

Emotions and Mindlines: A Palliative Care Perspective

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Doctor of Philosophy
2019

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Statement of Authentication

I, Michael John Hodgins, state that the work presented in this thesis is, to the best of my knowledge and belief, original except as acknowledged in the text. I hereby declare that I have not submitted this material, either in full or in part, for a degree at this or any other institution.

(Signature)

Declaration

This research has been conducted with the support of the Australian Government Research Training Program Scholarship.

Acknowledgements

To the amazing patients, carers, nurses, doctors, administrative team, and managers who were involved either principally or peripherally in this project, I thank you from the bottom of my heart. My experiences with you have deeply influenced how I consider the world around me. This thesis is first and foremost dedicated to you. To my supervisors, thank you for your tireless work. Your guidance and collegiality have helped so much throughout this process. Ann you have instilled in me a level of professionalism and drive I had not thought possible. Jayne, you're thoughtful and grounded wisdom has been an inspiration over the course of this process. Thank you both for seeing this through with me.

To the uncredited 'supervisors' and mentors who have helped guide this project and provided sage advice at key moments: Katherine Boydell, Aileen Collier, Ryan Frazer, and Margaret Vickers. Katherine, your wisdom is only surpassed by your humility and care. Aileen, your thoughtfulness and good humour has been consistently inspiring for me along my journey. Ryan, thank you for the guidance you provided in trying times. Margaret, in the brief time you were involved in this project you provided an enduring impression on my scholarship. Thank you all.

To my immediate family, Mum, Dad, Peter, Asha, Andrew, Luke, Sally, Kath, Dave, Cristina, Ariana, James, Elle, Harvey, and Tate thank you for asking, listening, caring, and being 'there'. To my friends, thanks for all the beers.

Finally, to my amazing wife Ali. You have supported me mentally, emotionally, financially, through thick and thin, over the course of this journey. There are few words I can put down that express my gratitude and appreciation for all that you do. Anything is possible when we're together.

Abstract

This thesis explores the relationship between emotion and mindlines in palliative care. This contributes to the processual turn in organisational studies by using Deleuze and Guattari's (1987) notion of the assemblage to illuminate the processual nature of knowledge translation in palliative care. The processual perspective of organisational theory clarifies the mutual shaping between the 'material' and the 'social' when considering how emotion affects knowledge and practice. An emerging paradigm of evidence-based practice privileges the socially-constituted nature of knowledge, predicated on interaction and subjectively experienced by individuals. This follows the contention that clinicians do not consistently consult explicit forms of evidence, often in the form of clinical practice guidelines, to inform their practice. Gabbay and le May's (2004) concept of mindlines attends to this paradigmatic shift. The concept focuses on collectively-reinforced, internalised tacit guidelines informed largely by clinician interactions with networks of trusted sources. The importance of mindlines in palliative care is evident in extant literature as it accounts for the translation of tenuous and fluid practices that are vital in end-of-life care. However, scholars are yet to elucidate the ways emotions affect the development and shaping of mindlines.

This study employed a 12-month ethnography within a public community health centre that offered palliative care to patients living at home. I collected qualitative data while shadowing and observing nurses as they delivered, planned, and/or discussed palliative care (and related matters), focusing specifically on critical incidents. The analysis was informed by Deleuze and Guattari's (1987) transcendental empiricism and the concept of the assemblage to articulate how emotions are constituted with other parts of community-based palliative care mindline assemblages and how emotion can stabilise and transform mindlines in this context. = Within this conceptualisation, mindline assemblages were considered virtual diagrams of practice, produced through the arrangement of ideas, practices, human and non-human actors, and

emotions. This study described the multiple, and at times competing mindline assemblages constructed from interviews, observations, and a journal, specifically highlighting the acceptable emotions or emotion rules that were part of the assemblage. Mindlines assemblages included: humanistic practice; physiological care; rapport building; death care; institutional logics; and self-preservation. The explored critical incidents of palliative care, considering whether mindlines assemblages remained stable within an incident noting that mindline assemblages were essentially contingent on processes of de-territorialisation and re-territorialisation.

This thesis contributes to organisational scholarship by applying the assemblage to describe the observable social organisational forms, and the forces of stabilisation and transformation in health organisations. The social organisational forms of emotion and knowledge occurred as a mindline assembled from the concepts intrinsic to the mindline (ideas), the material actions that correspond with the mindline assemblage (practices), the emotions that were discussed or experienced in close proximity with the mindline assemblage (emotions), and the different roles that clinicians, patients, and carers adopted in relation to these mindline assemblages (identities). Mindline assemblages were also regularly shaped by decoding and de-territorialisation. Clinicians were required to constantly rethink and *re-feel* palliative care in terms of the diverse challenges and flux of relational forces.

The findings suggest greater attention needs to be given to emotion in the context of knowledge translation by researchers, policymakers, managers, and practitioners by accounting for emotions within explicit assemblages of practice and allowing for interpretative, flexible, and relative ideas of care within emotional contexts. This study provides a conceptual and methodological foundation for further study on mindlines as assemblages, which should be taken up by scholars working within the broad field of knowledge translation. For managers and clinicians, this study suggests greater opportunities should be provided to clinicians to

reflectively and reflexively examine how they are moved by patients, carers, colleagues, and managers. In concert with extant research, this study underscores the significance of a model of care that enables transdisciplinary communication, or a globalisation of specialisations and disciplines.

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Chapter 1: Introduction

1.1 Prologue

Without feelings insignificant decisions become excruciating attempts to compare endless arrays of inconsequential things. It's just easier to handle those with emotions — Ann Leckie, *Ancillary Justice*

The room is small and dark. It is pervasively damp and has a smell of old carpet, making it feel like an underground classroom I used to sit in for school assembly. The feeling might also be due to the class-like presentation I am watching. There are around 30 people here. Generalist nurses and allied health professionals are here to learn ‘the ABCs of palliative care nursing’, an education program developed by the local health district¹. I sit among the class, trying to document the presentation and inconspicuously investigate the minutia of audience reactions.

The presenter is a specialist nurse who is participating in my doctoral research. She exudes excitement about the palliative care messages she is tasked with presenting. She speaks confidently and I can tell she is enjoying herself as she makes jokes and animatedly performs the characters in her many stories. I also know she is excited because I have spoken with her about the presentation and what it means to her. She values the opportunity to present her experience of palliative care to people less familiar with the specialty.

The presentation’s first session of the day culminates with the presenter playing a video for the audience. The video was made by the nurses at the nearby community health centre that delivers community-based palliative care. For the purposes of communicating the nature of

¹ New South Wales (NSW) health service provision is delegated to local health districts, which provide services in a range of settings across the state. Eight local health districts cover the Sydney metropolitan region, and seven cover rural and regional NSW.

community-based palliative care, the staff at the centre filmed a fictional home visit, written and performed by both generalist and specialist palliative care nurses. The plot of the film involved a home visit, labelled as a ‘typical’ home visit, with a patient, who could not speak English, and her daughter and granddaughter.

The first scene begins at a door of an inconspicuous house. Two women stand at the door and knock. Another woman opens the door and greets the women, who formally introduce themselves as community nurses. The woman at the door invites the nurses inside. The scene moves to the nurses, patient, and carers inside the patient’s home seated at the dining table. The camera pans back and forth across the five figures seated at the table as they discuss the patient’s symptoms and medication. The patient does not understand English and the patient’s daughter interprets in Cambodian for the patient. The film uses English subtitles to show the Cambodian communication between patient and carers. The medication is haphazardly organised, as demonstrated by the carer’s difficulty finding the different medications in the home.

The scene settles into a rhythm, the crux of which is the miscommunication of the patient’s diagnosis – the elderly patient does not know she is dying. The daughter takes a moment to express to the clinicians a desire to not inform her mother of her serious prognosis, spoken in English. Back in the room where we watch the video, an audience member turns to her colleague and gives a small snort of laughter, to which the colleague responds with an eye-roll and shake of his head before folding his arms and returning his attention to the screen. In the scene, the patient’s confusion becomes pronounced and crescendos into a heartfelt plea to the nurses to tell her what is wrong with her as visible tears begin forming in her eyes and her voice wavers audibly. At this point I notice the presenter gaze out at the audience drawing her eyes across the faces in the room. She gives a smile that also exudes seriousness, as if she is

trying to acknowledge both the pantomime nature of the film as well as plead to the audience to receive and interrogate the underlying message.

I find it hard not to be moved by the film. I feel the tension of the nurses, who are tasked with weighing the wishes of the daughter, which involve attention to Cambodian norms, against the patient's confusion and despair. The 'patient's' performance is particularly evocative, as the nurse playing the part candidly conveys bewilderment and anguish. I feel the nurse's performance, recalling moments of anger, sadness, or confusion that have driven me to physical sensations of anxiety and distress. Moments when I have felt the churning sensation in the pit of my stomach, and the uncontrollable shaking of my hands.

The emotion expressed in this instance is moving, but I must stop and think: why do the nurses who made this resource include this performance? Intending to be an educational tool to show typical home-based palliative care, this film had no explicit reason to contain the emotional performances it does. When I align these feelings with what I see on the screen, I wonder, do I come a little closer to understanding what this patient's distress might be like? When I spoke with the nurse playing the patient about her performance, she spoke of embodying suffering as she engaged with a day-to-day reality of palliative care from a different perspective:

In that moment, I just felt the helplessness that this patient must be going through. It's something that we see all the time and I feel it's really important to show people how challenging it can be when you're entering people's homes.

The situational and spatial weight of 'challenging' emotional despair that this nurse reconstitutes through her performance is telling. It is a 'moment' the nurse realises and actualises, through performance, the patient's perspective. Up until this moment, the film exudes a detached emotional palate, cast via the formal introductions of the nurses and the

prescriptive ‘script’ of the different symptoms and medications that the clinicians inquire about. The expression of confusion and anguish performed by the nurse stands as a jarring break from the calm and formal interaction preceding it, necessitating consideration of how the clinicians might approach this situation.

I begin my thesis by describing this experience because it encapsulates the intersections between the patterns of meaning that shape practice, the emotions inextricably woven within this meaning, and the situational complexity inherent in palliative care. This complexity requires clinicians to constantly shift their practices and emotions in the context of practice. The clinicians here physically inhabit the bodies and feelings of a patient, carers and clinicians respectively, negotiating and representing the norms of palliative care. They use this film as an emotive way to capture and convey, what they call the ‘realities’ of ‘typical’ community-based palliative care. To paraphrase the nurses themselves, there was an imperative to keep true to the real life experiencing of emotion in the delivery of palliative care in the home. The language of ‘realities’ represents the collective experience of the team, the patterns of experience that form the ways of seeing the world shared by the members. In my research I sought to understand the relationship emotion has to the patterns of meaning and threads of collectively shaped ‘reality’ that become practice. I contributed to bringing the intellectual and the emotional into a productive proximity in palliative care (Braunmühl 2012, p. 238).

1.2 Introduction

In this section, I connect my journey of discovery to pertinent literature and my research question, justifying the need to contribute knowledge about emotion and mindlines within organisational studies. This is a contribution to the processual turn in organisational studies by using Deleuze and Guattari’s (1987) notion of the assemblage to illuminate the processual nature of knowledge translation practices in palliative care. Processual approaches in

organisational research are based on several key assumptions, principally that objects of study are temporally continuous and without a finite end point. These approaches avoid examining organisations through reductive analytic perspectives that discern discrete, isolatable events and objects of research, instead embracing approaches that more readily adhere to the complex and chaotic nature of reality (Alvesson, Lee Ashcraft & Thomas 2008). Encompassed within processual approaches to organisational research include attention to temporality, the history and culture of organisations, and political processes (Dawson & Andriopoulos 2014, pp. 188-221). Important in the context of my thesis, the processual perspective of organisations involves attention to heterogeneous elements within an area of inquiry, including the ‘material’ and the ‘social’. This processual approach is important to consider how emotion affects knowledge and practice given the inherent heterogeneity of these elements. I believe it is useful to include my own path through the development of my research focus as a foundation for this thesis and provide justification for my contribution to knowledge: to answer the ‘so what’ and ‘why’. I weave together the answers to these two questions aligning my personal experience with the wider scholarly context.

My first experience in university was studying education to become a primary school teacher. It was during that time I became curious about the theories of learning and education, with an interest in the philosophy of the mind extending as far back as Descartes. When I moved into a teaching position straight from university, I became disenchanted with the mundanity of the work, desiring to pursue some of the curiosity I had previously fostered. A serendipitous opportunity allowed me to become a research assistant on a project exploring innovative, art based qualitative methodologies. During this project I further examined philosophies of knowledge and their relationship with practice and behaviour change.

My focus landed on the concept of knowledge translation (KT). KT is here understood as the creation, circulation, and sharing of knowledge. This is viewed as important in the context of

developing and delivering timely and innovative products or practices in many industries and services (Leonard-Barton 1998; Orlikowski 2002). KT is vital, particularly in healthcare, where evidence-based practice helps to facilitate the use of limited resources and promote professional accountability (Greenhalgh et al. 2004). Since the 1990s, the evidence-based healthcare (EBHC) movement has witnessed a plethora of studies dedicated to ensuring clinicians are putting evidence garnered from research into practice. Searching ‘evidence-based’ in any current medical journal will yield a staggering number of results focusing on the improved availability of research evidence. Studies, for instance, gauging clinician ‘adherence to’ (Clark et al. 2017; Hall et al. 2015; Kamal et al. 2016) and ‘compliance with’ evidence, in its various manifestations (Bussi eres et al. 2012; Cloyd, Hernandez-Boussard & Wapnir 2013). Most attempts to bridge the evidence to practice gap are dedicated to providing research evidence explicitly in accessible forms such as printed education materials (Barwick, Peters & Boydell 2009).

My experience led me to a reoccurring contention in EBHC: that clinicians do not consistently consult or follow explicit research evidence, suggesting an inherent limitation in EBHC (Bryant et al. 2010; Gabbay & le May 2004; Runciman et al. 2012). Critics of the dominant EBHC models suggest this might be due to a linear view of knowledge belying the multidirectional, fluid, and ‘self-organising’ (Wieringa & Greenhalgh 2015, p. 8) aspects involved in the dissemination of knowledge. This linear conception overlooks the interaction between individuals and explicit knowledge, accessible in the form of a clinical guideline or memo. Theorists have long argued that knowledge is situated and context-dependant (Nonaka, Toyama & Konno 2000; Polanyi 1966), which contravenes the positivist, objective view of knowledge as scientific facts that exist in a vacuum. This situated nature of knowledge holds not only in social sciences but also in the science of clinical trials (Greenhalgh & Wieringa

2011). Facts are understood differently based on political and cultural positions and principles like equity, harm minimisation, and confidentiality (Wieringa et al. 2017).

The complexity and inherent challenges associated with EBHC and related research are an ongoing concern, yet to be sufficiently addressed as the ‘original goals of EBHC to provide a methodology to generate independent truths and objectively assess the certainty of facts have so far proved elusive’ (Wieringa et al. 2017, p. 4). Wieringa and colleagues drew on Latour (1993) to make a case for EBHC that reflects a ‘middle kingdom’. In this middle kingdom *all* forms of evidence are deemed worthy of interpretation and translation and ‘the art of casuistry’ (Jonsen & Toulmin 1988, p. 16) is considered in a context of diverse social values. Wieringa and colleagues (2017, p. 5) stated the need to reason at all levels: ‘not only from the individual to the general or from the general to the individual but from individual to individual’. This requires a focus on the interactive processes of knowledge creation, rather than merely explicit knowledge (Wieringa & Greenhalgh, 2015). Knowledge should be understood as ‘a social product rather than something generated through the operation of a privileged scientific method’ (Law 1992, p. 381).

As I further investigated the ongoing problems of EBHC, I became attracted to these alternative conceptions of EBHC, deviating from the hegemonic linear, top-down approaches favoured by clinical and implementation research (that is, systematic reviews and randomised control trials at the top; case reviews and anecdotal evidence at bottom NHMRC 1999). Gabbay and le May’s (2004) ‘mindlines’ approach was one alternative perspective of evidence-based medicine evoking ‘socially constituted knowledge’ (p.4), promoting the importance of clinical networks of trusted sources. Gabbay and le May’s theoretical work on mindlines supports a multidirectional conceptualisation of knowledge, which accounts for the complexities of KT. They describe mindlines as ‘collectively reinforced, internalised tacit guidelines’ (2004, p. 1) that clinicians build (or grow) and draw from to inform their day-to-day practice. Mindlines

adheres to a perspective of knowledge as socially constituted, with strong emphasis on the importance of networks of trusted sources. This work fostered my desire to contribute to this field to explore the ‘organic rather than rational’ processes of knowledge development, accounting for how clinicians build and turn over mindlines (Wieringa & Greenhalgh 2015, p. 8).

My opportunities in health research grew and I explored KT in different fields. I returned to university, this time with greater drive and interest, to attain a Masters in Qualitative Health Research. Following this, I became a research assistant to explore best practice in community-based palliative care. My experience researching palliative care led to a greater appreciation for high-quality community-based palliative care. This is particularly because of the global rise of cancer, chronic illnesses, and multi-morbidities, along with ageing populations (World Palliative Care Alliance 2014).

Most Australians wish to die in their home (Foreman et al. 2006; Higginson & Sen-Gupta 2000; Productivity Commission 2017). There is a great deal of complexity around this issue as people’s preference to die at home can change over time (Gerber, Hayes & Bryant 2019; Gomes et al. 2013; Hoare et al. 2015). However, a report by the Australian Productivity Commission (2017) found that although many individuals choose to die at home, many die in a hospital or aged care facility. The report echoes ongoing calls for better equipped community-based palliative care services to enable more people to die at home (Swerissen & Duckett 2015). This is not only to address patient preference, but also because of the benefits community-based palliative care services are associated with including improved quality of life, reduced symptom burden (Gomes, Calanzani & Higginson 2014), and better patient and carer satisfaction (Brumley et al. 2007).

The benefits of increasing access to community-based palliative care comes with challenges due to the complexity of care delivered in the home. The complexity and contingency of

community-based palliative care prompts clinicians to work within a specialty that ‘means different things to people at different times’ (Collier et al. 2019, p. 99). The journey to the end of life is a unique experience. The dying process can be peaceful and/or tumultuous, existentially destabilising and/or spiritually affirming. A clinician delivering palliative care is required to create a stable and comfortable environment for a patient who is dying. Additionally, patients and carers are expected to assume what were once clinician responsibilities, which creates additional complexity (Jenerette & Mayer 2016).

During my experience researching community-based palliative care, I inevitably began to connect my experience with my interest in KT and the philosophy of learning. This is an ongoing concern in palliative care demonstrated by consistent limitations in the delivery of evidence-based palliative care. Despite previous attempts to translate research evidence into palliative care practice (with emphasis on end of life decision making), these attempts are not readily transferring into service delivery and individual clinical practice (Gott et al. 2012). Although evidence-based clinical guidelines can be informative, their translation into practice requires clinician empathy, perceptiveness, and creativity to attune to the dynamic circumstances of patients and their carers. As Montori (2016) attested, ‘Evidence does not care. But, that is the job: it is to care. In doing so, we must be careful, and we must be kind. The rest are important adjectives’ (p. 8). The difficulty in applying clinical research in palliative care was demonstrated by the persistent use of anticholinergic drugs for respiratory tract secretions in every day practice, despite a lack of research evidence to support their use (Khalil & Ristevski 2018). This has created challenges for the delivery of palliative care, as the policy rhetoric of a ‘palliative approach’ to medicine is not always translated into clinical practice (Gott et al. 2012). Evidence in palliative care reflects a complex constellation of ‘constructed facts, propositions, experiences, biographies and histories and is ultimately an exercise of judgement bounded by time and context’ (Kitson 2008, p. 5). Calls have been made for

palliative care scholars and practitioners to produce a ‘critical yet pragmatic approach to applying evidence in complex healthcare situations that are as dependent on context, human interactions and sense-making as on clinical sciences’ (Yardley, Martins & Walshe 2019, p. 1).

As I considered these concerns in palliative care and KT, I questioned how the emotional experience of delivering palliative care affected clinicians’ mindlines. Emotions are inherently part of healthcare, where a strong trend of patient-centred care requires compassion and empathy, founded on emotion work (Gray 2009; Hochschild 2015; Kleinman 1988; Riley & Weiss 2016). However, KT scholars have generally avoided in-depth engagement with emotion. Many theorists concede that emotion is important in KT (Damschroder et al. 2009; Greenhalgh et al. 2004; Nonaka & von Krogh 2009), however there is little elucidation of this importance and the relationship between emotion and the ways in which knowledge is translated, created or ‘used’. This is of concern considering the plethora of literature emphasising the importance of emotion in social life (Kemper 1978; Parkinson & Manstead 1993; Shott 1979; Tiedens & Leach 2004). Although this literature does not necessarily emphasise the importance of emotion for KT, it underscores the importance of emotion in social interactions. With the relatively newfound importance of social interactions for KT, there is a need to study emotion in this context. Clarifying how emotions are constituted or arranged within mindlines can address this gap in literature and research.

In order to examine how emotions and mindlines fit together for clinicians, researchers need to tease out the diverse ontological elements of the mindline, and consider the embodied physical experience of practices, as well as the influence of social interaction with the world around us. The complexity inherent in exploring embodied and social elements of mindlines, which are always contingent, contextual, and emergent, requires a frame that can encompass the diverse and shifting elements. The work of Deleuze and Guattari (1987), specifically their

notion of agencement, or ‘assemblage’ as it is commonly translated, is a framing that can help explore mindlines as provisional, territorial arrangements comprised of things that are diverse in kind (Anderson & McFarlane 2011). Assemblage theory is also concerned with the productive making and unmaking of territory as a combination of material and immaterial forms. These co-produced forms hinge on what works. With Deleuze and Guattari’s (1987) assemblage theory as a conceptual framework we can reconceptualised mindlines as complex assemblages of things diverse in kind. To understand the role of emotion in mindlines it is important to capture the ideas, materials, practices, and emotions bound together in collectively established virtual maps of ideas practice. But this analysis only provides an insight into mindline as virtual plans, removed from the real world of practice. To understand how these mindlines work in practice we need to analyse practice to determine how emotion contributes to points of flux and difference among changing mindlines *in situ*.

Scholars have applied the philosophic and analytic principles of Deleuze and Guattari (1987,1988) as part of the processual turn of organisational studies. With what Sørensen (2005) called a fetish for the fringes and the margins, he argued that organisation theory should be ‘an elaborately developed question, rather than a resolution to a problem, an elaboration, to the very end, of the necessary implications of a formulated question. It is the rejection of absolute normative institutions that Deleuze and Guattari’s philosophy hinges upon, presented in their first volume of *Capitalism and Schizophrenia: Anti-Oedipus* (1984) as a critique against the fascist institutionalisation of psychoanalysis. The application of this philosophy in knowledge translation in organisations has focused on the heterogeneity engendered by a Deleuzoguattarian (i.e. relating to, or characteristic of the works of Gilles Deleuze and Félix Guattari) interpretation of knowledge (Bissola, Imperatori & Biffi 2017; Gherardi 2003; Islam 2013; Lawley 2013; Linstead & Thanem 2016; Thanem 2004; Wood 2002).

1.3 Research Objectives

My thesis sought to determine how emotions are entwined with different kinds of knowledge, including explicit evidence, practical wisdom, and intuition in mindlines. My analysis required an approach that could frame the heterogeneous elements of emotions and knowledge translation to illuminate the conditions that arrangements of emotion and knowledge were made possible. Using the conceptual framework of the assemblage (Deleuze & Guattari 1987), my thesis articulated how emotions are constituted with other parts of community-based palliative care mindline assemblages - the various elements that make up different ways to enact palliative care. This was achieved by identifying emotional mindline assemblages in community-based palliative care, elucidating how emotions help to mutually constitute or contest collective and individual mindlines in practice. The complex, virtual arrangements of materials, ideas and desires within the mindline are representations of the way things should work. Mindlines become apparent through clinician's articulation and performance of actions, emotions, human and non-human actors, and the identities or 'subjects' they constitute. The epistemological positioning offered by assemblage theory helped to interrogate both key concepts proposed in this study: mindlines and emotion.

1.4 Structure of thesis

My thesis is structured into eight chapters. Chapter 1 will conclude shortly, which explains and justifies my study. In chapter 2, I present a literature review and the context for the study, elucidating the bodies of literature pertaining to KT, emotion, and palliative care. I then provide an account of how I synthesised this literature for this study, foreshadowing the research design to follow. In chapter 3, I detail the conceptual framework for my thesis, providing an ontological and epistemological foundation for my methodology. I then describe the methodological approach and the ethical framework of my study. In chapter 4, I outline the

research methods, describing the field sites and operational processes of data management, the recruitment and data collection processes. Finally, I present my approach to data analysis leading to an outline of the results to follow.

In chapter 5, 6, and 7, I present my results. In chapter 5 I examine the different mindline assemblages that were conceptually conceived within community-based palliative care, describing the arrangements of ideas, practices, emotions, and identities that constituted these mindline assemblages. In this chapter I demonstrate one of my contributions, which is the unique reconceptualisation of mindlines as assemblages of ideal palliative care. I also demonstrate the contingencies of emotion inherent within different mindline assemblages. The stability and/or flux of mindlines coexist with the stability and/or flux of emotions, as these emotions are inherently part of arrangements of palliative care. In chapter 6, I explore generally the movements of mindline assemblages within the home and the weekly meeting where the team reviewed palliative care patients. I explicate the contingency of emotions as a constituent part of these movements within social contexts. In chapter 7, I present the third part of my findings as vignettes to explicate how these mindline assemblages operated in practice *in situ*. In this chapter, I describe the fluctuation of different assemblages across clinical encounters, designated as processes of de-territorialisation and re-territorialisation within critical incidents. In chapter 8, I discuss my contribution to knowledge and the associated practical and theoretical implications. I then outline the research limitations, and propose future research directions to continue to explore, understand, and promote the relationship between emotion and mindlines.

Chapter 2: The literature on mindlines, emotion, and palliative care

2.1 Introduction

In this chapter, I review the literatures associated with KT and emotion and their relevance to palliative care, highlighting specific connections to Deleuzoguattarian research in organisational studies that relate to a processual perspective of KT, which reflects the unstable and continuous nature of organisational knowledge (Wood 2002). Given the relevance of literature related to healthcare, management, and psychology, I contended with clashes of methodology and orientation. Even a peripheral reading of emotion literature can prompt a reader to navigate multiple interacting epistemological influences. These influences extend from the positivist and post-positivist paradigms of neuroscience, psychology, and some sociological work (Fredrickson 2001; Moon et al. 2009; Patulny 2015) to the deconstructionist, post theory work of some cultural and feminist scholars (Ahmed 2013; Butler 2006, 2016). Indeed, there is a similar paradigmatic challenge when engaging with complexity in health service research. The mainstay positivism of ‘gold standard’ EBHC requires a stability and knowability of truth to construct generalisable epidemiological products (Protevi 2009). However, this ontology has been critiqued and scrutinised given the acknowledgement of socio-cultural influences on health(care) (Duff 2014; Fox 2012). This has prompted a greater focus on social interaction research, which is key to mindlines, through observation, discussion, as well as acknowledging situated ‘knowing-in-practice’ among organisational members (Gabbay & le May, 2011; Nonaka, 1994; Orlikowski, 2002; Wieringa & Greenhalgh, 2015). My thesis as a linear, structural apparatus, devoted to a single field or paradigm might have reduced and minimised the wild profusion of my empirical work. To ensure I harness the

potential of this interdisciplinary milieu, it was important to provide an epistemological framework that underpins the logic of my study allowing for pragmatic multiplicity to attend to diverse voices in the research.

As qualitative scholars have suggested, epistemological pluralism can help to enhance research of the kind I set out to undertake (Denzin 2010; Lather 2006; Miller et al. 2008). While some organisational scholars have disagreed with interdisciplinary approaches (Pfeffer 1993; Sorge 1997) others have pointed towards organisation theory's inherently interdisciplinary roots, which continues to move the field forward (Thanem 2004). In this thesis I have attempted to use interdisciplinarity work as a way of thinking and doing, harnessing its potential to unify disparate literatures with their alternating theories, methodologies, and epistemologies. I have opted for the ontological unity of Deleuze and Guattari (1984, 1987), which is, paradoxically, a multiplicity. Consistent with the Deleuzoguattarian concept of the rhizome, interdisciplinarity constitutes movement in multiple, potentially simultaneous directions and the generative connections among different points, anchored by a unifying issue or topic of inquiry (Bissola, Imperatori & Biffi 2017). Deleuze and Guattari offered important instruction when considering and undertaking interdisciplinary research, as Coleman and Ringrose (2013) attested. They described 'the necessary interdisciplinarity of thinking and doing [of]... Deleuze's work... where theories and ways of doing that are key to specific disciplines are thought in relation to other modes of thinking and doing – and are perhaps transformed in the process' (p.2). For instance, Deleuzoguattarian thinking enabled my study to engage with not only the organisational contexts involving social and political forces shaping actions but also the internal psychodynamic forces of emotion. Where in my thesis I turn to literature related to healthcare management, emotions, or palliative care, I have remained consistent by considering how these contexts work within a Deleuzoguattarian ontological lens. This approach enabled me to consider how these fields contribute to an analysis of emotion and mindlines in palliative

care. For instance, in this chapter, I describe my arrival at an interactionist approach to emotion informed by Ahmed (2004), which opts for heterogeneity and materiality in identifying its objects of analysis, which aligns with Deleuzoguattarian scholarship.

The potential of Deleuzoguattarian philosophy is yet to be realised in organisational studies, despite its influence on social, cultural, and literary theory (Linstead & Thanem 2016; 2017; Sørensen 2005). Organisational scholars have used Deleuze and Guattari's (1984, 1987) work to problematise the field, questioning the epistemological and ontological assumptions of organisation theory, suggesting that an organisation is auto-subversive, without a solid foundation and is constantly changing (Linstead & Thanem 2016). Sørensen (2005), relying on Deleuze and Guattari's work, proposed an alternative ontological underpinning for organisational scholarship in which organisation, chaos, and change are inseparable, forming 'organizing refrains' (p. 129). The use of Deleuzoguattarian thought in organisational studies has begun to take exciting and experimental forms, for instance Pick's (2017) application of literary theory and fiction (*Cloud Atlas* by David Mitchell) to create new ways of thinking about organisation theory, challenging prevailing ideological assumptions and problematizing current paradigm assumptions. My thesis contributes to the processual turn in organisational studies by using Deleuze and Guattari's (1987) notion of the assemblage to illuminate the processual nature of knowledge translation practices in palliative care. This chapter develops a conceptual 'common ground' within a Deleuzoguattarian ontological lens between the fields of emotion and mindlines locating this common ground in palliative care. Each section begins by addressing the key tenets of the field and then focuses on the elements associated with the thesis.

2.2 Locating and conceptualising mindlines

The following section is presented in five interrelated sub-sections to contextualise mindlines and describe the relevant process addressed in this study. The first sub-section situates mindlines in the broader context of EBHC and KT. The second elucidates mindlines, unpacking its theoretical foundations and relevance to this study. The third sub-section describes theory and research related to identity as a constituent part of mindlines. The fourth examines stories and storytelling in mindlines as a vital component of KT. The fifth sub-section explores the importance of space and networks to develop mindlines, and the implications for this study.

2.2.1 Situating mindlines

To understand the connection between emotion and KT, I drew on Gabbay and le May's (2004) mindlines approach, which is situated in literature related to the creation and sharing of knowledge. KT as a field of study has connections to psychology, sociology, and organisational theory (Nilsen 2015, p. 28). In healthcare, the increased focus on KT is strongly associated with EBHC. EBHC is 'the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients' (Sackett et al. 1996, p. 71) has been a gold standard in healthcare delivery for most of the 21st century. EBHC has largely maintained a positivist view of knowledge, with 'logical positivism... the epistemological parent of EBHC' (Loughlin 2008, p.666). EBHC generally frames evidence as 'facts' about the world assuming 'that scientific beliefs stand or fall in light of the evidence... [representing an] understanding of evidence [that] is explicitly positivist' (Goldenberg 2006, p.2622). This view implicitly conceives scientific facts as knowledge, existing in a vacuum and can be transferred to passive recipients in the form of guidelines. EBHC thus involves a systematic search for

evidence, an appraisal of the validity of the evidence found, incorporation of patient views, and the application of findings (Gray 1997; Sackett 1997).

The era of ‘evidence-based everything’ (Fowler 1997, p. 1) has fostered growing attention to implementation science, which is ‘the scientific study of methods to promote the systematic uptake of evidence-based interventions into practice and policy and hence improve health... it includes the study of influences on professional, patient and organisational behaviour in healthcare, community or population contexts’ (Foy et al. 2015, p. 2). In this context, evidence-based interventions are typically those supported by robust science, like clinical practice guidelines (Turner et al. 2008). The acceptance and routine use of evidence-based interventions as a field of study encompass practice and policy, as well as professional, patient and organisational behaviours. To inform how evidence is introduced into, and sustained within health services, researchers and clinicians are often required to engage with a vast suite of theories, models, and frameworks. Despite the apparent value of theories, models, and frameworks, they might not necessarily be the panacea to the well-cited ‘chasm’ (Institute of Medicine 2001) between evidence and practice. For instance, Bhattacharyya and colleagues (2006) argued that the expressed use of theory does not necessarily help to determine the applicability or relevance of evidence – nor does theory always clarify how an intervention should be moulded to ensure it is fit-for-purpose, which ‘undoubtedly involves the diluting effect of “common sense”’ (p. 1). Progressive scholars have furthered this charge, challenging the quest to simplify (if not de-complexify) the complex, politicised, highly-contested, and regularly-reforming context of healthcare (Aranda & Jones 2010; Bowen et al. 2009; Braithwaite et al. 2016; Engebretsen et al. 2016; Gray et al. 2014; Greenhalgh & Wieringa 2011; Lipsitz 2012; Stokes, Checkland & Kristensen 2016). Rapport and colleagues (2017) encouraged health service researchers to go back to basics – ‘to lay down the ground rules for their research, discuss rigorous, methodologically sound procedures, and consider how their

findings will lead to implementable study outcomes’ (p. 9) – this might be achieved via their ‘suggestions for overcoming some of the challenges of implementation science’ (p. 7).

These concerns represent the epistemological divide in EBHC, particularly around divergent thinking in clinical practice or the dilution of ‘common sense’ (Bhattacharyya et al. 2006, p. 1; Kitson 2008). Notably problematic with hegemonic approaches in EBHC is what counts as ‘evidence’ and connectedly the appraisal mechanisms for evidence (Greenhalgh 2013). Wieringa and colleagues (2018b) critiqued the ontological view of truth within EBHC, what they term the ideal limit theorem, a view of truth as capable of being revealed over many investigative events in many communities: ‘conceptually, it cannot deal with the single case scenario in the clinical encounter – the original situation for which evidence-based health care was developed’ (p. 934). This follows other scholars critiques of EBHC, which, they state, trivialises the application of findings and downgrades the place of ‘judgement’, ‘opinion’ and emotion in the application of evidence (Greenhalgh, Howick & Maskrey 2014; Loughlin 2008). Put simply, this understanding does not allow for knowledge – or ‘knowing’ – to be situated in the actions of organisational members as they engage the world (Orlikowski 2002).

Wieringa and colleagues (2017) reasoned that efforts to purify a complex clinical reality have largely been futile. Drawing on Latour (1993), they argued for EBHC that reflects a ‘middle kingdom’, where the science-nature dichotomy is reflexively rejected; where *all* forms of evidence are deemed worthy of interpretation and translation; where ‘the art of casuistry’ (Jonsen & Toulmin 1988, p. 16) is considered in a context of diverse social values, and the need to reason at all levels is acknowledged – ‘not only from the individual to the general or from the general to the individual but from individual to individual’ (Wieringa et al. 2017, p. 5); and where the limitations of evidence-based healthcare are readily recognised. Towards this aim, Greenhalgh and colleagues (2015) advocated for paradigmatic plurality, where EBHC embraces different values – the humanistic, different knowledges, and different forms of

evidence – particularly that which is ‘personally significant’ (p. 9). Loughlin and colleagues (2017) encapsulated the debate to date, reaffirming the importance of theory to make sense of practice. In this sense, they asserted, the EBHC debate has progressed by employing wider conceptions of evidence, drawing from philosophy of phronesis (an ancient Greek term meaning practical wisdom) (Little 2003; Wieringa & Greenhalgh 2015), human flourishing (Loughlin et al. 2012) and scepticism (Feragen 2017). Loughlin and colleagues (2017) also advocate for pragmatic theoretic plurality:

When dominant theories begin to function not to facilitate but to impede further progress, it is our duty, as a community of practitioners and intellectuals, to be prepared, in principle, to retrace our steps, to make revisions to our underlying conceptual framework that may or may not include reintroducing ideas that form part of our intellectual heritage. (p. 911)

Criticisms of EBHC regarding its tendency towards reductionism, modernism and the marginalisation of selfhood have been refuted. Thomas (2016), explicating both the ‘soft’ and the ‘strong’ (p. 503) critiques of EBHC, claimed that EBHC is neutral with regard to questions of selfhood because it is a method for providing sound healthcare, rather than a ‘doctrine’ (p. 505). Thomas reasoned that, as a method, EBHC cannot implicitly represent a denial of selfhood: ‘A mathematical method for describing an object in no way entails or implies an attack upon, or a denial of a poetic account of the very same object’ (p. 505). Thomas portrayed EBHC as capable of integrating ‘the self’ in the form of patient values and circumstances. He cites ‘a growing body of research’ (p. 506) that connects meaningful conceptions of selfhood to health outcomes. Despite this defence, Thomas (2016) conceded that EBHC might indeed foster threats to the inclusion of selfhood, despite its formal commitment to the contrary, undermining his defence.

Deleuzoguattarian thinking is useful when critiquing linear models of knowledge delivery as part of the processual turn in organisational studies. Wood (2002) articulated organisational knowledge using Deleuze and Guattari's concept of transversal communication to critique linear and homogenous conceptualisations of knowledge management and 'transmission' (p.159). Opposing the rationalist tendency to manage knowledge, Wood's use of transversal communication clarified heterogeneous 'novel alliances' (p.160) within organisations, where 'complex ligatures... span *across* different entities' (p.159, emphasis in original). Similarly, Gherardi (2003) described knowledge as both 'social and material' (p.352), comparing organisational knowledge to mythos, which operates by 'establishing social bonds among different persons, generations and different contexts of use' (p.353). Lawley (2013) applied Deleuze and Guattari's (1987) concept of the rhizome to organisational theory, which is based on the root system to represent non-hierarchical structures, constantly in motion. He used the rhizome to explore how innovation is collective and collaborative in nature, developing naturally through connections within suited knowledge domains. Similarly, Bissola, Imperatori and Biffi (2017) used the rhizome as a theoretical framework for entrepreneurship learning and innovation. Their analysis focused on a postgraduate entrepreneurial programme to activate a rhizomatic learning process. The programme enabled a 'flowing reality' learning process in which heterogeneous subjects interacted to create collective knowledge 'that defines the evolution of the flow' (. Their work demonstrated the unstable and continuous nature of organisational knowledge, helpfully elucidated using Deleuze and Guattari's concept of the rhizome. Collectively, these authors applied Deleuzoguattarian concepts to knowledge management – however, these concepts are yet to be used to clarify health management and knowledge translation. Bringing this processual understanding of knowledge to health services might transcend the limits of EBHC, moving closer to a plane of immanence that allows experimentation and freedom for clinicians to deliver good care.

2.2.2 Mindlines and their relevance for KT

Rather than overturning the modernist rational and scientific aspirations of the EBHC movement (Wieringa et al. 2017) most scholars of the post-evidence paradigm contend that the EBHC movement has its limitations, with many continuing to problematise the idea that evidence is ‘both discrete and isolatable’ (Wood, Ferlie & Fitzgerald 1998, p. 1729) for the benefit of healthcare broadly. Gabbay and le May’s (2004) seminal work arose among these critiques of the EBHC due to a ‘concern about the persistent mismatch between the rational, linear, scientific approach that EBHC demands and the pragmatic, workable approach demanded by the messy world of practice’ (p. 5). Gabbay and le May’s ‘mindlines’ adheres to this widened perspective of evidence-based medicine to include ‘socially constituted knowledge’ (p. 4), promoting the importance of networks of trusted sources. This work exists alongside other significant theoretical work supporting a multidirectional conceptualisation of knowledge, which accounts for the complexities of KT processes. Gabbay and le May defined mindlines as:

collectively reinforced, internalised tacit guidelines, which were informed by brief reading, but mainly by their interactions with each other and with opinion leaders, patients, and pharmaceutical representatives and by other sources of largely tacit knowledge that built on their early training and their own and their colleagues’ experience (p. 1).

In their ethnography in an English general practice, they showed that clinicians preferred to rely on these mindlines for knowledge and guidance and rarely accessed research findings, clinical guidelines and other types of formal knowledge directly unless they had a specific ‘difficult’ case to manage or discuss (Gabbay & le May 2004).

Mindlines are a feature of ‘knowledge-in-practice-in-context’ (Gabbay & le May 2011) i.e. knowledge that is continually co-constructed rather than knowledge as discrete facts only produced externally to time and space and thus requiring dissemination or translation in a linear reasoned way (Wieringa & Greenhalgh 2015). Subsequent research supported Gabbay and le May’s findings (Bengough et al. 2015). Examples of the use of mindlines for KT have included pharmacists and others, who have ‘tapped into’ mindlines as a way of co-constructing evidence-based drug and other information with general practitioners (GP) as a means to improving practice (Gabbay & le May 2011). Another example is the use of academic detailing as an interactive and social translational approach to improve primary care for people with chronic breathlessness (Collier et al. 2015).

These findings suggest that EBHC requires much more attention to the co-construction of knowledge in terms of interpersonal networks and social context (Scottish Government 2016). Gabbay and le May (2011) highlighted that their articulation of mindlines does not inherently seek to undermine EBHC. To the contrary, they argued that by understanding how ‘knowledge-in-practice-in-context’ unfolds, we might better use evidence to ‘shore up and strengthen the evidence-base’ that underpins mindlines (p.12). This language suggestively aligns with more recent debates of EBHC advocating for greater parity between situated clinical judgement and research evidence (Greenhalgh, Howick & Maskrey 2014; Loughlin et al. 2017; Wieringa et al. 2017). This has been acknowledged as an ‘innovative approach to the disciplinary-evidence divide’ (Reid 2014, p. 49).

Gabbay and le May (2011) built on, and contextualised for healthcare, Nonaka and colleagues’ organisational knowledge creation theory (OKCT), which identified conditions enabling

knowledge creation to improve innovation and learning in organisations² (Nonaka 1994; Nonaka & Takeuchi 1995; Von Krogh, Ichijo & Nonaka 2000). It places knowledge on a continuum, fluctuating in form between explicit and tacit, with tacit knowledge being automatic, non-directed, and non-intentional and explicit knowledge involving cognitive processes that are flexible, controlled and intentional. Tacit knowledge is a vital and often malign component of this process. As Nonaka (1994, p. 8) stated: ‘the schemata, the mental models, beliefs and perceptions so ingrained that we take them for granted’. Tacit knowledge is tied to physiology, the senses, motor functioning, and to the relative history of physical movement in the world (Varela 1992) and is necessary for many practices, from inherent physical functioning to the insights or inspiration needed for creativity (Polanyi 1966). Knowledge oscillates between the two ends of the continuum via knowledge conversion, a process that ensures explicit and tacit knowledge are mutually enhancing to create new knowledge (Nonaka & von Krogh, 2009).

Mindlines are collective representations of the way things should work in clinical practice. A mindline is not a thing in itself. It is a relation between things: among clinicians, between clinicians and patients, between patients and ‘practice’. Mindlines encompass human bodies, non-human bodies, identities, ideals, and emotions. Deleuze and Guattari’s (1987) assemblage theory, which inquires into the virtual structures underpinning our reality and the coherence between thought and action, helps us to consider mindlines differently. Principally, however, I will describe the constituent elements of mindlines as they have been used in initial and subsequent applications, and their resonance in theory and practice.

² Gabbay and le May (2011) explicitly state that rather than focus on the creation and diffusion of innovation, as the OKCT does, mindlines is more concerned with acquisition and adoption of new knowledge – a generally more pertinent aim in the context of healthcare.

2.2.3 Mindlines and identity

Gabbay and le May's (2004, 2011) work emphasises a conception of knowledge as 'a social product rather than something generated through the operation of a privileged scientific method' (Law 1992, p. 381). Identity is a popular topic of organisational studies encapsulating a suite of analytical resources dedicated to examining the meanings individuals attach to themselves and others (Brown 2015; Sveningsson & Alvesson 2003). A forerunner to identity research was Goffman's (2002) dramaturgical perspective highlighting the performative nature of identity as individuals enacted positive images of themselves to others. This dramaturgical approach to impression management affords a great deal of individual agency, as the individual is not considered to be passive (Edgley 2003). Rather, individuals negotiate meanings of their lives in social situations with others. Goffman (1959) suggested that self-presentations are not simply for others, but can represent how a sense of self is developed for others (Van House 2011). Goffman's distinction between 'front stage' (performances enacted with an audience present) and 'backstage' (performances that are out of character with a non-present audience) is relevant for considering the multiple and at times contradictory identities individuals ascribe to.

Ongoing identity formation has been termed identity work. Sveningsson and Alvesson (2003) defined identity work as 'forming, repairing, maintaining, strengthening or revising the constructions that are productive of a precarious sense of coherence and distinctiveness' (p. 1165). Extending this definition, Deleuze and Guattari (1984, 1987) as well as others (Zembylas 2003) have analysed the mutually constitutive formation of identity through both internal and social means. This allows for an: 'integrated notion of identity rather than a dichotomy between individual functioning or socio-cultural processes. This provides an approach that refuses the singularity of each 'component' of identity formation' (Zembylas 2003, p. 223). Deleuze and Guattari's (1984, 1987) relational ontology clarifies identity with

reference to embodiment – specifically, they defined embodiment as what a body can do, rather than what it is. Identity is not an affixed, independent entity, but is situated within a network of biological, psychological, cultural, economic, and abstract relations to bodies, objects, technologies, ideas, and social organisations. Changing or extending the relations between bodies within an assemblage might enable new identity-positions, such as ‘expert patient’ or ‘resisting health consumer’ (Fox & Ward 2006).

Identity work lends itself to an exploration of mindlines because it explains ongoing sensemaking in the construction of self-identity and social identity (Watson 2008), aligning with the integrated notions of collective and individual mindlines. Thinking conceptually with identity also allows for the inclusion of emotion. As Haviland and Kahlbaugh (1993) stated, emotions are the ‘glue of identity’ as they provide meaning to experiences. The performance-based elements of identity work (Creed & Scully 2011), which builds on the work of Goffman (1968), further resonates with the performative nature of emotion and storytelling in mindlines. Performative interactions are vital for the formation of identity, for instance in the display of leaders’ or managers’ moral positions (Beech 2008; Fineman 2003). Noteworthy is the work on how emotions can be used as a discursive resource to establish, maintain, revise or reject work-related identities (Clarke, Brown & Hailey 2009; Coupland et al. 2008; Zembylas 2003). Despite the importance of emotion in identity work, the emotional character of identity work is still under-explored (Winkler 2018). In his review of identity work in organisations, Brown (2015) highlighted considerable scope for research on how identity construction is influenced by emotions. Heading this call, Winkler (2018), reviewed identity work to explore how scholars approached and incorporated emotions into identity formation. His review identified three ways that empirical studies incorporate emotions in identity work: nominally identifying emotions as a trigger for identity work; illustrating identity work as an emotional endeavour; and/or describing the emotional impact of successful and unsuccessful identity work. Despite

this work, Winkler (2018) conceded the limitations of literature to date, calling for more research ‘to understand the mutual constitution of emotions and identity work’ (p. 129). Emotion within identity work is often predicated on stories and storytelling. In the next section, I describe the influence of storytelling on identity formation and mindlines.

2.2.4 Storytelling in mindlines

Storytelling features prominently in the mindlines understanding of KT as Gabbay and le May (2011) found storytelling for knowledge sharing seemingly ‘instinctive’ among clinicians (p. 116). Storytelling and narrative analysis have become popular within the social sciences (Ahmed, 2004; Butler, 1997; Pentland, 1999) including management research (Baruch, 2009; Rhodes & Brown, 2005; Tsoukas & Hatch 2001). In the context management discipline, story is often used interchangeably with the term ‘narrative’ (Dawson & McLean 2013). Labov (1997), an influential narrative scholar, viewed narrative as part of the broader field of storytelling, where ‘narrative is the representation of events, [and] story is an event or sequence of events (the action)’ (Abbott 2008, p. 19). ‘Story’ can be understood in many ways, but traditionally it has been understood as a retold chronology of events with a plot and set of characters. Stories often evoke causality, explaining a complex event or series of events coherently in terms of an underlying theory or ontology that the teller imparts (Czarniawska 1997). However, this simplistic description belies the potential complexity in the literature on narratives. Scholars have challenged the linearity and temporal retrospectivity of traditional approaches (Boje 2008; Wiebe 2010) or urged for ‘polyvocal narratives of organizational change’ (Buchanan & Dawson 2007, p. 669). Stories enable sensemaking that is inherently open-ended, distinguishing it from theoretical and propositional explanations for organisational phenomena that tend to abstract from lived experience, subordinating particular facts to general principles (Islam 2013). Stories engender coherence when explaining complex sets of events by ascribing meaning and enabling temporal connection to the complexity,

ambiguity, and unpredictability of social and organisational experiences (Dawson & McLean, 2013). Stories constrain and determine behaviour by providing a rationale for decision-making and action (Fisher, 1985). Additionally, knowledge is both held within stories and exchanged through narrative processes such as conflict and resolution (Connell, Klein & Meyer, 2004).

The importance of stories is reflected in healthcare, where clinicians consistently entwine clinical information into stories of personal experience to share knowledge and generate effects (Greenhalgh, Trisha & Hurwitz 1998; Hunter 1991). The idea that clinicians base their practice on stories has consistently provoked fears regarding the limitations of anecdotal evidence for the ‘exact science’ of effective treatment. Yet the EBHC was initially portrayed by Sackett and colleagues (1996) as the marriage of objective evidence and an individual’s expertise acquired through first-hand experience (Greenhalgh, Trisha & Hurwitz 1998). It is this first-hand experience where most shared clinical stories are based. Gabbay and le May (2011) described how clinicians relate and compare elements of a story, such as the illness script, the treatments attempt, and so on, with the relevant mindline developed from training, experience, and explicit evidence.

