Deleuzians of Patient Safety:

A Video Reflexive Ethnography of End-of-Life Care

Aileen Collier

Doctor of Philosophy

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Certificate of Authorship/Originality

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged within the text.

I also certify that the thesis has been written by me. Any help that I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

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List of video vignettes∗

∗ Video clips have restricted distribution and disclosure

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Glossary of abbreviations

ANUM	Acting Nurse Unit Manager
CCU	Coronary Care Unit
CPR	Cardiopulmonary resuscitation
CT scan	Computed Tomography scan
CTC	Cancer Therapy Centre
DNR	Do Not Resuscitate
EDD	Expected Date of Discharge
EN	Enrolled Nurse
GP	General Practitioner
ICPS	International Classification for Patient Safety
ICU	Intensive Care Unit
IIMS	Incident Information and Management System
M&M	Morbidity and Mortality
MRSA	Methicillin-resistant Staphylococcus Aureus
NSW	New South Wales
NUM	Nurse Unit Manager
OECD	Organisation for Economic Co-operation and Development
PEG	Percutaneous Endoscopic Gastrostomy
RN	Registered Nurse
SUPPORT	Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment
WHO	World Health Organisation

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Glossary of hospital roles and terms

Director of Nursing	The Director of Nursing is a registered nurse who oversees the nursing care of the acute hospital.
General Manager	The General Manager oversees the management of the acute hospital
Clinical Nurse Consultant	A senior nurse appointed to a particular speciality area with a minimum of five years post-graduate experience including experience in and approved post registration qualifications in the specialty field she/he is working in.
Specialist Palliative Care Team	The specialist palliative care team is a multidisciplinary team working in partnership with other healthcare workers to provide palliative care to patients and families in a range of settings.
Staff Specialist/Specialist	A senior level doctor who has attained a fellowship of a recognised Australasian specialist college and has spent at least five years in the practice of medicine
Social worker	A social worker is an allied health professional who provides counselling and support to patients and families as well as other practical assistance including coordination and participation in case conferences, discharge planning, and financial support.
Diversional Therapist	In this thesis a diversional therapist is an allied healthcare professional who coordinates and provides diversional therapy for individuals and groups in the palliative care in-patient unit, the palliative care day hospital and patients' homes. The diversional therapist facilitates leisure and recreational activities and programmes to support peoples' wellbeing.
Junior doctor	In this thesis, a junior doctor can refer to a registrar (A doctor who is training in a particular medical specialty, such as haematology) or a resident (The most junior doctor on the team, also known as a Resident Medical Officer)
Registered Nurse	A registered nurse refers to a nurse who has completed training and is registered with the nursing and midwifery board of Australia. A registered nurse is accountable for the provision of nursing care in a range of settings and delegates care to enrolled nurses and other healthcare workers.
Enrolled Nurse	An enrolled nurse is a nurse who has complete enrolled nurse training and provides nursing care in a range of settings. An enrolled nurse works under the direction and supervision of a registered nurse.

Nurse Unit Manager	The Nurse Unit Manager is the nurse in charge of managing the ward. A NUM is a registered nurse (RN) who oversees, co-ordinates, and directs the activities of nurses in a specific ward or unit of a hospital or community team, including outpatient departments. The NUM is also responsible for the business and management functions and processes of the ward or unit.
Senior nurse	In this thesis, a senior nurse refers to an experienced nurse with more than three years post-graduate clinical experience.
Grand Rounds	In this thesis, ‘grand rounds’ refers to a weekly presentation open to all healthcare professionals in the acute hospital. Specialist teams rotate responsibility to present a ‘case’ of interest or research findings pertaining to their specialty.

Glossary of key terms

Space	A dynamically produced and reproduced product of interconnection that is always unfinished where everything is connected to everything else in pre-discursive and practical ways.
Affect	The capacity of one body (human or otherwise) to affect or be affected by another incorporating pre or transpersonal intensities that exceeds any single human subjectivity.
Multiplicities	The simultaneous enactment of objects when those objects are said to be the same and where different realities co-exist in independent locations without interfering with one another.
Assemblage	Non-static collections of heterogenous human and non-human affective entities. In this thesis, the term assemblage is used instead of space to foreground multiplicities.
Becoming	The dynamic unfolding of 'being' that is always immanent and moved or activated in relation to the collective body.
Nomadic Subject	A subject that is open to becoming-other, resisting fixed identity, order and categorisation.
Body with Organs (Body Singular)	A clearly bounded individual or fixed enclosed unit in which organs are enveloped in a container of skin and the body is a set of physiological processes as in the medical-technical view
Body without Organs (Body Multiple)	A body (human or otherwise) that can mean different things at the same time and emerges from the physical and social world.
Territorialisation	'Normalisation' of social structures that produces order and categorisation.
De-territorialisation	Denotes escape from predetermined patterns of order and categorisation.
Lines of flight	Creative potentials that lead to de-territorialisation
Adverse Events	In this thesis, adverse events refer to events defined by patients and families as harmful as well as by healthcare workers and clinical governance departments.
Becoming-harm	Collectives of human and non-human affective entities that predispose patients, families and healthcare workers to harm.
Clinical technical assemblages	Assemblages that are privileged towards technical medical procedures and are focused towards the needs of healthcare workers and the hospital rather than patients and families.

Affective Atmospheres	Atmospheres that emanate from but exceed the assembling of bodies affecting and being affected.
Becoming-safe assemblages	Collectives of human and non-human affective entities that predispose patients, families and healthcare workers to safety and make healing possible.
Healthcare Safeties	The combined safety of healthcare workers, patients and families leading to safety that is co-produced.

Glossary of data sources

FI	Field Interview
EFN	Ethnographic Field Note
PC	Phone Call
RD	Reflective Diary
SSI	Semi-Structured Interview
VRM #1	Video Reflexive Meeting (small group-internal)
VRM #2	Video Reflexive Meeting (one-on-one)
VRM #3	Video Reflexive Meeting (large group-external)

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Abstract

This thesis explores healthcare space(s) towards the end of life. It critically examines the links between the places/spaces where dying people find themselves, and how spaces enable or constrain their agency and contribute to the quality of the care they receive. There is a dearth of research that is concerned specifically with end of life care space(s) and patient safety. This thesis addresses this gap. It draws on several theoretical approaches. Principally concerned with the concept 'space', the theoretical lens of the research is inspired by French philosophers Deleuze and Guattari.

This thesis differs from previous studies by positioning dying people centrally in the research. Using an indigenous ethics research framework of relationship and reciprocity, the study challenges current positioning of dying patients as vulnerable research subjects. In so doing, it searches out alternatives to conventional methods in order to give recognition to agency. Comprising a written dissertation and a video component, this thesis integrates the visual with the written text providing a platform for the reader to process it somaesthetically.[1]

This research study found that the field of patient safety does not presently address the care quality and safety needs of dying people. Habitual care patterns expose dying patients and their families to harm along with those healthcare workers caring for them. Visual methods provide a disruptive innovation that challenges these normative and habitual rhythms of inattentiveness to healthcare (un)safeties. This thesis finds that safety and 'healing' reside within dynamic assemblages arising from bodies affecting and being affected by others. When healthcare workers 'learn to be affected' and thus become attuned to the implications of safety and dying, healthcare safeties become possible. Healthcare safeties are contingent on weaves of commitment netting in relationships of trust by bringing together healthcare worker expertise and the expertise of patients and their families to *co-produce* safety. This thesis contends that rather than a place where interventions happen, healthcare settings *are* clinical interventions. Lastly, researcher stances and research methods are, therefore, not to be formed separately from the healthcare setting but to be articulated through and in the setting,

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[1] A term coined by Shusterman to represent a philosophy that takes account of the body: "denotes not mere physical body but the lived, sentient, intentional, body that involves mental, social, and cultural dimensions" (Shusterman 2011, p315).

and become a part of it. This methodological conclusion indicates that we as researchers need to move away from our conventional and habitual patterns maintained by disciplinary status and constraint, in order to become part of open-ended, collaborative communities unfolding research and lived change together.

Chapter 1 Introduction

Section 1.1 Introduction

This research was undertaken in association with a larger study titled Examining Organisational Complexity and Clinical Risk to Improve Hospital Patient Safety targeting how clinicians communicate in the context of clinical risk and how ward spaces enable or constrain patient safety.[2] This research is related to but independent of the larger project. This thesis explores healthcare space(s) towards the end of life. It critically examines the links between the places/spaces where dying people find themselves, and how spaces enable or constrain their agency and contribute to the safety and quality of the care they receive. There is a dearth of research concerned specifically with end of life care space(s), and with the implication of space for patient safety. This thesis addresses this gap.

This thesis differs from previous research by positioning dying people centrally in the research. In so doing, this thesis searches out alternatives to conventional methods for safe dying. It consists of a written dissertation and a video component, which comprises a DVD, composed of eight participant vignettes. The thesis contributes empirical data towards answering the question ‘what constitutes a safe healing space’? Using video techniques in a novel way, and grounded primarily in an ethnographic study of end-of - life care it challenges current positioning of dying patients as vulnerable research subjects. Applying an indigenous research ethics framework of relationship and reciprocity, it seeks to uncover agency, knowledge and expertise of patients and their family caregivers as well as of healthcare professionals.

The research fully embraces ‘mess’, uncertainty and transformation. Situated within this theoretical perspective, the methodology captures end of life space(s) in which the complexity of human action and interaction is embedded in the material environment. In engaging with this complexity, the research does not draw a boundary between the

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[2] The aims of the larger project were as follows: to formulate communication strategies and spatial−design principles that promote and maintain patient safety in organisations that harbour clinical risk; to re−invent patient safety research by creating space for experience−based enquiry that involves clinicians and researchers in reflecting on and intervening in clinical practice, and to theorise experience−based enquiry as research that seeks to act as a feedback dynamic for professionals working in high complexity organisational environments.

researcher and the researched. Rather, it explores spatiality where all parties are integral to space making.

The ‘mess’ that this methodology reveals and that it to some extent produces results in a complex research route incorporating multiple methods, but also a route that fosters creativity and innovation for patients, families and healthcare workers as well as myself as the researcher. This thesis shows how creative collaborations formed with patients, families and healthcare workers open up new worlds and reveals otherwise intangible ways of seeing and being.

Section 1.2 Background

The impact of death and dying on individuals, families and communities, as well as society as a whole, can be profound. Many people now die from chronic illnesses and have care needs spanning years or even decades. Further, the majority of people with a life-limiting illness will spend most of their time at home and in acute care hospitals rather than hospice or under the care of specialist palliative care services (Palliative Care Australia 2010, p14). Importantly, and in the oft cited words attributed to Dame Cicely Saunders, founder of the modern hospice movement (1918 - 2005), the quality of care people receive and “how people die remains in the memory of those who live on” (United Kingdom Department of Health 2008). Care at the end of life is a metaphor for care of vulnerable people throughout the system:

> *“How we care for the dying is an indication of how we care for all sick and vulnerable people. It is a measure of society as a whole, and it is a litmus test for health and social care services” (United Kingdom Department of Health 2008, p10).*

The contemporary social landscape is such that death and dying frequently occur in institutions, with hospitals being the most common place of death in Western countries (Seale 2000). In her ethnography of American acute hospitals, Kaufman (2005, p19), described the complexity of issues surrounding the manner in which death and dying are enacted as “The problem of hospital dying”. There is substantial concurrence in the literature that western healthcare systems are not addressing the needs of dying patients and their families. Despite recognition several decades ago that patients dying in acute hospitals suffer high levels of mental as well as physical distress (Hinton 1963), studies continue to reveal the distressing nature of dying in contemporary society and the inadequacies in care provision.

Up to 70% of people die in institutions (Foreman 2006; Palliative Care Australia 2010). These institutions however, are frequently organised around the goal of cure, with a focus on hospital efficiency, routines and tasks that anticipate patients' expected recovery (Palliative Care Australia 2010). These goals are inconsistent with the needs of the dying and their families (Pincombe, Brown & McHutcheon 2003). With a focus on cure, investigations and medical interventions can often continue right up to death (Middlewood, Gardner & Gardner 2001; SUPPORT 1995). A recent Western Australia population based study undertaken by McNamara and Rosenwax (2007) confirmed the complexity of dying with chronic illness. In a review of death certificates, the study showed only 22% of cases had just one cause of death listed. This is supported by recent Australian national statistical data that report the average number of diseases at death as three (Australian Institute of Health and Welfare 2012). McNamara and Rosenwax also reported that a high proportion of people spent a significant amount of time transferring back and forth from hospital, and a large proportion of carers expressed high levels of pain, suffering, and unmet concerns.

Closeness of death frequently goes unrecognised. Clinicians' failure to acknowledge that patients are dying is notable in the literature. Studies highlight difficulties in diagnosing dying (Christakis ; SUPPORT) and even when recognised, poor prognosis is rarely communicated to patients and families (Bradley et al. 2001; Jacobs et al. 2002; SUPPORT 1995). The frequently cited seminal Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT 1995) highlighted the focus on cure and considerable inadequacies in the care of seriously ill hospitalised adults. For example, 38% of patients who died were found to have spent at least 10 days in an intensive care unit (ICU), pointing to unrecognised prognoses and the possibility of unnecessary treatment interventions. Of the 263 heart failure patients studied, 40% received a major treatment intervention in the last three days of life, confirming that clinicians prefer to treat rather than acknowledge death is imminent.

The result of this lack of acknowledgment of imminent death is that relief of pain and other symptoms is often inadequate. Another is that response to the psychosocial needs of patients and their families is poor (Bradley et al. 2001; Jacobs et al. 2002; O'Hara 2006b; Parish et al. 2006; SUPPORT 1995). SUPPORT authors reported that only 47%

of physicians knew that their patients preferred to avoid CPR, while 46% of 'do not resuscitate' (DNR) orders were written less than two days before death. In addition, family members reported moderate to severe pain as an issue for 50% of conscious patients who died in the hospital.

Most notably, the intervention phase of the SUPPORT study failed to produce any significant improvement in quality of care. Assisting clinicians with the earlier identification of dying patients did nothing to alter behaviour in terms of communicating prognosis, perhaps highlighting the complexities involved in acknowledging the dying process, making end-of-life decisions and responding to the multiple needs of patients and families in the hospital environment.

SUPPORT study investigators concluded they had overemphasised the rational decision-making process, and underestimated the human aspects of suffering and death (Benner, Hooper & Kyriakididis 1999). In other words, response to the richness and mystery of the unfolding situation of dying cannot be reduced to reason and logical decision-making. Thus, strategies and processes based on reason and logic and seeking to produce procedures and decision guides failed to address the problem of determining and organising dying. The language of rational decision-making is not rich enough to encapsulate relational, moral and ethical issues that unfold over time. In other words:

> *"reducing the complex human event to rational calculation about what to do and when oversimplifies the demands of the situation by reducing them to decisions rather than finding a good path or being true to the possibilities of the situation as it unfolds" (Benner, Hooper & Kyriakididis 1999, p348).*

Arguably, the relational, moral and ethical dimensions of death and dying require greater depth of understanding of healthcare settings if the 'problem of hospital dying' is to be addressed. The question of creating a health system that addresses safety and quality of end-of-life care is one of urgency, affecting us all. Given an ageing population, where the number of people living with a chronic or complex illness is predicted to increase (Palliative Care Australia 2010), the need for further investigation of appropriate models of care is substantial. In order to address these challenges there is a need to take account of the complexity of current healthcare settings.

Governments, to some extent, recognise that more research is needed. For example, a U.K. Department of Health Strategy Report recommends that more research is needed on all aspects of end-of-life care (United Kingdom Department of Health 2008). A recent Australian Commonwealth Government report also recognises the inadequacies of end-of-life care:

> *"The current experience of end-of-life care in Australia is disparate and inconsistent and we cannot, in good faith, promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health system can do better" (Commonwealth of Australia 2009, p107).*

There is considerable consensus among healthcare professions, academics and policy makers of the need for healthcare reform and further research on end-of-life care is necessary. In particular the need to investigate environments of care and communication about end of life care are priority areas (United Kingdom Department of Health 2008) and provide the rationale for this research.

Section 1.3 Theoretical Framework

The thesis draws on several theoretical approaches and from a number of disciplines. Principally concerned with end of life care spaces, this research is inspired by French philosophers Deleuze and Guattari. In essence, this thesis is concerned with thinking spatially; that is, with affect and with transformation(s). What these terms mean and how they are applied will be clarified as the research unfolds. This thesis draws from activist philosophy characterised by Deleuze and Guattari's use of the term rhizome taken from botany. Rhizome, from the Greek, is a mass of roots: "a continuously growing horizontal underground stem which puts out lateral shoots and adventitious roots at intervals" (Oxford Dictionaries 2012). For Deleuze and Guattari, the rhizome becomes the metaphor for an alternative to the hierarchical ordering represented by the organisational structure of the root-tree system. The rhizome, with its adventitious roots, favours a nomadic system of growth and propagation resisting chronology. In other words, the rhizome, sending out roots, from both the top and bottom of its nodes represents non-linearity and multiplicity:

> *"Let us summarize the principal characteristics of a rhizome: unlike trees or their roots, the rhizome connects any point to any other point, and its traits are not necessarily linked to traits of the same nature; it brings into play very different regimes of signs, and even nonsign states. The rhizome is reducible to neither the One or the multiple" (Deleuze & Guattari 1987, p21).*

Rhizomatic thinking inspires this thesis in several ways. First, it is not bound by discipline-specific rules. While the structure of the thesis follows a traditional approach of introduction, literature review, methodology, data analysis and conclusion, the chapters of the thesis address multiple connections that produce numerous pathways. Second, the thesis contains the different affective modes of visual data as well as written text to communicate its message. Further, rhizomatic thinking enabled my own various identities, including nurse, person and researcher, to be revealed reflexively within the text in a non-linear manner.

A "rhizome has no beginning or end; it is always in the middle, between things, interbeing, intermezzo" (Deleuze & Guattari 1987, p28). This study, seeking out agency of the dying, building it, and working with it required an opportunistic approach and a willingness to proceed in any direction, any time. Just like the rhizome, the study is a series of inter-connected networks that grow and change. Researching rhizomatically opens up spaces where people and communities can connect. But opening up spaces of connection is not straightforward and poses significant ethical challenges.

Section 1.4 Ethical Approach

Notwithstanding the ethical issues that arise in any ethnographic study, some have questioned whether dying patients should be involved in research at all given the fatigue and symptoms that can accompany terminal illness and the seeming impossibility of their benefiting from it (Janssens & Gordijn 2000). The dependency of dying patients on healthcare professionals making them particularly vulnerable and more likely to be coerced into taking part in the research was also a concern. Their dependency tends to be seen to detract from their ability to give honest evaluations of care (Addington-Hall 2002).

Given that research relating to end-of-life care has the potential to impose a significant burden on patients and their families, the research process needs to provide an opportunity for benefit to outweigh harm and to add value to patients' and families' lives during the research as well as beyond it. Perhaps understandably, these issues cause concern for institutional ethics committees concerned that research relating to end-of-life care may not be objective and scientific. My own research was no exception, relying on a research design that incorporates filming of participants.

