first encountered them, assuring them that participation was voluntary, and they should sign the consent form if they wished to participate. Although patients were not included in the research focus, I developed an information sheet specifically for guests and patients to the hospice, so that they were aware that research was taking place and a researcher would be present for an extended period of time. As with all social research, my observations occurred in a 'natural setting' (Hammersley and Atkinson 2007: 211), one where staff members, guests and patients would come and go, so it proved challenging to ensure that all workers in the hospice remained fully informed at all times. It is considered 'impractical' to ensure repeatedly that all individuals associated with a large organisation remain informed throughout a fieldwork period (Murphy and Dingwall 2001: 340). This was especially so on the in-patient unit, where workers would work different shifts week-to-week and I would only meet some staff members once throughout the six month period.

I would introduce myself whenever I saw a member of staff whom I did not recognise and provide them with an information sheet. However, in doing the research, I soon discovered that 'signed consent forms do not guarantee participants' understanding' (Murphy and Dingwall 2001: 342). They were often impractical in the 'field' as they consisted of four pages of substantial detail covering all of the necessary bases and so the workers often did not have the time to read them. The information sheets were then adapted, and the information increased again with the 2018 GDPR regulation changes. Consequently, there was often a lengthy interval between disseminating the information sheets and the staff members finding the time to be able to read them. As busy individuals working on a demanding hospice ward, many of the in-patient workers would ask me to quickly summarise the contents rather than personally read the entire leaflet. On the first day of the fieldwork, I had a rather naïve misconception about *ethics* being a challenge for merely the beginning stages of the fieldwork. So, I entered the ward on day one of the fieldwork with a folder of unsigned consent forms and information sheets to hand out immediately to all ward staff. In practice, I regularly engaged in a waiting game that involved a period of ethical dubiousness between supplying an information sheet and waiting for the consent form to be signed.

The issue of consent remained a perpetuating issue throughout my fieldwork and one that I constantly reflected upon as a fluidly evolving process. As Murphy and Dingwall (2001) note, ethnographic research tends to sit on the fence between overt and covert research, where consent from all of those walking into a research site at any time is entirely impossible. So, in

many instances it was necessary to seek retrospective consent. Where a nurse asked me to join her immediately as she went about a ward round and administered medicines to patients, I did not have time to ask her beforehand to complete a consent form. I could either allow the impracticality of in-practice ethics to stop me from experiencing first-hand the work of a palliative nurse or ask for consent at a later point in time. It was necessary to gain consent retrospectively, after this event took place. I had to make many other 'on-the-spot' adaptations to my methodological and ethical research approach throughout my six months in the hospice. Valentine (2007: 172) points out that ethical guidelines can often reinforce a 'tendency to separate ethics from the everyday business of research' as well as one's own stance on ethical issues and the situations that emerge from doing the research. Ethical encounters were navigated throughout the entire research process; before, during and after leaving the field, and I encountered some ethical issues that were not anticipated. Therefore, I acted with a degree of flexibility, engaged in thorough discussions with my supervisors and academic colleagues throughout and used my understanding of ethical guidelines to navigate the muddy waters of ethical appropriateness.

It was quite a perplexing situation that I was faced with when two of the housekeeping assistants verbally assured me, they wanted to take part in the research, yet they did not understand my reasoning for needing signed consent forms. As Price (1996) notes, signed consent forms can jeopardise confidentiality, especially as participants are requested to print, sign and date their name. This seemed to form part of the housekeepers' reasoning for why they did not want to sign a form. They questioned the formality of the process, asking why such a formal document was necessary if they could assure me verbally that they wanted to participate and understood the research. After some discussions with my supervisors, I decided I would use my existing data about the housekeeping assistants, after checking once again with them that they were sure of their participation in the research and what this entailed.

Ethnography is ethically problematic, with situations and questions seeming to present to the researcher on an almost daily basis. The process required constant reflexivity on just what I was doing in the field and *how* I was doing it. For De Haene et al (2010), repeated evaluation of consent improves the ethical soundness of the study. However, in the midst of fieldwork it is often impractical and rather self-important to interrupt active interaction and activity to remind the workers of my role as a researcher. Each day, I was distinguished as a researcher by wearing a University lanyard and by my lack of a medical uniform. Eight posters were also

displayed around the hospice in very prominent places. These were positioned on the in-patient unit at both nurse's stations, in the reception area, café, staffroom and in the day unit. However, after around four weeks of being in and around the in-patient unit, I arrived one morning to find the posters on the first ward had been taken down. Immediately, I found the gatekeeper, Eileen, to discuss this and try to figure out why they might have been taken down.

I go to find Eileen to ask her whether any of the staff have expressed issues with me doing the fieldwork. She says no and tells me to put more posters up, but she does go on to say that I should think about moving on to the day hospice soon. She says she thinks she knows who has taken the posters down and tells me certain people like to "keep the ward clean and tidy". I feel uncomfortable, thinking that my presence on the ward has made it somewhat *untidy*. When I go back, I ask the staff on the in-patient unit whether I can put the posters back up and they say it's fine. I proceed to put the posters up but know that I should start observations on the day hospice after this day ends.

So, moving on to the day hospice was a natural, if somewhat forced, progression with the feeling that I might have been overstaying my welcome on the in-patient unit. As Reeves (2010: 320) notes, rapport can become a source of 'control' for gatekeepers and the participants in a setting. Wherein researchers depend on 'the establishment and maintenance of positive relationships' to 'gather rich and detailed data' (Reeves 2010: 321). Much of ethnographic fieldwork involves negotiating relationships and maintaining positive participant perceptions. When the posters were taken down suddenly on the in-patient unit, I reflected upon the apparent rupturing of rapport and existing relationships with staff members working on the in-patient unit. As Shurmer-Smith (2001: 360) writes, ethnographic research is a risk-taking activity, one wherein the researcher is thrown into unfamiliar ground where at times they can feel 'self-conscious and anxious' (Crang and Cook 2007: 56). At a time where I felt I was developing some trust and a slight amount of belonging in an unfamiliar territory, I suddenly felt unwelcome by the taking down of the posters that I had put up on the ward.

The interview situation was a much more formal process and offered a simpler way of gaining informed consent. In the confines of a small room, where I had the participant's complete attention, I was able to read the information sheets through with them, answer any questions, remind them of their rights as a participant and ask them to sign a consent form. However,

informed consent was not the key ethical challenge in the interviews with staff members. For Alaszewski (2006) narrating a suffering experience has the potential to cause upset. Asking my participants to talk about their work, which involves alleviating suffering at the end of life, frequently caused some distress. Many of my participants were brought to tears by talking about their work experiences or their own first-hand grief narratives, demonstrating the emotional and personal nature of their work. I adopted De Haene et al's (2010) approach to repeated consent, wherein I made sure to ask all distressed participants whether they were willing to carry on with the interview. At times, there were necessary pauses to allow the participants to recollect their thoughts, but all of the participants expressed a desire to complete the interview. As a researcher, it was often necessary to adapt the questions after a participant had been distressed, thinking quickly and reflexively about ensuring the interview situation was a safe environment. Many of the participants described the interview as enjoyable, suggesting that this was something that they *wanted* to speak about or express. There is the acceptance within sociological research that articulating a suffering or grief narrative can evoke distress as well as have the potential for being therapeutic (Frank 1995; Elliott 1997). I have begun to identify my own embodied, emotional and ethical experiences of being in the field, and in the next section I reflect on my negotiations of relationships, emotions and space while in Broad Lane hospice.

## **Embodied Ethnography: Reflecting on emotions, relations and space**

### ***A Researcher's Emotional Work***

Being present and doing ethnographic research in a hospice over six months was an inevitably unnerving prospect. It was necessary to engage with some of the key texts concerned with hospice or medical ethnography (Hockey 1990; Atkinson 1992; Lawton 2000) to gain an understanding from those that had experienced the same or similar issues previously. Emotions were intrinsic to carrying out this research throughout the many hours of fieldwork, transcription and analysis. Kleinman and Copp (1993: 2) argue that researchers do emotion work, by adapting their emotional expression and 'moulding their feelings' to meet the expectations of others in the setting. In doing this research, I was entering into a relatively unfamiliar and daunting territory. When a nurse asked me on my first day in the hospice whether I would 'mind being in a room with a dead body', I suddenly felt that I had plummeted into an unknown environment, having never seen a dead person's body before. Valentine

(2007: 174) argues that emotional challenges form ‘part of the everyday business of qualitative research’, calling for constant self-reflection on methodological and ethical decisions made during the research process. After all, as Denzin (1984: x) points out, ‘to be human is to be emotional’, and therefore emotions should be considered in each part of the research process.

This section seeks to shed light on my own research experience as an embodied one, moving about spatially in the hospice and experiencing it as a physical place of emotions and relationships with others. In seeing the field in this manner, I also aim to challenge the qualitative health research field as one that tends to be ‘bodiless’ (Ellingson 2006: 301), and provide a reflection that includes ‘emotive, personal descriptions’ as a way of ‘accounting for and discussing methodological implications’ of doing research on hospice work (Borgstrom and Ellis 2017: 1010). Borgstrom and Ellis (2017) point out the recent increase in texts exploring the methodological, ethical and practical issues related to doing such research. However, they also call for further reflections on the ‘doing of death-related research in ... reflexive and explicit ways’ (Borgstrom and Ellis 2017: 101). In the following, I draw on snippets of fieldnotes in order to illustrate my experiences of doing the observations and reflect on them in a manner that highlights the complexities of ethnographic research in the hospice space. It is particularly important to explore this as fieldnotes, data and analysis are often somewhat shaped by the researcher’s ‘thinking about [the] data’ (Ely et al 1997: 206), which is intertwined with how they experience the field.

In conducting her ethnographic hospice research, Lawton (2000: viii) describes how ‘the mere mention that [she] conducted a study in a hospice provides a terse, “oh that must be very depressing” and a prompt change of subject’. This was inevitably something I experienced, both in an academic and personal sense, whenever I revealed the context of my research. Friends, family and peers would ask ‘*why*’ I would *want* to spend six months in a hospice. As researchers we conduct research in the contexts of our own personal lives, which is often difficult to disentangle from our research. Hockey reflects on the ways in which her own experiences of death ‘triggered research questions’ (2007: 440) in her seminal anthropological thesis. The beginnings of my research came shortly after a close family member had passed away in a hospice, and although the research focus did not stem from this experience, the timing meant that talking about my research inevitably became more of a taboo subject with some close family members. Adopting Hockey’s (2007) personally reflexive stance, our personal experiences, bereavements and memories are intrinsic to the ideas that we hold before entering

the field. In *doing* research related to death and dying, I inevitably take my own previous experiences into my work, and it is necessary to reflect on these. In one sense, I undertook emotional work during the research, whilst researching some of the emotional practices used by hospice workers.

As the following extract from my fieldnotes show, those I encountered in the field and the lives that ended while I was in the hospice touched me and the passing of patients was something that I reflected upon. Although my research was not focused on patients, I inevitably interacted with them while omitting these interactions from the writing-up. I grappled with feeling uncomfortable in such situations, especially on the wards:

Lily and Melanie (two of the senior nurses) invite me into the utility room, which is a small locked room with several cupboards full of medicines and needles. I check whether it is ok for me to stand by the door and watch them as they prepare the syringe driver. Melanie turns to me and in a hushed tone she warns, “I should tell you that this next patient is 50 years old, she’s just had her birthday here. We made it nice for her, with balloons and prosecco... She loved it”. I reply, “is it just this room next door?”. She nods, “she’s got a little grandson - he’s lovely! She’s wrote birthday cards up until his 21<sup>st</sup> birthday and memory boxes”. After we enter the patient’s room I feel out of place and awkward. I stand by the door and try my hardest to smile as the nurses joyfully make jokes and laugh.

Bringing in the sensory and emotional experience of doing fieldwork into the fieldnotes ‘adds flesh and bones’ to research accounts, as well as providing a sense of what care settings ‘look, smell, sound and feel like’ to the researcher (Edvardsson and Street 2007: 25). The sensory focus in thinking about the intricacies of the sights and sounds in these fieldnotes presents a vivid corporeal scenario for the reader and illustrates how events unfolded in time and space. As I have reflected on in these auto-ethnographic fieldnotes, the fieldwork was an emotional experience, and this was more so in certain situations that resonated with me or felt familiar. Woodthorpe (2011: 100) questions the extent to which ‘the researcher removes themselves’ from their research ‘narrative’ while ‘*knowing full well*’ that the subject will be ‘one that they will personally encounter eventually’. Death is an inevitably personal topic to research, as we are all mortal beings, and being in the presence of death calls us to be more aware of our own, and our loved ones, mortality. Not acknowledging the emotional impacts and influences on the

researcher, Woodthorpe (2011: 107) argues, ‘leaves subsequent analysis disconnected from the reality of the mortal human condition’. Attempting to disregard my own emotional experiences, relationships and interactions with the hospice staff in this thesis would be to overlook the entanglement of emotions in our day-to-day interactions with others, and ultimately go against the exact premise of this research. In the fieldnotes, I frequently detailed the joyfulness shared by the hospice workers, the radios playing cheery, up-beat songs and the jokes shared on the corridors. However, there were times where I also reflected on the conflict between the hospice as a place of dying, sadness and grief as well as a place of humour and light heartedness. My own experiences and interpretations of the hospice space are embedded in the research findings, and especially where I go on in this thesis to explore how the workers created and worked to maintain a sense of joyfulness and normality amidst the patients’ death and suffering.

### *Navigating the Hospice Space*

Being on the busy in-patient unit as a researcher, my own actions and movement were often in stark contrast to those of the workers. While I would be sitting, inactive for long periods of time throughout the day, workers would come and go busily moving about the wards. Crang and Cook (2007: 55-56) reflect on the ways in which we can incorporate ‘temporal and spatial regularities’ to ‘structure fieldnotes’ and guide our thinking about the data. On many occasions, I reflected on the mundane, day-to-day decision making involved in knowing where it was appropriate for me to sit or linger in the hospice. Having decided not to adopt a role as a volunteer, this was especially so in the in-patient unit, where I would often find myself inadvertently eavesdropping, sitting in someone else’s chair or becoming just a little *too* involved in the workers’ interactions.

The workers would often ask me whether I was ‘waiting’ to speak to someone or wondered *what* I was in the hospice for that day. Comments like these would make me feel spatially self-conscious. Being an ethnographer involves being a ‘lone ranger’ (Fine 1993: 269) at times, and entering the hospice as a researcher forced me into an unfamiliar place, where I quickly needed to become acquainted with people that I did not know. As Fine (1993: 273) notes, we ethnographers often ‘crop’ the individuals in our research that disrupt our affairs from unfolding ‘sweetly and well’. Ethically, I reflected every day throughout the fieldwork about whether I was a disruption to the day-to-day workings of the hospice and whether my ‘hanging

around' there was an annoyance to those working within the space. There was often a sense of the workers' trying to *figure out* 'what my angle was' (Crag and Cook 2007: 149). On the in-patient unit, my day would consist of repeatedly shifting between the two wards to avoid overstepping my welcome in either space. My experiences resonate with those of Ellingson (2005; 2006), who adopts an embodied, sensory approach to doing the research, wherein she reflects upon moving about her field, bringing in her bodily experiences of conducting ethnographic observations. Her study took place a geriatric oncology clinic and she similarly describes sharing chairs and counter space with the participants:

'As a person of provisional status in the clinic, I vacated a chair anytime I saw clinic personnel looking for a place to sit; I was willingly complicit in order to preserve my access to the clinic. This pecking order of privilege was carefully maintained.' (Ellingson, 2005, p. 125)

In the field, researchers are inevitably lower in the 'pecking order of privilege'. Similarly to Ellingson, I too vacated chairs and spaces when a staff member or a relative looked as if they wanted to sit down. My behaviour was an attempt to ensure that the fieldwork unfolded 'sweetly and well' (Fine 1993: 273). In doing this, I also consciously avoided lingering near conversations where relatives were distressed or staff members were exchanging intimate details about certain patients. As Ellingson comments, this type of 'complicit' behaviour protects our access to the field, which seems to be permanently ambiguous and somewhat unstable. There is a constant sense during fieldwork that stepping one foot out of line or going beyond the gatekeepers' expectations of your role and position in the field, could lead to an early end to the research. The regular awkwardness of my time observing on the in-patient unit contrasted with the ease in which I settled into the day unit. I spent most of the final four months of fieldwork on the day unit and the relationships I had developed there made it difficult to leave.

### ***Leaving the field***

Leaving the hospice was a process, rather than a quick decision. The process began with some lengthy reflections, discussions with my supervisors and negotiations with Eileen, the gatekeeper. Reflecting on the data that I had amassed over the previous six months, I took the decision to take my leave from the field in October 2018. Although, as I have discussed in this

chapter, fieldwork relations were not always smooth and easy, I came to enjoy being in the hospice and getting to know those working there. However, this was problematic at times. It became more difficult to record fieldnotes and *think* like a researcher as I became more familiar amongst the staff members. As Ballinger (2008) notes, over-rapport can be problematic in various ways in ethnographic research. It may involve the researcher's loss of the capacity to see the events and interactions in the field 'with the fresh eyes of an outsider' (Ballinger 2008: 589). I had become involved in craft making, tea making and general light-hearted banter between patients and staff, and so it was becoming more difficult to write the fieldnotes. In the final few weeks of fieldwork, I went to the hospice to conduct the interviews and then I would often visit the day hospice to enjoy some time with the workers and patients.

Leaving the hospice was more difficult than I had expected earlier on in the fieldwork. As Reeves (2010) notes, this process of getting out of the field is rarely discussed in ethnographic accounts of fieldwork. There is much consideration about ethical encounters before and during the fieldwork process as well as deliberation about how we enter the field. However, there is little discussion about how we take our leave in the field. Lofland and Lofland (1995: 62-3) note that 'the handling of these voluntary departures probably deserves more careful thought and pre-planning than field-workers have traditionally given to it'. The literature often neglects the process, as if ethnographers leave their fields quietly and suddenly, which is obviously not the case. In a snippet from my very last fieldnote, the relationships I had developed in the hospice were evident:

After my interview with Emily, a health care support worker, she said they would be sad for me to leave, "we've loved having you, it never felt like you were in the way. You've slotted right in". I agreed and said that it had felt like that for me too. I then went to Eileen and told her I had finished my interviews and thanked her for her help. "Don't worry", she said, "just make sure you keep me updated with it all. Go and say your goodbyes and let me know when you're leaving". She put her hand on my shoulder. Eileen was probably one of the less tactile members of staff, but I felt like this was her way of showing some affection.

Beyond the emotions of leaving the field, taking my leave also came out of a saturation of data (Glaser and Strauss 1967). Glaser and Strauss (1967: 61) describe saturation as 'no additional data', whereby the researcher observes and notes similar scenarios, which amount to the same

themes previously recorded. The themes began to blur into one, and I was re-exploring the same aspects of day-to-day work in the hospice over and over again. I observed four main themes within the data, and these are presented in Chapters Four to Seven. The decision to leave the field was not an easy one. I brought relationships to a close that were becoming ‘firmly established’, and which I was reluctant to ‘relinquish’ (Seale 2012: 254). However, the evidence of firm relationships further supported my case for leaving the field, as I had begun to feel *a part* of the day hospice set-up. At times I was drafted in to make cups of teas and help patients with craft-making, and I frequently found myself playing dominoes with another staff member and one of the patients. Although the feeling of being welcome, especially as a one-time-outsider, was pleasing, I had become more and more distracted by the practical activities in the field, finding it increasingly difficult to jot down notes and think *sociologically* as well as analytically about what was happening.

## **Conclusion**

This chapter has outlined the methodological approach and the ethical as well as practical decisions taken during the research process and whilst I was in the field. I have incorporated reflections on my role as an ethnographic researcher in the hospice and detailed both the challenges and successes of doing this ethnographic research as well as the negotiation of ethics as a fluid process throughout the entire research process. This chapter highlights the importance of reflecting on our embodied, emotional and relational experiences of doing ethnographic research, especially in the field of death research. As Visser (2017: 6) points out, we should look ‘to take “the emotional” out of the margins’ when putting together our research findings and outputs. This chapter has provided insight into the methodological decisions as well as descriptions of the emotional work involved in doing ethnographic hospice research. I have also illustrated the embodied experience of being in the hospice, moving about the wards as an outsider and moving whenever I overstayed my welcome, as well as the experiences of sitting still amidst the busyness of the hospice staff. These experiences are inevitably embedded in my analysis and interpretation of the data, so it is necessary to reflect on these as well as the snippets of auto-ethnographic fieldnotes included in this chapter. Doing research related to the processes of death work, dying and bereavement is inevitably sensitive. However, it is ‘*more than*’ a ‘sensitive subject’ (Woodthorpe 2011: 100). Doing death research calls into question our roles as researchers and how ‘we “should” feel’ at certain moments of death, and forces us to deliberate the ““appropriate” courses of action to take’ before, during and after the research

(Borgstrom and Ellis 2017: 95). Hence, I have detailed, in this chapter, the complexities of doing this research, reflecting upon my decision-making processes, which were necessarily flexible and adapting to each circumstance as situations transpired in Broad Lane hospice. This chapter has portrayed the emotional, relational, spatial and ethical aspects of doing the ethnographic research. I will now turn to the experiences, perspectives and accounts of the hospice workers at Broad Lane.

## CHAPTER FOUR

### Sensory Care: Silence, Touch and Taste

*‘Emotions shape the very surfaces of bodies, which take shape through the repetition of actions over time, as well as through orientations towards and away from others. Indeed, attending to emotions might show us how all actions are reactions, in the sense that what we do is shaped by the contact we have with others.’ – Ahmed 2004: 4*

#### Introduction

Sociological work on suffering has identified the difficulty in adequately describing, articulating and expressing the experience by the use of spoken words (Scarry 1985; Das 1997). Encountering ill health is said to ‘block or distort’ the senses (Corbin 2003: 261), and modern diagnostic tools have resulted in a decline in the importance of the senses ‘such as touch in favour of the visual’ (Bates 2019: 13). The illness experience is often one that is portrayed as an ‘absence of the senses’ (Bates 2019, 2020) and the hospital space is constructed as an ‘unaesthetic place’, wherein the food is ‘unsavoury’, tactile contact is ‘perfunctory’ and odours are ‘antiseptic’ (Howes and Classen 2014: 58). Such experiences of place and the senses shape the embodied day-to-day experiences of ill health, as ‘the body takes shape through its interactions with other objects, bodies and landscapes’ (Macpherson 2010: xiv). This chapter expands on this sociological work by examining the alternative *sensory* forms of care and interactions which the workers described as shaping the patients’ embodied and emotional experiences. I focus on the workers’ influence over notions of choice and agency at the end of life through the three sensory domains of silence, touch and taste.

The chapter illuminates how the hospice workers utilised the different senses to provide care for the patients and the participants’ accounts highlight the ways in which they often influenced the patients’ sensorial and affective experiences. I draw on their use of physical touch and the significance of being silent to illustrate how the workers overcame the limits of verbal expression to enact other forms of care that were engaged with the sensory. The preparation of food also emerges as an important act of care, that potentially sustains or threatens a sense of choice and autonomy at the end of life. I engage with these often unspoken, subtle and tactile

forms of sensory care to illuminate the significance of thinking with the senses to explore reactions to and engagements with suffering. Here, silence is a carefully considered *action* and a form of interaction. The workers often described influencing a certain emotional response in the way that they touched, were present with or prepared food for patients. By engaging with an individual's particular sensory needs and desires, the workers could potentially preserve a sense of choice and identity at the end of life, and by not attending to sensory differences, the hospice workers sustained imbalances of power and threatened a sense of autonomy. This chapter contributes to the existing work on suffering, as an affliction embedded in multiple silences, and I engage with the relationality of suffering and end of life experiences to illuminate how the workers 'shaped' (Ahmed 2004: 4) emotional responses through these sensory forms of care.

## **Silence**

### ***Doing and Saying 'Nothing'***

Many of the staff in different roles across the hospice described the significance of silently 'being with', and being 'present' with, the patients. They often placed importance on simply 'being there', rather than verbally interacting with patients. Silence could be said to evoke different feelings at times, and Back et al (2009: 1113) explain that 'there are silences that feel awkward, indifferent, or even hostile, there are also silences that feel comforting, affirming and safe'. Moreover, silence, in the clinical encounter, is said to foster a deeper interaction, which supports listening and asserts a reassuring presence to patients (Back et al 2009; Savett 2011; Tornoe et al 2014). The following extract is taken from observations of a 'Schwartz Round', which was a formal offloading session for all hospice workers arranged by Chris, one of the specialty doctors. The Schwartz Rounds took place on a monthly basis while I was at the hospice, and the topic of this session focused on 'a challenging day at work'. Laura, one of the occupational therapists, had been asked to share her own experience of a particularly challenging day. She remembered a patient with rapidly progressive cancer. His condition had meant that he was unable to walk unaided. Laura reflects on the patient feeling adamant about carrying on with his hobbies, one of which involved being independently mobile to take photos and then edit them on his computer, which was on the top floor of his house. Laura described taking the patient to a set of stairs in the hospice and asking him to manage just a few steps by

himself. In the extract from fieldnotes below, Laura recounts the aftermath of showing the patient that they would not be able to walk up their stairs at home unassisted:

“He broke down in that moment when we sat him back down in his chair, and I felt like I couldn’t hug him, you know, with some patients you just don’t feel like you can, but in that moment, I put my hand on his hand like this [*she puts both arms out in front of her and places one hand on top of the other gently*] and it felt like forever. I bet it was only a few seconds, but I just felt like that were the right thing to do then. Just be silent, and then he just said, ‘right then’, and it’s like he knew then that he wouldn’t be able to do those things again that he liked to do and just the normal things.”

Laura describes the patient’s distress as they realise the losses caused by their illness. She illustrates the ‘crumbling away of former self-images’ (Charmaz 1983: 168) that were somewhat shaped by the patient’s ability to engage in ‘normal things’. While Scarry (1984: 4) has described physical pain as ‘resistant to language’ as an ‘unshareable’ experience, emotional suffering also defies spoken word. Morris (1997: 28) describes suffering as beyond comprehension, ‘resistant to description’ and verbal articulation. This ‘clichéd’ (Morris 1997: 27) depiction of suffering portrays the event as lonely, isolating and sequestering, as the individual is abandoned in their voiceless state. My findings also illustrate the silence of reactions towards suffering and pain at the end-of-life. Laura shares the patient’s inexpressibility in reacting to and engaging with their distress. This echoes the broader societal silence towards death and dying, in which we ‘often do not know what to say’ (Elias 1985: 23). Bauman (1992: 130) argues that death has no meaning in our ‘language of survival’, which is often oriented towards preserving life and so cannot ‘grasp the condition’ of death. He notes that the ‘dying die not so much in *loneliness*, as in *silence*’ (Bauman 1992: 131), as the living find it difficult to communicate with them within the confines of their language of survival. Laura describes not having the means to verbally express and interact with the patient, and she emphasises the difficulty of using a language which was not fit for articulating such immense pain and suffering. However, the extract depicts how she adopts another form of expression, which isn’t reliant on verbal, spoken word. Laura reaches out to touch the patient and is silent with them, yet present and sharing in an unspeakable experience.

Laura describes the patient's suffering existing 'in what [they] could not say' (Frank 2001: 354), which was too intense for verbal expression and articulation. Laura's silence illuminates how verbal communication fails us in these moments in the absence of appropriate and adequate words to react to suffering. However, these different, sensory forms of care are said to express compassion when verbal communication is not possible, as Laura explains it 'felt' like the '*right thing to do*'. Laura describes interpreting the silent, inferred cues given-off by the patient to decide what action, or *non*-action, to take. This emphasises how suffering *is* often inexpressible in spoken word, however the hospice workers practiced alternative, sensory means to care for the patients and be present with them in their pain.

The workers often described knowledge of how to interact with different patients as developed over time. The significance of silence and the use of physical touch varied between patients and different situations. The workers often relied on cues and an in-depth knowledge of individual patients in making decisions about how to interact and engage with them. As Lawler (2006: 190) describes, doing or saying nothing often involves 'a lot of doing something'. The workers were skilled in coming to know the limits of their patients' tactility and the appropriate ways to react according to the individual. Laura continues to suggest that silence often replaced spoken words in certain situations where verbal expression failed:

Laura explains, "it's really hard to tell people that you can't do all of those things that you used to enjoy ever again... and what I've learnt is, often, you haven't got the words. To be silent is the only thing you can do. Through doing this job and all the training, I've learnt that silence isn't bad. I used to feel so awkward about silence. Now I just let it happen and that's what I did with them." Chris, the specialty doctor, agrees with Laura, "sometimes the only thing you can do is just *be*, it's about being there, sometimes that's all that they want".

Laura had worked at Broad Lane for just over a year, working in a similar role in a hospital setting prior to working in the hospice. She describes experiencing silence previously as 'awkward'. She explains that over time working in the hospice she had become accustomed to allowing silence to 'happen', because 'often, you haven't got the words'. Laura illustrates the way in which care can be disclosed through 'silent intimacy', wherein 'closeness' is not always 'accompanied by a dialogue of mutual disclosure' (Jamieson 1998: 8). Both Laura and Chris agree that care can be performed by doing nothing, or doing very little, and at times this was,

in fact, very appropriate. Meaning is still inferred through an absence of words, as ‘absences powerfully influence people’s conceptualizations of themselves and the world they engage with’ (Billie, Hastrup and Sorenson 2010: 4). ‘Being there’ or ‘just being’ with the patient signified a way of caring for and about the patients where language and spoken word were redundant. Silence was not simply the absence of words, but often a *different*, more appropriate, means of interacting with the patients.

Silence was an important form of expressing care and being with the patient when spoken words were limited. Christensen, Hockey and James (2001: 69) argue that ‘links’ between individuals ‘need not necessarily privilege spoken language nor be confined to speaking subjects’. They differentiate between the types of silences used in ‘indirect communication’, one of which conveys ‘that which it is barely conceivable to articulate in language’ (Christensen et al 2001: 70). In Laura’s encounter with the patient, silence conveyed that which could not be verbally expressed. Other members of staff also suggested that they lacked the adequate words to respond to the suffering their patients experienced. However, in doing and saying nothing, the workers were involved in complex and intimate encounters, or interactions, with the patients. This supports Lawler’s (2006: 188) argument based on her ethnographic observations of nurses ‘doing nothing’ at the end of a patient’s life. Lawler (2006: 188) highlights the ‘multiple meanings’ of doing nothing, which demonstrates the complexity of the work that is carried out during these moments of apparent absence of words, stillness and silence. This type of end-of-life work is often hidden and private, as moments of not doing, and in turn this form of care work has often been neglected within sociological discourse on clinical relationships. However, Laura’s description of this scenario illustrates how the workers thoughtfully developed understandings and an awareness of each patient to respond appropriately in ways that felt ‘*right*’.

Many of the workers referred to simply ‘being with’, or ‘being there’ for, patients in physical presence, but in the absence of spoken words. This suggests that their reactions to suffering were often verbally inexpressible and so there was often meaning to be found in *not* doing and *not* saying anything. In my interview with Martha, a physiotherapist working in the hospice community team, she emphasises the importance of *being with* the patients. Silence became an active form of care where words were not available or felt inappropriate:

*Martha, specialist physiotherapist:* Oh yeah, I do it all the time... have a hug, let me just sit with you, yeah, sometimes, just, sometimes you don't even have to be saying anything, you just need to be with somebody.

Within their silences, Martha describes an emotionally charged and intimate relationship between herself and the patients. She states that 'you don't even have to be saying anything'. In the absence of words, care and intimacy are still expressed by the hospice staff, and they were oriented towards the tactile needs of the individual patients. They considered the patients' different situations to interpret the most appropriate way of reacting and then interacting with them. One of the clinical nurse specialists that worked in the community, Elizabeth, similarly expressed in our interview that '*sometimes there are what seems like, no words, nothing*'. When some situations and events felt particularly distressing for all involved, being silent was the only option. However, these encounters involved *not* doing as an interactive form of caring for the patient. Borgstrom, Cohn and Driessen (2020: 207) have discussed 'non-interventions' as a form of care in palliative care work, and they state that moments of 'nothing', which involve being present with patients, and 'not physically doing something' are, in reality, 'deliberate and careful acts of passivity'. Martha, Laura and Chris emphasise the significance of these shared moments of doing and saying 'nothing', as moments which require thoughtful consideration and an in-depth knowledge of each patient to assess the appropriate method of non-action. Silence unfolds in the moments of shared distress, wherein the workers shared in the patients' pain and suffering. Rather than abandoning them, 'distanced' through silence (Bauman 1992: 131), the workers negotiated around the limits of language to use silence as a deliberate action and form of interaction to overcome the verbal inexpressibility of pain and suffering. As Laura suggests, 'you haven't got the words' to react and engage with the suffering of another, and the limits of verbal expression give way to silence as an alternative, and important, *form* of interacting.

### ***Powerlessness***

Doing nothing and simply being present with patients in silence was often an active way of caring for the patients, where words failed both the patient and the worker. The nature of hospice work means that the staff at Broad Lane provided end-of-life care when all other clinical treatments had been exhausted. Borgstrom, Cohn and Driessen (2020: 206) describe palliative care workers as 'the nothing', stepping forward when other clinicians retreat and

when ‘nothing further can be done’ for the patient. Drawing on their study with a group of palliative care nurses, Arman (2007: 91) states that ‘an attitude of ‘I am here for you’’ can somewhat help to alleviate a patient’s feelings of ‘loneliness, suffering and the threat of death’ at the end of life. Where words fail, simply being present and actively *doing* nothing for or with the patient expressed care and intimacy. Chris had worked as a specialty doctor at the hospice for around four years, having moved from ‘General Medicine’ in a hospital and GP setting previously. He stated that he entered hospice work to be able to spend more time interacting with and caring for patients. He spoke of the significance of ‘being present’ with patients, when all other clinical treatments had ceased:

*Chris, specialty doctor:* The, probably the one thing that can really help in that scenario where you feel powerless either to change a physical symptom or a, you know, an emotional state is for that person to know that even though you can’t – you – you’ve reached the limit of what you feel you can do, that you – you – can still be another human being, who cares and – so – it [touch] just communicates that very powerfully and you know, I guess, I’d like to believe that that in itself will make, as part of that therapeutic relationship, even if their life is gonna continue being a mess or their physical symptoms will continue being a mess that actually amidst that, we’re not gonna say ‘well actually we’ve done all we can’ and turn around and walk away, we’re gonna say ‘well we’ve done all we can, we’re doing all we can and we’re still here and we’re still present with you’ erm... so yeah, physical touch communicates that very well.

The nature of hospice work often means that care carries on after clinical medical treatments have been exhausted and when the clinician becomes ‘powerless’ clinically. Chris highlights the use of different forms of care: silent co-presence and tactility in place of traditional medicines and treatments. In these instances, he offers himself to the patient as a ‘another human being’ as opposed to a clinical doctor. The act of being physically present, witnessing and experiencing *with* the patient can help to express care and ease their feeling of being alone. Their accounts of actively doing, or saying, nothing highlight the hidden emotional work that is carried out in silent interactions and encounters between patients and staff in the hospice. Chris refers to feeling ‘powerless’ and this suggests a feeling of failure in not being able to cure, or medically treat, the patient in a clinical sense. This powerlessness is oriented towards an embedded notion that a ‘cure is posited to be the only form of success’ (Borgstrom, Cohn

and Driessen 2020: 209). However, the workers in the hospice emphasised the value in doing nothing and being with the patients as a way of relieving their pain and suffering at the end of life.

Chris describes continuing an embodied, intimate social relationship with the patient after they have exhausted all options for recovery or treatment. Levinas's (1988: 158) philosophy of suffering explored the uselessness of suffering, being 'for nothing'. However, if there remains one 'use' for suffering, it lies in its ability to call for compassion from those that bear witness to it. As Levinas argues, another individual bearing and sharing in the suffering experience can relieve the loneliness of the experience, helping it to be shared out rather than isolated to one individual:

'The caress of a consoler ... does not promise the end of suffering, does not announce any compensation, and in its very contact, is not concerned with what is to come with afterwards in economic time; it concerns the very instant of physical [and psychological] pain, which is then no longer condemned to itself, is transported 'elsewhere' by the movement of the caress, and is freed from the vice-grip of 'oneself', finds 'fresh air', a dimension and a future.' (Levinas 2001: 93)

For Chris, touch acts as a means of expression within the patient-doctor relationship when all other means of interacting with the patient and treating them seem to be exhausted. When there is nothing left at the doctor's medical disposal, all that is left is to show compassion by simply *being* there with and physically reaching out to the patient. Being in the patient's experience helps to relieve the condemnation of suffering to 'itself', freeing it from 'the vice-grip on 'oneself'' (Levinas 2001: 93). Chris describes being in the patients' suffering and their experiences of physical symptoms as 'another human being'. This emphasises the 'relational assemblage' (Dragojlovic and Broom 2018: 22) of suffering moving across persons in the relationship. Where clinical medical treatments are based on 'doing' for or to the patient, Chris marks a transition to '*being with*' the patient and sharing in their end-of-life experience. He accepts that 'even if [the patient's] life is gonna continue being a mess or their physical symptoms will continue being a mess', he can ease the patient from the isolation of their suffering. Chris illustrates the easing and alleviation of suffering through doing nothing but sharing in the experience and freeing it from 'oneself' (Levinas 2001: 93). He refers to the 'therapeutic relationship' between himself and the patients, as one that involves very little

medical treatment, but relieves pain by *sharing* the burden of dying between the patient and himself. He uses silence, presence and touch in place of clinical treatments or invasive investigations. Where he feels ‘powerless’ in relation to treating the physical ailments of his patients, Chris suggests that he influences the patients’ experiences of *social* life. By being there with his patients alongside them in their suffering, he loosens the ‘vice-grip’ (Levinas 2001: 93) and the hold of suffering on an individual person. We can see touch and silence as options for the hospice worker when the ‘limits’ of typical clinical medicine have been exhausted, and where the limit of other forms of expression have been reached. Touch as well as being present with the patient are forms of embodied and sensory interaction, that remain at the hospice workers’ disposal, and the significance of these forms of care lay in the *sharing* of the experience, as it is no longer confined to an individual.

## **Touch**

### ***Intimate Touch***

Where the limits of verbal expression and the use of clinical treatments had been exhausted, the hospice workers turned to other forms of caring, employing the use of two other sensory expressions: silence and physically touching the patients.

*Martha, specialist physiotherapist:* I would say that if you compared me to a, I suppose, if you compared me to, like, a community physio who doesn’t, erm, do palliative care, I wouldn’t be frightened of going in and giving somebody a hug. Be that the patient, be it a relative, I wouldn’t be frightened of holding somebody’s hand or just sitting with somebody, cos that’s an extra isn’t, whereas all physios are used to touching people, they’re probably not used to comforting people.