In knowledge management literature, stories can help to share knowledge in organisations (Ball & Ragsdell, 2003; Denning, 2001; Ward & Sbarcea, 2001). The use of stories as a KT tool can be an effective means of disseminating research evidence to people living with disability and their healthcare providers (Smith et al. 2015). Bourbonnais and Michaud (2018) posited that storytelling can appeal to both the reason and the emotions of audiences, pragmatically contextualising research results in terms of interest and usefulness. In a systematic review of the use of art and narrative as a KT tool, Gonzalez De Armas, Archibald and Scott (2017) surmised that narratives have the capacity to ‘communicate and express complex, insightful, and meaningful messages that transcend the capacity of everyday language and other modalities of communication’ (p. 120).

In the study of organisational change and sensemaking, stories have been shown to play a significant role (Baruch, 2009; Dawson & McLean, 2013). Collective storytelling in these contexts has been described as a ‘system in which the performance of stories is a key part of members sensemaking and a means to allow them to supplement individual memories with institutional memory (Boje 1991). Active engagement by listeners via checking, challenging or reinforcing means the face-to-face oral sharing of stories is important (Connell, Klein & Meyer 2004). Stories can subvert the ordered nature of reality and offer a more realistic diverse and fragmented view of reality (Boje, 2008, p. 1). By helping to collectively generate shared interpretations of organisational complexity, stories can guide people through uncertainty and change (Lissack, 2012: 168–9). Dawson and McLean (2013) closely studied these effects by examining miners’ storied responses to the introduction of a poorly received performance appraisal system. Here conflict and resistance came to the fore through storying processes where workers’ identities were vulnerable and/or threatened. The stories they developed in response to the change enabled sensemaking and sensegiving and became a powerful discursive tool to ‘shore up their challenged identity’ (p. 220). Stories were entwined in contextual and political processes, with a storyteller actively engaging in moving an audience through features that accord with audience belief and experience. Evidence to date confirms that stories are central to the establishment of collective mindlines and identity through contextual and temporal interconnectedness.

2.2.5 Space and networks

To understand clinicians’ various stories and how they can serve as a hermeneutic to understand organisational complexity, it is important to understand the spaces and networks in which knowledge generating stories unfold. The cycle of building and turning over mindlines suggests an ‘ongoing social accomplishment, constituted and reconstituted as actors engage the world in practice’ (Orlikowski 2002, p. 1). This perspective views practitioners as purposive

and reflexive, continually and routinely monitoring the ongoing flow of action – their own and that of others (Wieringa & Greenhalgh 2015). Monitoring the self and others draws attention to the importance of interaction – not only among individuals, but also non-human actors that mediate interaction, such as technology or implements of a trade (Law 1992). Mindlines rely on professional interactions paralleling literature associated with collective sense-making, communities of practice, and actor networks in knowledge management (Gabbay & le May 2004; Law 1992; Wenger, McDermott & Snyder 2002). For Nonaka (1994), ideas germinate within the minds of individuals, but it is through various modes of interaction that these ideas are developed. That is to say, ‘communities of interaction’ contribute to the amplification and development of new knowledge’ (Nonaka, 1994, p. 15).

To facilitate these communities of interaction, Nonaka and colleagues (2000) suggested that a shared context in motion is required – or ‘ba’. Ba, which roughly translates to place, encompasses the physical, historical, cultural, and social spaces, where knowledge is shared, created, and used. Akin to a community of practice, where a group of individuals share knowledge, learn together, and create common practices (Wenger et al., 2002), ba serves to develop a shared language, clarify prior knowledge, and form a frame of reference. However, ba differs from a community of practice as it represents where new knowledge is created, rather than the interaction with knowledge embedded in the community. As such, the ba of knowledge creation is the time and place in which relevant processes occur. The shared space for emerging relationships, or the ba, can be ‘physical (e.g. office dispersed business space), virtual (e.g. email, teleconference), mental (e.g. shared experiences, ideas, ideals), or any combination of them’ (Nonaka, Ikujiro & Konno, 1998, p. 40).

Nonaka and colleagues (1998) defined and described the different bas that contain the SECI processes: the originating ba, the dialoguing ba, the systematising ba and the exercising ba. The originating ba is particularly important when considering emotion and is associated with

socialisation where individuals share experiences, feelings, emotions, and mental models. This ba offers a 'context for socialisation, since an individual face-to-face interaction is the only way to capture the full range of physical senses and psycho-emotional reactions, such as ease or discomfort, which are important elements in sharing tacit knowledge' (Nonaka et al., 2000, p. 16). Here tacit knowledge is shared among individuals, generally via face-to-face interactions, but also experienced through practices and the observation of practices. In palliative care, this ba is the informal interactions among clinicians and between clinicians and patients and carers. These interactions take place continuously before, during, and after the delivery of palliative care. The dialoguing ba is associated with externalisation and involves consciously constructed dialogues where mental models and skills are shared and reflected upon. Here, tacit knowledge is made explicit through dialogue and the use of metaphors and stories to represent shared ideas and make sense of situations. In the context of palliative care dialoguing ba might involve scheduled case review meetings in which clinicians discuss the ongoing care of patients and/or during clinicians' education sessions. The systematising ba (previously cyber ba) involves interaction in collective or virtual spaces, outside of real space and time. Here, the combination of explicit knowledge takes precedence through virtual interactions enabled by online networks facilitated by email and collectively accessible documentation. In palliative care, this might entail the documentation of clinical notes using the District intranet as well as clinical practice guidelines, although these are largely externally developed. Finally, the exercising ba provides support and context for the internalisation of knowledge via transcendence and reflection through action. Individuals in the exercising ba embody and enact explicit knowledge received in the dialoguing and systematising bas. In palliative care, the exercising ba often involves hands on training or monitoring clinical competencies by auditing. Considering these spaces collectively helps to locate where and how

emotions are felt and/or expressed, influencing the spiralling of information through the SECI processes.

What is arguably different for healthcare organisations compared to Nonaka and colleague's consideration of successful companies is the greater focus on top down approaches to the combination process, fostered particularly by the strong emphasis on evidence-based care. The perception, more often than not, is that evidence must and should come from external sources, solely through high level quantitative research like RCTs. This can reduce support for the knowledge and experience generated in the originating ba and places a more significant focus on the explicit knowledge of the cyber ba. Although this can be important for sharing the efficacy of pharmacological and surgical treatments, quality palliative care requires a greater focus on the emotional and experiential knowledge assets generated in the originating ba.

The importance of ba has been echoed and elucidated in research on how clinical networks operate and their impact on quality care. Clinical networks are here understood, as per Goodwin and colleagues (2004) as social-professional structures comprised of doctors, nurses and allied health care professionals tied through inter-dependencies such as collegiality, friendship, referrals, function or common interest. Braithwaite and colleagues (2009) cited two different network types: purposefully designed networks, funded or imposed by a government, management group or other governing body, and naturally formed networks, composed of emergent relationships among clinicians through professional interests, friendships, supports, referrals, and advice. Delineating these two network types parallels the theory on ba, which can be built intentionally or created spontaneously. Many purposefully designed clinical networks in Australia were established by state governments to foster collaboration on quality and service improvement (Wistow et al., 2012). Although these networks, can foster multidisciplinary collaboration and evidence-based care (Harvey, 2000; Tolson et al., 2007) they can be limited. A bottom-up approach led by clinicians is needed to balance these top-

down approaches harnessing clinicians' natural practices to form systems of mindlines to promote continuous quality improvement with effective self-regulation (Braithwaite, Runciman & Merry, 2009). Despite clinical networks and networks needed for the diffusion of evidence and innovation have witnessed scholarly interest, Lomas (2007) argued there is little incentive provided by health care or academic institutions for establishing and developing them. Corner (2015) noted the limitations of pouring compartmentalised knowledge into complex connected systems, advocating for activities and strategies that instead foster connection between people, practices, ideas, and knowledge. Some scholars instead argue for an approach termed knowledge brokering, a more formalised linkage and exchange between researchers and practitioners (Lomas 2007). This might be fostered by taking advantage of 'opinion leaders': individuals within a network considered influential by other health professionals (Churruca et al. 2019). However, what opinion leaders do and the circumstances in which peers are likely to be influenced by them is socially contingent, for instance, depending on how credible or specialised they are (Locock et al. 2001).

The mindlines framing of KT, including the storying nature of mindline forming and the context in motion required, are important to consider because they emphasise the interactions that occur between clinicians and the individual, internalised process of synthesising the outcomes of these interactions. This way of framing KT allows for the analysis of the emotions that occur or are performed in interactions and represented in the stories shared between clinicians. In the next section, I will explore the literature on emotion in detail, locating the influence of emotion literature in KT and organisational research.

2.3 Locating and conceptualising emotion

The following section is presented in three interrelated sub-sections that contextualise and gives direction to the study of emotion as it relates to mindlines. The first explores differing

approaches to emotion in the literature and presents the justified approach adopted in this study. The second explores literature relevant to emotion in KT. The third explores emotion as it relates to practice, specifically emotional labour and emotion talk.

2.3.1 Conceptualising emotion

Emotion, like KT, has been conceptualised in many ways in research in a variety of fields including healthcare (Robichaud, 2003) organisational research (Elfenbein, 2007; Lord & Kanfer, 2002), social psychology (Forgas & Smith, 2007), human geography (Pile, 2010), and education (Savage, 2004). There is a history of division regarding what constitutes an emotion, particularly between socio-cultural and psychodynamic approaches (Hochschild, 1983; Kemper, 1981). In this vast and disparate body of work, emotion has been described in contradictory ways, also complexified by the interchangeable use of the term ‘affect’ for emotion (see, for instance, Thrift 2004). Establishing a false binary between the two concepts is potentially limiting and unnecessary (Stearns 2019). However, the concepts can be understood as distinct as ‘affect’ captures a wider, more abstract notion, a ‘non-conscious experience of intensity; it is a moment of unformed and unstructured potential’ (Shouse 2005, p. 1). Affect is strongly associated with non-representational theory and provokes difficulty in being grasped and represented through linguistic means (Pile 2010). Although emotions are related to affect, they are representative of conscious, cognitive, and personal expressions by our bodies (Bondi 2005; Pile 2010; Thien 2005). Zemblylas (2016) described the distinction, with affect being a ‘category that encompasses affect, emotion, and feeling’ (p. 541) with affects always embedded in acts and practices. Emotion is more readily represented and localised in personal experience and expression because it signals cultural constructs and conscious processes (Massumi 1995), and as such is the predominant term used in this thesis.

A mainstay of emotion literature and the first significant conceptual approach to studying emotions is the psychodynamic approach that evokes emotions as solely internal, biological, feelings felt in relation to external stimuli (Parkinson, 1995). Ahmed (2013) noted that this corresponds with everyday language that signifies emotion, presupposing interiority: 'I am feeling sad'. This is crucial in psychology where feelings are experienced internally and then expressed outwardly in an 'inside out' model (Ahmed, 2013). A second paradigm in emotion research developed from criticism of this movement and corresponded with the influence of social constructionism. Socio-cultural approaches to the study of emotions placed them within and dependant on social experiences and cultural contexts (Hochschild, 1983; Kemper, 1978; Lutz & Abu-Lughod, 1990; Parkinson, 1995; Savage, 2004; Zembylas, 2007). In socio-cultural approaches to emotion, the conscious, active processes of emotion management are emphasised, rejecting the passive reception of emotions in the psychodynamic approaches. These processes are strongly influenced by learned convictions and rules and are often improvisations based on an interpretation of objects or situations (Cornelius, 1996). These perspectives of emotion are often drawn from symbolic interactionism, identifying the role feelings play in social control, as emotions are shaped by the definitional and situational influences stressed by symbolic interactionists (Shott, 1979). However, these approaches are limited due to their narrow view of emotions as linguistic and conceptual constructs assembled in relation to others, often ignoring the importance of individual embodied experiences of emotion (Zembylas, 2007). Burkit (1997) critiqued the 'one dimensional' (p. 42) nature of defining emotion through cultural rules and conventions guiding interpretation of events stating that sensations are 'necessary components of emotion' (p. 42).

Providing more of an ontological and epistemological 'fit' in the context of KT and mindlines is the 'interactionist' (Savage, 2004, p. 27) approach to studying emotion. Drawing from both socio-cultural and psychodynamic approaches, the interactionist approach is important to

understand emotions as embedded in social and cultural contexts, with an emphasis on the roles that language, bodily performance, politics and culture more generally play in the constitution of emotional experiences. Vital to this approach is an acknowledgment of the socially embedded nature of feeling and experience and that these ‘sensate, corporeal’ (Burkitt, 1997, p. 43) feelings and experiences are localised in the body and relationships between bodies (Pile, 2010). The ‘interactionist’ approach is reflected in Ahmed’s (2013) use of the term ‘impression’ over experience to describe emotions. This is to avoid presupposing a divide between bodily sensations, emotion, and cognition in analytic work regarding emotional experience. Furthermore, ‘impression’ not only suggests a cognitive and an emotional response to an object, but also physical contact: ‘we need to remember the press in impression’ (p. 6).

Ahmed (2004, 2013) consistently reinforced the notion that emotions ‘do things’ (p. 26). Specifically, Ahmed stated they work to align individuals with collectives through the intensity of their attachments. In her examination of the potentiality of emotions, Ahmed’s close reading of texts conceived emotions as a folding of both the outward, in through social and cultural sharing of emotions, and the inward, out, through the embodied, felt nature of an emotion impressing upon an audience. For example, in her interpretation of an excerpt from the Aryan nation’s website, Ahmed unpacked the unifying effects the text generated through hate, identifying the shared bodily sensations between author and reader. The ‘togetherness’ of the hatred towards non-whites sought to make the collective ‘appear as if it were a body in the first place’ (Ahmed, 2004, p. 27) capable of both feeling and expressing collective emotion. Ahmed (2013) drew from Freud (1975) and the psychoanalytic notions of social bond forming through emotion. Emotions have been defined as crucial to establishing the social bond, in mass psychology and psychoanalysis (Blackman & Walkerdine, 2001). Building on this work, Ahmed (2004) attended to ‘how the collective takes shape through the impressions made by bodily others’ (p.23). Here, the feelings for the collective are compounded by the aligning

forces of the feelings about those outside of the collective. Examining the aligning nature of emotions, and the resistance to these aligning forces, serves to elucidate the effect of emotion on the generation of mindlines.

2.3.2 Emotions in KT

The role of emotion in KT somewhat parallels the movement in feminist research to colonise ‘emotion-as-knowledge’ (Tamboukou, 2003, p. 210). Feminist scholars have argued that emotions were historically constructed as epistemically subversive to promote dispassionate investigation and undermine the epistemic authority of social groups associated with emotion (Jaggar, 1989). But the emotional ‘turn’ in educational and sociological theories has reinstated the connection between emotions and knowing. Jaggar (1989) stated that emotions are inextricably associated with evaluation and observation as they provide the experiential basis for values. This conceit is echoed in psychological literature associated with emotion, asserting that events are coded automatically in terms of their meaning for the self (Ekman, 1992; Frijda, 1986; Scherer, 1995). Efforts are being made to entwine emotions and reason in sociology and human geography (Patulny et al. 2019)

In psychodynamic studies exploring emotion and knowledge, emotion has been found to influence the way people interpret, judge, and respond to social information and how information is accessed, processed, and managed (Isen, 2008). As enduring emotional states that enable access to personal resources during different emotional states, positive emotions can helpfully shape what is observed, how it is appraised and evaluated, and how key messages are learnt (Forgas & Smith, 2007; Jaggar, 1989). Furthermore, mood-congruent material is often processed more deeply with greater associative elaboration and as such, learnt better, relative to material that is misaligned with mood (Forgas & Bower, 1987). This is suggested within recent change management literature – Steigenberger (2015) for instance, proposed that

emotions, like hope, can ‘shape [the] content and motivational strength of sensemaking accounts, influence the likelihood that a person will engage in sensegiving activities and will be willing to accept inter-personal sensemaking outcomes’ (p. 432).

Exploring positive emotion as a driver for behaviour change, Boyatzis’ intentional change theory (ICT) presents a way to understand how both individuals and organisations can achieve desired change, emphasising the necessity of ‘deep positive affect’ (Boyatzis & Akrivou 2006; Van Oosten 2006). The ICT is built on five ‘discoveries’ or aspects of learning: the ideal self; the real self; a learning agenda; experimentation and practice; as well as developing supportive and trusting relationships that make change possible. In this theory, Boyatzis and Akrivou (2006) used the terms affect and emotion interchangeably, quoting Watson and Tellegen’s (1985) definition of positive affect as a state of high energy, full concentration, and pleasurable engagement. Positive emotion was said to activate and articulate ideal self, which is linked to self-regulation. The will to change and self-regulate can be fostered by positive emotion, which creates an affective tone prompting the specific cognitive processes that take place. Studying the organisational value of the ICT, Van Oosten (2006) noted the power of positive emotions to create and sustain cultural transformation. Organisational transformation success arose partly because of the ‘resonant relationships’ (p. 715) of the change framed in the positive, resulting in stronger relationships and communication. Van Oosten’s findings support the relevance of emotion in KT, positioning emotion as spaces (or ba) for KT imbued with and referencing emotion, to promote cultural transformation.

Emotion was nominally addressed in Nonaka and colleagues’ (2000) OKCT both in the sense that emotions are shared ‘experiential knowledge assets’ (p. 21) and a context for the SECI processes. Personal and collective emotions can provide a frame of reference, ascribing meaning and value to knowledge objects within ba, both as inputs and outputs. Kaiser and Fordinal (2010) devised the term ‘vocation ba’ to describe the specific space in which emotion

driven self-transcending knowledge is generated and converted to embodied knowledge. Self-transcending knowledge is concerned with a fulfilling life, work and happiness and closely aligns with Boyatzis and colleague's (2006) concept of the ideal self, driven by positive emotions. Kaiser and Fordinal (2010) suggested the factors enabling a vocation ba are a trusting atmosphere, time for unstructured thinking, the use of metaphoric language, and coaching techniques. These enabling factors can contribute to the vocation ba that helps individuals detect their needs for a fulfilling life and work and promotes self-transcending knowledge, which is 'knowledge about the highest future possibility' (p. 931). Emotion literature in KT has been primarily drawn from a psychodynamic understanding of emotion as an appraisal mechanism and motivation for action. While important, this work neglects emotion as practice and the more complex space of emotional labour and emotion talk, which is addressed in the following subsection.

2.3.3 Emotional labour and emotions 'at work'

To understand if and how emotion relates to KT, it is important to understand emotion as a translatable practice in service provision. Described as the management of feelings to create a publicly acceptable bodily display by workers, Hochschild's (1983) 'emotional labour' concept drawing from Goffman (1968), places emotion squarely within the terrain of service provision. Hochschild (1983) distinguishes the term emotional labour from related concepts of emotion work and emotion management: 'I use the term emotional labor to mean the management of feeling to create a publicly observable facial and bodily display; emotional labor is sold for a wage and therefore has exchange value. I use the synonymous terms emotion work or emotion management to refer to these same acts done in a private context where they have use value' (p. 7). In her study of flight attendants in a commercial airline, Hochschild explored the labour required in emotional detachment or emotion suppression as inevitable and necessary in-service provision. She argued that labour was required in deep acting to consciously suppress

unfavourable feelings, like anger or fear, and in surface acting when expressing desirable emotions, by using body language, facial expressions and words that express warmth, pleasantness, and politeness. Hochschild's concept explained how and why practitioners might induce or suppress emotions, or foster emotions in others, to perform their roles (Williams, 2013) and how crucial emotional constraint and stress control can be to work performance (Knights & Thanem 2005).

Importantly for Hochschild (1983), emotional labour is the analysis of workers' emotions through a Marxist lens, identifying the commodification of feelings in organisations. Hochschild and subsequent others (Grandey & Melloy 2017; Jeung, Kim & Chang 2018; Kammeyer-Mueller et al. 2013; Li & Liang 2016; Mesmer-Magnus, DeChurch & Wax 2012; Riley & Weiss 2016; Yang & Chen) have critically analysed how workers' feelings can be manipulated or exploited for financial gain. Commodified feelings are often necessary for workers to meet organisational demands, provoking a cost to the worker when required to act in ways that oppose how they feel. Hochschild and others have argued this process intrinsically alienates frontline workers from their emotional product. This is because managers own and control the form, timing, giving, and withdrawal of workers' feelings, moods, and displays, so they 'belong [more] to the organization and less to the self' (Hochschild, 1983, p. 198 cited in Brook, 2009). In 'caring' professions, like palliative care, the commodification of professionals' emotions is often linked to emotional labour while engaging with their patients. Riley and Weiss (2016) highlighted the gendered focus of emotional labour research in nursing and midwifery, with scholars exploring how professionals are socialised to manage their emotions, principally by suppressing or controlling their feelings.

While Hochschild's (1983) emotional labour concept remains influential, some scholars have suggested that an organisation's influence on emotional labour is overstated. They highlighted the unmanaged spaces that offer respite from managerial control, as well as the satisfaction

from caring (Bolton 2000; Rodriguez 2011; Theodosius 2006). This critique rests on the notion that Hochschild artificially overemphasised the divide between the public and private performances of emotion management. Bolton (2005) argued that Hochschild missed the distinction between emotional labour in the production of commercial services and emotional labour as part of professional norms. Brook (2009), however, rejected the notion that emotional labour involves the commodification of workers' emotions only when commercialised for profit, arguing that workers can never truly be free from organisational demands. Using Hochschild's reading of Marx, Brook argued that labour power is unlike other commodities – this is because employers are unable to control its final form or cost, given their inability to detach it physically, mentally, or emotionally from the individual worker. The supposed unmanaged spaces are 'contradictory experiences where workers are able to utilize the indeterminacy of the labour process to alleviate and/or oppose their day-to-day alienating existence at the frontier of control' (Brook, 2009, p. 546).

Hochschild's concept of emotional labour has inspired debate on the distinctions between internal and external manifestations of emotion. Knights and Thanem (2005) noted the importance of managing the feelings of an inner self and 'carefully and systematically managing the body' (p.8). This importance is somewhat lost in the 'disembodied character of Hochschild's analysis... reinforced by the distinction she makes between physical and emotional labour' (p.16). In their consideration of embodied emotional labour, Knights and Thanem (2005) argued for an embodied sociology of emotions, which aligns with the interactionist approach, outlined at the beginning of this section. In addition to the assemblage approach to embodied emotion, Hochschild's work was linked to Deleuze and Guattari's (1984) critique of capitalism, where they argued capitalism 'constantly seeks to avoid reaching its limit, while simultaneously tending toward that limit' (p. 34). Specifically, capitalism

colonises human subjectivity as a profitable source of emotional labour (Munro & Thanem 2018).

In human geography, the centrality of emotion for constructing different roles has been explored extensively (Amin & Thrift 2007; Bondi, Davidson & Smith 2012; Dyer, McDowell & Batnitzky 2008; Hesmondhalgh & Baker 2008). Earle (2009), focusing on the 2008 global financial crisis, explored the emotions related to trust and confidence in financial decisions and the usefulness of these discursive emotional positions for government initiatives. Feminist scholarship has been particularly prominent in this field, challenging the dominant construction of emotion as gendered and irrational to reveal emotion as a critical asset, rather than liability, in completing commercial exchanges (Kelan 2009; McDowell 2013; Morini 2007). Warren (2016) investigated the intimate, conscious, and situated bodily feelings that helped surfboard-makers construct and understand their role. The male surfboard-makers involved in his study demonstrated how emotion enabled them to perform certain kinds of work. A central tenant of this work is a focus on the embodiment of emotions and identity work, which is closely aligned with the work of KT scholars working outside of the (post)-positivist paradigm.

A concurrent body of literature exploring emotion at work is associated with identity construction through emotion talk. This literature, developed from social interactionism, is founded in the premise that many emotions are evoked by the 'real, anticipated, imagined, or recollected outcomes of social relationships' (Kemper, 1978, p. 32). Reddy (1997) explored how emotional gestures and utterances 'alter the states of the speakers from whom they derive' (p. 327). He cited feminist ethnographies of emotion (Abu-Lughod, 2016; Lutz & Abu-Lughod, 1990; Rosaldo, 1984) drawing from Foucault's notion of discourse, Bourdieu's concept of practice, and feminist critiques of essentialism, to understand emotion states as an effort to offer 'an interpretation of the unobservable' (Reddy, 1997, p. 331). The emotion statement, termed 'emotive' is an inescapable facet of social life, shaping social identity and relationships

and, through its performance directly affects the world. Smith's (1978) influential work exploring the construction of identity through talk explicated the ways emotional resources are used through talk and 'credible performance' to construct and define another as mentally ill. In healthcare, the role of talk in identity construction has been examined in doctor-patient consultations, where patients' accounts contained emotive and vivid descriptions of their experiences (Webb & Stimson, 1976). In this construction of identity through emotion talk, elements of drama constitute what Webb and Stimson called atrocity stories. These emotion-laden stories are used not only to make sense of past events, but also to redress power imbalances between doctor and patients by construing patients as rational and sensible beings, and chastising doctors' actions as inappropriate, irresponsible, or insensitive.

2.4 The setting of the research: palliative care

The following section is presented in three interrelated sub-sections that provide context for palliative care where this study took place. The first defines palliative care, highlighting the varying practices involved. The second explores literature relevant to KT in palliative care. The third explores the literature associated with emotion in palliative care.

2.4.1 Palliative care

Palliative care focuses on improving quality of life through pain relief and symptom management to promote a self-determined good death (Collier, 2013; Finlay, 2003). This focus aligns with the concept of 'dignity' in dying (Abiven, 1991) and thus encompasses the psychosocial, spiritual, and existential (Chochinov, 2002). According to standards produced by Palliative Care Australia (2005), a palliative approach is one that addresses 'the holistic needs of patients and caregivers that is reflected in assessment and in the primary treatment of pain and in the provision physical, psychological, social and spiritual care' (p. 11). This reflects Saunders' (1978) seminal work addressing 'total pain', as well as the World Health

Organisation (2008) definition. In all, an underlying feature of commonly accepted palliative care practice appears to be an effort to provide personalised and compassionate end-of-life care by maintaining and supporting links with the individual's everyday life.

In practice, the elements that make up palliative care are disparate and support for decision making, attention to carer wellbeing, and other peripheral factors are incorporated. Palliative care encompasses both pharmacological treatments for symptom management and relief to improve wellbeing, addressing issues associated with pain management bowel movements, nausea and vomiting, mental health, and sleep as well as non-pharmacological treatments (Lindqvist et al., 2012). The complexity of non-pharmacological treatments can be challenging for palliative care, encompassing the psychological, social, and ethical, while communicating effectively and being attuned to family and carer issues and diverse cultural contexts. This is because of the difficulties in 'quantifying' the 'intangible' appropriate outcome measures in studies seeking to evaluate practice (Hack 2012, p. 682). Minimal attention has still been paid to how staff use non-pharmacological approaches to optimise wellbeing and comfort in the very last days of life (Ferrell et al., 2000). However, research has demonstrated the importance of fostering close connections within palliative care teams, across the specialist and generalist divide, and with patients and carers (Collier & Gott 2018; Collier et al. 2019; Seow et al. 2017). This emerging research underscores the importance of investigating how collective mindlines are fostered in palliative care, and their role in shaping quality practice.

Prior to the 21st century, there was a general trend away from dying at home and towards dying in a hospital (Palmer, 1993; Scotch, 1970). Recently, dying at home has become more prominent, largely because of increased community-based resources dedicated to this role, engendering an aspirational focus of much palliative care. However, this remains a contentious assertion partly due to the changing needs and preferences of patients and carers over time (Gerber, Hayes & Bryant 2019; Gomes et al. 2013; Hoare et al. 2015). Regardless, there are

ongoing calls for better equipped community-based palliative care services to enable more people to die at home (Productivity Commission 2017; Swerissen & Duckett 2015). Community-based palliative care is conducted in patient homes and largely involves addressing new and ongoing symptoms, managing and advising on medication use and facilitating allied healthcare such as occupational therapy and social work. Palliative care delivered in patients' homes significantly decreases the number of emergency department and hospital admissions (Peters & Sellick, 2006) and increases the quality of life and general wellbeing of patients (Brumley, Enguidanos & Cherin, 2003).

2.4.2 KT in palliative care

The 21st century has witnessed many top-down attempts to translate research evidence into palliative care practice. Contemporary local examples include government guidelines outlining palliative approaches in healthcare (Commonwealth of Australia 2011). Another approach is the Respecting Patient Choices program, designed to train healthcare providers to facilitate discussions about advanced care planning; document plans appropriately; and facilitate organisational change to support advance care planning (Austin Health, 2006). The Better Palliative Care in Aged Care measure introduced by the Australian Government has led to the Decision Assist project providing specialist palliative care and Advance Care Planning advisory services nationally to aged care providers and GPs caring for recipients of aged care services (Department of Health, 2016). International approaches to KT in palliative care include the Liverpool Care Pathway. The Liverpool Care Pathway for the Dying Patient (LCP) is an approach to care that includes a set of interventions, aimed to replicate standards of palliative care within hospitals. This approach stemmed from a belief that acute care settings did not provide adequate care for patients with life-limiting illnesses. These KT vehicles have generally enabled greater access to research evidence and agreed standards of 'quality practice', however they are limited by not accounting for the 'messy world of practice' (Gabbay

& le May 2011, p. 5). This is reflected in the difficulties in translating relational and ‘holistic’ approaches into personalised palliative care (Gott et al., 2012). Additionally, complex interactions with patients and carers and the associated emotional labour tend to be difficult to translate via explicit means. As is the tacit and practical know-how of managing a clinician’s movement in the intricate space of patient homes. The translation of these practices is much more amenable to fluid and situated approaches to KT, described in mindlines.

The importance of mindlines has been alluded to in reviews of KT in palliative care (Degner, 2005; Parker, 2014). These accounts note the tenuous and fluid practices indicated in community-based palliative care. Complex ‘bad news’ interactions with clients as well as the tacit, practical know-how of managing one’s movement in the intricate space of homes are considered, revised, and validated in an indefinable way. In her paper exploring the importance of theory for KT in palliative care, Degner (2005, p. 112) acknowledged the importance of Gabbay and le May’s (2004) work for future KT in palliative care:

Such mindlines were vividly exemplified when one of our students ingenuously stated, after completing a systematic review for our Evidence-Based Nursing Practice course, ‘But I don’t believe [the evidence]!’ Yes, new evidence based on statistical differences is ‘pallid’ to practitioners and much less compelling than the evidence of their own eyes. So, we need to attend to historical examples to constantly remind ourselves that what is obviously effective to us today may go the route of bleeding or indeed the radical mastectomy of not so long ago.

Here Degner describes a ‘eureka moment with her students, discovering the deficiencies of EBHC and the ability for mindlines to address this deficiency in palliative care. Since Gabbay and le May’s (2004) original study, there has been an increasing emphasis in policy and

research on patients' actively participating in their own healthcare, represented by concepts such as self-management, co-production, co-decision making, and co-design (Gabbay & le May 2011). This is partly due to the centrality of patient and family decision-making in palliative care.

Within Australia, mindlines in KT is slowly being adopted with efforts to recognise the complexities of palliative care and recognise clinicians authority to create and act on evidence (Collier et al. 2019; Iedema et al. 2019). For example, the KT project CareSearch uses peer review and stakeholder groups to ensure evidence is not only contextualised for practice but considers the most appropriate online format for sharing. Accordingly, evidence might be presented in multiple formats, including tweets, blogs, guidelines for particular audiences, e-learning modules, and curated hubs of information for specific practitioners (Rawlings D et al. 2017; Tieman 2016). Ultimately however, more work is needed in palliative care to understand how codified knowledge is, or is not, integrated with clinical knowledge so that care is individualised and best practice palliative care is increasingly available to all (Yardley, Martins & Walshe 2019).

2.4.3 Emotion in palliative care

Clinical roles are 'lived and thought through emotions' (Anderson & Smith, 2001, p. 7). Emotional labour is particularly evident in healthcare. This has developed from a now strong trend of patient-centred care requiring compassion and empathy, founded on emotion labour (Gray 2009; James 1992; Kleinman 1988; Riley & Weiss 2016). This view rejects a historical perception of nursing as unemotional physical labour, which is reflected in task-orientated approaches to nursing and the predominance of the biomedical model (Melia 1987; Walsh & Ford 1989; Williams 2013). In community-based palliative care, clinicians experience and witness a variety of emotional states due to the nature of their work (Weissman 2009). In this

context, importance is placed on the psychosocial and emotional aspects of patient care (Commonwealth of Australia 2011). Research on palliative care clinicians' emotions has been primarily concerned with negotiating social interaction and giving voice to dying patients (Li & Arber 2006) and the emotional strain associated with moral distress (Brazil et al. 2010; Weissman 2009) particularly around ceasing treatment (Harrington & Smith 2008).

When considering palliative care clinicians' emotions, it is worthwhile considering moral distress. Moral distress has been described as outcomes of moral conflicts experienced by clinicians as part of their commitment to, and empathy for patient experience and their directed effort to alleviate suffering (Hanna 2004). Moral distress can occur when clinicians are unable to pursue an ethically appropriate course of action due to external or internal constraints (Weissman, 2009). Palliative care clinicians are especially susceptible to moral distress due to the tension between the core values of palliative medicine and those of non-palliative medicine. The focus of non-palliative care teams remains almost solely on curative treatment, with investigations and active treatments often continuing until the last days of life (Hillman & Chen 2009). This focus can diminish the management of pain and other symptoms, often to detrimental outcomes (Clark et al. 2014; McNamara & Rosenwax 2007). Alternatively, the goals of care for palliative care clinicians revolve around addressing physical, psychosocial, and spiritual concerns, rather than attempting to prolong life at any cost (Commonwealth of Australia 2011; WHO 2008).

Due to moral distress and work needs, emotional labour regularly forms a key component of care for patients with life-limiting illnesses (Gray 2009; Gray & Smith 2009). Often clinicians providing care at the end-of-life are required to suppress anger and despair during particularly difficult or harrowing experiences to normalise the patient and carer experience of patients and carers. Dissonance between felt and displayed emotions has been linked with burnout and the formation of the 'hard nurse' (Brotheridge & Grandey 2002). Clinicians also use emotion work

to reduce the perceived severity of life-limiting illnesses for patients who do not talk openly about their prognosis (Copp 1996). In her study conducted at a hospice, Froggatt (1995, 1998) found the containment of undesirable emotions was vital to construct an intimate relationship between nurses and patients, which nurses viewed as pivotal to their role.

Additionally, and importantly for this study, emotions are made relevant in palliative care nurses' daily practices through emotion talk, here understood as using specific words to 'attribute feelings and meanings to the shared and lived experiences' (Li & Arber, 2006, p. 28). Palliative care clinicians regularly conceptualise emotions in talk using metaphors. Froggatt (1998) found that metaphors, such as 'breaking down', 'raising feelings', or 'venting feelings' (p.334) served to construct emotional expression in patients and clinicians as movement or energy. Emotion talk can sooth social interactions and give voice to dying patients' words and actions, serving to translate patients' behaviour and construct their moral identities (Froggatt, 1998; Li & Arber, 2006; Perakyla, 1991). Li and Arber's (2006) study of the construction of palliative care patient identity through talk explored how nurses constructed the credible and troubled patient through talk. In these instances, emotion talk centred on the dying trajectory, the deteriorating emotional body, and the sound mind as resources. Nurses used atrocity stories to express their opinions and feelings about harrowing patient experiences or doctors who might have behaved insensitively (Li 2005). Perakyla's (1991) ethnography of hope work in hospitals also explored emotion talk in the construction of moral identities. Through reciprocal relationships, dying patients and clinicians constructed the hopefulness of situations, what Perakyla termed reciprocal 'hope work'. Patients and doctors collaborated to construct a hopeful and positive situation through dialogue using terms like 'feeling better' (p. 420) or 'getting better' (p. 421). Doctors used phrases and words to evoke hope and optimism, supported by the patient in the interaction, they also served to reduce the hopefulness of situations via emotive language such as 'past recovery' (p. 421). These expressions of emotion

in palliative care talk serve as an analytical focal point for this research and the subsequent development of a theory describing the influence of emotion on mindlines.

2.5 Conclusion: uniting the literatures

In critiquing and synthesising the disparate literatures on mindlines, emotion, and palliative care to inspect the spaces between, this chapter has focused on the nexus of this research. This nexus is the space where emotion and knowledge meet in palliative care, often in the stories shared by palliative care clinicians that contain and construct identities, attitudes, beliefs, and practices. There remains a substantial gap in the literature regarding how emotions are entwined with different kinds of knowledge, including explicit evidence, practical wisdom, and intuition in mindlines. In essence: how does organisational knowledge stabilise and transform in varying emotional contexts? My analysis required an approach that could frame the heterogenous elements of emotions and knowledge translation to illuminate the conditions that arrangements of emotion and knowledge were made possible.

Using the conceptual framework of the assemblage (Deleuze & Guattari 1987), my thesis set out to articulate how emotions are constituted with other parts of community-based palliative care mindline assemblages - the various elements that make up different ways to enact palliative care. This is achieved by identifying emotional mindline assemblages in community-based palliative care, elucidating how emotions help to mutually constitute or contest collective and individual mindlines in practice. The complex, virtual arrangements of materials, ideas and desires within the mindline are representations of the way things should work. Mindlines become apparent through clinician's articulation and performance of actions, emotions, human and non-human actors, and the identities or 'subjects' they constitute. The epistemological positioning offered by assemblage theory helped to interrogate both key concepts proposed in this study: mindlines and emotion. In the next chapter, I describe this conceptual framework in

more detail. Following this, in chapter 4, I describe the methods used to achieve my aims: an inquiry of critical incidents in palliative care settings using a qualitative approach to collecting and analysing data. As I will detail in chapter 4, focusing on critical incidents as assemblages aided my understanding of the effects of emotions in constructions of temporary and enduring individual and interpersonal mindlines.

Chapter 3: Research framework

3.1 Introduction

In this chapter, I outline the conceptual, methodological, and ethical considerations of my study. In the first section, I outline the challenges presented by the varying theoretical approaches to emotion, justifying my decision to draw on Deleuze's transcendental empiricism to frame my study. I also outline the implications of this approach for conceptualising emotions and mindlines. I then present the methodological framework justifying the logic of the study, the research methods, and the research product. In the third section, I describe the ethical framework of the study, outlining how it was developed and maintained for the safety and benefit of participants and me.

3.2 Conceptual framework

3.2.1 The nature/culture dichotomy

To understand the heterogeneity of emotion and mindlines required me to consider how best to address the nature/culture divide. Duff (2014) noted the tendency in health research to become 'caught in the paradox of subjectivity' (p. x) because of this divide, as research acknowledges the importance of individual lived experience on the one hand but abandons subjectivity to offer generalisable results. He noted that this critique was provided by Foucault (1978) who problematised the human subject as an object of human science due to the ontological status of the embodied subject. Duff (2014) noted that Deleuze and Guattari (1987) offered a solution the 'bewildering ontological pluralism' (p. xi) of modern health and social sciences. Deleuze's (1988) transcendental empiricism abandons the ontology of nature or culture, offering a vital topology of the inside and the outside. This is a folding topology, where

the inside is always yet another fold of the outside, just as the outside is always a folding of the inside. In the context of emotion or mindlines, the embodied subject is implicated in a process of folding between an ‘inside’ of affect, feeling, information, or subjective experience with an ‘outside’ including the folds of other bodies, organisational systems, technologies, habit, and practices (Deleuze 1994).

A Deleuzoguattarian approach attends to the problem of dichotomy in emotion research by ‘insist[ing] on the processual nature of the socio-material’ (Müller 2015, p. 30) rather than rely solely on the totalising structures of psychodynamic or socio-cultural approaches. This is founded in an ontological perspective that enables heterogeneity:

There is only one reality, but that reality is multiple in and of itself and we need conceptual tools like Deleuze and Guattari’s concept of the assemblage to disentangle it and render visible its constitutive threads. (Buchanan 2015, p. 387)

In this ontological reality events occur on two mutually constitutive planes at once: the plane of immanence – constituting the affective, abstract, and symbolic; and the plane of consistency – constituting the concrete, physical world we can touch (Buchanan 2015). Within this approach, subjectivity and embodiment can be considered assemblages of the inside and the outside, or ‘forces and processes distributed in multiple, dynamic and recursive relations’ (Duff 2014, p. xii). Nature and culture are not ontologically distinct, but rather mutually constitutive.

3.2.2 Assemblages and territorialisation

A Deleuzoguattarian perspective offers a toolkit to examine the affective and the relational processes of a ‘becoming’, a state that opposes the rigidities of structure, of reality drawn from intensive singularities that coalesce into an assemblage of human life (Duff, 2014). Deleuze’s concept of the assemblage has proved influential in many fields of research, with many unique

readings of assemblage theory emerging from Latour (2005), DeLanda (2016), Grosz (1994) and Bennett (2009). Müller (2015, p. 28) since defined assemblage as ‘a mode of ordering heterogeneous entities so that they work together for a certain time.’. Assemblage theory is relevant to emotion and mindlines because they resist closure (Anderson et al. 2012). Rather than draw on *a priori* elements, relations, or groupings, assemblages provide ‘an openness about spatial form that follows from an experimental stance that is attentive to how provisional orderings cohere in the midst of and through ontologically diverse actants’ (Anderson et al. 2012, p. 173).

Assemblage theory is also concerned with making and unmaking territory – the stabilising lines of articulation and destabilising lines of flight (Wise, 2013). It is through ‘follow[ing] the multi-various lines that twist and turn and finally intersect’ (Buchanan, 2015, p. 387) that we might apprehend the assemblage. In practice, Deleuze and Guattari described assemblages as tetravalent, composed of two axes, each with two sides (Deleuze & Guattari 1987; Dewsbury 2011). An assemblage is the productive intersection of independent forms: forms of content (actions, bodies, and things) and forms of expression (affects, words, and ideas) (Buchanan 2015). An assemblage emerges from the productive but contingent co-functioning of these material and immaterial forms. These co-produced forms hinge on what works. Deleuze and Parnet wrote, ‘the assemblage’s only unity is that of co-functioning: it is a symbiosis, a “sympathy”’ (2002, p. 52). Any apparent unity results from what Buchanan (2017) describes as ‘mutually agreed upon illusions of coherence’ (p. 465). Assemblage is a way of accounting for degrees of stability and contingency within living, working arrangements; it is a way of explaining apparent order without reifying structure.

Deleuze and Guattari (1987) described a second axis of co-functioning, comprised of ‘territorialisation,’ which is here understood as the making and unmaking of territory. Assemblages always produce territories; these need not only be places, but also include

arrangements of bodies, subjects, things, and ideas (Buchanan, 2015). The concept of territory speaks to consistency and flux; as ‘re-territorialized sides [...] stabilize [the assemblage], and cutting edges of de-territorialization [...] carry it away’ (Deleuze & Guattari 1987, p. 88). Müller (2015) explained, assemblages ‘establish territories as they emerge and hold together but also constantly mutate, transform and break up’ (p. 29). Importantly, with every de-territorialisation is a corresponding re-territorialisation. For instance, when a person is forced to cross a geopolitical border, they might be de-territorialised as a ‘citizen’ and re-territorialised as an ‘asylum seeker’, ‘illegal migrant’, or perhaps even ‘community member,’ depending on the expressive machines at work. It is through these processes of (re)territorialisation that an assemblage produces a ground upon which certain work and words can manifest.

Assemblage and territorialisation provide entry points to explore mindlines without delimiting what they might look like. Thinking with assemblages prompts the question: does it work; rather than: is it true (Massumi in: Deleuze & Guattari 1987). This does not mean assemblages can be described through ‘obvious mechanical explanation’ of arrangements; as Buchanan (2015) argued, that is ‘precisely not what Deleuze and Guattari had in mind’ (p. 384) when developing the assemblage as a concept. For Buchanan, Deleuze and Guattari were less concerned with material objects than they were with assemblages as ‘purposeful’ and ‘beneficial’ living arrangements (p. 385). Material objects can form part of an assemblage, but they should not become the central point of analysis. This understanding of the assemblage has implications for my understanding of emotion and mindlines, which I will now detail.

3.2.3 Mindlines as assemblages

Deleuze and Guattari’s (1987) notion of the assemblage was immensely productive in thinking mindlines as complex, virtual arrangements of materials, ideas, and desires. Mindlines are representations of the way things ought to work. They are understood and expressed by

clinicians through their description of actions, emotions, human and non-human actors, and the identities or ‘subjects’ they constitute. They follow a creative involution, a process of ‘scrambl[ing] simple genealogical lineages’ (Wood 2002, p. 160) and representing a ‘labyrinthine movement of engagement, intervention and intersection in which the boundaries of individuals, artefacts and machines are constantly being formed and deformed’ (p.164). Mindlines are a mixture of heterogeneous elements. However, as Wood (2002) instructed in relation to organisational knowledge, mindlines must be divided into constitutive differentials to make the invisible visible: ‘Knowledge is expressed on the one hand by the totality of elements of different natures but also in the interval that is established along a particular line’ (p.167).

This reading of mindlines follows Deleuze and Guattari’s (1987) thinking, who ‘tend[ed] to proceed from the abstract to the concrete’ (Buchanan 2015, p. 389) starting with ideas that subsequently function as structures of reality that are de-territorialised or re-territorialised. A mindline, like an assemblage, is purposeful; ‘the deliberate realisation of a distinctive plan (abstract machine)’ as opposed to ‘a happenstance collocation of people, materials and actions’ (Buchanan 2015). Gabbay and le May (2011), although limiting flux, similarly noted that the intersection between patient and practitioner realities in the form of a clinical interaction is where an ‘abstract’ mindline can take shape as a ‘practical, concrete outcome’ (p.187). Mindline assemblages are solutions to a problem that benefit someone or something within or outside the assemblage (Adkins 2015). An assemblage always serves a purpose (Buchanan 2015). Put simply, mindlines in Gabbay and le May’s (2011) work are assemblages working to benefit patients in the context of health care. But this definition is limiting. As I will show in subsequent chapters, contradictory mindline assemblages might benefit patients and/or carers and/or some clinicians and not others and/or institutional logics. It is this fluctuating benefit that dictates the instability of mindline assemblages in practices.

To consider the mindline as an assemblage further, we might consider a type of mindline commonly articulated by scholars following this approach (Barley et al. 2008; Cowdell 2019; Grant, Sullivan & Dowell 2013; Wieringa et al. 2018a), the prescribing mindline. In their book, Gabbay and le May (2011) describe an instance of a GP prescribing exercise for someone presenting with depressive symptoms. To understand when this prescribing mindline is enacted and why, we can use the assemblage theory to unpack the heterogeneous elements that make up the mindline assemblage. For instance, the ideas or evidence at the heart of the prescription, the practices involved, the emotional milieu of the interaction between patient and clinician, the identities bound up with this practice, and the ideals and emotions associated with overmedication. Framing mindlines as mindline assemblages follows Gabbay and le May's (2004) original intention to understand and describe socially shared knowledge and embodied patterns of behaviour. Assemblage framing helps to pull the mindline apart and consider what the important elements of the mindline are and in what context it is useful.

Thinking the praxeological poetically, mindlines are a metaphorical allusion to the lines between interconnected minds (Gabbay & le May 2011). These might be lines established within a health service or a real or virtual community of practice. By thinking of mindlines using Deleuze's work, we might reappropriate the metaphor to become the establishment of territorial lines within minds. When an arrangement of bodies, ideas, acts, and emotions work harmoniously, they work within these lines. As I will explicate, these territorial lines are represented by clinicians as lines of stability. But in practice these lines are often dismantled in 'flight' (Wise 2005, p. 80), or de-territorialised, becoming something else that is ultimately productive. When the unexpected or the maladaptive occurs in practice different territorial lines of possibility can be (re)created, remarking the lines within a clinician's mind, creating a new territorial demarcation or 'mindline'. The stability or flux of mindlines co-exist with the

stability or flux of emotions as these emotions are inherently part of palliative care arrangements.

3.2.4 Emotion in a Deleuzoguattarian conceptual framework

Deleuze's oeuvre is helpful in my study because it allowed for a plurality between the inside and the outside. This closely aligns with Ahmed's (2013) challenge to the dichotomy of emotion and reason, and her insistence on implicating the complex relations between power, emotion, affect, and subjectivity. An assemblage approach is helpful to explore the fluid and boundary-crossing nature of emotion in palliative care. It allows for multiple disciplines and perspectives to co-exist within the research itself, incorporating all types of knowledge including the personal and aesthetic. This reflects my conceptualisation of emotion as negotiated or constructed during interaction, mediated to a large extent by language, but also allows for embodied accounts of emotion to fold into the thesis, emphasising 'the seamlessness of thinking and feeling through exploring the role of language, body, and social practices' (Zembylas 2011, p. 35). This approach to studying emotions was also inherently politicised as it prompted interrogation of the dominant historical and cultural norms shaping how emotions are expressed, and who gets to express them, and under what circumstances (Holmes 2004).

Conceptually, mindline assemblages allow a multitude of equally relevant relations among people, materials, and emotions. Within assemblages, the non-human, both corporeal and incorporeal, can act on human subjects, promoting or delimiting their agency. The work of Latour (2005) has been influential in showing that material objects can and frequently do have agential power. Equally pertinent within assemblages are emotions, or as Deleuze (1988) conveyed, affects. Contemporising the work of 17th century philosopher Baruch Spinoza, Deleuze (1988) theoretically described the affective capacities of emotion. Spinoza conceptualised ethics as an ethological concern (i.e. the study of a body's capacities). For

Deleuze (1988), joy is experienced through a powerful, productive composition of two bodies. In contrast, sadness occurs during an encounter between two bodies that are in disagreement. Joyful compositions between bodies are powerful and productive, while sad compositions decrease capacity to act and experience. Joyful combinations produce new, more powerful relations, while sad relations with other bodies threaten cohesion, stability and sustainability (Deleuze 1988). Spinoza's affective theory is ultimately an ethical one, where joyful or sad relations are framed in moral terms as good or bad. Deleuze (1988) wrote: 'That individual will be called good (or free, or rational, or strong) who strives, insofar as he [*sic*] is capable, to organize his encounters, to join with whatever agrees with his nature, to combine his relation with relations that are compatible with his, and thereby to increase his power' (1988, pp. 22-3). Duff (2015) used the example of binary sexual identities to explicate Deleuze (1988) and Deleuze and Guattari's (1987) argument: 'binary identities like male/female and gay/straight limit a body's power of acting by regulating the field of affects and encounters such a body may legitimately experience' (p. 32). Deleuze's reading of Spinoza has been considered as an anathema to the 'oppressive' experiences of organisational life (Scott 2010, p. 176).