These issues are not unique to dying patients (Addington-Hall 2002). Arguably, established ethical principles apply to contact with all participants of human research, and there is no reason to consider end of life and palliative care as a special case (Casarett & Karlawish 2000). While institutional ethical clearance for the research was sought and granted from both health and university institution human research ethics committees, I considered it of critical importance that an ethical framework govern the research itself. Frank (2005, p965) recommends Bakhtin's description of Devushkin's feelings to provide caution as to how social science should not leave its subjects feeling "predetermined and finished off":

> *"Devushkin had glimpsed himself in the image of the hero of 'The Overcoat,' which is to say, as something totally quantified, measured, and defined to the last detail: all of you is here, there is nothing more in you, and nothing more to be said about you. He felt himself to be hopelessly predetermined and finished off, as if he were already quite dead, yet at the same time he sensed the falseness of such an approach" (Bakhtin 1984, p58).*

An institutional ethics framework attempts to protect the vulnerable but is unable to prevent research of any kind producing a 'hopelessly predetermined and finished off' participant. Therefore, I take a reflexive approach that actively seeks to avoid 'predetermining and finishing off' any participants and one in which participants are active agents in the research. I draw from ethics and values grounded in Christian theology and enacted within an indigenous research ethics framework.[3] The present research, by removing the boundary between the researcher and the researched, acknowledges ethics and epistemology as inseparable. I view the research as addressing

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[3] Ethical values of "spirit and integrity, reciprocity, respect, equality, responsibility, survival and protection" (National Health and Medical Research Council 2003, p8).

‘questions to be lived’ rather than ‘problems to be solved’. In this regard, I look to the Alphonso Lingis’ “ethic on accompanying the dying” (Hooke 1997, p153). Lingis contends that ‘the very ‘seeing’ of the mortality’ of the other provides the foundation necessary for ethics (Hooke 1997):

> *“Community forms when one exposes oneself to the naked one, the destitute one, the outcast, the dying one. One enters into community, not by affirming oneself and ones’ forces but by exposing oneself to expenditure at a loss, to sacrifice” (Lingis 1994 , p11-12).*

By exposing myself, in the way that Lingis suggests, I hope to apply humility that manifests as a kind of rhizomatic ethics. That is, rather than an a priori set of judgements, I endeavour to activate practical strategies to situations as they unfold and in collaboration with others. This philosophy of ‘doing with’ rather than ‘doing on’ translates into a need to put participants’ voices at the centre of the study, and to hear their perspectives on suffering and healing. Most importantly, I respect the imperative to create a ‘safe’ environment, given that the aim of this research is the study of ‘safe healing spaces’. This ethic is the moral basis for involving dying patients in my research and is the foundation for transformation of both participant and researcher. I explain the indigenous research ethics framework in which I foreground this ethical approach in greater detail in Chapter 3. This approach, driven by people’s agency and a central tenet of the thesis, is brought to life in Chapter 5 where I reflexively examine research relationships, interrogating the ethics of the research and appraising relationships between patients, families and healthcare workers and other stakeholders.

Section 1.5 Research Approaches-A synopsis

The study is primarily an ‘interventionist ethnography’ (Mesman 2007). Entering into collaborative relationships with participants potentially transforms both researcher and participants. The research is unavoidably interventionist (Henriksen 2002) and intervenes explicitly to disrupt end of life care spaces. It does so by using video alongside ethnographic methods enacting what is termed ‘video-ethnography’ (Carroll, Iedema & Kerridge 2008; Iedema et al. 2006c). Video ethnography can interrupt the social landscape creating a “local interactional space” (Mesman 2007, p281). Like Mesman (2007, p282), “I hope in a humble way, to contribute to the optimisation of patient safety" for people who are dying and their families. This research addresses the following five research questions:

1. What are safe healing spaces towards the end of life?
2. Can healthcare space(s) enhance safety and healing?[4]
3. What do collaborative practice-oriented feedback and reflexivity approaches utilising visual methods contribute to end-of-life care research?
4. Can visual methods promote the stories of research participants and advance a more meaningful dying experience?
5. Can visual methods communicate principles, strategies and systems to facilitate improved end of life care to consumers, clinicians, service providers, administrators, designers, planners and policy makers?

Research design

In answering the above research questions, multiple methods were employed including ethnographic field observations, field interviews, semi-structured interviews, participant generated video accounts, and video reflexivity. Chapters 3 and 4 outline these methods in detail. Inevitably 'on the ground' research methods evolved and changed as the research progressed. In collaboration with participants, they remained, however, informed by an indigenous research ethics framework of building relationships and reciprocity, seeking out peoples' agency, and working with it.

Field sites

This thesis considers 'the field' as research site, non-static. That is, methods needed to account for peoples' movements through space and time, in predictable and unpredictable ways. This translates to a need not to be confined to any one place as field site. Practically, however, fieldwork required entry points. The research empirically focuses on two main field sites or what I call 'located entry points'. The first of these is a palliative care day hospital that forms one component of a metropolitan palliative care service. Other components of the palliative care service include a 20-bed inpatient unit, outpatient clinics and after-hours telephone advice service for people diagnosed with a

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[4] Where healing is defined as "the physical, psychological, social, and spiritual processes of transformation that increase resilience and coherence and where wholeness is cultivated" (Miller et al. 2003, pA82).

life-limiting illness. The second entry point is a large metropolitan tertiary referral hospital; a major trauma centre for the state of NSW with approximately 855 beds providing medical, surgical, emergency medicine, intensive care, oncology, mental health, women's health and newborn care services. The reasons I elected these healthcare settings as field sites is explained at length in Chapter 4.

Structure of the thesis

This thesis is written at several levels. The first level is an empirical study of 'patient safety' related specifically to dying patients, their family carers and healthcare workers in the healthcare environment. It builds upon previous explanations of patient safety related to end-of-life care. The second level is a reflexive account of methodology using emergent and visual methods. The third level is a critical account of 'space' applied to patient safety and end of life care, inspired by the theoretical lens of Deleuze and Guattari. It uses theory to transcend static notions of space to show how space is produced by clinical interventions rather than simply providing a place or container where clinical interventions happen.

The thesis is structured into nine chapters. The next chapter (Chapter 2) is titled 'The Problem of Hospital Dying' and provides a review of the literature and the context for the study by addressing the notions, ideas and debates that populate the domain of death and dying.

Chapter 3, 'Theoretical Perspectives', provides the basis for foregrounding the key concepts of 'space' and 'affect' as the overarching concerns of this thesis articulated through the theoretical lens of Deleuze and Guattari. Theoretical underpinnings are prefaced by first providing the historical background to the research informing my own positioning as researcher.

Chapter 4, 'Methods', is dedicated to the process of the research itself, detailing how the theoretical and methodological approaches outlined in Chapter 3, Theoretical Perspectives, were enacted in practice. Outlining the practical and technical components of the research methods, the chapter describes the field sites, details equipment and operational processes of data management. It includes the recruitment and data collection processes and presents the approach to data analysis including video reflexivity.

Chapter 5, ‘Methodological findings: forming communities and building agency’, presents the ‘methodological’ findings of the research. The chapter examines research relationships and forming of communities in ‘real’ situations. Informed by an indigenous research framework, it critiques the ethics of the research and focuses on the development of research relationships.

Chapter 6 to Chapter 8 contain the empirical findings of the thesis. They contain both visual and textual data. Participants’ visual narratives are woven together with the written word. The reasoning for each chapter is realised by visually presenting patient[5] participants at significant points in each chapter. Participants are introduced requesting that the reader view the corresponding visual vignette as the anchor point for the ‘reading’ of key sections. Anchoring to individual stories serves as a heuristic device for each chapter. These stories interact across the thesis as a whole encompassing several analytical layers of the thesis: the analytical process that I as the researcher have engaged in from the outset; the analysis by participants themselves and the readers’/viewers’ own analysis. Chapter 6, ‘Safeties and Un/safeties’, introduces key findings by defining safety according to participants. Chapter 7, ‘Finding Patients and Families in Patient Safety’ explores the ways in which patients and families participate in safeties and un-safeties. Chapter 8, ‘Becoming-safe assemblages’, describes the conditions that predispose participants to safety and make healing possible. The final chapter, Chapter 9, acts as a conclusion drawing out the implications of this thesis, and explicitly answering the five research questions.

The next chapter, Chapter 2 reviews the literatures that populate the main themes associated with dying in today’s social landscape. These important works alongside my professional experiences as a palliative care nurse have provided the entry point and consequently the springboard for me to extend end-of-life care research.

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[5] Recognising participants as fellow human beings and as persons, I am uncomfortable with the use of the impersonal ‘patient’. I have chosen, however, to use it for practical reasons to avoid confusion for the reader.

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Chapter 2 Literature Review

Section 2.1 Introduction

This chapter provides the context for the study by addressing the notions, ideas, and debates that populate the domain of death and dying. It foregrounds the current research by providing a critical appraisal of the literature that contributes to these ideas and debates. The literature review was an iterative process driven by the need to investigate environments of care and communication about end of life care (United Kingdom Department of Health 2008); key concepts related to the larger research project including patient safety, space and place, and by a need to accommodate a range of voices including patients, families and clinicians as well as conventional research studies. These literatures together with my professional experiences as a palliative care nurse provide the entry point for me to extend the field of end-of-life care knowledge and provide the rationale for this research.

This chapter is structured in four main sections. Section 2.2, titled 'Socio-political Setting' is concerned with the socio-political context of death and dying. In particular it considers the influences of the technological progression of healthcare on end of life care. Section 2.3 is titled 'The Good Death?' This section provides an historical context of how the idea of a good death has arisen and explores this concept from the perspectives of patients, families and healthcare professionals. Section 2.4 is titled 'Medicine and Nursing: The caring professions.' It broadly examines the position of medicine and nursing in end-of-life care including the effects of death and dying on professional carers and the implications for care delivery. The final section (Section 2.5) is titled 'Space, Place and Safety'. It considers the concepts space, place and safety as they relate to end-of-life care. More specifically, the interconnectedness between space, hospital and home, spirituality, and safety is examined. The chapter concludes with a summary of the empirical gaps concerning the problem of hospital dying enabling the aim of the research to be defined.

Section 2.2 Socio-political Setting

This section examines the wider socio-political context in which death and dying are situated. It begins by exploring the current healthcare landscape. This foreshadows discussion of the biomedical approach to healthcare and its burgeoning technologies. The influences of these technologies and the professionalisation of dying arising from them are explored including the ethical underpinnings of medicine. Finally, efforts to counter the effects of such technologies are discussed, including advance care directives and the hospice and palliative care movement.

The healthcare landscape

The healthcare landscape and hospitals in particular have become increasingly complex settings of healthcare provision. The last 100 years has seen a significant change in the nature of disease, rapidly evolving technology and a subsequent dramatic change in the role of hospitals (Commonwealth of Australia 2009).

> *"Once upon a time, hospitals provided little more than solace and isolation to people afflicted with infectious diseases such as leprosy, polio and diphtheria. But as technology and medical advances transformed our capacity to save lives, hospitals evolved into places that provided highly specialised services with most people beginning and ending their lives in hospitals" (Commonwealth of Australia 2009, p104).*

Western societal values, and politically driven healthcare funding structures, are focused towards 'life saving' technologies and interventions. The acute hospital environment and its prevailing culture give credence to cure over care, with death often defined as medical failure. This is accompanied by an emphasis on throughput and a propensity to "move things along" (Kaufman 2005, p96). This may be exacerbated in the Australian Healthcare system as a result of a reduction in bed numbers to a level below that of other Organisation for Economic Co-operation and Development (OECD) countries (Sammut 2008). A recent government report purports to address the issues of an aging population and growing cost demands of chronic illness by recommending a system that focuses on prevention and taking healthcare to patients in the community (Commonwealth of Australia 2009). It is the very advancements in medicine, however, that have produced a situation in which an increase in life expectancy increases the likelihood of living with chronic health conditions that will inevitably lead to increased requirements for care (Callahan 1990; Sammut 2008). Curative medicine underpins much of chronic disease treatment. The capability of medicine to cure, however, will always be limited (Giordano & Jonas 2007). That is to say, there will always be something that cannot be cured. Callahan calls this the 'ragged edge' of medical progress. No matter how far medical advancements are pursued, there will always be eventual decline and death for the individual and there will always be more progress to be made. In other words, there will always be an: "Ever-evolving point where sickness and health, life and death, come roughly and irregularly together" (Callahan 1990 p221). Put starkly, for every disease that is prevented or cured there will be another to take its place. Every time one is saved from the brink of death, there will be a next time one needs to be 'saved' and may be lost. Thus, a healthcare policy founded upon preventing chronic illness and, at the same time, promoting medical progress becomes economically unsustainable rather than cost saving.

Current Western healthcare systems are founded on the principles of a biomedical model (Giordano & Jonas 2007; Marcum 2008a; Wade & Halligan 2004). The biomedical model is believed to have originated from Descartes' thinking and motivated by a Newtonian mechanical philosophy (Marcum 2008b). The Cartesian body-mind split understands the person as a mechanistic body, composed of functional parts that interact with the mind as identity and energy source. The body, a scientific object, is seen as composed of parts made up of physiological systems that medical science aims to fix (Marcum 2008b). Medical treatment is organised around medical specialties that focus on a particular physiological system. Under this model, assessment of a patient by numerous different specialists during the course of a single hospital admission is commonplace. The current view of the patient, filtered through the biomedical lens, has arisen and evolved historically into a kind of objectification of the person as a set of organs, a set of systems to be treated, a 'medicalised body' and one that constructs the body as 'anatomy' (Brown & Webster 2004). This view of the body as an object detached from its surroundings is what Deleuze and Guattari call a 'Body with Organs'. The next chapter (Chapter 3) extends this critique of the body further and defines 'Body with Organs' in greater depth.

The prevailing biomedical model is embedded within a 'high modernity' society (Giddens 1991) in which there is an incredible pace and scope of change and in which there is always uncertainty as to whether or not knowledge today will need to be revised tomorrow. It is within this era of rapidly developing medical technology, and of increased longevity, that the complexity surrounding the healthcare response to death and dying arises. The ability to prolong life and decision-making involving highly technical care are hostage to pervasive uncertainty about whether someone is on the threshold of death or not (Brown & Webster 2004). The difficulty of diagnosing dying adds to the difficulty of end-of-life decision-making.

Facing end of life, doctors are not good at developing prognoses, and overall, have a tendency to undermine pessimism and reinforce optimism (Christakis 1999). This is particularly evident in relation to chronic disease trajectories in the context of greater longevity; for example, chronic obstructive airways disease and chronic heart failure or dementia (Coventry et al. 2005). Even when doctors recognise a high possibility of the patient dying during hospital admission, they tend towards not communicating this to the patient (Bradley et al. 2001; Sullivan et al. 2007). While 87% of doctors recognised that death was imminent over the course of the hospitalisation, only 11% reported speaking personally to the patient about dying (Sullivan et al. 2007, p882). The pervasiveness of norms surrounding the imperative to cure can be so powerful that doctors perceive that the very act of delivering prognosis itself can influence the timing of the death (Christakis 1999). Likewise, nurses tend to avoid discussing prognosis or hospice care with their patients (Bradley et al. 2001). Furthermore, communication between nurses and patients and families in relation to the psychological, social and spiritual needs of patients and their families is rarely documented in medical records (Parish et al. 2006).

Hospital death in a highly technological environment, with ‘heroic intervention’ is often portrayed as the most unnatural and inhumane of deaths (Seymour 1999). There is a commonly held view that humane care and high-tech hospital treatment are mutually exclusive. Furthermore a hospitalised death is associated with the:

> *“Fear of being caught up in a medical juggernaut driven by a logic of its own, one less focused on human suffering and dignity than on the struggle to maintain vital functions” (Moskowitz & Nelson 1995, pS3).*

It is in the context of this medical juggernaut that patients have been described as: “an object of clinical vigilance but invisible at the personal level” (Almerud et al. 2007, p151). This view has been challenged, however. For example, an alternative approach aligned with Giddens (1991) structuration theory has been proposed (Barnard & Sandelowski 2001; Seymour 1999; Timmermans 1998). These authors argue that meaningfulness is constantly and dynamically negotiated, and is temporally and spatially situated inclusive of the physical space, but not reduced to it. The view that healthcare professionals are mindless followers of technological directives, and not people enmeshed with both patients and technology, does not take account of social contexts and the meanings attached to them (Barnard & Sandelowski 2001). Whether the patient is cared for in a highly technical environment, or attached to an array of medical equipment and tubes does not determine whether care is humane or not. Rather, it is the meaning attached to the care and manner in which it is provided that determines humane care (Seymour 1999). Individual healthcare professionals determine whether or not patients feel 'human'. These healthcare professionals can potentially enable the maintenance of 'the lived self' through their presence, unlike technological equipment (Gramling 2004).

Heroic measures (i.e. attempts to grant the patient the full array of treatments irrespective of their likelihood of dying) are perhaps a symbolic way of saying that the person is worth every effort, and that this value is manifested in the rituals of extreme intervention measures (Benner, Hooper & Kyriakididis 1999). Emergency department resuscitation attempts have been viewed as a biomedical ritual facilitating a 'status passage' and that going through the motions of cardiopulmonary resuscitation creates a period of liminality where there is time for loved ones to prepare for the transition from life to death (Timmermans 1998). Others argue (Benner, Hooper & Kyriakididis 1999; Kearney 2000) that imposing medical technical interventions within such a technological environment serves to enable the distancing necessary when healthcare professionals are confronted with the pain, suffering, and dying of fellow human beings.

The biomedical model is functional and necessary and has served to enable the effective treatment, cure, and prevention of numerous disease processes. The biomedical model leads to control, even of life threatening illness, albeit temporarily, as well as making a significant contribution to quality of life (Giordano & Jonas 2007; Kearney 2000; Porter 1997). Moreover, it is a necessary component of care in responding to physical symptoms such as pain (Kearney 2000; Lewis 2007; Wade & Halligan 2004). However, there is a body of literature that questions modern medicine's biomedical approach

(Wade & Halligan 2004), particularly in relation to care of the dying (Lewis 2007). Biomedicine is unable to fully explain all forms of illness and positions the patient as a passive recipient of treatment provided by the doctor (Wade & Halligan 2004).

Lewis (2009) asserts that the biomedical model is merely limited by the fact that it has been built upon a biological science that is not focused on the individual. As such, the discipline of biological science should be called upon to assist medicine in establishing a new biomedical model of the individual as a biological entity. There is a need for additional or alternative models that recognise a humanistic perspective (Charon & Wyer 2008; Giordano & Jonas 2007; Kearney 2000; Wade & Halligan 2004). A humanistic perspective is one that views the patient as a subject who is embodied in space and time. Rather than the body being something that the subject possesses, our humanness is a lived whole that cannot be split into body and mind (Cassell 1991, 2004; Tauber 2000). In this realm it is not bodies that suffer but people (Cassell 1991, 2004). Chapter 3 takes up this argument again, when consideration is given to views of the body in this thesis. Cassell affirms the need for medicine to reassert its healing and caring roles alongside the role of cure. Arguably, the suffering and grief that accompany the human passage of dying necessitate going beyond the physical to encompass the whole person (Kearney 1992, 2000). A whole person is not a person configured as biological, psychological, social and spiritual one (Hutchinson 2011) but rather one who is viewed as a subject, embodied in space and time in relation to their social context. The hospice and palliative care movement has attempted to respond to this appeal for care of the whole person. The next subsection provides a critical appraisal of palliative care philosophy.