Many of the staff at Broad Lane, including Martha, had worked in similar roles elsewhere before working at the hospice. They made comparisons regarding the ways that care could be enacted in a ‘comforting’ manner, as opposed to more of a clinical technique. Martha makes the distinction between ‘touching’ patients to treat a physical ailment and ‘comforting’ them through a ‘hug’. Both involve the use of physical contact. However, only the latter involves an affectionate action. She describes comforting patients as ‘hugging’, ‘holding someone’s hand’ or ‘just sitting with somebody’, explaining that these practices are ‘an extra’, supplementary to

basic clinical care. Martha describes these ‘extras’ as forms of care and expressions of comfort to the patient, and these fell beyond the limits and boundaries of what Martha considers to be a typical clinical relationship. In illness and disability, Price and Shildrick (2006) explain, that bodies come to be handled in a clinical, rather than affectionate, manner:

‘Hands held, coffees drunk together, dances and hugs, the afternoons in the sauna or spa pool, the mutual touches of friendship, of comfort, of joy, of sadness translated into the moves and actions needed to lift me, to help me transfer, to climbing in the bath with me to help me bathe.’ (Price and Shildrick 2006: 71)

Much of the data, including the extract from my interview with Martha, highlights the ways in which the workers comforted the patients with intimate movements and physical closeness. Rather than the body being handled as an ‘object of the workers’ labour’ (Twigg et al 2011: 173), Martha describes intimate embodied affection between herself and the patient. Price and Shildrick (2006: 69) explain that touch is ‘an interactive sensation’ that can be considered as important as our sense of sight, mapping out the spaces around us and the distances between ourselves and others. However, in adulthood we begin to consider ourselves as ‘singular, unified and bounded’ (Price and Shildrick 2006: 70). Physical contact often becomes less welcomed and considered a threat to the personal boundaries upheld between bodies. Chronically or terminally ill individuals are often increasingly subjected to frequent physical contact, and it is usually the kind of physical contact that surpasses and disrupts the norms of separation from other bodies. Price and Shildrick (2006: 71) refer to touch as ‘unwanted tactile proximity’ and a ‘dangerous possibility’ that becomes more frequent with ill health or disability, as bodies have to be ‘moved’, ‘transferred’ and supported in carrying out day-to-day tasks. Martha suggests that she provides the typical care of a physiotherapist, but she also provides ‘extra’ affectionate care to her patients through ‘hugs’, ‘holding somebody’s hand or just sitting with [them]’. The distinctions between mechanical and ‘perfunctory’ (Howes and Classen 2014: 58) forms of physical contact, such as transferring or helping a patient to move from one space to another, and intimate closeness, such as a hug, are not as straightforward as Price and Shildrick propose. Martha describes relating to and interacting with the patient’s body with warmth and intimacy as well as helping them to move as part of the physiotherapy work.

The accounts of physical touch and embodied closeness between workers and patients in the hospice illustrate a navigation of and a respect for individual patient's boundaries. Many of the workers asked the patients whether they wanted a hug or spoke of developing an understanding over time of their patients' boundaries of tactility. The day unit Sister, Eileen, had worked in the hospice for over twenty years, having been there since it first opened. She explains that 'you have to be careful, because there's people that don't like to be touched, but as I say once you, you know, it's instinctive – you – you will know', demonstrating how the workers developed relationships of intimacy based around their understandings and knowledge of the patients' boundaries. Rather than bodies becoming mere 'objects' of labour (Twigg et al 2011: 173) to be handled and manipulated in a certain way, the patients were interacted with as individual persons. Kelly, one of the specialty doctors, also explained that 'I always ask, unless I feel like I know them well enough to just give them a hug'. This illustrates how intimate, physical care was individualised to each patient.

The affection expressed through touching patients emphasises the need to adopt another form of caring, especially in situations where spoken words seemed inadequate or inappropriate. The intimacy of being physically present and close with the patients allowed for relationships that were embedded in emotional expression and feeling. The sensation of being touched in a therapeutic, comforting manner engaged the patients in a sensory experience and many of the participants suggested that it often led to an emotional outpouring. In the following extract, Lauren, one of the complementary therapists in the hospice, explains how the smells of massage oils and the feel of her touch can often result in an 'emotional release' for some patients, as the sensation contrasts with their previous clinical experiences:

*Natalie:* Yeah, so you tend to use oils, to get different smells?

*Lauren, complementary therapy coordinator:* We do, and the oils help with the emotions as well, sometimes when people come in for a treatment, just the touch in itself or the smell of the oils can just be enough for an emotional release. So, they may come in to us and it may be that I've touched that patient's hands and arms and we're just starting a treatment and they've got tears rolling and I'll say to them, 'are you okay?', you know, really checking up on them. One patient in particular said, 'I'm absolutely fine, it's just nobody's touched me in a way like this in such a long time' and it can be that they feel as though they've been poked

and prodded, medically, and they've not had a positive touch experience and that can release a lot of emotions for a patient.

The intimate touch contrasted with the medicalised, clinical 'pokes' and 'prods' that the patients had experienced previously in other clinical relationships. These interactions, such as the example that Lauren refers to here, are embedded in intimacy and closeness for the sake of comforting the patient, as opposed to diagnosing or treating them for their particular physical ailment. In this, they focus on alleviating a *social* pain, which is embedded in both their experience of physical illness and the resulting disruption to their relationships and interactions with others. Lauren distinguishes between positive and negative 'touch experiences' for patients, and she characterises clinical 'pokes and prods' as negative bodily contact. Her comforting touch contrasts with the actions devoid of care and intimacy that Price and Shildrick (2006: 71) describe. The clinically detached movements to 'lift', 'transfer' and 'help' are mechanical and physically oriented, whereas Lauren's therapy is emotionally charged through engaging with the physical body as a site for potential pleasure. Lauren attempts to provide the patients with 'positive' bodily experiences, where they may have felt their boundaries of space and physical contact were overstepped previously in other clinical encounters. This suggests that 'suffering occurs in relation to other people and factors... [It] moves with and across people' (Dragojlovic and Broom 2018: 157), as patients' suffering can be accentuated when they are subject to invasive medical treatments. Furthermore, a sense of self is shaped by embodied and sensorial relationships with other persons. Ahmed (2004: 11) explains that as social beings we are 'moved by the proximity of others', and our engagements or encounters with others shape our sense of self. 'Bodies take the shape of the contact they have with objects and others' (Ahmed 2004: 1). Thus the 'negative' sensory and bodily experiences the patients share within clinical relationships have shaped their understanding of their own body; as a site of pain rather than comfort or pleasure. Lauren attempts to draw on the use of comforting touch and sensual smells to reconstruct the patient's body as a site of more positive, affirming experiences.

As an embodied sense of self is shaped by interactions and relationships with others, we can see how suffering can be either accentuated or alleviated through different sensory experiences and interactions with other people. The hospice workers influenced the ways in which their patients experienced their bodies and sense of personhood at the end of life. Wolkowitz (2006: 164) explains how 'different kinds of touch construct patients and are experienced by them

differently'. Lauren described how the smells of the 'oils' and the 'touch in itself' are a comfort to the patient, enabling an emotional expression and a feeling that they could safely express their emotions freely. Touches that exercise power and control can mould patients' bodies into 'objects' (Twigg et al 2011: 173) of the workers' labour, whereas touch as comfort and as therapy can help patients view their bodies as potential sites of pleasure as opposed to, or as well as, pain. Lauren describes how her embodied interactions with the patients often influenced how they saw their own body, changing it from a site of 'perfunctory' (Howes and Classen 2014: 58) medical work, to a place of intimacy and comfort. This illustrates how the 'interactions with other objects, bodies and landscapes' impact on one's experience of the body, and ultimately, of the self (Macpherson 2010: xiv). Another complementary therapist explained that carrying out 'reiki'<sup>11</sup> and other treatments leads to an open interaction about 'certain things [the patients] wouldn't tell other people', and this illustrates how embodied interactions between the therapist and patients lead to an emotional release. The physical touch of the hospice worker can be seen as an enabling force, allowing for an emotional expression and release through crying, and the significance of touch unfolds in light of the limits of verbal expression. Overall, the hospice workers exert a significant power over the patients' sense of self and their freedom of emotional expression through their handling of the patients' physical bodies.

Where the patients' physical ailments had deprived them of something - whether it be the ability to walk or to express their own pain in spoken words - the workers engaged with the other senses to interact with and care for them. In the following extract, Elizabeth, one of the clinical nurse specialists working in the community, describes caring for blind patients and touch being particularly important in these encounters and interactions:

*Elizabeth, clinical nurse specialist, community team:* I mean the lady yesterday, er, I don't know her very well and she's registered blind and erm... again, how things stay with you, I thought of all the people I've nursed who are blind – they – all of 'em in my experience have always wanted to reach out and touch the person – if they feel they can – who are talking to 'em. Now, I get a lot of warmth from the patients I look after, as I said, that that's one of the reasons that keeps me going.

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<sup>11</sup> 'Reiki' is an alternative form of therapy which involves light touch and the placement of hands on different parts of the body.

You get a lot back, hell of a lot back. Yeah, absolutely. I mean this lady you know... erm, she just wanted to – to – to reach out and touch me and I, I'd say, oh gosh, lots of people do, get 'old of me, kiss me, hug me, you know, really comfortable at doing that.

Elizabeth explained that the majority of blind patients she had cared for wanted 'to reach out and touch' her. Touch was a means of developing trust and a relationship with the person caring for them, especially when the patient lacked visual awareness. Elizabeth refers to the ways that patients initiate physical proximity and closeness. She states that 'you get a lot back', meaning that she feels as though tactility and intimacy are reciprocal actions, enacted both by the worker and the patient. This resonates with Dragojlovic and Broom's (2018: 3) depiction of 'affective assemblages' between persons and bodies in the clinical care encounter. Dragojlovic and Broom challenge the idea of care as an '*action*', with a clear distinction to be made between the care-provider and care-receiver. Dying can often be seen as a very individualised experience, underpinned by individualistic interventions, treatments and medical discourse (Broom and Kirby 2013), however, through incorporating a sensory focus into thinking about end-of-life relationships, we can consider the ways in which care and suffering are fluidly relational across bodies and within relationships. Furthermore, the workers engaged with the different senses, to perform care and interact with patients in ways that were most appropriate, and this demonstrates the flexibility of care relationships and interactions within the hospice space. The hospice workers' accounts suggest that care operated as a connectivity, or an 'entanglement' between 'bodies, techniques and practices' (Dragojlovic and Broom 2018: 45). The workers illustrated how their handling of the patients' physical bodies and their engagement with alternative sensory forms of care influenced the patients' sense of emotional connection to their body – either as a site of pleasure or pain. These extracts illuminate the significant role that the workers play in their patients' experiences of suffering, which unfold *in relation to* them as well as the other people that they come into contact with.

### ***Medicalised Touch***

The dependence and vulnerability of the patients often emphasises the imbalance of power between the patient and the hospice worker. Enabling an '*emotional release*' can be a potential source of embodied power. Barkty (1990: 115) explains that those 'feeding egos and tending wounds' often experience their care practices as 'mighty power'. The hospice workers

frequently provided the patients with comforting, affectionate embodied interactions and many alluded to the ways in which they held an influence over how the patients experienced their bodies. In the following extract from fieldnotes taken on the day unit, physical touch is used to provide comfort and reassurance, again enabling a patient's emotional release:

One of the health care support workers, Jenny, greets a patient with a hug and sits down beside them at the crafts table. Nicola joins them at the table, she asks how the patient has been and the conversation quickly turns to the patient's end of life wishes, "I know it's personal, but do *you* want to be at home? I know it's difficult to talk about...". Nicola gently asks about where the patient wishes to die, trying to allow the patient time to express her wishes. I notice that Jenny has been clasping the patient's hands within her own since sitting down with the patient at the table. Nicola brings up her own parent as an example for the patient. "I know we've got an amazing community team but it's up to you". Jenny's hands remain in place clasping the patient's, she sits, silently looking at the patient, while Nicola continues to ask the patient about where she wants to die.

In this extract, one of the support workers working in the day unit clasps a patient's hands within her own, as her colleague asks the patient whether she wishes to die at home or in the hospice. In some ways, this further demonstrates the use of intimacy and corporeal affection towards patients. However, the extract also establishes how these intimate displays of affection can be ruptured by managerial and bureaucratic motivations. The day hospice nurse, Nicola, emphasises the 'amazing community team', showcasing her colleagues' working in the community and the 'amazing' care they provide to patients in their homes. This illustrates the ways in which 'personal objectives [can] become confused with those of the occupation or organisation' (Dingwall et al 1988: 220). The extract portrays a person-centred moment of care, wherein two carers are focusing their attention on one patient who is nearing the end of life and using touch to grapple with a potentially 'uneasy' interaction (Hockey 1990). However, the seeping through of advertisements for the 'amazing [community] care' against the backdrop of lengthy waiting lists on the ward can suggest how such encounters can become 'surveillance apparatus', to 'monitor and evince the patient's personal identity' (Armstrong 1983: 459). Getting to know patients as individuals, as whole sentient beings nearing the end of life, reinforces, perpetuates and can somewhat extend imbalances of power in the clinical hospice encounter. This was made particularly pertinent in my later interview with Nicola, where she

explained that ‘the better relationship you’ve got with [the patients], they’re more likely to open up and tell you anything and everything’. Moments of openness and honesty regarding where a patient wishes to die have the potential to become infiltrated with administrative management tactics and advertisement for potentially attractive options to the dying patient. Furthermore, we can question the meanings behind tactility and physical closeness, as Nicola highlights the importance of developing relationships to find out ‘anything and everything’ about the patients.

Turning to the hospice wards, physical contact was often stifled by the use of latex gloves and bright blue plastic aprons, which the workers put on just before they entered a patients’ room and discarded into the appropriate bins once they exited:

Sally enters the patients’ room directly opposite where I’m sitting next to the nurse’s station. She emerges just a few seconds later calling Katy, one of the health care support workers, to ask her whether the patient’s bedding has been changed this morning. Katy says yes, and Sally responds by asking Katy to go into the patient’s room with her. They both exit together, and Katy is clutching a stained bedsheet at arm’s length from her body, “she keeps messing”, she says, while discarding the sheet into the laundry room and then fetching a fresh white sheet from the linen cupboard. Katy asks another support worker to help her move the patient to change the sheets, while Sally carefully wraps a blue plastic apron on top of her uniform and pulls a pair of clear latex gloves on to her hands. Finally, she grabs a bedpan and enters the patient’s room.

The meticulous routine of dressing in protective gear to clean and see to the patient depicts the differences in intimate physical contact between the day unit and the in-patient wards. Hoists were used for lifting some patients into bathtubs, which removed physical intimacy and closeness between nursing staff and patients. Rolls of aprons and boxes of latex gloves were fixed onto the walls next to the doors to each of the patients’ rooms. Lifting, moving and cleaning patients are examples of ‘medicalised touch’ (Wolkowitz 2006: 164) enacted within the hospice, which differed from the sensual skin-to-skin contact and embodied interactions between the day unit staff, the complementary therapists and their patients. Touch was often oriented to the physical needs of patients on the wards. Shakespeare (2003: 51) states that hoists and latex gloves serve to protect workers from contamination and contact with bodily fluid. In

doing so, Shakespeare (2003) notes that such materials often restrict the development of rapport through a lack of skin-to-skin contact. The use of such artificial materials places a 'physical and moral distance' (Cregan 2006: 54) between the workers' and the patients' bodies. Gloves and aprons stifle a sense of relational and sensorial closeness, and the sense of intimacy which could be found in moments of physical touch.

There were intimate moments of physical contact on the wards. Housekeeping assistants adjusted blankets, hugged and held the hands of patients as they entered the rooms to clean. I also observed nurses on their ward rounds who administered medicines and lingered for a little while to gently touch their patient's skin, as a way of showing affection and reassurance. However, patients on the wards were usually struggling with severe physical symptoms and the healthcare providers on the ward were often inevitably more focused on the physical side of their patients' conditions. In contrast, the day unit was a place of relaxed social interaction and respite for the patients with palliative (but largely, manageable) needs. In my interview with Amy, one of the nurses working on the in-patient unit, she highlighted the potential inauthenticity of the intimate interactions between workers and patients. She suggests that physical encounters with patients were usually focused on getting patients to open up and talk more freely about their symptoms and conditions:

*Amy, staff nurse, in-patient unit:* ... Touch, physical contact, physical closeness, eye contact, sitting on the beds, holding their hands, having a laugh, erm, just holding their hands when they're dying. The physical contact is very comforting, and people like to do that, and psychologically it's known that if people hug you, you're more likely to like them and say things to them.

Amy describes comforting patients through intimate closeness and highlights how this is often a deliberate, carefully considered tactic. For Amy, touching and being close to patients is a means of getting them to 'say things' they might not have freely said. Dingwall et al (1988) outline the ways in which developing relationships with patients can influence their behaviour, rendering them more knowable and easier to understand. When the subject of physical touch was approached in the interviews, the majority of the participants were very mindful and considerate of their physical approach to their patients. This means that many of the workers were aware of the importance of touching patients and directing physical contact within interactions with them. Amy was the only participant to reflect on her motives for being

physically close to patients and, more specifically, being close with patients to increase the likelihood of them ‘liking’ and ‘saying things’ to her. However, several hospice staff explored the importance of getting close with patients, so that they ‘open up and tell you anything and everything’ (Amy, day unit nurse).

May (1992: 594) reflects on the ‘shift’ in caring for patients as ‘individual subjects’ to getting to know them as whole persons, which implies ‘plastic and informal interactions’. This has the effect of ‘routinising personal encounters’ between patient and clinician, as they are carried out with the same aims (May 1992: 594). Amy refers to artificial interactions that *make use* of bodily proximity and touch to create a sense of security as well as a feeling of trust in the patient. This resonates with the sense of ‘performativity’ that Broom and Cavenagh (2011: 107) depict in their study of an Australian hospice. Amy suggests the manipulation of physical and emotional closeness to engage with the patients, in a way that is not ‘interactionally authentic’ (Broom and Cavenagh 2011: 109). May (1992: 594) suggests that these kinds of ‘friendly and familiar’ encounters between patient and clinician are ‘transformed into the site of work’. Like the moment in the day unit, where Jenny clasped a patient’s hand as Nicola asked where the patient wished to die, Amy utilises the physical intimacy of skin-to-skin contact as a means to an end. Amy’s defence for being physically intimate with patients, to build a relationship of honesty, openness and trust, reinforces the encounters that May describes. He calls this the ‘therapeutic gaze’, an adaptation of Foucault’s (1975) ‘clinical gaze’, which incorporates this form of psychological and emotional care of patients through getting to know them as individual persons (Bloor and McIntosh 1990; May 1992). This therapeutic gaze exercises a further domain of power by looking at the ‘*experience* of illness’, beyond physical symptoms (May 1992: 600). Amy describes practicing and, somewhat, manipulating physical closeness and intimacy in order to get close with as well as develop an understanding of the patient, which would make other aspects of her work much easier.

## **Taste**

### ***Personalising Food***

The workers turned to sensory forms of care, such as physically touching patients and being silently present when words were limited. Furthermore, different aromas were used to bring about a certain emotional affect, therefore demonstrating the entanglement of the sensory and

emotional experiences of dying. The café was the hub of the hospice and particularly, the centre of the day unit. It was a place where the day hospice patients could mingle and interact while eating freshly cooked foods each lunchtime. Relationships between the patients and the hospice staff were developed, made easier or more difficult, through the act of feeding, preparing food and eating. There is limited sociological literature on the acts of eating, feeding and food-work towards the end of life (Gunaratnam 2001; Naithani et al 2008; Heaven et al 2013). Ellis (2018: 354) emphasises the importance of viewing the end-of-life experience through a lens of ‘everyday materialities’, and she refers to the significance of food, the sense of taste and eating, in order to appreciate the relationality of the dying experience.

Food work tends to be overlooked within sociological discussions of formal caring relations. Pierson (1999: 130) states that assistance with feeding is a ‘complex and embodied activity, which appears so mundane that it is taken for granted’. However, Ellis (2018) draws on data from her hospice ethnography to explore the ‘entangled materiality’ of food, bodies and care, wherein familial relationships and day-to-day interactions unfold within the context of food, feeding and eating at the end of life. For Ellis (2013, 2018), focusing on food in this context can provide an insight into the day-to-day ‘doing’ of familial relationships. In the following section, the ‘food work’ (Heaven et al 2013) carried out by the hospice workers in their interactions and encounters with patients will be considered in order to explore further the way in which the sensation of taste as well as the actions of feeding and eating are significant in shaping the relationships between the workers and the patients. Food is at the core of our everyday lives, providing necessary nourishment and sustenance, and relationships can be framed around eating and feeding. In terminal illness, the materiality of food and actions of feeding or eating become an important site of ‘social and symbolic significance’ (Ellis 2018: 363). In this way, those that prepare and provide food to hospice patients play important roles in maintaining or further disrupting the sense of mundanity attached to food consumption as well as the ‘lived flow’ of human experience (Kleinman 1992: 174).

At Broad Lane, the café and communal areas were central hubs of shared interaction between the hospice volunteers, staff and patients. The lingering smell of freshly baked cakes could be smelt when I arrived early in the morning at the hospice and the smell of hot food emanated from the kitchen at lunchtimes. Different times and activities of the day were marked by the smell and preparation of food. The patients on the wards were served three freshly cooked meals at the same time each day. There was a menu that the patients could choose from, which

included a variety of hot and cold options. The patients attending the day unit were served snacks throughout the day, and they could choose from freshly baked cakes, scones and biscuits. At lunchtimes, they would be served sandwiches, or a hot meal for a small subsidised fee, in the café. The nurses and health care support workers would stand back and oversee the day hospice patients from a distance, watching on in case they needed to provide any assistance.

In the following extract from my interview with one of the cooks, Zoe, she explores the importance of ‘attending to difference’ (Driessen and Martin 2019: 1) in terms of appreciating the different desires, wants and tastes of the hospice patients. Zoe explains how she often prepares different dishes according to patients’ preferences, likes and dislikes, meaning that she often prepares food that was not listed on the café menu:

*Zoe, cook:* ... I did have a patient in here a couple of weeks ago, erm, she’s unfortunately passed away and she used to say to me [laughs] ‘when are you on? What – what – days are you on?’ I’d say ‘oh, you’ll be alright, erm, they’ll look after you’, ‘oh I know but I like it when you’re on cos you know how my jacket potato wants doing’

*Natalie:* Do you get to know, like with patients -

*Z:* Some, yeah

*N:* What they want, how they like it and things like that?

*Z:* Yeah, and I try to adhere to that, but it don’t always go down very well [laughs]

*N:* So even though you’re not on the ward, do you feel like you know what’s going on?

*Z:* Yeah, you take notice don’t you, especially when, I mean, there’s a patient that’s been in for a few weeks now, and I’ve got really friendly with her parents and, erm, I know that she likes things in a dish, I know to cut it up for her and... but I don’t know when I’m not here if that’s happening.

Zoe explains how she develops knowledge about the patients and how they like their food prepared. She places importance on being able to choose what to eat and consume at the end of life. Simple actions of preparing the food in a certain way, such as cooking a ‘jacket potato’ to the patient’s liking or cutting a patient’s food into a ‘dish’, equate to an individualisation and personalisation of food for the patients. Where they lack the ability to prepare food themselves and are dependent on others to do so, Zoe ensures their ability to choose is

preserved. This echoes the findings from Driessen and Martin's (2019) ethnographic fieldwork on care relationships and everyday life for people living with dementia in residential care homes. They state that mealtimes in health care settings are social experiences, wherein:

'Individuality may be done (for instance through attending to food preferences, diets or (in)abilities related to taking in food) or undone (for instance through the universal nature of institutional food).' (Driessen and Martin 2019: 2)

Zoe's efforts represent how 'individuality may be done' within clinical settings and in the relationships between workers and patients. Driessen and Martin (2019: 4) distinguish between three interlinking 'repertoires' in which caregivers consider the idiosyncrasies and differences of dementia patients. These repertoires include: knowing residents, providing choice and catering to their different identities. Zoe attempts to get to know patients well, provide them a choice beyond a limited menu as well as cater to their different tastes. Zoe catered to patients' identities in relation to food preferences, enacting simple differences in preferred tastes as well as the patients' (in)abilities to consume certain foods. She navigated the patients' limitations to eat certain foods, cook and prepare their own dishes, personalising the food she prepared in accordance with their needs and desires.

Much of the end-of-life experience is beyond the patients' control. Bates (2019: 13) emphasises 'the value of control or choice over sensescapes'. In their conditions of social dependency on others, such as Zoe, food becomes an element that the patients *can* exert some control over, as Zoe prepares dishes they desire, in the ways that they prefer. Referring to their ethnography of a dementia ward, Featherstone and Northcott (2020: 49) argue that the patients who were dressed in 'institutional clothes' felt an embodied and material sense of their personhood being 'stripped away' within the setting, as they experienced the loss of 'control and agency' over what they wear. In a similar way, Zoe emphasises the materiality of food and the sensorial experience of consuming different foods as important to the patients' sense of agency and control at the end of life. Zoe continued to say that preparing foods in a certain way for individual patients 'don't always go down very well' with her colleagues in the kitchen. Zoe also felt worried about whether her colleagues were preparing food in a way that considered the patients' likes, dislikes and eating abilities on her days off. She faced resistance and criticism from her colleagues for caring for patients and cooking for them in that way. Such tensions suggest that this manner of caring for patients was not shared amongst all the hospice

cooks. Her worries regarding her colleagues' treatment of the patients in her absence illustrates how individuality can be both 'done' and 'undone' within care settings (Driessen and Martin 2019).

End-of-life suffering is said to involve a threat to the 'lived flow' of human experience, a reorientation of how we experience our social lives, roles and identities (Kleinman 1992: 174). Therefore, it disrupts the ways in which we experience our everyday in relation to those around us. Suffering impacts on the very core of everyday social life, and food can be understood as an important material substance, which either unsettles or sustains a feeling of 'personhood' (Cassell 2004) for those reaching the end of life. Preparing food according to different tastes and needs or preparing dishes from a fixed menu in a fixed 'institutionally mandated' way represented the difference between seeing the patients as individual persons and rendering them 'invisible' (Featherstone and Northcott 2020: 55). At a time where patients were experiencing loss of control and agency over many different areas of their life, Zoe preserved a sense of choice and identity through the preparation of food. Individuality can be '*undone*' (Driessen and Martin 2019: 2 emphasis added) through the de-particularisation of food and the serving up of 'institutional' meals (Featherstone and Northcott 2020: 49). Zoe emphasises the importance of preparing food as an act of care that either individualises or works to deindividualise patients at the end of life. In the kitchens, which were spatially distant from the wards, the cooks influenced how the patients there experienced a sense of autonomy over what food to consume at the end of life. This brings to the fore the significant role that such workers play in shaping the end-of-life experiences of hospice patients.

Zoe detailed how she would come into work an hour and a half early every day to bake cakes, an undertaking that she was not paid for by the hospice or asked to do, but it was appreciated by the staff and patients. She explains how her bereavement experiences have shaped her understanding of and the meanings she attached to food at the end of life:

*Zoe, cook:* I like to think it makes a difference, yeah, erm, yeah, I think it does. Again, going back to how I felt, er, when my dad was on end-of-life [care]. He were so upset when there were something that he couldn't have, he swore at them and said 'well forget it then', and I just think even if they don't eat it, just doing it for them, it could be the last thing they've asked for.

*Natalie:* And do you feel like that's appreciated?

Z: Yeah, I did once get a letter, there was a gentleman in and all he wanted was a sausage sandwich and the lovely card that I received from his daughter, yeah it made me feel, yeah...

N: Just cos of the sausage sandwich?

Z: Yeah, just a simple sausage sandwich, and she said that he kept going on about this sandwich right up to him going unconscious sort of thing, so for me, yeah, it made me feel valued, yeah...

For Zoe, making and serving food was a way of attending to the patients' sensorial desires of 'comfort' and 'taste' rather than their needs for nutrition (Ellis 2018: 361). Food was homely and comforting, and Zoe placed emphasis on fulfilling the patient's sensory desires at the end of life, such as the 'simple sausage sandwich', which was not listed on the menu. Having experienced tensions related to food at the end of her father's life, she felt passionate about enabling the patients to be able to choose their meals, which could be 'the last thing they've asked for' before their death. Providing freshly cooked meals was a means of enacting care and developing an intimate embodied relationship with patients from the kitchen, wherein Zoe got to know the patients' needs and wants. Home cooked food, for Zoe, was more 'personal', and the act of preparing it for individual patients was 'laced with intimacy and warmth' (Hollows 2008: 63) shared between Zoe and the patients in the form of hot, fresh, personalised meals. For Zoe, cooking, and cooking in such a personalised way, was a means of demonstrating care and being intimate with the patients on the wards, from her distant place in the kitchen.

Zoe's attentiveness in getting to know the patients' idiosyncratic tendencies in regard to food tells us how intimate relationships were spread out across the different spaces of the hospice. Although Zoe was very rarely present on the wards, she came to know patients and could attend to their individual needs. Driessen and Martin (2019: 11) emphasise the undervalued work of food preparation as the cooks consider individual preferences and develop a knowledge of differences between patients, which is 'crucial in enacting individuality'. In treating patients as individual persons with individual tastes, we can see the *relationality* of individuality, as patients can be served en masse 'universal ... institutional food' or home cooked, personalised food, which considers the distinction between persons (Driessen and Martin 2019: 2). Zoe's patients were particularised and their food personalised as a result. She illustrates food work as a way of preserving choice during moments of dependency. These relationships emerge through physical dependency, and socially embedded personhood can be preserved (or

threatened) as a result of the actions of the cooks. Serving and preparing food en masse overlooked the differences between persons, neglecting their personhood and the significance of sensorial desires at the end of life, leading to a possible ‘loss of self’ (Charmaz 1983: 168). This emphasises the relationship between the senses, identity and suffering, as the cooks in the kitchen played an important role in either sustaining or unsettling a sense of socially embedded personhood at the end of life.

### *Problematizing Taste*

While Zoe attempted to personalise food and prepare dishes to reflect different patients’ needs and desires, some of the other workers problematised different tastes as well as the patients’ desires to eat certain foods that were considered inappropriate in light of their medical needs. During my observations of lunchtimes in the day unit, the support workers and one of the nurses would oversee the patients and be on hand to step in quickly, if any of the patients needed help with eating. In the following extract taken from fieldnotes, the day unit Sister, Eileen, watches over the patients as they eat their lunches in the café. She expresses her frustration about a patient eating ‘big meals’, despite having an intestinal ‘blockage’:

Jenny, one of the health care support workers on duty, is serving up the patients’ lunches. I stand by the door to the day unit with the Sister, Eileen, who is watching over the patients. She tells me that one of the patients is at “risk of choking because he’s got a blockage ... he’s been told what to eat, but he still sits there eating big meals then ends up choking”. She sighs in annoyance and rolls her eyes as the patient is served a hot meal of what looks like sausages drenched in gravy with chips and a side of chunky vegetables. She looks away and says angrily, “I’m gonna have to get over there and do a Heimlich manoeuvre in a minute”, she sighs, “you see, we’ve offered to liquidise his meals. That’s what he needs to be eating, and he did it once, but that’s it”. She looks at me and laughs, “sorry, we’re not very compassionate, are we?”.

Eileen describes attempting to enforce ‘liquidised’ meals for a particular patient in order to avoid aggravating his ‘blockage’. This extract also depicts the tensions between the cooks in the kitchen, who look to satisfy the patients’ desires and attend to personal choice, and the clinical needs of the patient in the context of their illness. Eileen suggests that the patients

continue to exercise their own freedom to choose, resist medical advice and challenge the impending threats of their own mortality. As Cook, Crang and Thorpe (1999) suggest, eating is ‘an active part of identity practice, through which identity is constructed’, and resisting medical advice is a way in which identity continues to be constructed, while the power exerted through the ‘clinical gaze’ (Foucault 1975) is resisted. Eileen watches over the patient, aware of the possible hazards as the patient gulps down a heavy meal, instead of a liquidised lunch, which she considers a ‘safe’ option for the patient. She emphasises food as a ‘functional’ necessity, instead of a luxurious and pleasing ‘domestic meal’, outlining the tensions between an ability to choose and the need to feel satisfied (Ferrie 2010). As Weiner and Will illustrate (2015: 209), ‘people draw on their embodied experience and their pleasure in eating’, and ‘when people like the taste’ of something they are less likely to see it as a medicinal or ‘functional’ food product. Liquidising the patient’s sausages and chips would inevitably remove ‘the forms of sensual pleasure (how food looks, feels, tastes and smells)’ (Gunaratnam 2001: 300) derived from eating food in its proper form. By enforcing the liquidising of his meal, this would also diminish another source of control for the patient over their lives and choices. The café becomes a ‘clinical space’ wherein the patients’ are subjected to the hospice workers’ ‘gazes’ (Evans et al 2009: 720) over the foods they chose to consume.

Eileen struggles with allowing the patient to have autonomy over the meals they choose to consume and fulfilling her role as a nurse who is there to provide a safe and comfortable environment:

Once the patient in question has finished eating, a volunteer tells Eileen that he has complained of his throat hurting. “Well that’s no surprise is it?”, she walks away from the café area angrily. I ask her if the patient is stubborn. “Well he is, yeah, they [the patients] have all this advice they get and some of them just won’t follow it, like with morphine, we tell them it’s safe if took properly, you won’t get addicted, but some of them just won’t take it and sit there in pain and I want to just – [she does a punching motion in to the air and grimaces]”.

“Everyone has a choice I guess?” I ask.

“Well yes they do, and when it’s my time I’m sure I’ll be the least compliant patient, so I do understand, I do”.

Food and consumption are intricately linked with our feelings of autonomy and agency, as we exercise choice over the foods we consume and how we prepare them according to our individual tastes (Turner 1984). Eileen describes the patients' resistance to food and medicine in the hospice as being '(non)compliant' behaviour. Her reaction to such behaviour demonstrates her knowledge as a Sister in the day unit, and her knowledge of what she feels is best for her patients based on the clinical guidance. This exists in contrast to the patient's desires for certain, clinically and medically inappropriate, foods. In his work on institutions, Goffman (1968: 16) explains how patients are often stripped of their identities in a social and cultural sense, so that they can be 'shaped and coded into an object that can be fed into the administrative machinery of the establishment'. In this case, Eileen emphasises the need for the patients to conform and mould their behaviour in ways that concur with the clinical and medical guidance. Imbalances of power operate through Eileen's watchful gaze over the patients and within the 'advice' shared with the patients, which she expects the patients to adhere to. The patients are subject to a process of 'normalisation' through the gaze and the spoken words of the workers (Foucault 1991: 308), who problematise certain behaviour according to the prevailing medical advice.

Individual choice, difference and identity were sustained by many of the hospice workers through food work and feeding practices. Many of the workers acknowledged the importance attributed to food at the end of life as a comforting indulgence reminiscent of 'home' (Rasmussen and Edvardsson 2007). However, certain needs, desires and food habits were problematised by the workers, and this was evident in their interactions. While the hospice cook, and some of the other workers in the hospice, considered the different needs of the patients, the cultural identities of different patients were also overlooked as important aspects of their personhood. The following extract taken from the fieldnotes describes an exchange in the 'breakout space', which was a space situated between the wards designed for the use of patients' families, but was often in fact a transitory space where nurses quickly made cups of tea and volunteers chatted in between seeing patients. The extract depicts the aftermath of a spillage in the fridge, discovered by one of the nurses:

Standing in the 'break out' space between the two wards, I overhear one of the nurses sigh, "I know whose this is", she holds up a Tupperware container with a dark liquid in it. "They need to label it and date it if they're going to put stuff like this in here... it's leaked everywhere. It stinks". She looks to one of the volunteers

and says, “they bring food in cos he doesn’t like the stuff here”. Then she walks to the ward, coming back a few minutes later with a patient’s relative by her side. She shows the relative the mess and tells them that any food left in the fridge needs to be “sealed, stood upright and dated”.

Broad Lane hospice was situated in a small, majority white, working class town with a comparatively small ‘Black and minority ethnic’<sup>12</sup> population in relation to the national demographic (ONS 2011; ONS 2019<sup>13</sup>). This population has more than doubled over the last twenty years. Whilst I was in the hospice there were no racially minoritized<sup>14</sup> staff members or volunteers and very few minoritized patients. In the above fieldnote, the nurse presumes immediately that a spilt food item that ‘stinks’ belongs to a Muslim patient on the ward or one of their family members. The patient and their family are singled out as the culprits. While many of the workers supported the patients in enabling them to enjoy their favourite foods before they no longer could, there seemed to be exceptions. In my interview with Amy, a staff nurse on the ward, she describes minoritized patients as a potential ‘problem’ in the hospice. This suggests a certain understanding and stereotype of the *normal* patient. Furthermore, this normalises white patients as unproblematic persons in the hospice, while othering minoritized patients and highlighting the apparent differences between groups, especially in terms of food consumption. The leaking food in the fridge represented a conflict and clash between the normal, (un)problematised ideals and the problematised patient. These ideals privileged certain tastes, while problematising others.

Driessen and Martin (2019: 11) draw on their ethnographic data in residential care homes to suggest that menus cater to different ‘tastes, identities and abilities’, yet there is less of a choice for different preferences, cultural differences and wanting to eat outside of designated mealtimes. The above excerpt suggests that different tastes and smells were accepted, while others were treated with outward disgust. The spilt food in the fridge seems offensive to the nurse and problematic in various ways, as she emphasises the rules of fridge-use. She implies that the patient’s family have been inconsiderate to others in improperly sealing the food and failing to label as well as place it correctly. Essentially, the spilt food item is ‘matter out of

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<sup>12</sup> I use this term in quotation marks to reflect its use in the original source. I recognise the problematic and ‘highly contested’ nature of this term (Gunaratnam 2003: 17).

<sup>13</sup> References are omitted from the reference list to preserve the anonymity of the hospice and participants.

<sup>14</sup> Where I am not referring to an original source, I use the term ‘minoritized’ or ‘racially minoritized’ as penned by Gunaratnam (2003: 17) to highlight the active ‘processes of racialization’ and ‘minoritization’.

place' (Douglas 1966), disrupting the acceptable as well as the desired olfactory and sensory organisation of the hospice. Sensory experiences can either 'indicate sameness and belonging' when they are 'familiar and meaningful to all' or they can 'mark otherness and difference when [they are] new to some' (Walmsley 2005: 43). In this situation, the smell and the sight of the spilt food in the fridge represents the differences in relation to tastes and foods. This situation indicates how the senses are rooted in individual preferences, which are in turn culturally and socially located.

The hospice menu was usually catered to a certain taste, and the fieldnote above suggests that patients with a different cultural identity to the majority struggled to find an appealing option. Gerrish et al (1996: 43) suggest that food is a site of 'ethnocentric thoughtlessness', and within care relations, 'failure' to attend to culturally oriented dietary requirements is due to either a 'total non-recognition of their distinctive cultural expectations' or a recognition of the issue that in turn leads to a 'narrow stereotypical definition of 'what they eat''. The above excerpt from fieldnotes illustrates how the hospice menu fails to cater for different cultural identities and tastes, while also portraying stereotypical dimensions of othering in regard to 'what they eat' (Gerrish et al 1996: 43). If food is an important material and symbolic social practice that can somewhat maintain a sense of identity and individuality at the end of life, then the hospice struggles with sustaining the identities of those that do not fit within the 'majority' demographic. Gunaratnam (2001: 304) identifies the 'unproblematic' nature of individual choice in relation to food when the choice is made by the 'majority'. Therefore, whiteness is constructed as sameness in an unproblematic sense. The problematisation of racially minoritized patients and their families portray the limits to enacting individualised care through the preparing, handling and serving of food in the hospice.