Reflecting Spinoza, an ethical aim is to increase the body's capacity to affect and be affected. This framing of emotion suggests the importance of investigating the ethological composition of bodies and subjects to identify the specific relations, affects, and events that enable joyful or sad encounters between bodies. Ethology is a way to distinguish between elements, forces, or relations that promote the power of acting of a given assemblage of health, and those which decompose or frustrate this power. In this study, I use this ethology to explore the relations, affects, and events that support, for instance a clinician's ability to care, their self-preservation, or the institutional logics within and beyond the centre.

3.2.5 Summary and limitations

The epistemological positioning offered by Deleuze helped to interrogate both key concepts proposed in this study: mindlines and emotion. This suggests that inquiry should focus on social interactions in healthcare where person-environment transactions occur and involve investigation and critique of the discursive and performative construction of emotions and ‘knowledge’ in a situated approach accounting for the complexities of clinical practice (Schutz, Hong, Cross, & Osbon, 2006; Doane & Varcoe, 2008). Based on this conceptual framework, my empirical task was to document the array of bodies, technologies, affects, and events ‘involved’ in mindline assemblages to consider who was benefiting in these assemblages. I then considered how these assemblages were de-territorialised and re-territorialised in practice, with particular attention to the affective dimensions of mindline assemblages.

There is a growing body of work that I drew from that has strived to emulate this paradigmatic direction in emotion research, privileging fluidity across the social, cultural, political, intrapersonal, and embodied dimensions of emotion (Ahmed 2013; Braunmühl 2012; Butler 2006, 2016; Chubbuck & Zembylas 2008; Savage 2004; Warren 2016; Zembylas 2003, 2007, 2016). These studies recognise emotions as embedded in particular social and cultural contexts, emphasising the role of language, bodily performance, politics and culture in the constitution of emotional impressions. Ahmed’s (2013) work, while not always explicitly stated, is heavily inspired by poststructuralism and, specifically, Deleuzoguattarian thought with a focus on the mutual composition of discursive and embodied emotions and how they produce subjects’ identity (Mumby & Putnam 1992). An approach following Ahmed’s (2004) emphasises the role language and culture play in constituting the experience of emotion. Ahmed’s (2013) conceptual approach interrogates the naming and performing of different emotions in emotion texts. Words used in relation to emotions are not assumed to be simply labels for ‘emotional things’ describing pre-existing entities or natural events. Rather they are seen as assemblages

‘of complex ethnotheoretical ideas about the nature of self and social interaction’ and as ‘actions or ideological practices’ serving specific ends to create and negotiate reality (Lutz 2011, p. 10). My approach similarly aimed to unpack the complex layers of meaning and movement represented by the words associated with emotions.

There are irrevocable limitations with any paradigmatic position. The prospective limitations of my theoretical framework relate to the constructiveness of a post-structuralist approach, the limitations of plurality, and the problem of representation. Alvesson and Sköldberg (2017) outlined the general limitations of post-structuralist methodologies, including its limited constructiveness. Although well-documented in critiques of post-structuralism, this ‘deconstructive’ methodology can help to breakdown taken-for-granted ideals, thoughts, and practices, while sensitive to ‘variation, fragmentation and process’ (Alvesson & Sköldberg 2017, p. 206). This is particularly helpful in the context of emotion in KT, where emotion has largely been portrayed and understood as disrupting rational logic or ‘subversive of knowledge’ (Jaggar 1989, p. 151). As Ahmed (2013) acknowledged, the inherent ‘risk’ of pursuing multiple, diverse intellectual histories is not doing justice to them. The notion of pluralism in qualitative research might attract innate criticism due to a preference for a single measure of good qualitative research (Carter & Little 2007). To rebuke this criticism, Carter and Little (2007) pointed to the diverse, equally valid modes of research and thinking, citing Kaplan (1964), who argued that ‘the world of ideas has no barriers, within or without, does not call for one true “logic” to govern it. The conviction that there is such a logic – as it happens, ours – is a parochialism.’ (p. 8). Plurality is particularly important for the study of emotion where there have been consistent critiques of the singular logics of ‘one-sided paradigms’ (Zembylas 2016, p. 564) in favour of research that includes psychoanalytically informed theories alongside critical social and political theories (Athanasίου, Hantzaroula & Yannakopoulos 2008; Hook 2011).

Another challenge pertaining to the epistemological positioning of this research is one of representation. Specifically, the nature of researching emotions prompts the question: how can I accurately represent the embodied dimensions of emotion in a linguistic medium? In my thesis, I am effectively turning the body into text. The inclusion of observation data and my emotion journaling aimed to avoiding a linguistic and textual reductionism notable in many post-structuralist methodologies (Alvesson & Sköldbberg 2017). Emotion journaling in particular was an attempt to add to the linguistic accounts and give them a greater, personal emotional context. This thesis is not an auto-ethnography. However, I reject the ‘view from nowhere’ of positivist objectivity (Haraway 1988) and I demonstrate this by writing in first-person avoiding presupposing the generalisability of lived experience and critically reflecting on my experience as the researcher in this study (Lincoln & Guba 1985). As a study of emotion, I am aware of the inherent limitation of this thesis as a linguistic medium. Reid (2014) cautioned against ‘the conviction that we can use language to make sense of the world, including its non-linguistic elements’ (p. 217). However, the representation of emotion through any form, be it linguistic, visual, or aural, is mitigated by the histories of contact of the recipient (Ahmed, 2013). I attempted to mitigate this concern by allowing space for my own embodied experiences, such as those I described in the prologue, to provide a second layer to my analysis, to describe my emotional impression in the hope of conveying to the reader what was felt in particular situations.

3.3 Methodological approach

Deleuze’s empiricism is situated within broader trends in social sciences towards ‘materialist’ and ‘processual’ approaches to methodology (Coleman 2013; Denzin 2019; Jackson 2013; Lupton 2019). This follows an ontology that construes ‘the world as an ongoing process in continual transformation’ (Massumi 2015, p. viii). Deleuze described this approach as a

discrete methodology, capable of inspiring research more sensitive to ‘what we are doing’ (Deleuze, 1991, 133). Ultimately, the methodology borne of a Deleuzoguattarian approach to research is required to account for ‘the multi-various lines [of an assemblage] that twist and turn and finally intersect’ (Buchanan, 2015, p. 387). The movement in Buchanan’s description of this type of account hints at the processual and unfixed nature required in the methodology and product. As per section 2.1, the interdisciplinary nature of my thesis was purposefully contained by considering how the diverse disciplines of emotion and knowledge translation work within a Deleuzoguattarian ontological lens. Hence, I drew from a processual approach with the assemblage at the centre of inquiry.

Assemblage thinking has informed contemporary organisational studies (Canniford & Bajde 2015; Fuglsang & Sørensen 2006; Murray 2013; Thanem 2011). In reviewing this milieu, Duff and Sumartojo (2017) elucidated three main ways the assemblage was used. The first is as a description of observable social organisational forms, like Prince’s (2013) description of the instrumentalisation of culture and creativity in global policy programmes. The second is as an analytical value that provides a particular orientation to the analysis of social problems, like Arsel’s (2016) conceptualisation of markets as assemblage to re-examine commodity recirculation systems. The third is as a concept to think about the ways forces of stabilisation and transformation play out in diverse organisational settings, like Duff’s (2014) own study of material resources within fluctuating mental health recovery assemblages, as well as Bissola and colleagues’ (2017) description of entrepreneurial learning processes in flux. Duff and Sumartojo drew on the third way, using the assemblage to analyse creativity and creative practice, eschewing the reification of creativity in terms of unique skills or ‘unruly’ passions in favour of identifying the real conditions in which creative practices emerge from heterogenous human and non-human arrangements. Because of the ability to both describe the social organisational forms of emotion and mindlines and to explore the stabilisation and

fluctuation of these forms, my thesis drew on the first and third ways to use the assemblage. This meant using the assemblage to articulate how emotions are constituted with other parts of community-based palliative care mindline assemblages; and exploring how emotion leads to the stabilisation and transformation of mindlines in this context.

The assemblage as a methodological approach was used in qualitative organisational studies, particularly in the sociology of health and illness, cultural studies, medical geography, disability studies, and medical anthropology (Fox 2012, pp. 63-75). Koro-Ljungberg and Barko (2012) noted that the assemblage can aid qualitative inquiry, given its ability to remove the finality of the object of research evoking the 'heterogeneous within and from out data of inquiry' (p. 258) reflecting a processual epistemology that allows attention to multiple and diverse objects of inquiry. Orienting to the assemblage can infuse different stages of a qualitative research project; for example, by decentering the human and repositioning nonhuman objects as agents in the research process (McLeod 2014). Thanem (2004) used such decentering to analyse organisations, applying Deleuze and Guattari's 'body without organs' (BwO) to organisational studies. He argued that Deleuzoguattarian philosophy provides opportunities to think about the forces of embodied desire that disrupt, undermine, and escape organisation, upset the homogeneity of organisational life, and overpower organisations to such an extent that they cease to be organisations. According to Thanem, Deleuze and Guattari encourage experimentation with what a body can do in the workplace. He uses the example of a management consultant hired by a multinational footwear manufacturer that leaves her business suit and bullet points at home, to change into guerrilla gear and, in a client meeting, physically express the concerns of low-cost country sweatshop workers. Thanem writes that 'people's actions and responses are beyond the control of individual participants or the group as a whole, and people may be able to enlarge their understanding of difference by becoming someone else than they already are' (p. 213).

As an analytical tool, the assemblage can also help to explore the restrictions history places on the number of possible variations of realised assemblage. Buchanan (2017) used Lea's (2014, 2015) ethnography of a policy debate regarding the implementation of Australia's strategic Indigenous housing and infrastructure program (SIHIP) to illustrate an analytic application of the actant and assemblage. Lea considered how these discussions established the internal (conceptual housing essentials, such as water, sewage, climate control) and external (materials and costs) limits on the Indigenous housing assemblage. By bringing conceptual and material limits together in a dialectic fashion, Lea 'exposes the critical shallowness of policy thinking which is more focused on ticking boxes in the expressive sphere than it is in creating enduring, liveable houses in the material sphere' (Buchanan, 2017, p. 469). My approach similarly aims to map the internal and external limits of mindlines – distinguishing the conceptual and material limits of specific mindlines. This mapping focuses specifically on mapping emotions in relation to mindlines, which, as discussed in section 2.3.1 can be considered both conceptual and material in the sense they can be discursive constructs and tangible felt impressions.

New materialism also draws on the assemblage (Fox & Alldred 2016; Lupton 2019). Within new materialism, the assemblage is the primary focus for analysis, accounting for both non-human elements and human relations. New-materialism uses assemblage to reach beyond the confines of conventional human-centred research to explore how materials assume characteristics reminiscent of human interaction (Bennett 2009). It prompts scholars to consider how matter and other non-human elements have agency – or a capacity to act – that changes, depending on its place within its assemblage (Duff 2013). New materialism pays heed to how energy or labour is expended to assemble the collective body (McLeod 2014). This might involve an analysis of how: associations are created between elements in the assemblage (relational connections); different elements of the assemblage work on each other to create non-conscious experiences of intensity (affective forces); and an assemblage promotes novel

capacities to act (Lupton 2019). These analyses can help to articulate the agency of non-human materials within the assemblage, an agency that represents the ‘on-going labour of bringing disparate elements together and forging connections between them’ (Murray Li 2007, p. 263).

New materialism has used the assemblage to helpfully elucidate the more-than-human elements in health services and healthcare. For instance, Price-Robertson, Manderson and Duff (2017) used the assemblage to explore recovery approaches for mental health policy and practice, focusing specifically on family recovery. Their use of the assemblage helped them to account for the varied human and nonhuman entities and forces involved in the creation and maintenance of family life and the implications for recovery trajectories. Viewing families as heterogeneous assemblages allowed them to implicate the significance of emotion and identity in family recovery processes. Malins (2016) followed a similar analytic pathway in her study on women injecting drug users, exploring the relationship between bodies (bodily practices, identities, appearances) and city spaces. She also used Deleuze’s (1988, 1995) concept of the ‘fold’ and Butler’s (2011a, 2011b) concept of ‘performative’ identity to explore how women injecting drug users, through their embodied performances and their narratives of space and risk, enfolded and unfolded the spaces and discourses they encountered. This approach enabled Malins to describe the relationship between physical spaces – both material and discursive – and women who inject drugs in those spaces. She prompted a consideration of how we understand risk and safety in these environments, affecting relational connections with cohabitants of those spaces. Dennis and Farrugia (2017) used Deleuzoguattarian-informed new materialism to study the marginality of pleasure in alcohol and other drug (AOD) policy, related health interventions, and public discourse. This analysis cast the research ‘subject’ as emergent, whose form and capacities are co-constituted by assemblages of human and nonhuman forces, which together shape what a subject can do. The authors review the literature on drug pleasure to describe how pleasure was done and what it did – how pleasure was

comprised of complex assemblages that allowed new subjectivities, bodies, substances, and concepts to flow. For example, they describe Bøhling's (2017) exploration of online 'trip reports' that map how pleasure is done and to what effects. These reports enact caring pleasures that co-constitute ethical possibilities for living that expand the consumers capacity to act, think and feel in the world.

By using the assemblage in my research design, I will: articulate how emotions are constituted with other parts of community-based palliative care mindline assemblages; and explore how emotion stabilises and transforms mindlines in this context. As part of this approach, I will map the internal and external limits of mindlines – distinguishing the conceptual (ideas, emotions) and material (identities, practices, emotions) limits of specific mindlines. I will also identify the conditions in which mindlines transform in community-based palliative care.

3.4 Ethical Framework

Institutional ethical clearance for the research was granted from both health and university institution human research ethics committees (SWSLHD reference number: HREC/17/LPOOL/133; Western Sydney University reference number: RH12468). Alongside institutional ethics, it was important to set out a clear ethical framework due to the potentially intrusive and distressing nature of the research context. This project involved my close contact with patients with life-limiting illness and their carers in their homes. Introducing healthcare into the home, particularly end-of-life care, can change the relationship between the self and the home (Angus et al. 2005; Brown & Colton 2001). Palliative homecare is an acutely intimate form of care, and my fear as an ethnographer was of interrupting these spaces and creating undue tension and stress for patients, carers, and clinicians. I was particularly anxious about the 'vicarious and voyeuristic' nature of my presence (emerald & Carpenter 2015, p. 15). To manage these fears, I engaged in an 'uncomfortable' (Pillow 2003, p. 8) reflexivity, seeking to

know, while simultaneously situating this knowing as tenuous. Through a process of critically self-reflexive practice, I constantly reviewed the appropriateness and impact of my presence in potentially sensitive situations. Termed here a situated ethics, this process involved acknowledging the complexity of each situation. As such, ethical decisions accounted for the precise way situations occurred (Simons & Usher 2000).

Situated ethics also served to address the mental and emotional toll of shadowing. The emotional toll of ethnography requires consistent emotional reflexivity to strategically navigate the data and replenish emotional energy as a researcher (Blix & Wettergren, 2015; emerald and Carpenter, 2015). To replenish my emotional energy during periods of anxiety or stress, I stepped away from the research, for instance by taking breaks during fieldwork or leaving the centre for periods of time. This helped not only as a self-preservation mechanism, but it often also reinvigorated my attention and energy in the field.

Two ethical dilemmas were prominent during the research. First, managing my own position as a 'researcher' when in situations that required me to assume a hands-on role such as helping a nurse move a patient or providing information about a home visit I had witnessed. Second, managing my own safety and wellbeing when confronted regularly with life-limiting illness, death, and suffering. My observation of, and proximity with, death and dying was distressing at times and had the potential to compromise my personal safety. As a non-clinician, I was exposing myself to a space and system of practices I was unfamiliar with and did not have the training or experience to conduct palliative care. My role in patient homes was predicated on observing and, essentially, staying out of the way.

Following a situated ethics, it was important for me to identify times and places that might be perilous as they occurred. I did this by first confronting my own feelings about situations, asking myself, am I comfortable with this? Once I had assessed my personal comfortability, I would either overtly inquire with clinicians, patients, and carers about the acceptability of my

presence or actions, or quietly followed the lead and direction of the clinician who I shadowed. When asked to help a clinician or patient, my self-reflection often reinforced my innate sense of duty to support people who are in need. This became steadily more apparent during fieldwork as I developed heightened sensitivity to patient and carer needs and the plight of resource-poor clinicians who were not always able to attend to those needs. For example, during a home visit a clinician attempted to move a patient from their home bed to a hospital bed alone. Hospital beds are often used in home-based care to make washing an immobile patient easier, help with treatment, and moving patients for circulation. I recognised the need to move the patient, as the patient and carer were elderly, and the patient would have no way of moving to the hospital bed without help. It was a simple choice for me to assist the clinician because patient's safety or her own might have been compromised. Moments where I had the capacity to assist, relegated my unobtrusive researcher persona to the background.

There were times when I was required to observe or engage in activities that challenged me mentally and emotionally. There is often a toll following continued exposure to suffering, the sensory and bodily changes associated with life-limiting illness, dying, death, and bereavement (Dickson-Swift et al. 2006; Lawton 1998). While the practical and personal support from my supervisors were important to me, for instance by allowing opportunities to debrief and giving me positive feedback, self-care was also a prominent focus of the management of this ethical concern. Taking time to reflect, both alone and with loved ones, on what I engaged in, as well time away from the field to recharge and centre myself, were invaluable in this process.

3.5 Conclusion

In this chapter I have outlined the conceptual underpinnings of my research approach and the associated implications for emotion and mindlines. I also described the methodology and

ethical framework the research ascribed to. In the next chapter I detail the methods used, connecting these methods to the logic of the conceptual framework.

Chapter 4: Methods

4.1 Introduction

In this chapter, I detail the research setting, the participants, and the methods to explore the relationship between emotion and mindlines. In the first section, I describe the context, the process and challenges involved in accessing the site, participant recruitment, and the participants involved. In the second section, I detail data collection, which involved ethnographic methods of shadowing, interviews, and journaling. In the third section, I describe my analytic method with the help of examples. In the fourth section, I outline the presentation of my findings, explicating how I have organised my analysis.

4.2 Setting

4.2.1 Research site

In consultation with the Area Community Director of Nursing and the Area Palliative Care Manager, I identified a community health centre based in the South Western Sydney Local Health District of NSW. This site was identified as appropriate due to its reputation as a high-performing health service and its amenability to the prospective study. The service had an established reputation with the executive members I met with for its quality palliative care due to positive client feedback. The site had also recently been involved in a similar study, with clinicians at the centre being shadowed and interviewed. This experience and reputation meant the project was less likely to negatively impact the efficiency and effectiveness of a high-performing service.

South Western Sydney Local Health district was governed by a large and complex organisation with an annual budget of \$1.8 billion, providing a range of health services across multiple

clinical streams. The Local Health District covered an area of approximately 6,000 square kilometres, the home to more than 960,000 people, or 12% of the NSW population as of 2016 (SWSLHD, 2017). The district's population was expected to increase by 30% over the next 15 years, due mainly to extensive development in the region including major infrastructure projects such as an airport and associated aerotropolis. The population of the district was culturally diverse with 16,000 people who identified as Aboriginal or Torres Strait Islander, 44% of the population born overseas, and 51% of the population who spoke a language other than English at home (SWSLHD, 2017). Some of the main languages spoken locally were Arabic, Vietnamese, Spanish and Cantonese. The district was also a major point of settlement for refugees with approximately 10,932 refugees, 41.7% of all refugees in NSW, resettled in the area between 2005 and 2011. The district also experienced social and economic disparity with some of the poorest communities in NSW measured by the socio-economic indexes for areas (SEIA) in 2016 (SWSLHD, 2017). The district also had higher rates of people with disabilities than the NSW average.

The selected community health centre was one of 12 community health centres and five hospitals across the district. The centre served as the main community health hub for a local government area, bordered by six other local government areas that are part of the district. The immediate area the centre service reflected the diversity of the wider district with 1.4% of the population who identified as Aboriginal and Torres Strait Islander elders, and 39.4% of the population born overseas (SWSLHD, 2016). The most prevalent populations other than Australian were Fijian, Iranian, and Vietnamese. The most common language other than English spoken at home were Arabic (9.5%), Indo-Aryan languages (6.5%), and Vietnamese (4.2%). The area had seen similar numbers of humanitarian stream refugee settlement with 3,377 settlers arriving in the area between 2010 to 2015. The area had higher rates of cancer and diabetes and more coronary heart disease and chronic obstructive pulmonary disease

hospitalisations than NSW suggesting greater involvement of palliative care (SWSLHD, 2016).

Within the district, community-based palliative care involved a team of specialist nurses whose consultancy role supported the generalist community health nurses, who primarily case managed specific palliative care patients when they lived at home. Community health nurses were not only required to deliver palliative care. Their workload also involved, and was at times overshadowed by, wound care, administration of intravenous antibiotics, and draining bodily fluids, among other tasks. The palliative care team was also supported by palliative care medics based at the local area hospital who attended both regular case review meetings at the centre and home visits when required, for instance to review medication regimes that offered limited value. Aside from palliative care, services provided by the selected centre included community health nursing, child, youth, and family services, sexual assault counselling, aged day care and respite services.

4.2.2 Field access

Once I had identified the community health centre as the research site, one barrier we encountered was from a newly-appointed executive of the wider district. His concern was related to the site having recently had an ethnographic research project conducted there. He was concerned about the distribution of research attention across the district, rather than being localised at one site. At this point, I had submitted an ethics application for the site and established a relationship with the nurses based at the centre and the affiliated specialist medics. This relationship was fostered through my involvement with the previous study based at the centre. As such, the nurses knew me well and were generally comfortable when I was present and shadowing them. My supervisors and I thought that this established relationship was important as it might have provided clinicians with opportunity to be more forthcoming about

their emotions and decision-making with me. Although it is impossible to state unequivocally that this was the case, the nurses and medics I shadowed and interviewed regularly provided intimate data about their feelings. I was able to have conversations with nurses and medics about potentially negative feelings, essentially from the outset of data collection. My presence at the centre was unobtrusive in that the administrative, managerial, and clinical staff knew me well and allowed me to sit in meetings or roam the centre freely as I chose. This unfettered access to the study site provided me with rich data about the wider organisation and the informal interactions among clinicians.

While the executive member stated a valid concern for the district, I contended that, it would be disadvantageous to my project due to time constraints to attempt to establish a similar relationship with a different community health centre in the district. I had developed and proposed this project, confident that I would be working with clinicians I had established a relationship with. Although it would have been possible to address this issue by spending time familiarising myself with a new community health centre, this could have affected the opportunities to collect meaningful data. The executive member ultimately agreed to our request. Despite this, I was under the impression that he would scrutinise the project closely, ensuring I justified my insistence on the site. This shaped my project to give greater attention to the applicability of my findings for the district. Put simply, I gave significant attention to findings I would present to him following the project. This was not inherently disadvantageous as it was and is important to consider the practical implications of any research. However, as the stated purpose of a doctorate is a theoretical contribution, my attention needed to be on the theoretical implications of my findings in the first instance.

4.2.3 Participant recruitment

My relationship with staff members at the centre offered the possibility of discussing the proposed project with the nurse unit manager (NUM) and executive team, who in turn made access to the field site possible. I met with the NUM of the centre along with the clinical leaders of education and palliative care to describe the study and address their questions and concerns. To invite prospective participants to this study, I discussed with the NUM the opportunity to present the study during a staff meeting. During this meeting, I outlined the study aims and ascertained potential participants interest in participating. Following this, I liaised primarily with the clinical nurse consultant for palliative care, arranging weekly visits to the site. My decision to liaise with the clinical nurse consultant was based on my relationship with her, easing communication; and her position as the clinical palliative care lead at the centre. Although, his relationship might have limited my opportunity to consider other perspectives within the team, it remained an efficient and effective way to organise my time throughout data collection.

Initially, my site visits were to coincide with the weekly case review. I chose to observe the case reviews as these were the most significant and regular context for the discussion of palliative care. During the case review, generalist nurses, specialist nurses and, in some instances, medics would convene to review current palliative care patients and plan care for each patient. The meetings were mostly held in a meeting room, with a television screen to display patient notes and document the plan of care. The formalised location of the case review served to emphasise the importance of these meetings, suggestive of its importance alongside executive meetings that took place in these rooms. Attending the case reviews was also an opportunity to recruit participants to shadow as I was able to observe and speak with all the nurses based at the centre. This is because the case review was structured around three 'clusters' of the local area serviced by nurses. Each cluster included five to eight generalist

nurses and one specialist nurse overseeing healthcare delivery. Every week, nurses of a different cluster presented patients at case review in a monthly rotating system. As each week of data collection progressed, I recruited new nurses to shadow or interview. My ongoing presence onsite also enabled me to informally discuss the possibility of shadowing and interviewing nurses as I serendipitously met them in the halls, offices, or the lunch room.

4.2.4 Participants

I collected data in the form of observational fieldnotes and interviews with 17 primary participants. These primary participants were nine generalist nurses, five specialist nurses and three specialist medics. They are here labelled as primary participants to distinguish them from secondary participants, who were patients and carers. I shadowed nine clinicians in total on multiple occasions, five specialist and four generalist nurses, and I observed two of the medics during a joint home visit while I was shadowing a nurse. Shadowing involved following, observing, and conversing with primary participants usually for a whole day. This typically encompassed documentation, organising equipment, liaising with patients, GPs, or family members, and interacting with fellow staff members, within and beyond the centre. Although shadowing is unlikely to capture all of these facets of work, I tried to maintain a presence with clinicians at the centre when they conducted administrative tasks.

Although there were a core group of primary participants involved in observation and interviews, I regularly spoke informally with other clinicians or observed them as they interacted with colleagues. This increased the likelihood of engaging with diverse perspectives and practices. I collected the informed consent of all clinicians I observed during home visits, in case review meetings, or during informal conversations at the centre. Some preferred not to be shadowed, either due to a busy workload or personal preference. The nature of community-based care offers independence and solitude, which some clinicians value as

part of their role. I attempted to avoid pressing the case with those who might be disinterested with being shadowed to avert a negative reception of the project.

I observed or documented the discussion of approximately 50 secondary participants: patients and carers of patients. Carers here are the individuals present during a home visit who participated in a patient's care. They included family members, friends, and neighbours. The recruitment of patients and carers was to occur through a formal telephone call from the clinician I was shadowing prior to attending their home. While this usually occurred, sometimes clinicians were unable to contact a patient or carer before the home visit. This meant that the clinician or I was required to introduce myself and describe the study to the patients and carers during the home visit. I attempted to mitigate patient and carer discomfort by inquiring with them if they would prefer me to wait outside during the consultation. Although it is difficult to assess how my presence affected primary and secondary participant behaviour, I attempted to be reflexive with clinicians following home visits, inquiring as to whether they, or the patients and carers, changed their practice due to my presence. I understand reflexivity here, which differs from reflection, as a critical examination of the factors that influence knowledge production (D'cruz, Gillingham & Melendez 2007). I documented noteworthy reflexive discussions in my observational fieldnotes.

4.3 Data Collection

Over 12 months I shadowed clinicians, documented observational fieldnotes, interviewed clinicians at different points during shadowing, journaling my own emotional responses to critical incidents. With roots in anthropology and sociology, ethnography can help to capture social interactions and behaviours that occur within communities or organisations (Delamont 2004; Reeves, Kuper & Hodges 2008). An ethnographic approach influenced by Deleuze offers a 'wild empiricism that can see and capture the unstableness of everyday life' (Renold & Mellor

2013, p. 28). In ethnography, one can ‘follow the actors’ to assess the specific relations, affects, and events that actors themselves nominate (or reveal) while becoming (Duff 2014). Ethnography enables the capture of the ‘awkward, messy, unequal, unstable, surprising and creative qualities of encounters and interconnection across difference’ (Stewart 2007, p. 128). Ethnography requires immersion within the context being studied, complemented by gathering observational and interview data (Anspach & Mizrahi 2006; Reeves, Kuper & Hodges 2008). As much as it is achievable, ethnography enables a researcher to share with participants their environment and worldviews. Thinking with Deleuze, ethnography involved the study of events and sets of encounters, by which the particular assemblages of palliative care were mediated (Duff 2014). To manage data collection, I used a modified approach to the critical incident technique (Flanagan 1954) to bind units of analysis or assemblages constituted of emotion, mindlines, embodied practice, and my own multi-sensory bodily experience, or ‘plane of immanence’ (Deleuze & Guattari 1994, p. 36). The data I generated were classic ethnographic observation, capturing the everyday happenings, textures, and contours of community-based palliative care, paying particular attention to emotional moments as defined by the participants and me. In the next sections, I detail the different methods I used with examples.

4.3.1 Critical incident technique

To explore emotions in the context of mindlines, I wanted to observe clinicians practice. However, due to the large amounts of raw data often generated in ethnographies, and because I wanted to concentrate on how emotions affected mindlines in practice, I refined my focus. Specifically, critical incidents were initially the unit of analysis to discretely bind a singular assemblage of emotion and mindlines. The critical incident technique (CIT) is a research and educational method, developed initially as ‘a set of procedures for collecting direct

observations of human behaviour in such a way as to facilitate their potential usefulness in solving practical problems' (Flanagan 1954, p. 327). Critical incidents are atypical to everyday practice, either a positive experience or a situation where a clinician, patient, or carer has suffered in some way (Rich & Parker 1995). Palliative care clinicians witness a variety of incidents outside the normal range of everyday healthcare. This is due to the 'holistic' nature of the work, as clinicians strive to address not only the physical issues of patients but also the psychosocial and spiritual (Chochinov 2002).

The initial decision to use critical incidents as a unit of analysis was to enable me to observe clinicians apply mindline assemblages during a potentially emotive period. Using emotive data would I could then examine the effects of emotion on decision-making, creative thinking, motivation and interactions. The term 'critical incident' seemed appropriate as a legitimate unit of analysis, however, my approach differed from other approaches that attempted to simplify a moment in time to how it ought be (Gerrish & Lacey 2010). There is ambiguity in relation to how CIT is defined and described in the literature (Bradbury - Jones & Tranter 2008). In the absence of a widely agreed definition I forged my own approach to CIT. My approach followed new materialist approaches to research: rather than asking what a method is, I was asking what it can do (Fox & Alldred 2016; Lupton 2019). Reflecting a Deleuzoguattarian approach, I defined critical incidents as moments of de-territorialisation and re-territorialisation proliferating different assemblages of community-based palliative care (Deleuze & Guattari 1987). For Deleuze (2002), the assemblage is 'the minimum real unit' as opposed to 'the word, the idea, the concept or the signifier' (p. 38). This approach takes emotion and mindlines as an event, what I have termed the critical incident. This necessitated an initial focus on the 'dynamic unity of this event... starting in the middle as Deleuze always taught' (Massumi 2015, p. 48).

The ‘glow’ (Lupton 2019, p. 4) of affective intensity in critical incidents came about because of my own emotional reaction, or one that I observed from a clinician, patient, or carer. When I experienced an affective intensity during a home visit – for instance when a carer complained about a doctor she had visited, or while hearing a patient’s story of suffering – I documented it in my field notes, describing the scene as best I could. I observed and documented clinicians’, patients’, and carers’ facial expressions, body language, and tone of voice. I would ask a clinician directly about how a specific moment of affective intensity made them feel to gauge their perspective of the affective intensity I experienced. The critical incidents I selected, based on their affective intensity, occurred before, during, and after home visits with patients and during the case review. Incidents could be intrinsically emotional; for instance, one incident occurred as a result of a specialist nurses expressed anguish over a patient’s death, an atypical emotional reaction considering clinicians’ proximity with death and dying. I also captured and documented moments that were less emotive, for example a nurse negotiating a patient complaint or a medic conducting a typical assessment.

Critical incidents as I defined them proved valuable as units of analysis, avoiding an overwhelmingly large amount of disconnected data. For example, rather than focus on the many unique instances of palliative care while shadowing, I focused on a singular incident. I was then able to map the real-world assemblage of that incident and connect it to the virtual diagrams of mindline assemblages proffered elsewhere, during subsequent conversations. The dynamic, continuously fluctuating assemblages of critical incidents in community-based palliative care provided a fruitful unit of analysis to establish the relationship between emotion and mindlines. To understand these incidents, I shadowed, interviewed, and journalled, which I will describe in turn.

4.3.2 Shadowing

To document affectively intensive critical incidents, I shadowed clinicians to observe their practice. Shadowing was predicated on extensive familiarisation with the study context. During a previous study at the centre, I had developed friendships with many of the staff members. While some nurses were less comfortable with the prospect of being shadowed, most were comfortable with my presence demonstrated by their collegiality with me. Particularly proud moments were when my presence was noted as not just a ‘researcher’ but as a member of the team. The NUM would often tell me that I was ‘part of the furniture’ and nurses would often joke that I could be an honorary palliative care nurse if I was not terrible at mathematics (I had facetiously sat an exam to test my ability to formulate medication quantities for syringe drivers and failed miserably, much to some of the nurses merriment). This relationship eased entry into the field and, seemingly, meant nurses spoke freely about their thoughts, feelings, and actions with me.

I established a routine by attending the case review each Thursday morning and shadowing a nurse thereafter. Case review allowed me to observe clinician interactions and explore some of the norms of palliative care. During these reviews, I developed an understanding of how clinicians used emotion to shape collective and individual mindlines. For instance, I observed how they framed palliative care patients or approaches and how emotions were used discursively in these contexts. I documented my observations during case review in fieldnotes, an example of which is as follows:

Patient described as not knowing prognosis. Carer refusing to inform patient for fear of rapid deterioration. [Specialist Nurse 1] uncomfortable about the situation. Having to ‘walk the line’ between informing the patient and not saying too much. [Specialist Nurse 1] expresses unease at this role and also

fear for her own position i.e. exposing the ‘secret’ status of the patient.

[Specialist Nurse 1]: ‘Poor old [patient] what are we going to do with her?’

[Specialist Nurse 2]: ‘Very, very, very short of breath’ emphasis with repeated words. Been fiercely independent and losing that independence is distressing. Connection with dog – discussion of the important emotional connection with pets. Can make the process of dying complicated.

While at the centre, I spoke with nurses, the NUM, and administrative staff and observed their interactions. I also inquired about clinician availability for shadowing at other times. This routine was not always viable. There were periods when staff availability was limited due to periods of leave and because university nursing student placements attended the centre to shadow staff for support and mentorship. Additionally, clinicians were required to provide specialised clinical expertise to other health services within the district. Despite these setbacks, I conducted approximately 100 hours of observation and shadowing.

In this study, shadowing meant being ‘on the road’ with clinicians because it involved travelling with them in a fleet vehicle. On commute, I discussed with them upcoming home visits, attended visits, and debriefed thereafter. I usually recorded conversations with nurses before and after home visits when viable and appropriate. As a non-clinician researcher, I was treated like a student. Initial periods of shadowing provided me with access to the ‘basic training’ type information that junior clinicians are presented with when joining the service. I was able to, and often did, ask ‘stupid’ questions about nurse and medic actions and patients’ clinical contexts, like: why did you do a particular action, or what do you think will happen following this home visit? The nurses and doctors I spoke with seemed comfortable with my questioning and these conversations provided ample data.

While shadowing, I penned my observations and later typed my fieldnotes as a form of analysis. This provided opportunity to rethink my observations and ‘plug in’ (Jackson & Mazzei 2013,

p. 262) theory and other data as part of my analysis, which I discuss in a subsequent section.

Here is an excerpt of my field notes while attending a home visit with clinicians:

Attended [home visit] with [Specialist Medic, Specialist Nurse, Generalist Nurse] for a patient assessment. Specialist Nurse stated to me previously that this was to assess the patient as she had been deteriorating. Before entering the house, we stood in the driveway of the house and [Medic name] stated that she was worried that the daughter was giving her too much Valium and it was killing her. Lots of trepidation in the voice of the Medic about stating this. [Specialist Nurse] agreed giving a similar opinion from her experience. Went to the front door, carer (patients' daughter) greeted us warmly. [Specialist Medic] had a personable approach to communicating with patient, hugging her up on entry and encouraging the job she was doing caring for the patient. Led into the patient's room who was lying on the bed very unresponsive. [Medic] did an assessment with patient, which involved checking pupillary response, feeling the patient's stomach, listening to her breathing, and checking her blood pressure. The Medic sat next to the bed while assessing the patient, stating to the patient her actions before doing them: '[Patient name] I'm just going to listen to your chest for a moment. It might feel a little cold' (field note, 12/04/18).

In this field note, I documented the experience as best as I could, noting the individuals present, their actions, and some preliminary sensations, at times naming emotions ('lots of trepidation') and/or documenting smells or physical sensations. I used a semi-structured approach to observe different assemblages of palliative care and interactions among clinicians, patients, and carers. This involved documenting the 'goings on' around me, along with my feelings as I settled into the environment, reflecting on the ambient atmosphere, for instance whether loud or quiet,

relaxed or tense, busy or placid. At times I relied on short-hand notes and single words to trigger memory when I had time to document.

4.3.3 Interviews

Following a day of shadowing, I invited clinicians to participate in a retrospective, semi-structured interview (See Appendix 1 for interview guide). This would either occur in person immediately after shadowing or a few days to a week later via telephone. The interviews were structured to guide a discussion of critical incidents and a general discussion of the emotional nature of palliative care. The aim of these interviews was to provide participants with an opportunity to reflect on the emotions experienced during these incidents and the effect of these on their thinking and actions. These interviews helped me explore clinicians' subjective experiences of the assemblage of the critical incidents. My questioning was designed to elicit responses related to the affective intensities of the incident, essentially revolving around the questions: what did you do; and, what informed your thinking and action?

The interviews were interpretive in nature to encourage openness to emerging themes (Sampson & Atkinson 2011). Although the interviews were loosely guided by key questions, they were informal and significantly guided by the clinicians' perspectives and interests (Anderson et al. 2012; Müller 2015). Participant lines of thought were explored with clarifying and follow-up questions and probes to expand participant responses, encouraging answers that were more descriptive and avoided misinterpretation (Deleuze & Guattari 1987; Patton 1990). Most interviews occurred in person at the centre immediately after shadowing. However, some were conducted up to a week following the period of shadowing either in person or via telephone. Interviews were recorded to aid recall and I documented observations during and/or immediately afterwards. These included observations of non-verbal aspects of the interview, the physical setting, and the personal interaction (Hammersley & Atkinson 2007). The

interview transcripts were often analysed in conjunction with fieldnotes about critical incidents to aid interpretation and provide descriptive information. The following excerpt demonstrates how I wrote my thoughts immediately following an interview with a clinician:

I found the interview with [generalist nurse 12] challenging as she was reluctant to expand on many of her responses. She discusses palliative care in a very practical, straightforward way (what other clinicians derisively term ‘task-oriented’). She rarely places her own feelings explicitly in the discussion of care, which ostensibly minimised relational and emotional ‘opportunities’ in the interview. My sense is that this is because she prefers to approach her work from an unemotional standpoint, which makes it easier to engage with and detach from the work. This has implications regarding the self-preservation mechanisms of nurses and also the value of emotional ‘ambivalence’ for nursing practice (field note, 17/04/18).

Discussion topics that arose during these interviews included: how clinicians felt during a critical incident; changes in feelings (emphasising emotional, bodily, psychological, and social); factors that informed clinician decision(s) or actions during and after the incident; and how emotional impressions might have shaped specific actions (e.g., identified anger leading to consulting with managers, identified shame of a perceived failure prompting a change of practice). Interviews would often progress onto a general discussion of the emotional nature of palliative care, with discussion of other incidents that had elicited strong emotional impressions experienced by participants. These conversations helped me to connect the recently experienced critical incident with a wider array of emotional experiences in community-based palliative care.

4.3.4 Journal

This study required me to attend to my subjectivity in the research process using reflexivity to better represent, legitimise, or call into question my data. My presence as the researcher had inherent effects on what I observed, necessitating my reflexivity throughout the research process, requiring me to interrogate and convey my own voice (Delamont 2004). This involved considering my emotions as they related to my place in the research and the knowledge I produced as I engaged in the complexity of community-based palliative care (Holmes 2010). Additionally, by entering into data collection with an understanding of emotion as an embodied and experienced state of being, it was important to explore my own emotional responses to critical incidents during data collection to better understand those of clinicians (Mitchell 1997). As Massumi (2015) stated, ‘to think through affect is to continue its life filling, life forming journey... it is lived or it is nothing’ (p. viii). For Deleuze, there is an epistemological and ethical priority to ‘live our immersion in the world’ (Massumi 2015, p. 45). A great deal has been written about how research and researchers are inextricably entangled within the assemblages they study (Coleman 2013; Jackson 2013; Lupton 2019). This has prompted calls for ‘interpretive, critical, performative qualitative research that matters in the lives of those who daily experience social injustice’ (Denzin 2019, p. 723). To account for my own, lived, immersed, emotional impressions during data collection and reflect on the impact this project might have, I maintained a weekly journal to reflect on my experiences. The journal was written as a personal, affective account to avoid disconnecting myself from the ‘mangled’ assemblage of diverse elements in the field (Lather & St. Pierre 2013).

When examining emotions, researchers ‘must work on their own feelings, modifying them to model the emotional experiences of people’ (Leavitt, 1996, p. 530) in various contexts. This practice can help with the ‘resonances’ (Zembylas 2007, p. 66) needed for effective data collection and analysis. Maintaining an emotion journal helped me move beyond linguistic or

textual *outside* accounts of critical incidents, to account for the experiential ‘impressions’ (Ahmed 2013, p. 6), or *inside* accounts of critical incidents. An empathic mode (feeling with participants) became a prominent approach to my writing in this context. I attempted to place myself within, for instance, the clinician perspective, frustrated by the incompetence of a poor handover from the hospital or, overjoyed to discover a patient’s pain had been bought under control. Feeling with the participants enabled ‘conversation and the re-telling of experiences and confidences that constitute the data and direct its interpretation, analysis, and writing up’ (Ahmed 2013, p. 878; Zembylas 2007). Paying attention to and reflecting on this approach also clarified how emotions were connected with social hierarchies, as my emotional reactions revealed the social entanglements that contributed to the power-saturated dynamics I was intrinsically involved and complicit with (Braunmühl 2012). Ahmed (2004) described this political component of emotional analysis: ‘emotions become attributes of bodies as a way of transforming what is “lower” or “higher” into bodily traits’ (p. 4) creating distinct hierarchies in embodied sensation.

Journalling my emotions was challenging for two reasons. First, following a long and tiring day of field work (where there was sparse time to document simple observations, let alone my emotional experiences of events), I would often prefer to detach from my doctoral research by relaxing, watching television or connecting with friends and family. The effort needed to document my own feelings after an eight-hour day was both arduous and at times emotionally exhausting. In addition to the mental effort involved, documenting my feelings made them real and forced me to confront what I had experienced. Like talking about a traumatic event out loud to someone, new emotions can sometimes surface, or existing emotions can be magnified. At times, the writing or talking about an experience would reposition my view of what I said or did in a negative light, like mulling over what one might say following a job interview, or conversation with a respected colleague.

An example of a particularly challenging and confronting journalling session followed an instance of shadowing when a nurse required my assistance to move a deceased patient's body to wash difficult-to-reach parts and to put on the patient's clean clothes. I later wrote about, and was confronted by, the reality of what I had been through:

Moving this patient's body around, feeling the full weight of him as I struggled to roll him to his side evokes now a seesawing feeling. The duality of the body as both a once living man, who lived a rich life connecting with so many people and, now, as an object with weight, needing to be moved. I move from a feeling of guilt thinking about him as an object or 'merely' a body without personhood, to a reluctant acceptance of his personhood as no longer present in this object (journal entry, 14/12/17).

This emotional revelation was propelled by journalling, which was personally and existentially challenging. This process forced me to confront my own ethics around how I considered and treated a body, and whether I should have got involved in this process at all. This was a positive experience in the context of my thesis due to my emotional resonance with clinicians, who attend to these situations regularly. However, this did not lessen the challenge of confronting these experiences a second time around.

The second challenge was maintaining a connection between my experiences and those of the participants. Given the focus of this project, it was important to consider the relationship between my emotions and mindlines, as they were enacted and embodied within community-based palliative care. However, at times my journalling appeared self-indulgent, whereby I treaded into the realm of excessive self-contemplation, reducing the significance of a wider social view. Gannon (2006) noted that post-structuralism disrupts the notion that autoethnographers can write the self, and 'stresses the (im)possibilities of writing the self' (p.

474). However, he also provided a blueprint to meet this challenge. In his analysis of writing the self through the works of post-structuralist authors Foucault, Barthes, Derrida, and Cixous, Gannon described the ‘exemplary textual strategies that we might take up and improvise on’:

These authors write themselves as unreliable and contradictory narrators who speak the self—the multiple selves that each of them is and have been—in discontinuous fragments informed by memory, the body, photographs, other texts, and, most importantly, other people. In different ways, they displace the speaking self that is the subject, object, and the (im)possible production of autoethnography (p. 493)

I acknowledge the limitations and ‘unreliability’ of my perspective in my journal, but I embraced this characteristic of the work, to avoid using my journal simply as an analytical tool, but rather as another piece of data that would help interrogate my findings. This meant my journal provided my emotional context of a critical incident that I could compare with clinician perspectives, and my *in-situ* observation. Despite the aforementioned challenges, emotional journaling was an important ethical and empirical contribution to my thesis because it helped me to document my affective resonances with clinicians and give me greater insight into the emotional milieu of community-based palliative care.

4.4 Analysis

An account of mindline assemblages, thinking with assemblage theory, required me to focus on identifying the various assemblages by which palliative care outcomes were enacted or expressed (Duff, 2015). As such, it was important for me to attend to both the stories, performances, language, and texts (outside) as well as the embodiment and intensification of feeling of myself and clinicians (within). My thesis uses the assemblage to: articulate how emotions are constituted with other parts of community-based palliative care mindline

assemblages; and explore how emotion can stabilise and transform mindlines in this context as described in section 3.2.3, the assemblage theory helped to unpack the heterogeneous elements that make up the mindline assemblage. For instance, the ideas or evidence at the heart of the prescription, the practices involved, the emotional milieu of the interaction between patient and clinician, the identities bound up with this practice, and the ideals and emotions associated with overmedication. My analysis progressed in two mutually constitutive modes of reifying affective resonances and plugging in theory. Although I describe these modes distinctly for clarity, analysis was far from linear, with both occurring in tandem. Analytic resonances emerged as I explored each of the different modes at different times and compared across the budding products. I started from the middle of a critical incident assemblage, following narrative analytic methods. I then worked outward through a rhizomatic process to explore the emotional influences on mindlines from the case review, the centre generally, and beyond. Deleuze and Guattari's (1987) concept of the rhizome represents non-linear and non-hierarchical thought. The concept is borrowed from the natural root system, opposing traditional thought, which is better represented as tree-like in that it follows a linear pattern, branching off at various points. My use of a rhizomatic process meant there was no fixed centre or order, but a multiplicity of expanding and overlapping connections (Masny 2013). This strategy allowed for the flow of different disciplines, the interweaving of diverse theoretical and methodological inputs (Cohena & Kratzb 2009). What grows from rhizomatic process is a multilimbed, emergent mess, sensitive to 'variation, fragmentation and process' (Alvesson & Sköldberg 2017, p. 206).

The first part of my analysis involved rewriting the narratives of the data based on affective resonances, predicated on the notion that 'experience is shared and that experience itself is storied, or it has a narrative pattern' (Sandelowski, 1991, p. 162). Using narrative analysis, I reconfigured resonant critical incidents into coherent storylines. I selected a narrative approach

because of its capacity to account for multiplicity, attending to the ‘complex constellations of beliefs, values, emotions, intentions, identities, attitudes, and motivations’ (Vindrola-Padros & Johnson 2014, p. 1) that clinicians used to express themselves. The narratives were representations of affectively resonant moments and clinicians’ stories when discussing their actions and emotions with me.

The storylines of individual and shared experiences of mindline forming and the emotions experienced in these stories were important in analysis (Holloway & Freshwater 2007). Incidents were rewritten into a narrative structure, focusing on the characters involved and the temporal structure of the events infused with personal insights from my fieldnotes and emotion journal. Reordering critical incidents into coherent and legible stories clarified the dynamic, continuously fluctuating systems of meaningful experiences related to community-based palliative care. The selection of critical incidents to rewrite and include in my thesis were based on my affective resonance with the data that ‘glowed’ (MacLure 2013). Glow, or affective intensities in data is ‘abstract or intangible’ and can be an embodied reaction to ‘the emergence of sense in encounters with data’ (p. 661).

Following the analytic approaches of researchers working in a post-structural paradigm, I considered what my data did rather than what it meant (Lupton 2019). As I reread my field notes and transcribed interviews, I identified resonant stories in terms of their affective resonance and their connection to theory. I initially focused on some of the ‘intense’ moments of data collection, for example when I had helped a nurse move and wash a deceased patient, or when I heard a story that moved me emotionally. In trying to understand clinicians’ collective mindlines, I was often caught in the glow of their humanist practice. Their attention, and ways of enacting that attention, towards suffering individuals resonated with, and reconstituted my own values, creating an affirming joyfulness. This prompted a deeper interrogation and awareness for similar and different affective resonances related to humanist

practice. I moved from these moments outwards, capturing and rewriting the disparate stories of my experience and those relayed to me by nurses.