The hospice and palliative care movement

A growing expectation of a different kind of death has in part developed through the modern hospice movement. The movement evolved out of the drive to improve care of dying patients (Finlay 2003) and hospices themselves developed from the recognition that the needs of cancer patients towards the end of life were unmet in the hospital environment. The principle of the ‘hospice’ as a place of refuge for travellers on some difficult road dates to the 4th century (2007). It was the opening in 1967 of St Christopher’s hospice, London, however, that heralded the modern hospice movement. Dame Cicely Saunders’ vision was driven by witnessing the physical and emotional distress of dying hospital patients, and what she saw as the failure of contemporary medicine to respond to the suffering and alienation of these patients. Her vision was one in which patients facing the end of life required what she called "care of the heart" together with well-developed and researched medical skills (Saunders 1996, p318). Recognising that the social life and search for meaning was important to the person, as well as treating the physical pain, she coined the term 'total pain' to encompass the physical, emotional, social and spiritual complexity of pain. Saunders talked of the need for "the freedom of each individual to make his or her own journey towards their ultimate goals" (Saunders 1996, p319).

Out of the hospice movement emerged the new specialty of 'palliative care'. Hospice philosophy was, and is, being globally adopted as the model of excellence in providing quality care of the dying, and has done much to pioneer improved care over the past forty years including advancements in pain and symptom management and encouraging dialogue about death and dying (Saunders 1996).

Specialist hospital palliative care teams strive to enhance the care of dying patients and their families in hospitals, with education as a major focus. However, there are emerging issues surrounding the palliative care response, and the specialty of palliative care faces numerous and onerous challenges. First, as a relatively new medical specialty, with its focus on quality of life rather than cure, the healthcare professionals within it engage in a struggle over its identity, value, and status as a specialty distinct from other medical specialties. This is most evident in the context of the biomedical model, and the Western healthcare approach in which the dominant paradigm rewards a rational analytical, logical, evidenced-based practice approach (Kearney 2000). As Cassell puts it:

> *"The dominance and success of science in our time has led to the widely held and crippling prejudice that no knowledge is real unless it is objective and measurable" (Cassell 1991, 2004, p viii).*

This privileging of reductionist materialist science is at odds with a philosophy that aims to respond to the whole person as a unique individual, creating tensions between medical science and palliative care.

Second, palliative care philosophy places value on open awareness of dying, where loss is anticipated, and grieving initiated. It involves coming to terms with one's own dying, putting affairs in order, making decisions about end-of-life care and the preferred place of death (Pastrana et al. 2008). For the most part, patients want their doctors to be open with them in disclosing both good and bad news (Fallowfield 2001). Contrary to the popular belief that telling patients their prognosis might relinquish any hope they may have, doctor-patient collaboration and acknowledgment of the patient as an individual have been found to promote hope (Hagerty et al. 2004). The open awareness paradigm, however, leads to several challenges in responding to 'hospital dying'. Being in open awareness is wholly dependent on a diagnosis of dying and recognition of one's own dying (Seale, Addington-Hall & McCarthy 1997). This underpinning value of open awareness assumes the value of self-determination and a desire on behalf of patients to engage in such a process. Yet, while most patients and families want healthcare professionals to be honest with them, not all want full disclosure (Gott et al. 2008) As their illness progresses, patients often want less prognostic information, whereas their carers may have an increased need for information (Fallowfield 2001). Furthermore, older patients do not necessarily want an open awareness of death and dying (Gott et al. 2008). Subsequently, a value of 'open awareness' has, to some degree, resulted in the construction of a correct 'way to die' which can in turn result in labelling of patients who do not or cannot follow such a 'correct way' (Zimmerman 2007). In other words the normative paradigm of open awareness might function as "a reductionist and restrictive force" and one that patients are expected to live up to (Goldsteen et al. 2006, p384; Gott et al. 2008).

This may be particularly problematic in the acute hospital setting where open awareness is in direct conflict with the prevailing biomedical model, in which the primary focus is on treatment and cure. When there is uncertainty about medical outcomes at the threshold of dying, and futility is suspected, the medical imperative towards the goal of cure takes precedence (Christakis 1999).

Importantly, the value of open awareness arose out of the care of people with cancer, a diagnosis in which the illness trajectory is more predictable than chronic disease patterns that have materialised in the last few decades (Seale, Addington-Hall & McCarthy 1997). The move over recent years to openly discussing diagnosis and prognosis with patients has not proliferated far beyond cancer patients. Death was unexpected by both patient and family in situations of non-cancer in Seale, Addington-Hall & McArthy's study of awareness in dying, suggesting that open awareness was not the norm for this patient group. Further, non-cancer patients may not want to be aware of their imminent death (Gott et al. 2008). While the specialty of palliative care has increasingly recognised its potential contribution to non-cancer patients, this remains an area for further development, and palliative models of care that are appropriate to the needs of patients with non-cancer are in their infancy (Aldred, Gott & Gariballa 2004; Fitzsimmons et al. 2007; Gott et al. 2008; Gunda, Thomas & Smith 2005). In addition the goal to reach one's potential, and a coming to terms with endings may be largely the favoured modus operandi of those in higher socioeconomic groups (Seale, Addington-Hall & McCarthy 1997). Perhaps those in marginalised groups are less autonomous and have less power and resources to assert their individual rights or perhaps they are less concerned with doing so (Seale, Addington-Hall & McCarthy 1997).

There are further problems with this approach. To be in open awareness requires a person to be cognitively able to engage with the medical process. For example, this would not be possible for patients with advanced dementia. Furthermore, autonomy and self-determination are perhaps specific values of Western culture and not necessarily the values of others particularly cultures that hold a collectivist value of decision-making. For example, open awareness may not be a value held among ethnic Chinese for whom open discussion of death and dying is taboo (Hsiung, Ferrans & Estwing 2007). When there is a collectivist rather than an individualist philosophy, patients may have a preference for information to be negotiated through a family member (Hsiung, Ferrans & Estwing 2007).

Lastly, the specialty of palliative care itself has been charged with the medicalisation of dying. The 'clinical gaze' described by Foucault (1975) suggests an objectification of patients who are caught up in the power of the doctor's clinical wisdom. This view corresponds with Illich's (1976) medicalisation critique in so far that medicine is seen as a power that vanquishes human agency and in which patients are stuck in "A sticky web of medical power from which they are unable to emerge" (Peterson & Bunton 1997, p101).

Kearney (1992) warned of the medicalisation of palliative care. He predicted that the biomedical model would prove too dominant to keep sight of the holistic focus expressed in the WHO palliative care definition[6] (Sepulveda, Yoshida & Ulrich 2002).

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[6] "*Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by*

In essence, Kearney was warning of the establishment of the ‘palliative clinical gaze’. This criticism stems from the fact that there is now a substantial group of palliative care clinicians who take the view that the medical role within the specialty should be solely one of ‘symptomatologist’, a role that responds to physical symptoms alone. In other words a view that returns the body to a set of organs or anatomy and renouncing the role of healthcare workers in responding to suffering in its totality (Ahmedzai 1997).

Nevertheless, those palliative workers who endeavour to keep sight of, and uphold, the initial values of holistic care in a healthcare system that does not give full value or recognition to them, are inevitably left to confront the tensions that exist both outside of, and within, the specialty. Palliative care services in hospitals and indeed throughout the entire healthcare system struggle to deliver care according to the visionary philosophy of Saunders (1996) and the WHO definition of palliative care (Sepulveda, Yoshida & Ulrich 2002). These services are situated at the very heart of the biomedical epoch and are unable to compete for what are often seen as ‘soft resources’. Economic accountability requires ‘evidence-based medicine’ that can justify cost in terms of clinical effectiveness. Attention to the emotional and moral aspects of illness (Tauber 2000) or “care of the heart” (Saunders 1996, p318) are often outside the material parameters of measurement. Emotional and moral aspects remain intangible and this guarantees their marginalisation in funding, planning and policy.

In sum, the ‘open awareness’ paradigm has received much attention and critique. In particular, open awareness assumes self-determination and the principle of autonomy. A critique of these principles and their effects is the focus of the next part of this section.

Bioethical context and the issue of autonomy

This part interrogates the accepted ethical principles of current medical practice further. In particular the premise behind the principle of autonomy is questioned. This precedes a short critique of advance care directives as a possible solution to counter unnecessary hospitalisation and unwanted treatments.

Further dilemmas are encountered as a result of the difficulty of applying the accepted ethical principles of current medical practice. Specifically, beneficence (to do good), non-maleficence (do no harm), justice (equity of healthcare and distribution of scarce

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means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (World Health Organisation 2012).

healthcare resources), and autonomy (to deliberate, judge, choose and act upon different possible courses of action) (Beauchamp & Childress 1994). These ethical principles developed out of the drive towards individual rights (Drought & Koenig 2002). Beneficence and non-maleficence are open to interpretation, not only between patient and doctor, but also within the family unit and among healthcare professionals. This is particularly so within the plurality of healthcare teams, where opposing views of different healthcare professionals often co-exist. Applying the principle of justice is even more problematic and controversial when issues of economics, resources, and fairness come into play in relation to making decisions around whether or not to withdraw or withhold expensive medical treatments. Whether it is at all possible for clinicians to be expected to facilitate decision-making regarding the treatment of specific patients within the wider framework of the consideration of fairness for all is highly questionable (Hillman & Chen 2009).

The assumption that the ethical construct of autonomy can be applied to decision-making in circumstances of threat to ‘ontological security’ is troublesome. Not only do physical constraints place limits on available options, but also what Benner et al (2003, p558) call “vulnerabilities of embodiment”, which challenge the capability for autonomous decision-making. That is to say, it is misleading to present the dying process only in terms of rational choices about treatments or strategic decision-making. There are finite limits to choices at the end of life. Treatment options and the possibility of ‘salvage’ are limited by dying itself (Benner et al. 2003).

Moreover, the very notion of autonomy is challenged within the social complexity of the hospital environment, where everyone ‘muddles through’ (Kaufman 2005). When asked to make decisions as proxy, families express inadequacy in making judgements around withdrawal of treatment, feeling that they do not have the expertise to make such judgments (Jacobs et al. 2002). End-of-life decision-making can be a burden for family members, who often feel that decisions are not theirs to make without having the ‘expert’ knowledge of the doctor (Steinhauser et al. 2000b). The trouble with the ethical construct of autonomy is that it assumes the patient and family have the capacity to be autonomous in isolation of the psychosocial context of what is happening. For example, Kaufman (2005, p74) observes that: “Patients and families are not unencumbered actors making treatment choices in social isolation or in isolation to webs of power”.

The prevailing model is one in which higher value is placed on reason and logic than on affect in decision-making. Patients and families are often expected to be able to make reasoned and rational decisions in an unfamiliar environment, often under great stress and when they are grieving (Hillman & Chen 2009). The value placed on reason over emotion is arguably patriarchal, and patients or families may be left feeling inadequate, having failed morally if they do not make the 'Gold standard' mark within a dominant model of rational decision-making (Eliott & Olver 2005). That is, if they are deemed unable to make a reasoned informed decision in isolation of their emotional state in a timely manner. Structured attempts have been made to address end of life decision-making proactively so as to reduce this kind of conflict. This is achieved by establishing and formalising individual's wishes prior to end of life events requiring decision-making, as an advance care directive.

Advance care directives

While advance care directives have gone some way to responding to unnecessary hospitalisation and unwanted treatments, their use is not widespread. Furthermore, without a fully integrated approach to implementation and community education, healthcare professionals are often left feeling uncertain about their role in enacting the plan, leaving no guarantee that patient wishes will be respected. Moreover decisions made today, may not be the same decisions that would be made under actual circumstances (Nolan 2004). When emotions are charged, and patients and families are expected to make complex decisions under stressful circumstances, faced with the uncertainty of life and death in the moment, a whole new meaning is made that may alter one's position significantly (Eliott & Olver 2005). Meaning is made in a social context and in interaction with the environment (Kaufman 2005).

Conclusion

This section has focused on the influences of a 'high modernity' society in which rapid change and technological advancements are a normal part of everyday life and one in which the societal and medical imperative is postponing death and achieving immortality. Medical research and healthcare systems are configured to achieve these goals in a culture in which death is representative of medical failure. In contrast, the hospice and palliative care movement asks one to accept death as a normal part of the life cycle, especially when faced with a terminal illness. These opposing ideologies alongside unrealistic community expectations situated in a complex dynamic health system are enacted at the bedside, resulting in conflict over end of life treatment decisions and care.

Initially set up to counteract the biomedical approach in caring for terminally ill cancer patients, the hospice and palliative care movement has done much in its attempts to de-medicalise care of dying patients and their families, yet it struggles to retain its original philosophy and goals, and it, too, is now faced with the charge of medicalisation of dying given its orientation towards the technical management of physical symptoms (Kearney 1992). While the hospice and palliative care movement has provided exemplars of interdisciplinary teamwork this has not been translated into mainstream healthcare. Moreover, interdisciplinary working in palliative care units is also under threat in a healthcare system that competes for resources on the basis of a positivist, evidence based-approach. The next Section 2.3 appraises end-of-life care literature further through the lens of a ‘good death’.

Section 2.3 A ‘Good Death’?

The idea of a ‘good death’ is central to hospice and palliative care philosophy and evolved out of the drive to improve care of dying patients (Finlay 2003). However, the notion of a good death predates the hospice and palliative care movement as well as medicine itself (Kellehear 2007; Walters 2004). It is not the intention of this thesis to study the historical and cultural background of ‘the good death’ in depth. In order to make sense of current understandings however, it is necessary to discuss historical context of death and dying in order to place the central thesis in context.

Prior to the enlightenment, death was inevitable and the idea of a good death was focused on finding cultural and religious meaning (Callahan 2000). The Enlightenment refers to the age in which reason was advanced as the legitimacy of authority in Europe (Porter 1997). Intellectuals of the Enlightenment influenced by the Baconian view proclaimed that science and technology would create a better future and enhance social progress as well as man’s control over nature, ultimately followed by the defeat of disease (Lewis 2007; Porter 1997). Marquis de Condorcet (1743-1794) declared that medical progress accompanied by the civilisation process would extend longevity, perhaps even to the point of immortality (Porter 1997).

With this rise of modern medicine in the 18th and 19th Centuries, medicine looked to science in seeking victory over disease. Previously common causes of death came to be seen as preventable and when death did occur, 20th century medicine began to see death as a failure (Porter 1997; Walters 2004). In this epoch, the good death is one that can be prevented or postponed. The legacy of this era is one of death as the enemy. Medical science and technology is driven towards eliminating disease. Implicit in such elimination is the goal of eliminating death (Callahan 2000), resulting in the current tensions between medicines' imperative to cure and its role in care of people who are dying (Callahan 2000; Kellehear 2007; Walters 2004).

Prior to the Enlightenment, death had religious associations and was connected with being at peace with God, enhanced by the presence of family and friends around the bedside to witness the spiritual goal of the dying person coming into a right relationship with God (Walters 2004). While desirable, being free of pain and symptoms was not people's primary concern. Suffering in this context could enhance the value of one's death (Walters 2004); endurance of suffering was virtuous and even worthy of sainthood (Walters 2004). As religious authority declined and public life became increasingly secular, spirituality became a private choice for the individual decision maker (Rumbold 2002). By the 19th century, Europe was on the threshold of industrialisation. Science and medicine were challenging religion as the cultural authority and it became more common for people to enter and leave the world in the attendance of a physician rather than a priest (Porter 1997).

The hospice movement endeavours to thwart modern medicine's technologised response to death. It has encouraged open discussion of death and dying and aims to redefine death as inevitable (Callahan 2000). Growing public awareness of the 'hospice' alternative to the medicalised death has elevated issues of death and dying on the public agenda. In an era of an ever increasing lifespan and a technological imperative, unnecessary prolongation of life is being publicly questioned (Porter 1997). One response to this has been a thriving advocacy movement for voluntary euthanasia and assisted suicide (Callahan 1990). What is referred to by McInerney (2000) as the 'requested death movement' defines the 'good death' as one in which the individual is able to choose how and when they die. While voluntary euthanasia is accepted practice in some countries such as the Netherlands, acceptance in other countries has been mixed. Significant controversies around the ethics of voluntary euthanasia in a religious and morally pluralistic society remain (Lewis 2007). For example in Australia in 1997, the Federal Parliament overturned a Northern Territory law allowing medically assisted euthanasia (Porter 1997). Pressure groups such as Exit International operating in the UK, New Zealand, North America and Australia campaign for legislation to permit assisted suicide as well as promoting information on what they call 'accurate and concise end-of-life choices information'. Conceivably, the societal push to legislate in favour of voluntary euthanasia has arisen from inequity of palliative care provision ensuing from the complex needs of older adults with diseases such as chronic respiratory and/or cardiovascular illness and dementia, resulting in 'cure' or 'kill' as the only options (Seymour 2007). However, even with the most equitable provision of care for the dying, the values of control over one's own destiny including the expectation of control over the timing of one's death may prevail. Although in fervent opposition to voluntary euthanasia and assisted suicide, the hospice and palliative care movement also encourages individual choice and decision-making over one's dying (McInerney 2000). Acceptance (of one's dying) and autonomy are strongly held values within palliative care philosophy and encourage individuals to make choices about how they live and die (Zimmerman 2012). Perhaps the individualism and self-determination of modernity's cultural mind-set have created both the hospice movement and the right to die movement even though they are in vehement opposition (Walters 2004).

Having introduced the notion of a 'good death' in a historical context, this concept is now explored further from the perspectives of patients, families and healthcare professionals.

Patient perspectives of a 'good death'

First of note and already highlighted is that for some people, open awareness does not necessarily equate with 'good dying' (Zimmerman 2007, 2012). For example, concepts of autonomy were alien for many older people with a diagnosis of heart failure interviewed in Gott et al (2008) study; many of who did not want an open awareness of death. This study was consistent with research carried out by Vig, Davenport and Pearlman (2002). Older patients who took part in this study, like the participants in Gott et al study, also regarded a 'good death' as one of which they did not have impending knowledge (Vig, Davenport & Pearlman 2002). Many older patients equated a good death with one that happened quickly and in one's sleep (Vig, Davenport & Pearlman 2002). This is consistent with an earlier study whereby participants expressed a desire for sudden death, which was not mentioned by staff (Payne et al. 1996). There were also participants who took part in Vig, Davenport & Pearlman's (2002) study who expressed the opposite, however. That is, a good death as one that is anticipated allowing one to put things in order. Importantly, there was considerable heterogeneity of participants' views. That is, fewer than half of the study participants cited the most frequently expressed characteristics of a 'good death' (Vig, Davenport & Pearlman 2002). A later study by the same authors explored how terminally ill men diagnosed with end-stage heart failure or cancer regarded good and bad deaths (Vig & Pearlman 2004). Like Vig, Davenport & Pearlman's (2002) earlier study, there was considerable heterogeneity of participants' views. Components of a 'good death' included being free of pain; 'going quickly' and in one's sleep and being at 'peace with God'. In contrast a 'bad death' included being dependent and a burden on others (Vig & Pearlman 2004).