## **Conclusions**

The narratives and experiences of the hospice workers at Broad Lane suggest their influence over the patients' sensorial and embodied end of life experiences. Through these accounts, we can see the ways in which these relationships unfold with imbalances of power, wherein the workers often shaped the patients' end of life experiences through the way they cared for, interacted and engaged with the *sensory* needs of the patients. They shaped the patients' experiences of their own body as a site of comfort, pleasure or pain, through gentle touch and intimate contact. The limits of verbal expression gave way to these different forms of

embodied, sensory care, as the workers negotiated, and often found ways to overcome the inexpressibility of suffering. Being there with the patient and being silent was an active form of caring and a way of interacting, as opposed to a way of keeping the patients ‘at a distance’ (Bauman 1992: 131). The workers navigated the patients’ losses by individualising them as persons to provide them the contextually appropriate embodied and sensory care, as well as becoming physically close to patients and serving food in a different way, according to tastes, desires and needs. Such actions could help to ease the patient’s suffering and, as Lauren suggests in Section 2, enabled an ‘*emotional release*’ within physically intimate interactions. Many of the workers’ accounts of their interactions challenge existing notions of mechanical bodily contact in clinical relationships, where the caregiver ‘helps’, ‘lifts’ or ‘transfers’ the patient (Price and Shildrick 2006: 71) as an ‘object’ (Twigg et al 2011: 173) of their labour. The relationships and exchanges described here are often intimate, embodied and affectionate, illustrating the significance of drawing upon a range of sensory forms of care, such as touch, taste and the use of silence, as opposed to only verbal exchanges, in hospice work. This chapter contributes to the existing literature on suffering, by illustrating the need to think with the ‘democracy of the senses’ (Back 2007: 8) to explore how the *silences* of suffering give way to different forms of engaging, reacting to and demonstrating compassion in the face of suffering. Here, silence is often a thoughtful and carefully considered action, which, alongside physical touch, expresses the care and intimacy that words cannot.

This chapter also illustrates how certain behaviours were problematized by staff at Broad Lane, and how physical contact and the body were, at times, manipulated as a means to achieve a certain emotional affect. I have suggested that the relationships between the hospice workers and patients were embedded in imbalances of power and through their sensorial and embodied actions, the workers were in a position to either preserve or deny the patients’ individual preferences in relation to physical contact and food. Touch could be used to bring about an emotional affect, which I argue illustrates the imbalances of power and the workers’ *awareness* of their ability to bring about this affect. The problematisation of certain foods and tastes was embedded in shared, socially constructed notions of (ab)normal sensory desires and preferences. I have documented how sensory forms of care could individualise patients, accounting for their differences as persons, while also demonstrating the ways in which such forms of care could extend the differentials of power by problematising certain patients and their behaviours. Zoe, in the kitchen, preparing food in a personalised manner, contrasts with Eileen’s annoyance about a patient eating ‘big meals’. Specifically, this chapter outlines the

ways in which the staff across Broad Lane play a significant role in influencing the patients' experiences of their body as a site of pleasure, or pain and ill health. This chapter builds on the existing understandings of the body as a site of social interactions, relations and exchanges with others (Ahmed 2004; Macpherson 2010). Through the hospice workers' accounts of these relationships and interactions with patients, we can see the exact influence they hold over their patients' experiences of dying and their embodied sense of identity at the end of life. By adopting this relational framework and focusing on the subtle, unspoken sensory forms of care, this chapter illuminates the relationality of suffering as shaped by embodied and sensorial interactions *between* people. Suffering emerges through and within sensory and embodied relationships with others, and Wacquant (2015: 2) argues it is developed over time, as a 'layered product of our varied individual and collective histories'. This chapter emphasises how the senses are negotiated by the hospice workers, in a way that either sustains or further unsettles a sense of personhood, which, in turn can either extend, or ease, suffering.

## CHAPTER FIVE

### Managing the Sensory: Dirt and Order

*'It is hardly surprising that ageing and death are viewed so negatively – they are unwelcome reminders of the inevitable decay and defeat that are in store, even for the most vigilant of individuals.'* - Featherstone 1991: 186

#### Introduction

The previous chapter has illustrated how the hospice workers carried out sensory forms of care, which could influence the patients' emotional and embodied experiences at the end of life. This chapter will develop this notion further, by expanding on the workers' *management* of the sensory inside Broad Lane. I will explore their day-to-day practices to contain and navigate the sights, sounds and smells that were constructed as offensive and abnormal. The chapter will consider how the workers negotiated their immediate sensory reactions to maintain a sense of ordinariness and normality in response to potentially 'threatening' (Elias 1985: 23) and 'polluting' (Douglas 1966: 100) processes at the end of life. Certain noises and smells symbolised potential disorder, as 'reminders' (Featherstone 1991: 186) of mortality for the other persons present. First, I will explore the duality of 'dirt' by examining its nature as a symbolic and material presence in the hospice, representing disorder and physical dirtiness. Secondly, the chapter will illustrate the hospice workers' everyday actions to manage signs and sensory symbols of disorder in the hospice, such as shutting doors, closing curtains and ushering grieving relatives into designated 'quiet rooms'. Finally, I will examine how the workers reconstructed notions of 'normal' attached to the body and bodily boundedness to normalise certain aspects of their work and the dying process. This final section will expand on the 'normal' as a fluid, relational concept, which the hospice workers continually constructed and reconstructed in their interactions with their colleagues and the patients. Overall, this chapter examines the idea of a typical death in the hospice, one which speaks to ideals of a reserved, bounded and peaceful affair, wherein the person can remain *socially* present until and after their biological death (Lawton 1998, 2000; Elias 1985; Gunaratnam 2009). However, I seek to extend these ideas further by exploring the processes of *renormalisation* that render the abnormal a little more ordinary. In doing so, I illustrate how the management of the physical and sensory aspects of dying are key for the workers in order to maintain the *sociality* of the person at the end of life.

## **The Sociality and Physicality of Dirt**

Kevin, one of the health care support workers that had worked in a palliative care context for over twenty years, believed that ‘you never get used to’ the sensory experiences of the work. In contrast, he described the learned practices that enabled him to continue engaging in offensive tasks and the ways in which he would disguise his external reactions in front of patients. Kevin explains that ‘you try not to breathe through your nose’, creating a makeshift boundary against the odour. Douglas (1966) suggests that individuals practice such methods of avoidance and distance to uphold barriers against potential contamination and pollution. Many of my fieldnotes depict a pleasant sensory environment. There was the drifting of the smell of freshly baked cakes through the day unit, café and reception areas, and bunches of flowers were dotted through the wards. On the ward the atmosphere was usually ‘cheerful’ and fresh air often drifted through. My observations took place over the Spring and Summer months, and this meant that the large ceiling windows were open on hot summer days allowing a breeze to filter through. The experience of death that was sustained in the hospice was usually a quiet, clean, peaceful and orderly process. The messiness, noises and disorder of death rarely seeped through to impact the social order and social life of Broad Lane. Those deaths that were vocal, busy and messy, typified disorderly deaths. The following fieldnote describes the unusual presence of a lingering odour emanating from an in-patient room on the first ward:

I sit at the desk by the radio in the first ward; the radio is on as usual. For the first time that I can remember, I smell an unpleasant smell drifting from one of the patients’ rooms. As the door to the patient room next to me opens, Yvonne and Karen, two of the housekeeping assistants, exit the room, one walking out of the room backwards, spraying a thick stream of air-freshener as she goes. The smell is then all of a sudden overpowering, of artificial lavender.

In this extract, two of the housekeeping assistants on the in-patient unit emerge from one of the patient’s rooms attempting to dissipate the faint odour with the scent of artificial lavender. The extract illuminates the ways in which offensive smells are disguised and covered up to avoid ‘polluting’ the surrounding areas, and, as a result, the hospice remains a sensorily and aesthetically pleasing space. In particular, the housekeeping assistants made an effort to maintain a hygienic and pleasing space, conducting thorough ward rounds each morning and

afternoon. The hospice often smelt distinctively of nothing, as if the ‘illusion’ (Hockey 1990: 86) to be maintained was one of *nonentity*, so as not to offend the sensory experience of visitors and patients in the hospice. The practices of sustaining cleanliness and quietness maintained the boundaries of life and death, managing the experience of dying for those that were still living. Offensive smells were ‘matter out place’ in the shared spaces. The fieldnotes suggest that offensive smells were also negotiated by the housekeeping assistants as part of the ‘symbolic reproduction of order’ (Shove 2003: 83) in the hospice. The housekeeping assistants managed the smells emitted through bodily secretions and leakages, which threatened to invade the shared corridors of the hospice. The immateriality of the sounds and smells, which were ‘out of place’, suggests both a symbolic and material nature of dirt. Emitted from a corporeal and physical body, the sounds and smells lost form as they drifted between places, becoming symbols of decay and death as they surpassed physical boundaries.

In the ‘back stages’, as they might be referred to in Goffman’s (1959) terminology, such as staff meetings and board rounds, the reactions to patients’ bodily excretions would often differ from those expressed in front of patients in the ‘front stages’. The following fieldnote provides a snapshot of the discussions between ward staff in a morning board round, which usually took place in the doctors’ office. Morning board rounds were held each day and were attended by key members of staff working on the in-patient unit. The senior nurse, specialty doctor, consultant and ward clerk were all in attendance during this particular meeting:

The staff members in the room take notes about each patient. Referring to one of the in-patients, Kelly, the specialty doctor, asks whether the patient’s urine has been sent off to the lab for tests, “you could smell it all the way down the hall the other day”, she exclaims with a grimace. She appears to smell the lingering urine, as if it were still there. The nurse then notes this down, supposedly as one of her tasks for that day.

Kelly stresses being able to ‘smell [the urine] all the way down the hall’, describing the way in which the odour drifted into the shared corridor between the two wards on the in-patient unit. The patients staying on the in-patient unit had a private room with their own bathroom, and some rooms had a balcony overlooking the hospice gardens. The layout of the hospice had changed over the last ten years, when the small shared wards had been separated and renovated into fourteen in-patient rooms across two wards. With the shutting off of individual patients,

the smells, sights and sounds of the dying process could also be kept contained to the private rooms. However, Kelly describes the odour seeping into the shared spaces of the in-patient unit, drifting from the patient's room and becoming 'matter out of place' on the corridors of the two wards (Douglas 1966: 4). The smell of the urine is described as a matter for concern, intangibly wandering across the hospice ward, which was invisible and challenging to contain. In her ethnographic observations, Lawton (1998: 134) describes the immateriality of odours in the hospice, as they drifted between different 'boundaries and spaces of other persons and other places'. The urine was originally a bodily emission, which became an incorporeal entity transgressing the boundaries of space and potentially 'polluting' (Douglas 1966: 100) the shared spaces of the hospice as well as the other persons present. The extract depicts the practices of containment and management of the carnal emissions on the in-patient unit as well as the ways in which certain odours can become an 'out of place' entity.

Lawton (1998) and Twigg (2000) illustrate the ways in which odours challenge the ideals of a somatically bounded body, especially towards the end of life. Repulsion is here experienced through smelling the patient's urine, demonstrating the ways in which 'dirt' can be experienced simultaneously as both a material and non-material entity. Symbolically, the seepage of the odour into the shared spaces disrupted the clean and hygienic spatial ordering and pleasant *aromas* of the hospice. The practices to contain, control and manage such odours reflects the needs to maintain boundaries between persons and places within the hospice. The workers on the hospice would practice methods and techniques to shut away smells as well as to shut smells *out* of their own bodily orifices, such as 'not breathing through [the] nose', to maintain their own boundaries and escape the unpleasantness of a certain smell.

The specialty doctor, Kelly, proceeds to mention another patient, who she describes as 'bringing up ... bright yellow sputum':

Another patient is mentioned and the doctor states that his sputum needs to be sent off for lab tests, "the stuff he was bringing up at the weekend was bright yellow", she says appearing concerned and expressing this as another matter of urgency for the nurse.

Kelly addresses the nurse with concerns regarding the odorous urine and the offensive sputum, delegating the task of handling the substances and sending them for testing. While dirt itself,

existing both intangibly and materially, presents as a disruption to the social order of the hospice, *doing dirty work* or tasks represents a hierarchical ordering within the hospice. Proximity to dirty matter is said symbolically to represent one's positioning in a hierarchical system. Drawing on her anthropological work with the 'Coorgs' of South India, Douglas (1966) explains that their hierarchical caste system is structured around purity and proximity to bodies and bodily matter. Those lower in the Coorgs' caste system would participate in tasks that involved closer proximity to faeces and blood as well as the washing and dressing of corpses. The material presence of dirt symbolises the systematic and structural ordering of a particular society. In the context of the hospice, those more senior in the occupational hierarchy would often delegate 'dirty' tasks to those working in lower status positions. Twigg et al (2011) explain that doctors often engage in body work in a very limited sense. They describe the symbolic as well as material practices doctors draw upon to place distance between themselves and the patients, such as wearing cloaks or gloves, as well as delegating certain dirtier tasks to their colleagues. Within medical professions, dirty work is largely structured around the occupational hierarchy of the organisation, often being seen as gendered and low status work (Bolton 2005). In the extract above, Kelly delegates the two tasks, which involved handling offensive bodily matter, to the nurse present in the board round. This limited snapshot illustrates the delegation of certain *dirtier* tasks to other workers and the practices of distancing dirt to exert status.

In contrast to the in-patient unit, which was partitioned into separate patient rooms, the day unit was a relatively open and shared space. The day unit was open to patients three days a week, situated in the conservatory attached to the hospice café, where patients mostly sat in comfy lounge chairs or around the crafts table. The day hospice staff also held a board round meeting each morning, before the patients arrived. The two nurses on the day unit, Eileen and Nicola, usually led this meeting and reviewed each patient attending that day. Eileen and Nicola often delegated certain tasks to the health care support workers, who were usually more present in the day unit in comparison to the nurses. While the support workers would sit and make crafts with patients as well as serve them drinks and food, the nurses would move constantly between their offices and the day unit. The nurses would come into the day unit for short periods at a time in between administrative work to administer medicines and talk with the patients. Most of the intimate care work, such as toileting, was often carried out by the health care support workers. The following extract is taken from a morning board round meeting on the day unit:

I'm sat with two of the health care support workers and both of the nurses at the crafts table in the day unit room. Eileen (the day unit Sister) and Nicola (the day unit Nurse) are reviewing each patient that is due to attend today. Nicola says that they have a new patient starting, "he's 96... Eileen, I don't know much about him, so you'll have to fill us in". "Well, I don't know much, I just took the phone call", Eileen explains, "and it says here 'sloppy stools', so we need to find out whether he's incontinent and his needs there...". Both health care support staff grimace at the task to come. "Yes, so we'll have to assess him," replies Eileen.

The patient's 'sloppy stools' present the workers with a task which has the potential to disrupt their own sense of corporeal 'integrity' (Lawton 1998: 134), which reconstructs their identities as dirty *workers*. Advocating for both the symbolism and materiality of dirt, Hughes et al (2017: 119) draw on their ethnographic study of refuse collectors to explain the ways in which proximity to dirty matter both 'positions individuals' within the social structures of society and is also experienced through the 'materiality of smells and touch'. The workers across the spaces of the hospice, and particularly those working in close proximity to patients, experienced the breaching of boundaries through being physically close to another person's bodily fluids and excretions. The tasks highlighted in this section often challenged the ideals we hold in wider Western society of 'normality and acceptability' (Hughes et al 2017: 114), as the workers were confronted with tasks that are viewed with disdain and disgust in everyday social situations, such as physically dealing with another person's bodily matter and fluids.

These behind the scenes exchanges between the workers about the dirtier aspects of their work are often in contrast to those presented in the previous chapter. These exchanges often depict disgust and repulsion in comparison to the intimate, sensual and caring relations between patients and workers, as presented in Chapter Four. However, in their ease of discussing bodies and bodily fluids, the workers illustrate the ways in which dirt is both symbolically and materially negotiated. The workers' proximity to such matter suggests the ways in which they manage patients' leaking bodies to sustain a sense of *sociality*. Dirty matter was often negotiated in such a way that maintained social life, while the patient's corporeal boundedness was coming undone. The workers managed the symbolic and social connotations of bodily disintegration, recognising the abnormality, while negotiating their own sensory experiences.

In doing so, they would also render the ‘extraordinary ... seemingly ordinary’ (Ashforth and Kreiner 2002: 217). This is a matter which this chapter will return to later.

## **Ordering Disorder**

### *The Signs of Death*

Many of the practices to manage sights or smells on the ward focused on maintaining an odourless and a peaceful environment. In modern social life, the dying process is said to be ‘removed so hygienically behind the scenes of social life’ and ‘human corpses’ are ‘expedited ... odourlessly’ (Elias 1985: 23). The hospice was often organised in a manner that reflected the shutting away of noticeable signs of death and dying. For example, the closing of doors and the drawing of curtains between the hospice wards, as deceased patients were wheeled out through a side exit, highlights the discreet manner in which death was negotiated by workers and volunteers in the hospice:

The first ward is hectic, with nurses and support workers popping in and out of different patients’ rooms. One of the nurses, Lily, tells me that most patients are receiving bed baths or medications, as they do each morning. I head to the breakout space to wash my empty mug and begin talking with one of the volunteers. After a few moments, another volunteer shuts the door to the second ward and draws the curtains shut on a small window in the door. The volunteer tells me that the undertaker has arrived to remove a dead patient, “we let nurses and staff go through, but we ask any visitors to wait, it gives them their last bit of privacy and respect. So, one of us guards the door”. As a group of visitors head toward the second ward they are stopped by the volunteers and are asked to wait. After about 10 minutes one of the volunteers pokes their head around the door to the ward and asks a nurse whether it’s ok to let the visitors through now. The nurse presumably gives the “ok”, as the visitors walk through. I walk through shortly after and see the housekeeping assistants wheeling their cleaning trolley into the newly empty room.

The volunteer explains that shutting the doors to the ward, as the corpse is taken out of the hospice, provides the deceased patient with ‘their last bit of privacy and respect’. In doing so,

those present in the hospice, such as relatives and other patients, are also ‘guard[ed]’ from the removal of the corpse. Death was concealed from visitors and patients in the hospice by a process of ‘screening off’ the event (Elias 1985: 23). However, the management and conduct of its concealment often revealed its occurrence. In the silences, the closing of ward doors and the drawing of curtains, the volunteers, staff and patients ‘colluded’ (Komaromy 2000: 303) together to ensure that deaths were discreet and the removal of corpses transpired as a quiet affair. The volunteers operated in a supportive role, upholding the practices and processes of the paid members of staff by ‘guarding’ the doors as the deceased patient was taken out through the side exit. Thus, the paid and the unpaid individuals in the hospice worked in conjunction to uphold the illusion of order, whilst negotiating the *disorder* of death. However, the practices of disguising a death rendered it obvious, and these processes were accepted without question by the visitors. Although the volunteer explains that the practice of concealment provides the patient with ‘privacy and respect’, it also hides the removal of the corpse from other hospice patients and visitors. Death is a marker of disorder and the dead, a reminder of mortality (Elias 1985; Featherstone 1991). The dead body is taboo, as ‘the antithesis of the living body’ in a society where ‘life’ and ‘death’ stand in a ‘dichotomous relationship to one another’ (Hallam et al 1999: 126). The doors and drawn curtains act as makeshift barriers to hide the processes of removing the corpse, while the volunteer acts as a ‘guard’ between the living and the dead.

While the volunteer in the extract above states that creating a barrier between the removal of a corpse and other patients or visitors provides the deceased with ‘privacy and respect’, their actions suggest that the sights and sounds of death were also stifled to protect others from recognising the impending certainty of their own mortality. During my observations on the in-patient unit, one of the nurses, Amy, described ‘managing’ the loud, vocal distress of a patient’s relative after the patient’s death:

“I heard someone crying, and at first I had to check my patients, make sure that they’re all okay. She was extremely distressed, so, I took her into a quiet room. Then I tried to find out the situation, because at first you think it might not be related to the hospice, it might be something else. You have to manage it... because if an individual is upset and another visitor or patient here hears it, then they’ll think, ‘that will be me’”.

While the sight of dead bodies can be hidden to some extent by the closing of doors and the drawing of curtains, the sounds of dying or grief are much more difficult to ‘manage’, as loud sounds escape barriers and seep through doors. The nurse attempts to contain the cries of the relative by ushering them into a ‘quiet room’, away from the shared corridor between the two wards. However, sounds challenge as well as transgress the boundaries of space, threatening the symbolic distinctions between life and death in the hospice. Elias (1985) argues that emotions are privatised along with bodily leakages and corporeal secretions. Therefore, the aural, visible and malodorous signs of death are negotiated in order to sustain the boundaries of the living and the dead as ‘dichotomous’ categories (Hallam et al 1999: 126). In her multi-method study on the management of death in nursing homes, Komaromy (2000: 305) argues that the workers engage in a ‘partial and incomplete’ performance to portray the ‘illusion’ to other patients and visitors ‘that nothing has happened – despite obvious evidence that it has’. In Broad Lane hospice, a patient’s death was often signified ritualistically, as a subtle and discreet occurrence, with the lighting of a candle on the ward and the placement of fresh flowers in the twenty-four hours after a death. Death was managed so that it seemed unimposing on the social life of the hospice. Rather than hidden, the hospice staff confronted death with rituals that signified its peaceful and inevitable presence. Komaromy (2000: 311) alludes to the ways in which the visible signs of death were hidden in the nursing home, while there was a lack of ‘effort’ in those particular sites to dull the sounds of departing corpses. In this instance, the staff on the ward ‘colluded’ to conceal the signs of two separate deaths. However, death collided with the social and shared spaces of the hospice as the sounds of a relative’s distress were audible throughout the ward. Furthermore, the rituals after death provided ‘obvious evidence’ for a recent death, while constructing the event as a peaceful affair.

The routines of ‘guarding’ closed doors, shielding visitors from the sight of corpse removal and the subsequent lighting of a candle indicate the death of a patient. In contrast to Komaromy’s (2000: 311) findings, there was an ‘effort’ to dull the loudly distressed sounds of a relative’s grief. Furthermore, this account from Amy illustrates the ways in which the sights and sounds of death are managed in order to shape the experiences of other patients and visitors to the hospice. She explains that hearing the distressed cries of a visitor in the hospice often signifies the death of a patient, which ultimately leads fellow patients to feel reminded of their own impending death, thinking *‘that will be me’*. Douglas (1966) explains that being in close proximity to any signs of death or a corpse symbolises a danger to the living. Therefore, the negotiation of the sights and sounds of death were an attempt to preserve a social order within

the hospice space amidst potential *disorder*, as death symbolises disorder when it seeps into mortal social life, embodying all that is opposed to life as its ‘antithesis’ (Hallam et al 1999: 126).

### ***Problematised Deaths***

During my observations on the in-patient unit, one of the nurses, Amy, told me that there was a Muslim patient staying on the ward and he required a male nurse to carry out physical care, such as bathing and helping him to go to the toilet. She stated that ‘it will be interesting. It always is when there is someone of a different ethnicity on the ward’. The hospice demographic seemed to reflect the wider demographic of the town it is situated in, and there were very few minoritized patients, volunteers and staff. In my interview with Amy, I reflected back to this interaction. Amy described minoritized patients as a ‘*problem*’ as they often grieved loudly and ‘vocally’. This reflected the normalised standards of death as well as the normalised ideal of *who* their patients were as shared by some of the Broad Lane staff. Elias (1978 [1939], 1985) emphasises the western norms of dying, as a sombre, reserved and quiet affair, wherein the body is bounded, and bodily functions are privatised. However, Amy suggests that certain patients needed to be managed, as they disrupt the ideal norms of dying in the hospice.

*Natalie:* One thing I wanted to ask you, I remember you told me there was a Muslim family on the ward, and the patient needed a man to do his physical care. How do you get round those different cultural norms?

*Amy, staff nurse, in-patient unit:* Yeah, there can be issues with that, erm, there is sometimes ways round it. Like before I worked here, I looked after a Muslim guy who didn’t like the girls to see him naked, so I would bathe him in his pants and wrap him a towel afterwards... but yeah, it can be a problem, it can be a problem and their customs and beliefs can be a problem because when somebody dies in certain cultures, they are extremely vocal.

*N:* What, the families?

*A:* Yeah, and extended families, usually Muslim families but also sometimes Afro-Caribbean, people like that, they are very vocal emotionally, it’s how they are, erm, and you always have loads and loads of the family around, which can be distressing to other people who aren’t used to that, and we’ve had to somehow get the balance.

The hospice is positioned in a mostly white working class area in the North of England (ONS 2019), and all of the workers I met during my time in the hospice were white. Much of the existing literature on end-of-life care and relationships tends to overlook and '[does] not engage with questions of racialised difference' at the end of life, or in structures of hospice care provision (Gunaratnam 2009: 7). However, some of the existing literature, from scholars such as Lawton and Elias, highlights how the 'unboundedness of sound' and the 'transgression of bodily boundaries' can present a threat to Western norms of the dying experience as well as the Western constructions of a bounded body (Gunaratnam 2009: 7-8). Amy suggests that 'Muslim' and 'sometimes Afro-Caribbean' families are 'extremely vocal', which she believes can cause distress to others present in the hospice.

Gunaratnam (2009: 10) argues that hospices are not necessarily silent places, as 'everyday hospice life can be 'natural' and 'noisy'', with the 'rhythmic' and 'routinized' sounds of trolleys being pushed about the wards, syringe drivers being administered and the workers chattering. However, within hospice space the expressions of distress and pain are suppressed, as they disturb the 'social order' of the space, that is ordered around bounded bodies and medicalised practices (Gunaratnam 2009: 10). Broad Lane hospice was generally not a silent place, as the routine eruption of cheerful laughter and singing could be heard loudly each morning as the housekeeping assistants moved about the wards on their cleaning rounds. As the smells of cakes and hot meals emanated through the corridors, the sounds of the radio and light-heartedness could be heard. In contrast, the sounds of distress were confined to individual patient rooms or a number of designated 'quiet rooms'. These quiet rooms were small, with sofas, tables and chairs, and the rooms were positioned on a long corridor between the reception area and the wards. Therefore, the workers designed a certain auditory experience on the hospice ward, where certain sounds were permitted, however the 'vocal emotion[s]' of 'noisy *others*' (Gunaratnam 2009: 8) were unwelcome as they disturbed the order for those that 'aren't used to that' (Amy, Staff Nurse). Amy's narration of the 'problems' that certain families represent suggests that she divided different ethnic groups by the ways in which they managed their grieving and dying experience.

Amy describes the disruption that the workers were presented with, as certain deaths involve the coming together of 'loads and loads of family' and the 'vocal' expression of grief. She emphasises a shared, and challenged, ideal of a quiet and private death, while rendering the

dying experience one that can and *should* be kept quiet. Amy goes on to state that her work is made ‘difficult’ when families resist requests to be quiet and more refrained:

*N*: Does that make your job challenging?

*A*: Erm, it can do, but it’s sometimes the way you approach it and again, it does depend on the individual, some will respond well to you asking them, explaining to them, some families will just be a pain and that’s when it is difficult.

Amy differentiates between the ‘customs and beliefs’ of Black and Muslim patients, in comparison to white patients. She ‘normalises whiteness’ (Gunaratnam 2009: 12) as the prevailing standard of the death experience in the hospice and identifies problematic distinctions between a ‘peaceful’ normalised death (Gardner 1998: 515) and a ‘vocal’ minoritized death. Sound and noise become ‘matter out of place’, needing containment as they violate and disrupt the ‘peaceful’ order of the hospice. Out of place noises embody the antithesis of the ideal ‘good death’ in the hospice (Gardner 1998: 515). Gardner (1998) draws on her research with a group of Bengali Muslims in London to suggest that the discourse of a ‘good death’ differs between Muslims and non-Muslims. For the group of Bengali Muslims, a good death involved ‘being surrounded by kin reciting prayers’ as a cultural rite of passage (Gardner 1998: 515). In contrast, the workers caring for them described their dying process as sounds of ‘screaming’, which ‘destroy[ed]’ the ‘peaceful’ death of others present, overhearing the recitals. As in Gardner’s study, a good death in Broad Lane constituted a quiet, reserved death, which symbolised peacefulness as the epitome of the ideal passage. Ideals of an ‘acceptable’ and ‘good’ way to die were intertwined with quietness and ultimately with whiteness, as the prevailing norm in the hospice. Other forms of dying were to be ordered and managed as disorderly challenges to the ‘good death’. Amy describes this as finding ‘the balance’, while Gunaratnam (2008: 11) argues that the ‘balance’ lies between ‘a degree of openness to particular forms of suffering and dying’, while managing and ‘sanitizing’ other forms, which fall outside of the norm.

Suffering is simultaneously ‘pattern[ed] and singular’, and Gunaratnam (2013: 348) stresses that care workers should be understanding of the different cultural experiences of death, dying and grief, while also caring for the individualised forms of suffering. The sweeping judgements Amy makes in regard to the ‘vocal’ experiences of Muslim and Black patients as well as their families downplay their *individualised* differences. She remarks that ‘some families will just

be a pain’, classifying groups of persons as problematic based on discourses of cultural and racial difference. The end-of-life experience can be a time in which previous lived traumas of racial inequality and harassment can come to the fore, which demonstrates the complex, fluid temporality of suffering in the end of life experience (Gunaratnam 2013, 2014). As Ekblad et al (2000) explain, the power exerted over dying bodies as well as the use of medical equipment and tools can result in the resurfacing of lived traumas for individuals with previous experiences of forced displacement. Hospice workers and carers of the terminally ill can, in turn, reinforce culturally defined suffering by ‘exert[ing]’ control over ‘the movement, boundaries and rights’ of patients’ bodies within hospice space, through institutional practices grounded in white as well as *Western* ideals of the ‘bounded identity’ and ‘biomedicine’ (Gunaratnam 2009: 10). As Amy guides ‘vocal[ly] emotional’ relatives into side rooms and asks them to be quieter in their distress, this suggests that control was exerted over (what was considered to be) disorderly behaviour.

There is a complex need to attend to the ways in which different persons and those of a different ethnic and cultural background suffer at the end of life. Amy describes these differences as ‘*problem*’ behaviour, which emphasises the Western ideals of normality at the end of life, as based on the containment and isolation of potentially ‘polluting’ behaviours. The ‘good death’ within the hospice corresponded to a peaceful, quiet and contained death, without leaving room for different interpretations of what defines a ‘good’ or an acceptable death. The previous chapter illustrated ways in which silence was used to express care and compassion towards patients, however this use of silent interaction overlooks the different manners of suffering at the end of life. ‘*There is no single way to suffer*’ as it is embedded in ‘cultural worldviews and social conventions’ as well as ‘historical and material circumstance’ (Wilkinson and Kleinman 2016: 2-17, emphasis added). This extract from Amy illustrates both the socially and culturally embedded nature of suffering, while also depicting the ways in which the plurality of suffering can be overlooked by the workers in the hospice. Again, I emphasise the relationality of suffering and dying, as the hospice workers exert an influence of what can be considered as ‘normal’ ways to die and grieve.

Similar sentiments were echoed by other hospice workers through grumbles of discontent in the staff rooms regarding the presence of an interpreter for a Muslim patient. One of the other nurses disclosed that they felt the family were ‘taking over’ the ‘relaxation room’ with their *out of place* belongings, rendering the room unavailable to workers and other visitors. Such

statements echoed sentiments of othering and an anti-immigrant rhetoric within the hospice. A support worker also described the disruption that had been caused by the same patient requesting a male support worker for his intimate and physical care, due to religious and cultural reasons. I only encountered three male staff on the wards during my time there and the shortage of male nurses and support workers would have undoubtedly made this more difficult to carry out. The cultural differences at the end of life were often a source of annoyance to some of the workers, as the different ways of dying disrupted a sense of order and challenged their ideals of a good death. Disorder was *reordered* through silencing, containing and concealing auditory, visual and olfactory disturbances.

## **Normalising the Abnormal**

### ***Reconstructing the 'Normal'***

The hospice workers on the ward often disguised, or shut away certain deaths, which were noisier, messier and more imposing to the social life of the hospice space. These practices helped to maintain privacy and personhood for the patients as well as to sustain a certain social order within the hospice setting. This section pursues this issue by examining the workers' efforts to *reconstruct* 'normal' in the face of the disordered abnormality of death and dying. Rendering the abnormal *normal* was also a practice to make the work easier to carry out. The processes rendered the 'extraordinary ... seemingly ordinary' (Ashforth and Kreiner 2002: 217) within a work context that disrupted boundaries of normality and often 'violated' the workers' sensory experiences of 'touch, smell and sight' (Twigg et al 2011: 172). In the following extract from fieldnotes, taken after shadowing two housekeeping assistants on their morning rounds, they describe cleaning up the contents of a stoma bag from the floor of a patient's room:

Once the housekeeping assistants have finished their 'ward round', we chat by their tiny storage cupboard, which featured posters of David Beckham. Karen says that they are expecting a patient in the hospice in the next day who is around 40 and has been in the hospice previously, "he's got a stoma and he plays with it", Karen grimaces. "Eugh", says Yvonne, "he drops all the *stuff* [contents of the stoma bag] on the toilet floor, doesn't he? For us to clean up". "Yeah, he's a bit messed up", Karen agrees. They both look at me, making disgusted expressions.

The unboundedness of the patient's body is negotiated in a way that resists and challenges the workers as well as disrupting the orderly process of carrying out their tasks. The housekeeping assistants react in disgust while reflecting on the patient's actions, describing how the patient would empty their stoma bag on the floor and leave it for them 'to clean up'. The way in which Karen and Yvonne describe and understand the act suggests a 'disguised, low-profile, undeclared resistance' (Scott 1990: 198) towards them, as their work involved entering and cleaning the patients' rooms. Using waste or faeces as a weapon is described by Foucault (2006 [1973-74]: 25) as a 'centuries old' act of resistance, and a symbol of uprising, against those in a status of power or control. This fieldnote illustrates the disgust brought about by the material presence of dirty matter and the symbolic disorder that is caused when dirt is physically present. Levels of power and hierarchies operated in the social minutiae of the hospice as they do in wider society. The housekeepers' description of the patient's action, which may be an act of resistance or a show of disregard towards the housekeepers, also elucidates a potential 'reduction ... to [the] body' (Foucault 2006 [1973-74]: 21), where the body becomes a viable form of expression and a way of creating disorder by *bringing* matter out of place. The act is described as a disruption to the housekeepers' orderly processes of work. However, they describe persisting to 'clean up' the patient's faeces. Featherstone and Northcott (2020: 105) draw on their ethnographic study of a hospital dementia ward to argue that silently working often 'reinforced the invisibility' of the patients. Here, the housekeeping assistants *abnormalise* the actions of the patient, which shapes their work as more ordinary.

Karen and Yvonne's description of handling and cleaning up the patient's faeces shows their physical proximity to dirty matter in carrying out their work. Their descriptions also illuminate the symbolic connotations of proximity to dirt, which are constantly made and unmade through the *doing* of their work. They react to the patient as dirty, with expressions of disgust in both a verbal ('*eugh*') and a non-verbal sense, which renders their usual work 'seemingly ordinary' in comparison to the handling of the patient's stoma contents (Ashforth and Kreiner 2002: 217). Hughes et al (2017: 114-15) draw on their ethnographic data with refuse collectors to explore the circumstances in which members of the public become seen as 'dirty' by the refuse workers. Those that 'publicly expel mucous [and] dirty the [freshly cleaned] streets' disrupt their 'process of bringing order to dirt', and for the refuse workers their actions cast doubts over 'who, after all, is *really* dirty'. This re-normalises the work by making reference to the abnormal tendencies of some members of the public and renegotiating who the dirty individual

is in this encounter. Karen and Yvonne describe a similar process of reclassifying *who* is dirty in their encounter with the patient.

For Hughes and colleagues, the refuse collectors were disrupted in their ordinary day-to-day routines of disposal by the presence of excrement or waste that had been placed into incorrect bins, creating disorder in an orderly pattern of work. Karen and Yvonne were disordered in their rhythmic work routine by the presence of the patient's stoma contents, again as physical 'matter out of place' on the bathroom floor, which constituted a symbolic reordering of dirt, as 'the dirty workers' (Ashforth et al 2007: 149) expressed their disgust at the dirty *patient*. This elucidates the ways in which dirt is a material entity 'materialised in sliminess and/or stickiness that can adhere to and stain clothing and the skin' (Simpson and Simpson 2018: 5), as well as a symbolic presence that can make, and unmake, 'dirty' *identities*. Miller expands on Douglas's account of 'matter out of place' by explaining that dirt evokes emotions, such as disgust, when it is associated with the person who has failed 'to maintain his public purity and cleanliness of person' (Miller 1997: 4). Dirt existed within these relationships, and disgust was evoked towards a person rather than simply an 'out of place' entity. In this context, the housekeepers react in disgust to the patient's failure to maintain his bodily integrity and the ideal standards of cleanliness.

The housekeeping assistants described a scene in which dirtiness was symbolically reordered and their profession potentially tainted by the actions of a patient. This suggests the seeping in of categories of 'normality' and 'abnormality' (Foucault 1991: 199), which were continually reconstructed within the hospice. For Foucault, the body is an important site of power structures, surveillance and control, wherein the body is regulated both internally by the individual and socially by external regulation. He describes the 'judges of normality [as] present everywhere' (Foucault 1991: 199) and the medical encounter as an important site of surveillance, where the 'normalising gaze' operates within oneself and through the eyes of others. The situation that the housekeepers describe tells us of their process of symbolically reordering dirt and dirtiness, making their work easier to carry out as they uphold notions of normal and abnormal behaviours.

Much of the work tentatively straddled 'the boundaries of what could be accepted as normal' (Hughes et al 2017: 113) in terms of physical closeness to dirty matter, and some of the workers practiced humour to negotiate this proximity to dirt. Dirty humour both made reference to the

abnormality of the work and was an attempt to normalise the tasks at hand. In the following extracts, one of the ward nurses that had worked in a palliative care context for around thirty years, but had only worked at the hospice for one year, describes the use of dirty humour to ‘defuse the situation’:

*Natalie:* So, is the humour normally related to things going on on the wards?

*Amy, staff nurse, in-patient unit:* It can be, yep, sometimes it might not be but, I wouldn’t, when I say related, it’s never specifically at a patient. I mean, one that comes to mind is, I had a night shift with this particular care assistant and to say that every patient we went to shit the bed was an understatement and we spent all our night just cleaning up shit, nobody’s fault it – but – you know literally from – and when I say cleaning up – you know [pauses with a distressed look] and when we finished we have what you call a Bristol stool chart, which we document things on. So, she said ‘we shouldn’t have it typed, maybe we should have it colour coded, if it’s this it’s this and if it’s this it’s blue’ and I said ‘and if it’s baby shit it’s too much curry’ so we started laughing and then I said ‘what about smell-a-vision as well’ and she said ‘that’s too far!’ and we burst out laughing.

Humour is a well-documented part of dirty work professions, and existing research explains that humour can be a tool to provide relief in stressful or offensive situations (Twigg 2000; Sanders 2004; Boyle 2005; Cain 2012). Much of the existing research highlights the rational composure presented in front of patients, or clients, contrasting this with the light-hearted and humorous interactions behind the screens (Lawler 1991; Cain 2012; Funk et al 2017). Amy describes how the humour is used in such a way that makes light of a challenging situation as a process of ‘letting off steam’ (Bolton 2005: 181). However, much of this existing research depicts a binary discourse, which largely refers to front stage/backstage emotional management techniques (Sanders 2004; Boyle 2005; Funk et al 2017) and overlooks the processes of symbolically reordering and remaking of categories of normality.