The second mutually constitutive part of my analysis involved describing the mindline assemblages that I interpretively developed across my data by mapping the internal and external limits of mindlines – distinguishing the conceptual (ideas, emotions) and material (identities, practices, emotions) limits of specific mindlines. Assemblages produce territories; these need not only be places, but also include arrangements of bodies, subjects, things, and ideas (Buchanan, 2015). Following assemblage theory, I wanted to create space to consider the different ideas, practices, emotions, and identities that constituted mindline assemblages at the centre. This work is presented as a description of the elements that make up different mindline assemblages in chapter five, the first of three results chapters. This map is structured according to: the concepts the mindline assemblages are drawn from and/or evoke (ideas); the material actions that correspond with the mindline assemblage (practices); the emotions that participants discussed or experienced in close proximity with the mindline assemblage (emotions); and the different roles that were adopted by clinicians, patients, and carers in relation to these mindline assemblages (identities). These structural motifs were selected because they evoked an encompassing heterogeneous structure of the mindline assemblage, with each thing playing a prominent role, working on the other things in the assemblage. The collection of motifs within the mindline assemblage structure developed deductively by acknowledging recurring elements in assemblages used by other scholars (for instance new materialist scholars who use assemblage theory to identify how materials assume characteristics reminiscent of human interaction) and their relevance to identify relationships between emotion, knowledge, and practice. I also developed this structure inductively by reviewing my data to understand how clinicians promoted and/or denoted important elements of their own practice.

Mapping the mindline assemblages involved ‘plugging the theory and data into one another’ (Jackson & Mazzei 2013, p. 261) to maintain a substantive connection to the theories of emotion and institutional logics, that might be pertinent in my consideration of assemblages. Preliminary coding to organise and represent data was helpful, albeit limiting, as it precluded the ‘dense and multilayered treatment of data’ (Jackson & Mazzei 2013, p. 261). I discovered that I was unable to do justice to the messiness of the assemblages of community-based palliative care and the critical incidents I had observed. Moving beyond coding, I ‘read-the-data-while-thinking the-theory’ (Mazzei 2014, p. 743) entering the assemblages of critical incidents, and the wider assemblages of community-based palliative care practice. By plugging in, I read data and theoretical text through, with, and in relation to each other to construct a process of thinking with the data and with the theory. Specifically, I considered my data, transcripts, field notes, and journal entries, through diverse theoretical lenses. For instance, I incorporated Ahmed’s (2013) consideration of how emotions ‘fix’ and move the self and others. Ahmed’s theories offer a way to understand emotions as an outcome of bodily memories and histories of contact between racialised, gendered, sexualised, and otherwise differentiated bodies. Ahmed (2004) emphasised that emotions ‘do things’ revealing ‘the movement and attachment implicit in emotion’ (p. 27). She cited the Latin etymology of the word ‘emotion’: *emovere* meaning ‘to move’ or ‘to move out’ signifying the movement inherent in the understanding of the word. I used this understanding to examine the movement in metaphors (e.g. ‘letting out emotion’), in embodiment (physical acts of movement conveying emotion), in joining bodies together (i.e. the collective of palliative care), in separating bodies (the ‘us’ and ‘them’ of palliative care and non-palliative care clinicians). I rewrote data with theory to reproduce assemblages of emotion and mindlines. In the following interview transcript, for example, I plugged it into Ahmed’s interweaving of the personal with the social, or ‘how we inhabit the world ‘with’ others’ (p. 28). The excerpt is from a field note that I

transcribed during a conversation in case review. The conversation between the specialist and generalist nurses pertained to talking about death with patients, and the excerpt is from an experienced specialist nurse:

Some of the doctors will say, ‘Have you done the end of life plan; have you talked about where they want to die’? But you know, you can’t. We’re the nurses that are going to be going in for the next, maybe next year. So, you can’t go in like a bull at a China shop. You sometimes have to build up that rapport and then when the opportunity comes, so I think that can be taught (specialist nurse).

My initial readings of this data focused on the relational context, the different identities present in the conversation including the doctors, framed in terms of their imperative for action, and the nurses, framed in terms of their need to preserve relationships with patients and carers. Plugging in theory meant I was more attentive to the movement entwined in the metaphors and actions spoken by the specialist nurse. In this excerpt, I returned repeatedly to the simile of the bull in a china shop, with its evocation of uncompromising, callous anger. I asked, what was the stickiness inherent in this evocation, or ‘the transference of affects’ (Ahmed 2013, p. 91) among objects? How does the sticky affects of the bull construe the doctors’ imperative, or oppose the nurses? Following these kinds of movements, similes, and metaphors in data, principally through writing, I developed my analysis and results to present a relationship between emotions and mindlines.

Other theoretical perspective informed my analysis, including Deleuze’s (2007) reading of Spinoza’s affective theory, prompting attention to actor’s pursuit or experience of ‘joyful’ or ‘sad’ arrangements in community-based palliative care. I was also influenced by readings of Foucault (1978, 1982, 1987), necessitating attention to the product capacity of power and resistance. Through a Foucauldian reading of the data, I asked how participants related to

themselves and became subjects that governed themselves or were governed by others (Rose 1998). Inherent in this approach was a reading of emotions through the relations of power inherent in emotion talk – the ways emotions create communities and legitimise political decisions through the work of affective economies.

My analysis also involved documenting and plugging in my conversations with my supervisors, who helped shape my analysis. The proceeding fieldnote followed a conversation with my supervisors, which I plugged into my observation to create new perspectives and resonances:

New grad student doing her case review – all business. Sticking to the distinct Medical facts of clients. She is formerly a hospital-based nurse. Uniform is different – watch is clipped to the front of the scrubs, pens in sleeves. This is in contrast to the generally more relaxed appearance of other nurses. Her language is different – she appears nervous, likely due to [Specialist Nurse's] commanding presence. Her way of presenting her cases is through a common sense, emotionless transfer of data.

A later conversation with Ann and Jayne about this sparked a discussion about the experience of palliative care nurses embracing the emotional, verses newer, less experienced nurses avoiding the emotional, less readily relevant information. Following this discussion, I commented that more experienced nurses were more likely to readily talk about a patient's personality, or family, or pet. These topics would often become emotive and emotional, with nurses expressing anger, sadness, or joy, at different stories and experiences with patients. Sometimes these references did not make for pressing,

medical facts pertinent to a case review. However, through field work I observed that less experienced nurses, generally more familiar with hospital settings, were more likely to avoid these topics, relying more heavily on cold facts of a case. From the supervisory meeting notes: Newer clinicians vs experienced clinicians' expression of emotion. Older clinicians seem to be more open to expression of emotions – leaving 'room' in case review meeting for case managers description or expression of emotion. Ann stated that this was not necessarily reflective of the literature on newer clinicians training and education on the importance of emotion in clinical care. Michael exploring the idea that this is reflective of experienced palliative care clinicians' acknowledgment of the importance of emotion as a component of patient care. Also, younger clinicians may be more inclined to perform an emotionless 'sterile' ideal of handover for more experienced clinicians whom they expect to favour an emotionless approach (field note, 07/03/2019)

4.5 Presentation of findings

In this chapter, I described and justified the methods used to explore emotions and mindlines in palliative care. The methods were appropriate as they addressed the research question and reflect an epistemology that privileges the interpretive and situated nature of knowledge. In the following three chapters, I synthesise the emergent findings. In the first chapter, I begin at the middle, describing the mindline assemblages that I interpretatively developed through analysis. I arrange each mindline assemblage in terms of the ideas informing this mindline assemblage, the practices and emotions this mindline assemblage allowed for, and the subjective identities

constituting these mindline assemblages. A concern that is inherently part of assemblage analysis is: where to stop. How do I know that I have accurately mapped a whole mindline assemblage in my analysis to achieve rigour? Deleuze and Guattari (1987) insisted that their approach is pragmatic, arguing that concepts, ideas, images, and stories are made to be used, regardless of their ‘truth’. Guattari (1995), emphasising this idea, wrote: ‘Just as an artist borrows from his precursors and contemporaries the traits which suit him, I invite those who read me to take or reject my concepts freely’ (p. 12). My aim was to use the concepts, ideas, and stories collected during fieldwork to do something, to produce a new way of thinking or seeing mindlines.

In chapter five, I explore the movements of mindline assemblages within the home and the community health centre, explicating the contingency of emotions as a constituent part of these movements within the social. In chapter six, I present a series of vignettes to explicate how these mindline assemblages operated in reality. These vignettes are based on some of the critical incidents I identified during my fieldwork and follow the narrative structures I employed in analysis. Using these vignettes, I describe the fluctuation of different assemblages across clinical encounters, designated as processes of de-territorialisation and re-territorialisation within critical incidents.

For ethical and pragmatic reasons, managing participant identity in my thesis was challenging. I wanted to avoid identifying those I shadowed and interviewed to maintain their safety and trust. However, I also wanted to represent individuals’ organisational and cultural contexts. Take for instance, one clinician who explicitly stated her practice was informed through affective resonances of her cultural background, or the relationships among clinicians that were constrained through hierarchical structures between generalist and specialist nurses and medics. To manage this challenge, I maintained clinician anonymity by referring to them by numbered designations of generalist nurse, specialist nurse, or specialist medic. I have

deidentified the patient and carer data, excluding information, such as their living arrangements that might be potentially identifiable.

Chapter 5: The mindline assemblages of community-based palliative care

5.1 Introduction

In this chapter, I present the mindline assemblages prominent in clinicians' conceptualisations of palliative care based on interview data, observations, and my journal. Collectively, I summarise the mindline assemblages related to community-based palliative care that shaped practice. This underscores the ways emotion was implicated in these assemblages of palliative care that were purposeful. These purposes were varied and could include benefits to patients, carers, clinicians, or the organisation. While there were many mindline assemblages that I could have explored in my analysis, I focused on those most prevalent within clinicians' talk and actions. The mindline assemblages I focused on were associated with: humanistic practices; physiological practices; rapport building and preserving; death and dying care; professionalism and institutional logics; and self-preservation. I drew on theory to elucidate the emotions and ideas entangled within these mindline assemblages, articulating theoretical concepts that informed my analysis where appropriate. I describe mindline assemblages in terms of the concepts the mindline assemblages are drawn from and/or evoke (ideas), the material actions that correspond with the mindline assemblage (practices), the emotions that were discussed or experienced in close proximity with the mindline assemblage (emotions), and the different roles that I observed clinicians, patients, and carers adopting in relation to these mindline assemblages (identities). These structural motifs were selected because they evoked an encompassing heterogeneous structure of the mindline assemblage, with each thing playing a prominent role, working on the other things in the assemblage. In community-based palliative care, these diverse ontological elements came together to produce provisional,

purposeful arrangements, establishing shared notions of what palliative care was. The relations that were invoked among elements within assemblages, or the ‘encounter[s] between subjects, bodies and worlds, and the affective modulations these encounters inspire’ (Duff 2014, p. 37) provoked rich analytical material, creating connections between seemingly disparate elements, for instance the emotions related to pain implicated in physiological attention in palliative care.

5.2 Humanistic mindline assemblages – ‘What’s in your heart’

Even though we were on the ward, it was a patient obviously, it was in an acute setting, but he was dying. We didn’t just care for him; the daughter would come in and on the weekends and she would bring in lunches and we’d have family lunches and things like that. I know things are different now on wards but that’s what we used to do, and it really helped the family get through the process. I think and it made us look more human I guess too. I think that’s important that we’re not just the nurse and I think... we did get to know them because this particular person was in hospital and one day he just said to me ‘I haven’t been outside for, I think it was like six months he hadn’t been outside of the ward, and I said ‘Right, that’s it. I’m going to take you outside today if it’s the last thing I do.’ So, during his lunch break, I wheeled his bed out and we went outside, and I just felt so bad. I remember thinking there were fires and it was smoky as and I’m just thinking, you poor bugger; like, the one day I’ve bought you out [laughs] and he goes ‘No... this is beautiful. This is just fantastic... This is just unreal’ ...I remember that particular moment. I thought, you know what, he ended up dying not long after that, but at least I did

something. Personally, it just made me feel good that I could do something like that for someone else. But also getting to know the family I think is very important going through that journey, communicating to the family this is what's happening (generalist nurse 1).

5.2.1 Ideas

Humanistic practice is a long-held ideal of healthcare discourse, regardless of specialty (Kinmonth et al. 1998; Stewart 2001). Yet, to the clinicians at the centre, the inherent context of palliative care required a unique approach that favoured patient and carer choice above all else. Cicely Saunders wrote of the individualism, autonomy and control inherent in hospice philosophy that extends from the patients to the clinicians delivering palliative care (Thoresen 2003). Similarly, mindline assemblages of humanistic care at the centre involved a relationship between clinicians, patients, and carers that increased agential capacities of patients and carers to attend to 'non-clinical' desires. Clinicians framed humanism by de-territorialising objective clinical identities into re-territorialised 'human' or 'non-clinical' identities. This subjective identity came with increased capacity to act outside the boundaries of clinical care or institutional logics, described as 'the belief systems and associated practices that predominate in an organizational field' (Scott et al. 2000, p. 170), often in the form of promoting more 'holistic' care. Humanist care, as I understood it, invoked patient-centredness:

Palliative care... is... not just the nurse, the patient; it's the patients in the centre and we're around them... In that circle, you've got the nurse, you've got the doctor, the OTs [occupational therapists], the physios

[physiotherapists]; everyone is involved in palliative care (generalist nurse 1).

As patients and carers experienced dying and death, an uncontrollable physically and an emotionally traumatic event, clinicians enshrined their right to determine their care as an agential imperative:

Acknowledge her, because this is about her. She's still alive. She's still with us so let's respect her for who she is. I think that's important (specialist nurse 1).

The arrangement of patient or carer agency within humanistic assemblages was a vital conceptual piece, central to understanding when and how humanistic care was necessary. In some conceptualisations of humanistic mindline assemblages, for example, this was a processual reframing of a patient's disease or emotional experience, towards their 'personhood':

You feel that, despite the suffering, you see them as [a person].
Because what happens [with medicine] is, we see them as diseases and that's when we lose out on the experience of what medicine is (specialist medic 1).

Because of the centrality of 'personhood' or patient agency within humanistic mindline assemblages, practices and emotions were less bound to rigid or explicit structures or guidelines. As long as an assemblage maintained the patient or carer desires within it, it aligned with the humanist ethos of palliative care. While this was a prevalent ethos, I will explore exceptions in subsequent sections of this chapter.

5.2.2 Practices

The humanistic assemblage clinicians described was enacted through discursive empathetic reframing, as medics and nurses emphasised patients' lived experiences. Nurses took pride in conveying acts that focused on patient need as indicative of quality palliative care. Regardless of a patient's stubborn or 'challenging' behaviours, clinicians reminded each other and themselves that a patient was suffering from a life-limiting illness, and so required patience and careful attention to their needs.

Key to the broader humanistic mindline assemblages were practices of acknowledgement. To enable patient agency, you have to first acknowledge the patient, which was arranged by conceptually centring the patient within the care, accompanied by tacit body language practices (e.g. sitting next to the patient during a home visit, looking at them and directing questions to them, using the patient's name often in an interaction):

I need to acknowledge that [the patient] is important as much as I possibly can. Even if it's a physical touch of the hand. A big smile. Something to let her know that I'm here for her, even if that's the only thing she's understanding is that this woman is here for me (specialist nurse 2).

This excerpt evokes patient centrality within the mindline assemblage of humanistic palliative care, as well as the embodied practices that help to demonstrate this centrality. Interactions were regularly framed around acknowledging the patient. Acknowledging the patient could be as simple as listening to them:

Sometimes, all you really need to do is be an ear to listen to them. Because maybe [his] wife has had enough of listening to it all. You

know, nobody in the hospital listened to him at all... So, I think it's great. That's what I think is important (specialist nurse 1).

The act of listening, particularly to that which was beyond the territories of patient-clinician interaction norms (e.g., asking the patient about their weekend, what they did for work, talking about the pictures on the wall), was highly prized within humanist mindline assemblages. This conceptually softened patient-clinician boundaries, establishing a more productive bond, allowing nurses to attend to non-clinical desires.

Humanistic mindline assemblages were sometimes practically framed through ironic articulations of the dichotomy between the fast-paced world of other healthcare services and the soft-skills of community-based palliative care. During one case review, clinicians jokingly equated their practices with emergency medicine tropes, like 'emergency hand-holding', or calling out for 'a cup of tea, stat'. Implicit in these articulations was the perceived value of palliative care in the wider context of medicine. 'Get out of my way, I've got case reviews in 10!' one nurse joked as she passed me in the hall following a previous discussion about the heightened stress of practicing in emergency departments at hospitals. In these moments, palliative care did not equate with other forms of medicine, largely due to the gentler, more genial practices involved. The nurses extolled the virtues of these practices as a core component of the care they delivered:

Even though we're looking at all the clinical symptoms, reassuring her makes a difference. You'll see me when I'm there; I'm telling her 'Look, you've done well cleaning the house'. Just making a compliment makes her feel better... just not looking at all the clinical stuff, but it's the emotional, the holistic side of nursing that has a massive impact on the patient as well (generalist nurse 2).

Acknowledging and centring the patient within assemblages of humanistic care meant attention could proliferate in the form of connections to and from the patient. With the patient central and dictating terms, the clinicians described practices within this assemblage as multifarious. The only definable practices and relationships were those that were purposely beneficial to the patient and/or carer. This broadened the conceptualisation of care in what was frequently defined by clinicians as ‘holistic’ care, allowing practices that attended to physical and physiological health, as well as social and spiritual wellbeing. For instance, one specialist nurse extolled the virtues of a patient’s visit to the pub, and her responsibility to create that capacity for the patients:

It’s my job to support them to do the things they like to do. With [patient], he likes to go to the pub. And I think it’s a good diversion for him because it takes him away from thinking about what he’s got. Although patients like that commonly will isolate themselves, he’s actually brave because he is out there looking for that social connection, to be able to keep living the way he likes to live his life... I mean, the hospital told him that he’s not going to go past Christmas. You feel that, you go there, and that family was all in the house; they’re all gathered. [The carer] was not as loud as she was now. And you feel it. They were preparing themselves for [the patient’s death], but he picked up. He picked up because he started going back to the pub (specialist nurse 4).

What was important in this nurse’s care was not only enabling her patient to attend to the pub, but the positive ripple effects this had on the family. The mark of quality care was the altered, more positive demeanour of the patient and the household collectively.

Nurses at this research site imbued their discourse and actions with this widened perspective of care. They described holistic care as moving beyond physical symptoms in the first instance:

It's not just about physical pain, is it? They might be feeling other things, or they may have frustrations that can impact on caring for them (specialist medic 1).

While holistic care was defined as 'looking at everything', it was often assembled with common practices, including knowing about the family support and carers assisting the patient or enabling the social activity of a patient. In the excerpt at the start of this section, the nurse spoke about caring for the patient's family members.

Humanistic mindline assemblages also encapsulated carer care. One nurse spoke of attending to the family as part of the palliative care she provided:

[The specialist medic] and I ended up clashing a little bit because I said, 'His wife's not coping' and she said, 'No, you're listening to the wife. We have to do what's best for the patient.' It's not just one person, it affects everyone else (specialist nurse 1).

Community-based palliative care required negotiating domestic relationships and responsibilities. When a patient began losing functioning and chose to stay at home, often (however, certainly not always the case) family members or close friends began to care for the loved one at home. This new domestic situation regularly caused tension, with frustration for both patients and carers regularly boiling over to clinicians. Clinicians were invariably caught up in these tensions as they negotiated care between the patient and carers. In some instances, clinicians were required to balance the needs of the carers against the needs of the patients. During a case review, one specialist nurse expressed concern about a patient's carer dedicating too much time to the care of the patient, as opposed to spending time with her partner and

children: ‘There’s no quality time spent with the kids... It definitely could have an effect on the relationship’. The nurse suggested referring the family to counselling. Understanding patient and carer perspectives and the nature of their relationships necessitated an ability to empathise with patients and carers both individually and as a team. Experienced clinicians reframed patient and carer perspectives (which clinicians regularly identified as exemplary clinical practice).

Ostensibly mundane practices, like making a cup of tea for a patient, bringing in the washing, or discussing who will care for pets after the patient has died were assembled within mindline assemblages of humanistic care because of their significance to patients and carers. Nurses emotively acknowledged the dichotomy between these mundane acts and their effects on patients and carers:

It’s just a chat over a cup of tea; but that conversation might be something that’s really important for that person who might not see anyone else for that whole week (specialist nurse 3).

The specialist medics and nurses framed holistic practices as ethically and substantively relative to individual clinicians. One experienced specialist nurse cited how a generalist nurse applied this maxim well because she ‘thinks about the patient’s dog’. The generalist nurse’s attention to patients’ pets followed her own fondness for animals and brought this joy to her holistic practice. Specialist nurses would regularly state that, even though the generalist nurse was not a palliative care specialist, she acted in a ‘palliative way’ by focusing on what was important to patients and carers.

During my time at the research site, one specialist nurse produced an education material to assist nurses to document their assessment of patients’ palliative care needs during home visits. The placard displayed the acronym POMSNAME to prompt nurses to document: pain, oral

care and orientation, mobility, social context, nausea and vomiting, appetite, medication, and elimination. Regular conversations ensued about the validity of the acronym and whether it was holistic if limited to these foci. Some clinicians suggested additions, like shortness of breath and sexual health. These conversations opened moments within the team of clinicians to reaffirm the maxim of holistic care. ‘That’s what we do. To care for a patient holistically means we have to look at everything’ (specialist nurse 5). The placard ignited emotive stories about how holistic palliative care should be. For instance, one nurse described her encounter with a patient who had asked if it was safe to have sex if they were completing a course of chemotherapy. Emotionally charging the holistic nature of her experience reinforced its importance among other nurses, reinforcing their collective ‘attention to everything’.

Nurses often cited the need to operationalise holistic care through relational acts with patients, providing them with the tools and impetus to define their own care:

I will say, ‘Okay, so what matters to you now that you’re back at home from the hospital and you know you are aware of your condition?’ And then that’s when they will say to you, ‘Oh, it matters to me that I’m here and I’m able to spend time to with my kids’ or you know, ‘I can still go out to church’. Different people ask about different things (specialist nurse 4).

According to some senior nurses, to enact holistic and humanist mindline assemblages, you had to establish a relationship with patients and carers, attending to their individual concerns and preferences. In section 5.4 I explore the connections between humanist assemblages and rapport mindline assemblages.

5.2.3 Emotions

Humanistic mindline assemblages afforded multifarious emotions, linked closely to what patients or clinicians might be, or were feeling and the attachments made between patients, carers and clinicians. Emotion in this context was inherently linked to patient experience. As nurses and medics perceived and empathised with patient suffering, it opened new capacities. As specialist nurse 4 said, ‘You feel sad for your patients... [and] that emotion will push you to... look out for things.’ Emotions around patient suffering assumed a heightened embodied and empathic sensibility, tying clinicians to patients and carers:

I think that’s what palliative care is about... [not] just saying, ‘Hello how are you’ And not physically touching it, because you’re not a disease, you know? And I think we need to understand that. You’re are still human, you want to be loved, you still want to be cared for and you are still important. I always say that you are my prime focus, so I always want you to know, and we’ll seal it with a touch (specialist nurse 1).

Patient agency was beautifully evoked by this nurse through a notion of being ‘loved’. Ahmed (2013) noted that emotions work to differentiate individuals by identifying those with a capacity be loved or to be ‘grieved’ (p. 124). Legitimising care was inherently embodied as the ‘movement of contact’ (Ahmed 2013, p. 194) physical or emotionally with patients and carers, creating grievable patient bodies, and thus substantiated their physical, mental, and emotional pain and suffering. Ahmed (2013) discussed the ‘affective bond’ of love through Freud as ‘crucial to the formation of subjectivity, sociality and even civilisation’ (p. 125). Love becomes the creation of the patient subject as capable of being loved. It is a way of valuing something inherently. Ahmed argues that the valuation of love creates an idealisation and a ‘making of likeness’, binding the lover and the object together.

This resonates with my findings, where humanistic mindline assemblages implicitly afforded this binding through empathy. Acknowledging and working within an assemblage of patient agency required relational connections with the patient, built through empathetic sensibilities:

You're putting yourself into their shoes you know? What if I have that disease; what happens to me? Isn't that what you're supposed to have – empathy? (generalist nurse 3)

This participant's question recurred throughout the study in varied forms: what if this patient was me, my child, or my friend? Personally, sensing physical, mental, or spiritual suffering, even if manufactured through illusory suffering, was described as a prerequisite of palliative care – 'what you're supposed to have'.

Binding the affective forces of love and empathy often promoted emotional labour that represented increased conscientiousness to minimise suffering:

When I see kids, particularly if a client's a parent and they've got small kids around the age of my kids... you feel sad for the kids and the partner as well, especially if it's a young client that's been affected with something terminal... You become more conscious of everything that you say, because they're already suffering and it's giving them an emotional burden (specialist nurse 4)

Comparing a patient's circumstance to one's own demonstrated the empathic nature of perceived suffering: it created productive bonds between clinicians, patient, and carers. Suffering, although not always spoken about directly, became an undercurrent of humanist mindline assemblages, sweeping a nurse's own emotions and actions in seemingly significant ways for the nurses and medics providing care:

You've got to make them feel worthy, particularly those that are terminally ill... When I go see my patient, I try to be fresh air to them; like a fresh burst of air. I don't say, 'Oh my god. Work is so busy today. [I'm] lucky I made it to your house' I don't say that. I [say], 'Yes you're my first patient [I've] seen' [even though] they're the eighth patient [I've] seen (specialist nurse 4).

Many nurses adjusted their emotional dispositions to 'make [the patient] feel worthy'. They shaped their practices around patient and carer emotions, conforming to certain scripts to abate or disrupt negative feelings. By reconfiguring patient's and carer's negative emotions, primary participants construed negative emotions as unhelpful or distracting:

I always try and focus on... encouraging them to do what they love to do very much. I don't say, 'Oh, you're going to do this because you've got this much [time] to live now'; I don't dwell on that. It's more of a positive vibe... Not just with the patient, also to the family member as well – the next of kin, because it affects them as much as it affects the patient (specialist nurse 3).

Emotion created a relational attachment to the patient and carer, forming a collective body where pain and suffering in their many permutations are shared between clinician, patient, and carer (Ahmed 2013). One nurse described the like-minded marks or, in Ahmed's (2013) terms 'impressions', of care that were vital to cohabiting the place of care between clinicians and patients through relational attachment:

You want to leave a mark on a client, and you want to leave a good mark. And you want that experience that they've had with you to be memorable for many good reasons. And I want to be the kind of nurse

that has an impact on a client for good reasons. And I also would like that to come back to be the same when I needed... I'd want my needs met in the same way that I think that I'm helping the others in palliative care, the same with my family. If my mother was in that situation, I would want only the best. I would want the nurse to come in wholeheartedly. While she is here, she is fully giving attention to my mother at the best of her capacity (specialist nurse 1).

Relational attachment here can be likened to empathy. Theorist appreciation for the empathetic sensibilities stretches as far back as Hume (2003). Hume spoke of feeling with another's experience enabling an appreciation of how the other feels. Despite contention in the literature, there is a general consensus that empathy refers to understanding how others feel emotionally, with a capacity for appreciating another's unique or 'strange' (Code 2013) experience, rather than one's own. The strangeness entailed in this definition of empathy represents the boundary crossing nature of empathy; the ability to enter another's body and appreciate the difference of their situation. In terms of palliative care, a capacity for empathy as a way to appreciate difference helped clinicians appreciate and respond to a patient's experience.

5.2.4 Identities

Clinicians viewed their humanistic practices as unique, distinguishing them from other healthcare professionals who largely focused on physiological aspects of health. In the context of multidisciplinary practice, emotion delineated and blurred a palliative care identity. Emotion shaped how clinicians interacted with other professions; it also consolidated humanistic mindline assemblages, reaffirming what it was, and how to enact it. This was important in knowledge sharing because how other professions aligned with or diverged from those values became touchstones of what to do or what not to do.

Some nurses regularly separated clinical practice from their palliative care identity, one that embodied empathy, patience, respect, and compassion. This identity and its association with relational care stemmed from collective understandings, within and beyond the research site:

It's about experiences you bring with you. If this was your mother, what would you want? Would you want somebody at the end of the door going, 'Is everything right here? Well, we'll be back later when somebody speaks English'. It's not on (specialist nurse 2).

Clinicians discursively separated palliative care from other healthcare specialties by accentuating patients' and carers' physical, physiological, social, and spiritual experiences. To nurses and medics, the importance of 'humanism' – rather than 'just [being] the nurse' – de-territorialised palliative care identity from a clinician or institutional identity and re-territorialised into a human identity distinct from clinical subjectivities. Discussions of humanism evoked a desire to frame nursing, particularly palliative care nursing, as going beyond what was expected of 'just nurses' and the wider medical community. Nurses talked explicitly in terms of 'boundaries' of professionalism, and how palliative care required moving those boundaries: 'We've got all these professional boundaries, but I always think you've got to do what's in your heart, what's right for you' (specialist nurse 3).

To be human rather than a clinician means professional boundaries of practices and emotion were disassembled to allow a clinician's 'heart' to guide action. What resulted was an identity that could deviate from institutional logic or healthcare norms while still maintaining a strong connection to palliative care. The notion of rule bending or deviating from institutional logic has been explored in literature related to positive deviance, understood here as a 'collection of behaviours that depart from the norms of a referent group, in honourable ways' (Spreitzer & Sonenshein 2003, p. 209).

Within humanistic mindline assemblages, nurses conceived themselves as ideologically heterogeneous, a necessary requirement to produce new ways of caring. To appreciate a patient's dog, for example, was an intrinsically individual value, drawn from the clinician's own perspective rather than a collective identity. This story was promoted by a specialist nurse, not because they wanted other clinicians to think about patients' pets, but rather to think about their patients as humans, with individual values. For Kelly et al. (2015), values are a psychological heuristic that represent 'the world as we think it ought to be' (p. 2). They are inherently relative and provide a foundation for how we interact with the world on all levels:

Our hopes, beliefs, politics and religions, about which we (appropriately) feel emotions, provide us with the frame or the lens with which we see the world, our ambitions for the future and our understanding of the past.

Deleuze and Guattari (1987) noted that value-based assemblages are a distinct mode of organisation, where people come together to achieve something because of the values they hold. These assemblages work through a shared belief among actors within the assemblage that something *should* happen. This can enable variations in possibilities to enact palliative care. A clinician would care about a patient's dog because that was important to those actors within an assemblage; a clinician would get a patient's washing in because she knows the patient can't manage it herself. Shared values among clinicians and patients were working assemblages of palliative care.

When actor values did not align enough to work within a given assemblage, clinicians faced difficulties. This happened, for example, when a patient was reluctant to be seen by a palliative care specialist, stating it a 'waste of time'. This kind of response required a rethinking of how an assemblage might work, and it required time and ongoing connection between patients, carers and clinicians to establish how values within a palliative care assemblage might work

together. This fostered attention among clinicians to rapport, which I will discuss in a subsequent section.

5.3 Physiological mindlines assemblages

Michael: So, what's [patient's] situation?

Generalist nurse 2: So, [the patient] has lung cancer. She has peripheral neuropathy, so nerve pain... She was getting lots of pain towards her right thigh. She used to be on Lyrica [medication used to treat pain caused by nerve damage] but they've stopped that. She's currently on Ordine [opioid analgesic used to relieve severe pain]; she's taking that twice a day. The other symptom was shortness of breath. The nodules that she had around her lung had decreased a little bit, so breathing is okay but once she stops taking Ordine, then she'll notice it a bit. Recently, she's been experiencing increased weakness and dizziness and about a week ago, it turned out her thyroid had been fluctuating, it went down with medication, so that made her feel better. But the issue was her diabetes medication; she wasn't taking it correctly. She was taking double the dose for one of them and half the dose for the other. So, I had to clarify all that with her and now it's like we're thinking it might be her having postural hypertension. So, when you stand up your blood pressure drops down heaps and makes you dizzy. So, I'm going to check her blood pressure to see if it's all right and if it's not okay I'm going to call the GP.

5.3.1 Ideas

Mindline assemblages that were framed as humanistic, generally, departed from the kinds of assemblages preoccupied with the body. Physiological mindline assemblages framed care in terms of a biomedical model of prevalent in Western healthcare systems, which primarily operate on the principle of a Cartesian body-mind split (Marcum 2008; Wade & Halligan 2004). The biomedical model of healthcare systems conceptualises the person as a mechanistic body, composed of functional parts that interact with the mind as an identity and energy source (Marcum 2008). This objectification of patient bodies as a set of systems to be treated is implicit in modern healthcare services that silos disciplines based on their specialities. This constructs the body as anatomy, detached from its surroundings in what Deleuze and Guattari (1987) called a 'Body with Organs'.

Palliative care clinicians prided themselves on their holistic care, suggesting a conceptualisation of health as more than the traditional notion of 'normal functioning' or the absence of disease. However, to care for the whole patient required care of the body, addressing the physiological symptoms of a life-limiting illness. Patient comfort as a goal of palliative care and a good death was contingent on alleviating the symptoms that caused discomfort. This largely revolved around managing different types of physical pain or discomfort through pharmacological intervention. Despite the exaltations of holistic care within the centre, physiological care was given high priority. For instance, the POMSNAME placard I described in section 5.2, ostensibly developed by a specialist nurse to prompt other nurses to widen their focus, was made up mostly of physiological foci (i.e. eight of the nine items: pain, oral care, orientation, mobility, nausea, appetite, medication, and elimination).

5.3.2 Practices

Physiological care had a central place during home visits. Clinicians initially questioned patients about their pain or bowel movements. A particularly important practice as part of these mindline assemblages was medication management. Patients with life-limiting illness often have pain relief needs that change quickly as their illness progresses. Ensuring a patient's pain was 'under control' was vital to physiological comfort, increasing a patient's capacity to function and carry out everyday activities. This often involved asking patients to locate and rate the types of pain they experienced and encouraging carers or patients to document the frequency and efficacy of medication use. Also, regular inquiries about the frequency and consistency of a patient's bowel movements were prioritised during home visits, as the nurses were well-versed in the importance of the bowel to absorb medication. As nurses were unable to prescribe medication, specialist medics were asked to attend home visits to assess a patient's medication regime. This gave them a unique role and status during a home visit and during joint home visits, specialist medics often took centre stage in patient interactions. Nurses were also required to attend to syringe drivers, which were devices that automated the delivery of subcutaneous or intravenous medications for patients who were unable to take them orally or who required high dosages. Syringe drivers needed to be refilled and reset usually every 24 hours, so home visits were scheduled daily for this task.

While pain and medication management were the frequent focus of physiological mindline assemblages, a patient's physiological maladies could be diverse. Nurses were required to: assess patients for diverse services, such as speech or occupational therapists; deliver wound care for fungating tumours or bed sores; or offer advice on eating and sleeping habits. The importance of physiological care was reflected in the education sessions scheduled for the specialist and generalist nurses based at the community centre. Those I attended while

shadowing involved, for instance, the different pain medications, how to apply a newly developed wound dressing, and how to assess death to complete an interim death certificate.

Physiological mindline assemblages were regularly contested by humanistic mindline assemblages, as what might be good for a patient's body could impede their social, psychological, spiritual, or cultural capacities. Patients would express concern about medications that caused drowsiness or deny offers of surgery to avoid pain and trauma. These conflicts resulted in the de-territorialisation of physiological assemblages to become something different, sometimes humanistic assemblages that were encultured and/or gendered. In the following excerpt, a specialist nurse described this remaking of a physiological assemblage into a more humanist assemblage:

Sometimes [palliative care requires] a little bit of intuition. I was telling you about that lady... a Tongan lady that had had rectal cancer and had not wanted surgery and not wanted chemotherapy, but it was treatable and probably curable at that particular time. And because she's chosen not to have anything, then it became not curable. She was still having treatment, but I just had a little conversation with her, [where I offered] changing the male surgeon to a female surgeon and all of a sudden, she jumps at the chance. And you know, I still don't know why it was her. The girl that I was with said, 'Why did you say that?' I said 'I've got no idea' I just thought about it and thought, this is a lady my age, she's had lots of children, I wonder does she not feel comfortable with a male surgeon? (specialist nurse 5).

The specialist nurse evocatively described the re-territorialisation of attention from a straightforward physiological concern about the 'treatable' disease to become a humanistic concern. The initial 'offer' of surgery was absent this attention to the cultural and gendered

concerns of the patient. When the specialist nurse re-territorialised her practice into a humanistic assemblage that enabled empathy, it offered her the capacity for ‘like-mindedness’ with a ‘lady my age’. The specialist nurse could appreciate the productive potential of a female surgeon within this new assemblage. This ‘intuition’ was a process of re-territorialising assemblages allowing for new emotional capacities.

The nurses’ limited time meant they sought ways of co-opting physiological mindline assemblages to become simultaneously productive in other ways. This kind of mindline assemblage co-opting was prolific, as clinicians entwined moments of physiological care with humanistic care or rapport building. Taking ‘obs’, or patient vital signs, for example could be simultaneously co-opted to become a rapport building assemblage as a nurse would ask about the patient’s child, facetiously mock the football team they supported, or take a moment to hold a patient’s hand. One exemplar occurred while I shadowed a specialist nurse when a patient required a laxative to alleviate his constipation. The specialist nurse decided to make the patient a laxative milkshake, while conversing and joking with the patient and his carer. This moment was a beautiful demonstration of humanising a practice implicated in a physiological mindline assemblage.

5.3.3 Emotions

Emotions within physiological mindline assemblages fluctuated. At times, clinicians spoke of the need to think beyond emotion to: ‘put your feelings aside’ to attend to matters affecting the patient. This did not necessarily equate with uncompassionate practice. Clinician attention to physiological pain provoked intense emotional and empathic reactions: ‘He must be in so much pain, we just need to sort it out’ (generalist nurse 4). Specialist medics embodied compassionate professionalism. They did not establish familiarity with patients in the same ways or as readily as nurses did. The care they delivered was less about relational attunement, while still

important, and more about the specific mechanisms that impeded patient functioning. According to some nurses, specialist medics epitomised compassionate attention to physiological concerns and inculcated these values in colleagues:

I think they're a different breed of doctors that... go into palliative care. I think they have a lot of compassion and I think that's also what palliative care is all about... compassionate care... I think they do a lot more holistic care (generalist nurse 5).

The specialist medics differed from other 'breed[s]' of doctors. According to the nurses who were shadowed, they were more likely to understand patient and carer needs, and genuinely care. The participants revered these doctors because of the compassion they witnessed and experienced:

[The medic] just gets to the real nut of it... She's a good interviewer... She just takes it slowly and gets everything she need[s] to, out of them... Doesn't jump around; sticks to the point (specialist nurse 3)

Compassionate care, or 'seeing the person in the patient' is a core value of healthcare (Goodrich & Cornwell 2008). Compassion is 'how care is given through relationships based on empathy, kindness, respect and dignity' (Cummings & Bennett 2012, p. 10). Historically, this has been conceived in clinical practice as thinking 'with suffering' (Tierney & McKinley 2002, p. 25). Perceptions of suffering influenced practice as part of palliative care. For instance, as one specialist medic described her attention to evidence in her practice, she voiced a desire to connect with suffering as one component of evidence:

It's still pain; it's still suffering. But it's existential and as a doctor we don't readily have connection to it. [Suffering] is always going to be [associated] with the pastors or the priests or the social workers or the

psychologists. [But I] seek to understand [suffering]. So, because of the work that I do, I do a lot of reading, not medical reading, but... [about] what is pain, what is suffering, why does it happen, what are the factors that shape [suffering] and help it in different ways?
(specialist medic 1)

This participant was enthusiastic about ongoing professional development on suffering, while acknowledging the importance of ‘connection’ to patient sadness and her limited connection to it. However, she conceptualised the connection to suffering as more than physical, but also spiritual (pastors or priests), social (social workers), and mental (psychologists).

In her description of the contingency of pain, Ahmed (2013), quoting Spelman (1997), noted that compassion can reinforce patterns of subordination responsible for suffering. She spoke of the ‘over-representation’ of pain despite its elusive nature in representation: it is intrinsically difficult to appreciate someone’s actual experience of pain (Scarry 1987). Primary participants also spoke of pain as an ‘unknowable’ state:

We can’t possibly know what they are going through physically, but we need to be with them and do what we can to help them, and listen to what they’re saying (specialist medic 2).

This notion evocatively came to the fore when patients needed pain relief medication – a point of contention between palliative care clinicians and GPs who were often responsible for prescribing medication. Clinicians provided stories about GPs who doubted patient accounts of pain, particularly if they previously used illicit drugs intravenously. While discussing the use of medicinal marijuana one specialist nurse took maligned GPs for their poor prescribing practices:

Then the media get hold of it and [say], ‘Your GP can prescribe it’.

No, the GPs can’t prescribe it. The GPs are never going to prescribe it.

They can’t even fucking prescribe Endone for people, what makes you

think they’re going to prescribe marijuana? Idiots (specialist nurse 5).

As one nurse stated, GPs and other specialties did not ‘trust [patients] to know their own bodies’. Nurses eschewed this tendency by trusting patient’s, partially to ensure productive clinical relationships:

It’s not for us to say whether or not he’s feeling that pain. If he tells us

he’s in pain, we’ve got to listen to that, otherwise he’s going to tell us

to get stuffed (specialist nurse 1).

Ahmed (2013) critiqued medical language for reducing pain to the severity of bodily damage. She drew on Butler’s (2011a) concept of materiality to broaden the understanding of pain to include an understanding of the consequences of an injury, embodied histories and memories. Pain is entangled in previous experiences of pain. As such, witnessing others pain can create different appreciations of their unique context and history (Frazer & Waitt 2016). However, Ahmed emphasised the impossibility of ever knowing another’s pain. Rather than attempt to ‘capture’ pain, she instead suggested sharing empathic pain through narratives while accepting the impossibility of never truly sharing an experience. At the research site, as in other contexts, experiences of another’s ‘unknowable pain’ presented an ‘urgent ethical challenge’ (Frazer & Waitt 2016, p. 186), prompting feelings of hope for things to be different.

As patient’s case managers, nurses took ownership of disparate physiological concerns, often demonstrating frustration, anxiety, or grief when they were unable to be rectified. During one home visit, a generalist nurse expressed frustration about not being able to diagnose the cause

of a patient's cough. This physiological concern, while seemingly minor, caused patient and carer 'anxiety' and 'hopelessness':

I know her condition is getting worse, [but] she's hopeless. No one knows what's causing the cough. If we knew what was causing the cough and we weren't able to treat it, that might be a different thing. The fact that we're not able to treat it because we don't actually know what the cause is, that's even more frustrating because you need to know the reason for the coughing. I think that's definitely something that plays a major role in [her anxiety] (generalist nurse 2).

The ability to be moved by something like a cough, for instance, represented a nurse's ability for affective attunement with patients and carers. Clinicians developed and sustained relationships where they could be moved by patients and carers as new physiological maladies arose:

Every experience that I've had in palliative care makes me a deeper, better nurse, where I'm a little bit more in tune; maybe watching a little bit more closely, maybe listening between the lines, I think that comes with experience (specialist nurse 1).

'Affective attunement' between palliative care clinicians, patients, and carers has been explored (Collier 2013, p. 204). It requires a 'nomadic' openness or willingness to move with patient and carer experience of, for instance, pain. Becoming 'affectively attuned' can enable somatic awareness of the problems and remedies of suffering (Shusterman 2006, p. 12). Collier's argument suggested that clinicians need to meet the needs of dying patients, their families, and healthcare workers, by being reconstituted as 'learning to be affected' (p. 204). She drew from Latour (2004) to define this as a clinician's body having the capacity to be

moved or activated by other bodies both subjectively and objectively in the context of the patient interaction. This movement parallels Ahmed's (2013) description of the power of emotion and its capacity to move people. Additionally, drawing on Deleuze (1995; 1987) Collier, notes a body learning to be affected is a becoming body, with no fixity. In my findings, clinicians spoke of 'just knowing' what the right thing to do was in certain circumstances. Take the specialist nurse's ability to identify the importance of a female surgeon for a patient and her description of her action as if it was something that came to her in that moment. Her openness to the patient's gendered concerns was enabled because of her reading of palliative care as being able to be consciously moved via emotion. My findings represent this capacity for movement in both the individual's experience of another, and the individual's connection to the collective, as bodies are inherently moved in relationships with the wider collective (Ahmed, 2013).

5.3.4 Identities

There was a noteworthy pattern in the tension between humanistic assemblages and physiological assemblages. As a patient's illness becomes less 'treatable' or 'curable', clinicians considered patients as moving from a predominantly biomedically focused purview of specialities, such as oncology or cardiology, to the holistic and humanistic purview of palliative care:

They come out to us and I think they're a little bit shocked because no one at the hospital has asked them about their spirituality before. No one has cared about their socialising. It's like, 'Why's this person asking me about this?' (specialist nurse 3).

This was demonstrated when inpatients who were discharged from the hospital moved into new assemblages of community-based healthcare provision. Participants alluded to discord

between palliative care and other specialities, like speech pathology, oncology, haematology, and an array of other ‘-ologies’. This manifested as outbursts of anger from palliative care nurses and doctors towards cardiologists and nephrologists. These occurred in collective settings, like case reviews, as well as private discussions about patient care:

I think [palliative care] is the only stream that does [continuity-of-care]... well, whereas other teams will focus on cardiac or orthopaedics and that’s their only focus (generalist nurse 1).

Poor referral processes reified the foreign ‘-ologist’ as unempathetic of patients, carers, and the nurses. In these identity-shaping stories, the ‘-ologist’ would refer patients to palliative care with limited detail on patient history and patient preferences. This made it difficult for the primary participants to initiate contact with a patient and continue their care:

They’re only interested in looking after their specific thing. They don’t look at the whole patient. As soon as they can’t treat them anymore, they just dump them off (specialist nurse 5).

During a conversation about the future of primary diagnoses in palliative care, a specialist medic suggested that cancer diagnoses will decrease while cardio-, respiratory-, and renal-related diagnoses will increase. This prompted a specialist nurse to lament the fewer referrals to palliative care by cardiologists, who ‘treat and treat and treat’ patients rather than refer them to a palliative care service. Personal attributes of arrogance, single-mindedness, and an inability to empathise with patients consistently bubbled under the surface of these stories.

Generalist and specialist nurses sometimes viewed themselves as a bridge between the complex and systematised biomedical model of healthcare:

[We’re] not interpreting but relaying the messages or relaying information from the doctors... to the patient in a more common-sense

way and not so medical as the doctors always tend to do and making that stage as comfortable and as pleasant as possible (generalist nurse 6).

Despite the seeming divergence between the established biomedical model and palliative care, clinicians recognised physiological symptom management as part of their role. Generalist nurses, for instance, were case managers for patients and saw their role as reactive, addressing concerns as they arose and establishing relationships with other specialties when needed, which I will discuss in section 6.3:

Pal care to me seems a much more responsive thing, where they have pain at this level, they will fix this pain. We're not going to give them pain relief if they don't have that pain. You're going to give the diabetic medication to stop the diabetes going off... so pal care to me seems more responsive than preventative... so you're going to more respond to what their needs are (generalist nurse 7).

The biomedical model of healthcare has been critiqued for its 'disciplining of the flesh' (Petersen & Bunton 1997, p. 81) prompting rethinking of this model. Although it is beyond the scope of this thesis to add to these ongoing critiques, clinicians and patients often prioritised a physiological attention to the body. Despite clinicians' widened offering of care, patients regularly complained about physical pain in the first instance of a home visit. This might be because patients were, having already experienced the biomedical focus of oncology, cardiac or nephrology departments, disciplining themselves within a system preoccupied principally with their bodies. However, pain can be existentially challenging, warranting clinical attention in palliative care. Ahmed (2013) noted that pain returns an individual's attention to the body or their 'bodily surfaces'. An individual's appreciation of their own body is absent when functioning normally and so disappears from view (Leder 1990). A patient's experiences of

increasing pain or other symptoms intensified feeling, defining the contours of the surfaces of a bodily dwelling: ‘as pain sensations demand that I *attend* to my embodied existence, then I come to inhabit the surfaces of the world in particular ways’ (Ahmed 2013, p. 27, emphasis in original). A preoccupation with pain and other maladies in palliative care suggests an important entrenched ideal in addressing an existentially threatening experience. It was important for nurses and medics to be familiar with different kinds of pain, such as neuropathic pain, referred pain, or chronic pain, and understand the different medications capable of addressing different pain. This mindline assemblage heightened a focus on patients’ pain in places like case review and other clinician interactions, belying the holistic ideals expressed elsewhere.

5.4 Rapport mindline assemblages

Specialist nurse 3: [I’ve told the patient] no, but we need to know today if you’re nauseous, okay?

Generalist nurse 4: I can see that he gets a little bit irritated even when we do it, but I’m mindful of that now.

Specialist nurse 3: Yeah (laughs) so then he rang his daughter and went (makes a frustrated noise and laughs). Yeah, and I kept saying that, ‘No, no, no, but we need to know. I know we’ve asked these questions, but we need to know this every week’... Maybe he’s getting the hang of it now.

Generalist nurse 4: And a lot of his answers tend to be the same so that I’ll, even if I ask, try to ask him [about his nausea] it’s always the wife who answers.

Specialist nurse 3: I think he was on his own the day we were there, but it didn't help. So, I suppose you just have a chat with him to get it out in a general way, you know?

Generalist nurse 4: I think you just keep talking and let him correct you. That's what I've found. That's worked out a lot easier.

5.4.1 Ideas

Rapport mindline assemblages were purposeful, focused attempts to foster productive clinician-patient or clinician-carer relationships. Rapport is a well-established ideal in healthcare because of its association with positive patient outcomes (Leach 2005). Defined as a 'harmonious relationship' (Spink 1987, p. 21), primary participants deemed building rapport as mutually beneficial for clinician, patients, and carers. Conceptually, a clinician could not deliver palliative care effectively without rapport. Patients and carers were given access to effective palliative care based on these relationships and treated to warm companionship with clinicians.

5.4.2 Practices

For primary participants, many actions were attributed to the nebulous ideal of building rapport such as presence, physical contact, non-clinical conversations, humour, and being forthright. This quality is not unique to palliative care, but the participants identified themselves as paying particular attention to relational modes of rapport. This manifested as clinician deference to the patient and carer in certain situations, with nurses modifying their persona to match the patient or carer's temperament. If a patient and carer were jovial and happy, nurses would joke and laugh along with them. Alternatively, downcast patients and carers in despair would be met with quiet, respectful, and understanding clinician personas. Exceptions to these movements

with patient temperament were usually the result of clinicians' enactment of institutional logic – sticking to the 'script' – or self-preservation, which are discussed in sections 5.4 and 5.5.