Characteristics of a 'good death' identified from the literature more broadly include the following themes: First, pain and symptom control is frequently mentioned as of key importance (Vig, Davenport & Pearlman 2002). Interestingly however, patients in the Payne et al (1996) study placed less emphasis on symptom control than did professional staff. Second, psychological and social components including maintaining connections with friends and family and reconciliation become important. Third, spiritual components, including being 'in touch', having the opportunity to review ones' life, having a sense of completion and relating to a higher being greater than oneself are deemed significant. Lastly, the need to be able to communicate effectively with healthcare professionals is highlighted. Patients express a desire to be treated as a person experiencing an illness, rather than as a patient in a disease stage. Being recognised as unique individuals, and understood in the context of their lives, values, and preferences, are what matters most (Cherlin et al. 2004; Clark 2002; Kuhler 2002; Masson 2002; Steinhauser et al. 2000b).

Hope is associated with characteristics of a 'good death'. In a biomedical paradigm, hope is frequently constructed as the hope for cure. In cases where patients continue to hope for cure when clinicians deem treatment to be futile, medical teams frequently become concerned about unrealistic hope and 'denial' by patients and families (Eliott 2009). Hope for 'more life' is perpetuated by the influence of medical technology and public expectation. Further, it serves to give value to relationships and so it may be unrealistic to expect patients and families to relinquish such hope (Eliott 2009). Sullivan

(2003, p393) argues that the relationship between hope and hopelessness at the end of life is much more complex than its reduction to the issue of prognosis in medicine. He argues that there is a diversity of hope possible at the end of life: “A hope for dignity, intimacy, and salvation” that “encompasses nearly all that human culture and spirituality have to offer”. Hope from finding meaning, from beliefs and faith, from close relationships, enjoying a sense of humour and a sense of maintaining dignity and being symptom-free have all been expressed by patients towards the end of life (Greisenger et al. 1997; Hagerty et al. 2005). This suggests the importance of a redirection of hope towards those things that enable engagement with life (Eliott 2009; Sullivan 2003). Such engagement is important in relationships with healthcare workers as well as others. Dying patients have a need to reciprocate and contribute to others by way of knowledge, time or gifts and wish to participate in the same interactions that are important throughout all of life (Steinhauser et al. 2000b).

Family perspectives of a ‘good death’

Of particular importance to family members is not to be abandoned by healthcare professionals and for them to be cared for as a family (Cherlin et al. 2004). At the same time, families express a desire for their loved ones to be treated as individuals, and for them to be ‘known’ (Masson 2002). They seek respect for the patient. Inherent in this respect is attending to the patient’s basic self-care needs, as well as providing for the patient’s basic level of control over every day decisions (Teno et al. 2001). Families look to healthcare workers for facilitation of family processes such as “making visiting and being present easy” to enable them to spend time with their loved one and to be kept informed of signs of impending death (Cherlin et al. 2004, p114). Moreover, they judge healthcare professionals on their ability to do so. Additionally, they expect contact from professionals after the death such as a phone call or a note (Cherlin et al. 2004). The relationship between clinicians and family members in the context of end-of-life decision-making is particularly worthy of study as the impact of the experience of the dying episode can have a profound impact on the family unit. Physician empathy as death approaches can reduce caregiver depression and lighten psychosocial burden into the future (Knight & Emanuel 2007).

While some sections of healthcare such as community health, paediatrics, obstetrics, and palliative care address the family as the unit of care, i.e. care is directed towards the family as opposed to the individual patient, this is not necessarily the case in the typical adult acute hospital, where care of the family may not be the cultural norm to the extent it might be in a children's hospital. The hospital can be a confusing and stressful environment for families. Although care may not be specifically directed towards family, they are often asked to contribute to, or make, complex end-of-life decisions. They may also be asked to act as proxy for a loved one, such as whether a relative should be resuscitated or not (Hillman & Chen 2009).

Healthcare professionals perspectives of a 'good death'

The perspectives of several disciplines described here include those of nurses, doctors, social workers and chaplains. Nurses are concerned about the patient being comfortable and free of pain and other symptoms (Costello 2005; Griggs 2010). Nurses describe a good death as one where the patient and family are aware of the prognosis and goals of care, and these matters are included in discussions (Costello 2005). Nurses require implementation of appropriate care plans including 'do not resuscitate' orders. Also of importance to nurses is that families are present with the patient (Costello 2005; O'Hara & Collier 2008; Sorensen & Iedema 2007). Conversely, nurses equated a bad death with having insufficient time to get to know the family, and deaths where the goals of care were uncertain and unclear (Costello 2005). When the death was sudden and unprepared and impacted nurses' abilities to manage organisational demands, it was perceived to be 'bad' (Costello 2005). Such events created what Costello referred to as the 'sentimental order' of the ward, whereby the 'atmosphere' or mood of the unit influenced nurses' feelings. Further barriers to a 'good death' at home include a lack of necessary resources such as medication and unsuccessful interprofessional relationships (Griggs 2010). That is, when the GP and community nurse have conflicting values and goals of care.

In Steinhauser et al's (2000b) qualitative study to identify the attributes of a good death with a range of participants including physicians, nurses, social workers, chaplains, hospice volunteers, patients, and bereaved family members, participants were particularly concerned about dying a painful death. Healthcare participants suggested that some of these fears would be mitigated by clear treatment decisions and planning in collaboration with patients and families. Furthermore, patients and families wanted to know what to expect as the illness progressed and death approached. They were concerned with spirituality and finding meaning including reviewing one's life. Participants highlighted the importance of relationships and dealing with issues of conflict resolution. Independent of whether participants were patients, families or professional carers, they articulated a need to recognise each other as unique and individual persons beyond the role of patient, doctor or social worker. In addition, professional participants highlighted the need for their own preparation for death and dying and the importance of exploring how their feelings might impact the capacity to care for patients and families.

All of the above themes were present in Steinhauser et al (2000b) analysis. There were differences however according to participants' social and professional roles. For example, social workers spoke in terms of the family unit whereas chaplains discussed ethical issues. Physicians' discussions were more medically focused and only rarely mentioned 'contributing to others' or 'completion'. Similarly, a medical focus and concrete tasks were regarded as the way in which doctors conceptualised death in an ethnographic study of an intensive care unit (Iedema et al. 2005).

Whether there can be any such thing as a 'good death' at all has also been questioned (Masson 2002; Scarre 2012; Walters 2004). For Scarre (2012, p1085) even the best deaths fail to be good deaths. In order for a death to be good, an individual must simultaneously hold together an awareness of the existential significance of the event with an "absence of mental anguish" These, suggest Scarre, are mutually exclusive. Masson (2002) argues that rather than a simple set of core characteristics, 'good death' is much more multifaceted and complex than a set of core features and is contextually defined. While Masson (2002, p191) posits the phrase "good enough death" to give recognition to the dynamic contingencies that play out in real life, Walters suggests the phrase "dying with panache", instead of 'good death' to give recognition of:

> *"The sense of dying in one's own way, in one's own style, may well include the elements of protest, complaint and awkwardness, perhaps with humour, perhaps with curses, without all the problems necessarily being resolved or all the relationships restored, but with integrity and honesty" (Walters 2004, p408).*

Portrayals of the way death and dying are talked about in everyday life perhaps serve to highlight Walter's stance. That is to say, a 'good death' is individually determined, as the next section demonstrates.

Portrayals of the 'good death' and 'bad death'

When the topic of 'the good death' was discussed on Radio National's 'Life Matters' programme (Delaney 2007) invited guests shared what they themselves hoped for at the end of life:

> *"I'd like to have control over the situation as much as humanly possible, control over where I die and who is with me when I die, people I love, they're the ones I'd like to have around. I'd like to have choices, in other words, not to be told what to do, but perhaps most importantly to maintain awareness as much as possible right to the very end" (Dr Michael Barbato, Palliative Care Physician).*
>
> *"Ideally, I'd like to die at peace and in a tranquil way with a great deal of acceptance and a lot of people around me, loved ones around me. My choice of place of death would be in the home, but that's not always possible, but deeper than all of that, a sense of peace in the way I live my life now. Contemplation on death is how you live your life now as well, and that is the main preparation for death" (Sebhana Barzaghi, Psychoanalyst and Zen Buddhist teacher).*
>
> *"I want to be surrounded by people who love me and I want to be able to lie there and quote that fantastic quote out of the movie 'Hook' – 'That was a great game!" (Molly Carlile, Grief Counsellor and Palliative Care Educator).*

This wider 'good death' debate is closely associated with the construct of 'dignity'. The term 'dying with dignity' is frequently used to equate with 'the good death'. Dignity defined by terminally ill patients themselves is closely linked with themes of a good death. Dignity preservation goes beyond disease progression to include perceptions of how autonomy and individuality are safeguarded and respect and privacy maintained (Hack et al. 2004; Walsh & Kowanko 2002). Perhaps the common thread running through the quotes above is the value of dignity preservation. Dignity preserving perspectives have been associated with: First, 'continuity of self'; that is a sense of the essence of who one is able to remain intact. Second, 'role preservation'; when there is some ability to continue to function in one's usual roles a sense of congruence with how ones views oneself is maintained. Third, 'generativity/legacy'; individuals gain some comfort in knowing that something enduring of oneself will continue beyond death. Fourth, 'maintaining pride'; an ability to maintain a positive sense of self is important to people. Fifth, 'maintaining hope'; that is, one is able to see life as having some kind of meaning or purpose. Sixth, 'autonomy/control'; a sense of control over one's circumstances is important. Seventh, 'acceptance'; resigning oneself to changing circumstances. Finally; 'resilience/fighting spirit'; this is associated with having the determination to overcome concerns related to one's illness and to optimize quality of life (Chochinov 2004). Importantly, in an earlier study by Chochinov, in-patients were mostly likely to suffer an increased desire for death, which was associated with a sense of 'fractured dignity'[7] (Chochinov et al. 2002). When dignity is intrinsically present, experiences of death and dying can be profound. Bereaved family members' voice how the experience of being with their loved one during their dying and death is felt, especially at home:

> *''I wasn't aware of anybody else apart from myself and Dad. For those two minutes it was just me looking at Dad. I wasn't looking at the candle. But just for those two minutes, it was just something suspended" (Donelly, Michael & Donelly 2006, p356).*
>
> *"I nursed my husband for 9 weeks. It was an incredible time ... like meeting together for the first time again in 40 years ... experiencing falling in love all over again" (caller), (Delaney 2007).*

In sum, while the literature highlights commonalities related to 'a good death', validation of the concept is fraught with difficulty. This is due, in part, to the need for recognition of individual differences and the need to focus on the patient as a person (Vig, Davenport & Pearlman 2002). A 'good death' may be considered differently by different sectors of the population. In order to offer patients and families help that is timely and appropriate to them there is need to address changing needs across time and space, and to include the views of patients (Clark 2003). Having considered the notion of a 'good death' in context, the next section (Section 2.4) continues to explore how healthcare professionals negotiate death and dying in greater depth.

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[7] That is to say, people who self-rated their loss of dignity as 3 or above on a 7-point sense of dignity scale where 0=no sense of loss of dignity, 2=mild, 3=moderate, 4=strong, 5=severe and 6= extreme sense of loss of dignity.

Section 2.4 Medicine and Nursing: The caring professions

Appraisal of the literature has so far highlighted the complexity of attitudes, preferences and experiences of dying. In the earlier section where perspectives of a ‘good death’ were considered, healthcare professionals articulated a need for their own preparation for death and dying and the importance of exploring how their feelings might impact the capacity to care for patients and families (Steinhauser et al. 2000b). This section considers in greater depth the positioning of healthcare professionals in the healthcare setting where dying is encountered.

It should be noted that this section does not set out to privilege any particular healthcare discipline.[8] Yet, review of the literature brings to light that studies pertaining to professional caring often favour nursing. This section, however, is not a discourse analysis of ‘caring’ literature. Rather, it is an attempt to appraise the topic from differing perspectives. It begins, therefore, by specifically examining the role of nurses, who are frequently positioned in the literature as key advocates of end-of-life care. Then, multidisciplinary care more broadly is appraised. This foreshadows exploration of what is meant by the ‘art of nursing and medicine’ within the context of caring as a professional goal. Finally, the issue of compassion is discussed including the expectation that healthcare be underpinned by compassionate care. This discussion of compassionate care foreshadows discussion of the place of empathy in delivery of such care. Finally, consideration is given to the needs of professional carers of dying people. The impact of caring including the potential threat to ontological security and issues of death anxiety and emotional labour are reviewed.

Nurses as advocates of end of life care

Nursing advocacy is considered a central feature of nursing practice (Hanks 2008; Vaartio & Leino-Kilpi 2005). Nurses are seen as ideally placed in healthcare to advocate for patients given their position alongside the patient at the bedside (Hanks 2008) and particularly so in end of life care (Thacker 2008). Advocacy in end of life care has been defined as assisting patients and families to “overcome barriers that impede the care path” (Thacker 2008, p174).

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[8] I am aware here, that as a nurse, I may be inclined towards a nursing bias.

Aspects of the nursing practice of advocacy are inclusive of protecting the patient, listening to the patient, moral and ethical decision-making, facilitating patient autonomy and promoting wellbeing (Sorensen & Iedema 2007; Thacker 2008; Vaartio & Leino-Kilpi 2005). Illustrations of such actions were evident in an end of life care project (O'Hara & Collier 2008). For example, nurses' frustrations with delays in medical referrals to specialist palliative care physicians were dealt with by direct referral to the palliative care nurse in order to 'bypass' the medical hierarchy. The palliative care nurse would, in turn, act in an advocacy role, not only on behalf of the patient and family, but also on behalf of the ward nurse.

However, nurses also expressed their powerlessness and frustration with decision-making (O'Hara 2006b; O'Hara & Collier 2008; Sorensen & Iedema 2006). This was noted within the context of conflict arising from unclear treatment goals especially when issues relating to life-sustaining treatment and comfort goals were divergent. Nurses report their particular distress and frustration at being caught up in the conflict between treating teams while trying to fulfil their advocacy role and at the same time communicate supportively with patients and families (O'Hara 2006b; O'Hara & Collier 2008). They voice a desire to give quality care, but are limited by the medical hierarchy and organisational complexities in which they operate (O'Hara & Collier 2008; Sorensen & Iedema 2006). In particular, the distress experienced by nurses in witnessing heroic and medically futile interventions is recognised as an impetus for nurses individually and collectively to give voice to these issues (Ferrell 2006; Sorensen & Iedema 2006).

Nurses function within the social complexity of the organisation, and their effectiveness as advocates is limited in a system that privileges cost control and medical intervention (Benner, Hooper & Kyriakididis 1999; Sorensen & Iedema 2007), and in which there are multiple medical specialists. A collaborative team approach is highlighted as being of particular importance for effective end-of-life care (Ajemian 1993). Care goals are connected to the dynamic nature of complex decision-making as well as the actions of others. Instead of resisting evaluation of the attitudes, values and actions of others, nurses need to confront them if they are to be successful as advocates. Professional advocacy is called for along with patient advocacy, requiring nurses to have organisational and political skills as well as effective skills in managing the needs of patients and families (Sorensen & Iedema 2007; Sorensen, Iedema & Severinsson 2008).

Doctors and end-of-life care

The requirement that nurses advocate for patients is based on the premise that there is a necessity for them to do so with their medical counterparts. Doctors are frequently criticised for being unable to provide end-of-life care that meets the needs of patients and families. Yet, from their perspective end-of-life decision-making is far from easy (O'Hara & Collier 2008). They have difficulty talking about end-of-life issues (Fallowfield & Jenkins 2004). This perhaps is not surprising given that undergraduate level doctors have little exposure to dying patients and training is focused on cure. This leaves junior doctors feeling ill-prepared on completion of their training (Gibbins, McCoubrie & Forbes 2011). The next sub-section considers a collaborative team approach as the solution to medicine’s problematic relation to end-of-life care.

A multidisciplinary approach

A collaborative team approach has been promoted as a necessary facet of quality healthcare. Multidisciplinary teams are characterised by a group of members primarily recognised by their professional identities in which association with the team is secondary to the professional role identity. They are characterised by structures that are hierarchical in nature. Hospital teams are characteristic of the multidisciplinary approach, in which disciplines and even specialty teams within disciplines operate in silos resulting in fragmented and unsatisfactory end-of-life care (Curtis & Shannon 2006; Ferrell 2006; O'Hara 2006b; O'Hara & Collier 2008; Sorensen & Iedema 2007).

This is in contrast to interdisciplinary teams which function as a unit and have an identity greater than individual professional identities (Ajemian 1993; Hall & Weaver 2001). Effective interdisciplinary teamwork is fundamental to delivering end-of-life care (Ajemian 1993; Curtis & Shannon 2006; Davison & Hyland 2003). No one professional discipline or individual healthcare worker alone is able to respond to the complexity and multiplicity of issues that a life threatening illness and care at the end of life creates (Ajemian 1993).

The palliative care interdisciplinary team approach, in which people rather than diseases are central, is endorsed as an exemplary model (Connor et al. 2002; Davison & Hyland 2003):

> *"Palliative care has acquired and implemented many of the attributes of high-performing knowledge-based enterprises, such as excellence in learning and multidisciplinary cross-functional work teams, in ways that would make it the envy of highly profitable businesses" (Davison & Hyland 2003, p104).*

Such a model is one in which teamwork is driven by the specific needs of the patient and family at any particular time. Team members are able to dynamically regulate appropriate to what is required, always with the overarching goal of promoting the best possible experience according to the wishes and needs of patient and family. That is, team members adjust across disciplinary, team and organisational boundaries to meet patient-led needs and goals. This kind of teamwork is characterised by a shared responsibility within the team as opposed to a rigid hierarchical structure whereby leadership is clearly defined and static. Such teams are distinct in their flexibility and adaptability so that the most appropriate individual team member is able to respond and lead at a particular moment in time (Davison & Hyland 2003; Iedema et al. 2005).

This necessity for effective collaboration of healthcare professionals in teams has become particularly pertinent in the context of a healthcare environment that is dynamic and complex, and within a system that is struggling to meet the demands of increasing technology, an ageing population and chronic and complex illness. Within this dynamic and complex system, organisation of hospital work will need to transform into a much more collaboratively functioning locale (Davison & Hyland 2003; Iedema et al. 2005). If such challenges are to be met, alternative models and approaches to the organisation of healthcare delivery and team working will be required (Connor et al. 2002; Davison & Hyland 2003; Sorensen, Iedema & Severinsson 2008).