Amy’s sense of humour, in regard to ‘cleaning up shit’, was a process of re-constructing a sense of ‘normal’. She describes that ‘every patient we went to [that night] shit the bed’ and we can see how the work confronts as well as challenges *normal* physical boundaries between persons and bodies, as the unboundedness of the patient dirtied and violated the workers own sense of bodily integrity. This gallows humour was used as a ‘defensive’ practice to ‘counter

the taint' associated with the task of cleaning up another person's excrement (Ashforth et al 2007: 49; Simpson et al 2012). Amy is aware of the abnormality and taint associated with her work and uses this humour to somewhat normalise the tasks at hand, emphasising her ability to 'tackle any type of work' (Hughes et al 2017: 115). This emphasises the fluidity of 'normal', as a malleable social construct, adapted to make socially abnormal actions and behaviours seem *more* normal. As opposed to Foucault's (1991: 180, emphasis added) concept of the 'normal' and 'normalisation', which identifies the '*correction*' of behaviour towards the normal, Amy *reconstructs* her own, her colleagues' and potentially the patients' sense of normal. The mastery over 'cleaning up shit', which Amy shrugs off with a joke about Bristol stool charts, is emphasised here where Amy describes the ease with which she can negotiate situations typically considered abnormal. Rather than 'correcting the abnormal' (Foucault 1991: 200) she finds a way of reconstructing that which is unknowingly abnormal, to make it seem a little more ordinary and easier to deal with. Thus, she draws 'meaning' from the ease of her 'willingness' to joke about and participate in 'dirty and mundane tasks that others avoid' (Stacey 2005: 845). Again, there is a symbolic renegotiation and reconstruction of that which is considered normal, orderly and acceptable in the face of abnormality and disorder.

Amy continues to explain that this sort of dirty humour is used to navigate the sensorily more challenging aspects of the work, so that the workers could carry on with the work and go 'back out' to 'clear up a couple of shitty beds':

*Amy:* ... It's just a way to defuse the situation cos we'd been very, very busy, we were physically tired, and it's a horrible thing to say, but we knew we smelt, and you know, the patients were very distressed by what was happening. We felt for them, and they felt indignity, and they felt they were a burden to us, so there was all that emotion and physical busyness, and one of the patients died, and it was a couple of quick comments, to ease the tension... went back out and went and cleared up a couple of shitty beds, but yeah, it just defuses the tension sometimes.

The humour helps to build and sustain a 'close working community' (Bolton 2005: 177), as Amy and the support worker share in their own sense of dirtiness and the challenges they were facing. The work on this particular night shift challenged ideas of 'normality and acceptability' (Hughes et al 2017: 114) as well as their corporeal sense of integrity. The unbounded bodies of the patients transgressed the workers' own carnal and sensory boundaries, as Amy describes

that ‘we knew we smelt’, demonstrating the infiltration of the patient’s odours and leakages onto them. Lawton (1998: 134) describes the manner in which smells and fluids ‘emitted from the unbounded body...extend the boundaries of the patient’s corporeality ... seep[ing]’ into the ‘boundaries ... of other persons and other places’, therefore challenging the worker’s sense of ‘integrity’. For Lawton (1998: 134), the tactics to ‘maintain the integrity of their own selves’, carried out by workers and fellow hospice patients, were concerned with avoidance and removal of unbounded patients into enclosed spaces. However, Amy and her colleague draw on processes that attempt to render the ‘extraordinary ... seemingly ordinary’ (Ashforth and Kreiner 2002: 217). Amy’s reference to feeling a need to ‘defuse the situation’ and ‘ease the tension’ establishes the *abnormality* of this particular situation, while the subsequent joking about the ‘Bristol stool chart’ and continuing to ‘clear up a couple of shitty beds’ suggests a process of ‘counter[ing] ... taint’ (Ashforth et al 2007: 149) by normalising the situation at hand. This was a process of negotiating the ‘aspects of bodily existence that modern society is reluctant to acknowledge openly’ (Twigg 2000: 397), such as the uncontrolled bodily emissions and odours at the end of life. Amy describes negotiating the situation by rendering the situation a little less abnormal and, again, reordering a disorderly set of unfolding events. With the death of a patient, and ‘every patient [on the ward] ... shitting the bed’, the patients’ unboundedness symbolised the rapid undoing of the hospice’s social order. Sharing a joke and persisting to carry out the work reinforced a sense of order both between the workers behind the scenes and with the patients on the ward.

Joking ‘eased’ and ‘defused’ certain situations as a shared way of coping between workers while negotiating the aspects of the work that challenged notions of bodily and sensory integrity. However, humour was also used with patients to again defuse uncomfortable situations which forced closeness and ‘dissolved boundaries between people’ (Twigg 2000: 402). The sharing of jokes between workers behind the scenes supports the existing literature that indicates the need for this ‘emotional process work’ in healthcare (Boyle 2005: 48). Many of the workers referred to the shared spaces of the hospice as ‘the shop floor’, or ‘the floor’, demonstrating a distinction between the spaces in front of and away from patients, which resulted in and shaped different forms of behaviour. The use of dark humour away from patients emphasises this need to process the challenging and offensive aspects of the work in order to carry on. However, dark humour was also frequently shared with patients, especially body-focused humour, such as ‘dirty jokes, sexual innuendo and ‘lavatory’ humour’ (Twigg

2000: 401). In the following extract from our interview, Nicola, a staff nurse on the day unit, describes making a joke with a patient while trying to undress them:

*Nicola, staff nurse, day unit:* Yeah, yeah, I mean I were helping an old man other week with Eileen [day unit Sister] go to the toilet but struggling to get his zip open and he'd got his inhaler, you know, asthma inhaler in his pocket and without even thinking, cos sometimes I think 'oh, Nicola, you shouldn't 'av said that', he laughed, he found it funny and Eileen just sort of went [frowns], and I went "is that your inhaler in your pocket or you happy to see me?" and he laughed and – but – then after you think it could 'av gone the other way but I just hope that I gauge which patients I can say things to and which ones I can't.

The use of humour reorders the situation as a little less abnormal for all involved. As Twigg (2000) illustrates in her study with care workers providing intimate care to older and disabled people in their homes, 'jokes were a useful distraction' for the more 'embarrassing' aspects of the work, such as dealing with bodily motions. Jokes seemed to navigate the abnormal situations of nudity and bodily functions, by making them more normal and acceptable. The use of humour with patients, which was frequent on the day unit, often referred to the patient's deteriorating bodies or sexual innuendos. Although there were limits of acceptability, as Nicola states she hopes she can 'gauge' which patients are happy to participate in a joke, the use of body related humour with patients illustrates the fluidity of emotion work. The humour seemed to develop a sense of camaraderie between patients and the workers in a similar way in which the jokes between workers develop 'close working communities' (Bolton 2005: 177). However, the humour used with patients was often made at the expense of their dependability, thereby emphasising the existing hierarchies of care between workers and patients.

Modern Western discourse dictates that 'selfhood is dependent upon the possession of a physically bounded body' (Twigg 2000: 396-7). Therefore, involuntary and leaked bodily emissions conflict with the standards of bodily boundedness, undermining and threatening the accepted image of the individual body as a private, independent entity. Nudity provokes embarrassment and shame, as an 'unnatural' situation in a modern society with 'systematically develop[ed] new standards and thresholds of shame' (Elias 1978 [1939]; Gornicka 2016: 149). This means that in negotiating the patient's bodily excretions, and undressing patients, the workers are attempting to re-normalise that which is widely considered abnormal behaviour or

taboo. Their attempts to share a joke with each other and with the patients illuminates the ‘unnaturalness’ (Gornicka 2016: 149) of nudity and bodily emissions, as their interactions negotiate the embarrassment and ‘tension’. The notion of ‘normal’ is malleable within these interactions, it is continually reconstructed and reshaped to fit the scenario at hand.

### *Not Reacting*

The response to the situations presented in the extracts above, which challenged Western ‘standards of outward bodily propriety’ (Elias 1978 [1939]: xi), indicates a negotiation of the ‘[non] somatically bounded body’ and the attempt to maintain a level of order, acceptability and normality amidst disorder (Lawton 1998: 123). In certain situations, the workers felt it was inappropriate to joke and use humour. Instead, a non-reaction was expressed as another practice of ordering and normalising. The nature of smells and odours, as uncontrolled seepages into other spaces and bodies, presented unique challenges to the workers, as ‘boundary-transgressing’ matter (Twigg 2000: 397). In the following extract, one of the health care support workers, Kevin, discusses a student trainee reacting inappropriately to the smell and sight of the patient’s ‘rotting’ flesh. This extract suggests an acceptable approach of navigating sensorially offensive experiences, as well as the ways in which normality is sustained:

*Kevin, health care support worker, in-patient unit: ... I were changing some man’s dressing and he had – I’d never seen it before – he had a cancer of the penis so it were all rotted away here [signals to crotch], it had all rotted away... And I had this student with me, and we’d done this patients cares and then I had to change his dressing and I took dressing off and I – I – there was a lot of odour, there was not a very nice smell and to look at it, you looked at it and it didn’t look very nice, you can imagine and I can remember this student he went ‘god!’ [he puts his hand up to cover mouth].*

*Natalie: In front of the patient?*

*K: [Nods] and I just carried on, I didn’t say anything, I just carried on doing what I were doing, talking to the patient and all that, whatever, sorting dressing out and then we came out I said to student ‘can I just ‘av a quick word?’ he said ‘what’ I said ‘no matter what you see, when you’re doing anything with a patient, no matter what ya see, no matter what ya smell, you don’t show any emotions’ he went, ‘oh my, Christ, I forgot’ I said ‘don’t worry about it, just as long as ya aware’*

Kevin describes the seepage of odours and the permeation of unpleasant smells that the workers were sometimes confronted with. The permeating odour causes disgust in the student trainee, who exclaims “god!” towards the odour of the patient’s ‘rotting’ flesh. Twigg (2000: 397) refers to ‘smell’ as ‘particularly significant’ due to the manner in which odours ‘extend’ the patient’s bodily boundaries, with an offensive odour suggesting loose or unbounded corporeality. As Miller (1997: xii) argues, disgust is ‘the most embodied and visceral of emotions’, it is also, at its core, a relational emotion coming about through another person’s ‘failure [to] keep ... presentable’, and the resulting presence of waste, or dirt. The student trainee places their hands over their mouth, to close their bodily orifice and prohibit the pollution of the odour and rotting flesh affecting their own sense of bodily integrity. Of particular interest here are the practices described and used by Kevin, as the senior member of staff, to normalise and reorder the situation. Kevin illustrates the significance of a non-reaction to the sights and smells, as he emphasises in his recollection that ‘no matter what ya see, no matter what ya smell, you don’t show any emotions’. To *not* emote or react (on Kevin’s part) to the trainee’s violation of the professional code also portrays normality and order to the patient. Similarly, the two housekeeping assistants described cleaning up after a patient emptied their stoma contents on to the floor. Here, Kevin ‘carries on’ in order to renormalise the situation, to make it seem as though the situation at hand was ordinary. Such actions, or in this case, non-actions and non-reactions, were attempts to re-normalise and reorder an abnormal situation.

This emphasises the influence the workers held over how the patients might experience their embodied sense of self through how the workers ‘interacted’ (Macpherson 2010: xiv) with and handled their bodies. Negotiating such situations by maintaining a sense of calm and silence illustrates the manner in which the hospice workers normalised decay and odour as aspects of death that *should* be normalised. Featherstone and Northcott (2020: 105) suggest that silent persistence ‘reinforces the invisibility’ of patients, to strip them of their identity. However, Kevin renormalises the situation for all involved and his non-reaction would shape the social identity of the patient. Kevin continued in our interview to suggest that his actions to retain normality lessened the patient’s feelings of ‘embarrassment’. Reacting to the odours and appearance of the patient’s rotting flesh would make the exact abnormality of their bodily condition apparent. Normalisation unfolds here as giving the meaning of normality to a situation, as opposed to ‘correcting’ towards a ‘normal’ (Foucault 1991: 200). This emphasises

both the abnormality of the deteriorating body as well as the need to normalise the experience for all involved. A shared sense of abnormality, between the workers and patients, results in a shared attempt to reinstate order and normalness.

The ‘collusion’ of silence, as described by Komaromy (2000: 303), appears again, this time through the shared non-reaction to conceal the sensory offence caused by the patient’s ‘rotting’ flesh. These practices of silence, which were embedded throughout different aspects of the hospice setup and within the processes of the work carried out by members of staff, in both the private and public spaces of the hospice, eased ‘tension’ and the practices reordered and normalised the disorderly and abnormal experiences of death. Throughout this chapter, the actions and interactions of the workers indicate a discourse of abnormality that is associated with dying and, particularly, unbounded dying. As Foucault (1991) suggests, this discourse that distinguishes between ‘normal’ and ‘abnormal’ is both subjected upon oneself and through the ‘normalizing gaze’ of others, especially by those in the medical encounter (Bloor and McIntosh 1990; May 1992). However, the hospice workers re-normalised and reconstructed a sense of ‘normal’ by moulding their reactions and interactions in a manner that provided and portrayed normality, as opposed to correcting towards the normal and this emphasises the malleability of the notion of normal as fluid and relational.

What is considered to be offensive is constantly reconstructed, made and unmade, through interactions and relationships between the workers and patients in the hospice. Through non-reactions, the workers are able to reshape the patient’s embodied experiences, as well as their own, to disguise abnormality with regularity and ordinariness. Kevin describes some of the usually unspoken rules shared by the hospice workers, explaining that *‘when you’re doing anything with a patient, no matter what ya see, no matter what ya smell, you don’t show any emotions’*. He refers to the distinction between being and not being with a patient, demonstrating the differences in interaction in the two situations. With a patient, a non-reaction sustains ordinariness, whereas away from patients an emotion, such as disgust, is permissible. He goes on to say in our interview that the ‘patient will pick up on’ any signs of disgust shown by the workers, further diminishing their loss of relational personhood as they feel ‘reduced to [their] body’ (Foucault 2006 [1973-4]: 21). Similar to Twigg’s (2000: 396) research on care workers, Kevin describes never being able to ‘get used to’ the visual and odorous aspects of the work:

*Kevin:* You never get used to them [laughs]. Yeah, you know, you just carry on, you just ... just try not to breathe through your nose or whatever but you just carry, you just carry on because they're embarrassed, to us it's nothing to clean somebody up but if you can imagine er, how it must feel you being incontinent and somebody's cleaning yer up, that – mentally – that's got to be the lowest of the low because you can't control your bowels or 'ote.

The unboundedness of carnal boundaries results in revulsion, as the body has become uncontrolled and the involuntary leakages signify dirtiness, which is attached to the person (Douglas 1966; Miller 1997). Kevin describes the practice of 'not breathing through your nose' in order to 'carry on' caring for the patient. This illustrates the closing of personal boundaries in order to sustain a sense of bodily integrity, order and control over one's own sensory experience. Not breathing through the nose also helps to sustain a sense of normality and ordinariness, as Kevin cares for the patient, outward disgust is withheld. To normalise the situation, Kevin describes the patient as 'embarrassed', feeling indignity and 'mentally ... the lowest of the low' due to their incontinence and dependability. This 'reorders' the patient, in almost a pattern of 'infantilization', which reshapes the patient as 'innocent of intent in making a mess, and vulnerable' (Twigg 2000: 401). Viewing the patient as vulnerable and innocent also helps to reorder the situation as *normal*, as Kevin manages his feelings by reconstituting the person into a childlike state. Again, unboundedness is seen as abnormal in adulthood, as it is classed as a key signifier of an autonomous, mature individual (Hockey and James 1993; Lawton 1998; Twigg 2000), and these practices help the workers to navigate their intimate experiences of situations, which are widely considered to be abnormal. The 'gaze' of *abnormality*, is therefore, accentuated, perpetuated and maintained by the practices to normalise natural, yet widely deemed unnatural, bodily functions at the end of life.

## **Conclusion**

This chapter has considered how the hospice workers managed the sounds, smells and sights which offended the sensory, as well as disrupted the social order in the hospice. Certain sensory omissions were constructed as 'out of place' in the hospice, and this chapter focuses on the routine practices and processes to negotiate, as well as reorder, the abnormal noises and excretions. In this way, the notion of the 'normal' was continually maintained, reshaped and reconstructed by the workers. 'Dirt' can be considered as both a material entity and social

construct in this hospice. Materially, the hospice workers managed the emptied stomas, the urine specimens and stained bed sheets. However, dirt and dirtiness also existed in the ‘eye of the beholder’ (Douglas 1966: 2), as the workers managed, cleansed and contained the signs, sights and odours that they considered offensive or abnormal. The material presence of dirt and death were navigated in order to maintain a certain pleasant, peaceful social order. Shutting doors and closing curtains, as they removed the dead body of a patient, and spraying lavender air-freshener to dissipate the odours coming from a patient’s room disguised the presence of *disorderly* death. Death was symbolised and acknowledged, through the lighting of candles and fresh flowers placed on the wards. Messy, *dirty* and noisy deaths were to be managed. Such deaths seemed to offend the sensory social order of Broad Lane, which was shaped, shared and reconstructed by the workers. The workers developed certain practices to negotiate dirt and the ‘violations’ (Twigg et al 2011: 172) of the sensory, by reconstructing what can be considered as ‘normal’. They reconstructed and renormalised certain aspects of the dying process to render these more normal for both themselves and the patients, using humour with their colleagues and *not* reacting in front of patients. In doing so, the workers influenced the patients’ sense of normality and a sense of social self. In these accounts, they demonstrate the ways in which they shaped the patients’ own experiences of the situation. This chapter illustrates how the workers’ constructions and navigation of the hospice space influenced the sensory experience of being in the hospice and the relationality of ‘normal’, as constructed within interactions between people.

The ‘normal’ was a malleable, fluid notion, continually shaped and reconstructed by the workers in their interactions with colleagues and the patients. Their work was oriented in certain ideals of normal vs. abnormal, and rather than correcting behaviour towards a normal (Foucault 1991), they *re-normalised* the abnormal, to make their experience of the work and their patients’ experience of their death easier to navigate and process. Drawing on the example of the housekeeping assistants, they acknowledged notions of ‘abnormal’ behaviour, while acting in ways that *reconstructed* the normal, by not reacting and silently going about their work. Kevin illustrates the need to *‘not show’* any reaction or emotion to offensive sights and smells, to reshape the situation as more ordinary. The workers’ actions (*or non-actions*) were embedded in their shared ideals on how to suffer, die as well as how to grieve, and so, some behaviours were problematised, as challenging the notion of ‘normal’ and ideal, as too noisy or chaotic. By constructing and reconstructing normal within the hospice, in their interactions, reactions to and engagements with patients, the workers held a significant influence and power

over how the patients might experience their dying process and the hospice space. Suffering is embedded in social and cultural circumstance, as the experience involves the ‘crumbling away of former self-images’ (Charmaz 1983: 168), which are related to aspects of social life and relations with others. This chapter has examined how the workers’ management of the sensory aspects of dying, and their handling of the physical body, shape a sense of what the normal is and what constitutes as dirty. Overall, the chapter emphasises how suffering and dying unfold in relationships, and the hospice workers play a significant role by influencing the shape of the experience through their management of the physical body, the sensory signs of death and the organisation of the hospice space.

## CHAPTER SIX

### Maintaining the Social Self: Relationality, Reciprocity and Rites

*'Given that personal/social identity is constructed in life through social interaction, that is, by reference to others, it is only logical that this should continue to be the case in death' -*

*Hallam, Hockey and Howarth 1999: 114*

#### Introduction

This chapter explores the relational processes of dying as experienced and shared between the hospice workers and patients (Kellehear 2008, 2009). Drawing on the perspectives of the workers, the chapter illustrates how suffering is embedded in intimate relationships between the hospice workers, in which the patients' social personhood could be sustained through the actions of, and interactions with, the hospice workers. This chapter will be divided into three sections, each reflecting on different practices and processes of hospice work, examining the micro interactions, ritualistic processes and emotional management practices. Each of these sections seek to reflect on how the workers play a significant role in sustaining personhood, through exploring the manner in which they negotiate dying bodies and their own affective detachment to the patients in their relationships. Focusing on the actions and interactions of the hospice workers, the first section suggests that many of them come to know the patients as individual persons within the contexts of their lives and the 'structure of generality' (Simmel 1992: 61), in contrast with medicalised, routinised and 'abstracted' (Foucault 1975: 8) approaches to caregiving. However, the data also illustrates how this approach is continually challenged and ruptured, which further highlights how the patient's personhood could be impacted within these relationships with the hospice workers. The intimate relationships often resulted in 'blurred' boundaries, where standards of professional conduct were challenged and, subsequently, reinforced. Sharing in the patients' experiences and getting to know them as persons meant that many of the hospice workers described suffering *in relation to* the patients, in a reciprocal suffering. Finally, this chapter draws on the work of Baudrillard (1993) to explore how the hospice workers' handling of the patient and their physical body, before and after death, could potentially influence a socially embedded personhood and status in relation to others. The final section emphasises how the workers' management of the physical body, and their interactions with the dead or dying person, delay a 'social death', past the point of biological death.

## **Relationality**

### ***The Social Individual***

The modern hospice movement emerged with a holistic care ethos, wherein the patient was to be supported in their dying process and eased into a peaceful death. Cicely Saunders (1976) described the hospice care approach as focused on the individual person and on caring for them as an individual in order to support their 'peaceful' and meaningful death:

'You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.'  
(Saunders 1976: 1003)

In identifying this ethos, which is established on individualised caring relationships, the hospice movement emerged in contrast to the modern medical approach. 'Mainstream medicine' is said to be largely grounded in a curative approach, with investigations and treatments that are 'prioritised at the expense of individuals' (McNamara et al 1994: 1505). In this approach, the patient's specific, and often particularised, ailment is treated with methods to test, investigate and cure. In mainstream medicine, the patient is 'abstract[ed]' by the physician in order to better focus on their precise, and sometimes singular, ailment and objectively know the 'pathological fact' (Foucault 1975: 8-9). The patient is isolated by a medicalised focus on their illness, and the body is further abstracted by a focus on the bodily parts and organs that are seen as functioning independently from one another, rather than acting together to form a whole (Elias 1985; Simmel 1992).

Taking this even further, the hospice approach contrasts with medicine by caring for individuals in *relation* to their loved ones, rather than viewing them as functioning autonomously from other persons. Thus, the 'individuality of the individual, finds a place in the structure of generality'; the hospice patient is individualised in and through being seen as part of wider *social* structure, context and relationships (Simmel 1992: 61). If we consider the hospice ethos in comparison to the 'mainstream medicine' approach, the former seems to stand for 'caring' rather than 'curing' (McNamara et al 1994: 1505), as 'caring' focuses on looking after the patient as a holistic person, and the 'curing' approach focuses on treating the patient's

physical ailment. This chapter will illustrate this as a simplified method of contrasting hospice care with the medical approach. It tends to gloss over the tensions *within* modern hospice care that were particularly evident in this ethnographic fieldwork and the interview data. What emerged here was an aim shared by many of the hospice workers, namely to individualise their patients and come to know their social contexts, their roles, relationships and ties, combined with the pressures, challenges as well as disagreements of fulfilling their job efficiently and maintaining some emotional detachment.

The participants often noted the comparisons to be made between mainstream medicine and hospice care, especially when they had previous experience of working in a hospital context. Laura, for example, had worked in the hospice as an Occupational Therapist for just over a year after leaving her previous role at a local hospital:

*Laura, occupational therapist:* ... you're not just a number, that's what I found difficult working at the hospital, it were a bed number, it weren't a person, whereas here you're a person and your whole family's part of your journey, aren't they?

Laura criticises the hospital approach to treating patients as if they were solely 'a number ... a bed number', meaning that the broader generality, relationality and sociality of the patient's life was overlooked by the hospital workers. As Laura explains, the family of the patient is 'part of [the patient's] journey' at the end of their life, and so the workers integrated the patient's familial relationships into the delivery of care and their understanding of the patient's identity. This approach to caring for the hospice patients upholds the notion that our identities as *individuals* cannot be divided from or considered without acknowledging our relationships with others (Hockey 2010; Ellis 2013). The patient is individualised *through* being contextualised, through being understood as a part of their wider social life and their ties to other people within the 'generality' of society (Simmel 1992: 61). The hospital approach is remembered by Laura as opposed to the hospice approach by objectively rendering the patients as 'numbers', dividing them from their social identities and stripping them of their roles, as embedded in society. Lief and Fox (1963: 12) noted that medical students are trained to adopt a 'detached concern' with their patients, balancing 'detachment or objectivity' in order to make 'sound' medical decisions, yet also providing 'sensitive, understanding care'. Describing patients in the hospital as 'bed number[s]' suggests a detached approach to caring for them, where the patients are treated based on their 'physiological functioning' (Elias 1985: 89) as

opposed to their whole identity. The physical ailment(s) of the hospital patient are divided from their identity as a whole person, with familial and social relationships, and the individual is merely *generalised* as one of many (almost) identical cases in the hospital. The end-of-life care provided, as described by Laura, is evidently both an individualised and socialised way of caring for patients. Rather than treating patients as masses of sick cases, the hospice workers often described and demonstrated an effort to treat them as individual persons who exist and develop meaning in relation to others, while experiencing a life-limiting illness.

The medical model, which Laura identified in her previous place of work at a hospital, was described as prioritising the patient's physiological reasons for needing professional care and treating their symptoms. This 'reinforces the notion of individualised suffering' and overlooks the relationality of the patients' lives, their conditions and their deaths (Dragojlovic and Broom 2018: 44). Broom and Kirby (2013: 501) state that 'biomedical orientations toward (individualised) physiological control ... resulted in a largely patient-centred model of end-of-life care', as opposed to a person-centred focus. Thus, focusing on the patient's bodily symptoms results in a focus on medical treatments and interventions, which overlook the relational aspects of a patient's illness and/or dying experience. However, the extract from Laura's interview highlights the complex nature of this approach to caring for patients in the hospice. Laura illustrates how the hospital care stripped the patients of their familial relationships and from the broader contexts of their lives and providing care in this way meant that the patients were treated as nondescript 'numbers'. In both ways, the patient is de-personalised, with the focus of care in the hospital placed on symptom management, treatment and intervention through emphasising their 'bed number', which identifies only the file and notes associated with their admission, ailment and the medical observations since being there. Essentially, Laura suggests that the relationality of a person's condition, and more specifically their dying process, was not addressed within the hospital, where the care for the person 'lagged behind the care for their organs' (Elias 1985: 91).

Christine, who currently worked as a bereavement support worker, identified a similar comparison. Christine had previously worked as a nurse in the hospice and before that, a hospital nurse on a neurosurgery ward:

*Christine, bereavement support worker:* ... It's quite a privilege and it's like, you know, being at the start of somebody's life, the end is just as important and to be treating that person as that person, not as that illness.

*N:* Do you feel like you were doing that in the neurosurgery ward?

*C:* Yeah, yeah, it was, you know, certainly to the consultants it was, they'd come round oh 'this is the patient, with certain illness, with subdural' or they'd come round, 'this is patient with subdural or extradural' not 'this is Joe Bloggs, who's got this family, who are sat there absolutely distraught', it wasn't, it was just the condition that they focused on. Hopefully I didn't cos that's not me, but yeah, I think certain things, coming somewhere like this, it's very, very different but just as rewarding, if not more so I think.

Christine explains that in the hospice, the care is centred on 'treating that person as that person, not as that illness'. The hospital care described in both Laura and Christine's examples, strips the individual patients of their identities as both individual and social, or 'general', beings (Simmel 1992: 61). In contrast, the hospice workers particularise the patients *by and in* perceiving their identities as whole persons. The meanings attributed to individual persons are largely derived from our social interconnectedness as people; 'the concept of meaning cannot be understood by reference to an isolated human being' (Elias 1985: 54). Therefore, the meaning of the individual person is reduced and abstracted by overlooking their identity as 'persons' and treating them solely in terms of their physiological illness. Christine summarises the issues concerned with 'doing too much *to* the patient, not *for* the patient' (NcNamara et al 1994: 1505 emphasis added), by demonstrating how the patients on the neurosurgery ward were treated as their illness, which was their 'subdural or extradural' head injury, rather than by their *identity* as a person, within the context of their social relationships. Foote and Frank (1999: 166) note that biomedical approaches treat the patient 'in isolation from their context', treating '*only* the patient'. The hospice workers sought to manage and relieve patients' physical symptoms of their life-limiting illnesses, however many of the participants described how they would deliver the hospice care in a *person-centred* manner, rather than *patient-centred*.

The care depicted in the extracts above was holistically focused on the person as a whole with familial ties and wider social relationships. The workers attempted to maintain the dying person's identity and their social personhood that existed before the onset of their illness, by getting to know the person. In this sense, Christine also explores the holistic nature of hospice

work, which was described as focusing on the feelings of the patient as well as their family, ‘*who are sat there absolutely distraught*’, acknowledging the ‘embodied relationality’ and the ‘interconnectedness’ of the end-of-life experience (MacArtney et al 2014: 266). To fail to maintain the person, as described by Laura and Christine in the hospital examples, would be to strip and reduce the patient from their identity as a person. Therefore, ‘abstract[ing]’ them (Foucault 1975: 9) to know only their physical sickness and reducing them to the functioning of their organic ‘part-processes’ (Elias 1985: 89). Laura and Christine both observed the hospital care as contributing to the patients’ loss of identity, as the social ‘meaning’ of their lives (Elias 1985: 54) was overlooked by the hospital approach to care. Laura and Christine describe the hospital patients as abstracted, as ‘numbers’, treated only for their physical ailments, and isolated from their broader social relationships and social lives.

### ***Ruptures in the Relational Approach***

Many of the workers adopted an approach to caring that focused on the patient as a *person*. However, there were examples wherein this approach was challenged, as inappropriate and too time-consuming. For example, Jenny had worked as a health care support worker in the hospice for three years, working both in the day unit and on the wards as well as in the community team. She explains that she had been nicknamed a ‘*faffer*’<sup>15</sup> by her colleagues for attending to the patients’ personal grooming routines, especially on home visits, which were considered by her colleagues to be unnecessary tasks. There were evident tensions within the hospice, and emergent in the research data, where the different standards of hospice caregiving clashed, causing challenges for workers that delivered individualised and personalised care. Although Saunders (1967) identified hospice care as providing for the individual, who ‘matters because *you are you*’, this data also illustrates how this ethos could be challenged in practice. Modern hospices often operate with two divergent and juxtaposing ‘economies’ (Russ 2005: 129). One which focuses on an ‘ethic of pure gift, sacrifice and charity’ and the other which identifies ‘standards of efficiency and discipline, cost-containment and profit making’ (Russ 2005: 129). Jenny’s colleagues had presumed that cutting the patients’ hair, washing their dishes and applying their face creams were needless tasks, which were not part of Jenny’s role as a support worker. Their nickname for Jenny was embedded in the standards of efficiency and time

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<sup>15</sup> ‘Faff’ is British slang and can be defined as inconvenient tasks that require a lot of effort.

management, which challenged the hospice ethic of care and giving *'for'* (McNamara et al 1994: 1505) the individual at the end of life.

Jenny explains her reasons for helping patients with their day-to-day grooming routines as maintaining their dignity and sustaining their personal identity whilst at the end of life:

*N:* You go in and make sure that they're comfortable?

*Jenny, health care support worker, community team:* That they're comfortable, yeah, well I wouldn't want to lay there and have that [unchanged pants], you know and that's in my mind all the time, all the time. You know one lady that we have she waits, and she'll say, 'you on tomorrow' and I'll say 'yeah', and she'll say, 'will you wash me hair?', cos none of others will wash her hair

*N:* Oh really, so they get to know then?

*J:* Well of course they do don't they, they do get to know, yeah, yeah, I always put – she says 'it's only you that puts cream on me face', I say 'well you should tell 'em, tell 'em say put me some of that cream on me face please', cos they've got all this lovely stuff, got all the toilet bags and stuff, well she might have had cream on her face since she were eighteen, and then for her not to have it, it's not right is it?

Jenny also stated during my observations that she 'preferred' making home visits on her own, rather than in the usual pairs, as she was able to take her time with the patients in this way, demonstrating the challenges the workers faced when incorporating the person-centred approach to caring. She describes maintaining the patients' personal day-to-day grooming routines, everyday practices that they might have carried out each day before the onset of their illness. As well as maintaining their dignity and hygiene, Jenny also attempts to uphold the patients' sense of autonomy and choice where their physical decline may have hindered their own efforts. Being able to keep up with their personalised grooming routines and have their *own* choice of face cream applied, which they 'might' have used 'since [they] were eighteen', was central to reconstructing and sustaining a homely environment, wherein a sense of 'self and identity' could be maintained (Broom and Cavenagh 2011: 106). Jenny stepped in to carry out the everyday practices that the patients were no longer able to do. Here, we can see the significant role that hospice workers play in moments of social and physical dependency, to either preserve or further dismantle the patients' 'self-images' and their 'images in others' eyes' (Charmaz 1983: 191).

Most notably, Jenny describes how she could maintain the patients' sense of self and identity that was in place before the onset of their illnesses. Her care approach focused on 'doing ... to the patient' in a manner that was 'for the patient' (McNamara et al 1994: 1505). She preserved and sustained their everyday routines such as applying a certain face cream, which the patient might have used 'since [they] were eighteen'. However, Jenny claims that 'none of [the] other [workers] will wash [the patient's] hair' and that she is the 'only' worker that applies the patients' face cream. Broom and Cavenagh (2011: 106) note that being at home at the end of life is 'central' to sustaining some 'sense of self and identity' during the period of 'loss of control over the disintegrating body'. As the patients experienced an amplified loss of control over their bodily functions at the end of life, Jenny describes intervening in order to prevent a greater deterioration of their bodies by applying creams, cutting hair and trimming beards. As well as sustaining a normality, which had been in place in the patients' lives for many years, these actions were direct interventions in the natural dying process.

On the other hand, rendering the patient 'nothing', or 'nobody', neglected and abstracted the patients from their social roles, relationships and their socially embedded identities:

*Nicola, staff nurse, day unit:* ... certain things 'av been said to me that 'av - basically - I've been told that I get too involved and I give too much, erm, and for example, I don't mind saying this, [nurse in a senior role] once said to me, 'Nicola, why are you upset? That patient's nobody to you', so in her eyes because it ain't a member of your family or it ain't one of your friends, why would you get upset? So, she obviously doesn't build relationships and connections with people, erm, who's right, who's wrong? That's people's personal opinions but I can't change my personality, my characteristics.

In the extract above, Nicola, who worked as a Nurse in the hospice's day unit, recalls being told by her colleagues that she 'gets too involved' with her patients. Furthermore, she remembers one of the senior nurses challenging her outward 'upset' toward a particular patient's death. This extract suggests conflicting approaches to care, as Nicola believes that her colleague 'doesn't build relationships and connections' with the patients in the same way. This was also evident during my observations, where Nicola would spend much of her working day interacting with the patients in the day hospice and sharing in in-depth conversations, whilst

also being one of the more physically tactile members of staff. The approach to caring for patients that I have explored up to now in this chapter, that which *socialises* the individual patient in order to relate to them as persons, was not shared by all of the hospice workers. The typical hospice model of caring for individuals, rather than curing, conflicts with this isolating approach set out by the senior nurse. Interpreting the patient as ‘nobody’ isolates them from the other persons sharing in their dying process, such as Nicola. The patient is perceived as ‘nobody’, or *no one*, as they are divided from their social lives and relationships with others, which give ‘meaning’ (Elias 1985: 54) to a person and shape their identity. The senior nurse reminds Nicola that the ‘patient’s nobody to you’, demonstrating a rupture of the relational and holistic hospice approach by perceiving the individual as a non-descript and socially isolated ‘patient’, as opposed to a *person* with social roles and relationships. By categorising that particular patient as ‘nobody’ in relation to Nicola, the senior nurse also *deindividualises* all other hospice patients by overlooking their identity as social individuals. The patient is ‘abstracted’ (Foucault 1975: 8) from the very roles and relationships their lives are embedded in, becoming ‘nobody’ as their sociality and relationality to others is cut away. Reducing the patient to ‘nobody’ strips them of both their particularised and their general identity, as their identities begin to disintegrate once they are separated from the social contexts of their wider relationships.

Whereas the earlier extracts in this chapter suggest that the hospice workers individualised their patients by socialising and relating to them as persons, this example indicates a particular process of ‘abstraction’ (Foucault 1975; Cregan 2006) and reduction from the parts of an individual which contribute to their sense of identity and personhood. Rendering the patient a ‘nobody’ (Nicola, day unit Nurse) ‘abstracts’ them from their ‘integrity’ as whole persons by stripping them from the wider relationships and ‘environments’ that their lives are ‘embedded’ in and ultimately those that contextualise them as persons (Maynard and Turowetz 2019: 91). The senior nurse’s dialogue represents an omission of the relational approach to caring for patients as persons and a slip into the very medical, technological, individualised and isolating approach that hospice care is tentatively set against (McNamara et al 1994; Froggatt 1997; Dragojlovic and Broom 2018). In particular it illuminates how the patients were, in the previous extracts, individualised in relation to their sociality, whereas individualising them as isolated, asocial patients strips them of their identity and their sense of self, as ‘nobodies’. This sense of reduction, to ‘nobody’, represents a similar process of abstraction that is said here to occur in the medical sphere, where bodily parts and organs are worked on as separate and autonomous

fragments of the body (Foucault 1975; Elias 1985). The dying patient was taken as an individual part, separated from their relationships and contexts which are necessary to reinforce their identities as whole persons.

The extract below further suggests an abstraction and reduction of the individual person. This extract emphasises a conflict between a time-efficient ‘tick box’ approach, adopted by the senior nurse, and Nicola’s socialised relationships with her patients, which she describes as accounting for the patients’ broader social lives:

*Nicola, staff nurse, day unit:* When you, like, look at how I work compared to how [the senior nurse] worked, it’s just a case of erm, [sighs] ticking boxes ... I think if I worked how [the senior nurse] did, they’d still be quite happy with that, you’re just – you are – just a number, definitely.

Again, rendering the patient ‘a number’ neglects their identities as whole persons and is akin to perceiving them as ‘nobody’. As Elias (1985: 54) theorised, ‘meaning’ is understood through the interconnections between groups of people and persons, as a distinctly social category. ‘The concept of meaning cannot be understood by reference to an isolated human being, or to a universal derived from it’ (Elias 1985: 54). Therefore, the approach to caring for patients as ‘numbers’ fails to attach and *give* meaning to them as persons. They are instead reduced and abstracted, as isolated and de-socialised entities. There were evident conflicts between the hospice workers, where practices of efficiency and time management struggled against an ethic of giving, caring and socialising. Of note in this chapter are the conflicts between individualising the patient as a person, by relating to them as social persons, and de-particularising, as well as abstracting them as isolated entities by neglecting their relational contexts.

## **Reciprocity**

### ***‘Blurred Boundaries’***

The hospice workers often described physically and emotionally intimate relationships with patients. They also described reciprocal relationships, in which professional boundaries sometimes became ‘blurred’ (Eileen, day unit Sister) or unclear. Relating to the patients as

social individuals often meant that they came to know intimate details about their social lives. The ‘reciprocity of subjects’ (Simmel 1996: 111) is seen as the basis upon which social relationships ‘*between*’ (Simmel 1992: 689) persons are developed and maintained. The staff on the day unit described coming to know their patients as *persons*, and, in turn, letting the patients know a little about their lives. Due to my decision not to pursue NHS ethics and the focus of this research<sup>16</sup>, I was unable to record notes about the patients’ side of the exchanges, however the workers’ actions and their accounts of their relationships with the patients often alluded to the intimacy of their interactions and a reciprocal knowing of each other’s lives. The day unit Sister, Eileen, describes her relationships with patients as much more ‘social’ in comparison to on the ward. By this, she means that their conversations are often focused on the other aspects of their lives, beyond matters of ill health and the hospice.