Clinicians framed rapport building mindline assemblages in terms of overcoming barriers to connect with a patient – sometimes this was due to language barriers (given cultural diversity in the area), perceived patient (or carer) antagonism or mental anguish. Primary participants described the importance and validity of particular types of rapport as interconnected with patient and carer emotions. In the excerpt at the beginning of this section, the specialist and the generalist nurse discussed how reframing a question about nausea could appease a cantankerous patient. While facilitating palliative care training at a nearby hospital for allied health professionals, a specialist nurse told a story of rapport building patient rapport to exemplify its importance. It involved a patient who 'looked like a bikie'. In her words, she 'would have crossed the road if [she] saw him in the street'. The patient's physical appearance rendered him inaccessible to her, due to her stereotyped view of 'bikies' as involved in aggressive, if not violent acts. Using emotional labour to suppress her emotional reactions, the specialist nurse decided to compliment his motorbike. This led to a long conversation, which, in the mind of the specialist nurse, culminated with a trusting relationship with the patient. Due to her renewed, compassionate, and non-judgemental behaviours, she 'discovered' that he was 'a lovely man' – a positive ending to her story. To those present, the specialist nurse's aim was to reinforce non-judgemental rapport building to enable positive relationships between clinicians and patients. This was underscored through the inherent hopefulness imbued in a story about striving to and succeeding in overcoming the differences between nurse and patient. Presence, both physically and mentally, was important in rapport mindline assemblages. Nurses implicitly and explicitly purported the importance of spending long periods of time at patient homes:

Even though, at the end of the day, a lot of our patients die, to me knowing that I've given them all the care that I can give, I've done everything the best that I can in referring them. I've looked after the families as well as I can and given them the time. I think that's important; time (generalist nurse 4).

For many nurses, as with this generalist nurse, spending a long time with a patient was a physical demonstration of a nurse's attention and care. According to some of the nurses at the centre, the longevity of palliative care visits contrasted with non-palliative care visits:

You need to take that time in palliative care. For the [generalist nurses doing non-palliative care visits], it's just get in, get out. But in palliative care, it's about making sure you've got that connection and you're across everything (specialist nurse 3).

Presence also had an inbuilt organisational signifier at the centre. This is because palliative care home visits were allocated more time relative to other community healthcare visits. Furthermore, presence extended to ongoing contact beyond the home visit, as patients and carers could telephone a particular nurse at the centre. Cognisant of this longstanding relationship, the nurses recognised value in listening to patient and carer needs and investing time to ensure a shared understanding of these:

At the end of the day, we have to be great listeners, because we go in as a service. I think that's part of what we promise. We're going to deliver. So, you say to them, 'Here's our telephone number'. But we don't say to them, 'Only call us when it's urgent' (specialist nurse 1)

Noteworthy here, is how the nurse connected presence with rapport mindline assemblages, and humanistic mindline assemblages. Specialist nurses recognised how presence could enable

humanist care. Rather than discursively construct presence as a time-intensive burden, these senior nurses emphasised its care-affirming properties. Being ‘there’ for a patient provoked a deep, warm connection, as exemplified by nurses’ utterances and stories. These connections could be fostered through physical contact, as with one medic who described her approach when teaching students about breaking bad news: ‘I say to the students one of the things is leaning forward and perhaps patting them on the shoulder or the knee’ (specialist medic 2).

Palliative care was at times complicated by patients’ limited ability to speak English. The limited communication meant that direct acknowledgement through conversation and listening was problematic. In the following excerpt, a specialist nurse described her re-territorializing her acknowledgment of practices as physical contact to overcome this concern:

The other day I went out and the lady didn’t speak a word of English and so before I left, I gave her a back rub... I always say that you are my prime focus, so I always want you to know, and we’ll seal it with a touch (specialist nurse 1).

Physical contact and other forms of patient acknowledgement were important to medics and nurses; it helped them to reduce boundaries that typically separated them from patients and carers. After a home visit, a generalist nurse and I sat in the fleet vehicle and, unprompted, she recounted the physical contact with the patient that had affected her:

Have you noticed that, as soon as I walked in, she wanted to hold my hand? She didn’t really want to let go the whole time. [She wanted to] hold on to for reassurance as well (generalist nurse 2).

This act was important, not only for the patient’s reassurance, but also for the nurse as it sparked insight into the patient’s needs.

Some nurses spoke of the benefits of patient ‘compliance’ wanting patients to ‘listen to them’, for they had their best interests at heart. One generalist nurse suggested the ‘efficiency’ of connection with patients and carers, an efficiency that differed to ‘that of management and organisational efficiency’. Instead, this was an efficiency in ensuring patient ‘compliance’ and avoiding ‘disenchantment’ with the health care system. Rapport building to foster compliance was a complex issue. Acknowledging a patient’s impending death in community-based palliative care came with strong movement towards giving patients full control over their own healthcare. Nurses presented this ideal implicitly and explicitly: ‘[patients] do what they wish and we as clinicians support whatever that decision is’. Nurses ostensibly wanted to give patients control and freedom to manage their own care at home, but they often became personally invested in how a patient chose to do this. This personal investment came with a cost – to manage a patient meant having a stake in their compliance and behaviours, potentially reinforcing paternalistic care. For example, during case review, a generalist nurse presented a 90-year-old patient with bowel and lung cancer. She stated that he had not been taking medication, choosing to take vitamins instead. The specialist medic and the two specialist nurse’s reaction to this were overt and shared: while she stated this, they shared knowing glances and sly smirks. The tone of derision at the idea of vitamins being able to assist the patient was palpable. These displays suggested disapproval or discomfort at the patient’s decision. As explored in a vignette in section 7.3, fear of over medication for patients desiring lucidity during their final stages of life aligns strongly with the humanist mindline assemblages and those directed towards a good death. Clinicians were required to balance fostering rapport and establishing an emotional, invested relationship with allowing patients and carers to dictate the terms of their own care.

5.4.3 Emotions

Clinicians frequently spoke of trust as part of rapport. Establishing trust among patients and carers could help them to navigate awkward or morally challenging situations:

I think they trust me because every time there's an issue I've always tried my best to escalate it or do something about it. And the majority of the time it's worked (generalist nurse 3)

A specialist nurse told me a story of the importance of trust while looking after a patient she had developed rapport with:

I looked after this young man that I liked very much, he was from a Muslim background that I liked very much (At this point in the interview the participant stopped speaking, overcome with emotion. She continued speaking through her tears)... and I developed a very good relationship with him. He was about my age, had young kids, and I supported his family and I supported his wife, and you just build this trust; you do. And he wanted to die at home; that was his dream. I looked after him for a while and I remember listening to this lecture about doing bowel stuff and [they said] you have to get the trust of the patient before you do something like that, especially a young man. Anyway, I sat down with him and I said, 'You know, we're mates, and I want you to trust me, with what I'm going to do' and he was petrified (laughs). And anyway, even when I was doing the [per-rectal examination] he would stop me doing it, it was like it was really hard. But I said, 'Please let me do this. You have to trust me, just for your comfort measures' and he did (specialist nurse 1)

In this excerpt as in other instances, nurses looked to establish trust to provide particular kinds of care. At times, trust was required to care effectively, mitigating the well-established ideal of patient choice in medicine. Mol (2008) noted the discrepancy between the logics of care and the logics of choice, two rationales for healthcare practice. The logic of choice, focusing on patient choice is held as an important ideal in medicine, but often fails to account for a patient who might be unable or not ‘any good’ (p. 3) at making decisions. A logic of care focuses on what patients are capable of doing within the prisms of trust with a clinician. The clinician-patient relationship predicated on trust enabled different ways of caring that did not comfortably rest on a logic of choice. From the perspective of the specialist nurse, this was only possible because of trust and they were ‘mates’. These kinds of relationships had implications for clinician safety and care, evocated by the powerful emotions seemingly felt by the specialist nurse as she told me this story, which I explore in section 5.7. Although these relationships were a lofty ideal, they were not always possible, as I explore in section 5.6.

In describing these relationships, narrating moments to me and to each other, clinicians fostered an ongoing attention to joy-seeking, relationship building for patients and carers and themselves. I witnessed the powerful effects of this care on multiple occasions. Watching a clinician walk into a home and warmly hug the carer and bend down and gently whisper in the ear of the bed-bound patient. I witnessed teary-eyed carers as they described the importance of the nurse’s relationship as their spouse, parent, child, or another loved one deteriorated and died. I cannot overstate how important the relationship was for these individuals, even those acts that seemed mundane, like a nurse making a milkshake with laxatives to ease a patient’s constipation. For the patient and carer, this small act, along with the nurse’s personable manner (as she joked and asked about their family while making the milkshake), helped develop a bond that enabled trust, communication, and care. Joy-provoking moments of rapport building reinforced the importance of relational aptitude in an ongoing process of affirmation.

5.4.4 Identities

Generally, rapport building care was a relative mindline for participants, as the context of community-based healthcare necessitated an individualistic pursuit of this ideal. There was no singular assemblage of rapport or patient and carer interaction; instead nurses and medics relied on their own approaches:

When you look at say Palliative Care Australia standards there's a lot of these global statements about thorough assessment and supporting families and all the sorts of ways that we can show that we're doing that, like multidisciplinary team meetings and all those sorts of things... you can still meet all those requirements. But down to the actual interaction with your patient, it doesn't dictate how you interact with them. It's much more of a global thought process... You can't go by guidelines 'I must say it this way for this patient' It's got to fit right with you, and it's got to fit right with the patients (specialist medic 2).

Clinicians discussed patients with who they had 'special connections' – those who brought them joy or instances of positively affective relations. One specialist nurse discussed the relative nature of rapport building, noting the importance of both 'professionalism' and the familiarity and closeness that rapport building warranted:

At the beginning when you go in and actually do an assessment on somebody, you start to build that relationship from day one. So, you're building something. It might not be really friendly, buddy, buddy, want to have that touchy feely thing, because some people just aren't that. But you still have that professional, one-on-one... An example is [generalist nurse 8] who had a really good relationship with a lady that

(sic) had two young adult children. She was the one (sic) that had that rapport with them and got that rapport. They were very comfortable with her, much more than they were with really anybody else... and I remember that lady because [she] did a great job looking after those two young adults who were under 21 and looking after their dying mum. [generalist nurse 8] was clearly the right age, clearly had clicked with the family, and was seen as somebody who was mentoring and supporting those young girls (specialist nurse 5).

The patterns of these kind of relationships formed around personal traits: a clinician's age, cultural background, gender, or their comfortability with dogs for example could shape a relationship in different ways. Rather than chastise nurses for their myopia around certain patients, senior clinicians celebrated the uniqueness of the relationships, fostered through personal connections between clinician, patients, and carers. One specialist nurse worked with several patients who she labelled as her 'favourite' during case reviews when they were discussed. This typically provoked laughter from other nurses at the irony of the specialist nurse having multiple favourites: 'everyone is your favourite'. This 'favouritism' imbued other nurses' discussions of certain patients who they 'look[ed] forward to visiting' and who brought them joy.

5.5 Death and dying care mindline assemblages

Dying with dignity, to me, means having good communication with the client and family to understand their wants and needs; being empathetic, being respectful; it's in line with client and carers wishes. If a client is angry then that's okay, I think that's a healthy and understandable aspect of the dying process. You've got to remember

that it's the client at the end of the bed, not you. What they want and need come ahead of what you as a clinician may feel is the right decision clinically (specialist nurse 5).

5.5.1 Ideas

My interpretation of palliative care was shaped by participants' relationship with death and the emotional milieu among clinicians, patients, and carers related to death. Patient deaths were a consistent part of palliative care – from preparing a patient and carer physically, mentally, and emotionally for death, to assisting carers to manage the death through the single officially-permitted bereavement visit, as well as the unofficial telephone conversations, thereafter. Dying and death were a discerning feature of conversations about palliative care, establishing it as an important mindline assemblage for those at the research site. For instance, clinicians often idealised the 'good death' (Finlay 2003). Although research has cautioned against reducing care for dying people to a normative set of tasks (Collier 2013), a good death typically requires clinicians to deliver comfort; symptom control; patient and family education of disease progression; family presence at the time of death; and appropriate planning, for instance establishing 'do not resuscitate' orders when necessary (Costello 2006; Griggs 2010; Sorensen & Iedema 2007). Conversely, health professionals have equated a bad death with insufficient time to get to know the family and uncertain and unclear care goals (Costello 2006). These ideals were reflected as clinicians spoke of the importance of 'having a plan', ensuring awareness of death for patients and carers, increasing the frequency of their visits during the terminal phase, and attending to the emotional well-being of carers during and after the terminal phase of a patient's illness. These reoccurring practices and descriptions thereof established certain maxims within the centre about what clinicians should focus on to enable a

good death. Additionally, death care mindline assemblages incorporated unique emotion rules pertaining to fear, hope, grief, and loss.

5.5.2 Practices

Death care mindline assemblages during the stages following a patient's discharge into the community predominantly revolved around death talk. While a patient's prognosis could vary from years to days upon discharge into the community, clinicians were encouraged to talk about death with most patients. Talking about death was a complex craft. There were few explicit guidelines to help nurses and medics respectfully broach or have these conversations. Some materials were used, like a website that guided patients in planning for death or a book that guided parents' death-discussions with their children. However, talking about death with patients and carers was negotiated between senior and junior clinicians with no 'set formula', but certain guiding principles. It involved a relational give-and-take with patients; for instance, waiting for an 'opening' in a conversation or starting with an 'easy' entry to the discussion. This sometimes involved inquiring whether a patient wished to die at home or be admitted to a hospital or some other care facility.

At other times, clinicians noted the need to become confrontational in approach. The term 'confront' evokes a forward-facing, almost belligerent approach to death, which was reflected in some death-discourses. During one case review, a specialist nurse became forceful about the generalist nurses' discussions with patients about their 'deterioration' to ensure plans had been arranged: 'Sometimes it worries me that we don't have anything in place. I'm concerned that we're not treating palliatively' (specialist nurse 5). Her 'concern' for patients without end-of-life plans increased the temperature for nurses to act. 'Plans' could include a hospital admission or sourcing prescriptions to enable a patient to remain at home. Reflecting this 'confronting' mindline, some participants discouraged euphemisms for death. During a presentation on death

literacy, a social worker displayed a comical frustration with terms like ‘passed away’ and ‘no longer with us’. According to the social worker, euphemisms limited patient, carer, and clinician capacity to confront and accept death as natural and inevitable.

Despite a mandate from senior specialist nurses and medics to confront death, participants accepted this was often difficult. While discussing death talk with patients during a case review, a specialist nurse spoke of a patient’s daughter who refused to talk about her mother’s death with the clinicians: ‘Some people aren’t up to talking about death’ (specialist nurse 3). This reluctance reaffirmed that people ‘deal with death in different ways’, aligning with the humanist assemblages described earlier. The relative and individualistic nature inherent in these principles meant that clinicians could not take as read the necessity to discuss death with every patient or carer. Nurses were required to balance the confrontation of death with rapport building. Rapport building often involved maintaining hope in ‘looking forward to doing so many things’, particularly for patients and carers who were not ‘ready’ to discuss death:

I look at some patients and I go, ‘Ah, I can’t talk about end of life just yet’ because they’re looking forward to doing so many things and I’m scared that if I say, ‘So, can we talk about what will happen to you when you get to that end stage? Are you going to stay at home?’... Sometimes, I hold back on that one because I don’t want them to feel like, ‘Oh, [the nurse] is saying this and maybe it’s something she [as a healthcare professional] knows that we don’t’ (specialist nurse 4)

Entwined in nurses’ notion of ‘holding back’ was a rapport-preserving attitude. Nurses were concerned with maintaining a stable emotional equilibrium for patients and carers to avoid exacerbating their grief. According to some, exacerbating grief or despair among patients and carers could hinder effective care. Some rejected the pressure to confront death quickly, acknowledging their uniquely consistent role:

Some of the doctors will say, ‘Have you done the end-of-life plan; have you talked about where they want to die?’ But you know, you can’t. We’re the nurses that are going to be going in for the next, maybe next year. So, you can’t go in like a bull at a China shop. You sometimes have to build up that rapport and... I think that can be taught (specialist nurse 3).

Some nurses managed this tension act via relativist, relational understandings, or ‘feeling your way through’. There was no right time to broach death with patients or carers, but nurses had to be ready to talk about it when ‘the time comes’. Experience played a role in this intuition, but it was also helped by patient and carer realisation. For instance, patients that talked about getting better or about returning to work were considered to be in denial. If a patient began inquiring about their ability to partake in future activities, like a holiday, a nurse would take that as an opportunity to bring up the limiting effects of their illness, and also their impending death.

Participants’ death stories reflected a storyline, whereby patient and carer denial evolved into acceptance, followed by interest in a good death. When recounting these stories, participants described patient and carer denial with an unspoken imperative to gently coerce them to confront and accept their own death. ‘They can’t accept that she’s dying. I tried to bring it up with them, but they just shut it down straight away and won’t listen’ (specialist nurse 3). The clinicians in these stories negotiated this confrontation by establishing rapport with the patient in the first instance and then ‘bringing up’ death in a gentle but forthright manner. The resolution involved patient and/or carer acceptance of the impending death and subsequently planning for a good death: ‘Sometimes it’s bad [to not talk about death] because it’s not going to kill [the patient] to talk about the end-of-life care plan’ (generalist nurse 4). In these instances, decisions and plans were less prominent and left to the patient and carers to

determine. Senior nurses, for instance, emphasised the act of beginning the conversation, rather than arbitrating the content of that conversation.

Junior nurses idolised their senior counterparts' ability to discuss death with patients, maintaining their own emotional equilibrium. Following a bereavement visit, a junior generalist nurse told me how much she valued the specialist nurse's presence. She identified the aspirational ideal of the specialist's ability to confront a difficult conversation about death:

[She] always knows how to find a way to word her questions and the right time to ask about the situation. For example, how [the patient] passed away or how her funeral went? That kind of question. Whereas with me, I think I would be a bit more tabooed about it; so, I wouldn't have brought it up... I would have hopefully wait[ed] for the partner to talk about it (generalist nurse 4)

The participant articulated the importance of timing and a nuanced appreciation for context when deciding when to broach a death discussion. However, she also alluded to an enlightenment; an ability to confront something that was beyond the normal boundaries of social practice. Seeing death as 'tabooed' limited what the junior generalist nurse was prepared to do, when she did it, and how. The specialist's ability to transcend taboos demonstrated an alternative approach – one that could forge positivity and hope in an otherwise bleak context.

5.5.3 Emotions

Belying the projection of an emotionally-balanced, unflappable clinician confronting death, participants admitted the emotional toll of witnessing death and dying. One specialist nurse, through tears, divulged a story of her experience with a patient's death that she 'liked very much'. This story was both powerful and noteworthy because it differed from the norms of palliative care:

It was a Friday the last time I saw him and, on the Saturday, [his wife] took him in to hospital and he died the Monday or the Tuesday, and I didn't get to say goodbye to him. I know that he went in and he knew that that was it. He wasn't going to come home and say goodbye to his children. It was a really, very difficult time. Sometimes those are the things that you can't live with, you need to forgive yourself. Nobody puts you under that pressure. Nobody does. I ended up speaking to [specialist medic 1] because she was with me the whole time and she said, 'You need to forgive yourself', which you do, but you don't want to live with those regrets and, in this job, you've only got such a short period of time and you've got to do everything because you've promised yourself to do it and you've got to do it and they are very little windows opportunities... and especially when you can relate at such a young age (specialist nurse 1).

Implicit in this story is its rare nature, evocated as a 'very difficult time'. Clinicians required to confront death acknowledged the emotional fortitude they needed and the inevitability of emotional barriers breaking down:

We have this kind of saying: 'You chose to do that work, so you've got to deal with it. You've got to be strong'. But that is wrong. We chose to do the job, but it doesn't mean that we don't have feelings (specialist nurse 2).

Feelings were permitted by clinicians only during 'difficult' moments, because otherwise clinicians would become overwhelmed. For instance, sadness was often conveyed as acceptable within a palliative care assemblage after a patient's death:

I do feel sad because you spend so much time looking after that client and then you hear this. You expect it because of their prognosis and everything. But I guess when that time does come you can't help it.

Your emotions just all come (generalist nurse 4).

Literature related to palliative care clinicians' emotions describe anxiety and stress as the more prominent emotions experienced by clinicians in relation to death and dying (Sorensen & Iedema 2009). Zimmermann's (2004, 2007, 2012) examination of the terms, 'denial' and 'acceptance' in palliative care discourse noted the power inherent in those terms. For Zimmermann (2012), these terms construe the denial of death as an impediment to effective palliative care. Zimmerman (2004) noted the temporal nature of denial, spanning from being normal and healthy when terminal illness is first diagnosed to being maladaptive when maintained over long periods of time. In a subsequent paper on denial, Zimmerman (2007) noted that clinicians put the term 'denial' to use to present death denial as an obstacle to palliative care. Ultimately, she (2012) concludes that death denial is: 'a construction that is instrumental to uphold a certain 'way to die' represented by contemporary palliative care' (p. 218). Zimmerman's (2012) interpretation of acceptable 'ways to die' include open discussion of dying, dying at home, advance care planning, symptom management and stopping 'futile' treatments. In my findings, the emotions arranged with the mindline assemblages of death were often the competing emotions of hope and fear: hope for a good death and fear of a bad death. These might be considered mirrors of Zimmerman's (2004, 2012) terms: denial and acceptance, as denial is a manifestation of fear of a bad death and acceptance is a manifestation of the hope for a good death. Clinicians considered a patient's death from these emotional perspectives, expressing serene affections when talking about patients' death they foresaw as 'good' and expressing anxiety and fear when discussing potentially chaotic or painful deaths.

Hope and hopelessness are complexly arranged at the end of life belying the reductionism inherent in medical prognoses (Sullivan 2003). Hope at the end of life can include ‘dignity, intimacy, and salvation’ that ‘encompasses nearly all that human culture and spirituality have to offer’ (Sullivan 2003, p. 393). Clinicians redirected hope, both patients and carers and their own, away from the commonly assembled ‘hopelessness’ of a terminal diagnosis, towards alternative purposes such as spirituality, relationships, and the end of suffering. For instance, clinicians would describe their ‘peace of mind’ when preparing for a patient’s death. One nurse recalled being confronted with a patient who was dying during a home visit, and described purposefully working towards a stated of preparation with the family present:

I went in [to the home] and the patient was already in a coma, in the last stages of life. [She was] non-responsive [with limited] rise in her chest... and not even responsive to stimuli... You’ve got the family all sitting there. They look like they’re already mourning and there’s no medications there for me and I’m thinking, ‘Oh gosh’. Once you walk in, you can’t ignore what you’ve seen... Lucky the patient had medication morphine from when she was in hospital but [had] never used it. It was just an ampule lying around and I thought at least I’ve got that. So, I was able to put in the intima and then I taught the family how to administer the morphine and at least that was a peace of mind for them knowing that even if the morphine was effective or not, something was being done to help that patient, you know, in her dying phase... They were quite relieved that we turned up... because they thanked us [and] the level of stress, the anxiety had come down by the end of the day (generalist nurse 2).

The nurse's purposeful action alleviated her own and the family's fear ('I'm thinking "Oh gosh"'), to become hopeful ('something was being done') within the process of dying.

Another powerful instance I witnessed was of a patient experiencing pain and a persistent cough. The generalist nurse I shadowed had fostered a warm relationship with the patient. She sat with the patient and hugged her tightly as the patient stated that she was ready to go, indicating skyward: 'But he won't open the door for me'. The generalist nurse nodded and stated: 'It's not fair, is it?'. Linking death with hope enabled those with limited experience in palliative care (like junior clinicians and carers) to expand their comfort zone and appreciate the impending death. One specialist nurse demonstrated hopeful storytelling during a seminar she facilitated for allied health professionals on palliative care. She relayed the story of an 80-year-old woman who was dying, yet unwilling to acknowledge this. The specialist nurse built rapport with the patient and was trusted. This enabled her to use an 'in' to start the conversation, asking the patient what she wanted to happen to her pet when she died. This spurred a death discussion, prompting the patient to outline her version of a good death. The anecdote also enabled the specialist nurse to encourage seminar attendees to find their 'ins' with patients to prepare them for death.

Ahmed (2004) delineated hope as an empowering force. Stories about individual success can lead to hopefulness for those responding, which can prompt the 'healing of community' (p. 35). Moving stories about individuals who have been saved, of bravery, and overcoming pain are designed to empower. This parallels the hopeful ideals at the research site, parsed via stories articulating aspirational values imbued in specific acts. Hopeful stories often juxtaposed my own preconceptions of despaired and hopelessness surrounding palliative care practice and suggested a rallying point for other clinicians when encountering challenging and despairing patients and carers. This was particularly apparent, for instance, when exploring how medics and nurses confronted death, dying, and grief in their day to day practice. Alternatively,

clinicians also spoke of the ‘fear’ of bad deaths, using this fear to determine how to avoid them. Ahmed (2013) explored the global economies of fear, noting how fear becomes an imperative for action, for example the forming of government prompted due to fear of anarchy. The language of fear involves the intensification of threats. Fear provoking danger is a subject of the identities of whom is a threat. By assigning something a threat, fear works to align bodies with and against others. Establishing the threat of a bad death in palliative care fostered fear, aligning fearing bodies creating a distinct and unique collective of those who confronted death differently. This involved reconfiguring fear to be fear of a *bad death* than merely fear of death. Thinking of death differently through confrontation became a way to align with the palliative care collective, as different to those who are not practicing palliative care. This value fostered mindline assemblages of confronting death with patients in particular ways. Talking about death as a confrontational action differentiated palliative care clinicians from patients, carers, or other clinicians who are unable to approach death in the same way.

5.5.4 Identities

Participants attached dying and death to their palliative care identity. This was to be expected considering the proximal relationship between palliative care and dying. Participants acknowledged dying and death as part of their work. The ability to talk about and work with patients who were dying was juxtaposed by outsiders’ perceptions:

When I go to a party and tell people I work in palliative care, it really brings the conversation to halt. Most people just go, ‘Oh’ and leave it at that (specialist nurse 5).

Yet palliative care clinicians subverted the normative emotional states related to death, such as grief and despair, to foster mindlines assemblages more readily accepted by junior clinicians.

While death care was heavily implicated in palliative care clinicians' attention and practices, clinicians resisted the conflation of palliative care with death. Participant capacity to transcend taboos around dying, death, and grief was sometimes tempered by discourse that was less than forthright. For instance, a patient's prospective death was often described as 'patient decline', 'disease progression', 'final stages', or 'approaching the end'. Objectifying patient wellbeing with clinical references reflected an implicit understanding of death as only part of the practice of palliative care:

Palliative care to me is symptom management. So, it's caring for the patient that isn't just dying... palliative care should start a lot earlier on in diagnosis (generalist nurse 7).

Palliative care needed to work within institutional logics that subjugate palliative care to the end-of-life. However, clinicians regularly rejected this institutional logic, favouring a wider perception of palliative care. This manifested in a fervour when working against others' assumption that palliative care solely involved dying and death. Participants expressed a need to battle against a common perception of palliative care as bringing patients closer to death. For instance, some participants spoke of conversations with patients and carers who assumed palliative care clinicians were natural advocates for euthanasia. One participant said, 'Good pal[liative] care lengthens life rather than shortens life – if you're in pain, you're going to die quicker' (specialist nurse 5). Another participant stated the need to manage patients and carers perception of palliative care by distancing the specialty from euthanasia:

We don't want to be the ones euthanising people because we want to have that trust in the people that are fighting to live... If they think, 'Oh well, the pal[liative] care are the ones that euthanise, then how can we trust them?' (specialist nurse 3).

Hopefulness here was an important articulation of identity. Limited hope among patients and carers sometimes stigmatised the specialty of palliative care, hindering clinician ability to care. Consider my discussions with the specialist nurse about euthanasia. I told that I had assumed most palliative care clinicians supported euthanasia as aligned with the patient choice implicit in humanistic mindline assemblages. I was surprised when she expressed her reservation about this assumption:

People already think that we are only interested in death. If we're also then administering euthanasia, as soon as we meet a new patient, all they'll be thinking of is, 'They want me to die'... If they were on top of her pain and on top of her symptoms, maybe she wouldn't feel the need to end her life (specialist nurse 5).

It is worth noting here my position as an 'outsider' with my own presumptions about palliative care and death. My assumptions around euthanasia and palliative care stemmed from my perception of palliative care clinicians as comfortable with death. My presence onsite initially fed my presumptions, as I watched clinicians reappropriate death and dying through hope, reinforcing my own perception of palliative care clinicians as 'comfortable' with death. As my time progressed, I encountered more and more resistance to this notion, with clinicians emphasising the need to consider palliative care as 'more than just dying'.

5.6 Professionalism/institutional logics mindline assemblages

We are representing the service and it's important that we conduct ourselves in a professional manner befitting our status (generalist nurse 9).

5.6.1 Ideas

Balancing patient's and carer's multifaceted needs with the pragmatic operation of palliative care was a prominent concern for clinicians in my experience at the centre. I observed inherent tension between how humanist mindline assemblages were enacted and organisational pressures, particularly those related to time with patients, resource allocation, and the relationships with patients. I developed my own understanding of specific assemblages of what has been termed previously, institutional logics. Institutional logics have been defined as 'the belief systems and associated practices that predominate in an organizational field' (Scott et al. 2000, p. 170). I have chosen to combine the two forms of 'professional' and 'institutional logic' mindline assemblages as this reflects the indistinguishable conceptualisation between the two in my data. The notion that business-like managerialism and traditional professional values are being combined within a healthcare organisation is a notion with precedence in the literature (Noordegraaf 2007; Van den Broek, Boselie & Paauwe 2014). Even early conceptualisations of institutional logics in healthcare noted a shift from dominant professional logic to a dominant managerial logic through market mechanisms (Scott et al. 2000). My approach frames institutional logics assemblages through the perspective of clinicians as professionals working within an organisation.

5.6.2 Practices

The mindline assemblages of institutional logics were intertwined with the operation of the service, including clinical documentation procedures, a rostering of nurses' time, imperatives to discharge patients, and managing the use of resources, such as dressings, syringes, and syringe drivers. These mindline assemblages were embedded within the organisation of nurses' time and manager practices, for instance, allotted time limits for home visits, [REDACTED]

[REDACTED]

[REDACTED]. Nurses referred to ‘efficiency’ to denote institutional logic mindline assemblages, often considered by specialist nurses as minimising the work they do:

[REDACTED]
[REDACTED]
[REDACTED]

Some clinicians noted the importance of professionalism in the absence of rapport fostered with patients and carers. They stated this was a way to ensure purposeful and productive relationships:

Some patients you have a genuine relationship with, and others you have a professional relationship. There are patients that you don’t quite have that genuine relationship with a genuine feeling for... The slightly less lovable ones. You can still have a genuine relationship with a difficult patient. Difficult from my perspective (generalist nurse 10).

For this nurse, substituting ‘genuineness’ for ‘professionalism’ mitigated the ‘difficulty’ of certain patients who did not provide ‘feeling’. This suggests a pertinent counterbalance to humanistic mindlines, considering Ahmed’s (2013) notion of establishing individuals as those who could and could not be loved or grieved. Professional mindline assemblages were a safety net when rapport building failed:

Sometimes you don’t always click with the people around you; that’s just human nature. But it doesn’t mean... you can’t act professional and provide the care. You might not necessarily see eye to eye or get along, but it doesn’t mean... you don’t go in and act professionally and provide the same care (generalist nurse 8).

Deferring to the institutional logic mindline assemblages was, at times, a point of contention between the generalist and specialist nurses. Some specialist nurses bemoaned the inability of some generalist nurses to approach their palliative care differently to their other roles:

Some of the [generalist nurses], because they're seeing lots of patients in a day, they have to get in and out of the house just focusing on the wound care or whatever it is. They're a little bit more task-oriented. But when you're doing palliative care, it's not about the wound; it's about everything (specialist nurse 5).

Evocatively, the moniker of 'task-oriented' was used to delineate practices that did not reflect humanistic mindline assemblages. Generalist nurses had clear duties to complete during non-palliative care home visits, which were deemed to involve defined, measurable tasks, with clear expectations. These visits had an associate time imperative as part of the scheduling of patients. The relatively common 'wound two' visit was expected to be completed within thirty minutes, during which a wound dressing was removed, and the wound, cleaned, examined, and redressed. Specialist nurses noted that some generalist nurses framed palliative care in the same way, operating on the premise of delineated tasks to be completed during a palliative care home visit. A focus on the 'task' rather than focus on the 'human' was counter to how nurses viewed palliative care.

An artefact implicated often in mindline assemblages of institutional logic was an internet-connected electronic tablet given to nurses for point-of-care documentation protocols. During home visits, the specialist and generalist nurses documented clinical assessments and observations while with patients and carers before or after clinical tasks. Some nurses relished the 'protection' for both themselves and the 'service' the tablet afforded, as it served as a way to create a record of patient interactions:

We have to document everything on the tablet while you're there because you have to have a record of what happens. Not just for the patient, but to protect yourself and the service. You don't want somebody to turn around and say 'she did this' or 'she said that' if you have it documented then you've covered yourself (generalist Nurse 5).

However, many clinicians, particularly the specialist nurses, suggested the tablet impeded rapport building and humanistic practices due to the perceived appearance of disregard for patients and carers:

I don't use it during home visits because I want to make that connection with the patient, and I feel that if I'm sitting there typing away, I can't give them the attention they deserve (specialist Nurse 2).

Reinforcing this view, I never observed specialist nurses using the tablet during home visits. However, some generalist nurses maintained the use of the tablet to document in the home. Moments I observed seemed to prompt disconnection between generalist nurses and patients. The documentation process was slow, and nurses were unable to maintain eye contact and an easy, flowing conversation with patients.

Institutional logics were often framed from the perspective of protection, for instance when clinicians used a telephone assessment before the initial visit to identify hazards. Nurses who were concerned about a practice, were told to, 'Check what the policy says in the first instance' (specialist nurse 3). This approach to care provided a form of security for junior nurses who were less confident in their practice. As one generalist nurse stated, 'We've got policy for most things and I just think if you stick to that you've got yourself covered if anything goes wrong' (generalist nurse 11). Guidelines and policies clarified limits to what worked or was allowed

to work within palliative care. They were framed in terms of an initial logic that could ultimately be ‘short cut’:

When you’re teaching people, you need to teach them the exact policy way to start with because we all make our short cuts. When you start teaching them from the beginning what those short cuts are, they’ll then short cut the short cuts and then something goes wrong (generalist nurse 7).

This excerpt underscores the potential chaos that could arise without foundational guidelines and policy.

Patient discharge from community palliative care presented me with a unique perspective on the competing mindline assemblages at the research site. Process and discussion about discharge prompted a perception of patients through a lens of resource allocation. Organisational imperatives around discharge were prevalent and executive team members communicated these explicitly in discussions with nurses about patients. Loaded questioning, like ‘Why are we seeing this patient’ or ‘What are we doing for them’ prompted the nurses managing the patient to consider whether they should be discharged from the palliative care service. Contention around patient need for palliative care frequently arose during case review:

Having people on your books when you’re not really doing anything for them is inappropriate from a community point of view. I think we’ve got to be very clear about why we have them on our books. Are we doing anything clinically for them? Are we making a difference? If we’re not making a difference and they’re reasonably stable, then I don’t think that it’s unreasonable [to discharge them] (specialist Nurse 5).

This resource-based view harboured an underlying sentiment or a sense of duty for the ‘community point of view’ juxtaposed the rapport and humanistic mindline assemblages, which framed palliative care in terms of patient agency. Noteworthy in this excerpt is the nurses measure for value as making a ‘difference’. In this instance, valuable palliative care involved active intervention, with clinicians creating difference to warrant their involvement in a patients care.

At times, nurses evoked humanistic or rapport mindline assemblages to counter attempts by one senior specialist nurse to discharge the patient: ‘We’re the only people she sees all week. If I tell her we are going to discharge her, I think she will be very upset’ (generalist nurse 5). Nurses’ position as the sole point of contact for a patient, along with the bonds formed through the rapport building process necessary for effective care, meant that a patient’s discharge could be a difficult prospect. Ultimately, discharge was an institutional logic constantly on the periphery of managers thoughts as they attempted determine what was and was not a proper allocation of palliative care resources.

5.6.3 Emotions

Emotions were central to how clinicians typically understood and conveyed palliative care. Although, ‘what’s in your heart’ was permitted in humanistic mindlines assemblages, it was questionable within the perceived boundaries of professionalism and institutional logics. At times, clinicians noted a need to moderate emotion. They talked of ‘professionalism’ and ‘professional boundaries’, which were often contrasted with emotions: ‘We’ve got all these professional boundaries, but I always think you’ve got to do what’s in your heart’ (specialist nurse 3). Professional boundaries distanced clinicians from patients and carers. This suggested a need for emotional detachment in practice, which served both nurses self-preservation and the requirements of institutional logics. Nurses conveyed the importance of emotional

detachment for institutional logic mindline assemblages: ‘You feel sad for your patients. But then you still have to act professional. Sometimes you hold back on that’ (generalist nurse 2). The tension between the emotional and the rational, or ‘professionalism’ versus the felt sadness articulated by generalist nurse 2, was something that many nurses identified with. The notion that emotion can interfere with rational organisational goals and success and should be suppressed or denied is well established in literature (Fineman, 2000; Putnam & Mumby, 1993). Clarke and colleagues (2009) noted ‘emotional neutrality’ (p. 332) as a technique of control for managers who favoured organisational goals over feelings of morality or affective personal relationships.

The subjective constitution of emotional labour in the professional mindline assemblage was ‘allowed’ for clinicians, when it could elicit clinical or organisational goals, for instance, compliance. Wong and colleagues (2018) noted that notions of professionalism and professional identity for oncologists informed how affect and intersubjective connectedness experienced by oncologists were treated and expressed. Professionalism was assembled with oncologists’ performance and feeling of emotional neutrality. However, oncologists also positioned themselves as having emotions as part of their professionalism: ‘The capacity to be emotionally reflexive and give emotional labour are subjectively constituted and defined through individual understanding and skills’ (p. 11). Wong and colleagues used the term ‘bounded caring’ (p. 14) to describe the structure offered by professionalism while allowing emotional engagement. The notion of a boundary of care is evocatively aligned with the ‘territory’ of mindline assemblages.

There is a resonance between institutional logics and Deleuze and Guattari’s (1987) notion of axiomatically organised assemblages. For Deleuze and Guattari, an axiom is a rule that does not require the attribution of value, but rather, is inherently devoid of value. Axioms are ‘self-evident and without need of justification,’ (Saldanha 2017, p. 73) and provide a virtual

assemblage in and of themselves. While humanistic mindline assemblages were inherently value-based, institutional logics rested on self-evident axioms of ‘legal requirements’, ‘resource allocation’, and ‘time management’. Axiomatic assemblages, such as bureaucracies, require amoral actors to ensure rule compliance without fuss (Bauman 2000). Values and emotions inhibit the smooth functioning of an axiomatic assemblage (Gill 2016). My findings suggest clinicians attempt emotional detachment for similar reasons to ensure steadfast focus on axiomatic assemblages of palliative care.

Emotional detachment within the axiomatic assemblage, or care ‘bound’ within professionalism, often failed nurses. This misalignment between clinicians embodied knowledge and the organisational logic or legal requirements caused frustration and anger. Nurses often expressed feeling constrained rather than ‘bounded’ by institutional logics. One example related to nurses inability to verify a patient’s death and provide the necessary paperwork to have a body collected. According to NSW Health (2015) the verification of death is:

a clinical assessment process undertaken to establish that a person has died. Using a standard regime of clinical assessment tools, a registered medical practitioner, registered nurse /registered midwife or qualified paramedic can establish and document that death has occurred’ (p. 1).

During my study, registered nurses within this Local Health District were not permitted to sign an interim death certificate, unlike other Districts where they had the capacity to do so:

At the moment, we are not allowed to sign any interim certificate. We did the training online, but we haven’t been given support in relation to that (specialist nurse 2).

Unlike other specialities, death in palliative care was often anticipated with a probable cause. Additionally, according to District policy, the verification of death was straightforward, requiring a relevant clinician to confirm the patient has no palpable carotid pulse, no heart or breath sounds for two minutes, fixed and dilated pupils, no response to centralised stimulus, and no withdrawal or facial grimace in response to painful stimulus. Nurses regularly bemoaned the frustrating irony of being in a profession so familiar with death without the authority to verify it. When the nurses discussed this, some – particularly those with palliative care expertise – typically expressed anger towards the lack of common sense with this edict.

During fieldwork, I documented nurse's bemoaning of bureaucratic constraints such as this. Some clinicians felt like their judgement and internal knowledge was not trusted by those in power. Reid (2014) noted the implicit 'distrust' and subsequent supplementation of clinically internal knowledge (including tacit and embodied knowledge) with externally-developed knowledge in EBHC. He suggested the 'bureaucracy of evidence', which represents a default critical attitude of evidence appraisal has led to 'absolutely less trust going around' (p. 148). Perceptions of distrust in nurses' practices were apparent in my data, represented through emotional reactions to systems that oppressed their intuitive, humanist practice. Reid's assertion that 'being trusted is the pre-condition for developing skilful expertise' (p. 148) resonates with nurses' strong attachments to a palliative care identity that privileged intuitive 'feeling' through practice. The 'trust' required for the kinds of embodied practices I observed, like psychosocial care and confrontation of death, was one of the strongest indicators of the limitations of externally-produced, codified knowledge.

5.6.4 Identities

Incompatibility between a humanist clinical identity and an institutional, 'professional' identity caused significant strain for clinicians. Institutional logic mindline assemblages framed

palliative care as a discrete service, delivered by uncaring functionaries, rather than an open-ended process of negotiation with the materials at hand (Mol 2008). Some clinicians resisted the organisational pressures to become a non-emotional or uninvolved clinician:

You hear a lot of negativity from people, as you and I have seen. And I don't want to be that nurse where they say: 'Aw, yeah she had a lot on her mind, she was very busy' or 'She only came in for just this job and I had other things I wanted to talk about but she obviously doesn't know what she's talking about' or, 'She doesn't have the time.' I don't want to be that kind of nurse (specialist nurse 1).

The uniquely consistent role necessitated by palliative care mindline assemblages was displaced within these institutional logics, as patients were recast as 'clients', the preferred, consumer-driven moniker at the centre.

Participants maligned those who represented institutional logic mindline assemblages, like 'management', 'the government', bureaucrats, and administrators, questioning the accountability mechanisms espoused by the officials 'up the hill'. [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED] This anger reflected a pattern among palliative care clinicians who used emotion to advocate for patients (and carers) to ensure they continued to be supported by the centre, with managers (within and beyond the centre) positioned as the antagonist.

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED] This echoes other studies suggesting that nurses sometimes resist the organisational devaluing of emotional care to continue to derive meaning and satisfaction from their work (Rodriquez 2011). Instances like these depicted some managers as unable or unwilling to understand and/or enact palliative care. These depictions catalysed particular practices, and often fostered rule-bending behaviours, like extending a home visit for a friendly conversation with a patient, or keeping patients ‘on the books’ despite the absence of clinical need. The dangers of rule-bending behaviours are self-evident, threatening to promote actions and practices unsanctioned by legal or professional standards of practice. However, the inherent distrust assembled with institutional logics, as noted by Reid (2014), spurred experienced clinicians to trust their own perceptions rather than a guideline or policy.

[REDACTED]

[REDACTED] They made opaque references to ‘the system’ or ‘the organisation’. Consider my conversations with nurses at the centre about palliative care and emotion – these would often turn to the resources required to support the profession, including clinical supervision. They were dissatisfied with the psychological support they received, given the nature of their role. These conversations invariably turned to disparagement towards unnamed collectives that were said to undervalue palliative care, as demonstrated by the limited availability of psychological support, which I address in section 5.7 of this chapter. Participants positioned managers and the organisation as indifferent to, if not uncaring about, how they practiced palliative care.

Relatedly, palliative care identity fostered solidarity among the nurses and medics practicing in the centre, materialising a surface of collective bodies (Ahmed, 2013, p. 46). However,

defaulting to a professional identity could also provide security, cordoning caring resources in the name of ‘safety’ or ‘legal protection’.

5.7 Self-preserving mindline assemblages

I’m happy it’s done (laughs) I’m happy we got through the day without any issues and things that need a lot of work to fix I suppose. Because your day can be so unpredictable... You think you’re going to have a great day because your day looks really little; but it can change like that. Just by going to your first client and something goes wrong and it just throws your whole day out. So, it’s just nice that it was a good day (generalist nurse 11).

5.7.1 Ideas

The mindline assemblages I have described were typically forged to benefit patients, carers, or the institutional logics of the centre. I regularly observed these purposeful assemblages at work or entwined in narratives of ‘good’ palliative care. However, I also witnessed actions that contradicted the mindline assemblages I have described. During analysis, I considered the reasons for nurses’ actions, and this often involved nurses acting out a need for self-preservation. There is a breadth of research dedicated to palliative care nurse turnover and burnout, which has often been associated with moral distress (Brazil et al. 2010; Hanna 2004; Harrington & Smith 2008; Weissman 2009). While clinicians’ were sometimes distressed about patients who continued or ceased treatment, the issue of self-preservation was more complex. The care of people with life-limiting illness is highly stressful, potentially leading to cumulative grief as a result of not having the time or opportunity to completely or adequately grieve individual grief-provoking incidents (Stayt 2009). The effects of unaddressed cumulative grief can include: doubts about professional competency and identity; reduced self-

esteem; and a preoccupation with grief and death (Rando 1984). Nurses can experience difficulties in being both intimate with and distanced from the patients and carers they are providing care to (Stayt 2009). Strategies of self-preservation are therefore vital to ensuring nurses are safe and adequately caring for patients and carers.

5.7.2 Practices

Metaphoric allusions to ‘leaving your baggage at the door’ when visiting a patient seemed to focus attention on the patient and carer needs, but also suggested a disconnected and unemotional approach to practice. Nurses expressed their (perceived) need to suppress emotions in front of patients and carers. As generalist nurse 8 stated: ‘You have to put those feelings aside and focus on what’s in front of you. You can’t be taking your own stuff into a home visit.’ Clinicians were required to consult multiple patients each day, each with potentially sadness-eliciting situations. There was a fundamental need to insulate oneself from the emotional burdens of each patient to effectively address the concerns of the subsequent patient. Nurses also placed limits on what they were prepared to do. Patient scheduling was a contentious issue, with nurses bemoaning days with high number of patients to visit. They often rescheduled certain patients off their list to colleagues who had ‘easier’ days, with less patients. Nurses often ‘vented’ about patients or carers amongst themselves, with me, and with medics. Despite a discourse articulating the need to consistently place the patient at the centre of care, participants would disparage patients and carers, citing the need to ‘get it off their chest’. Albeit infrequently, clinicians took moments in case review to discuss specific patients or carers as ‘cantankerous’, ‘evil’, or ‘nasty’, largely reflecting the difficulties they had building rapport. In one interaction, the team discussed a patient’s ‘challenging’ personality: ‘you feel unwanted in the house’ (specialist nurse 5). One specialist nurse took a moment to mimic the daughter’s body language, sour-faced with arms folded arms in an intimidating stance. Another nurse

stated that both daughters were unmarried, and she could ‘see why’ that was the case. Rather than consider these as opposed to the well-established humanist aspirations of palliative care, clinicians spoke of these conversations as ‘important’ or ‘healthy’ moments to ‘debrief’. However, even in the process of debriefing though unchecked emotional expression such as this, clinicians took moments to reframe attention to the difficulties of patients and carers. In this instance, another nurse pointed out to the team that the patient, the ‘challenging’ daughter’s mother, was illiterate, suggesting the daughter was justifiably ‘protecting’ her. This represented a dissonance between empathising with the patient and carer as part of a humanistic mindline assemblage and using the case review to vent as a practice of self-preservation. Considering these acts as different mindline assemblages of palliative care presents them as equally viable, given the emotional context of the moment. When caring became difficult, self-preservation became necessary. When venting as a practice of self-preservation became ‘unhealthy’, empathy and humanism were reinstated.

5.7.3 Emotions

Like institutional logic mindline assemblages, self-preservation mindline assemblages involved emotional detachment. Finding the ‘limits’ of emotional investment in a patient or carer became an important way for clinicians to preserve themselves emotionally. This involved conserving their own caring resources: ‘You can’t take everything you see on board because it will just overwhelm you and you won’t be able to get through your day,’ (specialist nurse 4). Modulating sadness, for example, helped to protect participants from the potential potency of perpetual grief, given the nature of their work. Clinician reticence to ‘dwell’ on sadness reflected the temporal reality of community-based palliative care, without multiple disparate home visits scheduled throughout the day.

These notions of self-preservation reflect the dangers implicit in Hochschild's (2012) concept of surface acting, the performance of emotion that contradicts their genuine emotional state, which can produce an alienation of the self. But emotional detachment could be an important way to avoid becoming too affected by palliative care. Hochschild explicated the negative consequences for workers when emotional labour produces a genuine overinvestment of the self into the well-being of others. This has been examined in community-based care, where Stacey (2011) described how home care workers experienced unintended psychosocial consequences of 'losing themselves' or overinvesting in client care. One nurse evocatively described her own drive to overinvest in palliative care, implicating the potential detrimental effects of this investment:

I'm going in there passionately because I'm fulfilling some need on some level, whether it's theirs or maybe it's mine. Maybe I'm doing it for my needs; I don't know. At the end of the day, you've got to go home... [but] somewhere we're touched by these patients. I don't know what it is [patients and carers are] saying, whether we take it on board. They don't ask us to; nobody tells us to. My manager doesn't say to me, 'Hey, emotionally you're not good enough in this job'. But for some reason, we are emotionally attaching and we feel like we need to tick every box, or we haven't done our job properly. And I don't think anybody pushes us to do that... But I think some part of us, if we don't get the chance to complete that task or meet that need, that patient passes and you don't fulfil that, there must be a void, and we all get that (specialist nurse 1).