While interdisciplinary team working of this nature is manifest in palliative care units, little is understood about its relevance to other healthcare settings and patient populations. The characteristics of organisations and teams that enable interdisciplinary working need to be explored and the way in which professionals are socialised into teams through education and workplace culture considered in greater depth. Organisational structures that reposition all stakeholders as equal contributors to the team and decision-making within a ‘community of practice’ are required (Sorensen & Iedema 2006).

The art of nursing and medicine

Appleton (1994) portrays nursing art as ‘the gift of self’, and considered encounters to be ‘art acts’ when inviting and open body movement, posturing and touch occurred. Others (Chinn, Maeve & Bostick 1997, p91) have conceptualised nursing art as: “The nurse’s synchronous arrangement of narrative and movement into a form that transforms experience into a realm that would not be otherwise possible”.

To explore whether nursing is experienced and practised as a human art and to clarify the term in a nursing context, Gramling (2004) investigated what nursing art means to patients. Perhaps most revealing about Gramling’s study was that patients who articulated features of nursing art were cared for in a critical care unit; an area considered particularly scientific and technical and thus dehumanizing in earlier studies (Gadow 1980). In contrast, Gramling (2004) identified the following themes from patient narratives as representative of art in caring: ‘perpetual presence’; in other words, that the nurse was ‘there’ and poised ready to address the immediate needs of the patient. Second, ‘knowing the other’; that is to say, the patient was recognised as a unique person with whom the nurse had a reciprocal relationship and where the nurse remembered personal details important to the individual. Third, ‘intimacy in agony’ referred to circumstances whereby the nurse had an appreciable understanding of patients’ suffering and was able to respond to it. Fourth; ‘deep detail’ meant that attention was paid to physical care needs beyond the routine, attention to what Smith-Stoner (2007) describes as ‘the little things’ such as wetting of the lips, or a massage of the hand with a favourite lotion. Finally; ‘honouring the body’ meant respecting the patient’s body by requesting permission and providing forewarning of a move, or minimising discomfort during procedures (Gramling 2004). Most critically, these findings suggest that it is nursing care that determines whether a patient feels dehumanized or not rather than an object of medical machinery (Gramling 2004).

The historical foundation of the art of medicine is well recognised (Giordano & Jonas 2007; Hutchinson, Hutchinson & Arnaert 2009; Kearney 2000; Orfanos 2007). Healy (2007) reflects on the ‘art of medicine’ relating to four principles; mastery, individuality, humanity and morality. Mastery encompasses wisdom as well as expertise and the humility to listen and question. Humanity and morality are concerned with who the doctor is behind the mask of professionalism, attempting to connect to the patient as one human being to another and founded on acknowledgement by the doctor of the integrity required in his/her privileged position as the clinician (Healy 2007).

The very nature of ‘human to human’ contact and ‘gift of self’ are suggestive of entrance into a relational dynamic that impacts both parties, and has the potential for each to be changed by the encounter. Consequently, that encounter has the potential to be rewarding to the healthcare worker as well as the patient, since there is value in conveying meaning to the activity engaged in as the healthcare professional (Sobel 2008).

Nurses gain satisfaction from the human-to-human connection with their patients, and it is important to them that they are able to make a difference (Sumner 2008). Indeed treating patients without compassion can be distressing for clinicians. For example physicians attribute poor end-of-life care outcomes to team communication problems and the over use of ‘heroic interventions’ in seriously ill patients (Ruopp et al. 2005). Doctors become distressed by such ineffective communications just as do patients and families (Ruopp et al. 2005). If providing compassionate care is important to healthcare professionals, then it is necessary to understand what compassionate care is and how it is enacted.

Compassionate care

Compassionate care is to be espoused as a core value of healthcare provision (Goodrich & Cornwell 2008). Provision of care that is compassionate is enshrined in professional codes of conduct (Australian Health Practitioner Regulation Agency 2012) and included in healthcare policy documents (Cummings & Bennet 2012). In a recent discussion paper compassion is defined as “how care is given through relationships based on empathy, kindness, respect and dignity” (Cummings & Bennet 2012, p10). William Tierney and Elizabeth McKinley, both doctors diagnosed with cancer, advocate for compassion, translated as ‘with suffering’ from its Latin origins (Tierney & McKinley 2002). They provide the following advice to other healthcare professionals:

> *“Do not just focus on survival! Talk to your patients. Too often, you hide your personal discomfort with cancer and dying patients by maintaining distance from them in the guise of respecting their*

> *privacy. Instead, we encourage you to become more intimate with your patients' lives and to understand how they have been impacted by this dread disease. You must try to understand what it is like to have cancer, to live with it and be treated for it, and to survive it or succumb to it. Although this will sharpen your skills and empathy, it may increase your own pain and suffering. But there is no other way: embrace the pain and learn from it. Try to achieve a balance between being too aloof and objective (i.e. protecting yourself), and being so close to your patients that defeat and death become too painful and paralyzing. Learn gradually, test the waters, and immerse yourself slowly" (Tierney & McKinley 2002, pIII 25).*

Implicit in expressing compassion is the impact on the provider as well as the receiver. Compassion includes:

> *"Empathy, respect for the uniqueness of another individual, and an impetus to enter a mutual relationship in which not only the knowledge, but the strength and emotions of both parties can be fully engaged" (Lowenstein 2008, p12).*

Lowenstein's definition suggests that rather than something delivered by a healthcare professional to a patient, compassion is concerned with a mutual interaction between human beings. Furthermore, the notion of empathy is also implicated in the definition and thus requires further exploration in its own right.

Empathy

Empathy[9] takes its origins from the German *Einfühlung* meaning 'feeling into' (Neuman et al. 2009). Most definitions consider empathy as an affective reaction arising from the emotional state of another (Neuman et al. 2009). "Empathy accounts for the naturally occurring subjective experience of similarity between the feelings expressed by self and others without losing sight of whose feelings belong to who" (Decety & Jackson 2004, p71). Further, empathy has been distinguished from kindness and compassion as a form of understanding (Kohut 1980).

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[9] I consider the neurophysiological elements of empathy in the next chapter (Chapter 3).

Care is situated in the lived world of the healthcare professional, and within the social reality of a healthcare system and societal expectations. That is to say, it is not delivered in a vacuum. Where empathy may be cultivated in one social environment, another may undermine it (Benner, Hooper & Kyriakididis 1999). If the healthcare professional feels supported in the environment and has the time and resources to deliver the kind of care they hope to, perhaps empathy is more likely. While the fundamental moral motivation may be to allay another's suffering, and meet the patient as a fellow embodied human being, this is thwarted in the bureaucracy of a health-care system under pressure to prioritise funding targets above the needs of patients and families (Benner, Hooper & Kyriakididis 1999). In such an environment, less value is placed on the 'human', often non-tangible side of caring, diminishing it to a 'soft extra' (Milton 2008). This approach may be misguided. For example, there is increasing evidence suggestive of the significance of placebo and nocebo effects of medical interventions. An example of this is where the open administration of morphine post-operatively has added benefit over hidden administration (Benedetti et al. 2003). Conversely nocebo[10] or nocebo-related effects can produce unwanted side effects when healthcare workers or medical interventions are distrusted (Barsky et al. 2002; Flaten, Simonsen & Olsen 1999) and these may even reduce the efficacy of treatments (Benedetti, Lanotte & Lopiano 2007). Thus, communication between clinicians and patients may be closely linked with health-outcomes (Street et al. 2009).

Wear and Zarconi (2008) suggest that socialisation into the medical and nursing professions undervalues this aspect of healthcare, and serves to diminish rather than cultivate compassion. While the ethos of healthcare professionals may be one of entering the field to make things better, they often become less empathic and more distanced from patients during training and beyond (Wear & Zarconi 2008). Doctors adopt the attitude that true medicine lies in the natural sciences i.e. anatomy, physiology, biochemistry and statistical method (Gillett 2003). Nurse educators give a similar account reporting a decline in altruism towards the completion of nurse training (Johnson, Haigh & Yates-Bolton 2007). Even if doctors and nurses begin their education with attitudes and values of care and compassion, socialisation into their

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[10] *"The nocebo effect is a phenomenon that is opposite to the placebo effect, whereby expectation of a negative outcome may lead to the worsening of a symptom" (Benedetti, Lanotte & Lopiano 2007 p260).*

respective disciplines leads them to undervalue these attributes. Possible factors contributing to lack of care and compassion are now considered in greater depth.

Death anxiety

Apprehension of dying or what is called death anxiety has been associated with attitudes to death and dying (Rooda, Clements & Jordan 1999; Servaty, Krejci & Hayslip 1996). Fear of one's own death can have a critical impact on the capability for compassion (Kasket 2006; Shapiro 2008). Senior staff have been reported as having less death anxiety than junior staff (Servaty, Krejci & Hayslip 1996). However, more senior nurses are less likely to recognise the emotional needs of patients as well as their own needs (Rooda, Clements & Jordan 1999). Levels of death anxiety have been reported as greater for doctors than nurses even early in training (Servaty, Krejci & Hayslip 1996).

Kearney(2000, p18) argues that death anxiety may, in part, be responsible for "Dehumanising excesses of technological medicine as the defence activities of terrified human egos made mortality salient by constant proximity to disease and death". What is termed 'terror management theory'[11] is the production of an 'anxiety buffer' in response to unconscious fear of death. The development of an 'anxiety buffer' is created by suppressing the 'terror' at an individual level, while at the same time participating in the dominant culture. That is to say, terror management theory hypothesises that being part of a dominant culture reinforces the views of that culture and imparts a sense of self-esteem on the individual within that culture masking the 'terror' in the attempt to reduce death anxiety (Renkema, Stapel & Van Yperen 2008; Sani, Herrera & Bowe 2009; Solomon, Greenberg & Pysczynski 1991, 2000). In other words, the biomedical culture typical of a large acute hospital is structured so as to maintain cultural members' self-esteem and lessen anxiety. Taking up the views of the dominant culture may even lead to a distancing from, or demeaning of any alternative minority view that is contrary to that dominant culture (Solomon, Greenberg & Pysczynski 2000). This development of culturally-structured defence mechanisms, often unconscious, can result in the kind of 'dehumanizing excesses' articulated by Kearney, and detachment and denial of feelings identified in the important seminal work of Menzies (1960). Given that palliative care culture is one such alternative and minority culture in the acute hospital environment,

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[11] Solomon, S., Greenberg, J. & Pysczynski, T. 2000, 'Pride and Prejudice: Fear of Death and Social Behaviour', Current Directions in Psychological Science, vol. 9, no. 6, pp. 200-204.

terror management theory may in part explain the tensions between biomedical and palliative care ideologies. One effect of this tension is that the dominant curative biomedical culture distances itself from the minority palliative care culture.

Both nurses and doctors experience anxiety related to death and dying. Junior doctors and nurses are rarely prepared for the first experiences of death, experiences that stay with them and can influence future practices (Cooper & Barnett 2005; Sorensen & Iedema 2009). Given the medical acculturation into an analytical, rational evidence-based paradigm that serves to problem-solve, save and cure, doctors are expected to ‘get on’ and ‘deal’ with their own emotions (Kasket 2006). Furthermore, the strong influence of the medical professional expectation of ‘ultimate rescuer’ that situates the doctor as having medically failed when the patient dies can affect perceptions of clinical competence and create feelings of guilt about having let the patient down (Kasket 2006; Meier, Back & Morrison 2001). Such expectations surely take their toll on doctors. When 1435 newly qualified doctors were asked to describe a stressful work situation, the majority of scenarios were strongly related to severe illness and death (Paice et al. 2002). In having to get on and deal with their own emotions, doctors are isolated in managing patient deaths and ‘retreat to the safety of their professional roles’ avoiding the vulnerability that communicating prognosis and discussing death entails (Christakis 1999; Sorensen & Iedema 2009).

Despite the fact that nurses had some experience with terminally ill patients, either personally or during nurse training, there remained a ‘measurable uneasiness’ when working with dying patients, independent of the level of formal education (Weigel et al. 2007). Nurses’ anxiety often relates to being witness to what they perceive as futile treatment and being caught up in the middle of conflict (Ferrell 2006; Yang & McIlfatrick 2001). When a decision is made to change the goals of care from curative to palliative, the perceived departure of doctors can generate feelings of abandonment that contribute to anxiety (O'Hara 2006a; Sorensen & Iedema 2009). Despite nurses’ discomfort in caring for dying patients and their families, their experiences of doing so can be meaningful, using the dilemmas of their patients’ lives to inform their own lives both personally and professionally (Maeve 1998; O'Hara & Collier 2008). For example, nurses describe responding differently in personal relationships as a result of their professional experiences of death and dying. For instance, one participant quoted by Maeve (1998) articulates how working with dying people and seeing ‘life as too short’ influences her decision about ending a personal relationship that she feels is detrimental. Furthermore, when they are able to reflect on their work and actively negotiate the emotion that the distress of others causes, nurses are able to engage on a personal and human level (Sorensen & Iedema 2009).

Emotional labour

Brotheridge and Lee (2003, p365) define emotional labour as the: "Regulation of emotional display in an attempt to meet organisationally-based expectations specific to their roles". This places a demand for what Hochschild (1983, p7) describes as "deep acting", resulting in the worker becoming disconnected or alienated from an aspect of self: "either the body or the margins of the soul". 'Emotional labour' requires an individual to alter feelings in order to sustain the outward façade that promotes a particular state of mind in others. This incongruence of behaviour and emotional state raises the prospect of becoming emotionally disconnected from one's own feelings, and from the feelings of those around one (Brotheridge & Grandey 2002). The greater the gap between expected behaviour and emotion required, the greater the likelihood of burn-out, affecting the emotional, psychological and physical state of clinicians (Coomber et al. 2002). This can in turn lead to healthcare professionals negativity towards patient care (Firth-Cozens & Cornwell 2009).

All told, there is an appeal for healthcare professionals looking after dying patients and their families to deliver care compassionately. This requires clinicians to place value on authentic communication, with recognition given to understanding of oneself in relationship to others. Thus, this centres on encouraging authenticity that fosters openness and responsiveness within a relational dynamic and that acknowledges the mutuality of the encounter between the patient and healthcare professional.

Even when healthcare professionals have a consciousness of the personal and professional issues that impact on them as clinicians as well as on the care they provide, organisational and cultural limitations impede them from delivering care that meets the non-medical needs of patients and families. Clinicians are 'thrown in at the deep end' and expected to negotiate their own personal and professional anxieties that are often not conscious. A lack of professional and organisational value placed on 'the art of caring' may be to the detriment of patient care. In contrast, stress management and participation in mindfulness programs are associated with improvements in wellbeing and patient centred care (Krasner et al. 2009) and can reduce medication errors (Jones et al. 1988). Moreover, without recognition of the impact of emotional labour on clinicians in an increasingly complex and demanding healthcare environment, they too may suffer.

What this chapter points towards thus far is that neither the care of patients and families nor the work of healthcare professionals occurs in a social or material vacuum. That is to say, patients, families as well as professionals caring for them are entangled in a complex array of social networks and are in communication with their surroundings. Thus, in order to address questions pertaining to end of life care, research needs to take account of these interconnections and surroundings. The final section of this chapter therefore begins to consider matters of end-of-life care from the perspective of *where* it takes place.

Section 2.5 Space, Place and Safety

Space and safety are central to this thesis. This section begins to examine these concepts and how they are contextualised in the literature in relation to end of life care. It begins by considering space in terms of environments of care. First, themes of hospital and home are considered. Establishing the meaning of home as encompassing more than the physical dwelling place foreshadows a discussion of patient safety. Second, existential issues and the concept of spirituality in relation to end of life care are discussed. Critical appraisal of these key themes in the literature provides the basis for this thesis to begin to conceptualise space and safety differently.

Hospital and home

The place of death is often heralded as an outcome measure for palliative care services. The image of home death is seen as the epitome of the ‘good death’, while the hospital death conjures the image of a technical, impersonal, and even inhumane death described earlier.

Analysis of studies revealed a preference for dying at home for at least 50% of patients (Higginson & Sen-Guptil 2000). However, a longitudinal study looking at preferences for place of care and place of death over time for both patients and their caregivers highlighted that place of care is not equivalent to place of death (Agar et al. 2008). Death at home does not necessarily mean an individual was cared for at home at the time of their choosing and at a time that is most important to them. Similarly, even though the death occurred in hospital, the majority of care may have taken place at home. Agar et al (2008) recognise the need for two conversations: preference for current place of care, and preference for place of care at the time of death. Furthermore, the needs and preferences of patients and caregiver do not change in unison and thus further exploration of actual events and mismatches is required (Agar et al. 2008). Moreover, expressed preferences highlight further difficulties. Even if one expresses a wish to die in hospital, for example, it is unlikely that acute hospital admission would ensue solely on the basis of the patient and/or family’s expressed wishes at a particular time without a medical reason for admission (McCall & Rice 2005).

A range of disciplines has explored the concept of ‘home’ over the past decade. Views however are polarized in terms of how home is studied. On the one hand, ‘home’ and ‘place’, it is argued, are ambiguous terms that are highly emotive and subjective, thus unhelpful for purposes of research (Rapoport 2005). On the other hand, it is argued that by their very nature these terms cannot be ‘fixed’. Dovey (2005), drawing from Deleuze and Guattari (1987), argues that the meaning of home is ‘fluid’, ‘becoming’ rather than being. Thus, if home is not fixed but a symbol of the self where social and cultural identities are realised, as Dovey argues, then there are possible implications when the experience of home comes under threat (Dovey 2005). For example, when an individual is admitted to hospital, the meaning of home might take on special significance.

Home: beyond the dwelling place

The psychological meanings of home have been identified with such components as security and refuge, privacy, self-expression, reflection of one’s ideas and values, activity and locus for emotional experience (Despres 1991). A sociological perspective recognises ‘home’ as the centre for family life, a place of retreat, safety and relaxation, freedom and independence, self-expression and social status, a place of continuity and permanence, a financial asset, and a support for work and leisure activities (Somerville 1997). Somerville’s (1997) research around the meaning of home has only relatively recently emerged in the health literature (Bowden & Bliss 2008). The work of Gott et al (2004) identified that while older people saw home as an ideal place to be cared for at the end of life, care in the physical space of the house of the person was not seen as essential. Home was conceptualised as much more than the physical location. It was symbolic of familiarity and security, autonomy and the presence and memories of loved ones. Further, home was seen as a place of comfort as opposed to the orderliness imposed in an institutional setting.

The very moment of death at home can be a profound, highly charged event which demands skills of the health professional as an ‘unobtrusive guide’. Using stage as the metaphor for the death scene around the bed, the dying person and their loved ones become centre stage as the professional moves “off-stage” (Donelly, Michael & Donelly 2006, p364). That is to say, professional carers recede into the background as the dying person and their immediate family move toward the centre.