*Eileen, Sister, day unit:* Yeah, the bonds we – that – that’s one of the things that we, cos we used to have a lot of students come through and it was one of the things, cos I talked to ‘um a bit before they hit the floor, and I said to ‘um ‘you might find here that, erm, the boundaries are a lot, feel a lot more blurred than what they do elsewhere’, cos if you were on the ward and go into a patient’s room, you go in with a reason, you say like ‘have you had your bowels open, are you in pain?’, and you’ve got your uniform on. We didn’t used to have to wear uniforms by the way when we first started, erm, whereas here you’re approaching the patients very much in a social setting so you’re opening line, it might not be ‘av you had your bowels open?’, it might be ‘oh did you enjoy so-and-so last night?’ and it is – and – they want to know you, as you know, most of our patients know Nicola [staff nurse], they know Emily [health care support worker], they know – and – they know a bit about us. The thing is what you have to be very careful of not crossing that – that – line, we are still - we are not their best mate – we are – as close as you get to ‘um, you are still the professional, helping them and their care, you’re – you’re – not a family member, so there is a line, er, and there again, it’s a tiny bit like blurred, but erm, it’s very, you have to be very careful not to cross it.

Eileen refers to the boundaries between being the patients’ ‘best mates’ or their ‘family member’ and acting as a ‘professional’ as likely to become ‘blurred’ within the day hospice.

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<sup>16</sup> Please see Chapter Three for a detailed methodological and ethical reflection on this point.

She contrasts this with the ward, where interactions were framed around the patient's symptoms, pain and physical needs, and she uses the example of asking whether the patients had their 'bowels open'. The day unit is described by Eileen as a 'social setting', where the interactions are embedded in knowing the patient as an individual, with interests, hobbies and relationships. Eileen further emphasises how many of the workers, and especially those on the day unit, approached and related to the patients as persons and ultimately as *social individuals*. She emphasises that the physical symptoms seemed to be prioritised on the wards. On the in-patient unit, the staff entered the patients' rooms on their "rounds" of care', which often reduced the opportunity for 'uninterrupted or significant time to be spent with individual patients' (Featherstone and Northcott 2020: 77). The care on the wards was often routinised, with a set purpose and a set of tasks to be completed. My reflections of the hospice wards resonate with Featherstone and Northcott's (2020: 77) hospital ethnography, where 'the routine itself became the focus' and the efficiency of moving from patient to patient, as opposed to the social interactions and encounters. These tensions between the care approach in the day unit and on the wards support a wider trend within hospice care: the increasing prioritisation of the physical management of symptoms within the ward space and a more general medicalisation of hospice care (James and Field 1992; Clark 1993; Borgstrom 2015).

Eileen emphasises that 'we are not their best mate' and 'not a family member', which suggests that the depth of exchange in the workers' interactions with patients is continually limited by the need to maintain a 'line', between becoming a familial-like figure, as opposed to a professional care provider. Although Eileen explains that the patients 'know *a bit*' about the workers in a reciprocal knowing of each other, there was an evident limit to how much the patient could come to know the workers in turn as individual persons. She continued to explain in our interview that she sets certain parameters around the worker-patient relationship at actions, such as not 'exchanging phone numbers', becoming 'friends' on Facebook or meeting up with patients outside of the hospice. These constraints demonstrate how the intimacy of the relationships was restricted to the hospice space within a professional context. She also explained that developing intimate relationships with the patients meant that certain deaths were 'more difficult, emotionally', hinting at the multifaceted negotiations necessary for sustaining intimate, yet not too familiar, relationships. The extent of a reciprocal knowing of each other was limited by the 'line', or the 'boundary', of the workers' professionalism. As such, the 'line' and boundary in their relationships with patients means that reciprocity was

uneven, as the workers came to know the patients better, or more fully, than the patients could know the workers.

In the extract below, one of the nurses on the wards, Amy, illustrates the purposeful efforts to generate a reciprocal interaction, which again calls into question the authenticity of the dialogue between the patient and the hospice workers:

*Amy, staff nurse, in-patient unit:* The patients love to know a bit about you, a bit about your life, because it takes away from them being ill and it takes a bit of normality, and you know, you're going down a very personal journey with them. So, a little bit of information, a little bit of personal, erm, makes them feel more comfortable with you, less medical, more humour, and they can relate to you better

*N:* Do you then find they open up a bit more?

*A:* If you gel with them, yes, it's like everything else, if you gel with them, yes, if you don't but you know someone has to gel with somebody and yeah, they know a bit about you, then yes, if they've got a little bit of what they consider as a relationship with you, they do talk to you more, they do feel more comfortable, erm, you lose that medical bit, and they can say, sometimes, what they think and feel.

Most notably, Amy suggests that in knowing 'a little bit of information' about the workers, the patients feel that they have developed 'what they consider as a relationship' with the workers. On the ward, the workers were physically closer with the patients, as they negotiated the patients' bodies and physical symptoms each day and night. This extract from my interview with Amy also challenges the authenticity of the intimate exchanges between the workers and patients on the ward, by illustrating the premise of giving *in order to receive*, and in the hope of receiving, an unguarded account of how the patients 'think and feel', as they become more 'comfortable' in the presence of the workers. Amy presents a 'formidable trap', in the words of Foucault (1980: 114), to encourage the patients to "come to us, tell us, show us all that, confide in us your unhappy secrets". These imbalances of power manifest within Amy's efforts to provide only 'a little bit of information', to develop what the patients might '*consider* as a relationship' with her.

In their ethnographic study of hospice care, Broom and Cavenagh (2011: 107-8) emphasise this sense of ‘performativity’ in the interactions between workers and patients, as there seemed to be, for patients, ‘a sense of chat, but not conversation’ within an environment that was presented as ‘cheerful, but not truly engaging’. Thus, the interactions were deemed ‘less interactionally authentic’ (Broom and Cavenagh 2011: 109) than the sorts of exchanges an individual may engage in in a non-hospice environment. Broom and Cavenagh (2011: 109) conclude that these sorts of exchanges lead to particular forms of ‘social and identity disintegration’, which stem from the inauthentic exchanges with workers and the pressures on patients to uphold positive interactions while dying. Amy suggests that she gives ‘a little bit’ of information to receive and know a lot about her patients and their ‘very personal journey’ towards the end of life. This indicates that Amy forced certain interactions to initiate imbalanced and unequal exchanges. Both Amy and Eileen describe the ways in which the interactions across the hospice unfolded within set boundaries of professionalism which stunted the reciprocity of the exchange. Ultimately, the workers across the hospice engaged in intimate and in-depth relationships with the patients, negotiating the tensions between letting the patients know about them a little in return, yet sustaining certain limits to these relationships.

### ***Reciprocity and Suffering***

Up to now, this chapter has shown that, at times, the relationships between the hospice workers and patients were reciprocal. The workers illustrated multidirectional exchanges of knowledge and interest between themselves and the patients. Many of the workers referred to ‘giving’ themselves, or *of* themselves, in their emotionally and physically intimate relationships with patients. As Simmel (1992: 60) states, within our relations with others in the everyday there is a ‘continuity of gain and loss, of flux and of reflux’, where the individual gives of himself to receive in return. The relationships between the workers and the patients were evidently multidirectional at times, with exchanges flowing in both directions, as ‘interpersonal entanglements’ (Dragojlovic and Broom 2018: 23). Such intimate relations often meant that the workers shared in the patients’ suffering and pain.

In the following extract, Elizabeth, who had worked at the hospice for eighteen years, likens doing her job to emptying a bucket of sand and the bucket becomes depleted as she is ‘giving, giving, giving’ each day at work:

*Elizabeth, clinical nurse specialist, community team:* I was doing a course and it was a lady that had come to talk to us and she used, I use it a lot myself when I'm talking to others, and she suggested, if we think in a morning when we are doing this job, if you had a bucket and you could fill it with sand, and over the day you are giving, giving, giving and what's important is, before that bucket has run out of sand, you recognise that you need a layer – probably need more than a layer – to keep on coming, to sustain what we do.

In our interview, Elizabeth also explained that she had experienced ill health and repeated infections at times where she was in a 'vicious circle' of long days at work. She linked her physical ailments to the strains of her work, describing the exhaustion of repeatedly 'giving' herself in her work and in her relationships with dying patients. She describes suffering with, and suffering *in relation to*, the patients she meets and cares for in her work, demonstrating a complex, and at times messy, experience that is shared between the worker and patient. Managing the patients' pain, suffering and symptoms involves the workers directly in the patients' dying experiences, often as a form of 'collective suffering' (Dragojlovic and Broom 2018: 36). The emotions that the workers 'gave' and those that they experienced as part of their work formed this kind of emotional exchange in the hospice, where emotions seemed to be a resource that could become depleted. Emotions were navigated by the workers to develop relationships and establish certain interpersonal boundaries. Elizabeth illustrates a reciprocity in her relationships with patients. She describes a multidirectional 'gain and loss' (Simmel 1992: 60), with the workers *giving* themselves emotionally to the patients and depleting their own sense of self. Although care was often described by many of the workers as an offering, a 'giving' to the patients, Elizabeth's account depicts an exchange of emotions that occurs between persons, with the workers participating in the patient's death, rather than as an unaffected outsider.

As I explored earlier in this chapter, the workers often came to know the patients as individual persons with whole identities. In turn, many of the staff across Broad Lane described the patients' intimacy and openness towards them. We can consider Lauren, the complementary therapist who explained that her treatments often led to an 'emotional release', and Nicola, the day unit nurse who said patients often told her 'anything and everything' as she developed intimate relationships with many of them. These sorts of intimate relations towards the end of

a patient's life often meant that the workers found their own emotions more difficult to navigate. Elizabeth alludes to the 'affective assemblages' (Dragojlovic and Broom 2018: 3) between hospice workers and patients, wherein the dying experience and, by relation, any patient suffering is experienced *across* persons as a relational process. Elizabeth suggests that the care she provides to patients may become 'diluted' as well as her own personal well being, emotional stability and sense of self. She notes the need to 'sustain what we do' at work by managing certain limits and boundaries in order to protect against the absolute depletion on one side of the emotional exchange. Rather than care transpiring only as an 'offering' or a 'gift' (Dragojlovic and Broom 2018: 44) from the worker to the patient, Elizabeth suggests how dying and the emotions attached to the experience were sometimes '*shared*' as an 'interpersonal' 'entanglement' (Dragojlovic and Broom 2018: 23) of affective experience.

Elizabeth explains the feeling of having 'nothing left to give' to patients, as the 'bucket of sand' becomes 'really, really empty'. She explains that, at times, she has withdrawn from the 'suffering that we see' by turning down extra shifts or overtime, which again suggests the imbalances in the reciprocity of the exchanges, wherein the workers *can* withdraw from sharing the patients' suffering:

*Elizabeth, clinical nurse specialist:* ... Yes, I do feel sometimes that there is nothing else to give and I, many, many times, drive home at the end of shift and think, that bucket of sand is really, really empty now, you know, there is nothing. Often – I've always worked bank shifts – well many years I've worked full time and if I do overtime, but to me overtime shouldn't be to the detriment of your health, because of the suffering that we see, and if my boss asks me and I know that I can't come and give myself, there is no point, I'll say to her 'no I can't do that shift'. Sometimes it's lovely, who doesn't like extra money? But I do think we have to be true to ourselves and give ourselves that break.

Many of the other hospice workers also referred to 'giving' themselves in their work and implied that by 'giving' they became depleted in their own sense of physical and emotional wholeness. This emphasises the reciprocal and relational nature of the dying process, wherein it is experienced between persons in a 'multidirectional' (Dragojlovic and Broom 2018: 72) flow of shared and interpersonal affective experiences. However, she identifies the need to establish certain boundaries in order to avoid being left with 'nothing else to give', which

indicates how the shared experience can be negotiated by the workers, in contrast to the dying patients' inability to withdraw from their own personal experience. This emphasises the tensions between the need to maintain intimate social relationships, and share in the patients' deaths and their suffering, while also maintaining a necessary affective distance. Russ (2005: 129) refers to hospice work as a 'potentially self-dissolving project', as the workers attempt to negotiate intimacy by aiming to both 'limit and achieve' close relationships with patients, within the two conflicting economies of 'pure gift' and 'efficiency'. These tensions emerge within Elizabeth's need to avoid her own sense of self-deficiency and a loss of self through her reciprocal affective exchanges with her patients. Being '*drawn into*' (Eileen, day unit Sister) the patients' dying processes in a reciprocal exchange would result in a feeling of depletion, a personal loss as well as a potential 'detriment' to their 'health'. Other hospice workers recalled balancing intimate relationships with their patients, by absorbing the pressures from their colleagues to be time efficient, emotionally distant and avoid '*faffing*' unnecessarily (Jenny, Health Care Support Worker), all whilst providing '*good, palliative, holistic care*' (Eileen, day unit Sister). This thesis will consider such conflicts and tensions in further detail in Chapter Seven. Within this compromise between relating to the patients as persons and avoiding being left with 'nothing else to give', there was a need to uphold as well as continually negotiate certain professional boundaries. Some of the hospice staff suggested that they limited the reciprocity of their exchanges with patients, as they attempted to be close yet remain detached enough to avoid sharing *in* their suffering.

## **Final Rituals and Rites**

### ***Bodily Boundaries***

This chapter has explored how some of the workers cared for the patients as socialised individuals, often in reciprocal relationships. Isolating and abstracting the patients from their sociality, would mean treating only their physical symptoms with a 'tick-box' (Nicola, Staff Ward Nurse) approach. This approach was seen by many of the workers as a failure within hospice care, which ruptured the ethos and slipped into a medicalised, isolating way of caring. Part of their work involved negotiating the patient's deteriorating physical condition, while developing and maintaining intimate relationships.

In wider Western society, the bounded body is considered an autonomous, independent agent, and the unboundedness that can occur at the end of life often challenges and reorders how the body and, most notably in this context, how the *person* is experienced in relation to others (Douglas 1966; Twigg 2000). Hockey and James (1993) note that as people become more physically dependent, their social relations and interactions with others can alter and begin to break down. The paradoxical condition of physical dependency means that it often results in a loss of certain social relationships. However, the hospice workers came in at these moments and these relationships *emerged through* dependency. The workers often attempted to manage and negotiate the patients' physical unboundedness, and this often suggested that a controlled, contained death was considered a good, or a normal, death, wherein social relationships could be sustained. The disintegration of the physical body was negotiated by the workers in a manner that could help to maintain social relationships, where they became restricted at the end of life. As I explored in Chapter 5, the hospice could be considered a place that often mirrored and upheld societal notions of normality, as a microcosm of wider Western society. In the following extract taken from my observations of a staff meeting at the start of the day in the day unit, Eileen mentions a patient that is 'leaking'. She explains that the patient's husband is avoiding taking his wife to public places, demonstrating the wider breakdown of the patient's social involvement due to their bodily state:

Referring to a patient attending the day unit today, Eileen explains, "she's leaking now, and I think she finds it embarrassing. She says her husband finds it embarrassing too". Emily adds, "oh yeah, she wanted to go see 'Mamma Mia' didn't she? And her husband wouldn't take her - I would have took her". Jenny agrees, "so would I!". "Well, we would have been able to in the past", Eileen looks disappointed. "We used to take them loads of places, didn't we?" Emily adds.

The patient had expressed a desire to see 'Mamma Mia' at the cinema. However, her husband is described by the workers as too 'embarrassed' to take her. In response, the workers joined in agreement about wanting to take the patient. The patient is described as experiencing a forced social isolation in her familial ties due to the 'embarrassment' attached to her 'leaking' body. This demonstrates how the physical experience of one's body can impact on their sense of self, or personhood, which is developed in relation to other persons (Hockey 2010). Douglas (1970: 65) suggests that the 'social body constrains the way the physical body is perceived', as societal norms dictate a certain 'culturally processed idea of the body'. Thus the 'physical body

is a microcosm of society' as well as of the norms within it (Douglas 1970: 76), and the 'leaking' body is subjected to control, containment and boundary management, as it is a potential source of 'pollution' to others within social spaces (Douglas 1966: 100). Douglas explains that through socialisation individuals are taught how to control and manage their bodily functions, so the self-contained body is recognised as a marker in the progression to maturity.

The 'leaking' body is observed as physically dependent, as opposed to the self-contained, independent and mature body (Hockey and James 1993). The disintegration of the physical body, and an increased dependency on others, brought about the rupturing of many of the patient's meaningful social relationships and roles as an autonomous person. Increased dependency resulted in an increase in certain relationships with others, such as the hospice workers, but it also led to fewer social relationships as an autonomous individual. This thesis seeks to examine how the hospice workers engaged with patients in their moments of dependency and the roles they played in the patients' social lives. Evidently, ideas of personhood and a sense of self were embedded in Western ideals of the contained, bounded and physically independent body. We can explore, through the workers account, how the uncontained and dependent physical body shapes how the *person* is seen as an 'out of place' presence in certain social contexts. Their discussions highlight the loss of social self and increased isolation that can occur with the disintegration of the physical self through a loss of autonomous agency towards the end of life.

Eileen, Emily and Jenny distinguish themselves from those that are reluctant to be exposed to bodily matter, such as the patient's husband. The day hospice services were largely focused on fulfilling some of the core principles of traditional hospice care by seeking to alleviate the emotional and social distress of a life-limiting illness (Saunders 1964). The day unit sought to provide opportunities for interaction, the potential to develop relationships and take part in activities, make crafts as well as receive complementary therapies. By carrying out the intimate and, at times, unpleasant tasks, the workers were influencing the patients' ties to social life and a sense of sociality. In her ethnographic study, Lawton largely refers to hospices as 'no-places' (Lawton 2000: 121). However, she takes exception with the hospice's day unit. She describes the day unit space as a 'safe retreat' (Lawton 2000: 39), offering interaction and the chance to participate socially in relationships with the staff. Similarly, the day unit at Broad Lane was often a place of thriving interaction, and in the above extract, the day unit workers described

wanting to offer the patients a sense of social involvement. They stepped in where others retreated, or felt *'embarrassed'*, offering social interaction and often, a sense of normality. Furthermore, the hidden physical work of cleaning and toileting patients occurred inconspicuously and away from other patients. Leakages were seen as one aspect of the person, which was handled behind the scenes, in order to maintain a sense of personhood in their social relationships within the hospice space.

In the following extract from my interview with Amy, she describes 'rationalis[ing]' the situation in the moments leading up to a patient's death by cleaning up their bodily excretions and their soiled surroundings, so that their loved ones 'didn't see [the patient] like that'. Here, the physical appearance of the dying individual and their loved ones' feelings towards their physical state are acknowledged, as though their social existence can be maintained through the eyes of their loved ones:

As I sit with Amy opposite the first nurses' station, she tells me about a patient that passed away on the in-patient unit a few weeks previously. She tells me that the patient was in his thirties, and she describes him as "quite a large man". She explains that his death came within weeks of the initial diagnosis. "In his last few days he was having a lot of secretions", she straightens her face and lowers her tone. She explains it was affecting his lungs, "he was bringing a lot up through his mouth. So, I made a snap decision". She tells me that in the patient's last few hours alive, she ensured that the family members did not see the unpleasant bodily excretions. She states that they would have been "upset" by what they saw. "When a patient dies, their lungs and heart goes last... it follows a certain pattern, so you know when it will happen". She said, "I rationalised it and made it so the family members didn't have to see him like that... they didn't see him like that. I just did it, quick".

Amy does not go into any detail about the process of cleaning the dying patient. However, she illustrates the ways in which she 'managed the seemingly disordered process of dying' (Froggatt 1997: 134), which threatened the social order and notions of normality both within and outside of the hospice space. Here, we can see again how the hospice staff managed the sensorial aspects of dying and the patients' unpleasant excretions to maintain a *social* order, which is ultimately embedded in contained physical states and peaceful processes of death.

The workers seemed to share many of the wider societal ideals of a controlled, and most notably a contained death, as a ‘symbolic vehicle’ to work and aim towards (McNamara et al 1994). Both extracts suggest, in different ways, the violation of ‘systematic ordering’ and the challenge ‘dirt’ (Douglas 1966: 35) poses to the social order of the dying process, as a relational experience between the workers, patients and visitors to the hospice. Where the disquiet and unpleasant aspects of death crept into social relations, the workers often stepped in to ensure a boundary between social life and physical death. The patient’s relational social lives and roles can be sustained at the end of life by the reordering, renegotiation and *renormalising* of their disintegrating physical bodies. Amy cleans the seepages and secretions to make the patient appear physically contained in death, which she believed would preserve their social existence and previous social ties to others. Uncontrolled and uncontained bodies were negotiated and managed in order to sustain the patient’s intimate social relationships, both between the workers and patients, as well as with their loved ones, at the end of life. This tells us how the state of the patient’s body could either maintain, or limit, meaningful social relationships, and the workers influenced and negotiated this to certain ends.

### ***Biological Death and the Social Self: ‘Laying them to rest’***

The hospice staff enacted certain rituals which would continue to sustain the social presence of the patient up to and after their biological death. Amy described a ‘quick’ decision to clean a patient before they died, so that his family did not see his unbounded body, and here I illustrate the actions of a health care support worker in a process he refers to as ‘*laying them to rest*’. The following extracts depict Kevin’s routine after a patient’s death, to prepare them for viewing and their subsequent removal from the hospice. He describes each step of cleaning and turning the patient and redressing them in clean clothes, demonstrating the boundary between the patient’s dying bodily processes and their posthumous visual appearance. His routine of cleaning the patient, redressing them and placing flowers around their pillow were signs of prolonging social life as well as order amidst the physical disturbances of death. Kevin was one of the only male health care support workers in the hospice and one of only three men working on the in-patient unit at the time. In the following extract from our interview, he describes speaking to the deceased patient, talking through each movement and turn of their body, as if they were still alive:

*N:* So, you go in after they’ve –

*Kevin, health care support worker, in-patient unit:* We'll – we – lay 'um to rest and it's, so, like, like if a family went and asked to 'av this, er, clothes put on 'um and this sort of stuff. We actually talk to 'um while we turn 'um on their side and turn 'um on that side whatever, we're talking to 'um all the way through, they're always covered up, so.

*N:* They're covered up after they've passed away?

*K:* Well, if we're cleaning 'um up, we're always very discreet, nothing changes. Just because they've passed away, we still treat 'um like they're still there, like they're still here. We talk to 'em, we're discreet with 'em and keep 'um covered up, they're not just a piece of meat at end of day. It's still a person. It's still somebody's loved one and it's like when you do somebody's cares or whatever – how would you like to be tret? I – what – I – how I'd like somebody to look after me mother, that's how I – I do for them, what I would expect somebody to do.

Kevin describes treating the patients with the same discretion after their death, keeping them covered and talking to them 'all the way through' the process of 'cleaning' their bodies and dressing them in unsoiled clothes. The dead body becomes 'no longer a secure, bounded body', with its 'orifices threaten[ing] to contaminate the external world with internal body matter and fluids' (Hallam et al 1999: 127). For Hallam et al (1999: 127), the dead body embodies all that is uncontrolled and uncontained, so loses its 'integrity and wholeness'. Retaining the patient's sociality and their presence as a *social* being, after their physical death, regains and maintains order over a disorderly situation, wherein the dead body represents a potential site of pollution and impurity (Douglas 1966; Froggatt 1997). There is a refusal by Kevin to treat the patient as less of a social being and, as Kevin describes it, as 'a piece of meat', which would represent a complete abstraction of the patient's sociality and a reduction to mere physicality by stripping them of their former self-images and identity. The handling of the patient's body unfolds in a manner that maintains their social presence, and the physical preservation of their body delays the gradual drift into a natural and biological bodily decay or '*asociality*' (Baudrillard 1993: 201). A person's identity is embedded in their social and interpersonal contexts as well as their relationships between themselves and others, as a *social* individual, and by interacting with the patient's body, Kevin maintains their personhood after death. For Douglas (1966), the dead body represents a challenge to the dominant modern social order, of an individually bounded, controlled and autonomously independent corporeal entity. Kevin's efforts to maintain a socially present figure somewhat help to reinstate a sense of order and control. During the

impending physical breakdown of the body, the *social* ‘meaning’ (Elias 1985: 54) attached to the patient’s presence is preserved.

This social interaction, in which Kevin continues to experience the deceased patient as a social being after their death, involves a delaying of the ‘social death’ (Glaser and Strauss 1965; Sudnow 1967; Lawton 1998; Twigg 2000) after the biological death has occurred. In some ways, we can observe here an example of a social death occurring *after* the biological and physical death of the patient, as Kevin illuminates how sociality is sustained posthumously by his actions and *interactions* with the deceased:

*Kevin:* ...and what I really like to do, well, we might lay ‘um to rest and then, straighten them all back, cos relatives might want to come in later so I, sometimes, I walk out and I think ‘there’s a crease there, straighten that up’, ‘that pillow’, ‘that there’ cos I think that’s so important cos as soon as they come in and see what we’ve – see them laid there – that’s a memory for rest of their life, so it’s gotta be perfect. So I mean – sometimes – get that crease there – that pillow – just to look the best that we can and we tend to put a couple of flowers ‘ere [signals around his head], on pillow and it looks nice, but I think it’s so important to get that moment right cos that’s their memories and so you – you – it’s like giving them a picture to carry with them for the rest of lives... and most of time they’ll come out and, ‘oh thank you she looked – they looked – really nice’ and it’s – it – it’s a job well done. You can go ‘ome and you’ve – you – you’ve made somebody really ‘appy today. Somebody what was really sad, you’ve gave them a good memory like I said, for the rest of their life cos they’ll remember that.

Kevin details the meticulous routine of ‘laying’ the patient ‘to rest’, which involves straightening the creases in their bedsheets, plumping the pillows and sometimes placing flowers around the patient’s head. This process takes place before the deceased patient’s family visits and after that, the body is removed from the hospice by the undertakers. This routine allows the loved ones to visit their dead in a prettified and dignified state, where all of the physical signs of their passing have been removed. Kevin describes perfecting the scene, making the patient ‘look nice’ and he takes pride in how he arranges them and their bed. The work of those that are experts in the ‘disposal of human remains’ is focused upon containing bodily leakages to re-establish, somewhat, ‘the body’s boundaries’ that have come undone in

the dying process (Howarth 2007: 186). In her study of funeral directors, Howarth (1996) explains that in cleaning, draining bodily fluids and redressing the corpse, the body could still maintain a social presence and identity when viewed by their living loved ones. Kevin, the health care support worker, speaks of re-establishing the patient as a person and, ultimately, they remain a social individual after their death.

The routine, which Kevin refers to as 'laying the patient to rest', is a skilled, careful and practiced process of sustaining a sense of social meaning and order after a patient's death. Howarth (1996: 109) describes the processes of preparing a dead body for viewing as 'protect[ing]' loved ones from potential 'pollution' in the form of an unsettling sight that more closely represents the natural processes of death. The preparation described by Kevin allows the loved ones to 'enjoy' what Howarth (1996: 109) refers to as 'artificially prolonged meaningful contact', that delays the decay of the patient's physical body. Providing a 'good memory' for the viewing loved ones takes place against a backdrop of artificiality and ritual, with the use of props such as flowers, to delay the patient's social death and the 'sudden loss of signs that befalls the dead' (Baudrillard 1993: 201). This process can be 'readily imagined' in the 'decomposing face's loss of countenance or the corpse's loss of posture', and the dead are 'retrieved' from this state of 'natural death' and 'decay' (Benzer 2019: 127) through processes of preservation, to ensure they remain 'partners in [social] exchange' (Baudrillard 1993: 181) past the point of biological death.

The memory that is constructed is embedded in feelings for the patient as a still socially meaningful and, most importantly, a *socialised individual*, fending off that which is lost in physical death and through bodily decay, where the person begins to appear and *feel* to others less of a social being. Kevin prevents or delays, if even for a brief period, the process in which the '*asocial* flesh of the dead' (in a biological sense) begins to 'signify nothing'. He does this by enacting certain 'sarcophagic rituals' to maintain some 'appearance of life', or at least prevent the obvious signs of natural and biological death (Baudrillard 1993: 201). Baudrillard refers to the practices of the Canaque people in drawing on such 'sarcophagic rituals' that prevent the body becoming 'asocial' in death. Thinking about the hospice, we can draw on these examples to explore the ways in which Kevin and his colleagues delayed the evident signs of nature from seeping through and becoming apparent to others, by delaying physical decay and sustaining the sociality of the patient as a *person*. Death is embraced and presented here in a way that sustains the social lives of the dead. From this, the importance placed on

maintaining a social presence and identity, even after biological death, becomes apparent, and this seems to serve to maintain the dignity and boundaries of all of those involved in the social relationship with the deceased. His actions preserved the *social* existence of the dead patient in the eyes of those visiting them. Personhood is constructed through ‘social interactions’ and ‘by reference to others’ and so, Hallam, Hockey and Howarth (1999: 114) argue that it is ‘only logical that this should continue to be the case in death’. Kevin and Amy tell us of the ways in which the hospice workers shaped how the patients were perceived by others in the moments leading up to and after death.

Interwoven with the workers’ narratives of sustaining order and normality for themselves as well as the viewing loved ones were moments of intimacy and closeness in ‘laying [the patients] to rest’. The descriptions made by Amy and Kevin of cleaning both living and deceased patients’ bodies depict calm closeness with their patients in the moments just before and after death. Through these routines, rituals and rites, the workers at Broad Lane influenced the patients’ ties to social life at the end of biological life. Kevin refers to these ritualistic routines of cleaning and preparing the patient as his ‘most important and last’ task for the patients:

*Kevin:* Erm, it – it’s – sometimes when we’re doing the what-d’ya-call-it, when you’re laying ‘um to rest ... you – you’re – you – you’re a human hand, it’s probably the last, the most important and last thing, that the human hand can do for you, is to lay you to rest.

Kevin emphasises the contact and touch of ‘a human hand’ in preparing the patient after their death, demonstrating the emotional as well as physical proximity in these rituals and rites surrounding the moment of biological death. These routines involve socialising the person’s body once more, delaying the natural and inevitable processes of biological decay. Thus, maintaining their social identity and existence, as their loved ones are still able to view them as a social individual, with a continuing, meaningful social presence. Biological death ended the patient’s life, however through the actions of Kevin, their social interaction and relation to social life could be sustained. Here, the ‘death of the body’ does not ‘entail a complete loss of the *self*’ (Ribbens McCarthy and Prokhovnik 2014: 24). *Before* a patient’s death, Amy sustained their dignity and their existing sociality in the eyes of others, whilst they are biologically dying. She delayed social death before the moment of biological death. *After* death,

Kevin tended to the physical body to preserve and *reaffirm* the patients' previous ties to social life. Personhood exists in the eyes and corporeality of the bereaved persons. The hospice workers played a significant role in influencing how that transpired and they shaped the lasting 'picture' the bereaved would hold of their deceased. In both life and death, the body remained a marker of the person's physical state, and the way in which the workers handled the physical body could maintain social relations and a sense of social presence.

## Conclusions

The three sections in this chapter reflect on different practices, rituals and rites of hospice work, examining the micro-interactions, processes and emotional management practices of the workers. However, each of these sections explore how the workers play a significant role in sustaining the patients' personhood, through exploring their accounts of handling the patients' physical bodies and their affective 'entanglements' (Dragojlovic and Broom 2018: 23) with the patients. In doing so, the chapter has emphasised how dying and suffering unfold in relation, between the hospice workers, the patients and their loved ones. Some of the extracts presented here demonstrate the workers' engagements with patients as *socialised individuals*. I illustrate how they often developed an understanding of the patients in the contexts of their social lives and relationships. Many of the workers contrasted their approach to caring for patients with a medicalised approach, which was seen as de-particularising patients by abstracting them from the social 'structures of generality' (Simmel 1992: 61). At times, an abstractive, medicalised approach seeped into the approaches to care, and this illustrates the pressures and challenges many of the workers faced to develop intimate, yet affectively detached relationships. Within these intimate relationships, boundaries became 'blurred', and the workers often needed to reiterate their professional limits of social interaction in order to avoid feeling emotionally depleted by sharing in the patients' suffering. As the workers came to know the patients as persons, they often shared glimpses and insights into themselves, and they demonstrated a reciprocal knowing about each other. As the workers shaped the patients' experiences of death, dying and suffering, the workers were also shaped *in relation to* the patients' experiences, often experiencing a form of reciprocal suffering which emerged through their intimate relationships and interactions with patients. In this way, the chapter contributes to the existing literature on suffering, to emphasise the relationality of suffering, which occurs between a multiplicity of persons, and is embedded in the social interactions and relationships, as well as the actions of the hospice workers.

Finally, the chapter highlights how the workers handled the physical body, managing bodily leakages and the natural signs of death, to sustain a social identity in the eyes of the patients' loved ones. Drawing on Amy's decision to clean a patient before their death and Kevin's detailed illustration of 'laying the patients to rest' after their death, I illustrate how the handling and preservation of the physical body delays the '*asociality*' (Baudrillard 1993: 201), which creeps in during the physical dying process. We can appreciate how the workers' rituals after a biological death shaped the patients' ties to social life. Each of the sections in this chapter emphasise the significance of the hospice workers' role in the patients' dying process. By their handling of social relationships, interactions and the dying, or dead, body, they influenced the extent of the patients' social participation at the end of life as well as posthumously. Their handling of the physical body impacted on the patients' social self, and the hospice workers delayed 'social death' around the point of, as well as after, physical death. This chapter contributes to ideas of 'self' and 'personhood' by eliciting the interactive and interpersonal processes of sustaining identity around the point of death (Hallam, Hockey and Howarth 1999; Cassell 2004; Hockey 2008). We can examine how the hospice workers actions and interactions with the patients, as well as the ritualistic rites and practices after a death, were pivotal in either preserving, or further threatening, the patients' socialised individuality at the end of life. As 'social death' (Glaser and Strauss 1965; Sudnow 1967; Lawton 1998, 2000; Twigg 2000) can be brought about through a lack of interactions and relationships, *social life* could be sustained through the final actions of the hospice staff at Broad Lane. Western social norms dictate the abnormality of bodily unboundedness and the workers attended to the physical indicators of dying in order to preserve the patient's social relationships and their interactions with others. Their actions were embedded in notions of normal and modern civility. At the point of biological death, the *sociality* of the person could be maintained through the workers' social interactions with them and their handling of their *physical* body.

## CHAPTER SEVEN

### The Making of a 'Nice' Death: Time, Resources and Regulations

*'Our usual resourcefulness and industry have failed us, and this is something to be ashamed of in the world that measures human quality by the amount of know-how demonstrated in the efficiency and effectiveness of action.'* - Bauman 1992: 131

#### Introduction

Hospice care is, in its most ideal form, successful at alleviating suffering on a 'holistic basis' (Hart et al 1998: 69) and relieving the facets of 'total pain' (Saunders 1964: 68). Working in the sector was seen by some of the staff at Broad Lane as an opportunity for greater patient contact and interaction. Many of the workers told me how they entered hospice work in the hope of giving more time to patients, after working on hospital wards or in a different medical sector. However, they also expressed feeling increasingly time constrained, and they highlighted the social pressures they faced to be time efficient while providing care. Many of the workers related these pressures to the rising patient waiting lists, a shortfall of resources and a lack of staff. At the time of this research, Broad Lane hospice is an independent charity, reliant on over two million pounds of charitable donations through fundraising each year. In the last year, the hospice received under sixty percent of their income from the NHS. The other forty percent were raised through donations and fundraising. A board of trustees were responsible for the strategic governance of the hospice and for overseeing the work carried out by the hospice staff. This chapter illustrates the conflicts between those decisions made by the board of trustees and the hospice workers' priorities of caregiving in their everyday work.

Many of the workers described hospice resources, such as beds, finances and space, as under increasing demand. The day unit sister, Eileen, describes the feeling of '*giving more for less*' due to the growing 'financial constraints' and 'pressures'. These financial constraints were felt by the workers in their day-to-day work and in their relationships and interactions with their colleagues. The days that the day unit was open to patients had recently been reduced from four to three days a week. These changes had impacted the staff in different ways, showing some of the hierarchical disparities in the emotional work undertaken by the hospice doctors and consultants, in comparison to the nurses, support workers and the housekeeping staff. There were concerns that it was becoming more difficult to provide the sort of care that I

discussed in Chapter Six, where the workers described relating to the patients as *social individuals*. Some of the workers illustrated a shift towards more clinically driven care which prioritised treating physical symptoms. Furthermore, some of the staff described facing ethical and moral dilemmas concerned with prioritising a quality of life at the end of a patient's life, and external systems that failed to align with these hospice ideals. One of the hospice consultants, Faye, refers to these '*injustices*', and many of the other workers disagreed with a growing prioritisation of physical care over social and emotional care. This chapter explores the tensions the hospice workers navigated in balancing compassionate care with time-efficient practice. The chapter also illustrates the internal and external regulations the workers battled with in their interactions with colleagues and confrontations with certain systems, regulations and processes, which seemed to constrain their ability to facilitate what they considered a '*nice*' death in the hospice.

## **Time**

### ***Efficiency and Effectiveness***

The workers shared in their patients' dying 'trajectories' (Glaser and Strauss 1968: 5) and 'journeys' (Laura, Occupational Therapist) towards the end of life. Their day-to-day tasks were organised according to certain ideas of how much time they had available to spend with patients, and consequently how efficient they needed to be, as well as certain expectations of how much time the patient had left to live. On the wards, each day unfolded like the last: the patients were bathed in the mornings by the support workers, and the nurses administered their medicines; the housekeeping assistants would then enter to clean the rooms; food orders were taken by the volunteers; and the lunches were served around midday. On the day unit, patients were picked up from their homes and dropped off at the hospice at set times on set days; snacks as well as hot drinks were provided during the morning; and lunches were served at midday in the hospice 'café'. There were set periods of time allocated each day for craft-making, gentle exercise classes and quizzes. The days usually followed a set pattern and routine for both the workers and the patients as well as for those that came to visit. Providing hospice care in the community presented different challenges, as the workers had to factor in time for unexpected traffic and getting between patients' homes. Walter (1994: 145) argues that 'control' is a key aspect in hospice and palliative care work. Hospice workers seek 'control' over their patients' pain and their symptoms as well as an element of predictability in the manner that their illnesses

unfold. An uncontrollable, or uncontrolled, death is largely understood as a *'bad'* death (Bradbury 2000; Costello 2005). Chapter Five illustrated the way in which excretions and leakages were negotiated in a way that preserved the physical and social body, which suggests a construction of a *'bad'* death based on the uncontrolled body. The hospice ethos is traditionally focused on letting 'patients define their own dying' (Walter 1994: 29). However, there were tensions in some of the hospice workers' accounts between caring for the patients, enabling them to actualise their own understanding of death, and the workers' shared ideals of what makes a *'nice'* death.