With an enduring sense of duty for patients and carers, intense emotional experiences could prove 'too much' for clinicians, and subsequently clinicians permitted themselves and others

opportunity to ‘vent’ feelings as a process of self-preservation. I observed nurses expressing overwhelming emotions, such as anger, frustration, and sadness during interactions behind closed doors, where they were ‘allowed’ to ‘let it out’ because ‘everyone has those days’. Some clinicians spoke of the importance of camaraderie to alleviate the potentially detrimental emotional investment in patients and carers. Following a day of shadowing, a specialist nurse spoke of her own personal investment in palliative care and her attention to self-preservation, noting the importance of other clinical ‘experts’ to share the load:

How’d you feel at the end of the day? Does it settle well with you, is the important thing. Or do you walk out going, I should have done more? I should have done more. I should have done better. That’s what I think every day is about... At the end of the day have you achieved what you set out to do? If you haven’t then you’ve got tomorrow again. And tomorrow, you work a little harder. And when you don’t know something, you bring in somebody else who’s an expert that can help you. Because it’s like sealing the deal. It’s like okay, well I’ve started with this; this is what I want to achieve; couldn’t do it by myself so, so-and-so came in to help me (specialist nurse 1).

Debriefing and general discussion of emotions among clinicians emphasised the need for opportunities to reflect on the emotional milieu of palliative care: ‘I think it’s important that people take the time to reflect on their emotions and take the time to talk to somebody and just exchange that’ (generalist nurse 12). When emotions were not adequately reflected on, and when nurses were not given the opportunity to reflect, they felt underappreciated by the organisation.

During fieldwork, clinicians often associated my research questions about emotion with the presence, or lack thereof, of attention to clinicians' emotions, psychological support, and clinical supervision. They suggested clinicians' emotions were to be 'celebrated':

I find it a really interesting research topic. It's fantastic that it's come to the forefront and it's being discussed. It's probably been under the radar for a long time. No one has actually explored how we feel on our side. Because most things deal with the patient, the family's emotions, the patient's emotions and to look at our side, how it affects us as a single person going [into patient homes] and where do we go after we leave people's houses with the emotions? Not everybody is old and dies because [it's their time]. There's a lot of cases where people die unexpectedly. There's young people, our age people, our children's age [that we care for] and I think the emotional focus on that, how you deal with that really, it's brilliant that it's being addressed (generalist nurse 12)

The nurse in this excerpt alluded to 'the emotions'. Rather than identifying patient, carer, or clinician emotions, there is no easy way to disentangle these emotions, therefore warranting attention to different experiences. Clinician emotions as a focus of research became a regular conversation topic as nurses bemoaned how they were neglected emotionally, considering the suffering they witnessed and subsequent sadness they experienced. During fieldwork, one-on-one conversations often became moments of reflection on practice or emotion where I provided an attentive ear. These experiences cemented the mindline assemblages of emotional self-preservation as important for clinicians who lacked the opportunities to 'unload' their emotional burdens.

5.7.4 Identities

As palliative care was interwoven with challenging emotional terrain, clinicians were attentive to how they preserved themselves and their identities:

That's the problem with our job. It's a bit emotional, you know?

There's only so much you can do before you burnout. There's only so much torture you can put yourself through before you say, 'Look I can't do this job anymore' (specialist nurse 1)

This 'upper limit' was not explicated by the nurses, but her words suggested a personal reflection needed to determine the limits of care. There was a dehumanising element to the way some nurses considered how patients and carers, the organisation, or the more nebulous ideas of 'researchers' or 'academia' viewed them. They resented being cast as 'just the nurse', as they viewed it, without having an emotional and physical investment in palliative care:

We do so much for the patients, and they don't always see what happens behind the scenes. You go to the homes and sometimes you'll hear family members complain about other nurses or the lack of service or how everything has gone backwards... It's nice that they actually notice what you're doing, because it's hard work being a nurse. [It's] physically [and] emotionally draining; your registration's on the line and it's so easy for patients to make a complaint about you... So, if you build a good relationship with your patient, if your patient has got trust in you, you're less likely to have things go wrong (generalist nurse 2)

The emotionally draining nature of palliative care could be a point of contention for generalist nurses, whose roles involved wider remits:

I can't see myself doing palliative care full-time because it would be too exhausting. The emotional connection that you have with palliative care patients is really draining (generalist nurse 4)

To manage this burden, some clinicians relied on the reciprocity of the relationships fostered in palliative care, drawing from patient and carer gratitude to replenish their caring stocks. Patient and carer gratitude helped clinicians consider the quality of their work, and they took solace from moments of praise. Witnessing joy through a smile, a hug, or a laugh demonstrated the powerful effect of palliative care on participants, and they relayed this effect to others:

Satisfaction, for me, is basically being allowed to see that smile from that gentleman because they appreciate what you have done. And it's not much; it's actually accompanying them through this difficult journey (specialist medic 1)

Appreciation from bereaved carers, in the form of a note or a card, was important as they reinforced and invigorated nurses' attention to care:

When they have died and you go to their funeral and they want you to go right up the front, even though you're like, 'No I want to sit up the back'. They've recognised the care you've given them; they're happier; the journey has been a good journey for them (generalist nurse 1)

Emotional investment in patients and carers were 'worthwhile' for the recognition, validating the attentive, humanist ways clinicians cared. One specialist nurse described when she received a bunch of flowers from a deceased patient's relative, noting the way it affirmed her efforts to provide comfort for the patient and carers:

The other day I received a bunch of flowers from a relative, you don't know how much you're giving because you sometimes everybody's upset or they're sad or they're grieving or whatever it, when that bunch of flowers came it just says everything without saying anything at all, so you know you've given you're all. And that's what it's about, getting that feedback. You just don't get it I think as nurses generally we just don't get that, 'You've done a good job.' But in this job you get a lot of thanks, that's why I really think I enjoy it more than anything, you know you are doing a good job (specialist nurse 1).

In this excerpt, the specialist nurse highlighted the gratitude in palliative care, and the importance for her perceptions of her role. Gratitude and recognition reinstated the palliative care identity as one that was implicitly demanding, physically and emotionally. The need for recognition suggested the physical, mental and emotional expenditure necessary to practice palliative care well.

5.8 Conclusion

In this chapter, I described some of the prevalent groupings of mindline assemblages at the centre. With assemblage theory as an analytic framework I examined the emotions implicated within mindline assemblages of community-based palliative care. These descriptions, while helpful, are ultimately shallow in that it does not account for the messy, cross-contamination of these assemblages as they were considered and enacted in practice. For example, while I have described physiological and humanistic mindline assemblages distinctly, during a case review these assemblages would be arranged and then fall apart in a process of folding and unfolding. In a moment, a nurse could be ambivalently discussing a patient's diagnosis and, suddenly, express an evocative sense of sadness at the loss her young child must be

experiencing. In the next section I provide a description of the different contexts mindline assemblages were arranged within.

Chapter 6: Mindline assemblages on the road and in the centre

6.1 Introduction

In this chapter, I explore the movements of mindline assemblages within different contexts, explicating the contingency of emotions as a constituent part of these movements within the social. As virtual diagrams for practice, mindline assemblages were purposeful, working appropriations of an arrangement of ideas, practices, emotions, and identities. However, these assemblages did not always ‘work’ as intended in the complex environments of the home or within clinician to clinician interactions. Social life ‘is forever constituted or assembled in “masses”, comprising composite relations of desire, belief, and force that each effect a kind of sociality of the mass’ (Duff 2014, p. 101). Deleuze and Guattari (1987) conveyed the ‘social’ as without a discrete substance or domain. The social is a ‘field... animated by all kinds of movements of decoding and de-territorialization affecting ‘masses’ and operating at different speeds and paces’ (p. 220). Mindline assemblages implicated in these ‘fields’ could be shaped by decoding and de-territorialisation. Clinicians were required to constantly rethink and *re-feel* palliative care in terms of the diverse challenges and ‘flux of relational forces’ (Duff 2014, p. 102), shifting the types of emotional labour required while engaging with their patients. As demonstrated in this chapter, emotional labour as a commodity was often saved for the home, where relegating ‘inappropriate affects’ (Hochschild 2012, p. 59) or acting in specific emotional ways were vital to palliative care. Specifically, I contextualise the mindline assemblages I described in chapter 5, examining how they were assembled within the social ‘masses’ of patient homes, and during case review. These contexts were selected because they made up the majority of the palliative care practice spaces at the research site.

6.2 Palliative care assembled in the home

In this section, I describe palliative care assembled within patient homes, examining how mindline assemblages were implicated within the home and the emotions associated with these fluctuating masses. The assemblage of palliative care in the home was contingent on emotion. Patients, carers, and clinicians elicited diverse and constantly changing intensifications of feeling as a terminal illness progressed. Collier (2013), a former palliative care clinician conducting research in patient homes, conveyed the flux of affects, instigated by the patient, that shifted her thinking and practice:

Caring for dying patients in a community setting provided me with a very different perspective. Unprotected by the physical walls of the hospital ward, in territory unfamiliar to me, arriving at the door of a patient's home was quite a challenging matter. It was the patient and their carers who determined whether they saw me, how long I stayed or whether 'my expertise' was acted on. There was a distinctive quality of experience as 'the nurse' that was unique to witnessing death and dying in the home. Entering into what often felt like a 'sacred space' seemed at times like an intrusion. (p. 61)

The affects generated in home-based palliative care were contingent on the patient *and* the wider social masses they were arranged within, including family, friendships, work identities, cultural collectives.

6.2.1 Mindline assemblages in flux in the home

Palliative care mindline assemblages were intrinsically arranged with the notion of working within patient homes. According to participants, community-based palliative care differed

from hospital-based care. Community health clinicians were unable to accurately monitor patients once they had left the home and relied on patient and carer agency. Furthermore, home-based care required considerable foresight, planning, and emotional energy to accommodate different circumstances. In preparation for a home visit, clinicians considered: what had (or should have) occurred since the last visit; who was likely to be present and absent; how this might shape the interaction; and whether there will be time and space for a difficult conversation, given the clinician's other planned visits, among other considerations.

Some participants attached joy, hope, sadness, anger, fear, and/or disgust to patient homes – the array of emotions reflected the array of patients and the contexts of palliative care. Patients and carers could be antagonistic, hostile, or accusatory of nurses. This multitude of potential affects established the home as sacrosanct, requiring a delicate approach. The power relations that could subjugate inpatients were redressed in the patient home. Some participants constructed patient homes as sacred spaces where patients and carers had agency and control, removed from the sterility and subjectification of a hospital:

If anything, you're more respectful when you're going to patient homes because, in a hospital environment, the patient's in your environment. In the community, you're in the patient's environment... they call the shots (specialist nurse 1).

The nurses recognised how rapport mindline assemblages worked within this sacred space to help familiarise with a patient. This required them to dismiss unnamed others' assumption that familiarity was fostered by a brief home visit in which interactions with patients and carers were focused, if not clinical:

Being respectful and gentle is important. You don't want to race in bringing a bunch of noise into the house like a headless chook. You need to take the time to talk to patients (specialist nurse 3).

The nurses accentuated their attentiveness, care, and compassion when visiting a patient for the first time. Mindful they were being observed and judged, and that first impressions can count, they demonstrated a steadfast focus on patient and carer needs and wishes, clinical or otherwise. This mindfulness reflected the delicate balance between the emotional detachment of professional mindline assemblages and the empathy and compassion necessary in humanistic mindline assemblages. Nurses nodded to the emotional labour of solemnity, describing quiet and gentle physical actions as an effective method to distinguish practices in patient homes, putting aside the inappropriate affects like excitableness or flippancy. They signposted an underlying respect of the home, aligning with the humanistic and rapport mindline assemblages. This respect waned when confronted with uncomfortable or dangerous situations, but largely nurses attempted to maintain this balance. Often during these home visits, I found myself all too sensitive to any uneasiness brought on by tensions between nurses and patients or patient's frustration with their care. This was magnified by my position as a researcher and my inability to act in these situations in any immediately productive way. However, clinicians on a home visit could dictate the course of clinical conversation, with patient and carer guidance. They could, and often would act productively to shift the focus of the encounter, for instance by examining a patient's medication, discussing photos of family members, talking about any social outings the patient has had.

Clinicians re-territorialised their mindline assemblages to become effective in the unique space of the home, where 'anything can happen'. They also talked of their 'effects' or 'impressions' in these spaces, acknowledging the impacts of their presence on patient and carer lives:

It's very personal work... I'm a stranger going into someone's home, so I'm very aware of professional boundaries. I believe that there is a certain way that we are to conduct ourselves in someone's home. We leave an impression when we've been to the home (generalist nurse 9)

In the excerpt, the nurse connects the 'professional boundaries' of her practice with the potential detriments of negative 'impressions'. Professional mindline assemblages, or the 'certain way' she articulated, underscored clinicians consideration of practice in these spaces:

When you walk onto a patient's lawn, you don't just walk across the lawn, you follow the pathways. You ring the bell. You introduce yourself. You don't become familiar with a client just because you're going to their home (generalist nurse 9)

Nurses' metaphors of leaving 'impressions' is apt in this study, as it implies the affective nature of tangible practices in patient homes. Impression conveys a physical, embodied aspect of emotion, suggesting the embodied feelings related to a nurse's presence within a home (Ahmed 2013). This shaped the collaborative way the team worked, as nurses left certain impressions that could affect the way other nurses acted. These impressions could be problematic when, for instance, a nurse established a familial relationship with a patient and their family and another nurse entered the home with a curter, 'professional' approach, instigating tension. Emotional impressions in patients' homes reflected a commodity generated by the emotional labour of clinicians, creating more straightforward future interactions. The emotional-impression-commodity was directly connected to initial visits laced with respectful, sympathetic, professional and/or attentive clinical identities and bodies, contingent on clinicians' preferred approach and beliefs about appropriate care.

Collective understandings of respect in patient homes was also infused with cultural nuances as well. The centre serviced an area that was culturally and linguistically rich. According to some nurses, different cultures occasionally necessitated unique home-based practices. For instance, one specialist nurse shared her ‘discovery’ about Arabic families offering food:

When Arabic families offer you food, it’s very rude to reject it. It’s like they think that you think you’re better than them. So, I’ve learned to say yes to the food. But I say, ‘I can only have a little bit’ and so they give me a chocolate or wrap up a little baklava or something (specialist nurse 5)

It was important to avoid acts that others might misconstrue as rude or disrespectful. This resonated across nurses’ many home visits and was an important part of the community-based identity in the ways clinicians spoke of deference to patients and carers in these contexts.

Cultural nuance and different perceptions of respect added to a wider view of the home as a place that could invoke trepidation and fear. With newer patients, nurses were often unsure of ‘what they were walking into’. Nurses would have to be ‘prepared for anything’ when they entered a new home. According to some, this included unkempt or sparsely-furnished homes or patients and carers who were hostile or belligerent. During discussions at the centre, nurses would jovially compete with each other for who had been in the most unkempt home. Nurses would gleefully revel in a listener’s disgust while they talked off a hoarder who kept soiled nappies in bags in the living room. These kinds of stories were on par with conversations about the most gruesome wounds clinicians had seen while working. Nurses used stories of disgust or fear to reinforce the chaotic nature of community-based healthcare. One generalist nurse described to me her thoughts as a relatively inexperienced clinician when visiting a patient’s home who was dying.

Okay, I'm going to go to the house, even though I knew that when I walk in, it's going to be just right in my face because I don't have the resources; I don't have anything there to back me up or to help me (generalist nurse 2)

These data highlight the emotional labour required in these visits to manage the 'inappropriate affects' (Hochschild 2012, p. 59) of unkempt patient homes – a labour fitting within rapport mindline assemblages. But within arrangements of collegial support and 'venting' as part of the self-preserving mindline assemblages, inappropriate affects became appropriate and at times intrinsic to the character and identity of community-based care. These affects manifested in moments of debriefing in the car with nurses or back in the centre, removed from patient or managerial observation where emotional labour could be eschewed. These kinds of emotional discourses compiled with stories and experiences of familial connection with patients and carers established the home as a unique, albeit chaotic, space to deliver care, necessitating unique mental and physical approaches.

Delivering care in the community was an important part of the way nurses considered their mindline assemblages, where humanistic care and rapport building were enabled without the strictures of institutional logics. They proudly described their exploits when navigating unconventional situations – like the generalist nurse who was praised for delivering palliative care to a patient in a hotel:

This guy was an alcoholic living in a hotel. I was so impressed with [generalist nurse 13], the way she handled that, just went in and made that connection with him despite the situation (specialist nurse 5)

Mindful of their role in the community, these stories evoked the determination in the face of uncertainty and complexity. This pride fostered a resilient capacity to navigate unusual

situations, sometimes at their peril, as nurses would often confront risk. Some were caught in flood waters, entered homes with menacing pets, or delivered care in unsanitary conditions – yet each story demonstrated an ability to overcome adversity.

Despite the complexity of implicating mindline assemblages within the social mass of the home, many nurses formed important, purposeful, and affective bonds with some patients and carers, becoming ‘part of the family’. While ostensibly aligning with a solemn presence in patients’ homes, many physical acts seemed to represent ‘familiarity’ as I understood it. Consider for instance, when a nurse opened and walked through the front door of a patient’s home without knocking. This nurse later informed me that this was because the patient knew who she was and so felt comfortable to walk straight in. Nurses would often walk straight to the cupboard that held the patient’s medication and dressings to change a syringe driver or wound-dressing. Some nurses would hug and kiss patients and carers upon arrival at the home and again when leaving. These acts of familiarity were not sporadic occasions. Nearly every day I shadowed a clinician, I witnessed some form of a ‘familiar’ act in a patient’s home. Some of these acts paralleled the acts of humanistic and rapport building mindline assemblages, such as physical contact, that some nurses privileged during our discussions. Other acts appeared to represent a nurse’s comfort with a patient or carer, suggesting a reciprocal companionship. A consistent relationship between a clinician, a patient, and their carers seemed to be mutually beneficial. It offered stability and confidence in an otherwise precarious day, in which careful plans could readily go awry:

The home visit we had... was very comfortable. The patient and the wife were very welcoming, and I think it helps that I’ve been there before... I felt comfortable as well... It was very much an informal type of thing (specialist nurse 4)

Despite moments of familiarity, reciprocal companionship and humanism, nurses would find moments to ‘get down to business’, shifting from a familiarity to, for instance, the well-rehearsed POMSNAME questioning, or the moment to take ‘obs’. The interconnectedness between professionalism, rapport, humanist care, and self-preservation in the home was complex and always in flux, predicated on clinicians’ individual relationships with patients and carers. Clinicians would need to be ‘respectful’ in their movements and talk as well as ‘comforting’. They needed to maintain ‘professional boundaries’ while fostering a trusting and caring relationships, while also staying vigilant for the potential dangers of an unfamiliar environment. As I discussed in section 5.3.2, nurses needed to co-opt mindline assemblages to become simultaneously productive in other ways. In the home this kind of mindline assemblage co-opting was prolific, as clinicians entwined moments of physiological care with humanistic care or rapport building.

While shadowing another specialist nurse, I witnessed an exemplar of a moment of co-opting. During a home visit, the patient talked at length of many things, including a complaint about medications. Once the nurse and I returned to the fleet car, she expressed exasperation about the extent to which the patient complained; I too noted the patient’s long-winded diatribe. Yet the nurse’s expression belied her attentive demeanour in the patient’s home. I said that she showed no frustration or impatience during the visit. In response, she described the dual necessity of sifting through a patient’s story to get to ‘valid’ information, while demonstrating interest:

There are other things we need to talk about, so we’re putting the groundwork in. He’s talked about that episode and that episode has traumatised him. So, that means it’s significant. It was important and we need to acknowledge that. And unfortunately, listening to six hours of the same thing [is] what we need to do. And [we need to] look

interested as much as we can [*laughs...* to] pick up the most important things we can out of that situation (specialist nurse 1)

The nurse's reasoning shed light on the co-opting of multiple mindline assemblages in practice. Demonstrating interest was important in this context, as it enacted the acknowledgement and rapport needed for palliative care. This was 'groundwork' for the benefit of clinician rapport with the patient and carer. As with the previous wound-related experience, this nurse prized this relationship, a desire to strengthen it, or at least avert damage. The groundwork also served to tease out physiological and psychosocial information – the 'important' and 'significant' concerns of the patient and/or carer. Although this nurse was frustrated by the patient's desultory rant, she steadfastly attended what he said, identifying a 'valid' concern:

His point about medication was valid because he was saying, 'Don't throw more medication at me'. His fear was that we were going to sedate him. The more morphine we're going to introduce, the more drugs we're going to introduce, [he thinks:] 'I'm going to get more sleepy' (specialist nurse 1)

In this nurse's description was an underlying tension between what is needed, clinically, and what the patient desires. Again, the need for pain medication represented a clinical obligation the nurse had to assess against the patient's needs. Her assessment of the patient's 'trauma' attuned her to the significance of what he said. Her description of the event, like the aforementioned nurse, suggested her need to represent the 'service', another mindline assemblage at work within this encounter:

Sometimes you think to yourself, 'Just get to the bottom of what you want to say'. But at the end of the day, we have to be great listeners because we go in as a service. I think that's part of what we're going

to promise and deliver... I'm hoping... we've reassured the patient before we've left (specialist nurse 1).

It was important to mask frustration during the home visit to present a persona of the 'great listener', which was implicitly 'promised' by the service. This emotional labour stemmed from the mindline assemblages related to rapport at the centre, and here the specialist nurse acknowledged the influence of these mindlines on her practice. Clinicians often assumed the role of service ambassador as they delivered care in an isolated and individual way. At times, this accentuated the mindlines within the centre – connected by these mindlines, the nurses represented themselves and each other.

Other nurses indicated the capacities of emotions to achieved joyful combinations in palliative care, providing different dimensions of observation and action. The nurse who consulted with the loquacious patient described how she resourcefully used emotion to visibilise a patient or carer needs:

When you are more sensitive to what your patients' needs are... [and] able to plan for palliative care, I think emotions help a lot. You cannot do your job without emotions... That emotion will actually push you to look out for things that you can make a difference with in terms of patient care (specialist nurse 3).

This nurse's sentiments were shared by more experienced palliative care nurses. Emotion helped and hindered palliative care. For instance, it could hinder palliative care by clouding clinical judgement and obfuscating a 'bigger picture':

Having that guilt in relation to a patient's death can be very debilitating. You ask yourself, 'Could I have done something differently to prolong their life?' rather than learn from that experience

and move on. Also, you might have fear about giving pain medications because you think you might be causing more harm than good (specialist nurse 5).

Emotion – in this case guilt – was ‘debilitating’, and its suppression was important for self-preservation. This nurse also alludes to the fear arranged within mindline assemblages of a bad death. Although this nurse did not term it as professionalism, she also spoke of the need to avoid emotions to provide ‘good palliative care’:

A good nurse can will those emotions aside. If you are walking into a patient’s home who’s dying, in tears, not coping, then it’s going to be hard for the family because they may not trust what you are doing. You want to give confidence when facing that suffering or that despair (specialist nurse 5).

Clinicians who appeared to work well within these spaces in terms of their positive relationships with patient and carers seemed to embrace these chaotic environments, adapting quickly to different emotional and physical contexts. I observed clinicians move from a quiet and respectful façade in one morose home visit with a patient bed bound and carers in mourning, to a comparatively jovial and jocular façade in another home visit with mere minutes between. The shifting emotions and associated, identities and practices suggest the home visit as a space constantly being de-territorialised and re-territorialised to address new purposes and potential. Vital within this process was the relationship between clinician and patient, or clinician and carer, which, if working well, offered a stable foundation for the proliferation of care to unfold.

6.2.2 Reflexive emotions in fleet vehicles

While working in patient homes was sometimes managed via emotional labour, the fleet vehicles used to travel to and from patient homes were a private sanctuary, offering respite. It was in a fleet vehicle that I often witnessed the most unbridled displays of emotion. Occasionally, this was an outpouring of frustration, relief, or sadness, pent up during a visit, requiring some labour to manage feelings and perceptions of care. Some initial utterances of this labour occurred when I interviewed nurses in a fleet vehicle, immediately after a home visit. Relative to how they performed in the patient home, there was often a comparatively unchecked outlet of ‘non-clinical’ feelings without moderation, followed by ‘clinical’ clarification or re-territorialisation, attaching clinical insights to felt emotions:

This last visit we went to [laughs] was a bit [strained voice] freaky [laughs] and it’s very difficult to assess when you’ve got someone who doesn’t speak the language. So, there’s a huge barrier that you put between you, and you come in and try and help and they don’t understand, and you don’t know... how to help without speaking the language (specialist Nurse 1).

Here the nurse used a disparaging descriptor of ‘freaky’ before clarifying the ‘freakiness’ of the situation for my benefit: the difficulties with language and communication. These moments were often an opportunity for nurses to reflect on the visit, as with another nurse who co-opted her feelings view to attach clinical significance:

I’m a bit upset to see him deteriorating. To see the up and down. With palliative care they change, they fluctuate... [Me: What are the signs?]
The weakness in the leg; he used to be able to get around a lot more.
His personality hasn’t changed. Just the body [experiencing] weakness

overall. The cancer's starting to cause the body to become weaker (generalist Nurse 13).

Discursive connections between being 'upset' and identifying the cause of the feeling was important, as this attributed significance to the nurse's observations. It qualified her emotion as a valid way to appraise patient wellbeing. Similarly, another nurse examined the psychosocial support and care required for a 'sad lady':

She's a very sad lady that doesn't have great support. She has a brother that lives in Melbourne; doesn't talk to him very much, although she's a bit closer with him than he was before. The only thing in her life is that dog (specialist nurse 3)

Relative to patient homes or the community health centre, fleet vehicles were a safer space to vent frustration, anger, or sadness in response to patient and carer actions, manager actions, or a colleague's poor practice. The inappropriate affects within homes became appropriate, and nurses often alluded to the importance of these spaces to redress the emotional labour of home visits. At times while shadowing, a nurse would prolong their 'time on the road' by stopping at the side of the road or a McDonald's restaurant to complete their notes or simply converse with me before returning to the centre. They reported feeling comforted by the isolation, ascribing it a particular significance in their decision to work in the community:

I love being in the community, not having someone looking over your shoulder constantly. It's tough at times but I love the freedom you have (generalist nurse 2).

For some nurses, the fleet vehicle afforded an independence that, to some, fostered a more independent way of practicing. Although such independence was difficult for some less experienced nurses who wanted onsite guidance, it enabled others to enact a nuanced approach

to care. Many experienced nurses would talk freely about never returning to a ‘hospital setting’ with the constant supervision, and the greater imposition of institutional logics that entailed.

The constantly changing assemblages of palliative care within patients homes and fleet vehicles underscored the complexity of palliative care. Clinicians entwined emotions with ‘professional’ practice, validating their emotions by attributing them clinical significance. The home was space constantly in flux, with clinicians, patients, and carers engaging in a dance of adaptation to emerging relationships and affects. Clinicians understood these complex masses by ascribing them multiple and proliferating mindline assemblages, with identities constantly emerging and changing throughout a single home visit. In the next section I explore similar fluctuations within the case review.

6.3 Palliative care assembled in case review

In their initial study exploring mindlines, Gabbay and le May (2004) noted the importance of the ‘organisational features of the practice, such as the nature and frequency of meetings, the practice ethos, and its financial and structural features, including the computer system’ (p.3). In this section, I consider how clinicians navigated the multiple mindline assemblages and the subsequent portrayals of emotions in the case review. Manifestations of emotion or lack thereof aligned with how some mindline assemblages were privileged in clinical interactions flavouring how palliative care was enacted.

Case reviews were structured around each generalist nurses’ patient load with nurses presenting and discussing one patient at a time. One specialist nurse encouraged generalist nurses to remain for the full meeting even after they had presented their patients:

I want them to see how other people are planning for pal[iative] care and be involved in the conversation, so if they come across something similar, they’ve got some ideas (specialist nurse 5)

During case review a specialist nurse would chair and document the meeting with the specialist nurses supplementing the generalist nurses presentation with their own observations and perspectives. Some patients were managed exclusively by a specialist nurse and as such the specialist alone would present the patient's case.

6.3.1 Enshrining physiological mindline assemblages within case review

During case review, even with the familiar faces seen day-to-day in the hallways, my perception of interaction became increasingly formal. Largely, the feeling of formality stemmed from nurse acquiescence to physiological mindline assemblages. They presented patients primarily in terms of disease along with significant symptoms, such as pain, bowel-related issues, nausea, and social issues including those involving carers. Although there were no explicit designation of what nurses should present, junior nurses expressed an obligation to know their patients' primary diagnosis, appearing flustered or apologetic when unable to do this:

So, this guy... I can't remember what his primary diagnosis is, sorry.

I'll have to go back and look at the notes (generalist Nurse 4).

The importance placed on diagnosis further established the case review as a space for, primarily, physiological mindline assemblages. Specialist nurses would wait patiently while someone 'looked it up' on a laptop. This obligation was also demonstrated by the emphasis placed on case review preparation:

I made sure I knew it all yesterday afternoon so that I'd be ready for today (generalist Nurse 5).

The presence of a specialist palliative care doctor who visited the centre added to the formality of the reviews. They provided additional medical advice during case reviews and helped to formulate care plans.

An artefact that helped to enshrine the importance of physiological mindline assemblages in these contexts was the computer. While nurses presented their patients, a senior specialist nurse documented each patient's 'plan of care' on the computer, with the screen displayed on a television monitor for all to see. The specialist nurse privileged the documentation of physiological information within the plan of care, particularly noting the disease, problematic symptoms, and medications. The conversations that focused on social, emotional, or spiritual concerns were documented significantly less. Introducing the patient during the case reviews with reference to a primary diagnosis seemed to prioritise this aspect of care for some nurses, as more emotive or personal perceptions were saved until after the primary diagnosis, symptoms, and treatments were presented:

1. Generalist nurse 4: [Th patient], he's lung [cancer and
2. carcinoma]. He has [metastasis] in brain and bone. Currently
3. on active treatment at [hospital]. He lives with his wife and
4. daughter. He was initially visited by [nurse]. He was actually
5. referred twice and refused the service. They recently changed
6. their minds and want support. They're an ESL family so, when
7. I've been out, I've been getting the daughters to interpret. The
8. thing is, the daughter also has brain cancer. The last time I was
9. there, the patient's wife was laughing at daughter because she
10. doesn't understand what is going on.
11. Specialist nurse 3: I think her prognosis is that she's likely
12. going to die before the dad.
13. Specialist nurse 5: Jeez
14. Generalist nurse 4: The family want mobility support and
15. equipment at the moment
16. Specialist nurse 5: Have you thought about a social worker? It
17. sounds like they need financial and emotional support more
18. than anything

This excerpt was indicative of case review presentations. Nurses reference to illness, symptoms, and treatment (lines 1 to 3) were documented on screen, and were usually followed

by the most pertinent symptoms and/or social issues that need to be addressed (lines 3 to 11) which were left undocumented. The initial discussion and its documentation reflected the emotional detachments and identity requirements of physiological and professional mindline assemblages.

Prioritising physiological mindline assemblages within parts of the case review did not necessarily abate the discussion of wider concerns, as these conversations took an a more ‘undocumented’, proliferating form. This formulaic approach meant nurses could create a focal point around a specific concern. This focal point often fostered in depth conversation and I generally witnessed more emotions during these moments. Take for instance, the moment the generalist nurse identified the patient’s daughter as living with brain cancer and specialist nurse 2’s reaction (lines 8 to 14). This moment prompted conversation between all three nurses about the benefits of a social worker for the family. When nurses or doctors did become emotional, it was pronounced and heightened conversation about the issue at hand.

6.3.2 Discursive emotions re-territorialising case review

Nurses displayed emotion performatively to re-territorialise the case review to purposefully attend to an array of concerns. For example, clinicians used sadness to articulate patient contexts and accentuate certain features of care – be it the care of the patient, a family member, the self, or a colleague. This demonstrated the purposefulness of sadness within particular mindline assemblages. For instance, in describing a patient as ‘someone [who makes] you feel sad, when you leave’, one specialist nurse vented her compassion to colleagues. This influenced how they perceived the patient and planned her care to accommodate the patient’s (perceived) needs. Similarly, consider how a junior generalist nurse advocated for this patient by pleading for resources to moderate the patient’s loneliness: ‘I’m not going to discharge her because we are the only people she sees,’ (generalist nurse 5).

During the case reviews, the nurses referred to established emotion scripts or norms. For example, the discussion of children, either as a patient or a patient's family member, became a powerful marker. In one interaction, a nurse used the opportunity to review a patient to highlight family trauma:

1. Generalist nurse 13: [The patient] does get respite [through]
2. My Aged Care starting early next week so she can take [the
3. patient's grandson] for some therapy. He can't talk, he just
4. says 'Uh oh. Uh oh' That's the only word he uses.
5. Specialist nurse 3: How old is he?
6. Generalist nurse 13: He's two and a half I think.
7. Generalist nurse 14: He's developmentally delayed.
8. Specialist nurse 3: Oh, is he?
9. Generalist nurse 14: Yeah.
10. Specialist nurse 3: Is it just his speech though? Or is it
11. development?
12. Generalist nurse 13: Speech more than...
13. Generalist nurse 14: [The carer] said to me that it's going to
14. be traumatic for [the patient's grandson] if [the patient] passes
15. away.
16. Generalist nurse 13: They're very close. They talk to each
17. other.
18. Specialist nurse 3: The little one?
19. Generalist nurse 13: Yeah, the little one.
20. Specialist nurse 3: So, he's too young for... CanTeen [a not-
21. for-profit organisation that supports young people, aged 12 to
22. 25 years affected by cancer]?... Is
23. anybody involved? He's not at school, is he? So, he's too
24. young.
25. Generalist nurse 13: No, he's their all the time...
26. Specialist nurse 3: So, he's in a pressing gap. He's in limbo,
27. isn't he?
28. Generalist nurse 13: [The grandson] gives [the patient]

29. company.
30. Specialist nurse 5: So, how can we tap into something for
31. him then?
32. Generalist nurse 14: I guess if he's in school... contact the
33. school. But if he sees the grandfather deteriorate daily...
34. Generalist nurse 13: Yeah, and you don't know what he
35. thinks, you know? He can't express himself. All he says is
36. 'Uh oh'...
37. Specialist nurse 3: I wonder if we gave a rainbow book to the
38. mum to work through.
39. Specialist nurse 5: I think that's a good idea... I was just
40. thinking about, about [a] clinical psych or something; maybe
41. talking to [a clinical psych] about it and seeing what she can
42. suggest.

The distress imbued within reference to the child's disability (see lines 2 to 12), the child's potential trauma (see line 13, 14, and 15), his connection to the patient (see lines 16, 27, and 28), and the potential absence of support for the child (see lines 19 to 26) heightened the patient's needs. During the case review, this attention to emotive aspects of the patient's context by generalist nurses 13 and 14 ensured the specialist nurses attended to these needs. Explication of distressing contextual information helped to invoke empathy and guide care. This information re-territorialised the case review, shifting emotions, focuses and potential practices, sometimes through anecdotes that accompanied medical discourse. When clinicians went 'off script' by alluding to patient sadness or suffering, their persona changed. The words they used were more personal and colloquial. Generalist nurse 13's observation that the patient and his grandson 'talk to each other' (lines 16 and 17) was not pressing clinical information in the context of the discussion, but for the generalist nurse it served to establish a sense of connection. Foreshadowing the potential suffering following the patient's death established a collective fear for a bad death. Beyond word choice, clinicians' voices took on a different

timbre. Conversations were enlivened during moments imbued with emotion, creating a prominence amongst the more detached information relayed in case review.

Sadness and suffering were not the sole emotions I observed during case review. Case review could also be full of humour and joy as nurses and doctors celebrated care. This included the shared ‘victories’ in palliative care. During one case review, a nurse stated that her patient had been taking less pain medication, suggesting his pain was well controlled with the dosage prescribed. The specialist medic acted out an exclamatory joy and excitement: ‘Yes! That’s fantastic’ with accompanying body language of a fist pump in the air. The medic proceeded to tell the story of the patient’s pain; the disease was improving but the patient’s neuropathic pain was not reflecting the progress. She struggled to identify the cause of the continuing pain. The medic subsequently discovered the cause of the pain leading to her happiness about patient’s improved experience and satisfaction at having made the discovery. Case reviews could become celebratory, affirming positive practices. Another case review included a similar moment:

1. Generalist nurse 5: I have organised a home visit with the
2. patient on Tuesday. Just before I went to see him, I rang to
3. confirm... He just said, ‘Look darling, I’m having...’
4. Specialist nurse 3: (Laughs) Darling.
5. Generalist nurse 5: ‘I’m enjoying my lunch. I’m doing really
6. well, there’s no pain, there’s no constipation (laughs)’
7. Specialist nurse 3: (Laughs) It’s like he knows.
8. Specialist nurse 1: (Laughs) [He] ticks them off, ‘I’m eating
9. well...’
10. Generalist nurse 5: (Laughs) Does he know that? That’s what
11. I’m going to ask him... [He said], ‘I’m doing really well.
12. There’s no issue with me, I’m currently enjoying life with my
13. family and could I please have another visit on Wednesday?’
14. So, I said, ‘Yeah, that’s okay. As long as you’re doing well’ I

15. don't want to disturb him if he's just enjoying time with
16. family.
17. Specialist nurse 1: (Elongated) No. So, any treatment?
18. Generalist nurse 5: Ah no, didn't mention about chemo or
19. anything at this stage.
20. Specialist nurse 1: Pain's well controlled?
21. Generalist nurse 5: Pain's well controlled.
22. Specialist nurse 1: Excellent. You've got them good out
23. there.
24. Generalist nurse 5: Yeah!
25. Specialist nurse 1: [After discussion about scheduling visit]
26. So, you're happy?
27. Generalist nurse 5: Yep
28. Specialist nurse 1: I like it, I like it.

The most immediate joyfulness that I noted in the above exemplar was the recognition and affirmation from the senior nurse of the generalist nurse's practice (line 21, 22 and 27). Additionally, there were moments of humour around the patient's knowledge of the palliative care script (lines 5 to 11) and about the familiarity between the patient and nurse (lines 3 and 4). Acknowledgment that the patient was 'doing really well' and 'enjoying life' without 'issue' was a victory for the nurses. These moments emphasised the importance of rapport mindline assemblages, and the centrality of a patient who was not to be 'disturbed' if living comfortably. After the case review, I spoke with the generalist nurse about how she felt about her practice:

It's really nice to have that validation from [the specialist team] that I'm doing the right things. The fact that they support me so much means I'm doing the right thing and [will] keep doing that work (generalist nurse 5).

Case reviews were used to celebrate humanistic mindline assemblages by acknowledging moments of holistic care. Nurses spoke with pride and humour about attending to unique

aspects of care and the specialist team applauded these aspects of holistic practice. During one case review, a generalist nurse described a patient who experienced anxiety. Rather than discuss the immediate physical symptoms, she explained the patient was ‘scared of her mum’. The nurse organised a visit from a social worker along with her own weekly visits to ‘calm [the patient] down’. The specialist nurses took a moment to applaud the nurses’ actions, addressing not just the physical symptoms but ‘emotional issues in her life’. These affirming appraisals of holistic care imbued nurses’ and doctors’ motivations to incorporate unique forms of ‘care’ in their practice.

Case reviews were moments to review patient deaths to assess the ‘goodness’ of the death. These moments clarified the constituent arrangements of death and dying care mindline assemblages. In the following transcript, nurses indicated some of the emotion rules arranged within these mindline assemblages:

1. Generalist nurse 8: [Patient name] died peacefully at home. It
2. was a good outcome because that’s what he wanted.
3. Specialist medic 1: He was not somebody who complains
4. and that’s how he went. At night not bothering anybody.
5. Generalist nurse 8: [Carer] said it was the first night she slept
6. peacefully in ages. In the end, everyone rallied: the nephew,
7. the sister. It was a really good outcome. I called over for a
8. bereavement... visit but they stated they were, ‘Busy,
9. busy, busy’
10. Specialist nurse 3: That’s all you can do. It usually takes a
11. little time once everyone has left after the funeral and
12. everything when [the patient’s death] has starting to sink in.
13. That’s usually the best time [for a bereavement visit].

The presentation of the patient’s death as a ‘good outcome’ was associated with peacefulness and patient choice (line 1 and 2), the family’s involvement in patient care, (line 6 and 7), and the carer’s peacefulness (line 5 and 6). Also, the specialist medic’s poetic interjection (line 3

and 4) was important to reinforce the appropriate and individualised nature of the patient's death. These moments created a shared understanding around the goals of death, and features like patient choice and family involvement were reinforced. Additionally, the notion of 'peacefulness', the 'rallying' of the carers, and the time taken to let it 'sink in' indicate some of the emotions clinicians privileged in this context: resilience and tranquillity during death, and, in the time following death, grief. The moment enabled the specialist nurse to remind the generalist nurse about the timeframe for bereavement visits. Bereavement visits were home visits to carers after a patient had died. They were a point of closure for both the carers and the nurses and usually involved a nurse discussing how the carers were coping. During case review, palliative care mindline assemblages were reformed with specific allusion to affects such as the emotion rules of clinicians, patients, and carers and the embodied affects connecting individuals to one another in purposeful relationships.

6.3.3 Establishing assemblage limits in case review

Case review was a time for the medics and nurses to establish the mindline assemblages of palliative care, which included emotional performances to delineate mindline assemblages. These emotions could be directed at failure to address patients' symptoms, organisational barriers to effective care, a patient's non-compliance, or workload and fatigue among other frustrating elements of practice. Nurses and doctors at the centre experienced high patient-load along with staggeringly complex patient co-morbidities. This workload exacerbated expressions of frustration and anger, stemming from hopelessness and powerlessness at an ability to act. The following series of conversations surrounded a patient living with spina bifida, one of a class of serious birth defects called neural tube defects. The patient was bedbound living with comorbidities, pain, and chronic wounds. She had been a patient of the centre for a several years, formally as a wound care patient and transferred to palliative care

due to her pain and comorbidities. Specialist nurse 3 was frustrated about how the patients pain had been managed. During fieldwork, specialist nurse 3 arrived one morning distressed with tears in her eyes. I asked her what was wrong:

I'm frustrated about [the patient's] pain management. She is on 50 milligrams of Fentanyl, which is really high and it's still not working. The carers are really inconsistent. She needs full time care. We're just watching her deteriorate. We asked [the specialist doctor] for advice, but she came out and just [arranged the National Disability Insurance Scheme (NDIS)³] and didn't really address the pain. [She] was more worried about the wound care and was wanting [the generalist nurses] to do the wound care every day (specialist nurse 3).

A generalist nurse joined our conversation. Having cared for the patient, she shared her own perspective: 'Every time you get on top of things, they just throw something else at you' (generalist nurse 14). 'Something else' represented the patient's comorbidities and the structural barriers that limited effective care. The patient was described as a 'difficult' patient due to the verbal abuse and demands she occasionally metered out to visiting nurses.

Specialist nurse 3 was assigned to care for the patient. Along with specialist nurse 5, specialist nurse 3 had decided to get the patient's pain under control. They decided that the patient could be admitted to a palliative care inpatient unit, as it had the resources to continually monitor the patient. Two inpatient units were in close proximity: the local public hospital and a specialist

³ The NDIS is an Australian national insurance scheme that aims to support people with a permanent and significant disability that affects their ability to take part in everyday activities. The NDIS had been recently introduced at the time of data collection.

palliative care unit. Despite bed availability at the local hospital, the patient was unwilling to be admitted. Specialist nurse 3 suggested this might have been due to poor experiences with clinicians there in the past. Specialist nurse 3's frustration about the situation came to a head in the case review:

1. Specialist nurse 5: I understand choice, but at the end of the
2. day, we're not going backwards and forward, backwards and
3. forwards for another week. She makes a decision. Either she
4. goes in or she doesn't. She's got a doctor who will accept her
5. into [the local hospital], it may not be...
6. Specialist nurse 3: I haven't been out since, to actually tell
7. her
8. Specialist nurse 5: Yeah but you've sent some emails
9. Specialist nurse 3: Yeah, but I haven't actually been out to
10. visit the patient] to try and tell her that you need to go into [the
11. local hospital] not [the specialist palliative care unit (SPCU)].
12. Specialist nurse 5: Well, there's emails from [the medic] to
13. [the medic stating] 'They need to probably look at [the SPCU]
14. again', but [the SPCU] do not belong to us. They can choose
15. who they admit and who they don't admit, so we need to make
16. some decisions about what we're doing with it. She's either
17. going in or she's not, and if she's not going in then that's okay.
18. Specialist nurse 3: Everybody else that knows her for years
19. goes 'Aw, that's [the patient]'. But I've gone out there [with]
20. fresh eyes. Maybe I'm being conned by her, but she's popping
21. 20 milligrams of Endone and it's not even touching [the pain]
22. so she must be in pain

During specialist nurse 3's description of the situation (lines 8 to 10 and lines 17 to 21) her voice began to break. She audibly and visibly fought back an overwhelming emotion. At the end of line 21, she laughed, either out of exasperation or to ease the tension that her heightened emotions had wrought. For specialist nurse 3, there were multiple pressing concerns in this case including the patient's pain, her susceptibility to being 'conned', the patient's

unwillingness to be admitted to the local hospital, and the SPCU's rejection of the patient. The SPCU staff members were unwilling to admit the patient due to a perception that the patient was not palliative:

1. Specialist medic 1: [The SPCU] is saying no? Who in [the
2. SPCU] is saying no?
3. Specialist nurse 3: Well, [the admitting doctor] originally said
4. yes, but then she [said no]. It turned out when they'd looked
5. at [doctors' admission] letter, the end-of-life plan hadn't been
6. discussed.
7. Specialist medic 1: Why do you need to discuss end-of-life
8. with [the patient]?
9. Specialist nurse 3: Because if you go to [the SPCU] you have
10. to discuss...
11. Specialist medic 1: Yeah.
12. Specialist nurse 5: Yeah, but she's actually quite compos
13. mentis.
14. Specialist medic 1: Yeah, that's what I'm saying, but...
15. Specialist nurse 3: And that's the other thing she said, 'But
16. you haven't discussed end-of-life'. And I said, 'I did but, in
17. [the doctor's] letter, it wasn't addressed'.
18. Specialist Medic 1: Yeah.
19. Specialist Nurse 3: Yeah because if we send them to [the
20. SPCU] they have to... I said it in layman's terms to her.

The patient's designation as a chronic and complex patient as opposed to a palliative care patient complicated admission to the unit. The designation of 'chronic and complex' at the centre represented patients with one or more chronic conditions. The distinction between palliative care and chronic and complex care represented, in this context, the terminal nature of the conditions:

1. Specialist medic 1: Why aren't we discussing end-of-life with
2. her? What's the palliative care? Spina bifida, or...?

3. Specialist nurse 5: She's got lots of chronic conditions as
4. well.
5. Specialist nurse 3: And she's got some shortness of breath.
6. Specialist medic 1: It's going to be hard to discuss end-of-life
7. with somebody who's not [terminal], you know what I'm
8. saying? Not unless there's a terminal condition.
9. Specialist nurse 3: Yeah.
10. Specialist nurse 5: Yeah. But she'd sort of agreed that she
11. didn't want to be resuscitated and...
12. Specialist nurse 3: Because I'd said, 'Look we'd be sending
13. you to [the SPCU] for symptom management' But I said to her,
14. '[the SPCU] has a lot of clients that have a terminal illness so
15. they are going in for that. They have a not for resuscitation
16. policy' I said it twice to her. 'So, basically if your heart stops
17. beating, they're not going to start jumping on your chest'. And
18. I said, 'Would you really want that anyway?' And she said,
19. 'No, I wouldn't'.

The specialist medic's admission that the patient did not have a 'terminal illness' suggested the uniqueness of this patient's context. This was important point for this case as specialist nurse 3 and the other clinicians began to consider the patient's palliative care status. I spoke with specialist nurse 3 informally, along with other generalist nurses again a week later about the situation. Specialist nurse 3 was even more despairing than during the case review, rejecting the notion that the patient was a palliative care patient at all:

Someone should be taking care of these people and it shouldn't be us.
I don't mean to be awful, but it shouldn't be us. We have become a
dumping ground for these really chronic conditions and it's not fair. I
don't have the time anymore to care for real palliative care patients...
The government and the NDIS have failed these chronic patients for
so long (specialist nurse 3)

Specialist nurse 3's frustration and anger clarified some of the limits of compassion and humanistic care. Ahmed (2013) noted how emotions can 'delegitimise' speech by constructing speakers as 'out of place' or motivated by 'negative passion' (p. 169). Specialist nurse 3's self-assessment helped her to recognise her own de-legitimation as an embodied subject as she suggests she might be 'being conned'. However, specialist nurse 3 also used her palliative care identity to legitimise her anger, citing disruption to her role and identity. In Ahmed's (2013) words, specialist nurse 3's emotion moved her, involving 'an interpretation of sensations and feelings... in that what [specialist nurse 3] feels might be dependent on past interpretations... that come before her' (p. 171). In this way, clinician emotions can construct perpetuating boundaries of self-preservation that help them mitigate threats to their identity and work life. This is an allowance for contradicting the patient-centrism and humanism of other assemblages of palliative care. For specialist nurse 3, this was a limit of what could be done as a palliative care clinician and, to preserve her palliative care identity, she needed to identify this boundary. As discussed in section 5.7, there were limits to what clinicians could endure while delivering palliative care. Increasing workloads that deviated from palliative care modus operandi represented a bridge too far for some clinicians as they sort to erect boundaries of what was and was not palliative care. Specialist nurse 3's words also alluded to the misunderstanding of palliative care identity by the NDIS and government. Misunderstanding palliative care as something indistinct from chronic and complex care was a slight by the governing bodies that governed her practice. As a senior clinician, specialist nurse 3 established those limits for herself and others during case reviews and informal conversations with me and fellow nurses. The nurses shared specialist nurse 3's despair and frustration, noting the systemic failures with one nurse calling it a 'broken system'. Specialist nurse 3's colleagues also provided words of care and encouragement. As generalist nurse 14 said, 'You're doing a great job. You are such an amazing nurse [specialist nurse 3]. It's so inspirational for us junior nurses.' Like other

instances of expressed anger or frustration at the ‘system’, patients, carers, or other clinicians, this was a moment of bonding. Clinician hardships strengthened their connections. Moments of frustration were almost always followed by collective care and compassion. Ultimately, though, these expressions of emotions created boundaries of practice, identity and emotion, establishing the borders of mindline assemblages.