In contrast, professional caregivers can be seen as ‘intruders’, and pose a threat to the meaning of home. This was substantiated by Bowden and Bliss’ (2008) study of the impact of putting a hospital bed into the home. The introduction of technologies and assistive techniques symbolises deterioration in health, serving to transform the home into a different place, a home and a hospital, and in extreme situations, it became less than the home.

In the context of the ‘dense place’ of the meaning and emotion of home, and the blurring of home into hospital, Brown (2001, 2003) questions the appropriate relationship between private and public spheres if ‘home’ is to be pursued as the goal of care and place of death. He raises questions around the larger social narrative, questioning the ‘burden of care’, and challenges hospice philosophy to recognise the potential patriarchy of a philosophy of ‘care at home’ as the ideal. If the overriding narrative of hospice and palliative care philosophy is that only a home-located death equates with a ‘good death’ there is a risk of pursuing this as an ideal without fully understanding the consequences of both the burden of care on unpaid carers and the influence of professional carers on the meaning of home.

In other settings such as aged care, the meaning of home is associated with affective characteristics such as connectedness and reciprocal relationships (Rowles 1983). Home is conceptualised as a ‘process’ as much as a physical or existential ‘place’ (Molony 2011). It is associated with a place of refuge (Molony 2011) and is somewhere that fosters personal strength and accomplishment (Molony 2011).

When attempts are made to create a ‘more homely’ environment, such as that of a palliative care unit, where symbols are identified with the everyday, patients feel more able to retain a sense of personal control and remaining a ‘person’ and not a ‘mere patient' (Rasmussen & Edvardsson 2007; Wiliams, Dawson & Krisjanson 2008). Patients also describe feelings of being at home in the hospice. Such feelings relate to being able to keep one's individual rhythm, carrying out activities at one's own speed, being in a calm environment in which excessive noise is minimal, where it is possible to maintain a sense of connectedness with self and significant others, things and 'place'. Other symbols, such as the manner in which staff moved around, signalled their level of availability. Conversely, the absence of such symbols can have the opposite effect, resulting in feelings of alienation and disconnectedness (Rasmussen & Edvardsson 2007).

To the patient and family, the acute hospital environment is a foreign world, often full of threatening medical symbols (Radley & Taylor 2003). Elderly sick patients are frequently moved between home, nursing homes, and hospitals; and within the hospital from ward to ward where juggling of acute beds to meet demand takes precedence. In light of the meaning made of 'home' and 'homeliness', a significant challenge is posed in response to the needs of dying patients and their families, for whom the moving of locations of care can be particularly stressful (Burge et al. 2006). A recent literature review identified older people's institutional environmental need as a 'homely' physical environment. A homely environment was one that supported spiritual expression, facilitated social interaction but allowed privacy and access to the caring activities of staff (Rigby, Payne & Frogatt 2010). There is a widely held belief that single rooms are a necessity, yet for many people, shared rooms can lead to social interaction (Chaudhury, Mahmood & Valente 2005; Gardiner et al. 2011). Disciplines such as architecture have studied the relationship between the contemporary hospital and health more broadly, envisioning a future where the current 'Megahospital' may become obsolete (Verderber 2003). Architects have established relationships between the built environment and health outcomes (Devlin & Arneill 2003). For example, patient access to a window view has been associated with fewer surgical complications and a lesser need for painkillers postoperatively (Ulrich 1984). There is a body of work that provides recommendations for 'humanised design' (Devlin & Arneill 2003; Hosking & Haggard 1999). More recently patients have identified healthcare environments that are 'homely', support family functioning and normal lifestyle as well as being accessible and assisting movement through them as being important to their health and recovery (Douglas & Douglas 2005). What is less explored is the optimum hospital environment for palliative and end of life care (Gardiner et al. 2011), especially from the perspective of patients themselves.

Recognising the possible significance of the bed space to patients, Jordens, Lewis and Kerridge (2009) studied the personalised images displayed around the beds of children in hospital. They identified significant meaning and purpose of the displays beyond mere decoration. The displays served to function as a means of communication in their own right, and as an invitation to pursue further communication by other means. In another recent study bedside artefacts in the hospice were identified as being important in helping to recreate 'home' settings. Patients held at least one 'personally unique object' at the bedside that was significant in retaining a connection with home (Kellehear, Pugh & Atter 2009).

The studies described above are suggestive of a need for space and place to be conceptualised more broadly than the physical environment, to encompass the social environment. A deeper understanding of the blurring of meaning around issues of hospital and home is required. One way towards understanding the hospital versus home relation is through child-birth research. Much has been done to 'de-medicalise' the childbirth experience over recent years and provide homely or home-like experiences near specialty settings. Arguably, the dying experience demands an equivalent 'de-medicalisation' (Institute for Health Improvement 2006). There is an imperative to examine ways in which dying can be accommodated in settings that combine home-like and specialty features (Donelly, Michael & Donelly 2006; Gott et al. 2004).

Death at 'home' can be a profoundly meaningful experience but the meaning of home is not determined solely on the basis of the physical dwelling place. The meaning of home and homeliness appears to be closely associated with experiences of safety and security. Since feeling 'at home' encompasses more than the physical environment it is necessary to explore the concept of safety in relation to the healthcare environment.

Patient safety

Throughout the course of their illness patients living with advanced illness tend to have substantially increased exposure to medical errors, including medication mistakes, improper procedures, and missed diagnoses (Myers & Lynn 2001). The language used around 'safety' in healthcare highlights concepts such as 'medical error', 'adverse events', 'near miss' and 'incident reporting'. There is a tendency towards consideration of safety in technological terms. Current approaches to patient safety focus on healthcare professionals following a guideline or protocol (Australian Commission for Safety and Quality in Healthcare 2011). Safety is talked about in terms of 'do' or 'do not do'. The field of patient safety has, to date, dealt with iatrogenic harm by focusing on the individual actions of healthcare professionals and more recently on a systems approach to deliver safe healthcare. This is reflected in the language of western healthcare providers such as: targets; key performance indicators; efficiency and so forth (NSW Department of Health 2007). Patient safety, currently conceptualised, is principally assumed to be achieved through the application of and compliance with evidence-based guidelines and protocols (Runciman et al. 2012). Further, what a medical error is and how it is defined has been left almost exclusively to clinicians and researchers to define (Travaglia & Braithwaite 2009). Yet, previous studies have shown that patients were able to identify adverse events in their own care when not otherwise recorded (Weingart et al. 2005; Weissman et al. 2008), and their reports can be both valuable and original sources of information about adverse events. In these studies, however, clinicians defined whether or not an event was termed 'adverse'. The way that patients and families define and enact patient safety is less explored. Recent evidence suggests however, that not only do patients and families hold significant knowledge about healthcare safety and risks, but they also have important insights into opportunities for improving care (Iedema et al. 2012).

The International Classification for Patient Safety (ICPS) preferred term defines 'safety' as the reduction of risk of unnecessary harm to an acceptable minimum. However, harm is further defined as:

> *"Impairment of structure or function of the body and/or any deleterious effect arising there from, including disease, injury, suffering, disability and death, and may be physical, social or psychological. Suffering includes pain, malaise, nausea, depression, agitation, alarm, and fear" (Runciman et al. 2009, p23).*

This definition points towards the need for a redefinition of patient safety beyond the technical realm. Importantly, the uncertainty of not knowing the course of one's illness, its arising symptoms and potential death, gives rise to feeling out of control and unsafe (Rasmussen & Edvardsson 2007). Further, while much safety work of healthcare workers is explicit, and some safety work is recognised and valued by organisations such as hand-washing and preventing falls, the implicit unobtrusive safety work that goes on in the background often is taken for granted, and is therefore rarely made a part of patient safety considerations (Walker 2002). This may be a discreet referral to another healthcare worker following concern for an anxious patient, advocacy on a patient's behalf, or the timely anticipation of a personal need. Nurse skill, timely information, friendly human interest, and appropriate humour facilitate a feeling of safety (Walker 2002).

Others have called for the safety needs of dying patients to be specifically defined to include for example, inappropriate or non-treatment of pain and other symptoms (Myers & Lynn 2001) and to encompass key domains of the WHO definition of palliative care (Dietz et al. 2010). Specifically Dietz et al propose the following definition for errors in palliative care:

> *"The use of a wrong plan for achieving the aims of preventing and relieving suffering from pain and other physical, psychosocial, and spiritual problems. The error may be categorized according to the domains of symptom control, diagnosis, prognosis, communication, psychosocial, and spiritual assistance as well as advance care planning and end-of-life decision-making" (Dietz et al. 2010, p1471).*

Myers and Lynn advocate a research agenda that would include subjecting 'errors' such as these to the same kinds of accountability and governance that conventional errors are subjected to. They even pose the question as to whether unnecessary hospitalization itself should be considered an error. Myers and Lynn (2001) question how healthcare can be arranged in a way that provides safe and efficient care. That is to say, central to this thesis, Myers and Lynn begin to consider that current approaches to patient safety do not currently address the needs of dying patients and their families.

Emerging research in the broader healthcare field shows that safety depends on the ongoing interactions of people with one another and with their surroundings (Iedema et al. 2006b). Healthcare workers are continually and contingently defining and redefining and negotiating safety in situ (Bosk 2003; Hor et al. 2010; Iedema 2011b; Mesman 2011; Rowley 2011). If safety is contingent on the ongoing interactions with people and their surroundings, it follows that space and safety may be inter-related. That is to say, space and safety may be co-constituted (Mesman 2012). Furthermore, the nature of space may determine to what degree patients and families assess whether or not they feel safe, since the physical space is symbolically interpreted as representative of the care. For example, even if the quality of the care delivery is second-to-none, an unclean environment where there is no private space to grieve, and where healthcare professionals are considered too busy to provide human contact, can contribute to feeling unsafe and to a lack of security (Rasmussen & Edvardsson 2007). In this way, safety and space are closely related. A more encompassing definition of safety may be required, defining safety as practitioners' ability to avoid harm and suffering, and where harm is identified and acknowledged to be caused when practitioners fail to anticipate or make sense of suffering and address uncertainty about the future (Seymour 2007). People's need for safety and security is the condition of possibility for connectedness, and for relationship with self and others to be strengthened and restored (Kearney 2000). In other words safety means establishing 'safe spaces' for dying patients and their families. Given the unique and existential nature of all that facing one's death presents, the degree to which 'feeling safe' is possible admittedly remains questionable. Existential issues such as these make it necessary to consider the concept of spirituality and its relationship to safety and space.

Spirituality

The importance of addressing the spiritual needs of patients and their families is included in the World Health Organisation definition of palliative care (Sepulveda, Yoshida & Ulrich 2002). The hospice and palliative care movement may be partly responsible for bringing spirituality into the healthcare agenda.

The term spirituality is conceptualised in the literature as broader in scope than religion, and related to the search for meaning and purpose in life, a search that may involve a relationship to a transcendent power, power that surpasses any physical existence. Such a search for meaning becomes particularly heightened in the midst of facing death (Delaney 2007). Definitions of spirituality share a common theme of connectedness (Draper & McSherry 2002; Maclaren 2004; McGrath 2002, 2004; Moss 2002; Rumbold 2002). The concept of spirituality may also relate to the simple questioning of everyday life events (McGrath 2002). However, the fact that spirituality is an elusive term and is difficult to define contributes to significant debate around the topic (McGrath 2002; Wilding, Muir-Cochrane & May 2006).

Critiques of the developing body of literature related to provision of spiritual care challenge a reductionist approach to the study of spirituality (Draper & McSherry 2002; Kellehear 2002; Rumbold 2002). Seeing spiritual care as something to be prescribed and delivered to patients, as a clinical entity rather than an inter-subjective concept with a mysterious and elusive nature fails to acknowledge the diversity of the ways in which meaning is made and fails to recognise the social context in which individuals are situated (Hockey 2002; Kellehear 2002; Rumbold 2002). Some go even further suggesting that the inclusion of spirituality and spiritual care as a construct is unnecessary, paternalistic and possibly even harmful (Draper & McSherry 2002). Assigning a universal approach to the realisation of spirituality might attribute values to people that they may not share and therefore be disrespectful to both those who subscribe to a religious view and those who assume a secular orientation (Draper & McSherry 2002).

If conceptualisations of spirituality are to take account of diversity and social context, then arguably spirituality may be better viewed through a spatial lens. For example, Malpas (1999) argues that our mortal finitude and the finitude of place are inextricably linked. In other words, the awareness of our spatially-located physical existence in place, and in the places we dwell, and in which one's existence is rooted, enables us to grasp our temporality in place, and thus to grasp our mortality. When we become seriously ill and are facing death, the whole of existence in space and place is under threat. One's ways of 'living movement' in the world are lost (Morris 2004). 'Living movement' refers to one's sense of orientation, moving and grasping the world. It relates to the nature of residing in one's body, the sense of up and down and the ability to face or not face others and thereby to gain an emotional sense of place. Trust in one's own body space is threatened when dying, resulting in an identity change away from that of a healthy person, to one who is reliant on the medical world looking into 'the body space'; a reliance on a medical gaze into the space via x-rays and scans (Ragan et al. 2008). Hence, one's confidence and trust of having one's usual place in the world becomes threatened and is, to a large extent, handed over to clinicians.

This section has highlighted the interconnectedness of end of life care with the meaning of home, safety and spirituality. The kind of 'safe space' that encompasses security, stability and the protection from fear, anxiety and chaos can support agency. An example of this was highlighted by Bob Collins, a patient in Harold's Cross Hospice

Dublin some years ago, in dialogue with Dr Michael Kearney in a short film directed to palliative care professionals (Collins 2000). Relating what happened following admission to the hospice, Bob laments:

> *"I cannot emphasise enough the importance of this space to my healing ... just the mere fact of being in my own space, having my own place in which to read, cry, in which to embrace my girlfriend, my daughters, in which to express what is going on ... and from that day on, that night on, I began to heal almost tangibly".*

Bob reflected on 'healing' as what he described as 'a sense of togetherness in adversity', and of "having many helpers in paying attention to 'it', even when it was not clear what 'it' was". The kind of 'healing' that Bob describes may be concerned with the "Physical, psychological, social and spiritual processes of recovery, repair, renewal and transformation that increase resilience, coherence and wholeness" (Miller et al. 2003, pA83).

Along with Kearney , there are calls for medicine to re-examine its healing and caring or Hygiean capacity (Callahan 1990, 2000; Cassell 1991, 2004; Giordano & Jonas 2007; Hutchinson 2011; Kearney 2000; Lewis 2007; Marcum 2008b; Pellegrino 1999). There are concerns that curing and healing are diametrically opposed and rely on different epistemologies; the art of medicine required for healing and science for curing (Hutchinson, Hutchinson & Arnaert 2009). This view negates the possibility of the coexistence of healing and curing. However, it is conceivable that an integrative medicine is possible and that it is unhelpful to dichotomise medicine as art and science (Solomon 2008).

In his short film, Bob Collins introduces the ward sister and the team at Harold's Cross Hospice as helping him "create a space for healing to happen" (Collins 2000). In exploring what he calls a "caring presence" in nursing, Nelms (1996, p368) likens this to creating a home when a patient experiences "ontological homelessness" and creation of a place where the 'other's being' can be preserved and nurtured. Thus, attention to integrative medicine in terms of space may be particularly relevant to dying patients and their families. Thus, it becomes necessary to explore the terms 'space' and 'place' specifically.

Space and Place

Space and place are perhaps fundamental to the experience of the 'lived world', and an understanding and experience of the environments within which individuals function. Space has been seen as an abstract notion, a neutral container of objects, whereas place is concrete, an active vessel (Gesler 1991). Casey (2008) argues for a 'place' world rather than a 'space' world in hospitals, suggesting that when spaces become reconfigured as places, hospital rooms would somehow take on the inscription of previous patients, patients in space becoming people in places. Thinking in terms of a place world allows Casey to convey a zone of experience and meaning (Wilson 2003) in a way that space does not.

Critiquing the metaparadigm[12] of nursing concerning the environment, Andrews and Moon (2005) argue that conceptualisations of environment and space are too narrow and static, and are focused on the immediate surroundings of the individual and their capacity to adapt. Environment requires a more explicit status, a purposeful analysis such as that offered by the discipline of geography, which takes account of a person's relationship with space, the meanings made about it, and the cultural and symbolic meanings of place (Andrews & Moon 2005). Choporian (1986) has also argued for an expanded and more dynamic view of the conceptualised environment as a socially constructed 'space'. Space becomes 'a setting for interaction' for human beings relating to each other. As such, space is to some extent humanly construed. This setting is more than the physical environment where interaction occurs; rather, it is elements mobilised as part of the interaction (Giddens 1991). That is to say the features of the space, the symbols, artefacts, and ideologies associated with it potentially enable, constrain, or transform interaction (Tellioglu & Wagner 2001). While there are obviously cultural differences in the way that space is contextualised and the manner in which it is divided up and appointed value, there are also elements of space that cross cultural boundaries (Tuan 1977). Arguably, space and place are inextricably linked. The sense of who we are is dynamically created and recreated by how we feel about and in spaces and places.

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[12] A metaparadigm is the universal perspective of a discipline that identifies the primary phenomenon of that discipline and explains how it deals with those phenomenon in a manner unique to the discipline (Fawcett 2000, p4).

Section 2.6 Conclusion

This chapter has explored the complexity of dying in western healthcare systems. Specifically, critical appraisal of the problem of hospital dying has revealed:

- a societal and political setting in which the healthcare system struggles to keep pace with developments in technology, the demands of changing disease patterns of an aging population (Australian Bureau of Statistics 2009) and the resulting cost implications, creating a dynamic and complex hospital environment that struggles to meet the human needs of patients and healthcare workers.
- an inconsistency and disparity of end of life experiences in the typical modern acute hospital and its response to the physical, emotional, psychological and spiritual distress that manifest towards the end of life.
- a clash of the ideologies of the societal, medical, nursing and biomedical science imperative to cure at all costs, and the hospice and palliative care movement, which purports to accept death as a normal life process, with the goal of helping people to face death and loss.
- a paradox between the growing expectations of a ‘good death’ and expectations of a ‘hospital cure’.
- a persistence of the problem despite guidelines, protocols and pathways.

Acute hospitals have become increasingly complex settings and while the healthcare environment has been considered in areas such as birthing units, children’s hospitals and hospices, less attention by stakeholders has been paid to adult acute hospitals. efforts should be directed towards creating dying and death experiences in hospitals that are meaningful. Further investigation of how healthcare settings can be configured to facilitate the needs of seriously ill and dying patients and their families is required. Perhaps as important as the physical space, is the interrelationship between agency and space.

An exploration of spaces that promote safety beyond the technical, ‘healing to happen’, and that preserve and nurture the ‘other’s being’ is necessary. The aim of this research is to examine the links between where dying people are, and the extent to which spaces enable or constrain their agency and contribute to the quality and safety of the care they receive.

In order to begin to address how one might go about this exploration, it is necessary to examine in greater depth the theoretical, methodological and ethical underpinnings for researching space towards the end of life. The conceptualisations of space I have studied so far do not allow me to sufficiently study relationships as well as wider organisational components and artefacts of space, including the built environment in a holistic manner. The search for a more encompassing conceptualisation of space leads me to the philosophy of Deleuze and Guattari and the work of human geographers.