The intimate nature of the relationships between workers and patients, as explored in Chapter Six, meant that the workers frequently balanced spending time with patients, while not taking up too much of their own working day and time available to complete other tasks. In the following extract, Chris, one of the specialty doctors, explains his 'management' of time, especially during home visits, where the interactions often wandered into 'other things' beyond the patient's physical illness. Chris previously worked as a GP, and he stated in our interview that the time to talk with patients in those five or ten minute appointments 'just wasn't enough'. His move into palliative care work was embedded in a desire to spend 'a little bit more time ... to actually engage with people'. However, he also expressed in the interview how time with hospice patients can be limited and how dealing with physical symptoms was often prioritised as a result:

*Chris, specialty doctor:* When you clearly tell that somebody really wants to spend a lot of time with you, you want to give that to them cos clearly that's important... and it's hard sometimes when you have to end a consultation. I've had one or two patients where I know that if I see them at home, I could be there an hour or two, easily, and most of the time it isn't talking about their symptoms, it's often talking about other things that are going on in their lives, but clearly they find that important... and it's hard to manage that sometimes when I feel like, actually I've got other things to do.

Chris captures the conflict he faced between getting to know patients, in the context of 'other things that are going on in their lives', as opposed to knowing only their illness, by 'managing' his time to complete 'other' tasks. As I explored in Chapter Six, many of the workers described getting to know the patients as persons, interacting with them in the contexts of their wider

social lives. However, a lack of time threatened Mark's ability to develop these sorts of relationships. Chris acknowledges the importance of spending time talking with patients on topics unrelated to their physical symptoms, however he struggles with completing his 'other' tasks. This suggests a prioritisation of managing physical symptoms and rushing or 'ending a consultation' in order to move on to the next patient. Featherstone and Northcott (2020: 87) illuminate the 'fear of falling behind' schedules and sequences to see each patient over the course of a day. This fear often shaped the provision of care to the patient and interaction would be limited to only the necessities. Mark's example highlights a prioritisation, in which the more time-efficient and, ultimately, more manageable aspects of his work are assigned higher importance. Whilst he recognises the 'importance' for the patient of being able to discuss matters unrelated to their physical symptoms, he fears 'falling behind' (Featherstone and Northcott 2020: 87). The care of the dying exists 'in an uneasy tension' between 'care' and 'control', which Walter (1994: 146) describes as grounded in the opposing philosophies of 'compassion' and 'science'. In a broader sense, this focus on physical symptoms relates to an increasing routinisation, bureaucratisation and medicalisation of British hospice care (James and Field 1992; Clark 1993; Bradshaw 1996; Borgstrom and Walter 2015).

Chris describes 'good care' as 'time' spent with patients. However, the 'amount of work' to do means that he feels he cannot always provide this 'good care' that the patients 'deserve':

*Natalie:* And are there any parts of your job you don't like so much?

*Chris, specialty doctor:* I suppose, sometimes, if it's a busy day, erm, trying to, trying to manage that, if it's a heavy workload cos you still want to deliver that good care and give people the time they deserve, whereas if you've got a lot of work to do and you feel time pressured. Sometimes for me, personally I feel like I can't give them the care that they deserve and if you've got more time, you know, if I know I've got ten or twelve visits to try and fit in, I'm not gonna give 'em as much time as if I'd only got five or six in a day and I think for me personally I take that personally, cos I feel maybe I've not done as good a job as I should have done.

Chris prioritises being time efficient and getting through his visits quickly in order to complete other tasks and see a higher number of patients during his working day. In doing so, his interactions with certain patients become focused on the bodily aspects of their illness, as opposed to the less easily managed 'other' aspects. In this, Chris renders the non-physical

aspects of the dying experience as superfluous elements, as he prioritised those conversations that were easier to finish. Chris balances the ‘importance’ of interacting with patients on ‘other’ topics, unrelated to physical symptoms, with being an efficient consultant providing quality care. Chris understood ‘good care’ as time spent with patients, engaging in in-depth dialogue, which he often struggled to provide to a great extent. McNamara (2004: 935) draws on her ethnographic data to suggest that othering the non-physical issues related to terminal illness submits to the mind-body distinctions assumed in traditional medical approaches and biomedicine. Physical symptoms are easier ‘quantified or recorded ... and documented’ (Featherstone and Northcott 2020: 90). Therefore, the person can sometimes become ‘secondary to the timetables’ (Featherstone and Northcott 2020: 90) and routines of care, which dictate the time that could be spent with each patient. This extract from Chris resonates with the findings of Featherstone and Northcott (2020: 90), as he illustrates how the patients’ needs become ‘secondary’ to the ‘heavy workload’, the need to complete other tasks and see other patients.

Conversations concerned with the ‘*other*’ parts of terminal illness, such as the social and emotional suffering, were more difficult for Chris to direct, manage and, subsequently, end. With his ‘heavy workload’, Chris deprioritised the aspects of his work that were less easily managed, and these were usually the non-physical aspects of the patients’ illnesses. Bradshaw (1996: 418) argues that such prioritisation signifies less commitment to the ‘ethic of genuine and dedicated compassion’ of traditional hospice care. However, Chris attributes this to pressures on his time and subsequent ability to carry out non-physically oriented compassionate care. The care that I explored in Chapter Six, in which the staff at Broad Lane came to know the patients as individuals within the broader contexts of their social lives, could become deprioritised as it took more time to carry out. Mark’s ‘management’ of his time, through the ending of lengthy interactions, shows his need to strive for both ‘efficiency and effectiveness’ (Bauman 1992: 131). However, there are differing definitions and understandings of ‘effective’ hospice care. Chris illuminates the tensions between the institutional culture, which valued speed as efficient practice, and what Chris understood as ‘*good*’ care. There was a tension between effective care, which was described by Chris as ‘good’ for the patient, and care that is quick, easily carried out and time efficient. Chris suggests that the *quality* of interaction and care is, in fact, embedded in *time* spent with the patients, listening and talking about the ‘*other*’, non-physical aspects of their experience.

### *The Social Norms of Time*

Chris described balancing spending time with patients, providing what he considered to be ‘good care’ through in-depth interactions on topics unrelated to the patients’ physical illnesses, and managing time effectively to complete ‘other’ tasks. He explained that these pressures came about through the presence of ‘three or four times as many patients as ... ten years ago ... and there aren’t three or four times as many practitioners’. Furthermore, there were certain social pressures shared between and amongst the hospice workers, which reinforced the need to manage time effectively when seeing patients and visiting them in their homes. There were normalised notions of fleeting visits to patients, which sometimes meant that there was not enough time to establish close relationships, and the interactions were ‘less ... authentic’ (Broom and Cavenagh 2011: 109). Attending to the physical aspects of the patient’s condition often seemed to take precedence, as they were often considered easier and quicker than the non-physical ones.

Jenny, a health care support worker who usually worked in the community and whom I have referred to in this thesis several times previously, described in our interview that her colleagues nicknamed her a ‘*faffer*’. Her nickname implies that Jenny’s colleagues thought certain tasks (that Jenny liked to carry out) to be unnecessary. Jenny’s idea of caring for patients in their homes conflicted with her colleagues’, as she identified shaving and washing their hair as ‘basic’ tasks, whereas her colleagues recognised them as unnecessary ‘*faff*’. In her daily visits to patients’ homes, Jenny focused on the everyday tasks that the patients were no longer able to carry out by themselves, such as taking medicines, bathing, cleaning their homes and eating. In the interview, she recalled moments of feeding patients ‘M&M’s’ and laying with them on their beds. Jenny distinguished between the hospice workers that ‘don’t give anything of themselves’ in their relationships and interactions with patients and those, such as herself, that ‘give’ themselves to patients:

*N:* And you get satisfaction from that?

*Jenny, health care support worker, community team:* Oh yeah. Well, I like a man shaven! [laughs] I’ve got a bit of OCD, yeah, yeah, yeah. But I think the thing with carers – which is what I am really – I think they’ve been doing it a bit too long. They’ve been doing it too long.

*N:* So, does it become like routine to them?

J: Yeah. Go in, do this, do that, come out, go in, do this, do that, come out and don't give anything of themselves, you know, but I can never be like that, so.

By joking that she has 'a bit of OCD'<sup>17</sup>, Jenny abnormalises and pathologises carrying out the caring tasks that her colleagues deemed to be 'faff'. A 'normalising gaze' (Foucault 1991: 184) operates within the social pressures and shared norms of Jenny's colleagues through their nicknames and their collective approach to caring for patients. Priorities of care were reproduced amongst and by Jenny's colleagues, who defined what was 'considered valid work at the bedside' (Featherstone and Northcott 2020: 76) However, Jenny reconstructs and 'reorders' (Hughes et al 2017: 114) this idealised way of caring for patients by spending more time with them and tending to the everyday aspects of care. She accepts and recognises the way that her colleagues interpret her manner of working as abnormal, by joking that she thinks she might have 'a bit of OCD'. Here, Jenny acknowledges the normalised approach to caring, however she actively resists it. She does not attempt to reconstruct a sense of the normal approach to caregiving, she instead continues to carry out her *own* form of care, which is often different to that of her colleagues.

Jenny describes the pattern her colleagues adopt in visiting patients, by explaining that they 'go in, do this, do that, come out, go in, do this, do that'. For Jenny, this formulaic and methodical process does not involve 'giving themselves'. This form of caring is described as a routine that seems to be 'mere technique, devoid of compassion' (Bradshaw 1996: 141), which is at odds with Jenny's ethos of providing care. This kind of 'measured giving' is said to maintain boundaries, to make it easier to sustain a certain extent of care, to 'give everything but not one's self' (Russ 2005: 138). Jenny, like Mark, also recognised the significance of carrying out the type of care that means 'giving' one's self to the patient. However, she struggled with the pressures to be time-efficient, which her colleagues seemed to embrace in their repetitive sequences of home visits. The pressures Jenny faced and her description of the differences between herself and her colleagues illustrates that 'no matter how routinised an institution's methods for handling its daily tasks, those routines remain vulnerable' (Sudnow 1967: 171). Jenny claimed to challenge the monotonous patterns of routine shared by her fellow hospice workers by staying a little longer with patients in their homes and completing care that was deemed unnecessary 'faff' by her colleagues. Sudnow (1967) conducted his ethnographic

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<sup>17</sup> 'Obsessive Compulsive Disorder'.

study over two hospitals, however he explored a similar social organisation of death in which the value of ‘efficiency was held far higher than that of human dignity’ (Hart et al 1998: 67). Jenny’s describes her colleagues abnormalising her approach to care as an *inefficient* approach. The use of the nickname ‘*faffer*’ implied that Jenny spent time on unnecessary caring activities, and these tasks were most associated with sustaining the everydayness and normality of the patients’ lives.

In *not* giving one’s self to the patients in exchange, the workers also failed to sustain the patient’s own sense of identity and self by reducing them to their mere physical bodies of illness. Jenny attended to the parts of the patients’ bodies, and their experiences of ill health, that were deemed *unessential*. However, the cutting of hair, shaving of beards and applying of face creams contributes to a sense of everyday and normality. Featherstone and Northcott (2020: 49) note that the patients they observed on the hospital wards felt ‘stripped’ of their personhood and identities when they had to wear ‘institutional clothes’. Attending to the patients’ physical appearance sustained their feeling of choice and thus a sense of identity. The tasks not thought to be ‘*faff*’ failed to particularise the patient as a *person* and reduced them to their physical body, as a state of ill health and illness, and to their bodily ‘part-processes’ (Elias 1985: 54). This further illustrates the role that the staff at Broad Lane play in sustaining or contributing to the patients’ loss of self and sense of personhood at the end of life. The cultures of care that were shaped by pressures and organisational demands to be time-efficient impacted how care was delivered in practice. The social identity of the patients was ultimately impacted, as many of the workers deemed cutting hair, shaving beards and applying face creams to be unnecessary and time-consuming tasks. The seeping in of a more methodical, medicalised manner of caring again indicates a rupturing of the relational approach, as described previously in Chapter 6.

Russ (2005: 137) conducted her ethnographic study in an American hospice, and one of her participants explained that there are different ways to ‘change a diaper’, one which is ‘brisk and efficient: ‘it gets the job done’’, and alternatively, one is ‘more considerate’ and involves constantly checking with the patient, rolling them gently, to cause less embarrassment. As in Russ’s study (2005: 137), the workers at Broad Lane weren’t paid for making that ‘distinction’ between efficient care and caring for the whole person, and they similarly faced demands on the time they could spend on such tasks. As Eileen summarised, they were ‘*giving more for*

*less*'. There was a sense of maintaining detachment in order to achieve *more*; by visiting more patients and completing more tasks.

One of the day unit nurses, Nicola, refers to a 'ticking boxes' approach, which involved seeing the patients 'as numbers' and as tasks to complete over the working day. Like Jenny, Nicola's approach had been abnormalised by her colleagues and, in particular, by a senior member of staff, who claimed that Amy 'looked for problems':

*Natalie*: You do a lot of emotional work, as we've spoke about, do you think that's valued?

*Nicola, nurse, day unit*: Yeah, I do, yeah, from what they put in thank you cards to you and, yeah.

*Natalie*: What about, erm, in terms of your employees and managers, people like that?

*Nicola*: [shakes head] No, I don't think they value it. I don't think they value the emotional work. Like when you like look at how I worked compared to how [senior member of the nursing team] worked, it's just a case of erm, [sighs] ticking boxes, whereas I – I – found it important to know, I mean she once described it as 'I look for problems' and I don't look for problems, I'm just very thorough, erm, and I think the more time you give somebody and the better relationship you've got with them, they're more likely to open up and tell you anything and everything, erm, but no I don't think it's valued that. I don't think they value the emotional work. I think if I worked how [senior member of the nursing team] did, they'd still be quite happy with that, you're just – you are – just a number, definitely.

Nicola states that the senior nurse adopted a 'ticking boxes' approach in which they perceived the patients as 'just a number' or an isolated one of many cases. In this, the patients are abstracted from the 'meanings' (Elias 1985: 54) attached to them as social persons, as meaning cannot be derived from 'an isolated human being' (Elias 1985: 54). Such care is routinised, the same for each individual person, rigidly unchanging between patients. In contrast, the care that Nicola values sees the patient as an individual person, with individual needs, and this inevitably takes more time. This relates to and supports some of the data presented in Chapter Six, where several of the workers criticised medicalised care for reducing patients to mere 'numbers'. Nicola suggests that this depersonalised and detached way of caring for patients is held in

higher regard with the more senior members of staff, who she claims would 'still be quite happy' with that care approach. Her colleagues identified inefficiency as *ineffectiveness*, and she describes how the senior nurse criticised her manner of interacting with and caring for patients. Nicola outlines this 'ticking boxes' approach, as a formulaic method of caring with a 'technique devoid of compassion' (Bradshaw 1994: 141). Featherstone and Northcott (2020: 76-7) argue that on hospital dementia wards, 'organisational mandates' shaped the form of care on the wards, and these often devalued care that incorporates the different needs of individuals, which required 'expertise, flexibility, responsiveness and, often, a slow pace'. Nicola indicates that key figures at the hospice held an 'institutional commitment' to rigid and standardised ways of delivering care, in a time efficient manner, and this institutional commitment shaped the 'cultures' (Featherstone and Northcott 2020: 77) within the hospice space and the everyday practices of workers by dictating their priorities, pace and the day-to-day interactions between the hospice workers and patients.

Nicola also suggests that spending 'more time' with patients helps to develop a 'better relationship' wherein the patients are 'more likely to open up'. However, this involves entering into a relationship with, and forming some attachment to, the patient. This illustrates the challenge that hospice workers face in developing relationships with patients, in fostering an open dialogue, while maintaining detachment for the sake of efficiency. Russ (2005: 141) refers to this as an 'impossible' task, 'to give completely, yet never lose'. The social norms and pressures shared amongst the hospice workers were often embedded in the value of being time efficient, which meant that interactions were often cut short and interactions not as 'open' as they might be. Although the extracts from Mark, Jenny and Nicola, differ in how each of them responds to time pressures, they each reflect on the shared social pressures to manage time and complete tasks efficiently. Relating to a patient as a socialised person conflicted with many of the hospice workers' shared norm of managing and negotiating time constraints through remaining detached from the patients. These shared norms stemmed from the institutional commitments to time-efficiency as effectiveness, which were shared between the workers and impacted on the day-to-day care provided to patients.

## Resources

### *Prioritising the Physical*

There were evident tensions throughout the hospice between ‘the hospice ideal of the good death’ and protecting the hospice’s ‘vested interests’, which stemmed from the hospice management team and were embedded in the workers’ collective norms ‘of cost effectiveness, administrative imperatives, and the routinization of care’ (Hart et al 1998: 70). The scale often tipped in favour of the tasks and general approach to care that protected cost-effectiveness and time-efficiency, as opposed to the care approach that was embedded in ‘emotional work’ and being more ‘thorough’ (Nicola, day unit Nurse) in day-to-day interactions with patients. Although hospice care originally emerged with an ethos of caring for dying patients on a ‘holistic basis’ (Hart et al 1998: 69), the hospice workers’ narratives often illuminated a dissonance between providing compassionate, holistic care and time-efficient, cost-effective care. Where there were shortages of time or other resources, physical and medicalised care were often prioritised, overlooking the need for and importance of emotional care work.

Nicola describes these tensions between economic efficiency and providing holistic care for each patient:

*Natalie:* So, obviously Thursday’s are split into half days, is that a staff shortage or -

*Nicola, nurse, day unit:* It’s a financial saving. The argument was of shutting the Saturdays, then we’d ‘av the same amount of patients. Eighteen patients. Shutting Saturdays are apparently gonna save ‘um £50,000 a year. I don’t know where that money’s gone. Certainly not on wage rises for staff. So, there were sixteen patients there that we needed to fit into the week, so I think that’s how Thursdays came out, cos we had potentially sixteen in morning, sixteen in afternoon. So, I think if the demand continues to rise, then they’ll ‘av to do the same for Mondays and Fridays, which, it’ll be a lot more demanding on the staff. I mean, Thursdays I find really quite exhausting because, well, basically they might as well be the full thirty two people there all of the day, in that you feel you’ve got to, like, emotionally give

everything to the sixteen in the morning, but then an hour later you've got to give it all fresh again haven't you?

Nicola claims that the decision to 'shut' the day unit on Saturdays was a 'financial saving', which, she estimates, will save the hospice '£50,000 a year', freeing up money to save or put towards other aspects of the organisation. However, the decision meant that the sixteen patients who usually attended every Saturday 'needed to fit in' on another day of the week. So, Thursdays in the day unit were divided into two sessions, where one group of sixteen attended in the morning and another in the afternoon. Nicola states that Thursdays are 'exhausting' as she feels the weight of 'emotionally giving everything' to sixteen patients in the morning, and after they depart, she 'gives it all fresh' to the next set of sixteen. The financial savings of the hospice management come at an emotional cost to the hospice workers in a give-and-take exchange which saw Nicola struggling with the demands of seeing two sets of patients over the course of one day.

Nicola states that the 'emotional work' becomes more difficult to carry out with the managerial efforts to contain and manage costs, which placed an emphasis on detachment in order to be more efficient. The work is, at its core, 'self-effacing' (Russ 2005: 141), which often involves a loss of self through *giving* to another. The financial saving further emphasised the difficulty of the task of caring for another person at the end of their life under other social and temporal pressures. The workers were called upon 'to give completely, yet never lose' (Russ 2005: 141), twice over in one day with two sets of different patients, each with their own symptoms, identity and illness trajectory. Nicola also begins to explore the ways in which the managerial and administrative decisions, often made by a board of trustees, failed to match with and preserve her understanding of the hospice ethos, as well as how they neglected the everyday demands of caring for terminally ill patients.

The workers on the day unit were experiencing various different changes, and several of them voiced concerns that the service was shifting towards a more medicalised and physically oriented approach. The day unit Sister, Eileen, had worked in the hospice since it first opened and had experienced this shift in focus. She explained that she was 'frightened' that the hospice was 'losing this holistic thing'. Furthermore, Eileen stated that her job title had changed from the 'day *care* sister' to the 'day *therapy* sister', as the hospice found new means of 'getting commissioned' and 'increasing [their] funding'. This was, she claims, because 'you get more

money for therapies’, such as exercise and relaxation classes, as well as blood transfusions. This supports the view that physical aspects of terminal illness are increasingly prioritised in a bureaucratisation of British hospice care (James and Field 1992; Borgstrom and Walter 2015). Eileen also suggests that the relational, emotional and intimate aspects of the work were becoming overlooked as insignificant by the board, who commissioned and allocated funds to the different services and spaces in the hospice:

*Eileen, Sister, day unit:* The thing is, I – remember – I’ve got nearly 40 years of nursing, there’s that many buzzwords that – but – the word that really is the important word, it’s ‘holistic care’, and it became a buzzword. We go from task-oriented stuff, which is looking at the whole person. We seem to have forgotten that again and we’re going back more to compartmentalising stuff, erm, and giving priority to getting on top of symptoms and what have you... The point is that they won’t ever be feeling fully physically comfortable if their psychological needs aren’t met, but in a – in a – world where finances are finite I – you – you’ve got to deal with – so – things like a day hospice where most of what we do is quite hidden, we cannot tick a box to say ‘I’ve done this, I’ve done that, done the other’, it – it – it is more difficult then to say well, ‘what benefit are people getting?’. It – it – doesn’t tick an actual box and unfortunately it – it – you know, that will always be a problem, I – I – after years of battling that, I’ve come to accept that, that, you know, in the grand scheme of things to offer support in the day hospice will never be seen as essential.

Eileen states that ‘holistic care’ is being ‘forgotten’ about, and the way that care is carried out within Broad Lane, and in particular on the day unit, is shifting towards ‘compartmentalising’ patients in order to place more of a focus on getting their physical symptoms under control. The pressures to be time-efficient have illustrated the ways in which physical care is prioritised by many of the workers, as more certain, easier to ‘control’ (Walter 1994: 145) and manage parts of the patient’s condition. That Eileen refers to an increasing trend of ‘*compartmentalising*’ patients resonates with earlier extracts in this thesis, that illustrate the ‘abstraction’ (Maynard and Turowetz 2019: 91) and deindividualisation of patients. She continues to explain that one of the core principles of hospice care is embedded in seeing the patient as a ‘whole person’, with a multiplicity of needs at the end of life. She explains that a patient ‘won’t ever be feeling fully physically comfortable if their psychological needs aren’t

met' and therefore, the patient needs to be cared for as a '*whole* person'. For Eileen, one cannot be eased and alleviated without attending to the other, and there lies the traditional basis upon which hospice care was originally founded. However, the 'compartmentalisation' of patients, and the focus on getting in control of physical symptoms, emphasises the abstraction of patients to their bodily 'part-processes' (Elias 1985: 54), as opposed to a 'whole', with social, emotional and physical needs. Here, we can see the interplay between everyday practices of care in the day unit and the decisions made by board members about the hospice organisation.

For the day unit staff, this shift towards a medicalised, more physically oriented manner of caring for patients challenged all of the principles that the service was embedded in. Eileen describes their services as quite 'hidden' and unable to align with the 'tick box' approach of attending to routine tasks. The day unit was ultimately a place of unfocused social conversation and interaction. Sometimes there were classes and time was set apart for craft-making. Such activities are not 'easily quantified, measured, or recorded' (Featherstone and Northcott 2020: 76) and Eileen argues they 'will never be seen as essential' despite, in her view, offering great *social* benefits to the patients. The day unit staff explained that the majority of their interactions with the patients were not concerned with their illnesses and symptoms. My fieldnotes also alluded to this. Despite only focusing on the words, actions and gestures of the hospice staff, I was able to detail how they asked and spoke about the patients' hobbies as well as their social lives. Serious conversations were few and far between on the day unit and most took place privately in a corner of the room or in another part in the hospice. For Eileen, her concerns were vested in a potential loss of the identity of the day unit and a threat to its 'total care' approach (James and Field 1992: 1370). The informal chats, jokes shared, and varied activities were not focused on relieving physical symptoms. This made the day unit the service that it was, and it was a place distinct from hospital appointments as well as the hospice ward.

Eileen claims that these changes were due to the way that the hospice is funded and commissioned, by a 'board' of people with a 'finite amount of money', and their concerns were ultimately concentrated towards ensuring the availability of medical equipment and treatments for *physical* 'symptom control':

*Eileen, Sister, day unit:* I think it's because it's the way that services are commissioned now. In that if you're a commissioner sat on a board and you've got a finite amount of money to provide palliative care and you need to provide end-

of-life care in a patients home and make money available for syringe drivers and symptom control, that has got to take priority hasn't it? Hospices like ourselves rely very heavily as well on fundraising so a lot of it depends on what you're able to bring in on top, and I have to say the commissioners in [local area] have always been supportive of day hospice, as our trustees are, but equally they have got – they've got – a bigger picture, and I'm just spouting from my bit of the service, so I – I – you know, but my frustration – my frustrations – are coming from that people are - that make - decisions about our service, that actually have never seen it, you know, they've never been in, they've never seen it.

Eileen suggests that, for the hospice commissioners, the medical equipment used to ease physical symptoms at the end of life 'takes priority' over the interactional and socially focused care provided in the day unit. Such instruments and pieces of medical equipment were tangible, they could be physically implemented, and they offered a quantifiable impact. Eileen, like the hospice commissioners, strives for effective care delivery for her patients. However, this extract illustrates the tensions regarding the desired *effect*. She felt 'frustrated' that the decisions regarding the service and funding allocation stem from persons that have 'never been in' and 'never seen' the day unit. James and Field (1992) note the increase in the auditing of hospices, in order to justify funding from local authorities as well as central government, hence the services are often reviewed, critiqued and assessed by external bodies. They argue that assessing and measuring the core elements of hospice care, such as 'effective communication', 'empathy' and outcomes such as 'feeling' or 'well-being', is immensely difficult (James and Field 1992: 1370). These aspects of care are intangible and focused on alleviating the *social* and emotional features of suffering. Eileen depicts a devaluing of work that cannot be easily measured or 'ticked' off from a list of quantifiable tasks.

The measures used to assess quality often prioritised cost-effectiveness and time-efficiency, as opposed to the development of relationships at the end of life, and besides, 'the productivity of sitting, chatting with patients cannot be measured' (Walter 1994: 98). Striving for cost-effectiveness dictates *what* was considered as effective care, or an effective approach to care delivery, and so other aspects of care were relegated as inefficient aspects of hospice work. The commissioning and institutional organisation of the hospice shaped the workers' everyday practices and delivery of care. Furthermore, these shaped the *culture* of care within the hospice, 'narrowing' and 'directing' towards a focus on the care approaches and forms of work that

were more easily ‘recorded and measured’ (Featherstone and Northcott 2020: 143). The physical symptoms, such as pain, sickness or physical discomfort, were the more manageable and controllable aspects of a patient’s condition, which offered an immediate quantifiable and recordable outcome. Furthermore, attending to patients, as individual persons with individual needs inevitably took *time* and needed to be delivered at a slower pace, with a more flexible approach. Many of the hospice workers emphasised the importance of caring for the patient as an individual person and interacting with them as such. However, organisational demands, rigid regulations and pressures, from managers and their colleagues, often dictated, or at least shaped, their approaches to caring for patients. Bradshaw (1996: 418) notes that the means of ‘auditing [the dying process] as efficiently and effectively as possible’ shape the ‘ends’, as ‘real care’ gives way to the ‘application of ... techniques’. Through Eileen’s account, we can see how the organisational demands were challenged and questioned, and this illuminates the tensions between the organisation of the institution and the hospice workers’ different ideals of care.

### ***The ‘Conveyor Belt’: Beds and Waiting Lists***

Pressures to be quick and time efficient while carrying out care often seemed to stem from external regulations, financial constraints and decisions on the allocation of resources made by the board or trustees and commissioners. These decisions, pressures and ‘organisational mandates’ (Featherstone and Northcott 2020: 76) were felt by the staff and often seeped into their shared norms to shape the delivery of care. The workers across Broad Lane and those working in the community organised and negotiated their day-to-day work either in line with these time, financial and resource constraints, or by challenging the shared ideals of time efficiency and cost-effectiveness. The workers that challenged the ideals of being time efficient and cost effective were challenging the prioritisation of care, which gave precedence to the physical aspects of dying and took less time than in-depth social interactions and engagements with patients. In this, there was a balancing act between being efficient, yet also compassionate, spending time, but not too much, so that there would be enough time to see other patients or complete other tasks. The workers negotiated both the internal and external regulations in doing their work.

In the following extract, Chris recalls coming together with some of his colleagues to talk about a patient's recent death on the in-patient unit. It had previously been a tradition in the hospice wards to keep a bed empty for twenty-four hours after a patient's death. However, with rising patient numbers and a growing waiting list, the tradition had been phased out. For the nurses and support staff on the wards, this meant they were caring for a new patient soon after another patient's death, which had often happened in the same bed. Chris explains the difference in how he perceives a patient's empty bed, as a space for a new patient, and how the nurses felt 'upset' that he made it available so soon after a death:

*Chris, specialty doctor:* ... Everybody that was involved in her care, we got together and had an hour, tea and coffee, some biscuits and we all talked through how we felt, about how we'd, y'know, how we'd looked after, people talked through how they felt after she'd died. A bit of like, I hadn't realised the nurses were really upset that we'd admitted somebody the next day and until we had that sort of session talking and reflecting on her care, erm... cos from my perspective cos I see a waiting list of patients that need to come in and I see an empty bed, I think 'great, I can get somebody else in', but I hadn't realised the nurses at times can find that almost a bit disrespectful, that that bed was, in their eyes, is still warm and we're already putting somebody else in it, erm, so that helped me to understand how they feel, sort of.

*N:* Is that hard to manage for you, if you've got a waiting list?

*C:* Oh, it is, so you're torn aren't you, cos you want to also look after the staff but at the same time I know there's patients that need to come in and need that care.

The patient Chris refers to had been in the hospice ward for several months, and so many of the nurses had got to know and developed a relationship with them. Chris describes thinking 'great, I can get somebody in' the empty room and the empty bed. However, he failed to recognise the strong emotional attachments of the nurses to the patients. Furthermore, he neglected their need for a period of grieving and mourning. While the nurses see the deceased patient's bed as 'still warm', Chris sees the chance to cut the waiting list by one. The practice of leaving a bed empty is common within hospices, often as a signifier of respect and remembrance in honour of a deceased patient (James and Field 1992; Osterlind et al 2011). A candle was also lit on the wards for twenty-four hours after a death, which often brought about a more sombre atmosphere. Such ritualistic, collective actions 'recognise [the dead patient's]

place in the hospice' (James and Field 1992: 1371) as still socially present and not yet forgotten. These practices recognised, memorialised and symbolised the recently dead.

The hospice consultant, Faye, spoke about the same tradition and a similar situation. She further illustrates the disconnect between the hospice doctors and the other workers, such as the nurses and housekeeping staff, in their prioritisation of waiting lists and occupying empty beds, versus the need for time to grieve and reflect.

*N:* Yeah, so you don't do that [leave a bed empty after a death] anymore?

*Faye, Consultant:* No. And so, I think the nurses, some of the nurses, really struggled with that and very interestingly some of the cleaners said, cos obviously they go in and when the body's gone, they have to give the room a spruce up for the next person and one of them said she felt like she was 'washing them away', you know and... it felt, she felt it was quite disrespectful that it was almost like that, 'wash them away, clean them out and the next one comes in' and you kind of thought, I didn't even really think that. So, it's been very useful for me to listen to other people's point of views, but when you explained to her and said 'well we do it because of this' she was absolutely fine, but she just thought, 'oh they don't even have time to think' - cos she'd been here since it opened - to give that respect to somebody.

*N:* Yeah, and you've got that pressure of patients needing to come in?

*F:* Yeah. She didn't know that, she just thought we were treating it like a conveyor belt sort of thing. So, I think sometimes you don't realise the effect it has on everybody else, do you?

Both Chris and Faye initially struggled to appreciate the significance of these ritualised actions for the nursing and cleaning staff, who understand their lack of hesitation to fill the newly empty beds as 'disrespectful', because it signifies a disregarding of the previous patient. Walter (1994: 179) argues that rituals after a death, such as hymns and recitals at funerals, enable the shared expression of emotions which are usually kept 'repressed in everyday life'. Such practices allow for the expression of sadness, grief and mourning, for a while in the public sphere, making death and grief more manageable for those involved (Walter 1994).

On a symbolic note, the rituals in the hospice, such as lighting a candle and keeping a bed empty for twenty-four hours, signify the recent death of a patient in the hospice. The patients could be memorialised through these symbolic expressions of loss in the hospice. A lit candle and the empty beds signify a reconstitution of the person as still socially present and remembered in the hospice, thus reconstructing the meaning formerly assigned to the physically alive patient. Without these ritualistic practices, Faye suggests that the hospice becomes 'like a conveyor belt', of terminally ill patients entering the hospice and leaving for the mortuary. Thinking of the hospice as 'like a conveyor belt' signifies the abstraction of patients, rendering them superfluous, treated en masse and prepared for their fateful deaths by the hospice workers as well as the systems and processes in place to support this. Discontinuing these traditions helped to shorten the waiting lists. However, by not memorialising the patient, the workers felt that they were not able to grieve or emotionally process their death. Through the lack of memorialisation, the patient began to signify '*nothing*' after their death (Baudrillard 1993: 201). Through the 'washing away' of the signs of their social presence, they became 'asocial' (Baudrillard 1993: 201) and social exchange with the deceased ended. Their recent presence is forgotten, as their bed is cleaned, any previous signs of them are 'washed away' and the room prepared for the next patient. The previous chapters have reflected on the influence of the hospice workers in preserving the *social* individual through their actions and interactions with colleagues, the patients and their loved ones. However, we can see here how the financial pressures and demands on resources impacted on the day-to-day delivery of care and the enactment of socially symbolic rituals and rites. Faye describes how the cleaning staff felt that filling a newly empty bed failed to 'give that respect' to the deceased patient. This group participated in the 'washing' of beds and cleaning of rooms, and so they felt the transition of moving from one patient to the next. The pressures of lengthy waiting lists and a lack of facilities filtered through into the small routines, rituals and the everyday practices of the staff, as the social presence of the deceased was 'cleaned away' in order to make space for a new patient.

During my fieldwork, the hospice began holding 'Schwartz Rounds' on a monthly basis. Each Schwartz Round had a theme, where the workers discussed a certain emotional or social aspect of their work. The 'Rounds' were opportunities for all of the hospice staff, working in any paid position, to meet together, offload and talk through their emotional experiences of working in the hospice. I was able to attend one of the Schwartz Rounds, where the workers were asked to think about their memories of a 'challenging day' at work. The conversation during the

meeting turned to the tradition of leaving beds empty after a patient had died. One of the senior nurses commented that ‘we have a patient die, then the next day – or the same day – the bed is full again’, she continued to say how the nurses would have little ‘time to reflect’ on the patient’s death and would have to ‘switch from being sad to being there for a new admission, so fast’. The nurses and the cleaning staff both emphasised the need for time to process emotions and reflect on a recent death in a hospice. This illustrates the difficulty of undertaking emotional work and dealing with grief on a day-to-day basis in hospice work (Borgstrom and Walter 2015; Funk et al 2017). This is made more difficult by the shortening of time between a patient’s death and the admission of a new patient in the same bed. Most notably, these extracts highlight the conflicts between demands to occupy beds and cut lengthy patient waiting lists, and the hospice workers’ experiences of negotiating emotions and grieving a patient’s death. Similar tensions arise between being time efficient, cost-effective and providing intimate care by remembering the loss of a person after their death.

## **Regulations**

### ***Regulating Death***

Thus far, I have explored the social norms of time efficiency and cost effectiveness that were shared as well as challenged by the hospice workers. These norms were often dictated by senior members of staff and the ‘board’ and were shared between the hospice workers, reinforced through nicknames and direct criticism of fellow colleagues. Dying was seen by the workers as a personal ‘journey’ shared by the patients and their families. However, dying was also regulated by internal and external rules as well as more subtly by certain social norms, meaning that there was a more *ideal* way to die. Walter (1994: 90) argues that ‘on the one hand’ hospices are vested in ‘letting patients live as they wish until they die’, but on the other hand, they share an ideal of the ‘*good death*’, which is peaceful and where all involved are accepting of the inevitable outcome. Many of the workers described feeling threatened by certain rules and regulations, which sometimes hindered and challenged their shared ideal of a ‘nice death’ within the hospice. Faye, one of the hospice consultants, stated that there are certain ‘injustices’ that patients face at the end of life, which also challenge her ability to support the patients in what she thinks is a better way to die. As McNamara (2003: 99) found in her study of palliative care, ‘the autonomy of the patient is part of a rhetoric that is not always realised’:

N: Yeah, yeah, you mentioned the sort of ‘injustices’, what do you mean by that exactly?

Faye, Consultant: Yeah, cos things like, you know, you can’t have this at home, you can’t have this bed that you need so, or you have to do – you have to do – you can’t go home because there’s no equipment or – they’re not sort of major issues – but things that just really don’t need to be like they are, and then there’s a lot of things that, very rightly, are set up to make sure people don’t die, like sepsis is a big thing at the moment, so erm, and there’s really hoo-hoo, like, issues about trying to pick up sepsis sooner. Well, most of the patients on this ward will have symptoms of sepsis but they don’t need you to rush around and – and – it’s trying to stop people, erm, doing things to people that don’t need them doing.

Patient autonomy over their circumstances of death, as well as where they wished to die, was limited by the rules and regulations imposed on both the patients and the workers. Death is inescapable. However, Faye suggests that the manner in which the event occurred was constrained by the measures in place, such as having certain equipment, a hospital bed in place or treating infections that often naturally occur at the end of life. Autonomy, and the promise of it within palliative care, clashes with the ‘biomedical, organisational and moral culture’ of the institution (McNamara 2003: 106). The experience of death is, again, shown to be managed and regulated in an orderly manner. Furthermore, the creeping in of medicalised approaches to caring for dying patients is evident here, wherein Faye seems to question whether the hospice ideals are being threatened by attempts to establish greater control over the dying process. These difficulties, or as Faye calls them, ‘*injustices*’, are embedded in her standards and ideals ascribed to the dying experience. The language of medicine clashes with the aims and ethos of hospice care, which is grounded in ‘an ethic of genuine and dedicated compassion’ (Bradshaw 1996: 418), and a focus on quality of life at the end of life.

The language of medicine measures hospice care on physical aspects of care, as opposed to the alleviation of social suffering. Faye questions how ‘success’ can be measured against ‘something that’s deteriorating’, as death always occurs with some deterioration of the physical and/or mental form. As Bauman (1992: 12) states, ‘there is hardly a thought more offensive than that of death ... death is the ultimate defeat of reason’. Death is understood as a deterioration of the physical form, as a loss, and an ill-fate to be avoided. Faye’s attribution of deterioration to the physical state of death shows this more general understanding of death. She

explains that the measures to gauge success instead look at ‘where people die’, which, as I have already noted, is not always matched to the dying patient’s wishes:

*Faye, Consultant:* ... and I also think, it, there really isn’t – there’s such a lack of recognition of how this work is – is – important really, in kind of, because it’s a quality and it’s not sort of something you can measure, like when you do operations, you’re judged on how successful you are, they kind of league table people, but you can’t put this, cos whatever you do people get worse. So, when you do end up trying to measure success you end up being so – cos it’s – cos you’re trying to measure success against something that’s deteriorating, so it’s quite hard to distinguish what is improvement. Then you end up – you end up – hassling patients that much about ‘do you think, is there a little bit -’ you know - it ends up - you feel too intrusive. So, it’s very hard to kind of - how do we tell people that we’re doing a good job, and this is what people want, when everyone gets worse and dies? So, the measure is things like where people die, isn’t it? Rather than how they die.