During data collection impassive rationality and the relegation of emotions in clinician-to-clinician interactions aligned with physiological or professional mindline assemblages. When clinician emotions were discussed or performed during an interaction, it directed attention towards specific concerns or issues that were, generally, beyond these assemblages, becoming humanistic. In a ‘holistic’ specialty, where patient and carer psychological symptoms and psychosocial issues could be innumerable, this tactic helped to prioritise colleague’s attention. My experience at the centre suggests that emotions during clinicians-to-clinician interaction enabled knowledge sharing. They performatively redefined the boundaries of mindline assemblages.

6.4 Summary

In this chapter, I described how mindline assemblages worked within the social masses of the home visit and case review with particular reference to the emotions arranged within these assemblages. Abstract mindline assemblages as purposeful, working appropriations of the arrangement of ideas, practices, emotions, and identities moved and were reformed within these contexts. This movement was partly contingent on emotions, as clinicians were moved by emotions, and used emotions to move others, establishing boundaries of what was and was not palliative care. In the next section, I explore moments of de-territorialisation and re-territorialisation of mindline assemblages of palliative care in practice.

Chapter 7: Re-territorialisations of palliative care assemblages

7.1 Introduction

In the previous chapters, I presented a description of the observable social organisational forms of mindline assemblages of palliative care, explicated through data. I also examined the fluctuations of assemblages within the home and the centre. Mindlines are representations of the way things ought to work, but often these ideas, which function as structures of reality, are de-territorialised or re-territorialised. In this chapter, I present the lines of flight established between assemblages and the ways these lines are discerned in the varying emotional currents that affect bodies during events. This analysis is outlined as vignettes, as they were enacted in practice, noting the points of flux and difference among changing mindlines in practice. As per section 3.3, this chapter uses the assemblages to think about the ways forces of stabilisation and transformation play out in diverse organisational settings (Duff & Sumartojo 2017). Mindline assemblages were contingent on processes of de-territorialisation and re-territorialisation. If a mindline assemblage was purposeful and ‘joyful’ it remained stable. When an assemblage involved ‘sadness’ or reduced patient or clinician’s capacity, it broke down, becoming a new, differently purposeful assemblages of palliative care. In this chapter, I present vignettes describing clinician attention and action when negotiating de-territorialising and re-territorialising assemblages of palliative care. Contextually adroit clinicians enacted mindline assemblages by appraising patient disease and experience, their multiple identities, as well as their own and their patients’ emotional states. This involved a provisional (re)making of palliative care through labour. The vignettes provide different narratives of assemblages

encapsulating knowledge-in-practice, the emotional foundations for practice, and the associated implications.

7.2 A soft spot

When asked how emotion related to palliative care, generalist nurse 2 described an instance that prompted sadness and shaped her practice. She spoke of visiting a patient at home who had ‘multiple wounds, pressure sores that [were] big and necrotic on his feet and [who was] at home by himself’. The patient had recently returned home from hospital and had been allocated a ComPack – or community package – which can include assistance for personal care, domestic duties, transport, and social support (NSW Health, 2018). According to this participant, this package included showering the patient; however, he had not been showered and expressed ‘despair’ at the situation. She walked me through her thinking and actions in response to this situation, noting tension between her own stress, her clinical role, and the patient’s needs:

I walk in and then [the patient’s friend] tells me that the patient hasn’t been showered since Sunday, but it’s already Friday. It’s been five days... So, I walk in and there was a bit of despair there and the friend said to me, ‘Are you able to help shower the patient?’ And I’m thinking, ‘I’m already smashed by the day, I’m already stressed out [and] it’s my first patient’. So, I just thought, ‘Okay, I’ll help with the wash’. By the time we unstripped him, [I thought] I might as well shower him as well. We gave him a good wash, but at the same time, I was also stressing out. I was so busy. I’ve got all these patients, I’m on the afternoon shift and I was there, showering him, and I was also feeling dizzy myself. But, at the end of it, I felt glad that I helped (generalist nurse 2).

Generalist nurse 2 described the act of showering the patient as an extension of her clinical responsibility. Despite her clinical role, her busy workload, and her physical fatigue, she chose to stay to wash the patient – she chose to care. She described how this act was not the norm in home-based care, and it contravened organisational policy; yet she surpassed what was required of her:

It's just a one-off. It's not our policy to be washing our patients because then, the next time, they'll ask you to shower [them]. But I made it clear to him that that was just a one-off (generalist nurse 2).

The decision to reject the 'policy' to align her practice with humanistic mindline assemblages was impelled by the pity she felt for the patient:

I felt so sorry for him [and so] I would do that for him. But if it had been another patient, I would not [have]. I would have the guts to walk away [and] say, 'I can't'. I felt sorry for him... If you saw my other patient today... that was an emotional one; [but] she was easy to talk to (generalist nurse 2).

Through perceptiveness, pity, and agency, the participant connected with this patient and exercised a humanistic mindline assemblage of care that made a difference. Another patient might have been 'emotional' and this nurse normally would have the 'guts to walk away'. This suggests a stoic rejection of emotion to assert what was and was not the norm, distancing herself from the potentially dominating effects of sadness, aligning with self-preservation mindline assemblages. This was helped by recognising the other patient as 'easy to talk to', suggesting the rapport and comfortability that forms with ongoing psychosocial care. But this patient was different, forcing the nurse to re-territorialise her care.

In this instance, the nurse described, the coalescing, emotion-provoking features of this patient's situation. This situation nudged her towards caring for the patient (and helping the carer) in way that contradicted the policy, as she understood it, but aligned with humanistic mindline assemblages of practice. She immediately connected with the patient given his perceived loneliness and isolation:

[He was] just on his own. [He had] no kids, his wife [had] died, and he's living in a flat. He can't walk, he really should be in hospital. But his wish is to stay at home for as long as he can. He's diabetic. All this, I'm thinking, you just have a soft spot for him. So, I thought that was where emotion played a role. It persuaded my decision-making on what I'm going to do; whether I decide I'm going to wash him [and] I [don't] say, 'Look, I'm here to [just] do the wound' (generalist nurse 2).

Generalist nurse 2 compared the greater imperative of 'policy' with the immediacy of patient suffering. She displayed a cognitive dissonance, equating the importance of both policy and care beyond policy. This dissonance seemed to be temporal, affected by the presence of 'despair' or suffering felt, when compared to generalist nurse 2's perception of the less 'real' policy document. Generalist nurse 2 articulated the effects of the patient's suffering, evoking poetically the notion of softness, or in her words, a 'soft spot'. Having a softness for the patient de-territorialised the intuitional logic assemblages of the policy, rendering it incompatible with what was in front of her. This re-territorialised her care to become something else, something more human, which she acknowledged with metaphoric allusions to the hardened perspective of by-the-book policy and the soft, relational care she provided. A soft body can be prone to injury and easily influenced by others' demands. Generalist nurse 2 harnessed this softness to

embody the humanist and psychosocial elements of palliative care identity present in the centre:

Once you're able to do stuff that [a patient doesn't] expect you to do, that's when you're able to build trust with them. They trust you with your care, with what you're going to do next... If you've done this and that for them, then they're more likely to listen to what you've got to say... It's when you go and help out with the shower when they really need you to, that no-one else probably would; that's when the bond comes back, and they have more trust in you. They feel like you're actually being a nurse from their perspective (generalist nurse 2).

She articulated her connectedness to the patient, using it to foster trust, alluding to the rapport mindline assemblages and the 'efficiency' enabled in those assemblages. Feeling sad and allowing oneself to be soft, if not vulnerable to the injury of despair, helped to create agreeable interactions between clinicians and patients, thereby easing care. The decision to shower a patient might seem trivial in a greater medical context. However, in the context of community-based palliative care, it demonstrated how different knowledges – including (but not limited to) that about: palliative care identity, the organisation responsible for delivering it, as well as the personal experiences of clinicians, patients, and carers – were assembled within the patient-clinician relationship in purposeful ways. In this and other instances, organisational articulations of practice such as policies and guidelines were only as useful to nurses as the specific instances dictated. This aligns with Gabbay and le May's (2004) exploration of mindlines. Yet Gabbay and le May did not elucidate the emotional nature of this discernment. Nurses, like this participant, used their judgement, often based on emotional evidence within the patient interaction, to re-territorialise policies and guidelines to become other assemblages, aligning with humanist or rapport fostering mindline assemblages.

7.3 Put your feelings aside

Gabbay and le May (2011) articulated how clinicians' day-to-day roles involved negotiating multiple, competing roles and priorities, balancing, for instance, organisational and therapeutic responsibilities. Fieldwork enabled me to recognise how the different mindline assemblages were enacted and, in some cases, negotiated and modified by individual nurses in their practice. This could involve co-opting multiple mindline assemblages at once to achieve varying goals, for instance, building rapport, eliciting physiological information, and acting professionally. Co-opting mindline assemblages was shaped by patient, carer, and clinician emotions, as they felt their way through complex interactions. The ensuing vignette explicates the thoughts and actions of a nurse who juggled competing mindline assemblages with the immediate demands of patient and carer emotions. The nurse's approach reflected that of her colleagues as they visited patients in their home – they similarly straddled familiarity and professionalism, at one moment enacting humanistic and rapport building mindline assemblages, and in the next maintaining professional mindline assemblages. The features of the visit resonated with the paradoxical practices and emotions entwined in respectful distance and familiar closeness within the home visit, illustrating the shifting assemblages of palliative care and co-opting particular 'moments' to provide different kinds of care.

As we arrived at a patient's home, specialist nurse 4 noted that the patient had throat cancer and a tracheotomy and consequently found it difficult to speak. Most of her communication with this patient was via the patient's wife, who was also his main carer. We were welcomed by the patient's wife, who warmly hugged the nurse, and escorted us into a dining room where we sat at a dining table. The patient joined us from an adjoining room and greeted the nurse with a warm embrace, who asked how he felt. As the patient sat at the head of the table, responding to this query, the nurse proceeded through steps of a patient interaction that I had witnessed before. She asked about: the location and intensity of his pain; his medication; and

the regularity of his bowel movements. As the nurse had foreseen, the patient's wife, who seemed well-versed in her husband's situation and the palliative care routine, served as the conduit for this consultation.

Despite the nurse's clinical responsibilities during this home visit, she was calm. She later remarked that she found this home visit 'comfortable', which had been established through long-term contact with this patient and carer:

I think it helps that I've been there before... they know me, so it's like
[imitating patient], 'Hi, come on in' (specialist nurse 4).

Despite her relationship with this patient and carer, as demonstrated by the hugs and kind dialogue, this participant exerted a polite, distanced presence. She politely introduced me at the outset of the home visit, awaited invitation to enter the home, and inquired if she could sit at the table. She paid attention to everyone present, specifically looking at, speaking to, and touching the patient, despite chiefly conversing with the carer. The participant asked for the patient's and carer's permission to explain his symptoms to me.

This participant eventually asked about the patient's tracheotomy wound. The carer shared her concern with its smell. She recounted the patient's hospital-based doctor indicated the smell would not abate, becoming irate as she described the doctor's dismissive response. The carer said, 'It's important to us so he should take it seriously and not act like it's not important.' The patient, unable to speak, nodded while the carer spoke, signalling his agreement. The carer referred to the doctor's race, using it to explain the doctor's callousness to their concerns. Although the carer later downplayed this reference, it influenced the nurse's response, as she attempted to recompense for this perceived disregard: 'I'm very sorry that you had to experience that. It must have been very frustrating for you' (specialist nurse 4). She then explained that the smell emitted from the tumour. The nurse suggested that the doctor may

have been confused with the concerns of the patient and carer, and was focusing on the smell as a sign of infection, which it was not. She explained that, to test for infection, a doctor would swab the wound and test the swab. According to the carer, the doctor had not explained the protocol and expressed gratitude to the nurse for her ability to respectfully address the concern. Specialist nurse 4 was new to specialist palliative care, having recently transitioned from being a generalist nurse to a specialist role. This nurse's transition to a specialist nurse enabled me to witness how a palliative care identity evolves. During our time together, we discussed her perceptions of palliative care. Although she described palliative care as involving a wide remit of activities, it primarily involved managing patient and carer emotions as they lived with a life-limiting illness. In this vignette, specialist nurse 4's performance of empathy is arranged within a humanistic mindline assemblage. By acknowledging and empathising with the patient and carer's experience, this specialist nurse was arranging the emotional state with non-physiological concerns. The nurse later recounted her thoughts to me, noting the doctor's clinical focus, rather than a concern for the other-than-physiological problems of the smell. The separation of these two elements in the nurse's account was an important feature of the care provided. During the interview, she described her attention to both the carer's concerns and the doctor's appraisal. The nurse noted a need to modify how the information was communicated to ensure she did not follow the doctor's mistake and not communicate a rationale:

In a way, I'm trying to say to her, 'Look, sometimes the doctors could be right. It's not because the doctor didn't listen to you, but maybe the doctor was not concerned enough. If it's just the smell and it's not supported by any other signs that would indicate infection. Then that's probably the reason they didn't do anything'. But I don't want to say it straight to her. I had to educate her that these are the signs of

infection and there's a smell because your husband has cancer in his oesophagus. So that's when I educated her with the signs and symptoms of infection, and she was happy (specialist nurse 4).

This negotiation represented a tightrope that I saw many nurses and medics negotiate. Balancing the 'hard truths' of physiological mindline assemblages that, at times, impeded other kinds of care, with the carer's and patient's feelings and temperament. In the nurse's case, a physiological mindline assemblage was central to decision-making, particularly regarding the patient's resistance to antibiotics:

If the doctor keeps giving [the patient] antibiotics, then [he] can become resistant to it and when the time comes that he's got a real infection, his body is resistant to the antibiotics (specialist nurse 4).

For the nurse, it was important to co-opt this clinical reality with rapport and humanism, maintaining (if not salvaging) the doctor's perceived credibility:

You are educating the family and you are giving an assurance to the wife [so that] she will have her trust back to the doctor and she will not feel like the doctor isn't doing anything (specialist nurse 4).

For this nurse, maintaining the doctor's credibility represented a professional mindline assemblage: one of 'acting on behalf of the service':

We're all working together. Even if you could be working in the hospital, you work together. It's still a collective service. So, I don't like to exaggerate it and say, [voice changes to high-pitch, mimicking sympathy] 'I know, that's how [doctors] are' because that way I'm putting them down. It could be that they're just busy; that's why they don't have time to explain and it could be a chance for me to explain

it. That's when I'll take the opportunity. I don't like that other clinicians will put more fuel into the fire. It's pretty much building on the service (specialist nurse 4).

The nurse articulated a camaraderie with other clinicians beyond palliative care, nursing, and the centre. Despite the differing location and clinical role, she noted that her duty included defending and building the 'collective service'. Specialist nurse 4 view the service as 'all the people that [the patient and carer] come in contact with' in health care. For her, this collective required an empathetic and caring façade, to ensure continuity of care and to 'build' on patients and carers positive perceptions of health care.

She compared her practice to that of 'other clinicians' who 'put fuel on the fire'. Her statements suggest others failed to defend their colleagues both within and beyond the centre. This might be because 'other clinicians' valued rapport with patients and carers more than the professional mindline assemblages of the centre. The nurse's perspective encapsulated a tension in a clinician's responsibility to the patient, the carer, and the collective service. Her actions during the home visit embodied this tension, instructively. Despite the important clinical reality and her defence of the 'collective service', the nurse needed to ensure rapport and acknowledgement, so the patient and carer did not feel dismissed:

The patient is really voicing frustrations. They want to be heard; they want someone that will listen to them and will entertain their complaint... You've got to acknowledge what they're saying; what they're concerned about (specialist nurse 4).

The specialist nurse spoke of the connective materiality of transferred emotions across the patient-carer-clinician assemblage. In this excerpt, the movement of frustration from patient and carer to clinicians is only productive if it is received and entertained, rather than rejected.

Rejection of patient frustration was alternatively productive in self-preservation mindline assemblages, where clinicians avoided ‘taking on’ the negative emotions of patient. But for this nurse here, the patient and carer’s need to be heard related to a humanistic mindline assemblage. Despite her defence of the doctor and the system, she acknowledged the need to give voice to patients and carers who are often left voiceless during their experience with the health system. The participant co-opted the agential capacity building of humanistic mindline assemblages in deference to a professional mindline assemblage.

This nurse’s experience with the complaint explicated the tension between professional imperatives and the patient and carer’s emotions for nurses at the centre. Her motivation to ‘build on the service’ was extended beyond the centre to other clinicians. This nurse acknowledged this during an interview in which she included the non-palliative care doctor in the ‘collective service’ that was provided to the patient and carer. For this nurse, negotiating the patient’s complaint also stemmed from the humanistic mindline assemblages. Her demeanour in the home and our conversation thereafter suggested sensitivity to patient suffering, which shaped her actions. For instance, she described palliative care as requiring an attention to patients’ and carers’ ‘emotional burden’:

[Their suffering] is giving them a lot of emotional burden. They’re not able to do the things they love to do. In that way, you are more sensitive to that and when you talk to them you are aware of the situation and you’re more careful about what you say. You don’t want to hurt them more. You’re trying to be there to support them, but not in a way to make them remember what they’re going through again. I try to be positive when I see palliative care patients. I try to tell them the positive things that they’re able to do (specialist nurse 4).

Hope and hopefulness are signifiers of palliative care, represented in the diverse mindline assemblages of humanistic care, rapport building, and death and dying care. By directing attention away from what patients were ‘going through’, the nurse attempted to moderate patient suffering. She later described palliative care patients as ‘precious’, given their fragile emotional states. As a palliative care nurse, her role was to minimise negative emotions – and this required tacit knowledge:

When the patient is down, obviously I have to respect that, then I’m a little bit more: ‘Okay, I will sit down next to you and I will listen to your concerns’. And sometimes I will just listen; I just sit down next to them and listen to what they say (specialist nurse 4).

The duality of professional and emotional practices arose several times during fieldwork, evoking my distinction between humanistic and professional mindline assemblages. During our interview, specialist nurse 4 articulated the tension between emotional practice and professional practice, suggesting a dichotomy:

To be a professional, sometimes you have to put your feelings aside. But that doesn’t matter; you can always go back and draw on that feeling because that’s what actually makes you a better clinician (specialist nurse 4).

Here, the participant juxtaposed the two, suggesting their incompatibility. She also alluded to the consistent nature of emotion in palliative care, as something ‘you can always go back and draw on’. This is an evocative portrayal of using emotion to re-territorialise palliative care apart from the clinical, emotionally detached forms arranged within physiological and professional mindline assemblages. The specialist nurse commented further on that nature, citing the inevitability of sadness:

Sometimes you feel sad, but it's human nature. You feel sad for you patients. But then, you still have to act professional[ly]. Sometimes you hold back on [emotion]. [The patients and carers] are leaning on you. They expect to be happy all the time. And that's one thing they all say... 'You're always happy'. [I'm] like, 'Not really' [laughs] (specialist nurse 4).

This excerpt provides another account of the multiplicity of emotions arranged within palliative care, the emotional detachment of professionalism, the emotional labour of rapport, and the reflective nod to self-preservation. According to this participant, palliative care involved relegating her own emotions, particularly sadness, for patient and/or carer benefit. Like other participants, she said sadness negatively affected patients, carers, and clinicians. It stemmed from lost capacities and affects – the loss of a previous (pain-free) lifestyle; the loss of mobility and independence; an impending loss of life; and the loss of connection with loved ones. Returning to Deleuze's (1988) reading of Spinoza, we can see a vital parallel with the notion of 'sad' relations, those that decrease our power to act and experience. Instead, this specialist nurse worked towards a 'joyful' combination with patients, accentuating their capacities through active labour.

This nurses' comments denote emotional labour in practice and align with specialist nurse 4's perspective. Nurses acknowledged the performative aspects of their emotional labour, validating acts such as looking interested, laughing at patient jokes, or ignoring patient complaints, despite feeling sad, frustrated, uncomfortable, or angry. They described these performances as part of their core role, driven by the mindline assemblages of rapport building. Rather than stating it was how they acted, clinicians regularly identified these practices as 'who we are', suggesting a deep acting emotional labour.

Specialist nurse 4's home visit presented a unique view of the interaction of multiple, competing mindlines assemblages during a home visit. Specialist nurse 4 was required to juggle the demands of rapport building and comportment in a patients' home, with her obligations to professionalism and clinical camaraderie. My interview with specialist nurse 4 clarified her use of emotion as a resource to manage competing mindlines. Moments of 'professionalism' as opposed to moments requiring emotions were, for her, assessments contingent on perceptions and feelings related to patient suffering and emotional burden.

7.4 The right thing

In the preceding section, I explored how clinicians considered the dichotomy between different mindline assemblages in practice such as professionalism and rapport. Similar to this tension were the conflicts between humanistic mindline assemblages and legal imperatives represented as institutional logics. As I described in chapter 5, humanistic mindline assemblages and intuitional logic mindline assemblages were often at odds in palliative care. This dissonance produced frustration for some clinicians, as they witnessed a system failing to meet their standards of palliative care common sense. While shadowing, I discussed the dissonance between legal regulation on cannabis use and the realities of practice with a specialist nurse. The dissonance between the legal priorities and humanistic palliative care values was challenging for the nurse, as she contended with the suffering of the patient.

I sat in the fleet vehicle with specialist nurse 5 as we pulled out of the driveway. We had just visited a patient with mesothelioma experiencing painful migraines and intense headaches. She had been prescribed the opioid analgesic, Endone, and was taking it regularly, but it was not helping relieve her pain. During the home visit, the patient had initiated a discussion about cannabis use to help manage her symptoms. She had done her own research about its effects for patients experiencing her symptoms and was frustrated about not being able to acquire it

legally in Australia, despite it being legalised in some states of the United States. I asked the specialist nurse about her impressions of the home visit. She began by noting the patient's pain, her anguish, and her isolation:

She's quite a depressive type person. She's got that depressive personality, but she's been like that for a long time, before she even had the diagnosis. I don't think she had a lot of friends. She had a family. She had a mum that she cared for, dad that she cared for, and nobody else really did anything. She was married, she was pregnant and miscarried and then never had any more children, never fell pregnant again... It worries me because she doesn't really have a supportive network that, if she starts to deteriorate, then what? Nobody will be there for her because nobody's there now (specialist nurse 5).

This nurse's emotional response to the home visit was palpable. Her 'worry' about the patient's limited support network created a prominent attachment to this patient, as it represented impending suffering. During the home visit, I too was frustrated and saddened by the patient's pain, social isolation, and depressive manner. She seemed hopeless, begrudgingly accepting her life of pain, alone:

Michael: She does seem in so much pain and anguish.

Specialist nurse 5: And it's more like a psychological pain, isn't it?

That's what I think; it's more psychological.

Michael: Yeah, just at the end of her tether a little bit.

My emotional resonance with the specialist nurse in this moment seemed to foster a reaction from her. After acknowledging the patient's 'sadness' and 'psychological pain' the specialist

nurse began an angry diatribe at the patient's inability to procure cannabis, evoking an emotive plea representing an ethics of care inclusive of cannabis use for patients:

She's trying to do the right thing all the time. Like, really, I'd go out and buy fucking cannabis... I wish there was a source that you could go and bloody say to people, 'Go and buy it from here because at least it's reliable'. But you can't even do that because I don't know anybody that grows it (specialist nurse 5).

Despite acknowledging that it was not the 'right thing', the specialist nurse's anger was intended to articulate the 'common sense' of procuring cannabis by whatever means necessary. The willingness to skirt legal boundaries to procure cannabis highlights a discord between the values of palliative care, as understood by the nurse, and the values of the legal system. For this specialist nurse, the legal barrier to cannabis use represented the arrested development of Australian institutions to act in the best interests of people who suffered:

Really, it's just a plant like any other plant. It's like dioxin or aloe vera. Why is it that we can grow aloe vera, but we can't grow marijuana? In America, they do prescribe it. So, why are [American clinicians] prescribing it there and why are we going through all this shit to get it? ...I just want to know why [Australian health and legal authorities] have taken so long to do anything with it. They've taken forever. And that's the problem. It must be so frustrating for people. And if that was my family, I'd just go fucking buy it (specialist nurse 5).

Negotiating the dissonance between the organisational, or in this case, legal, priorities and humanistic palliative care mindline assemblages was challenging for this nurse, as she witnessed first-hand the suffering of the patient. The rhetorical questioning displayed her

incredulity of decision makers to not make cannabis legal for people suffering. This signposted her ideals of disassociating legality from assemblages of good care.

As the aforesaid exemplar illustrates, the desire for cannabis legalisation suggested an emotionally provoking mindline, reflecting the wider discourse of humanistic care. The notion of cannabis use for symptom management was valued by clinicians, and government and bureaucratic constraints around cannabis use generally angered them. Cannabis use as a topic of discussion in the centre involved tension between different forms of evidence for doctors and nurses. At the time of data collection, the NSW government was conducting clinical trials on cannabis products, exploring the use of cannabis and/or cannabis products in providing relief for patients suffering from chemotherapy-induced nausea and vomiting, and for symptom relief for those with terminal illness. These trials were well known to the palliative care team at the centre and provoked mixed reactions. They were at times perceived by nurses as necessary to solidify the evidence on cannabis use for palliative care patient. Alternatively, nurses stated their belief that the trials were politically motivated time wasting, or redundant considering the research conducted already in North America.

Conversations between nurses about cannabis use provoked interesting reactions as the tension between the immediate patient suffering warranting introduction of cannabis treatments and the evidence to date became apparent. During one discussion of cannabis use for palliative care patients, a specialist nurse rebuked the group present who were discussing the benefits of cannabis, with research she had read on the purported limited abilities of cannabis to be a ‘wonderdrug’ and the haphazard ways it was accessed and used. Despite this most participants felt strongly about the legalisation of cannabis for their patients, and the expression of these feelings shaped both attitudes and practice. While this didn’t manifest in direct procurement of cannabis for the benefit of patients, nurses and doctors spoke how they would not discourage people from trying cannabis as long as it would not interfere with the medication they were

already taking. They acknowledged that, despite the legal barrier, cannabis use could be a potentially beneficial drug for palliative care patients.

Emotions, particularly those related to suffering or despair, experienced during patient and carer interaction resonated with humanistic mindline assemblages prompting nurses' actions. The absence of emotion didn't necessarily suggest departure from these mindlines, but emotions described as felt or experienced during a patient interaction seemed to increase attention to the values underlying patient agency and a logic of care. These resonances suggested the importance of a knowledge translation vehicle that acknowledges the emotional, the experienced and embodied nature of actions that have consequences for individual patients and carers. While policy, guidelines and legal requirements remain important, they are not always in step with what a patient or carer wants or needs in every interaction. For instance, the reactions to cannabis use represented a discord between an institutional logic mindline assemblage, which could represent all sorts of perceived governance and oversight, and humanistic mindline assemblages fostered at the centre. Here the 'common sense' aligned with collective mindlines of practice was vital to caring in a way that was compassionate and, according to the nurses themselves, effective.

7.5 At peace

One incident I witnessed prompted insight into the relationship between emotion and mindlines in the context of death and dying. This incident exemplified similar participant experiences as they managed their emotion while patients were dying and/or had died, and as families made sense of these experiences. Upon arriving at the centre, I was informed that a specialist nurse was preparing to visit the home of a patient who had died overnight. I met specialist nurse 2 as she prepared to leave the centre, noting she was visibly upset. We went to the fleet vehicle she had booked and, as we buckled our seatbelts, I asked her about the patient. Through tears, she

recounted the situation: a relatively new patient to the centre had died overnight and his niece had informed the service that morning. As the patient's GP was not available, the death certificate was yet to be signed. Consequently, the patient's body remained in the home on a hot summer day, nearing forty degrees Celsius. The niece indicated she was 'not coping' with the death and the specialist nurse decided to visit the patient's home to offer help and support. This incident occurred against a backdrop of shifting policy within the Local Health District regarding the assessment and documentation of a patient's death (see section 5.6.3). There were stringent regulations pertaining to the collection of a deceased body by funeral directors. Specifically, a death certificate was required, endorsed by an accredited clinician once death is confirmed. From the specialist nurse's perspective, her inability to endorse a death certificate was an ongoing 'failure' of an institutional logic mindline assemblage:

With palliative care, we know that he is going to die at home, so we have to ensure that the services are in place... [But] there were complications from the very start of the referral we received, and then we also had an issue from a GP visiting at home as well (specialist nurse 2).

At the time, this participant expressed a more visceral, existential articulation of how she, the service, and the District had 'failed' this patient:

I just don't know what we are doing sometimes. We have done everything wrong by this patient as soon as he was discharged. And now he's lying at home and we can't do anything about it (specialist nurse 2).

For specialist nurse 2, an ambiguous de-territorialisation occurred that, rather than offering new possibility, destroyed the planned good death. What she could 'do' for the patient became

lost as the assemblages of ‘good’ palliative care broke and became something chaotic she could not reason with. The affective loss of freedom and action was mitigated by the institutional logics of dying at home failing the patient.

As we drove to the patient’s home, the nurse talked about the patient and what was so emotionally troubling for her about the situation. She recounted, with ‘frustration’, the mounting inadequacy of the ‘system’ to meet this patient’s needs as he was discharged from hospital. She referred to the rapid progression of his disease and the difficulties of acquiring the equipment he needed to die at home, as ‘out of control’:

There was an issue with referral, a confusion between chronic care and palliative care. The family members had to rent a bed, which, according to the receipt that I saw, was \$999 for the three days... It just makes me think that, knowing he has a clear goal, knowing that our goal is to keep him at home for as long as we can – but because of the other issues, things just got out of control (specialist nurse 2).

She connected her personal inability to rectify the issues that plagued the patient’s journey with the institutional mindline assemblages that hindered patient care. These included the poor discharge process, the limited communication between community health, primary care, and homecare services (among others), and most notably, her inability to verify the death. For this participant, the peripheral factors to this incident accentuated her emotional reaction to this patient’s death, particularly because the patient had lived in his house for his whole life and wished to die at home. The failure to ensure a smooth procedure following the patient’s death provoked frustration and despair:

We know... the patient wishes to die at home – he said that he was born in, and lived in that house for the last 82 years – so our goal was

to make sure he died at home and our role as a palliative care nurse is to ensure that there is a GP that is able to come to the house and to complete a death certificate (specialist nurse 2).

This detail imbued the incident with added emotional weight as the specialist nurse reinforced her desire to ensure the patient had a good death.

When we arrived at the house, the specialist nurse took a moment to calm herself. She talked through the emotional labour involved in presenting a composed front for the patient's family, stating a 'need to be strong for them'. We walked to the house and were greeted by the patient's niece along with other family members. I felt the anguish of the family and, knowing specialist nurse 4's feelings of powerlessness moments earlier, I was uneasy about how our presence could help their understandable frustration with the circumstance. The participant's interaction with the patient and his family, and her movements through the house belied her disposition moments earlier. She manifested as a confident nurse, ready to attend to the needs of the patient and his family. She first hugged the family members and inquired about their feelings. Then she made her way into the patient's bedroom, placed her hands on his body, and began speaking softly to him. Later, these actions took on a profound clinical significance when the participant recounted her thinking as she assessed the situation, in which a humanistic assemblage was co-opted to become a physiological assemblage of care:

At first, I saw that he wasn't in a bad shape, but he wasn't the best at all, as he was leaning to the side. His leg was sort of pushing against the bed. He was a bit low on the bed and the bed was wet, as told by his niece (specialist nurse 2).

While in the home, the specialist nurse advised the family members to contact the funeral director (to inform them of the situation) and organise another GP to verify the death. As the

participant took control of the situation, the mood of the home visit shifted, and I felt the process of re-territorialisation in flight as the nurse made her presence purposeful. Her ability to shift the mood of the home into a productive, positive space was remarkable. She did this by directing members of the family to productive tasks like contacting the funeral home, or helping her attend to the patient's body, by reassuring the niece and family members that the patient's death was peaceful, and through continuous positive affirmations of the patient's life, home, and family. The uneasiness I felt dissipated quickly as she undertook these tasks, and I became attentive to the effect this had on specialist nurse 2 herself.

While they waited for the GP, the participant informed the niece that she would wash and change the patient, a practice which she later referred to as 'after-death care'. This involved bathing the patient with a wet cloth, changing his soiled underwear and clothes, and attending to his oral care. She performed these acts in, what I noted at the time, a spiritual manner. She moved slowly, as if performing a well-formed ritual, speaking softly to the patient and the niece as she helped. As she finished the rite with a spray of the patient's aftershave, the participant remarked that he looked 'at peace'. Her tone of voice, posture, and facial expression conveyed a calm joy. The metaphor of the patient's peace mirrored her own, following the tumultuous 'battle' of her previous emotional states. The GP arrived soon after and verified the death. With a funeral home representative on commute to collect the body, the participant said goodbye to the family members with hugs, stating she would contact them in the coming days to inquire as to their emotional states.

Leaving the home, the participant was visibly satisfied with the visit. She later described her feelings to me, verifying peace and joy:

Knowing that he's at peace, it made me feel so relieved that I'm able to help him in that sense, even though it's something that I wouldn't have expected since the last time that I attended to [after-death care

was when I worked] in the hospital. But, having done that, it makes me feel a lot better, makes me feel that, okay, this is all I can do (specialist nurse 2).

This relief came from the participant's perceived sense of purpose for the patient and the family. It also came from her renewed sense of value for after-death care following a potentially negative experience as a hospital-based nurse. For this nurse after death had become a worthwhile purposeful mindline assemblage. This statement reaffirms how the immediacy of emotion can (re)shape new mindline assemblage territories, appropriating practices that count as valuable or purposeful for patients, carers, or clinicians. The specialist nurse assumed the family members recognised value in the 'after-death care' she provided (as she did not explicitly ask them) – and this presumption reinforced to her the worthiness of her performance. But it was also for the clinician herself, to establish her own worthiness as a clinician in this tumultuous time. The need to justify community-based palliative care, and the participant's capacities to the patient, the family, herself and perhaps me, as an outsider, aligned with the perceived importance of self-preservation mindline assemblages:

It was [an] opportunity to help him, to show the family that this is what we're able to do... At that time, we could see the family appreciate and see him, that he's at peace, well-prepared (specialist nurse 2).

As I sat with the participant at the centre following her day's work, she contacted the niece:

I just contacted the niece to see if the funeral guy had picked up the body... It has been picked up already... Now it's a matter of organising another visit after the funeral; maybe when the family's settled with the grief and we do what we call a bereavement visit. So, that's when

we go in to see if they need any extra help that we can supply for them
(specialist nurse 2).

Over several interviews, the participant described the incident as frustrating and confusing, rectified through calm appraisal of the patient and family needs, and practices to dispel or release negative emotions:

I became emotional this morning, right? And the opportunity to just get there and help him and let it all out, it was just, that's it (specialist nurse 2).

The emotionally-destabilising, de-territorialising nature of this home visit provoked a process of re-territorialising purposeful practices within the fluctuating social mass of a home. It was fuelled by peripheral influences, such as mindline assemblages of a good death and perceptions of limited support for the patient and family members from a variety of fronts. During the home visit, the nurse pushed aside these circumstances and attempted to expel or 'let... [them] out' during the after-death care she offered. The personal significance for the specialist nurse of caring for a body had been intensified by bearing witness to its effects on her and those close to the deceased. This emotional reaction informed her decision to rethink care for the body during a tumultuous incident, which threatened her faith in her profession.

Specialist nurse 2 represented the incident as an initial frustration and challenge, brought on by organisational inadequacies. The incident was personally managed through inward reflection, with the determination to 'do what we are able' for the patient and family members. This incident captures a team narrative of a nurse repurposing or reassembling palliative care following a breakdown, or, doing what they could despite the challenges they faced. Perceived barriers included (but were not limited to): mismanagement, absent or misguided policies, conflicting actions among different clinicians who cared for the same patient, and limited

resources, including time. The incident reflected a reaction to these de-territorialisations of palliative care, marking shifts among mindline assemblages. Incidents like these were a rallying pose for frustrated nurses to cling to, shaping emotional reactions and energy from a derision of institutional logics to pragmatic actions for the benefit of patients and family members. The incidents of emotion labour representing these ideals were apparent when nurses and medics composed themselves for a home visit after venting to me about mismanagement and disconnected services. Later, the specialist nurse articulated how this experience altered how she would approach future instances:

What would I [do] if I came across this issue again?... Act on it faster – knowing that he’s at risk to go at any time throughout his journey... taking the time to step back a bit and think, ‘What I can [*sic*] do for him right now? What can I do for the family right now?’ Taking a step back and taking time to prepare the body. I found... it’s sort of therapeutic (specialist nurse 2).

She spoke of her own decision-making as a re-territorialising process, articulating the movement involved: ‘step[ping] back’ and determining what was likely to be beneficial for the patient and the family. Here, she evoked a renewed sense of emotional labour, moving away or shunning her emotional position to consider her practice, pragmatically. Paradoxically, as I saw it, this emotional detachment, evoking professionalism, belied the emotional motivations that made her practice so effective in that instance. What I suggest instead is that the emotion rules shifted from the context of *in situ* practice, where it was acceptable to be affected by patient death and allow that affect to become productive in attending to the body and the carers. In my conversation with this nurse, her own emotion rules dictate an absence of feeling, or at least a relegation of feeling. These contradictory embodied and emotional positions were contingent on the context and moment, and the prospective affective capacities of her as a

professional, as a clinician, and as a human capable of powerful emotion. Emotion as a productive force was only available when that productiveness could be embodied in actions.

This incident shaped how the specialist nurse considered and practiced after-death care. As with the other incidents described in this section, her consideration and enactment of policy were shaped by and negotiated through her emotion. For this participant, the needs of patients and carers were priority because of their perceived suffering. She drew on the humanistic and death and dying care mindline assemblages, necessitating empathetic practice centred on the patient and carer. Emotions guided this nurse's actions and her identity as a palliative care clinician, despite the conflicting managerial and organisational barriers she faced. Instances such as this, heightened the importance of positive deviance, as nurses regularly perceived institutional logics as discordant with a palliative care identity.

7.6 Summary

In this chapter, I have presented mindline assemblages in action, outlined as vignettes, noting the points of flux and difference among changing mindlines in practice. The processes of de-territorialisation and re-territorialisation within these vignettes explicates the constantly shifting identities and priorities within a palliative care encounter. The shifting of emotion rules across a single interaction within these processes align with different ways of conceiving palliative care and different practices. Emotion was described as a motivator, a barrier to palliative care, and a way to improve care by enabling greater perception and acknowledgment of patient need. In their day-to-day actions I found that clinicians arranged emotions with different kinds of knowledge to divine practice. Emotion was a catalyst for how care was enacted and what practices were privileged in the 'here-and-now', shaped by the collective emotional position in relation to the organisation and the system(s) they were in.

Chapter 8: Discussion

8.1 Introduction

In the previous chapters, I have presented mindline assemblages as complex, virtual arrangements of materials, ideas, and desires and explored how these mindline assemblages ‘work’ in practice. This is a contribution to the processual turn in organisational studies by using the Deleuzoguattarian notion of the assemblage to illuminate the processual nature of knowledge translation in palliative care. The processual perspective clarifies the mutual shaping between the ‘material’ and the ‘social’ when considering how emotion affects knowledge and practice. In chapter 5, I presented the mindline assemblages prominent in clinicians’ conceptualisations of community-based palliative care that shaped practice. In chapter 6, I explored the movements of mindline assemblages generally within the home visit and case review contexts, explicating the contingency of emotions as a constituent part of these movements within the social. In chapter 7, I presented the lines of flight established between assemblages. I described the ways these lines are discerned in the varying emotional currents that affect bodies during community-based palliative care as vignettes, noting the points of flux and difference among changing mindlines in varying emotional contexts. In this chapter, I discuss my findings, highlighting my contribution to knowledge, the implications of my findings for theory, research, health services, and practice. I also outline the limitations of my thesis and propose future directions for subsequent research.

8.2 Contribution to knowledge

My thesis contributes to organisational scholarship by applying the assemblage to describe observable social organisational forms and forces of stabilisation and transformation in health

organisations. Novel to organisational studies is the use of the assemblage to situate emotion with knowledge translation. I attended to how emotion and mindlines were typically arranged together and how mindlines were transformed in the diverse emotional contexts of community-based palliative care. First, I reconceptualised mindlines as assemblages of ideal practices. Second, I clarified how emotion is bound within mindlines of practice. Third, by describing processes of de-territorialisation and re-territorialisation within critical incidents, I explicate the constantly shifting identities and priorities within a palliative care encounter. In this chapter, I unpack each contribution to knowledge, referring to extant literature.

8.2.1 Mindlines as assemblages of ideal practices

Understanding how knowledge is arranged and transformed with emotion is vital to organisational theory and practice in health service management, where a prevailing ontological hegemony of EBHC struggles to account for the application of findings in messy contexts (Greenhalgh 2013; Wieringa et al. 2018b). My foremost contribution to knowledge is in the form of reconceptualising mindlines, through the analytic lens provided by Deleuze and Guattari (1987) as mindline assemblages. This contribution was borne out of a fundamental need to address my research objective, asking how palliative care mindlines work in varying emotional contexts. To consider this required an ontological framing of my analysis of the heterogeneous elements of emotions and knowledge translation, illuminating the conditions that arrangements of emotion and knowledge were made possible. Assemblage theory provided a conceptual and an analytic approach to map the logic, or ‘operational sense’ of emotion and mindlines (Buchanan 2017, p. 463). Organisational scholarship has demonstrated the value of Deleuzoguattarian principles, namely multiplicity and becoming, to critique linear models of knowledge delivery as part of the processual turn in organisational theory (Bissola, Imperatori & Biffi 2017; Gherardi 2003; Lawley 2013; Wood 2002). Although scholars have applied these

principles to organisational knowledge management, they are yet to be applied to health service management and knowledge translation. I have bridged this gap by contributing to the concept of mindlines using the concept of the assemblage to describe how mindlines are composed and fluctuate, to integrate this scholarship in healthcare research and practice.

My framing of mindlines as mindline assemblages removes none of the original authors' intention for mindlines. The interpolation of assemblage theory and mindlines, rather than alter Gabbay and le May's (2004) original intention to understand and describe socially shared knowledge and embodied patterns of behaviour, presents opportunities consistent with this aim. Mindlines were conceived to widen the perspective of evidence-based medicine to include 'socially constituted knowledge' (p. 4) that is continually co-constructed (Wieringa & Greenhalgh 2015). The continual co-construction of knowledge aligns with a Deleuzoguattarian approach that establishes material entities, forms, spaces, and territories as 'objectively changeable... undergo[ing] destabilising processes affecting their materiality, their expressivity or both' (DeLanda 2008, p. 164). Similarly, Gherardi (2003) described knowledge as both 'social and material' (p.352). He compared organisational knowledge to mythos, which operates by 'establishing social bonds among different persons, generations and different contexts of use' (p.353). Mindlines are a combination of explicit, tacit, and practical knowledge. Assemblage framing prompts us to consider these diverse elements within their political, social, and emotional context. Within assemblage theory, we can consider mindline assemblages as being constantly (re)made as new materials, ideas, 'evidence' and, importantly for my thesis, emotion, come to be arranged within them. My exploration of mindline assemblages moves across the individual and the collective as I explored a 'common (and often emotionally laden) group identity that is shaped and reinforced through group interaction' (Wieringa et al. 2018a). Mindline assemblages also keep with the enduring definition of mindlines as knowledge-in-context-in-practice. Thinking mindlines with assemblage theory,

according to Deleuze and Guattari's (1984) account, prompts both questioning 'where [knowledge] comes from' and 'how [knowledge] works' (p. 109) in specific contexts.

In my thesis, I presented an analytic approach to examine mindline assemblages that allows the development of a normative account of knowledge-in-context-in-practice. Bringing this processual turn to knowledge within health services might transcend the limited plane of organisation that EBHC currently sits within, moving closer to a plane of immanence that allows experimentation and freedom for clinicians to deliver good care. Freedom to discern patients' needs and desires, for instance a desire to avoid pain medication to ensure clarity during the dying process, particularly when they contrast the evidence may provide clinicians more opportunities to deliver good care. The obvious concern with this kind of freedom in health care is divergence from evidence established as a norm to prevent unnecessary suffering. However, Deleuze's conception of normativity can provide instruction to abate this concern. Normativity, from Deleuze's (1992) perspective, is the measure of life extended to its limits, fully realising its 'power of acting' (p. 256). A body's power to act is 'the force effected in a body in its composition in an assemblage of intensive and extensive parts' (Duff, 2014, pp. 15-16). Conceptually, mindline assemblages provide a normative framework to consider the 'natural right' (Deleuze, 1992, p. 257) of bodies in the context of practice. In my analysis, I argued that mindline assemblages are constituted by (among other constituent parts) complex arrangements of ideas, practices, emotions, and identities. These arrangements lay out a purposeful virtual plan of what palliative care should look like in particular circumstance. The mindline assemblage is an arrangement or ordering. It functions as a mechanism of inclusion and exclusion with limits to what can and cannot be considered viable palliative care in particular circumstances (Deleuze & Guattari, 1987, p. 45). Needless or undesirable suffering, for example, is considered a point beyond the limits of normative palliative care. Therefore,

palliative care clinicians freely act within the normative limits established by mindline assemblages to avoid reaching a point of unnecessary suffering.

Mindline assemblages allow us to consider the productive intersection of forms of content (materials, bodies, actions) and forms of expression (ideas, words, affects) (Buchanan 2015). Mindline assemblages are repeating patterns of arrangements of forms of expression and form of content in 'reciprocal presupposition' (Deleuze & Guattari 1987, p. 66). By examining emotions and mindlines through assemblage theory, the actual acts of palliative care are conditional relative to the assemblages in which they occur. Buchanan (2017) reminded us that Deleuze and Guattari's philosophy centres on the notion that 'material must always be produced; it does not simply exist' (p. 470). The material acts of touching a knee when talking about death, washing the body of a deceased patient, giving a patient's dog a scratch behind the ears are all materials made possible within particular assemblages of palliative care because of the conditional emotional possibilities. These assemblages have forms of content and forms of expression and produce both material and ethno-political outcomes. Consider the emotionally detached reduction of patients to their diseases within physiological mindline assemblages in case review. Within these assemblages, patient-centric humanist care is relegated, prompting different outcomes in the plan of care. Mindline assemblages contextualise actual assemblages of palliative care, which take place in 'real experience' (Deleuze 1994, p. 69) and presents a novel way to understand the intersection between evidence in varying forms and real experience.

8.2.2 Mindline assemblages contingent on emotions

Although my re-conceptualisation of mindlines as mindline assemblages provides a unique contribution to knowledge, it does not inherently address my research objective: to describe how emotions are constituted with other parts of community-based palliative care mindline

assemblages - the various elements that make up different ways to enact palliative care. I set out to better understand emotions and mindlines to contribute to scholarship on the processual nature of knowledge translation practices in the organisational praxis of palliative care. My thesis addressed this goal by articulating the mindline assemblages in community-based palliative care, elucidating how emotions are constituted with other parts of the assemblages in practice. By thinking about mindlines as mindline assemblages, I extracted the various ontological elements that make up different ways to enact palliative care. In this framing, the inclusion of emotion coexists within mindlines along with the ‘skills, norms, attitudes, and infrastructural demands’ (p. 193) of clinicians. This is precisely why assemblage theory is so helpful in the context of my thesis, because it provides a way to analyse how emotion and mindlines fit together for clinicians (Buchanan 2017). In chapter 5, I presented a demonstration of this approach, analysing mindline assemblages related to community-based palliative care shaping practice. This underscores the ways emotion was implicated in these assemblages of palliative care establishing emotion as integral to the way palliative care clinicians make sense of the care they deliver and the decisions they make.

In their book, Gabbay and le May (2011) explicated the social (re)construction of clinical knowledge, implicating the fundamental nature of collective mindlines to knowing-in-context-in-practice. However, they fell short of articulating the emotional nature of this reshaping process. A vignette from their book illuminates how social and organisational contexts can shape knowledge, but fails to address the pertinent emotional component:

We are at an Oakville team meeting about a project designed to provide guidance based on activity data in order to help physicians modify their current practice. The team are discussing the findings of a recent audit and how it compares with current best practice. They are designing and refining a newsletter that will be sent to hospital physicians giving the

data about current practice and suggesting new guidelines. As they go through it line by line, comments fly from the clinical scientists and their assistants: ‘They’ll get pissed at us if we say that.’ ‘They will be misunderstood.’ ‘That should hit the spot’... The eventual product is agreed – a pristine and objective set of figures, graphs and ‘key points’. None of the data in the eventual product are untrue, but it is clear that they are not simply data; they have a very subtly negotiated data that have been subjected to judgements based on an intimate knowledge of the factors that affect practice (p.166).

My thesis addresses this gap through the use of the mindline assemblage analytic framework, specifically identifying and explicating emotions entwined with ‘knowledge’. An analysis of the preceding excerpt with renewed attention emotion might highlight the presence of anger, validation, or ambivalence and consider the ideas, practices, and identities these emotions were assembled with and helped to produce. Gabbay and le May (2011) provided limited elucidation of how these emotions were important to the ‘negotiation’ and ‘judgment’ of data (p. 166). By including attention to the discursive production of emotions in instances like this, my analysis adds a new layer of interpretation to Gabbay and le May’s (2004, 2011) work. I witnessed many similar instances at the centre of how information was (re)shaped through collective affective emotional positioning. In the aforesaid excerpt, the positioning of hospital physicians through emotional language affected the negotiation of data that are ‘not untrue’ (p. 166). In section 6.2, I detailed the ways clinicians performed or foreshadowed patient sadness and suffering, how they used joy to affirm specific palliative care values, and how frustration and anger established limits of mindline assemblages. These data highlight the emotional labour required in these visits to manage the appropriate and ‘inappropriate affects’ (Hochschild 2012, p. 59) of work. Emotion was vital to: negotiate care and establish priorities, like prioritising

the care of a disabled grandchild of a dying patient; and create space for the inappropriate affects of maligning patients to become appropriate within acts of self-preservation.