In the next chapter (Chapter 3) I advance the reasoning behind the research approaches. In order to do so, however, it is necessary for me to change gears. The chapter that follows addresses how I came to the research foregrounding my own ethics and values. This, in part, determines the ethical approach to the research more broadly and foreshadows an in depth theoretical discussion of how space might be defined in this thesis pre-empting the methodological approach and methods I used.

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Chapter 3 Researching Space: Theoretical perspectives

Section 3.1 Introduction

This chapter begins by providing a history of the research; that is, an account of the methodology within the personal context of the research topic (Silverman 2010). This prefaces an explanation of the theoretical and ethical underpinnings applied in this study to explore space towards the end of life that shape the methodological approaches from which I draw. Central to this thesis is a ‘nomadic’ approach. That is to say, this thesis is about resisting predetermined and predefined theoretical approaches and methodology. Instead, I am open to embracing opportunities and possibilities for this research to be different. What these differences are and how they manifest in the research is something that unfolds throughout the thesis.

This chapter has three main sections: Section 3.2 titled ‘Positioning the Researcher in the Research’ makes explicit my positioning as the researcher by openly presenting key experiences that foreground my own ethics and values. This foreshadows the ethical approach to the research more broadly. Section 3.3 is titled ‘Theoretical Perspectives: Defining space and place’ and describes the theoretical lens of the research including clarification of how the term ‘space’ is applied in this thesis. Finally, Section 3.4 titled ‘Methodological Approaches’ discusses specific methodological approaches that I have applied in the research.

Section 3.2 Positioning the Researcher in the Research

This thesis is grounded in my values as a Christian, my philosophical views of the social world, healthcare and the healthcare professional/patient relationship. Embarking on a research journey, the topic of the research, my theoretical assumptions, ethical framework, choice of method and my relationship with participants are significantly shaped by my own ethics and values, my personal and professional experiences as a nurse, as well as the opportunities and resources crossing my path.

At a personal level, the biblical perspective of what it means to be human underpins my view of self and others. I view humankind, made in the image of God, as first and foremost a community of persons. “Human beings are designed to know who we are by looking into the faces of others, but only by looking into the face of God do we know what it is to be human” (Watts 2004, p160). That is, God becomes visible in the face of the other. Or as Levinas puts it: “In the human face, the Other expresses his eminence, the dimension of height and divinity from which he descends” (Levinas 1969, p262). The implication is that every human being is somehow an impression of deity, and this underpins the conviction that others be treated with respect and compassion, and in contrast, every abuse against another is an act of abuse against God. This translates into needing to be present for the ‘other’, especially an ‘other’ who is suffering. It is the underpinning value of humility that defines my relationships with research participants. Humility is “the noble choice to forgo your status, deploy your resources or use your influence for the good of others” (Dickson 2011, p24). It is this value along with the practical ethics drawn from an indigenous ethical research framework[13] (2011) that underwrite the research relationships and that I describe in greater depth in Chapter 5. For now, however, I describe key experiences as a palliative care nurse that together with my personal values shape my assumptions, leading me to the present research, and the overarching thesis.

The research instrument-palliative care nurse: ‘insider’

My professional life has centred on caring for people diagnosed with a life limiting illness. I have contributed to the care of dying patients in a variety of contexts. For most of my nursing career, I have been what I will refer to as an ‘insider’ in what is now accepted as a medical specialty known as palliative care. I have been immersed in the identity of ‘care-of-the-dying’ nurse. Friends and family have questioned my motives for doing what they conceive to be ‘such a depressing job’. To the contrary, however, I have found the connections made and relationships built with dying people, their families, communities and the colleagues I have journeyed with to be a source of learning, wisdom and at times much joy. Thus, I approach this research and relationships with participants with this same spirit of energy and enthusiasm.

Yet, even my earliest experiences as a palliative care nurse have led me to interrogate care of the dying. Indeed, the very nature of the research topic and questions are perhaps the result of an entanglement of my professional and personal life experiences. In order

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[13] I define the relevance of indigenous ethical research framework later in this chapter.

to set them in context I provide a précis of key episodes that, in part, have helped to define this research and the thesis more specifically. For instance, as registered nurse in a new hospital-based palliative care unit, one could pass through swing doors into the neighbouring surgical ward and encounter an environment of differing décor, staffing ratios, ward routine and atmosphere. The way in which a dying person was cared for was determined by their place of care. If the palliative care unit was deemed as having particularly therapeutic attributes for dying patients with 'special' décor, a higher staff-to-patient ratio and different rules, then by implication, the neighbouring surgical urology ward did not. That is to say, by categorising the palliative care unit as a therapeutic place, the possibility of the surgical ward having therapeutic attributes was at best ignored and at worst denied (Willis 2009).

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.

Embedded as a specialist palliative care nurse in what Seale (1998) refers to as the revivalist discourse, I became a 'palliative care missionary' facilitating other healthcare professionals to embrace palliative care philosophy and enabling them to provide quality care for dying patients and families. The expectation that other medical and nursing specialties would welcome such a philosophy began to trouble me. The underlying assumption was one of there being a right and proper way of 'doing' dying. That is to say, a 'good death' is only good if it happens in a way determined by palliative care philosophy. I had further concerns regarding what I consider as a critical undertone within the palliative care specialty towards other healthcare professionals and sometimes even towards patients and families if choices made were inconsistent with a hospice paradigm. The specialism of palliative care, it seemed, was far from being 'value free' and imposed its own interests and constraints.

Further, there is an assumption that empowering other healthcare professionals through education and working alongside them will lead to improvements in care, when in fact there is perhaps much greater complexity at play. Reflecting on my earliest experiences as a junior nurse on a general medical ward, a better knowledge of palliative care would not necessarily have altered the way in which patients died there. Moreover, the notion of empowerment assumes that healthcare professionals are willing to become empowered (Baistow 1994). The very concept of empowerment itself is not value free and I explore this in more detail under the heading ‘Participatory Action Research’.

The research instrument-volunteer: ‘outsider’

A professional journey that took me out of specialist palliative care into overseas ‘development’ work and subsequently into the specialty of oncology and more recently project management provided an opportunity to function as ‘outsider’. The mutual exchange of cultures and learning at an individual level experienced as a volunteer in the Lao People’s Democratic Republic paralleled the reciprocal relationship with patients as a community palliative care nurse. Participatory rural appraisal methods were utilised in collaboration with the School of Public Health (nurse training school) to facilitate engagement between nursing students and rural villages during their community placement. Collaboration with villagers and local health workers to problem solve and create joint outcomes mirrored the nurse-patient relationship.

It became increasingly clear that I would learn and gain more from the volunteer experience than I would be able to give. Collaborating with local health workers to problem solve and create outcomes jointly was fundamental just as it had been in relationship with patients. In other words, what governed the work was a philosophy of ‘doing with’ rather than ‘doing on’. A philosophy of ‘doing with’ rather than ‘doing on’ translates as the need to put patient, family and healthcare worker voices at the centre and to acknowledge their perspectives on suffering and healing.

However, taking such an approach in Laos did not exonerate me from questions of accountability and moral responsibility given my knowledge, experience, professional skills and the other resources available to me. Moreover, unable to separate my ‘being’ into discreet professional and personal entities, I instead recognise these experiences in their totality. This often left feelings of uncertainty about my responsibility as advocate.

The research instrument-hospital nurse: ‘outsider’

Returning to the acute teaching hospital setting as lung cancer nurse I was struck by a palpable absence, in consultations and treatment decision meetings, of the social context and subjective experiences of patients or “voice of the life world” (Mishler 1984, p122). This apparent schism of person and patient was made most striking with projection of disease images in the form of scans, x-rays and cells onto meeting room walls. One patient in particular, brought this home to me. Sam (pseudonym) was asked to contribute as a member of an expert panel at a public forum to raise awareness of lung cancer. Sam projected a photograph of himself along with his wife and son on his PowerPoint slide strongly expressing the wish to be considered a person with loved ones rather than merely a number in the health system. This experience confirmed for me patients’ need to be seen as persons and not principally as x-rays, test results or scans.

The research instrument-project co-ordinator: ‘outsider’

As the facilitator of a project aimed at improving end-of-life care in the hospital setting I heard repeated tales of poor care and unmet need. An apparent deterioration of care and compassion within contemporary healthcare was evident. The issues of organisational complexity surrounding care of the dying in hospital thus led me to decide that it was necessary to initiate in-depth inquiry that makes patients, their carers and clinicians central to the research. It became increasingly clear to me that the “problem of hospital dying” is a complex one (Kaufman 2005, p19). As the authors of the SUPPORT study established, I concluded that study of the problem needs to acknowledge this complexity, look beyond reason and logic and recognise the emotional and moral aspects of suffering.

The research instrument-patient’s wife

During the fieldwork phase of the research my husband became seriously unwell. This manifested in a complex array of debilitating symptoms that proved difficult to diagnose. While I did not appreciate it at the time, this experience would make an important contribution to the thesis. In parallel with hearing the stories of participants, I, albeit to a lesser extent, was faced with the uncertainty of prognosis and negotiating the healthcare system as a family carer, moving in and across different space(s). I do not include this to self-indulge or use it cathartically (Carter 2010), but rather see it as a necessary reflexive endeavour that makes a contribution to the empirical work of the thesis.

Fundamentally, what these professional and personal experiences alert me to is the need to embrace both complexity and uncertainty. While I draw from a variety of disciplines and philosophies therefore, I do not hold to one single method or presupposition, instead seeking to be open to multiple possibilities. Thus, as the researcher, I try to remain open to genuine enquiry and to continual critique and challenge. This is of particular importance given my experience as a nurse, not wishing to let my clinical experience nor my theoretical readings predetermine study findings. I seek to retain a self-awareness of where I might be taking for granted the actions and behaviours I observe, keeping an open mind as to what I might find and being open to surprise. Second, I seek to enter relationships on different terms with people moving beyond a framework of 'empowerment'.[14] What these terms are, and how they manifest in the research is something that unfolds throughout the thesis.

Section 3.3 Theoretical Perspectives: Defining space and place

The previous chapter (Chapter 2) brought to light the need to study end-of-life care space(s). This chapter interrogates the concept of space in greater depth providing clarification of how the term 'space' is applied in this thesis.

Deleuze and Guattari: Space and affect

This thesis embraces complexity, uncertainty and openness and is inspired by French philosophers Deleuze and Guattari. Deleuze (1925-1995) spent most of his career as Professor of Philosophy at Universite de Paris VIII. Together with Felix Guattari (1930-1992) a psychiatrist, radical psychoanalyst and political activist, Deleuze formed a collaboration that lasted thirty years (Doel & Clarke 2004).

It is not my intention to provide an in-depth analysis of their philosophy. However, I draw upon their philosophy at several levels of the thesis. First, their insights help provide the philosophical foundation for the thesis as a non-static fluid entity. Resembling Deleuze and Guattari's concept of the rhizome, this thesis "has no beginning or end; it is always in the middle, between things, interbeing, intermezzo" (Deleuze & Guattari 1987, p25). That is, even at completion, it continues, just as the

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[14] I suggested earlier in this chapter that the term 'empowerment' is not value free. I critique this concept later in this chapter under the heading, 'participatory action research'.

rhizome, to throw off continuous roots and shoots; to produce interconnected networks opening up new possibilities. For example, the work presented here has already found continuation in a number of grants and collaborative opportunities. Equally, my thinking about end-of-life care continues to be reshaped, as it is informed by new relationships and events.

Second, I have looked to Deleuze and Guattari for concepts to assist in the generation of possibilities within the research. In order to consider what these possibilities might be and how they might emerge, I look first to Deleuze's own statement of philosophy:

> *"I'm not an intellectual because I can't supply views like that, I've got no stock of views to draw on. What I know, I know only from something I'm actually working on, and if I come back to something a few years later, I have to learn everything all over" (Deleuze 1995, p137).*

Like philosophy for Deleuze, theory in this thesis is about what it can *do* in the now. Deleuze proposes that inquiries should be functional or practical: "What does it do?" or "How does it work?" "We're strict functionalists: what we're interested in is how something works" (Deleuze 1995, p21). I take an analytical approach that 'un-divorces' thought from action and doing. In other words thesis findings are recommendations for actions and reports on actions rather than philosophical theoretical ideas and conclusions.

Deleuze and Guattari's philosophy is often held to be antithetical to Christian theology (Hainge & Cullen 2011). This thesis, however, holds these positions together. A critique of theology in Deleuze's writings is beyond its scope and deserving of study in its own right. I include a short commentary here, however, to provide clarity of my own position, having earlier stated my Christian belief and values. While theology is tangential to the thesis, it is necessary for me to reconcile these philosophical positions for several reasons. First, as a reflexive researcher, I need to integrate the theoretical underpinning of the thesis with my own Christian worldview. Second, analysis required me to account for spiritual themes arising from empirical data. Lastly, my review of the literature highlighted that issues of space and spirituality are closely connected. In particular, the whole of existence in space and place is under threat when one becomes seriously ill and is facing death (Malpas 1999). Deleuze and Guattari's metaphysics of multiplicity, relationality and creative becoming and my own spiritual lens are not mutually exclusive. Biblical scholarship positions heaven and earth, that is, God's sphere and our sphere, as inseparable:

> *"Here God is always at work in the world and God is always at work in and addressing human beings, not only through one faculty such as the soul or the spirit but through every fibre of our beings, not least our bodies" (Wright 2011, p18).*

Spirituality themes are also found throughout Deleuze and Guattari's writings and are at the very heart of the meaning and purpose of philosophy:

> *"The question: 'What is philosophy?' can perhaps be posed only late in life, with the arrival of old age and the time for speaking concretely. It is a question posed in a moment of quiet restlessness, at midnight, when there is no longer anything to ask ... in which one enjoys a moment of pure grace between life and death, and in which all parts of the machine come together to send into the future a feature that cuts across all ages" (Deleuze & Guattari 1994, p1).*

For Deleuze, philosophy was a creative endeavour favouring what was collective and transhuman, concerned with creative transformation (Doel & Clarke 2004). He does not dispense with divinity as a creative power (Goodchild 2011). In essence holding this philosophy together with my Christian faith allows me to focus on an embodied faith. That is to say, it is one that understands faith as a lived entity. In other words, in the spatial present what we are is what we do. What Deleuzio-Guattarian philosophy and Christianity have in common are humility, creativity and openness to things being different. By approaching the research with humility, I choose openness over any fixed position, seeking to be open to new possibilities along with participants.

Third, I look to Deleuzio-Guattarian metaphysics to conceptualise 'space' and 'affect' Extending the work of Spinoza, Deleuze expresses Spinoza's affectio as the capacity of one body (human or otherwise) to affect or be affected by another (Seigworth 2011). Here there is an important distinction from feelings. In 'What is Philosophy'? Deleuze and Guattari write:

> *"The percepts are not perceptions anymore, they are independent of the states of those who experience them; the affects are not feelings or affections any more, they surpass the powers of those, through whom*

> *they pass. The sensations, percepts and affects, are beings, which stand for themselves and transcend all experienceability" (Deleuze & Guattari 1994, pp191-192).*

Inherent in this paradigm is a move beyond subjectivity as individually constituted to one of group subjectivity. In other words, the individual is always already constituted from pre-personal or transpersonal intensities that emerge when bodies affect and are affected by one another (Massumi 2002). Thus, affect renders it impossible to apprehend space as a static and closed, coherent structure. The very recognition of our human interrelatedness is variegated spatially, and in turn renders space a critical subject of inquiry (Massey 2005). Importantly, "Space is open, multiple, relational, unfinished and always becoming" (Massey 2005, p59). Space is something that is dynamically produced and reproduced in pre-discursive, discursive and practical ways (Massey 2005; Thrift 2006).

Space is the very means by which Deleuze does philosophy (Buchanan & Lambert 2005). For Deleuze, nothing is outside of space. Everything is space (and time) specific. Everything is a virtual continuum that is framed with terms such as 'intensive spatium' in *Difference and Repetition,* 'Ideal or Metaphysical Surface' in *Logic of Sense*, 'plane of consistency' and 'smooth and striated space' in *a Thousand Plateaus* and a 'plane of immanence' in *What is Philosophy* (Burchill 2007). Foremost in this metaphysics is the idea of affect and space as 'dynamic event', where everything is always in a state of emergence, in a constant state of unfolding. Here, there are flows of energy and 'creative potentials', as Shotter describes:

> *"living organically organised and interactive modes of thought, in which the spontaneously responsive interplay of our bodies with the others and othernesses around us play a central role" (Shotter 2007, p122).*

It is this view of 'space' as a "swirl of affects" (2006, p143) that is central to this thesis. This view of space allows 'new fields of expression', new voices, subjectivities and/or actions to emerge. This conceptualisation of space, however, does not dispense with the physical environment. To the contrary, "the physical environment, rather than an inert materiality that humans can manipulate is an essential actor in producing space" (Little 1998, p75). Deleuze and Guattari use the term 'assemblage' to describe the process of coming together of this collection of heterogenous entities (Macgregor Wise 2011).

Assemblage arises from the French *'agencement'*, a term that harbours much more fluidity than its English translation indicates (Law 2004; Macgregor Wise 2011). Rather than a static structure, the assemblage is a 'becoming', bringing elements together inclusive of non-human and affectual phenomena (Macgregor Wise 2011). The notion of assemblage allows for multiplicities. That is, the simultaneous and variegated enactment of objects when those objects are said to be the same. In other words, there are many realities, rather than one (Law 2004).

It is important to acknowledge that this is distinguishable from pluralism, because variegation allows different realties to co-exist in independent locations without interfering with one another (Law 2004). This means that valid experiences can exist alongside dominant and sanctioned ones. For the present research, this means that those previously excluded from end-of-life research can now be included as also providing valid views on what is end-of-life care. This enables dying people, their families and healthcare professionals caring for them to be positioned centrally in the research. Further, it enables my own self, as researcher, nurse and person to be strongly present within the research.

I have elected to use the term assemblage instead of space and/or place in the thesis from this chapter of the thesis onwards. I retain the term space where participants have used it. Adopting the term 'assemblage' has several effects. It allows me to move away from the normative notions of 'space' as a container and 'place' as something dependent on what people do in it. That is to say, assemblage allows me to consider the multiple dimensions of space concerned with what people do, the context that they are in and where matters take place in combination. Furthermore, assemblage allows me to foreground the affective characteristic of space. Critically, it is not what the assemblage is that matters but what it can do. In the context of this thesis, I am concerned with assemblages as a collection of heterogeneous non-human and affectual elements that brought together express a particular character and determine whether or not patients are safe.