If we lack a ‘language’ to talk about death adequately (Bauman 1992: 130), then the way that death and dying are ‘measured’ as ‘success[ful]’ (Faye, Consultant) are also inadequate. The medicalised manner of ‘measuring’, that, Faye argues, concerns itself with the ‘success’ of ‘operations’, focuses on physical interventions and largely conflicts with the ethos of hospice care. The language of auditing the hospice and measuring quality on immeasurable parts of *social* life fails to make sense of or account for ‘the experiences and feelings of the individual and his or her friends and family’ (Walter 1994: 23-24). Walter (1994: 24) speaks in reference to the broader Western language on death, in which he argues society ‘does not know what to say’ in regard to death and dying ‘or how to say it’. In the context of the hospice, the external bureaucratic processes to measure and check for quality of care fail to align with the practices and goals of the workers at Broad Lane. The audits and measures of quality were seemingly embedded in the ill-aligned ‘language of survival’, which observes death as the cessation of all ‘meaning’ that should be avoided at all costs and managed by the undertaking of certain practical actions to extend life (Bauman 1992: 130). Hospice care does not concern itself, primarily in any case, with extending or prolonging life. Instead, the work of the hospice staff focused on maintaining quality of life during the dying process. The ‘league table’ is concerned more, as Faye says, with ‘where people die’, as opposed to ‘how they die’, as, after all, death

is the only certain fact of life. The bureaucratized and medicalized language currently used to assess for 'quality' fails to align with the hospice's practices, which were not embedded in 'survival' (Bauman 1992: 1301).

### *A 'nice' death*

Throughout this thesis, I have explored how the hospice workers constructed certain notions of the 'normal' dying process, and how they managed the sensorial organisation of the hospice to reconstruct death as a peaceful affair. The hospice staff often managed death in a way that ensured it transpired peacefully and appeared unimposing within the hospice space to visitors and other patients. They also grappled with the priorities of senior clinical staff, funding bodies and broader institutional regimes. These ideals often conflicted and collided, with the hospice workers struggling against certain rules and regulations that did not align with their shared notion of a 'nice' (Kirsty, ward nurse) death. Western societies are 'bereft of a communally acknowledged model of a good death' (Mellor and Shilling 1993: 423). Kellehear (1990) locates 'good death' within the social lives of the dying and notes that it can broadly be defined around these key features: an awareness, a preparation for death, the resignation of roles and the time for farewells. Thus, unexpected deaths or deaths wherein concerned persons are not accepting of that which is to come are considered as the antithesis, as 'bad' deaths. The hierarchical ordering of deaths in Broad Lane was constructed around sensory aspects, such as uncontained bodily matter, noise and the extent of uncontrolled suffering. In addition, they were also constructed around regulations and rules, which sometimes threatened the notion of a 'nice' death (Kirsty, Staff Nurse). As well as external regulations, the expectations of loved ones challenged the workers in their role in supporting the patients towards a more favourable death. In the following extract, Kirsty states that certain medical treatments are 'pushed' by the relatives of dying patients and explains that there has been a shift towards a more medicalised approach in the hospice:

*Natalie:* So, how is working in a hospital different from working in the hospice, like, are there any differences in terms of treatments?

*Kirsty, staff nurse, in-patient unit:* There can be differences. See, relatives here still can want to push. Erm... some of the things I find frustrating is [sighs], when to let go. Medicine has come so far in what we can do and what we can't do, but

sometimes there is very much, erm, a time not to do this and patients' relatives push sometimes to be very proactive and even in the hospice they push to be very proactive, when maybe, it's not quality time. That, I find very frustrating. You know, it robs people of quality time with their families.

*N:* So, is it more the relatives?

*K:* More than patients, yes and sometimes, generally in hospices now we do more than we used to, erm, and there's a fine line between why we're doing it, you know there really is a fine line between why we're doing it, you know, but you'll have patients come, for instances when somebody's got a PEG tube -

This extract suggests that patients are part of a multiplicity of 'entangled relationships' (Borgstrom 2015: 708) at the end of life, and decisions are often made by those around them. The 'non-compliance' (McNamara et al 1995: 231) and demands from the patients' relatives for the workers to be more 'proactive' in caring for the patient challenged Kirsty's ideals of the dying process. In this, Kirsty alludes to her own idealised 'nice' way to die, as well as an ideal time 'to let go' and accept the impending fate of death. Here, the relatives are evidently reluctant to accept the death of their loved one, and so Kirsty assumes this to be 'frustrating' and ultimately a death that is bereft of 'quality'. Her frustration stems from the relatives' lack of 'internalisation of [the] hospice philosophies' (McNamara et al 1995: 238), such as acceptance and compliance, which suggests that choice and autonomy challenge the workers' ability to exert control, manage and order the dying process in a way that they consider as ideal.

Kirsty's argument against extending certain treatments, such as feeding tubes, concerns depriving the patient and their loved ones of important 'quality time' at the end of life, by extending life beyond that which might naturally occur. In this, physical life is extended into artificiality. However, Kirsty explains that the patient's social death occurs, as the relationships between the patient and their loved ones are not of 'quality'. In Kirsty's example, the extent to which death can be managed and controlled by the workers, to provide that which is considered to be an ideal dying process, is limited by the autonomy of the patients and their relatives. She found herself relinquishing control, and ultimately abandoning imposing upon the relatives and patients her normalised ideal of dying, to facilitate patient autonomy. Kirsty explains that in hospices 'we do more than we used to', straddling a 'fine line' between extending life and supporting a *quality* of life. This seems to be a wider trend within British hospices and palliative care, which are said to be less 'effective ... at breaking the 'informal' rules of care', and

increasingly 'more bureaucratic and rule bound' (James and Field 1992: 1369). As well as struggling against the frustrations of 'proactive' relatives and patients, Kirsty feels the challenges to the hospice ethos from the formal policies and regulations, or lack thereof, regarding dying patients:

*Natalie:* What is a PEG tube?

*Kirsty:* When food goes in and they're fed in the stomach, through a bag. There is no policy in [local area] as to when you withdraw feeding. So, if somebody is dying you are still pumping liquids into their body, the body is shutting down, erm, and the fluids got to go somewhere, it can go on their lungs, around their heart, they can swell up. It can make the death quite unpleasant but there's no policy as to when you stop doing that.

*N:* So that's quite difficult for you?

*K:* Yes, because it's – it – the patient doesn't always have a nice death and the relatives also don't see a nice, natural death because dying is a natural part of living, and in this day and age death has become, for want of a better word, sensationalised.

The key issue that Kirsty takes is with prolonging death beyond the point of a natural death, with the presence of the feeding tube sustaining an artificial dying process, which becomes 'unpleasant' as it usually involves the excretion of fluids and visible physical swelling. The unpleasantness expands beyond the individual patient and to their relatives or loved ones, who fail to experience with them 'a nice, natural death'. The data has previously alluded to how the workers disguised uncontained deaths, with certain practices and rituals enacted posthumously, or just before death. Kirsty emphasises how a 'natural', contained death is the ideal 'nice' death. In Chapter Six, I explored how Amy cleaned a patient just before they died so that their family 'didn't have to see him like that', in a soiled and messy state. Here, Kirsty illustrates how intervening in the natural processes of death can bring about an unpleasant and messy state. Thus, the ideal death was embedded in notions of containment, peacefulness and predictability.

Rather than contradicting the previous data, this extract further highlights how control and certainty are key to the workers' roles in Broad Lane. It is not so much a denial of death that this data speaks to, and that the workers' actions were embedded in, but a 'denial of a 'bad'

death' (Bradbury 2000: 62). A 'nice' death is understood by Kirsty as a peaceful, well-managed death, and a 'bad' death' is disguised and denied, as opposed to the event of death itself. Thus, the shared ideal of what makes a 'nice' death is intertwined with notions of peacefulness as well as an uncomplicated and routine sequence of events. The presence of a feeding tube potentially provokes a prolonged, unpredictable and restless death, which could cause messy physical seepages, bodily deterioration and unwanted noise, for the patient as well as their loved ones and the hospice workers experiencing it second-hand.

The experience of dying is relational, shared and experienced between persons. Understanding death as a 'nice' process is dependent upon 'not only the needs of the dying but also those of the survivors and of the broader social orders as well' (Kearl 1996: 345). Walter (1996: 204) argues that individual choice and autonomy is possible in the dying experience. However, 'we also die as we live, as *social beings*' (Walter 1996: 204, emphasis added). Our choices are shaped, negotiated and legitimated by those present during the dying process, and subsequently our deaths are 'constructed together with others' (Walter 1994: 189). Kirsty describes deaths where the patient is fitted with a PEG tube and observes these deaths as unpleasant for the dying patient and the loved ones witnessing the physical signs of death. She struggles with these artificially sustained deaths, which cause unpleasantness for the patient and their loved ones, as well as unpredictability for herself, as her work focuses on 'serving not only the needs of the dying', but also the dying person's loved ones and 'the broader social orders as well' (Kearl 1996: 345). The presence of the PEG tube at the point of natural death threatens the hospice workers' shared ideal of the natural, normalised death, wherein the patient 'passes away from this world quietly, with dignity and without pain' (Costello and Horne 2003: 160). In addition to this, passing away with a PEG tube inserted is described by Kirsty as a messy, unpleasant death, with the presence of bodily excretions, demonstrating the shared ideal of an orderly, routine as well as *bounded* death.

Kirsty continues to challenge the medicalisation of hospice care, as treatments to prolong life past the point of natural death fail to sustain any 'quality' of life:

*Kirsty:* ... the medical profession goes and in some cases it's the right decision because they've got to make the decisions on a quick basis in casualty. I can understand that, but I was nursing a bloke who had erm, end stage Lewy bodies dementia, he was younger than me, erm, he had progressed to the point where he

could no longer eat properly or drink properly, erm, his wife just said, look, let nature take its course, but, erm, the specialist dietician decided that they wanted to put a PEG in. Why? Because his brain was stopping functioning, we had to have a big MDT meeting cos she wanted to put a PEG in. Why? What was the point?

*N:* Is that something that frustrated you?

*K:* Yeah, it did. I had the support of the family, the GP and the PEG dietician and it wasn't put in, but things like that are very frustrating because nature has its own way of dealing with things and why prolong a life for no reason whatsoever?

I previously explored how artificiality seeps into the rituals and rites of passage to delay a social death at the end of biological life. Here, sustaining life through unnatural, artificial and medical means is seen to *create* a messy, unpredictable death. Therefore, *'unpleasant'* deaths, with physical seepages, swelling and amplified uncertainty, are the proper antithesis of a *'nice'* death. Control, order and containment were some of the key principles in the work of the hospice staff to achieve a *'nice'* death. Within the hospice, these ideals of death and dying were shared amongst the workers, and these ideals impacted their care approach as well as their relationships with the patients. This meant that they often *'prescribed and normalised'* certain *'behaviours and choices'* (Hart et al 1998: 72). Kirsty abnormalises the decision to give the patient an artificial feeding tube, stating that this would result in an *'unpleasant'* death. This example illustrates the interactive and interpersonal nature of death and dying. The dying journey is understood as *'nice'* through the understanding and feelings of the dying persons' loved ones, the workers and the experiences of the dying patient. The meaning assigned to death was shaped by this plurality of people, as Kirsty battled with the wishes of the *'specialist dietician'*, which seemed to conflict with her ideal of a *'nice'* and *'pleasant'* death.

The hospice workers' socially shared and normalised ideals of dying are challenged not only by the patients and their relatives, but also through the creeping in of bureaucratised and more heavily regulated, medical approaches to care. Prolonging a life past the point of *'quality'* means that the person remains biologically alive without having a *'reason'*, as understood by Kirsty, to be so. Remaining alive, but socially dead, as *'essentially a corpse, though perhaps still 'clinically' and 'biologically' alive'* (Sudnow 1967: 74), is understood by the workers as worse than being physically dead. Timmermans (1998: 466), in his study of resuscitation efforts, argues that staff only attempt to sustain physical life when *'a sense of personhood remains'*; if not, their efforts become an *'empty ritual'*. Kirsty emphasises this by questioning

'*why prolong a life?*' past the point of reasoning, which seems to occur once the patient is no longer a socially meaningful person.

## **Conclusions**

This chapter explores the construction of certain normative ideals, which shaped the way that the hospice workers cared for patients before and after death. Many of the workers negotiated, and often struggled with, norms of time efficiency and cost-effectiveness in caring for the patients. They faced a conflict between providing holistic, intimate care and being efficient with their time and the other hospice resources. Consequently, there was often a 'prioritisation' of physical care (McNamara et al 1994; McNamara 2004). The hospice workers often navigated their limited time by focusing on the simpler tasks, which usually involved treating the patients' physical ailments and bodily issues. However, many of the workers acknowledged the need to spend time with patients, to provide care that engaged with the *whole* person. Therefore, ideals of effectiveness differed between the hospice workers as well as between the managerial team and the hospice staff. Many of the workers interpreted effective care as developing emotionally intimate relationships with the patients, which inevitably involved a slower pace and more time to talk with them about the non-physical aspects of their condition. From the 'tick-box' approach described by Nicola, to the consultants cutting waiting lists and filling newly empty beds, this chapter has illustrated the differing priorities of senior clinical staff in comparison to the nurses, support workers and housekeeping staff. Echoing the findings of Featherstone and Northcott (2020: 76) in their ethnography of British hospital wards, this chapter highlights how 'organisational mandates' shaped the everyday work of the hospice staff. The decisions of the board of trustees, who worked with a '*finite*' amount of money (Eileen, day unit Sister), often seemed to devalue and deprioritise work that 'could not be easily quantified, measured, or recorded' (Featherstone and Northcott 2020: 76). Many of the intimate, in-depth interactions that the hospice workers shared with patients, such as those in Chapter Six, were often seen by their colleagues and senior staff as unproductive and unnecessary moments of social interaction, or '*faff*'. Therefore, the workers often struggled against the seeping in of medical, routine and bureaucratised practices, which, again, 'abstracted' (Foucault 1975; Maynard and Turowetz 2019) the patients from their social contexts and, ultimately, their *social* suffering.

While struggling with an organisational culture of time efficiency *as effectiveness* in the hospice, the workers also grappled with their shared ideals of providing a '*nice*' death for their patients. In Section 3, one of the hospice Consultants, Faye, speaks of the 'injustices' that she believed prevented the patients from having a peaceful, natural death, which is un-chaotic and not restricted by certain regulations and rules. However, this is Faye's understanding and construction of a '*nice*' death. She points to medically imposed regulations that dictate where and how people die, while her colleague, Kirsty, emphasises the artificial deferral of physical death through forced feeding. These issues emphasise the way in which the 'language' of death, embedded in 'survival' (Bauman 1992: 1301), seeps into the hospice and fails to align with the shared ideals of dying a peaceful, natural death. However, while emphasising the externally imposed regulations and rules, the hospice workers also reiterate their own shared normative ideals of just *what* constitutes a *nice* death. Within Broad Lane, the hospice workers influenced the experiences and processes of death, as it transpired as a relational experience. Death was considered 'good' or '*nice*' when it 'served not only the needs of the dying but also those of the survivors and of the broader social orders as well' (Kearl 1996: 345). They shared a notion and a norm of death, which influenced how they provided care and interacted with patients and their relatives. They shaped death in a way that it 'served' the social order of the hospice, the needs of the relatives and their own shared ideals. This chapter also draws out the conflicts which have emerged throughout the thesis between the 'rational bureaucracy which has helped to tame death' and the 'individualism of the modern era' (Walter 1994: 23). The hospice workers' interests were vested both in cost effectiveness and time efficiency and in sustaining the patients' own sense of autonomy and choice at the end of life: a difficult task, which they negotiated each day in their work. This chapter draws together some of the core issues that I have grappled with throughout this thesis, by illustrating how the workers' approaches to care were often shaped by normative ideals, resource and financial constraints as well as organisational mandates and regulations.

## CHAPTER EIGHT

### Conclusions

#### Introduction

This thesis sought to explore suffering through the day-to-day experiences of hospice workers. I adopted an ethnographic approach to appreciate how the workers react to and engage with suffering, as well as the forms of interactions and relationships that they develop with colleagues and patients. The research examined the *hospice workers'* experiences of their interactions and relationships with patients, and in the fieldnotes I described only the workers' actions, words and gestures in their two-sided exchanges with patients<sup>18</sup>. This enabled a detailed insight to their work and informs the existing sociological literature on suffering by offering this alternative perspective. Much of the existing research on suffering depicts the experience as one that strips individuals of a sense of self or personhood, which is developed through relationships with others and roles in social life (Charmaz 1983; Cassell 1991, 2004; Wilkinson and Kleinman 2016). Furthermore, the literature highlights the social and cultural embeddedness of suffering, which is broadly defined as 'a product of cultural worldviews and social conventions' embedded in 'historical and material circumstance' (Wilkinson and Kleinman 2016: 17). This research sought to illustrate how hospice workers interact with patients in the context of suffering and I carried out observations in a hospice setting to appreciate the workers' routines, their everyday practices, their shared norms and organisational cultures. Much of the existing literature and previous empirical research tends to neglect the relationships that *emerge through* suffering, and the existing work often depicts suffering as a 'loss' (Frank 2001: 355). Therefore, this study sought to understand how the hospice workers navigate these relationships that exist in the context of suffering. This research tells us of the relationships that hospice workers develop with patients and how they engage and interact with them in moments of intense suffering and pain. As I conclude this thesis, I draw together the findings, which illuminate how hospice workers engage, relate to and interact with suffering as a relational, sensory and embodied experience. The hospice workers at Broad Lane played an important role in shaping the patients' end of life experiences and, in turn, they were often *shaped by* experiencing and witnessing suffering in their work.

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<sup>18</sup> I have reflected in-depth on this approach in Chapter Three.

In this conclusion, I will reflect on the use of an ethnographic approach to conduct the research, drawing on my experiences in the field to illustrate the emotional, embodied and ethically complex experiences of researching at Broad Lane hospice. In these reflections, I will also expand on the methodological contributions from this research, which speak to the emerging literature on conducting sensitive research and the emotionality of doing death research. Next, I draw together the key threads which are woven throughout each of the four findings chapters. These are explored under three themes – the sensory, the ‘normal’ and the social self. However, these themes are explored under a common thread, which emphasises how suffering unfolds in relation to other people. The workers shaped the sensorial, physical and social organisation of Broad Lane hospice, through their actions, rituals, norms and rites. By adopting a focus on hospice workers, this thesis provides an insight into how these groups navigate, experience and influence the suffering of hospice patients. I will also outline the limitations of the research and highlight potential areas for future research. One of the significant emergent findings from the research is the hidden work of those in auxiliary roles: working in the kitchen, cleaning staff and health care support workers. These groups tend to practice sensory forms of care by preparing and serving food, bathing patients and cleaning their rooms. They were often physically intimate with patients in between the core tasks of their roles. The work of these groups of hospice staff, who also tend to be hidden within the academic literature, deserves further, focused research. Finally, I draw the thesis to a close with concluding thoughts and contributions.

### **Doing Ethnographic Research at Broad Lane Hospice: Methodological Contributions**

Doing ethnographic research in the field places us at the heart of ‘the dense complexity of everyday social life’ (Atkinson 1992: 5). By adopting this approach in a hospice setting, I listened to, observed and experienced everyday life as it unfolded for the staff at Broad Lane. I was able to ‘go-along’ (Reed and Ellis 2019: 232) with the hospice workers at times. I went along as the nurses administered medicines to patients on the wards, the doctors went about their ward rounds, and I joined the housekeepers as they gently touched patients and adjusted their blankets in between mopping the floors. On the day unit, I was directly immersed in day-to-day life and found myself engaging in board games, exercise classes and helping to make crafts. Going along and being with the hospice staff as they were working provided an insight into the moments of physical intimacy that are often hidden behind walls and doors (Lawler

1991; Twigg 2006). Furthermore, it was during these moments that I was able to recognise the importance of focusing on the sensory in the hospice space. This was not my intention before entering the field. However, appreciating the sensory enabled me to grasp the different forms of interaction, the alternative sensory forms of care and the work involved in managing the smell, sounds and appearance of the physical space. Furthermore, researching the sensitive and potentially emotional topic of suffering presents unique methodological challenges, such as the difficulty of directly asking about the experience, which often defied verbal articulation. Utilising the sensory enabled me to appreciate the unspoken and notice the hospice workers' subtle gestures, physical movements and actions.

By appreciating the sensory, I was able to pay particular attention to the hospice workers' actions in the 'background' and their interactional practices that were 'half muted' (Back 2007: 80). Researching suffering is described as a challenging task, as the experience is difficult to articulate, describe and understand (Kleinman 1991, 1999; Frank 2001; Wilkinson 2004). This research demonstrates the importance of appreciating the 'democracy of the senses' (Back 2007: 8) in order to illuminate the subtle meanings of silence and physical touch as alternative forms of interaction, reaction and exchange. The difficulties of describing, verbally reacting to and engaging with suffering give way to these forms of interaction, which can be better explored through a methodological approach that utilises *all* of the senses. This approach appreciated the unsaid, the material and the intangible and, more broadly, the aspects of working life that the workers may not 'notice or easily put into words' (Crang and Cook 2007: 77). Therefore, this thesis offers a contribution to our understanding of how to approach and study suffering methodologically. Furthermore, the research explored the day-to-day experiences of a range of hospice workers, including the housekeepers, healthcare support workers and cooks at Broad Lane. This captured the roles and routines of those workers that are usually 'half muted' (Back 2007: 80) in the existing academic research on health care and hospice work. This thesis offers insights to the importance of engaging with the sensory to understand the everyday social life of a setting and in this context, to capture a sense of the experiences of the workers within the hospice.

I have also reflected in this thesis on how *I* navigated the hospice, negotiated and sustained relationships during my time there and encountered moments of ethical uncertainty. I describe how I managed my actions, emotional feelings, interactions and movements to ensure the success of the research and the well being of the participants. I detail how I often scribbled

fieldnotes in hidden spaces, transforming a bathroom sink to a makeshift desk to write down my notes, reflections and ideas. My reflections offer a contribution to the emerging dialogue on the ‘methodological implications’ (Borgstrom and Ellis 2017: 1010) of doing sensitive research and the emotionality of doing such research. ‘Researchers often filter *themselves* out of the research’ (Visser 2017: 11), and this thesis attempts to demonstrate the importance of reflexivity throughout the ethnographic research process by highlighting the challenges and complexities of utilising the method in practice. Chapter Three illustrates the embodied, emotional and relational aspects doing this research and ‘takes ‘the emotional’ out of the margins’ (Visser 2017: 6). Beyond these methodological contributions, the thesis offers contributions to our theoretical and substantive understanding of suffering. I will now turn to the key themes from the research findings.

### **Suffering in Relation**

In the beginnings of this thesis, I referred to the existing literature on suffering, which largely depicts a socially and culturally embedded phenomenon (Cassell 1991, 2004; Wilkinson 2005; Wilkinson and Kleinman 2016). Suffering is often characterised as a loss of, or a threat to, a sense of personhood (Charmaz 1983; Cassell 1991; Frank 2001). I discussed these contributions while highlighting our current lack of sociological understanding about how suffering is experienced by those working with and bearing witness to suffering every day in their work. In particular, I sought to understand how the staff at Broad Lane hospice engage with suffering in their work. The thesis engages with suffering as relational, sensory and embodied, through the perspectives and day-to-day experiences of hospice workers. The workers’ shared norms, which were embedded in the imbalances of power between them and the patients, shaped the sensorial organisation of the hospice space and the social constructions of ‘normal’ in the setting. With this focus on the sensory and the subtleties of hospice social life, the research captured the significance of silence and physical touch as forms of interaction and socially oriented *actions*. There was thoughtful consideration in these moments of inactivity and silence, wherein the workers considered the most appropriate forms of action and *inaction*. This illustrates the difficulties in articulating and reacting to suffering with verbal words, which various sociologists have considered previously (Das 1997; Morris 1997; Frank 2001). However, the findings elicit how the hospice workers utilised the senses to overcome this verbal inexpressibility of suffering. Furthermore, the workers’ management and handling

of the patients' sensory and embodied aspects of illness could either sustain or threaten the patients' sense of socially embedded personhood and identity at the end of life.

In particular, the hospice workers' power over sustaining *social* life can be seen in the way in which they handled the moments leading up to and after biological death. '*Laying the patients to rest*', a process referred to in Chapter Six by one of the health care support workers, illustrates the preservation of social life posthumously. Sustaining bodily boundaries delayed a *social death* (Glaser and Strauss 1965; Sudnow 1967; Lawton 1998, 2000). This thesis details the role that the hospice workers play in potentially sustaining the patients' personhood through their interactions and engagements with the person *and* their physical body. Their roles in providing palliative and hospice care are embedded in helping patients to 'live until they die' (Saunders 1976: 1003), and this research illuminates how they enabled *social* life up to and, importantly, *after* physical death. Social death can be seen here as delayed through the routine actions, social interactions and ritualistic practices of the hospice staff. This everyday work took place within a broader institutional and organisational culture. The hospice workers often struggled with decisions beyond their immediate control that prioritised the treatment of physical pain and symptoms. The acts of care that could sustain the patients' personhood, choice and identity at the end of life were often seen as the most time-consuming and inefficient tasks. These tasks were often simple and included preparing food in a certain way, applying face creams and taking a little more time to talk with patients. These simple, everyday practices attended to the 'perception of the patient by others but also by the *self*' (Featherstone and Northcott 2020: 47). Focusing on such practices tells us how personhood is embedded in the social and is either sustained or threatened by the simplest of acts carried out by hospice workers.

This thesis has paid particular attention to the workers' everyday practices, their routines and many of the taken for granted, often hidden, aspects of their day-to-day work in the hospice. Those who worked behind the scenes, in the kitchens or as housekeepers, provided care and significant moments of social interaction for the patients. By thinking about the shutting of doors, the drawing of curtains, the preparing of possible last meals, the laughter and singing around the wards and short, but intimate, moments of physical closeness between people, we can appreciate the way in which the processes of death and dying are handled and managed within the hospice space. This thesis has illuminated the significance of the work carried out by a multiplicity of staff in all areas of Broad Lane hospice. By taking the focus of the hospice

workers (as opposed to the patients), the findings illustrate how suffering is often embedded in the actions and perceptions of other people. The workers shaped the sensorial organisation of the hospice space and they described how their embodied actions brought about a certain emotional affect. Here, we can see the workers' power and influence over the experiences of suffering, death and grieving in the hospice. Furthermore, they preserved the patients' ties to *social* life at moments of physical death and sustained the boundaries between *disorderly* death and social life. I will now turn to discuss each of the main findings under three key themes – the sensory, the 'normal' and the self – which draw together and emphasise this relational nature of suffering.

### ***The Sensory***

This thesis set out to understand how hospice workers react to and engage with suffering, as well as explore the interactions that took place in the context of end-of-life suffering. Previous sociological studies have portrayed suffering as isolating, inexpressible and unshareable (Scarry 1985; Das 1997; Morris 1997; Frank 2001). The focus on the sensory captured the verbal inexpressibility of suffering, as the hospice workers described feeling eluded by language in some of their, more difficult, encounters with patients. Suffering is conceptualised as an experience that 'resists' and defies language, as it is often what we cannot 'come to grips with' (Frank 2001: 355). Our current mode of expression is, after all, embedded in a 'language of survival', oriented towards the prolongation of life and the delay of death (Bauman 1992: 131). This thesis explores the different forms of sensory expressions which were utilised in the context of relating to and engaging with another person's suffering. The ethnographic observations and corresponding interviews captured the significance and use of silence as a form of interaction and a socially oriented *action*. By doing or saying very little the hospice workers were in fact making deliberate and informed decisions about the best way to interact and engage with the patients. Many of the workers often came to know the patients' physical boundaries and acted in a way that was appropriate to each individual person. I argue that silence and physical touch were thoughtful forms of expression used by the hospice workers to articulate compassionate and intimate reactions to suffering in embodied, sensorial forms.

The simple acts of preparing and serving food in a certain way, the silent response of the doctor, or the gentle touch of a physiotherapist were significant in communicating all that could not be said. Zoe, working in the kitchen at a distance from the patients on the ward, described

satisfying their needs and requests, which she believed offered them choice and autonomy at a time in which their sense of previous identity was being stripped away. Food materialised and symbolised a sense of ‘control and agency’ (Featherstone and Northcott 2020: 49) over a situation which was often outside of the patient’s immediate control. This thesis elucidates the important work of those in the hidden spaces of the hospice, such as the kitchens, to care for patients through the everyday and necessary practices of food preparation. By attending to the needs of the individual *person*, the hospice workers illustrated how they might sustain the patients’ sense of self or form an understanding of their body as a site of comfort, intimacy and pleasure. Our understanding of our bodies and our perception of self ‘take the shape of the contact [we] have with others’ (Ahmed 2004: 1). The hospice staff were in positions in which they were able to exert a certain influence over how the patients experienced the end of life through these sensory care practices, as well as how they perceived their sense of self. Just as Zoe, the cook, prepared certain dishes according to patients’ needs and desires, other food choices, behaviours and sounds were problematised. Just as personhood and choice could be sustained by the workers, the extracts in this thesis demonstrate how they could be diminished and depleted. The workers illustrated how they formed and shaped a perception of the patients, as well as a ‘perception of the patient ... by the *self*’ (Featherstone and Northcott 2020: 47).

This study challenges the existing sociological ideas about suffering by emphasising the ways in which the hospice workers negotiated *around* its inexpressibility, by enacting alternative, sensory forms of care, such as being silent with and physically touching the patient. Rather than ‘distancing’ (Bauman 1992: 131) the patients in their silence, the workers described joining them there and being silently present *with* them in their pain. Whereas much of the existing sociological work on suffering has emphasised the inexpressibility of suffering, the workers at Broad Lane navigated this to develop relationships and be intimate with their patients, sometimes without the need for verbal expression. The findings indicate that the workers attempted to relieve patients’ feelings of pain and distress by doing or saying very little and this emphasises the importance of the sensory in suffering, and how *being* physically present can be seen as an attempt to relieve suffering through sharing in the experience. I argue that the hospice workers used alternative sensory forms of expression to defy and overcome the limits of verbal articulation in the context of suffering.

### *The 'Normal'*

Beyond these intimate and comforting sensorial practices, which often enabled and supported emotional expression, the relationships and interactions often unfolded with imbalances of power. Certain smells, sounds and behaviours were problematised by the hospice staff. They identified a certain 'normal' within the hospice space and rendered the abnormal as symbolically and materially '*out of place*' (Douglas 1966). The findings suggest that the hospice staff often managed the physical body to sustain a certain sensorial organisation and social order in the hospice space. The ushering of relatives into quiet rooms, the problematisation of certain ways of grieving or dying, and the cleansing of the body illustrate how the *messiness* of death was often concealed to preserve the social life of the hospice. In Chapter Five, I argue that the workers' handling of the physical body and its emissions continually constructs and preserves certain ideals of *normal* within the hospice. I argue that death was not an experience to be shut away and contained, but the *messier* and *noisier* processes of death were managed by the hospice workers to construct a certain social order and sense of organisation. The use of 'quiet rooms' by the workers shielded the hospice patients and their relatives from thinking '*that will be me*' (Amy, ward nurse). Death threatened to leak into the social life of the hospice space. Its sombreness collided with the laughter and chatter of the workers, and so they often practiced subtle techniques to *dull*, yet acknowledge and symbolise, its occurrence.

In dealing with their work, which often 'violated' their sensorial experiences of 'touch, smell and sight' (Twigg et al 2011: 172), the workers navigated shared notions of normal. They developed and practiced means of reordering their work to reconstruct it as a little more *ordinary*. Through the use of humour between themselves and with the patients, the workers reconstructed 'who, after all', and, I argue, *what* is 'really dirty' (Hughes et al 2017: 115). Not reacting, trying not to breathe through the nose and silently persisting with the task at hand were subtle practices which reconstructed a sense of normal, both for the worker and the patient. Humour was important - away from the patients - to re-conceptualise and renormalise the work, and with the patients, humour made light of serious moments of bodily disintegration or pain. I argue that these practices tell us how dirt and dirtiness are socially constructed and that they elicit the influence that the hospice workers have in shaping the notion of normal for all within the hospice space. They reshaped their own understandings of the work, for example, through making light of cleaning up excrement, to make 'extraordinary ... seemingly ordinary'

(Ashforth and Kreiner 2002: 217). In doing so, they recognised, acknowledged and confronted the exact (*un*)ordinariness of their work. These findings illustrate the malleability and fluidity of the normal, which can be reshaped to construct a *new* sense of normal in the particular circumstances.

As Kevin, the health care support worker in Chapter Five, said: '*no matter what ya see, no matter what ya smell, you don't show any emotions*'. Not reacting to the sight or the smell of decaying flesh was said to sustain a patient's feeling of ordinariness, and this highlights the weight of the workers' actions in shaping the patients' 'self-images' (Charmaz 1983: 161). They reshaped their own sense of normality and described shaping their patients', which renormalised the work for them and the situation for the patient, while acknowledging the exact *abnormality* of the situation. Furthermore, and I will turn to this in the next section, the hospice workers sustained the patients' ties to social life through preserving, managing and handling the physical body. These findings emphasise the way in which the notion of the 'normal' was continually shared by the workers, dismantled by the work and then re-constructed in their relationships with the patients and their colleagues. Thus, rather than correcting behaviours *towards* a normal, I suggest in this thesis that the workers reconstructed what, exactly, *could be seen as normal*, by 'colluding' (Komaromy 2000: 303) together to construct a new normal both for themselves and for the patients. This contributes to the existing sociological understandings of normalisation as a process (Foucault 1975; Ashforth and Kreiner 2002, 2013; Hughes et al 2017), by demonstrating the social construction of the 'normal' in practice.

Normalisation unfolds here as a process of moulding and shaping a situation to make it seem, to all those involved, a little more ordinary. By not directly 'correcting' (Foucault 1991: 200) a situation, the hospice workers often reordered what exactly could be understood as normal and this process often made their work easier to carry out. In bringing together the sociological work on the sensory, the normal and the self, the hospice workers negotiated excretions, sounds and odours in a manner that could sustain the patients' personhood at the end of life, or problematise their ways of suffering. There is '*no single way to suffer*' (Wilkinson and Kleinman 2016: 2), as it is rooted in cultural and social norms and circumstances. This research illustrates the ways in which the hospice workers subscribed to, *and constructed*, certain norms of suffering and dying as more ordinary than others. I argue that suffering was shaped by, and embedded in, the normative ideals and conventions of the hospice workers.

### *The Social Self*

The workers' handling of the physical body and their management of the hospice space to disguise some of the signs, odours and noises of death influenced the experience of social life inside Broad Lane. Elias (1985: 23) states that never before has death been 'removed so hygienically behind the scenes ... [and] human corpses ... expedited ... odourlessly'. He argues that death is experienced by the living as something 'threatening and contagious' (Elias 1985: 27), and so it is segregated and isolated from wider society, along with other matters of the body that are hidden from public social life (Elias 1978 [1939]). In some ways, this thesis does illustrate how the hospice workers shut away material evidence of death. The workers also managed the '*out of place*' auditory and sensory symbols of disorder to preserve a pleasant and peaceful space. However, I also found that death was not entirely hidden. Death was negotiated by the workers in such a way that it appeared to transpire peacefully, symbolised through the lighting of candles and the placement of fresh flowers. It happened regularly, often as a matter of routine, and usually the only clear sign of death would be a lit candle on the ward. One lunchtime, after one of the ward nurses returned from the staff room, she noticed a lit candle and remarked: '*I only went for my lunch!*'. Death was handled in a way that rendered it unimposing for the visitors to the hospice and the other patients there. Lighting candles and keeping beds empty for set periods were significant practices and rituals of memorial for many of the workers. These practices and hospice traditions offered the nurses and support staff time to grieve the loss of a patient and remember those who had recently died. However, they often grappled with the conflicting priorities of the doctors and consultants, who saw a newly empty bed as an opportunity to shorten the lengthy waiting list.

If suffering is a *loss* of, or at least a disruption to, a sense of socially embedded personhood and self, then the hospice staff held a great influence over the patients' extent and experience of suffering at the end of life. Their engagements and interactions with the patients were often grounded in getting to know the patients as *social individuals*, as individual persons who were located within particular contexts of their social lives and the broader 'structures of generality' (Simmel 1992: 61). They described knowing the patients as individual persons, through their roles, relationships and ties to other people. This approach could often be found in the simplest and most subtle of practices, which involved taking the time to develop relationships and accrue knowledge about the patients' lives. They assigned a '*meaning*' (Elias 1985: 54) to the individual patient as a person by situating them within the context of a wider social life. At

times, the hospice workers ‘abstracted’ (Foucault 1975: 8) (or, at least felt encouraged to abstract) the patients and divided them from these social contexts. This approach deindividualised the patients, stripped them from their socialised identities and rendered them ‘nobodies’ (Nicola, day unit nurse) in relation to the hospice staff. Here, we can see the influence the hospice workers held over the patients’ ties to social life and their identities as social beings. A loss of self and a loss of previous ‘self-images’ (Charmaz 1983: 168) could be intensified or delayed through the actions and gestures of the hospice staff. This illuminates the interactive processes of suffering at the end of life, as it occurs within these social relations in the hospice space. The workers’ narratives suggest that they played an important role in either sustaining or threatening the patients’ sense of self, by either developing an understanding of them as social individuals or abstracting them from their social lives. In this, the staff at Broad Lane shaped the experiences of those in the hospice through the construction of certain shared normative ideals and their management of the embodied, sensory and emotional aspects of dying.

There were a number of practices that sustained social interactions and relationships at pivotal moments before a patient’s death. One of the ward nurses described cleaning a patient’s body and bed and containing their leakages before they died. Amy describes cleaning a dying patient to make sure that their ‘family members didn’t have to see him like that’. In doing so, she shaped the ‘family members’ understandings of the patients’ death as a peaceful, organised affair. Such practices illustrate how bodily ‘containment’ (Hockey 2008: 351) was seen as a necessary condition for social interaction and exchange, even in these moments before biological death. In these moments, the workers sustained *social life* by their handling of the dying physical body. Where biological life cannot be extended, the workers preserved the social relations of the dead or dying. Here, we can see the interconnectedness between the physical body and the socially constructed perception of self, as well as the ‘interactive nature of personhood’ (Hockey 2008: 355). As social and biological life was slipping away, the social identity of the person was preserved in the eyes of those surrounding them and, most importantly here, through the actions of the hospice staff. Just as a ‘social death’ is rooted in a lack of social interaction and exchange, the workers could sustain and influence *social life* at the closing moments of biological life through their handling of the physical body. As they managed bodily leakages and emissions, they also maintained social relationships and sustained a perception of the patient in the *eyes* of their loved ones.