Gabbay and le May (2011) noted that mindlines eschews the tendencies of reductionism found in previously used concepts related to clinical pattern recognition. The inclusion of emotion can coexist within mindlines along with the ‘skills, norms, attitudes, and infrastructural demands’ (p. 193) of clinicians. This is precisely why assemblage theory is so helpful in the context of my thesis, because it provides a way to analyse how emotion and mindlines fit together for clinicians (Buchanan 2017). In chapter 5, I presented a demonstration of this approach, analysing mindline assemblages related to community-based palliative care shaping practice. This underscores the ways emotion was implicated in these assemblages of palliative care. With a mindline assemblage framework, we can ask what the conditions are in terms of emotions, spaces, or clinical identities where particular mindlines can be expressed.

My thesis provides a comprehensive account of how emotions are bound with mindlines, extending the scholarship of theorists in this field. Eminent organisational scholars who have used Deleuzoguattarian work to critique linear models of knowledge delivery, while opening the door for such an analysis, have indicated how emotions are inextricable from organisational knowledge (Wood 2002). Gherardi (2003) contended that knowledge is inherently bound with desiring production, a Deleuzoguattarian concept alluding to an affirmative state pushing us to constantly attempt to realise endless possibility. Desiring production is a ‘moving concept’ (p. 355) that ‘induces personal investment in a search process’ that can result in ‘revelation, as a rending experience beyond our control and management’. Gherardi asserted that emotions are a form of knowledge that maintains our epistemic link with the world through discursive practice. However, although Gherardi centred her analysis on emotions as bound with the desire for discovery and mastery of knowledge, my study underscores emotion as one of the entities in ‘novel alliance’ (Wood, 2002, p.160) with knowledge.

Current scholarly work, while profound, lacks the comprehensive connections between emotion and knowledge established as part of specific mindlines or ways of practicing. In the context of the 'here-and-now', emotions can impel action, often overshadowing guidelines or policy. For instance, for specialist nurse 2 (section 7.5) and the after-death care she provided, emotion became reason providing meaning and logic for her actions as the emotion she felt 'worked' purposefully in the context of the assemblage. This was because explicit material in the clinical encounter was absent and the immediacy of patient suffering impelled action that was fit-for-purpose. Fostering and managing emotional attachments to patients and carers were vital to how palliative care was enacted at the research site. Considering the mindline assemblage, we can ask what the conditions are in terms of emotions, spaces, or clinical identities where particular mindlines can be expressed.

Situating emotion within the mindline assemblages of palliative care opened possibilities to explore the cultural politics of emotion that de- or re-centre the patient in care. Mindline assemblages were applied as embodied patterns of clinician behaviour, but only if applicable to the arrangements allowed within a particular social mass. For instance, in section 7.2, generalist nurse 2's practice of showering the patient was a mindline that deviated from policy, due to the empathy felt for a 'grievable' (Ahmed, 2013, p. 124) patient. Or, following Deleuze and Guattari (1987), the 'becoming expressive' reference to the patient as 'suffering' acquired a performative function, framing the patient as deserving to be showered (Buchanan 2017). The performative function of the suffering patient was bound with the clinicians embodied empathy, implicating a mindline assemblage that purposely addressed that suffering. Part of the 'realness' Wieringa and Greenhalgh (2015) described as principle in mindlines theory is the emotion that is felt and attached to particular experiences and exchanges, here reconfigured as assemblages. My findings show that the affective resonance of suffering is an immediate, present sensation that stabilises some of the humanistic assemblages of palliative care, shaping

clinicians practice. Here emotions are assembled with the pieces of information that were transformed into action.

Within a mindline assemblage, emotions could become a technology of the self, as clinicians arranged their practice and identity with the dangerous emotional terrain of palliative care, 'living with' (section 5.7) the emotional burdens of facing death and dying. McKenzie and colleagues (2019) described the field of 'emotion management' as an apparatus of ideology and control, foster through unequal power relations between teachers and the institution. Within the emotion management assemblage, the emotions of the oppressed are moulded and suppressed into disciplined alignment with the operation of the institution (p.683). As specialist nurse 1 noted in section 5.5 following a 'very difficult time', 'nobody puts you under that pressure' to engage emotionally with patients, but yourself. Yet within the self-preserving mindline assemblage there remained an overarching imperative to 'manage', 'control', and 'live with' (section 5.5) difficult emotions to get the job done. This extends Gabbay and le May's (2011) findings by identifying the political machinations of emotion in the context of communities of clinical practice. Gabbay and le May described the collective identity as 'a social process of continual mutual heedful interacting between those who share it' (p. 163). In this sense, clinicians are 'heedful' of the internal limits of assemblages of palliative care. In the context of case review, these limits were pronounced when computer documentation was arranged with physiological ailments and emotional detachment, establishing limits of what can and cannot be documented (see section 6.3). This was also apparent with 'special' patients with who clinicians formed familial bonds (see section 5.5). Arrangements of emotions within mindlines assemblages were shaped by the home environment. In section 6.2, I explored how participants invoked representations of the home and how these representations were often arranged with emotions. As Lupton (1998) argued, sensory perceptions of spaces have a powerful role in the production of emotion. For example, for specialist nurse 2 in section 7.5,

it was not merely the condition of the patient that shaped her practice, but also the emotional reaction to the physical space she inhabited. Collectively, mindline assemblages as an analytic method opened up patterns of emotions arranged with practice; however these arrangements were far from stable. My observation of clinician-patient interactions prompted acknowledgement of the instability and flux of mindlines assemblages *in situ*, as explicated in chapter 6 and 7. In the next section I explore the theoretical implications of these observations in greater detail.

8.2.3 Re-territorialising mindline assemblages

As I have demonstrated the contingency of emotions and mindline assemblages in my thesis, I have also described the ‘complex ligatures’ (Wood, 2002, p.159) of materials, space, and identities that helped form novel alliances between emotion and knowledge. My empirical research about community-based palliative care demonstrates mindline assemblages as rhizomatic non-hierarchical structures of knowledge and innovation, which are constantly in motion, are collective and collaborative in nature, and develop naturally through heterogeneous connections. To create tangible means to discover and analyse them as a moving target, we can consider mindline assemblages in terms of the diverse purposes they serve, particularly those outside of the biomedical or institutional. The way palliative care clinicians considered their work evoked Deleuze and Guattari’s (1987) ideas. For participants, good palliative care did not have the same linear fixity plaguing other specialities, where healthy become sick, a cure is introduced, and sick become well. Instead, different assemblages of ‘good’ palliative care were (re)made as quickly as they were becoming unproductive. Contemporary literature of KT speaks to the complex world of clinical practice where patients and carers ‘live in the messy, idiosyncratic, and unpredictable world of a particular person in a particular family context or... in a context of social isolation and/or abandonment’ (Greenhalgh et al. 2015, p. 1). This ‘messy

world' is realised in community-based palliative care, with patients in a fluctuating space of the home, contending with physical, mental, spiritual and social threats to their personhood while living with a life-limiting illness. My analysis demonstrated that, within a home visit, differently segmented territories of practice were evident, sometimes as binaries, like professionalism and familiarity, attention to the body, and attention to the social. These differently segmented territories produced more or less clear delimitations on the clinician-self, resulting in ongoing variations in clinical subjectivity.

In their exploration of how mindlines relates with Wenger's (1998) communities of practice, Gabbay and le May (2011) noted that 'learning is as much about social relations – indeed about working out one's very identity as a professional – as it is about acquiring specific skills and knowledge' (p.134). During fieldwork, I found that collective identities were arranged within mindline assemblages. Palliative care clinician 'subjects' were connected with certain mindline assemblages, incorporating specific actions, values, and ethical positions. Contradictory embodied and emotional positions were contingent on the context and moment, and the prospective affective capacities of participants as professionals, clinicians, or humans. Emotion as a productive force was only available when that productiveness could be embodied in actions.

Deleuzoguattarian philosophy privileges becoming over being, contributing to an ontogenic rather than ontological concept of creation. According to Deleuze and Guattari (1987), the subject is explained in its emergence in an 'immanent process of differentiation or individuation, which never settles into a stable form of identity, but is forever individuating, differing from itself' (p. 12). Becoming is a process of active, purposeful differentiation, which is inherently dynamic and always immanent, non-linear and atemporal (Manning 2010). Palliative care identity thus can be thought of as contingent and becoming as clinicians are becoming-human in the context of humanistic mindline assemblages, becoming-medical in the

context of biomedical mindline assemblages, becoming-friend in the context of rapport mindline assemblages, becoming-professional in the context of institutional logic mindline assemblages, and becoming-self-preserving when physical, mental and emotional burdens become ‘too much’. I argue that this contingency is partially predicated on emotions.

Scholars have argued that individuals enact emotional self-control by thinking of emotions in terms of their ‘constructive’ capacity, and therefore acceptable or unacceptable in relation to identity (Beech 2008; Clarke, Brown & Hailey 2009). For instance, Zembylas (2003) explored how a teacher’s identity is constituted in relation to the emotional rules in the context in which she/he teaches. This establishes emotional self-control informed through power relations and emotion rules as a significant aspect of the construction of identity. Scholars have only recently begun to consider how these emotion rules and identity can change within a single interaction. My findings suggest emotion rules shift across a single interaction within processes of de-territorialisation and re-territorialisation. In sections 5.4, 6.2, 6.3, and 7.3, I explored how clinicians deferred to professional identities, fitting within institutional logic mindline assemblages when it afforded purposefulness, for instance security or self-preservation. Consider one clinician who, in one instance, quoted policy when attending a home that had a dog: ‘you have to make sure you put your dog away when we arrive’ and then flouted that policy in another home visit that day with a patient whose dog she knew. But, as in instances such as this, clinicians allowed those manifested identities to be dismantled and re-territorialised when sadness, compassion, or empathy were more productive to enact care. In my results, I discussed how clinicians co-opted certain practices to become something else entirely. In section 5.3, I examined how clinicians used practices to achieve multiple, at times divergent goals, for instance, co-opting taking ‘obs’ to foster rapport. In sections 6.2 and 7.3, I explored how this process also worked the other way around, with clinicians using familial, humanistic practices to make clinical observations, repurposing their becoming-friend identity

to a becoming-clinical one. This contention rests on a Deleuzoguattarian ontology, which resists the urge to affix static, enduring identities for individuals, preferring instead to privilege the multiple unique possibilities within a mindline assemblage.

Consider the POMSNAME acronym described in chapter 5 developed to aid nurses in their documentation. Although the specialist nurse ostensibly wanted to promote the practice of holistic care as she defined it, she inevitably was required to work within the institutional logics necessitating efficient and accurate documentation. In developing the tool, she noted the importance of the nine foci, almost all of which were biomedically oriented. However, she also regularly critiqued her own acronym in front of other clinicians, noting its inherent limitations in promoting ‘true’ holistic care. This ongoing self-critique reminded others of the value to widen their focus beyond the acronym. For the specialist nurse, it folded a humanistic ‘holistic’ identity around a biomedical clinical identity. This proliferating attention to multifaceted mindline assemblages suggests that, with attention to how mindlines are assembled within health care contexts, interventions can become multiterritorial, accounting for varying mindline assemblages.

8.3 Theoretical and practical implications

8.3.1 Implications for theory and research

My thesis contributes to organisational scholarship that applies the assemblage to describe organised forms, specifically of EBHC, and the forces of stabilisation and transformation in health services that disrupt the EBHC hegemony. Vital in this analysis is the prevailing role of EBHC in health services that maintains a hegemony of a plane of organisation, eschewing movement towards a plane of immanence in healthcare. My approach extends Gabbay and le May’s (2004, 2011) nascent critiques of EBHC, which problematises the linearity of bench to bedside. A mindline assemblage might be arranged with external evidence, but only because it

is 'locked into an image of itself' (Buchanan 2017, p. 465) as harbouring a type of agency based on a shared understanding of the importance of 'research evidence'. This belies situated real world practice occurring in the middle of things, where actions are not inherently driven by research evidence. Evidence within a palliative care encounter is only useful if it works within the emotional, ideological, practical, and identity-affirming framework of the assemblage.

My analysis presents an opportunity to consider the implications of emotion within EBHC. Within wider discourses of EBHC, there is a dichotomy of rationalism opposing situated, emotional actions, maintaining a 'modern functional social power' (Reid 2014, p. 174). This social power is linked, emotionally, to the simplicity of linear and 'hard' evidentialism: 'Action requires truth, evidence provides truth, and truth dictates action' (p. 178). The social power of 'evidence-basedness' was inherent within certain assemblages, for instance, during case review, but notably absent in others, for example, when establishing rapport with a patient. Other forms of evidence, such as experiential or emotional, took precedence for clinicians, as described in sections 6.3, 7.2, and 7.4. Greenhalgh and colleagues (2015) noted that the EBHC hierarchy of evidence devalues experiential knowledge, or, the 'anecdote' (p. 2). While their focus is on patient's lived experience, this is similarly extended to clinician's embodied knowledge. Reid (2014) noted that embodied knowledge has no place in EBHC discourse: 'under bureaucratic evidence-based healthcare, clinical embodied knowledge is unaccounted for and suppressed' (p. 168). This is because embodied knowledge can undermine the tenants of EBHC, as an extension of the mind/body dichotomy that EBHC discourse rests. Tacit and embodied knowledge can challenge EBHC because, by definition, they are difficult to engage with in an explicit and a generalisable way. This reflects a wider dichotomy between the tacit subordination of mind over body. Yet, through my findings, nurses' actions were predicated on an embodied sensibility. For instance, understanding the appropriate relational care when

receiving a patient complaint, knowing when to initiate physical contact with a patient or carer, understanding the importance of showering a patient, or attending to the body of a deceased patient. These actions were shaped by embodied knowledge, which is enacted through feeling patient suffering, or through seeking patient and carer joy in practice. Thornton (2006) identified tacit knowledge as an agent to repotentiate the patient as a whole person. It is no surprise then that embodied knowledge is so important within humanistic assemblages of palliative care.

Theoretically, my approach to mindlines provides a conceptual blueprint for other scholars to think with complexity in their conceptualisation of KT. Ultimately, a palliative care assemblage of practice distinguishes itself semiotically from other forms of healthcare. Following my experience researching palliative care, death and dying seems to prompt particular ways of seeing the world and different values entwined in care. The emotions and ideas interwoven in mindline assemblages within this context are unique; however, my analytic framework can provide value in other contexts. My approach centred on emotions, as they related to ideas, practices, and identities within given assemblages. However, mindline assemblages, as an analytic approach, allows for diversity of pre-individual singularities that give form to the intensive multiplicities by which the body and subjectivity emerge. Alternative singularities that might make up mindline assemblages could include habits, utterances, mannerisms, precepts, relations, desires, expressions, events, and/or signs. These singularities are pre-individual in the sense that they do not emanate from an individual body (or subject), but are the elements out of which embodied subjects are individuated (Duff 2014). Mindline assemblages provide scholars with opportunity to consider how alternative combinations of singularities are implicated in knowledge-in-context-in-practice.

My analysis has implications for theorising and researching the intersection between identity and emotion. The role of emotion in fostering professional identity has recently been identified

as an area in need of further study (Brown 2015; Winkler 2018). Brown (2015) asserted the ‘often emotionally charged’ (p. 26) nature of the crafting of identity, yet failed to detail the ‘charge’ of emotions at play. Winkler’s (2018) review of emotions in identity work suggests the small scope of emotions explored, with many studies focusing on anxiety, frustration and worry. Researchers have largely examined change in the workplace, social life, and culture. Winkler (2018) noted that these studies described identity work as fraught with fear, anxiety, angst and trepidation. As a future research direct, Winkler suggested the study of specific emotion words or bodily emotional expressions to make sense of the experience of identity threats, thereby establishing the person whose identity is challenged. My findings sit alongside research that examines emotion as a discursive resource in the production or rejection of professional identity (Clarke, Brown & Hailey 2009; Coupland et al. 2008; Zembylas 2003). For instance, the dichotomy of professionalism versus emotional practice for palliative care clinicians was echoed by Clarke and colleagues (2009) who explored managers’ antagonistic discursive resources. They noted conflation between professionalism and hard emotions, and the duality of between emotional detachment and emotional engagement. Conflict between ‘professionalism’ and emotional practice (section 5.3) resonates with the notion that ‘identity work may be a melange of different identity projects, co-present within the self but distinct and potentially conflicting’ (Beech 2008, p. 52).

My findings reflect Warren’s (2016) gendered examination of surfboard-making as an ‘emotionally rich form of labour’ (p. 36). The elements of emotion bound up in the identity and actions of surfboard-makers parallels the similarly emotional and embodied palliative care identity. Warren identified the idealisation of the ‘perfect’ surfboard formed through workers seeking embodied joyfulness in their actions and the inherently relational and individualised nature of the craft. This aligns palliative care clinicians’ joy-seeking identities and the relational and individual (humanist) nature of palliative care. Clinicians’ hope and joy were assembled

with particular identities and practices, shaping how palliative care was enacted. In this idealised conception of palliative care identity, driven by positive emotions, clinicians casted themselves and/or others as an archetypal hero of their palliative care stories, imbuing their actions with compassion, understanding, and empathy. Clinicians' conceptions of the 'ideal' (Wieland 2010) palliative care practitioner appeared to drive self-direction and desired future accomplishments that presented aspirational mindlines for other clinicians. These parallels across significantly disparate jobs suggest a theoretical transferability of emotion helping to substantiate relational and embodied professional identities.

8.3.2 Implications for health organisations

There remain inherent challenges in translating continental social theory into practice, and the work of Deleuze and Guattari (1984, 1987) is unwieldy and challenging. These challenges pertain to the authors' dense and haphazard stylistic approach, and the absence of clear, normative, or prescriptive axioms in their work. However, it is the rejection of absolute normative institutions that Deleuze and Guattari's philosophy hinges on. Deleuze and Guattari emphasised movement and openness in Deleuzoguattarian concepts, articulated via 'actualization and virtualization; structuring and the troubling of structure; potential and its realisation' (p. 45). They considered the combination of experimentation and institutionalisation to allow for joyful and novel combinations, while avoiding arrangements 'falling into lines of destruction – ethical, political and social uselessness' (Lawley 2013, p. 45). Thanem (2004) points to the extraordinary things possible when the 'nonorganisational' (p.215) desiring forces of organisational life exceed the mechanisms of organisation and control.

My findings suggest that leaders, executives, and policy makers within health organisations need to continue to be attentive to how mindlines are assembled within different contexts by

allowing for interpretative, flexible, and relative ideas of care within emotional contexts. This could be managed by creating stability within policy and guidelines, but allowing clinicians to re-territorialise these guides, or as one nurse described ‘short cut’ them. Again, we can consider Deleuze’s (1992) normativity to abate the obvious concern with this kind of freedom in health care, namely the divergence from evidence established as a norm to prevent unnecessary suffering. To work against the ‘oppressive’ experiences of the rigidly enforced select policy (Scott 2010, p. 176), promoting the joyful combination of bodies and materials in health organisation should be encouraged. This might be achieved by allowing clinicians to identify novel, exhilarating practices and moments that exceed expectation and increase individuals power in composition with others (Collier et al. 2019; Dadich, Collier & Hodgins 2020; Dadich et al. 2018; Dadich et al. 2015; Fulop et al. 2013). Deleuze and Guattari (1987) noted that modern bureaucracy within organisational life inevitably tends towards continual movement:

It is not sufficient to define bureaucracy by a rigid segmentarity with compartmentalization of contiguous offices... For at the same time there is a whole bureaucratic segmentation, a suppleness of and communication between offices, a bureaucratic perversion, a permanent inventiveness or creativity practiced even against administrative regulations (p. 214).

Clinicians should be allowed to learn to be affected in productive ways. Being affected can lead to important discoveries and experimentation in producing new assemblages of care. Research has underscored the importance of providing nurses with the capacity to engage in self-preserving behaviours and negotiate relationships with patients and carers to ensure adequate distance and intimacy (Mackintosh 2007; Stayt 2009). Based on my study and others’ research on emotion in professional life, clinicians should be provided with the opportunity to reflexively examine how they are moved by patients, carers, colleagues, and managers. This

might give them ‘recognition that their emotions have powerful epistemological and affective qualities’ (Zembylas, 2003, p. 229). Zembylas noted that a post-structural perspective on emotion that promotes the political, discursive, and embodied exploration of emotions, can encourage practitioners to examine the power of the emotions at work. This perspective can also reveal workplace norms that have shaped and sustained their identity. This has implications for education where critical pedagogies of emotion might add to a curriculum of clinical knowledge. This might be achieved by identifying and highlighting shared emotional experiences of clinical practice and troubling knowledge that might prevent good care. Approaches that imbue clinical education with emotional awareness are already underway (Guillemin & Gillam 2015; Malchiodi 2013) and my findings further justify this direction of educational practice.

My findings have implications for clinicians who work within the emotionally and mentally fraught space of death and dying. Stacey (2011) explored homecare workers’ experiences, describing the emotional labour inherent in caring for people in the home. She noted how this care was minimised or ‘unrecognised’ in policymaking and research. This is despite workers’ unique context: ‘where the primary social relationship formed is between aide and client’ (p. 62). Stacey noted workers’ isolation, absent co-workers, managers, and other patients. Here, the aide-client dyad was central to how emotional labour was defined, carried out, and experienced. Stacey used feeling rules (Hochschild 1983) to examine homecare, rather than that in a nursing home or hospital. The duality of feelings rules in the private space of home and the public space of work meant that homecare workers can be torn between institutional rules and a need to eschew ‘professional’ perceptions in the home. Stacey noted that, to manage this tension, homecare workers ‘erect boundaries where possible, but not at the expense of cultivating companionship with clients’ (p. 64). My findings emphasise and extend this work,

noting clinicians' impressive ability to wrangle multiple humanistic, physiological, and organisational purposes out of a single home visit, despite limited resources.

The humanistic, rapport building, and death care mindline assemblages outlined in chapter 5 were predicated on offering space for individual clinicians to enact their own contextual adroitness. Gabbay and le May (2011) explored 'contextual adroitness' (p. 90) connecting this idea with Bourdieu's (1977) notion of value-laden common-sense. They noted the importance of contextual adroitness for clinicians:

The evidence advocated by the EBP movement may be vitally important, but for clinicians it is just one source of additional information among many others that they need to take into account as they contextualise it, both within their well-developed existing mindlines and in terms of the individual case they are dealing with (p. 101).

An individualised approach to patient care is a mindline in and of itself. The relative nature of quality palliative care has been affirmed, as Collier and colleagues (2019) described quality home-based palliative care as meaning 'different things to people at different times' (p. 97). In my discussion with participants during and after fieldwork, they identified with many of the observations and preliminary findings of my work. They acknowledged how palliative care was linked to their individual, fluctuating emotional and personal becomings; each day or, indeed each moment would present a unique arrangement of care. Their practices were flexible, and they understood that 'what works for one client may not necessarily work for someone else' (specialist nurse 4). Ultimately, the participants used their embodied judgement, drawing from the values established using emotions, suggesting a situated knowledge-in-practice related to emotion and empathetic practice.

One concern surrounding a clinical body ‘learning to be affected’ might be the subjugation of ‘hard’ clinical truths for a reliance on patient need. Section 5.3 demonstrates an emotional body was not devoid of clinical nous or attention to alternative priorities. The clinical self as a competent and professional body is retained in encounters with patients and families. Collier (2013) similarly noted that the humanism in learning to be affected does not mitigate clinical technical competence and knowledge. Learning to be affected does not necessarily require clinicians to be forced into familial arrangements with patients and carers to achieve affective attunement. Research has minimised the role of ‘familiarity’ or relationship building to effective psychosocial care. Hill and colleagues (2014) challenged the suggestion that clinicians need be familiar with patients to provide psychosocial support. As Wong and colleagues noted (2018), professionalism can be bound with emotional caring, repudiating emotional detachment as a means to prevent clinician burnout and distress. Clinicians should be taught to engage with the ‘embedded emotionality within medical encounters’ (Wong et al. 2018, p. 15).

Clinical practice considered through a non-linear, becoming affected way has profound implications for the management of health organisations. Throughout my analysis, I drew connections to the managerial and bureaucratic conditions of palliative care assembled with emotional identity work. Much of these findings suggest ambivalence or antagonism towards figures representing bureaucratic oversight, such as managers and executive team members. For example, managers within and beyond the centre were positioned as antagonist in conflicts around patient discharge, time spent with patients and carers, and nurse empowerment to sign a death certificate. Framing managers as antagonists in practitioners’ stories to promote unity has been demonstrated elsewhere (Dawson & McLean 2013). My analysis suggests that antagonism towards bureaucrats can reaffirm the diametric components and values within other assemblages of palliative care. The axiomatic, ‘businesslike’ logic of healthcare organisations

often do not make space for values-based care. This might challenge palliative care context to become increasingly objectified and quantified, as evidenced by the adoption of a national program of performance indicators (Eagar et al. 2010).

The two competing ideals of valueless scientific evidence and value-based practice work together when considering health services via assemblage theory. In section 7.2, I noted dissonance in special nurse 2's thinking and actions. Her ability to feel her patients' suffering in a tangible, physical sense helped to re-territorialised mindline assemblages to incorporate policy. She relied on the patient's immediate need. For this nurse, and other clinicians, *in situ* emotion foregrounded suffering, making certain practice more purposeful within that assemblage. This helped to account for the discrepancy between what clinicians were and were not drawn to, when, and why. attention to evidence and moments of eschewing evidence in the form of guidelines and policy, in practice. Considering the 'paradox tolerant' nature of modern organisational identity, Clarke (2009) noted that individuals put into practice competing and often inconsistent sensemaking frameworks to rationalise inconsistent policies, values and practices. Rather than connect discrepancy between evidence and practice to cognitive dissonance theory, Reid (2014) aligned this tension with the emotional state of 'ambivalence' (p. 194). The pull between two competing things placed in opposition, such as research knowledge and practical knowledge creates emotional ambivalence. The multiple competing demands on the clinicians also suggests attention to complexity theory is required when considering how clinicians consider and enact evidence.

Greenhalgh and Papoutsi (2018) expounded on the benefits of complexity-informed health services research, noting: ...a mismatch between the 'patient in the guideline' and the 'patient in the bed' due to multi-morbidity and interacting sociocultural influence' (p. 1). They note that new staff roles, organisational forms, and technologies can worsen the problems they attempt to solve, with integrated care proving 'impossible to deliver in practice' (p. 1). They

suggested the conglomeration of complex organisational factors necessitates researchers ‘capability and capacity to handle the unknown, the uncertain, the unpredictable and the emergent’ (Greenhalgh & Papoutsis 2018, p. 5). For clinicians ‘at the coalface’ emotion can cut through, or drown out, the complexity they experience on a day-to-day basis. It would be hubristic to suggest that emotion can mitigate the complexity they face. Instead, thinking through emotions can signpost how to conceptualise complexity in healthcare by considering points of conflict between differing mindline assemblages – for instance the emotional detachment necessary for self-preserving mindline assemblages and the compassion required as part of some physiological mindline assemblages.

The tensions I have explored in my analysis between institutional logics and humanistic care were not inherently detrimental to effective practice. The tensions often created opportunities for senior clinicians to reaffirm important values and ways of caring in palliative care. This observation aligns with scholars of positive deviance, who have argued that adversity can foster opportunity for optimal practices (Issel 2017; Pascale et al. 2010). Positive deviance is a ‘collection of behaviours that depart from the norms of a referent group, in honourable ways’ (Spreitzer & Sonenshein 2003, p. 209). Positive deviance is socially driven and dynamic, centring on individuals who depart from expected practices to invigorate, strengthen, or galvanise a group pursuing a common goal (Gary 2013). Positive deviance provides a way for a group of individuals to collectively foster expertise to address intractable issues, such as the tension between organisational policy and value-laden practices that are misaligned with policy. The emotionally charged and nuanced terrain of community-based palliative care can provoke an ethical climate that fosters positive deviance as clinicians attend to multidimensional patient needs (Borry 2017). Managers of community-based palliative care should attempt to engage with the dominant ethical climates and values in the local context to determine the presence and virtue of positive deviance (Borry 2017). This is also a logical

extension of understanding knowledge creation as socially and contextually mitigated. The challenges of codifying and managing knowledge are well understood. My findings align with the notion that ‘we cannot control... interactions [nor] all aspects of resources and contexts’ (Wieringa & Greenhalgh 2015). However, we can create the conditions that give voice to practitioner emotions in the context of practice. Research has begun to address this gap using methods that prioritise values and emotions in the study of organisations, like Positive Organisational Scholarship (Dadich et al. 2018).

To bolster skilful expertise, positive deviance can add to healthcare practice. As Pascale and colleagues (2010) observed, ‘you can find positive deviants in pockets of most medical communities that are – right now – delivering higher value health care than everyone else’ (p. xii). Positive deviance within healthcare has enabled practitioners to ‘find better solutions and achieve better outcomes than others’, ‘follow uncommon or special practices and behaviours’, and ‘succeed using existing resources’ (Baxter et al. 2016, p. 196). Managers can also benefit from positively deviating individuals. In an examination of ‘diamonds in the rough’, Clancy (2009) found clinicians with managerial responsibilities valued the nurse who, ‘always finds a way to get the job done’, ‘is the glue that holds us all together’, and ‘is extremely resourceful, knowledgeable, and adaptable’ (p. 54).

In addition to positive deviance, the effective diffusion of the emotional and relational nature of care in the home is predicated on managers’ nurturing professional networks (Robinson et al. 2012). Gabbay and le May (2004, 2011) explore ‘trusted sources’ within mindlines. They examined clinical networks and how these networks shared and collectively negotiated knowledge to form mindlines. However, they did not clarify how multidisciplinary teams regard one another, and the emotional nature of these relationships. I use the term multidisciplinary instead of ‘trans’ or ‘interdisciplinary’ because multidisciplinary healthcare has been differentiated as that in which clinicians with different knowledge collaborate, rather

than combine or converge (Gatchel et al. 2014). Gabbay and le May (2011) described practitioners who intermingled and shared stories altruistically, with limited discussion of how participants appraised different professions as trusted sources or collaborative teammates. This might be due to a positive and collaborative context fostered at the sites for their study or a reluctance to explore this aspect of practice. However, poor multiprofessional relationships can thwart teamwork and compromise patient care (Ansari & Rassouli 2018; Mahmood-Yousuf et al. 2008; Sargeant, Loney & Murphy 2008).

I found the establishment and shaping of palliative care identity through emotion in the multidisciplinary network pervasive. Associating palliative care values, such as humanist care, rapport building, and confrontation of death, with different professions helped to align members of the palliative care team in contrast to professions who failed to meet assemblage requirements. Shared anecdotes about working with different professions informed how multidisciplinary relationships were perceived and how these relationships affected palliative care. Differing mindline assemblages differentiated specialities, like palliative care, oncology, psychology, cardiology or nephrology, creating and affirming specialities as ‘subjects’ of particular assemblages. Specialities were reinstated as subjects within particular mindline assemblages within interactions, such as ‘the GP who can’t prescribe pain medication’ (section 5.3), the cardiologists and nephrologists who primarily focus on curative treatment (section 5.3), and the managers who have limited capacity to consider the emotional toll of palliative care (section 5.7). This contention is limited because of the absence of these voices in this study. However, different professions inevitably garnered collective reputations among study participants.

Multidisciplinary practice is vital for modern healthcare and as such, it has become a prominent feature in many health systems (Lown & Manning 2010). This follows a better understanding of complex health issues and multi-morbidities, and an increasing recognition that addressing

these requires complementary skills, knowledge, and perspectives (McCallin & Bamford 2007). This is supported by evidence suggesting that integrated healthcare is associated with: improved patient wellbeing, reduced hospitalisation, decreased mortality rates, better staff morale, and reduced staff burnout and attrition (Safran & Beckman 2006). With the shift towards patient-centric care, multidisciplinary practice remains an important focus for research and practice within many Western health systems.

Although relevant to all domains of healthcare, multidisciplinary practice is particularly germane to palliative care (Hill 1998). This is largely because community-based palliative care reflects a biopsychosocial model of care, recognising a dynamic interaction between that which is physiological, psychological, social, and spiritual (Ansari & Rassouli 2018). Furthermore, end-of-life care can be emotionally-charged, particularly when cultural taboos hinder what patients and carers can discuss, when and how they can discuss it, and with whom. Despite the benefits associated with multidisciplinary palliative care (Forrest & Barclay 2007; Jongen et al. 2011), it is difficult to enact and demonstrate. Insufficient resources, including time, workforce capacity and funds, poor administrative processes, and ineffective interdisciplinary communication can hinder multidisciplinary care (Ratcheva 2009). In an investigation of 11 specialist home-based palliative care services in Canada, intra-team communication and team-building were viewed as more important than: clinical tools, standardised processes, specialised expertise, timeliness, physical symptoms, psychosocial support, spiritual management, education, peace and fulfilment, and patient advocacy (Seow et al. 2017). My findings suggest these barriers to effective multidisciplinary care were all evident according to participants.

One of the biggest barriers I focused on was friction. Friction is demonstrated by limited recognition of the different roles and areas of expertise of each discipline, hierarchies that serve to maintain power imbalances, and disparate discourses that stymie communication (Walsh et

al. 2010). I explored the complications of competing value systems within mindline assemblages that prompted multidisciplinary friction from the perspective of the palliative care team. The emotional attachments associated with multidisciplinary healthcare both hampered and promoted effective collaboration in this context, where value alignment was prominent. Thinking multidisciplinary care through Ahmed (2004) suggests more attention in research and practice is required to rethink modern healthcare structures that compartmentalise specialties. She critiqued the collective bodies evoked through compartmentalised nationalism, which, through emotions, can separate nationalities and ethnic identities. Allusions might be drawn with terror management theory (TMT), which purports that individuals bestow superiority to groups they identify with, to subvert their own mortality (Greenberg, Pyszczynski & Solomon 1986). According to TMT, close relationships within one's cultural group are fostered from a biological predisposition towards self-preservation. If one maintains the values set out by a culture, they are able to attain literal or symbolic immortality (Dechesne et al. 2003). These value-laden and emotional connections to the palliative care group were evident in my findings as nurses and doctors promoted the superiority of their attachments to the palliative care collective from the perspective of effective end-of-life care.

To contend with separation of nationalities and ethnic identities, Ahmed (2004) evokes Nussbaum's (1994) advocacy of a global citizen, which, through the emotional attachment of love, provides a feeling of allegiance for those outside of national boundaries:

We can feel close to others who are distant, by identifying ourselves as world or global citizens... Globality works as a form of attachment, as a love for those others who are 'with me' and 'like me' insofar as they can be recognized as worldly humans. It hence suggests that love can be the foundation of a global community, a community of others that I love. (p. 37)

Addressing the emotional friction of multidisciplinary palliative care might require an approach that mirrors the globality of world citizenship, creating new emotional attachments to healthcare provider collective. Implications for health service suggest a need for opportunities in community-based palliative care to share perspectives and values across diverse disciplines. This might involve movement of clinical bodies between and across what is currently considered disciplines or specialties, such as secondments. Additionally, collaborative reflexive opportunities could promote a shared understanding of the diverse roles required in palliative care. Cross-disciplinary video reflexive ethnography has a demonstrated capacity to reveal and shape the visible and invisible ways that clinicians work (Baxter et al. 2016; Pascale, Sternin & Sternin 2010; Willis et al. 2016). Similarly, training that involves different disciplines can help to improve communication and teamwork (Issel 2017). This is part of a broader push for ‘transdisciplinary’ as opposed to multidisciplinary approaches in healthcare (Nembhard & Lee 2017). This involves clinicians working alongside one another to create new and integrative knowledge to address complex issues and problems ‘through the practice of one’s profession and discipline in concert with others, instead of alone’ (Collier et al. 2019; Nembhard & Lee 2017 p10).

A concern with this approach would be losing the values of those perceived as ‘lesser’ specialties like palliative care, where the goals of care differ greatly from curative specialties. Fostering a global clinical identity might mean abandoning local attachments, such as attachments to community-based palliative care mindline assemblages. Ahmed (2004) noted that this might involve ‘disembodying’ or ‘detaching’ people from individual identities. She noted that giving up local attachments does not mean a suspension of attachment, but creating different attachments to globality:

one can become attached to movement itself as a new form of social bonding. Such an attachment to movement suggests that the ones who

cannot be admitted into the global body are the ones who remain too attached to the particular, the ones who do not (or perhaps even cannot) move away from home...Globality is now what would move one to tears (p. 37)

Considering my findings in concert with extant research underscores the significance of a model of care that enables transdisciplinary communication, or a globalisation of specialisations and the visibility of inspiring leaders. As Gabbay and le May recently stated (2016), ‘the common thread’ in mindlines development ‘appeared to be creating the space and the comfortable climate for respectful critical dialogue even during the everyday chatting and story-swapping we all enjoy’ (p.403). Fostering a wider community of practice can enhance clinicians’ professional capital and mindlines within that community. Greater professional capital can enhance the knowledge and skills assembled within mindlines in concert with shared values and ethos, and agreed ways of behaving, practicing and communicating (Le May 2008).

8.4 Limitations

My thesis has delved into the messiness of both emotion and mindlines in palliative care in my own way, without arbitrarily manufacturing cohesiveness from the complexities, ambiguities, and tensions I engaged with. The inexplicability of emergent mess as part of an assemblage approach means that there are invariably alternative routes I could have taken. In this section, I reflect on these alternative routes. Reflection on these limitations and the associated limitations could be addressed in subsequent research that extends my findings.

8.4.1 Mindlines and emotions not pursued

In chapter 5, I made claims about the mindline assemblages palliative care clinicians developed and enacted. I also made claims about the emotions I observed and experienced. Ultimately, these claims are limited by the data I collected and my experiences. Undoubtedly, there were other mindlines assemblages and emotions that shaped palliative care practice that I overlooked. This might be because they were absent from data, or because of my position as a non-clinician ‘outsider’. As a non-clinical ‘outsider’ I often asked ignorant questions like: why did you do this, where did that know-how come from, why is that important? This questioning meant I could often drill down to the impetus of a clinician’s actions, and because of my outsider status they usually gave me patiently detailed responses. However, this might have also led to missed opportunities to inquire more extensively into advanced ideas or practices. For example, having an in-depth understanding of pain relief medication might have provided me with a foundation to ask about why specific types of pain relief medication were prescribed in certain circumstances. Without ‘insider’ knowledge, I was unable to discern uncommon or out-of-the-ordinary mindline assemblages.

My experience of emotion also limits this thesis. Ahmed (2013) noted that our experience of emotion is shaped by our own histories of contact with the world. My interpretation of suffering in this thesis for instance, is contingent on my own experience of suffering, and of what is lost in potential suffering. Retrospectively, I acknowledge that my perception of suffering regarding certain life-limiting illnesses involved an embodied grief because of my. For example, during fieldwork, I walked into a nursing home to visit a patient with motor neurons disease (MND). I noted in my journal that I was ‘overcome by pity and despair for this young man, who was wasting away without a voice’. I imagined myself or my wife diagnosed with MND, knowing the imprisonment and death sentence it represented for either of us, fostered by the fear of being reduced and losing so much of what makes me, me. My ability to exercise

and be active. My ability to make music. My ability to talk and laugh with friends and family. This experience conjured strong feelings provoking renewed attention and inquiry into clinicians' experiences as they cared for this man. As such, my thesis is limited by those emotional resonances that were more prominent for me due to my own histories of contact.

To mitigate these concerns, I used a polyphonic approach to take in as many voices as possible using methodological plurality. Turning between a narrative approach and a discrete approach to analysis enabled my research to be situated in thinking and feeling, paradigm, to attend to language, performance, social construction and lived experience (Zembylas 2011, p. 35). Journalling my emotions during the research was vital, providing a reflective account of fieldwork that scrutinised what I knew and how I knew it (Finlay 2002). This practice created 'resonances' (Zembylas, 2007) with participants and added powerful and unique data and insight. The journal was a key starting point for much of the analysis, guiding what I did, when I did it, and how.

It is important to consider the benefit of paradigmatic multiplicities in the study of emotion to '[think] difference differently, [and] reappropriate available contradictory scripts to create alternative practices of research as a site of being and becoming' (Lather 2006, p. 52). Although my methodology provided unique analytic openings in the study of emotion in healthcare, it was not without its challenges and limitations. At times, it was difficult to pay equal attention to both the experienced and embodied emotional experiences and the socially and culturally constructed perceptions of emotion. Shifting between these perspectives necessitated a dual process, essentially doubling the coding and analytic leg-work. Conceptually, this was managed by refocusing attention on examining what emotions *do* within particular assemblages of palliative care, both in social interaction and as a product of private experiences.

8.4.2 Halo effect

Following a presentation to colleagues within my school, I was asked about ‘dealing with bias’ in this study. A colleague asked how I avoided the halo effect while observing clinicians. He highlighted the risk of conflating the difficult job palliative care clinicians do with their personal standing or ‘goodness’. During data collection, I formed a close kinship with many clinicians. As a friend and confidant for some, they considered me ‘part of the team’. Given the nature of the research, an intensive ethnography within the centre, my relational and emotional connection with participants may have been unavoidable. As I watched the clinicians empathising with their patients and carers and repeatedly going above and beyond what was expected of them, often in the face of logistic or personal barriers, I could not help but admire and feel for them. Reflecting on my position during fieldwork, I noted that I took up the causes of my participants easily. Lamenting with them. Grieving with them. Being excited with them. This was a fruitful position for me because the more I aligned with their causes, the more they shared their emotions and causes with me. For instance, emotional moments in the fleet vehicle were spurred by the trust and kinship I had with clinicians. They cared about me and the work I did, offering regular praise and encouragement. However, this in turn fostered a positive, uncritical appraisal of the decisions and actions I witnessed.

To combat the potential halo effect, I included structural mechanisms in my research process. In my journal, I critically evaluated my choices and how I portrayed clinicians in my results. With my supervisors I discussed my proximity to participants. During fieldwork I played a devil’s advocate, questioning clinician’s motives and assumptions. However, this was not as often as I would have liked. I was wary of overstepping my boundaries as an upstart young researcher and losing participant’s confidence and friendship. Ultimately, my research was shaped by my relationship to the clinicians I worked with. Feeling with those clinicians offered

important insights, but it also might have blinkered me to some of the less noble or altruistic actions of the team.

8.4.3 Alternative voices

My thesis promoted clinicians' voices as they delivered palliative care. At times, this meant marginalising the patient and carer, as clinicians' perspectives took centrality in narratives. Focusing on clinician experience in vignettes (rather than patient and carers) represented this focus. This focus follows my thesis objective, as it was clinicians' emotions and mindlines that I set out to study. I relied on the clinicians and my own impressions of the patient and carer interactions, without speaking with patients and carers. I acknowledge that patients' and carers' voices are vital to conducting thorough research on emotion and mindlines. Mindlines as a perspective of EBHC allows room to include patients and carers in the creation of valid knowledge and should be explored further (Wieringa & Greenhalgh 2015).

Additionally, managers voices were absent from my analysis. Given their prominent consideration within institutional logic mindline assemblages, I should have dedicated more effort to accessing managers perspectives. My brief interactions with managers suggested similar points of tension between providing care and ensuring the adequate operation of health services. These perspectives could have been investigated further to determine their perceptions of prominent mindline assemblages within the research site, and the ensuing complexity faced by managers.

8.4.4 Gender

Citing MacDowell (2011), Warren (2016) noted that the 'spaces of work (both paid and unpaid) are saturated with gendered meanings and discourses' (p. 50). In my study, I failed attend to the gendered meaning and discourse related to palliative care. I did not explore palliative care

as a gendered division of labour and the associated practices and identities assembled with for instance, humanistic mindline assemblages. There is an opportunity to draw on feminist economic geographies to address these concerns to emphasise the centrality of social constructions of gender in shaping working relations (McDowell 2013). This work might explore emotional social constructions of femininity in palliative care, and identify connections to holistic thinking and empathy in palliative care identity (McDowell 2009; Simpson 2004).

Additionally, I did not examine my position as a male in a female dominated working space with enough scrutiny, which may have benefited the researcher-participant dynamic (Simpson 2004). Simpson found that men benefit from a minority status in work contexts via assumptions of enhanced leadership and differential treatment. My gender might have influenced my perceived position, lending my voice more gravitas and potentially coercing participants in their responses to my questions. Although I did not discern evidence of this occurring, my retrospective view is limited. It would be

8.4.5 Leadership

One area of research that could have been explicated more fully was leadership. Due to the scope of, and time afforded, for this study, I did not attend to leaders' emotions. During fieldwork, some leaders expressed intense emotion and they reinforced these to colleagues through performance or narratives. These performances and narratives served to bound palliative care, delineating what was appropriate or inappropriate in particular settings. For some participants, these leaders were the protagonists in stories, demonstrating the values and ethics of a palliative care clinician. One individual at the centre particularly shaped how her colleagues spoke about and enacted palliative care. She was often the source of current best practices and sage advice. For this and perhaps other reasons, she was typically held in high regard. Given her influence, her words and actions moulded palliative care identity. She

championed ways of practicing care at meetings, often providing the last word as the fountain of knowledge for generalist and specialist nurses, as well as the specialist doctors. She articulated values in her highly emotive manner, displaying anger, confusion, and joy in performative ways. Although I did not address leaders' impact here, there is significant literature to build on.

8.5 Future research

As an emerging area of research, there is a need for a disparate research agenda that uses innovative methodologies and novel foci to explore emotions within mindline assemblages. My research did not limit the emotions experienced by clinicians or solely focus on positive or negative emotions. Future research should take this thesis as a foundation to examine specific emotions and their moving nature in clinical practice. Some of the emotions I observed or experienced might be relevant to many other forms of work. These included the emotions impelled due to tension between axiomatic mindline assemblages of institutional logic and the values of care. My study might be used to consider these tensions elsewhere.

Future research should consider mindlines assemblages and emotions beyond workplace. Having befriended some of the participants I worked with during data collection, I connected with them via social media, namely, on Facebook. I now regret the limits of my research scope as I witnessed the shared statuses related to palliative care and the conversations between nurses prompted in the comments. An analysis of digital mindline assemblages could clarify the role of emotion on KT in this novel arena. A developing body of literature focuses on the increasing influence of the 'digital age' and the potential role of social media and virtual spaces in transforming mindlines (Cunningham & Shirley 2015). Wieringa and colleagues (2018) digital ethnography explored how online environments provide a space for physicians to collectively form and shape knowledge. The continuously growing role of social media, online

forums, and digital applications in the development and transformation of mindlines suggests new avenues to explore emotion in this process. This could involve teasing apart the emotions bound within online mindline assemblages

A pragmatic research direction would be using this thesis as a foundation to explore how emotions effect the cycle of building and turning over persistent mindlines assemblages, while keeping alternative, less persistent ones afloat efficiently (Wieringa & Greenhalgh 2015). While Wieringa and Greenhalgh (2015) question ‘whether controlling knowledge creation is actually feasible’ (p. 8), they urge the importance of persisting with mindlines to ‘help us to see and find new events, insights and practices so we limit discontinuity or instability’ (p. 9). Recent literature has advocated for a narrative approach to ethics teaching as an effective and appropriate way to bring emotions into the training of clinicians (Guillemin & Gillam 2015). This follows Guillemin and Gillam’s (2015) contention that emotions have a ‘legitimate role in ethics teaching and professional identity formation in health professions education’ (p. 730). My research supports this approach and suggests that the inclusion of emotional narratives in knowledge creation and translation, for example in the development of guidelines and research material, could be a pertinent research direction. Opportunities for sharing embodied knowledge should also be encouraged and should include reflexive attention to emotion. This might be further explicated by examining the relationship between art-based KT and emotional mindlines.

Additionally, novel methodologies should be incorporated into the exploration of emotion and mindlines, particularly methodologies that incorporate collaborative approaches and aesthetic sensibilities. Art-based research encompasses the use of various media to (re)create and translate knowledge and represent the complexities of human experience (Gray et al. 2003; Knowles & Cole 2008; Mason 2005). Collaborations between artists and research can help to cross interdisciplinary boundaries, transcend the potential strictures of traditional modes of KT,

and develop innovative types of research (Boydell 2011; Cole & Knowles 2008; Gray & Sinding 2002; Kontos & Naglie 2007; Mitchell, Jonas-Simpson & Ivonoffski 2006). Art-based KT vehicles present opportunities to explore forms of research that reflect the richness and complexity of assemblage data and invite multiple levels of engagement that are sensory and emotional (Law & Urry 2004). An art-based health study revealed the value of including visceral, emotional, and visual elements in research creation and dissemination to allow access and representation of different types of experience and knowledge (Boydell et al. 2017; Hodgins & Boydell 2013). Future research could explore the potential for art-based methods to both examine and foster mindlines assemblages that are contingent on emotions, for instance conveying to junior clinicians the immediacy of suffering and the emotional experiences of palliative care. It can provide insight into the emotionality of the medical encounter by offering affecting accounts of practice.

8.6 Conclusion

My work supports Gabbay and le May's (2011) contention that conventional assumptions of the EBHC movement are ill-equipped to account for the nature of evidence and the context of its use. Reid (2014) advocated for a 'radical approach' to understand emotion and reason as ultimately the same thing, labelling rationalism a product of emotion: 'without emotion, no rationality is possible' (p. 204). My intention in this thesis is not to examine, as Reid did, the effects of emotion on EBHC discourse. However, cursory examinations of palliative care publications related to evidence-based practice suggest a maintenance of the dichotomy between hardness and softness, and a general subjugation of emotionality in EBPC. My thesis asserts that emotion is inherently part of the assemblage of 'complex [and] diffuse organisational processes' (Gabbay & le May, 2011, p. 198) of KT and as such should be accounted for by scholars, managers, and practitioners. Emotions underscore the strength of

value-based healthcare. Kelly and colleagues (2015) proposed that values imbue the ‘short cuts’ (p. 2) that provide clinicians and researchers immediate answers to issues and problems that they are confronted with daily. This idea extends from Nussbaum’s (2003) emphasis that all observed facts are contingent on our emotions. These emotions are consciously derived from our values, giving actions and decisions moral worth and significance. They provide new opportunities to consider complexity in healthcare, explaining the discrepancies between guidelines, managerial imperatives, and practices. Emotions can enable clinicians to learn to be affected. This thesis aims to provoke a critical appraisal of the role of emotion and KT, adding assemblage theory to the toolkit of those seeking to ensure richer forms of evidence-based knowledge.

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