After death, the hospice workers tended to the patients' physical bodies and, again, they preserved their patients' sociality and previous meaningful social ties to others. If identity is constructed through social life and interaction before death, it is 'only logical that this should continue to be the case in death' (Hallam et al 1999: 114). The health care support workers, such as Kevin, dressed and cleaned the dead patients' bodies, placed flowers and rearranged the pillows to prop the patients up in their beds before their loved ones visited them. These final acts reaffirmed the previous *social* identity of the person after their physical death. The workers would clean dead patients after their deaths, to enable social relations to continue between the deceased and the bereaved. They would also interact with the patients, seeing them as social beings with whom they could socially exchange with. These rituals and rites, both before and after physical death, illuminate the significant roles that the hospice workers play in sustaining the social interactions, social life and the social identity of the biological dead to *delay* a creeping in of 'asociality' after death (Baudrillard 1993: 201). The existing literature suggests that social death can be brought about through isolation and 'sequestration' of dying persons and decaying bodies within such spaces (Lawton 1998; 2000). These findings illustrate the influence of hospice workers in this process. They also tell us how the hospice workers *delayed* social death, as an interpersonal process, in the final moments of biological life and posthumously. This extends an understanding of the 'contained' (Hockey 2008: 351) body as a condition for social relation and social life, but also informs us how hospice workers managed the physical body to preserve social existence.

Finally, the workers were in turn *shaped by* the experiences of their work. They grappled with the inexpressibility of suffering, and some of the workers described feeling emotionally depleted because of their work and the intense, intimate relationships with dying patients. The findings indicate how the workers often suffered *in relation to* the patients by bearing in their experiences. In Chapter 7, Elizabeth describes feeling that '*sometimes, there is nothing else to give*'. She describes a bucket of sand which empties over the course of each day, over and over again. This sense of emotional depletion stems from the reciprocal nature of the work, where they often offered an insight about themselves in their interactions with patients. Hospice and palliative care work are 'self-effacing' (Russ 2005: 141). The hospice staff felt the pressures stemming from commissioners, senior clinical staff and management to provide efficient care within time constraints, financial pressures and demands on resources. They grappled with their shared ideal of what makes a '*nice*' death, which often conflicted with the patients' desires and those of their relatives as well as the concerns of the funding bodies. Within this, they often

developed physically and socially intimate relationships with patients and straddled the professional boundaries of their occupational roles. The work carried out by the hospice staff shaped not only their patients' experiences of death and dying, but their own understanding of death and sometimes their own sense of self. They were '*entangled*' (Dragojlovic and Broom 2018: 23, emphasis added) in their patients' experiences of suffering, experiencing second-hand the sensorial, emotional and embodied experiences of death. This was aptly summarised by Eileen, the day unit sister. I asked each of the participants at the end of our interviews whether they felt their work had '*changed them*'. Eileen, after twenty years working at the hospice, told me that her work had defined her as a person - '*well it has defined me. It's what I am. I wouldn't be who I am at all without it*'. Suffering existed *within* these day-to-day relationships, between the hospice staff across the hospice, working in a variety of different roles, the patients and their loved ones. As the workers shaped the physical and sensorial organisation of the hospice, they shaped the experiences of death within it, and by *doing* their work they were shaped by it.

### **Limitations of the Research**

This research focused specifically on hospice workers' experiences of suffering, examining the relationality of suffering through observations in the hospice and their accounts of day-to-day work. The decision to focus on hospice workers to study suffering was made in order to provide an original sociological contribution and perspective to the existing research. The existing literature largely explores the accounts of suffering individuals, such as people with terminal or chronic illnesses or those experiencing poverty and forced displacement. However, the research findings would have been strengthened at times by the voices of patients, offering the other side to the exchanges and interactions with the workers. The fieldnotes during the observations were recorded in a way that did not include the patients' words or actions, often drawing on the workers' reactions to, engagements with, and descriptions of, the patients' *interaction*. This was often difficult in practice, and there were times during the observations that I thought that the fieldnotes would have been better supported by details and notes which reflected the patients' voices and their actions. However, this conclusion has demonstrated the ways in which the study met the research aims, which focused on the hospice workers' reactions to and engagements with suffering as well as their interactions in the context of suffering. In order to conduct the research with a secondary focus on the patients, the study would have had to go through the process of NHS ethical approval. This is a lengthy process,

which Reed (2007) describes as ‘difficult, time consuming or simply impossible’, especially for an NHS ‘outsider’. As a PhD researcher, I decided against engaging with this ethical process, as the research had to be conducted within a relatively short time frame, in order to allow for time to analyse the data and write the thesis. On reflection, there was a large amount of data collected through this ethnographic research. Concentrating solely on the work of the hospice staff allowed for a deeper analysis and focused specifically on contributing the alternative perspective that has largely been neglected in the study of suffering: the care provider and the witness to suffering.

### **Implications for Future Research**

This thesis has identified several areas for further research. It emphasises the importance of the ‘sensory’ in the *doing* of hospice work as well as in caring for those reaching the end of life and posthumously. Furthermore, I studied a range of staff at Broad Lane hospice working in a variety of different roles. I argue that the work of those in understudied occupations, such as the cleaners, cooks and health care support workers, requires further research to really elicit their important roles within the hospice space. This becomes particularly important in light of the Covid-19 pandemic. Health care support workers in the UK, for example, have found themselves to be ‘centrally involved’ on the ‘frontline’ yet, they remain ‘amongst the lowest paid in society’ (Saks 2020). These groups are largely ‘invisible’ (Saks 2020) within academic discourse and literature on healthcare work and emotions. In the hospice context, the work of these groups often involves carrying out many of the tasks that are said to ‘violate’ sensory perceptions of ‘touch, smell and sight’ (Twigg et al 2011: 172). Therefore, I argue for research that combines a sensory approach to studying the hidden work of these groups.

- The research briefly touched upon the subtle practices to manage reactions to the smells, sights and sounds of hospice work. The hospice staff described ‘*not breathing through the nose*’ and the use of humour to manage the sensorial challenges of their work. Future research could develop upon this notion of normalisation in the context of hospice work, by focusing specifically on these practices during moments of intimate physical care.

- By gathering the perspectives and experiences of staff in a varied range of roles at Broad Lane, I illuminated the importance of those working in housekeeping, kitchen, and health care support roles. Much of the existing research on emotional work in healthcare tends to focus on nursing staff and doctors (Reed and Ellis 2020). The cooks, cleaners and health care support workers in this study often developed intimate and important relationships with patients and their relatives. Future research that focuses specifically on these groups could illustrate the significance of their everyday care practices and focus on how these groups navigate the emotional experiences of their work. A sensory methodology could be adopted to study these groups, who often carry out food work, physical care and enter the rooms at important moments to clean. This research demonstrates the care they carry out in between cleaning, cooking and providing physical care. These moments of intimacy and emotional care work need further research to appreciate the significance of their roles within the hospice.
- Due to the focus and ethical constraints of this PhD, I only reflected on the actions, spoken words and gestures of the hospice staff. I studied interaction through their accounts, experiences and I described one-sided exchanges between hospice staff and patients. This enabled me to pursue an understanding of how hospice workers navigate patient suffering. However, further research is needed that elicits this exact *interaction* between hospice workers and patients. I emphasise that, the hospice workers' experiences of patients' suffering are an important story to tell, and one that can be told further through a study that incorporates the dialogue of the patients in addition to the workers. Future research that incorporates both could develop on the ideas presented here, by exploring how patients feel *in relation* to the workers and appreciate how the workers' interactions and actions make them feel.

This thesis has emphasised why it is important to continue with this research agenda, in these novel and interesting ways. Thinking *with* the senses allows us to explore non-verbal interactions and alternative, sensory forms of care carried out by *hidden* groups of hospice workers. Furthermore, examining the subtle and unspoken practices tells us of the ways in which hospice workers navigate the sensorial, emotional and relational aspects of their work. '*Not breathing through the nose*' is an example of a very subtle practice, which powerfully influences the experience for all of those involved in the care relationship and helps to make

the work easier to carry out. I argue for ways of studying hospice work and reactions to suffering that incorporate a sensory methodology and focus on the subtleties of social life. These areas for future research have stemmed from my reflections on doing this study and the emergent findings from this thesis. Future research would continue to shed light on the importance of the senses and hospice workers' sensorial organisation of the hospice space. Here, I have presented a limited selection of ideas and there are undoubtedly other avenues and areas for research which would allow us to continue to explore the relationality of suffering and the significance of hospice work in shaping end-of-life experiences.

### **Final Thoughts and Contributions**

This thesis offers insights into how hospice workers react to and engage with suffering as well as how they interact with hospice patients. The empirical chapters present suffering as a relational experience in several ways. They illustrate the hospice workers' actions and interactions that could sustain or threaten a patient's sense of personhood. By engaging with the sensory aspects of hospice work, I have described the alternative and sensorially oriented reactions to and engagements with suffering. I explore how spoken words are only one way of reacting to moments of intense suffering and pain, and other ways of engaging with these experiences can include silence and physical touch. Throughout the thesis I have illustrated the influence of the hospice workers over the sensorial organisation of the hospice and particularly over the experiences of *social life* at the end of biological life. I have engaged with suffering as a relational experience. Through the lens of hospice work, I illustrate how it transpires within social interactions and relationships and the interconnections between the physical state of the body and the socialised perceptions of a *person*.

The study contributes to the theoretical understanding of suffering. I have detailed the interactions and relationships that take place in the context of suffering. Where the existing literature often characterises suffering as a 'loss' of social life, I have detailed exactly how sociality and ties to social life can be maintained and preserved through the work of the hospice staff. By adopting the focus of hospice work, we can see how suffering unfolds as a relational and interpersonal process in relationships that *emerge through* suffering. I have detailed how the hospice workers managed the physical body in a way that could sustain the social lives of the dying or dead patients. This extends our sociological understanding of the western norm of the '*contained*' (Hockey 2008: 351) body as a condition for social life and social interaction.

Here, we can see the significance of the work of the hospice staff, who managed the physical body in the moments before and after death to sustain the social identities and perceptions (*in the eyes of others*) of the patient. The way in which the physical body was managed to preserve social identity extends our understanding of personhood as a relational and interpersonal phenomenon (Charmaz 1983; Cassell 1991, 2004; Hockey 2008).

Furthermore, the findings suggest how suffering can be alleviated or sustained through interactional processes, such as the handling of the physical body and the workers' engagement with the patients' sensorial needs. The existing literature on suffering alludes to a social process. However, this research details how this occurs in the everyday spaces of the hospice and by focusing on the hospice workers, we can explore their influence in this relational process. The findings also illustrate how the hospice workers preserved patients' sociality and relations to social life after biological death, which calls into question our treatment of life and death, *and the living and the dead*, as 'dichotomous' (Hallam et al 1999: 126) categories or entities. Personhood and identity were embedded in social relationships with others, and this continued to be the case after death (Hallam et al 1999). I elucidate *how* the hospice workers preserved such ties to social life at these moments of biological death. The findings contribute to our understanding of how hospice workers manage the sensory and emotional challenges of their work. I detail a process of normalisation, through the reconstructing and reshaping of *what* exactly constitutes the *normal*. By re-normalising certain situations through the use of humour, or by not reacting, the hospice workers shaped their own understanding of the tasks at hand and they described reconstructing their patients' perceptions of their situations. This extends our understanding about the social construction of 'normal' by emphasising the malleability and fluidity of normality within the hospice space. Normal was moulded to make the work a little easier to carry out and normalise the circumstances the patients find themselves in.

I have also offered methodological contributions to knowledge in the use of a sensory ethnographic approach. Utilising this approach, I was able to detail the subtle practices the workers used to care for and interact with patients, by being silent and physically reaching out to them. Incorporating a range of perspectives and experiences from across the hospice, this research begins to highlight the hidden work of staff in understudied occupations. I highlight the hidden emotional and physical work that happens in hospice kitchens, behind curtains and as the cleaners mop the floors. The research informs our ways of knowing about suffering and

hospice work, providing insights to how hospice workers carry out sensory forms of care work. This also contributes to the sociological literature on suffering, by emphasising silence and touch as forms of interaction and compassionate reactions. Care could be found in the simplest of practices, such as preparing food in a personalised manner, cutting hair or applying face creams. This extends our understanding of ‘silence’ and *not* doing as appropriate reactions to death and dying. Here, I present silence as a way of being intimate and close to the patient, as opposed to ‘distancing’ them (Bauman 1992: 131). We do often lack a language to express death and suffering (Bauman 1992; Wilkinson 2004). However, the hospice workers found ways of overcoming these difficulties of articulation by utilising *all of the senses*. These findings also offer contributions to the sociology of work, and I call for further studies to explore the significance of the senses in hospice and health care work, especially in the work of those groups highlighted here.

As I write these conclusions and bring this thesis to a close, I must also reflect on the privilege of doing this ethnographic research and being *physically* present in Broad Lane hospice for a six-month period. It is difficult to envisage when we might be able to access such field sites again and, in particular, access hospice spaces and other medical institutions. I took for granted the ease with which I was able to access the hospice, notably without the need for personal protective equipment (PPE) or any medical testing. In doing so, I was able to document and detail the social and working lives of those at Broad Lane. In the midst of a global pandemic, it is difficult to predict when such research will be (safely) conducted again. My reflections on moving *freely* about the hospice space, shadowing hospice staff in patients’ rooms and attending ‘ward rounds’, seem very distant from the conditions a sociological researcher in a hospice would find themselves in today. However, it is essential that we utilise new methods and new ways of thinking to engage with the important questions asked in this study. I find myself thinking about the hospice and the workers at Broad Lane and considering how they are navigating the threats of the pandemic whilst continuing to provide care to terminally ill patients. Beyond the academic contributions of this research, this thesis highlights the emotional impacts on hospice workers of caring for patients who are reaching the end of their lives. The thesis illustrates the everyday working lives of those who have intimate, daily engagements with physical pain, suffering and death. I hope that these findings can inform our understanding of how such workers are often intimately and emotionally engaged with the work that they do and in their relationships with patients. So, as I end this thesis, such research seems more important than ever.

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## Appendices

### Appendix 1: Participant Profiles

Below, I briefly outline the participants that played a key role in the research and in this thesis. Some of the participants held very fleeting roles in terms of the research focus and data collection. For example, there were participants I only met once, spoke to fleetingly or observed for a very short period of time. Therefore, I did not gather the necessary detail to construct a profile of those particular participants.

*Eileen, Sister, day unit:* Eileen had worked at the hospice since it first opened, in the 1990s. In her role, she managed the day-to-day running of the day hospice and supervised the other staff working there. She had worked in that role for fifteen years and before that, worked as a staff nurse in the hospice. She played a key role in helping to organise the research and was a constant supportive presence in the hospice during the fieldwork. Eileen took part in both the observations and an in-depth interview.

*Jenny, Health Care Support Worker, community based:* Jenny had worked at the hospice for three years. She worked as a ‘bank’ worker, which meant that her shifts were very ad-hoc from week to week, and she could be asked to work on the wards or the day unit, but she was mostly based in the community. Before starting work in the hospice, Jenny worked as a probation officer for over thirty years. She had volunteered in the hospice before starting paid work and said that she applied for the job at the hospice after the death of her husband. Jenny took part in the observations and an interview.

*Martha, Clinical Specialist Physiotherapist:* Martha had worked at the hospice in the same role for over twenty years. Before that, she worked in a different town with cancer patients. She mostly worked in the community, visiting patients in their homes. Her role as a physiotherapist involved helping patients regain and redevelop their strength and mobility. She described the difficult conversations with patients, where they came to terms with a loss or decline in their mobility because of their illness. Martha took part in an interview and I was unable to observe her due to the nature of her role.

*Faye, Consultant:* Faye had worked at the hospice for thirteen years but had worked in palliative care for twenty years in total. She decided to specialise in palliative care after observing an interaction between a palliative care doctor and a patient during her years as a junior doctor. She felt that palliative care work offered the opportunity to spend more time talking with patients, as opposed to hospital or GP work. She described her days at work as varied, but she mostly worked in the community, visiting patients in their homes. She described the difficulties of balancing these visits with the audit and administrative work, which was also important in her role as a consultant. Faye took part in just an interview.

*Margaret, Support Services Supervisor:* Margaret had worked at the hospice for over twenty years and had worked in a number of different roles. She previously worked as a domestic and a cook in the kitchen. In her current role, she supervised the kitchen and housekeeping staff, organising their rotas and managing the building maintenance. She explained in our interview that when she applied for the job at the hospice she did not know what a hospice was or what the work would actually entail. She applied for the job because of the flexible hours, which worked for her and her family. Margaret only took part in an interview.

*Elizabeth, Clinical Nurse Specialist:* Elizabeth was based in the community and had worked in the hospice for seventeen years. She first worked in the day unit at Broad Lane, and then worked for a period of time on the hospice ward. She had worked in her current community-based role for seven years. She applied for a job at the hospice after her dad had passed away and felt that her experiences as a service-user drew her to work in palliative care. Her day-to-day role involved visiting patients in their homes, talking to patients about their symptoms and helping them to make decisions about medicines and treatments. Due to the nature of her role, Elizabeth only participated in an interview.

*Audrey, Health Care Support Worker, day unit:* Audrey had worked in the hospice for six years. She previously worked as a care assistant in a residential home. Her day-to-day work involved helping the day unit patients with physical care, such as trips to the toilet and eating. She would often sit with the day unit patients, talking with them, helping them with craft-making and playing games. Audrey participated in an interview as well as my observations in the day unit.

*Kevin, Health Care Support Worker, in-patient unit:* Kevin had worked at the hospice for seven years, having worked at another hospice nearby for twelve years before that. Before that, Kevin worked as a plasterer. His day-to-day work involved tending to the patients' physical needs, bathing and washing them, helping them to eat and moving them when they needed transferring or lifting. Kevin participated in an interview as well as my observations on the in-patient unit.

*Chris, Specialty Doctor in Palliative Care:* Chris had worked in the hospice for around ten years, having worked previously as a hospice practitioner at a General Practice. During his GP training, he was placed at Broad Lane for six months. He describes being attracted by the lack of strict protocol and lack of reliance on tests or treatments, alongside the freedom and time to talk with patients. His day-to-day work involved prescribing medicines, as well as engaging in in-depth conversations with patients about difficult issues and decisions. Chris participated in an interview as well as my observations on the in-patient unit.

*Emily, Health Care Support Worker, day unit:* Before Emily started working at the hospice, she worked as a hairdresser. She describes going into hospice work after her husband passed away. She had worked on the in-patient unit at Broad Lane previously in her seventeen years working at the hospice. Her current role in the day unit involved chatting with the patients, helping them with food at lunchtimes, playing games and making crafts with them. She was known for her craft-making skills and imagination, so she could usually be found at the crafts table. In our interview, she recalled helping patients to write cards and letters for their loved ones to open once they have passed away, as well as eulogies and silk scarves. Emily participated in an interview as well as my observations on the day unit.

*Zoe, Cook:* Zoe had worked at the hospice for just over two years, having owned delicatessens previously. She explained that she started working at the hospice after a family bereavement. In our interview she described arriving at the hospice an hour early each day to bake cakes for the day unit patients to eat as a mid-morning snack. She was passionate about adapting the menu to attend to the needs and preferences of the patients. Zoe participated in an interview.

*Vivien, Clinical Nurse Specialist, community based:* Vivien was based in the community team and had worked in palliative care for around thirty years. She had worked as a Macmillan nurse at a local cancer hospital for many years, before working at the hospice. Vivien describes being 'interested' in the patients that were dying, to ensure that they experienced a peaceful death.

Her day-to-day role involved dealing with a ‘*caseload*’ of patients, visiting them in their homes to assess their symptoms and devise a symptom management plan, as well as provide emotional support. Due to her role in the community, Vivien only participated in an interview.

*Laura, Physiotherapist:* Laura had worked in the hospice for a year. She decided to get a job in a hospice after a close family bereavement. Her day-to-day role involved seeing patients across the day hospice and the in-patient unit, as well as holding exercise classes and helping patients with their physical mobility. Laura participated in an interview as well as my observations across the different spaces of the hospice.

*Yvonne, Housekeeping Assistant:* Yvonne had worked in the hospice for over twenty years. Her day-to-day work involved cleaning the hospice wards and inside the patients’ rooms. Beyond housekeeping and cleaning, Yvonne developed intimate relationships with the patients and could often be heard sharing a joke with her colleagues as well as the patients on the wards. Yvonne opted not to participate in an interview but participated in my observations on the in-patient unit.

*Karen, Housekeeping Assistant:* Karen had worked in the hospice for around five years, and like Yvonne, she developed close relationships with the patients on the in-patient unit. The housekeeping assistants worked in pairs and so they were usually together. The two of them could be heard bursting out in song and sharing a joke loudly with the patients across the wards. Karen participated in my observations on the wards.

*Amy, Staff Nurse, in-patient unit:* Amy had worked in palliative care for around forty years but had only worked at Broad Lane for a year. She recalls deciding to go into palliative care after her experience as a trainee nurse. She describes caring for a patient that had advanced cancer but hadn’t been made aware of the extent of her illness. She described thinking that the patient was ‘*psychologically tortured*’ by the doctors and nurses keeping the facts of her condition from her. Amy participated in an interview as well as my observations on the in-patient unit.

*Nicola, Staff Nurse, day unit:* Nicola had worked as a staff nurse on the day unit for three years, and previously worked in different roles in the community team as well as on the ward. Overall, Nicola had worked in palliative care for around twenty years. She decided to apply for the job after working on a surgical ward in a hospital. She thought that hospice work would offer more

time with patients. She describes the decision as ‘*like a calling*’ after a bereavement. Her day-to-day role on the day unit involved assessing the patients, asking them about their symptoms and how they were feeling emotionally. She would then make referrals to the doctors and physiotherapists in the hospice. Her job involved noticing the small details, such as knowing when a patient was suffering with pain, or when their mobility had worsened. Nicola took part in an interview and my observations on the day unit.

*Lauren, Complementary Therapist Coordinator:* Lauren had worked at the hospice for over six years in her role as a therapist. Lauren held clinics every Monday for day hospice and out-patients, as well as the families of patients with palliative needs. She described sometimes seeing a whole family, to help with the emotions that each family member was experiencing in relation to the ill patient, as well as seeing bereaved families once the patient had passed away. Lauren only participated in an interview, as much of her work took place in a small therapy room located away from the day hospice.

*Christine, Children’s Bereavement Support Lead:* Christine currently worked as the lead of the hospice’s bereavement support service for children. She worked as part of a team supporting children that were experiencing the bereavement of a loved one. She also supported children who were not yet bereaved, to help them to deal with the terminal illness of a family member. She had worked in her current role for three years, but previously worked in the hospice as a nurse on the in-patient unit for around twenty years. She developed the children’s bereavement support service in the hospice after recognising a need for such a service for children. Now, she works thirty hours a week managing the service. Her day-to-day role involved running groups for eight children at a time and visiting families in their homes after receiving a referral. Due to the nature of her role, Christine only participated in an interview.

## **Appendix 2: Interview Schedule**

### **Before the interview**

- Agree a date and time with the participant.
- Provide an information sheet to read before the interview.
- Arrange room booking via the gatekeeper or at Reception.
- Relay the information to the participant.

### **At the point of written and verbal consent:**

- Introduce the patient to the consent form and check they have read the information sheet.
- If they have not yet read the information sheet, allow the participant time to do so and ask whether they need me to clarify anything.
- Read through the information sheet to make sure they have understood and agree to every part.
- Assure them that the interview will be confidential, with data stored in a secure location.
- Ask them whether they feel comfortable being audio recorded, show them the recording device. If they feel uncomfortable, I will offer to take written notes instead.
- Assure them that the data will be recorded anonymously, with the use of pseudonyms, and that recordings will be deleted after transcription.
- Reassure them that we can stop the interview at any point if they wish to. Explain that I might ask that they are comfortable to carry on at various points of the interview.
- Ask what time they need to finish the interview.

### **Signing of consent form:**

- If they feel comfortable with the information provided, both verbally and written in the information sheet and consent forms, I will ask them to sign the consent form.
- At this point, and before signing, I will also ask if they have any questions.
- I will ask them to complete and sign two identical consent forms; one for me to keep and one for them to keep.

### **Interview Questions**

Explain that I have a list of themes and broad questions that I hope to cover during the course of our interview, but also explain that our interview will be guided by the outcomes of our interaction and conversation together. I will explain that I will have the interview schedule in front of me throughout the interview, but I might not use it very often, as the interview is flexible and will be guided by their experiences.

### **Introductory questions**

- Job title
- How long have you worked in this role at the hospice?
- Has this been your only job in palliative care?
- Where did you work before coming here?
- What drew you to work in palliative care?

### **Day-to-day**

- Describe a typical day at work.
- What do you like about your work?
- Is there anything you dislike?

### **Emotions at work**

- How does your work make you feel?
- Do you tend to show how you are feeling at work?
- How do you feel about showing emotion at work?
- Can you tell me about a time where you have felt particularly emotional because of your work?
- What do you do when you feel yourself getting emotional at work?
- Have the ways that you deal with your emotions changed since you started working in palliative care?

### **Interaction: uses of humour and touch**

- I've noticed that many of the staff here use humour and laugh a lot of with the patients, and their colleagues, do you tend to use humour in your work? How/ when?

- Over the last few months, I've noticed that 'touch' plays a large part in the hospice, for example touching a patient to comfort them... I wondered whether you would agree with this?

### **Suffering: understanding and experiencing**

- What does the term 'suffering' mean to you?
- Do you find that, in your work, you experience a lot of patient suffering?
- How do you feel about this/ what you see at work?

### **Satisfaction at work**

- Do you think your work provides you with a sense of fulfilment?
- Do you think that the emotional work you do (i.e. listening, being with) is valued?
- Can you think of a time where you've felt particularly appreciated doing your work?

### **Relationships at work**

#### *Patients/ families*

- Do you ever feel short of time when with a patient/ family? How important is spending time with patients/ family?
- Can you tell me about the relationships you have with your patients/ their families?
- Do you tend to have closer relationships with certain patients?
- Can you tell me about a time where you've built a strong relationship with a patient or a family?

#### *Colleagues*

- Do you talk with your colleagues about how you've been affected by patients etc.?  
Does this help?
- How important are these relationships with your colleagues?

### **Emotional effects of the work**

- Do you tend to take your work/ the feelings that you've felt, home with you?
- How do you unwind after work?
- Does it help to talk about your work?
- How has the work that you do changed you?

**End/ wrap-up**

If the interview was particularly emotional, bring the conversation round to a positive experience at work. i.e. what do you enjoy about your work?

Is there anything you would like to talk about that we haven't mentioned?

**Concluding the interview:**

Thank the participant for giving up their time to take part. Explain that I will be transcribing the interview and reassure them that they have my contact details, should they change their mind about being involved in the research.

### **Appendix 3: Information sheet for hospice employees (participants)**



#### **Witnessing Suffering: A sociological exploration of how suffering is managed in professional lives**

As part of an Economic and Social Research Council (ESRC) funded PhD research project, I will be conducting research at Rotherham Hospice. This information sheet is to provide you with information about the research, so that you can make a decision on whether or not you would like to be involved. Please take your time in reading this information sheet, which explains what the research is about, why it is being conducted and what it might mean for you as a member of staff working at the hospice. I would be happy to talk with you about the research in more detail, so that we can discuss any questions you may have. You will be able to keep a copy of this sheet and will be given a consent form to complete, should you wish to take part in the research.

#### **What is the project's purpose?**

In my PhD research, I am interested in learning more about the day-to-day experiences of palliative care workers. I will be carrying out observations to better understand the routines and practices of staff working in a hospice. This will involve observing the social relationships and interactions between staff working at the hospice and their interactions with patients. I hope to gain a deeper understanding of how palliative care workers make sense of what they see and experience at work.

I will be observing members of staff working in different sections of the hospice over the next 3 to 6 months. After this time, I will be asking certain members of staff to participate in an informal interview, which will last around an hour.

#### **Why have I been given this information sheet?**

You have been given this sheet to read as the research is going to be conducted within Rotherham Hospice, where you work. The information sheet will hopefully make you aware of the research and why it is being conducted. You are being invited to take part and become more involved in the research.

### **Do I have to take part?**

I will be observing certain areas of the hospice and carrying out interviews with staff members that are willing to participate over the next 3 to 6 months. However, it is your choice whether or not to take part in the research. If you do not wish to take part in the study, please let me know and I will avoid collecting any information about your interactions or activities. If you do decide to take part in the research, you will be able to keep this information sheet and you will be asked to sign a consent form. You will be able to withdraw at any point during the research without providing me with a reason.

### **What will I have to do if I take part?**

If you decide to take part in the research, I will ask you whether you are happy for me to observe you while you are working and sometimes ask questions about your work. This will be for a short period of time, over a couple of days or weeks. I will be taking notes to record my observations.

After the observations, I might invite you to take part in an informal interview, which will last around an hour. This would be in a convenient place for you, at an appropriate time. You can decide whether you would like to take part in this at a later date.

The main thing to remember is to be yourself and to carry on doing what you normally do at work.

### **What are the possible disadvantages if I decide to take part?**

You might find that, at times, it is not convenient for a researcher to be present, observing you while you work. You should let me know if you feel like this and I will stop observing you or remove myself from the situation. You might also find talking about your experiences in palliative care work to be emotional or distressing.

### **What are the possible benefits of taking part?**

The research findings will be analysed as part of my PhD research, which hopes to contribute to the wider academic literature on suffering and emotional labour. While there are no immediate benefits of taking part in this research, you might find it interesting to be part of the project. You might also enjoy talking about and reflecting on your experiences at work.

**Who has ethically reviewed the study?**

The research has been ethically reviewed and approved by the Research Ethics Committee in the department of Sociological Studies at the University of Sheffield.

**Who is organising and funding the research?**

The research is being conducted as part of an Economic and Social Research Council (ESRC) funded PhD at the University of Sheffield.

**What is the legal basis for processing my data?**

According to data protection legislation, we are required to inform you that the legal basis we are applying in order to process your personal data is that ‘processing is necessary for the performance of a task carried out in the public interest’ (Article 6(1)(e)). Further information can be found in the University’s Privacy Notice <https://www.sheffield.ac.uk/govern/data-protection/privacy/general>

**Who is the data controller?**

The University of Sheffield will act as the Data Controller for the study. This means that the University is responsible for looking after your information and using it properly.

**How will the data be stored and kept confidential?**

The written notes will be kept in a locked cupboard, these will be written in an anonymised form. The electronic interview recordings will be stored on a secure server and within a password-protected file. Audio recordings will be transcribed and anything that you say will be anonymised. Your real name will not be used in any future publications or presentations and you will remain unidentifiable.

Please note that confidentiality would need to be broken if the researcher witnessed, or was informed of, serious malpractice within the hospice. In this situation, concerns would be passed on to relevant managing staff at the hospice.

### **What will happen to the results of the research?**

Participants will be provided with a summary of the research findings. I am very happy to come back to the hospice at a later date to present the findings to staff members and participants.

The research findings will be used in my PhD thesis as well as used in future research, journal articles and academic presentations. In accordance with my PhD funding from the ESRC, you will be asked whether or not you consent to your data being shared in the ESRC's digital archive, which can be accessed by other researchers. If you agree, I will ensure that the data is anonymised so that you are unidentifiable.

### **Contact details for further information, concerns or queries:**

PhD Researcher:

Natalie Richardson

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email: [nrichardson1@sheffield.ac.uk](mailto:nrichardson1@sheffield.ac.uk)

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**Thank you for taking time to read and consider the information in this sheet.**

## **Appendix 4: Information sheet for hospice visitors and patients (non-participants)**



### **Witnessing Suffering: A sociological exploration of how suffering is managed in professional lives**

I would like to inform you about a research study that I will be conducting at Rotherham Hospice. This research is being carried out as part of my PhD in the Sociological Studies department at the University of Sheffield. Please take your time to read this leaflet. It should explain to you what the research is about, why it is being carried out and what it might mean for you as a visitor to the hospice. Should you have any questions, views or concerns about the research, I would be very happy to talk with you. My contact details can be found at the bottom of the leaflet.

#### **What is the project's purpose?**

In my PhD research, I am interested in learning more about the day-to-day experiences of palliative care workers. I will be carrying out observations to better understand the routines and practices of staff working in a hospice. This will involve observing the social relationships and interactions between staff at the hospice and their interactions with patients. I hope to gain a deeper understanding of how palliative care workers make sense of what they see and experience at work.

I will be observing members of staff working in different sections of the hospice over the next 3 to 6 months. After this time, I will be asking certain members of staff to participate in a short informal interview.

#### **Why have I been given this leaflet?**

You have been given this leaflet, as you are a patient, volunteer or visitor to Rotherham Hospice, where the research will be carried out. By providing you with this leaflet, I want to make sure that you are informed about the research and what it might involve.

### **Do I have to take part?**

The research aims to look at the experiences of palliative care workers. Therefore, I will not be looking to observe, interview or record any information about patients, carers or visitors to the hospice. However, at times, you may be present while I am observing or talking to members of staff. The observations will take place over a few months and I will be visiting different sections of the hospice at different times. I will be wearing a University of Sheffield lanyard so that you can easily identify me at all times. Should you feel that you do not wish for me to observe any situations that you are involved in, you can tell me this and I will stop collecting data about the activities that you are involved in from that point onwards.

### **What are the advantages and disadvantages of taking part?**

There are no immediate benefits of taking part in the research. The research findings will be analysed as part of my PhD research, which hopes to contribute to the wider academic literature on suffering and emotional labour. Sometimes, the presence of a researcher might feel inconvenient or uncomfortable for you. If this is the case, please let me know and I can remove myself from the situation.

### **What will I have to do?**

There might be times when I am observing staff that are working with you. I will ask you if it is OK for me to observe staff members while they are working with you and I might take notes about what is going on. You can choose to talk to me, or you can simply get on with what you are doing. You can ask me to leave if you wish and this will not affect your experience of the hospice in any way. I will only take notes about staff working at the hospice, what they are doing and saying.

### **Who has ethically reviewed the study?**

The research has been ethically reviewed and approved by the Research Ethics Committee in the department of Sociological Studies at the University of Sheffield.

### **Who is organising and funding the research?**

The research is being conducted as part of an Economic and Social Research Council (ESRC) funded PhD at the University of Sheffield.

**How will the data be stored and kept confidential?**

I will only be taking notes about staff members, what they are doing or saying. These written notes will be kept in a locked cupboard and they will be written in an anonymised form. Your name will not be used in any future publications or presentations and you will remain unidentifiable.

Please note that confidentiality would need to be broken if the researcher witnessed, or was informed of, serious malpractice within the hospice. In this situation, concerns would be passed on to relevant managing staff at the hospice.

**What will happen to the results of the research?**

I will be providing the hospice with a summary of the research findings. The research findings will be used in my PhD thesis as well as used in future research, journal articles and academic presentations. In accordance with my PhD funding from the ESRC, the participants will be asked whether or not they consent to their data being shared in the ESRC's digital archive, which can be accessed by other researchers.

**Contact details for further information, concerns or queries:**

PhD Researcher:

Natalie Richardson

Elmfield Building

Northumberland Road

University of Sheffield

Sheffield

S10 2TU

email: [nrichardson1@sheffield.ac.uk](mailto:nrichardson1@sheffield.ac.uk)

Supervisor:

Dr Kate Reed

Elmfield Building

Northumberland Road  
University of Sheffield  
Sheffield  
S10 2TU  
email: [k.reed@sheffield.ac.uk](mailto:k.reed@sheffield.ac.uk)

**Thank you for taking time to read and consider the information.**

**Appendix 5: Poster placed around Broad Lane Hospice during the research**



**‘Witnessing Suffering: A sociological exploration of how suffering is managed in professional lives’**

*A research project is being carried out at this site.*

A PhD researcher from the Sociological Studies department at the University of Sheffield is carrying out a research project at Rotherham Hospice. The research will begin on Monday 9<sup>th</sup> April 2018 and is due to end approx. October 2018. The research will focus on the experiences of palliative care workers and look at how they manage their emotions at work.

I want to make sure that everyone who visits, uses and works at the hospice is informed about the on-going research. This is also to give you the opportunity to express any concerns and ask any questions you may have.

To find out more about the project, **please pick up an information leaflet from reception.**

Should you have any questions, contact the researcher:

**Natalie Richardson  
University of Sheffield  
Elmfield Building  
Northumberland Road  
Sheffield  
S10 2TU**

**email: [nrichardson1@sheffield.ac.uk](mailto:nrichardson1@sheffield.ac.uk)**

## Appendix 6: Participant Consent Forms - Observations



### PARTICIPANT CONSENT FORM: OBSERVATIONS

Title of research project: Witnessing Suffering: A sociological exploration of how suffering is managed in professional lives.

Please tick the box if you agree with the statement.

1. I confirm that I have read and understand the information sheet dated [        ] explaining the research project. I have had time to consider the information and the opportunity to ask questions about the project. I am satisfied with the responses to my questions. I know how to contact the researcher, should I need to.
2. I understand that a researcher will be present in the hospice for the purposes of researching how palliative care workers experience suffering in their working lives. This will involve the researcher observing staff working in certain areas of the hospice.
3. I understand that the research will include observations of my work. I understand that I can ask the researcher to stop observing me, or any situation that I am involved in, without providing a reason.
4. I understand that my participation in the research and interaction with the researcher is voluntary and that I am free to withdraw by contacting the researcher before 31/12/2018.
5. I understand that my responses will be kept confidential and will be anonymised. I understand that my name will not be mentioned in or linked to the research material and I will not be identifiable in any report, publication or presentation that comes out of the research.
6. I agree to take part in the above research.
7. I give permission for data to be collected about me, including any anonymised quotes and for this to be used in future research.

***You can still take part in the research if you do not agree to the following:***

8. It has been explained to me that the organisation that funds the research (ESRC) asks for anonymised copies of the data to be saved onto a digital archive run by the Economic and Social Data Service (ESDS) which can be accessed by other researchers.

9. I understand and agree that other authorised researchers may use my data in publications, reports, web pages and other research outputs. Only if they agree to preserve the confidentiality as set out in this form.

10. I agree to Natalie saving anonymised versions of the data in the ESRC digital archive to be used for future research and learning.

**So that the information can be used legally by the researcher:**

11. I agree to assign the copyright I hold in any materials generated as part of this project to the University of Sheffield.

Name of Participant	Date	Signature
_____	_____	

Lead Researcher	Date	Signature
_____	_____	

**Contact details for further information:**

PhD Researcher:  
Natalie Richardson  
Elmfield Building  
Northumberland Road  
University of Sheffield  
Sheffield  
S10 2TU  
email: [nrichardson1@sheffield.ac.uk](mailto:nrichardson1@sheffield.ac.uk)

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**In the event of a complaint:**

Professor Kate Morris

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University of Sheffield

Sheffield

S10 2TU

Email: [kate.morris@sheffield.ac.uk](mailto:kate.morris@sheffield.ac.uk)

## Appendix 7: Participant Consent Forms – Interviews



### PARTICIPANT CONSENT FORM: INTERVIEW

Witnessing Suffering: A sociological exploration of how suffering is managed in professional lives

Please tick the box if you agree with the statement.

12. I confirm that I have read and understand the information sheet dated [        ] explaining the research project. I have had time to consider the information and the opportunity to ask questions about the project. I know how to contact the researcher, should I need to.
13. I understand that my participation in the research is voluntary and that I am free to withdraw from the interview at any time without giving reason.
14. I give permission for the interview to be audio-recorded.
15. I give permission for the interview to be transcribed.
16. I agree to take part in the above research and understand that the project will include being interviewed and audio recorded.
17. I give permission for data to be collected about me, including any anonymised quotes and I agree that my words may be quoted in future publications, reports, webpages etc. I understand that I will not be named.
18. I understand that my interview responses will be kept confidential and will be anonymised. I understand that my name will not be mentioned in or linked to the research material and I will not be identifiable in any report, publication or presentation that comes out of the research.



Supervisor:

Dr Kate Reed

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S10 2TU

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