Fourth, this paradigm enables me to depart from a view of the person as a dissectible body in the way I described earlier under the heading 'The Research Instrument-Hospital Nurse; Outsider'. That is, a reduced view of the body, seen in terms of x-rays and scans. Rather, the body is defined by Deleuze and Guattari as one emerging from the physical and social world (Deleuze & Guattari 1987). What Deleuze calls a 'Body without Organs' (BwO), or what Mol (2008) calls the 'body multiple',[15] is always becoming, and inter-related with its surroundings:

> *"At any rate, you have one (or several). It's not so much that it pre-exists or comes ready-made, although in certain respects it is pre-existent. At any rate, you make one, you can't desire without making one. How do you make yourself a Body without Organs? You never reach the body without organs, you can't reach it you are forever attaining it. It is a limit..... The BwO causes intensities to pass; it produces and distributes them in a spatium that is itself intensive, lacking extension. It is not space, nor is it in space; it is matter that occupies space to a given degree-to the degree corresponding to the intensities produced" (Deleuze & Guattari 1987, pp149-151).*

Applied to the argument of this thesis, this means that a body can mean different things at the same time. This is unlike 'The body singular', one detached from its surroundings or what Deleuze calls a Body with Organs. The Body with Organs allows only specific and non-contradictory descriptions and experiences. The Body with Organs demands or invents certainty and authority. This view of the body is one of a fixed enclosed unit in which organs are enveloped in a container of skin and the body is a set of physiological processes as in the medical-technical view. In contrast, Deleuzian philosophy privileges becoming over being, contributing to an ontogenic rather than ontological concept of creation. Becoming is the dynamic unfolding of Being; a process of active, productive differentiation (Croft Wiley 2005). As such, becoming is inherently dynamic and always immanent, non-linear and has no beginning or end (Manning 2010). Here immanence refers to "Those passing everyday moments that never really present themselves to our conscious minds. They are the between-moments (where moment is inadequate in its description) of any-space and any-time whatever that come to constitute 'a life'" (2011, p185).

Subjectivity, considered as an always-unfinished product and able to be different things at the same time, allows for "neither the notion of a prior, essential self nor that of a passive, determined subject" (Fox 2002, p348). By being responsive to the potential that variegation and becoming offer, the subject may abandon its own strict definitions and

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[15] A body, Mol posits, can mean different things at the same time. That is it can be "more than one but less than many" (Mol 2002 p55).

habituated constraints: it may become ‘nomadic’. That is, it is open to becoming-other. The nomad relaxes order and categorisation:

> *“The nomadic subject is able to experience space in terms of haecceities*[16] *and thus lengthen the gap between perception and action in order to resonate with imperceptible forces of affect. This can in turn lead to a creative response uniquely suited to the actual and virtual relations of the present situation rather than a repetition of habitual patterns of action developed in the past” (Tamsin 2005, p167).*

Fifth, concerned with disrupting of habitual patterns, Deleuzio-Guattarian concepts provide the reference point for how I might ‘take things’ elsewhere. Here, I draw from the notions ‘territorialisation’, ‘de-territorialisation’ and ‘lines of flight’. Territorialisation is the result of ‘normalised’ social structures that produce order and categorisation (Albrecht-Crane 2011). De-territorialisation, on the other hand, denotes escape from this order and categorisation, making different patterns possible (Albrecht-Crane 2011). These forces, however, are not dichotomous but are held together. In a state of becoming, the Body without Organs is a territory frequently contested and fought over by opposing forces (Deleuze & Guattari 1984; Fox 2011). Here forces are not simply human but more-than-human and affectual. These competing forces mean that the Body without Organs is continually territorialised, de-territorialised and re-territorialised:

> *“The concrete rules of assemblage thus operate along these two axes: a territorialising norming axis and an axis that tends towards excess and breaking away or deterritorialisation” (Albrecht-Crane 2011, p143; Deleuze & Guattari 1987, p505).*

Deterritorialisation, or the breaking away from predetermined patterns and escaping order and categorisation is always possible. Deterritorialisation frees order and categorisation through ‘lines of flight’ opening up alternatives to what is:

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[16] Deleuze and Guattari use the term haecceity to convey ‘thisness’ or ‘event’ associated with the notion that individualities are never susceptible to being ‘pinned down’ (Seigworth 2011). Tamsin (2005) draws on this term to emphasise these characteristic of nomadology. That is, haecceities are becomings with other assemblages having capacities to affect and be affected.

> *"Lines of flight ...are primary, that is they are not phenomena of resistance or counterattack in an assemblage, but cutting edges of creation and de-territorialisation" (Deleuze & Guattari 1987, p531).*

The Deleuzio-Guattarian concepts of deterritorialisation, nomadology and lines of flight are critical reference points for this research. These technical terms, however, are not critical to the remaining chapters of the thesis. Rather, what is central to this thesis is 'how things might go elsewhere than where they have been'. That means asking how might end-of-life care be different, how might hospitals be different and how might this research 'be different'?

Finally, the philosophical position I assume allows for a methodological approach, inspired by John Law (2004, p i), that enables the methods of this study, not only to "describe social realities but also to help create them". Thus constituted, theory offers a way of inquiry that engages with overlapping realities allowing for research practices to participate in them. Deleuze and Guattari inspire methodologies that enable me to uncover and bring about new realities. These new realities, however, are themselves unable to be definitively packaged into singularly coded meanings, but rather form a part of a dynamic process, involving constantly evolving processes.

I recognise that embracing the spiritual and affective may be controversial in a research environment that privileges objectivity, logic and reason as its modus operandi (Law 2004). Nonetheless, as the authors of the already frequently cited SUPPORT study realised, by rationalising and objectifying 'the problem of hospital dying' they may have missed what is of critical importance. I continue to progress this theoretical argument throughout this chapter and as a further precursor to the next chapter on research design.

The 'science' behind the method

In addition to the philosophical perspectives of Deleuze and Guattari, I look to other disciplines to augment my theoretical approach. There is a paradigm shift apparent in the fields of psychology and neuroscience that increasingly recognises the importance of the networking between the unconscious bodily-based affective functions and the conscious functions of the brain (Schore 2009). This paradigm shift acknowledges the importance of affect to cognition including the recognition of affect and emotions as the primary medium of life-critical information (Boston Change Process Study Group

2007). Traditionally, the role of emotion in decision-making has been marginalised in mainstream cognitive science favouring the view that reasoning must not be hampered by feelings or emotion (Damasio 1994). Nonetheless, emotions, far from being an incursion into rationality, are entangled in the neural networking processes that enable all our personal and social decision-making (Damasio 1994). Social researchers have identified the significance of an 'adaptive unconscious' that affectively assesses the world and allows decision-making before the 'conscious mind' has even come into play (Wilson & Bar-Anan 2008). Critically, we are connected to the 'other' at levels never before acknowledged. Studies have now shown:

> *"That one engages in the intentional states of the other at a neuronal level by activating motor neurons corresponding to the intentional actions observed in the other but without having to imitate the others' actions" (Boston Change Process Study Group 2007, p847).*

Moreover, it is increasingly recognised that cognitive science may have privileged inner operations and models to the exclusion of the complex interplay between the 'inner' and 'outer', marginalising the role of the physical body and local environment (Clark 1998). The brain, as traditionally viewed, is unable to be dissociated from the remainder of the body (Boston Change Process Study Group 2007; Damasio 1994), calling into question the prevailing legacy of the Platonic-Cartesian scheme, which separates body, mind and soul as discrete components: "And since the mind or rational soul is distinct from the body etc., it is with good reason that it alone is called the soul" (Descartes 1985, p182).

The neuroscientific disciplines support a view of space as bodies affecting and being affected. Here, space is something that is dynamically produced and reproduced in pre-discursive ways as well as discursive ways (Massey 2005; Thrift 2006). Referring to non-verbal communication, Schore quoting Buchanan contends: "It is incredibly naïve to take conscious verbal communications as the primary way that people respond to each other" (Buchanan 2009, p529). Thus, an imperative of this research is to embrace the mess associated with entanglements and inter-relatedness of constantly evolving assemblages rather than attempting to erase such mess.

Embracing mess

> *"Making a thoughtful mess and refusing to clean it up" (Carter 2010, p143).*

By embracing complexity and uncertainty this thesis engages with mess. This messiness relates both to the social complexities of ‘doing research’ with dying people in ‘space’ and methodological mess. Carter argues that all qualitative research is messy but that the neatly packaged report clears this up by hiding the mess (Carter 2010). My intent, rather than ‘hiding the mess’ is to reveal it, making it transparent. Thus, I do not articulate the methodological approach as neatly packaged and as if it can be accounted for within a concrete description, pretending that each step is a ‘rational’ conscious decision. I seek instead, more modestly and with humility, to articulate the methodology in all its complexity, accounting for everything that has swayed it (Mann et al. 2011).

This research is particularly messy for the following reasons. First, it situates itself in the uncertainty of death and dying. Death and dying are inherently messy and uncertain. Further, it is not my intention to glamourise dying and death. The end of one’s life is a momentous event that comes at an unimaginable and immeasurable cost and one in which pain and grief are, for the most part, inescapable (Barbato 2010). Second, my methods are participatory and utilise visual tools. This involves setting out in uncertain directions along with participants, who are likely to have contested views and producing footage that is itself never ‘certain’. Third, agency imagined as embodied and driven by affect is a “spatialised subjectivity” (Massey 2005, p56). Thus space, as an ongoing product of interconnection, always leaves things unfinished as everything is connected to everything else (Massey 2005).

Rather than opting to clean up the mess I instead elect to engage with it. I do so for several reasons. Within the context of my own values as a Christian, I elect to be open, honest and transparent. I account for the quality of the research by enacting what Carter calls internal coherence (Carter 2010). That is to say, rather than procedural or instrumental checklists (Tong, Sainsbury & Craig 2007) and standard descriptions, I seek instead, to fully articulate the methodology (Mann et al. 2011).

In addition, the world, including healthcare delivery is increasingly complex. I argue, therefore, that it is necessary to engage with this complexity. This thesis challenges the assumption that prescription and knowledge are more important than visualisation and action, confronting the notion that order is the answer. I am not arguing that non-order is necessarily a good thing. However, what Law refers to as euro-metaphysics assumes that order is inherently good and that technologies can operate amid complexity when in fact, non-order may be what holds everything together and enables things to co-exist (Law 2004).

Finally, and importantly, by getting close to the mess and engaging with it, I become nomadic, being open to uncovering what is otherwise invisible. I approach inquiry in the manner argued by Law where inquiry engages with that which is:

> *"Complex and elusive, messy, textured, vague, unspecific, disordered, emotional, painful, pleasurable, hopeful, horrific, lost, redeemed, visionary, angelic, mundane, intuitive, sliding and unpredictable" (Law 2004, p6).*

In doing so, I endeavour to take 'creating a space for healing to happen' beyond rhetoric to reality. The study seeks to explore meanings and understandings acknowledging that the human condition is unable to be "neatly partitioned into life slices of reality seen through a lens" (Sullivan 2005, p6). Rather than existing as something independent of any human connection, the study recognises the complexity of human nature and behaviour. That is to say, taking a spatial approach to the research requires exploration of relationships and interconnections. I view knowledge as embodied and embedded. I adopt a spatial approach to acknowledge that people are entangled with each other, including myself as researcher, in different ways as they move through space. This translates as a need to consider a variety of perspectives rather than, for example, discrete groups of people such as doctors, nurses, patients or families in isolation. Moreover, to function outside of assemblages as the subject of study and as a detached and neutral observer is impossible. "We are entangled in our flesh, in our versions of vision and in relations of power that pass through and are articulated by us" (Law 2004, p68).

Rather than dismissing politics, the thesis recognises the social and political contexts in which the research is conducted and the positioning of myself as the researcher as someone with values, ideologies and experiences. As a researcher, I am an activist insofar as I 'interfere' with the world (Law & Mol 2002). In this way I, together with participants, co-construct knowledge as a product of the research process emerging from our interaction (Charmaz 2006). As such, the sharing and corroborating of perspectives between the researcher and participants is seen as establishing a useful knowledge base rather than as an obstacle to a purer knowledge (Sullivan 2005). This thesis acknowledges the value of knowledge and information held by participants and the contribution of clinicians themselves to improve healthcare (Iedema et al. 2006c).

This search for meaning needs to acknowledge the often intangible emotional and ineffable moral aspects of illness and dying (Tauber 2000). Many realities craft themselves into materials other than the linguistic. I argue, like Law, that attempts to study and describe the 'intangibility' of suffering in purely linguistic terms are bound to miss the point requiring different 'allegorical modes' (Law 2004, p147). Indeed Kleinman (1995) cautions against objectifying suffering, as suffering can only really be grasped from the experience of the sufferer themselves. As Law emphasises: "There is not that much room for the workings of the Holy Spirit in most parts of the Euro-American world, or the indefinite, or the multiple" (Law 2004, p118). Hence, conventional research methods are inadequate for exploring communicative environments that promote healing at the end of life (Clark 2003; Solomon 2003). As the human condition and interrelationships between individuals and their worlds cannot be captured easily with the written word, novel and creative methods beyond the text are needed to provide knowledge that will help us to understand the complex phenomena involved and to explore and interpret, imagine and conceptualise the care of the dying (Clark 2003; Goopy & Lloyd 2006; Morgan et al. 2009; O'Malley 2005; Solomon 2003).

Engaging with the spatial as affective unfolding requires an approach that explores the ways in which social organisation and the complexity of human action and interaction are embedded in the material environment. Organising of care happens in 'multiple fragmented contexts' and in many places simultaneously (Czarniawska 2007). Thus, the methodological approach needed to account for the emergences of practices and structures with different temporalities rather than relying on hierarchical or sequential ordering of activities. This necessitates the need to 'follow' participants over time and in different settings using a combination of methods.

The resulting approach is one that facilitates 'connections' to explore meanings and understandings, finding creative means for me to 'hear' participants. Thinking in spatial terms, I take the quantum view of Kearney (2000) that, rather than accepting the observer as discrete and separate to observed object, both exist in a 'participatory universe'. I engage in what Heshusius refers to as a "participatory mode of consciousness" or "an awareness of a deeper level of kinship between the knower and the known" (Heshusius 1994, p15-22). This requires a desire to let go of the perceived boundaries between self and other and thus decrease the distance between participants and me. This required me to enact the spirit or what (Jasanoff 2003) terms *technology of humility* and a turning toward the other in an attitude of openness and receptivity that I referred to earlier. In so doing I responded to intuitive calls to visit or call participants. Instead of eliminating chance encounters that are intrinsic to spatiality (Massey 2005), I followed up on these fortuitous encounters participating in meal breaks with healthcare workers as well as in 'formal' meetings. Further, I followed up on what I call 'affective leads'. Namely, encounters where I permitted Polanyi's concept of "tacit knowing" (Polanyi 1966, p4) allowing a kind of bodily or "somatic awareness" (Shusterman 2008, p139), to come to the fore. Chapters 4 and 5 will more fully explore how I enacted these 'participatory modes of consciousness'.

This methodological approach parallels the very messiness of social life itself as a "non-linear vibrant living matrix" (Kearney 2000, p23). Approaching the study in this way, I view the research as 'questions to be lived' rather than 'problems to be solved' (Kearney 2000). As Heshusius puts it, by enacting a 'participatory mode of consciousness' the questions:

> *"How do I know? and How should I live? — separated since the rise of Western science — become the same question again when value and fact, and, therefore, when ethics and epistemology, are acknowledged as inseparable" (Heshusius 1994, p20).*

Of course examining 'questions to be lived' is as much an ethical quest as it is an epistemological one. Integral to the research, I dedicate an entire chapter to the ethical approach as inseparable from methodology and methods. The remainder of this chapter, however, provides a description of the methodological approaches I have drawn from and their integration into the research including the analytical process. This foreshadows a detailed account of my own unique approach to research methodology and methods provided in the next two chapters (Chapters 4 and 5).

Section 3.4 Methodological Approaches

The methodological approaches that inform this thesis include participatory action research; video ethnography; participant video accounts; video reflexivity and indigenous methodology. By adopting multiple methods in the research I do not aim to directly access the ‘truth’ underlying ‘the problem of hospital dying’ or indeed, find answers to the problem. Instead, I aim to create new ways of looking at the complexity of end-of-life care through the merging into mutually evolving complex ‘realities’ allowing these realities to be seen in a way previously invisible (Heshusius 1994).

Participatory action research

Action research attempts to integrate theory and practice, action and reflection in a participatory way to identify practical solutions to issues of great concern for people (Reason & Bradbury 2001). Epistemologically, it recognises knowledge as something a group of people produce locally through the research process for their own benefit. If health is viewed in holistic terms then quality of relationships are not separable from environmental factors. Iterative reflective cycles can therefore aid understanding of complex situations (Hughes 2008). Thus, looking at the whole person in context and the multiple ways of knowing necessary to study safe and healing environments is consistent with a participative paradigm (Hughes 2008; Miller et al. 2003). By whole person, I do not mean a person configured as biological, psychological, social and spiritual (Hutchinson 2011) but rather one who is viewed as a subject, embodied in space and time and occupying a lived context in a world of social interactions. In other words, a body viewed as *body multiple* (Mol 2002). That is, one that emerges from the physical and social world and has capacity to affect and be affected at multiple levels (Fox 2011; Mol 2008). As I have argued thus far, the body viewed in this way requires a research approach that accounts for “spatialised subjectivities” (Massey 2005, p59). That is to say, a research approach that recognises research, researcher and participants as interconnected ‘becomings’. This renders a participatory approach not only consistent with, but, in fact, necessary for the present study.

In participatory research both practitioners and researchers are encouraged to be advocates embracing social justice as well as humane care (Hughes 2008). Nevertheless the researcher and research have their own agendas. Power imbalances remain even in participatory action research, challenging its emancipatory goals. In the context of development, participatory projects of empowerment cannot only place people under surveillance but: “The attempt to empower people is always an attempt, however benevolent, to reshape the personhood of the participants” (Henkel & Stirrat 2001, p182).

Seale (2007) agrees with these concerns in the context of social research contending that one person's liberation may be another's oppression. He further cautions that while social research should be informed by social theories and political values it ought not to be over determined by them. In other words, Seale argues that moral values and political positions ought not to be a substitute for research quality.[17] I have already argued however, that non-interference with an 'external world' is not possible. Detachment is, according to Haraway (1991, p194) never possible. "As we produce knowledges we are all located somewhere, in our practices and in our bodies". Accepting Haraway's argument that detachment is impossible renders me a part of space that I am researching. Concerned with space, this thesis is unable to escape affect. It is these more-than-human forces that define and populate space. Furthermore, in continual flux affective forces are implicated in ongoing territorialisation and deterritorialisation. Therefore, these dynamic forces are inseparable from political subjectivity rendering affect an inherently political concept (Williams 2010). Thus, while I do not seek to be explicitly politically positioned I am, by implication an activist unable as researcher to be value free. The approach I take is therefore one that necessitates acknowledgment of my values and political stance as a palliative care nurse researcher while simultaneously questioning these values and assumptions and being open and attentive to opportunities and how things might be different.

The visual

Communicating the nature of one's pain and suffering to another is inherently difficult. It is 'effortlessly grasped' for the person whose pain it is, while for the outsider it is 'effortlessly not grasped' (Okon 2006; Scarry 1985). Indeed words can lose their signifying function when a person is dying (Hooke 1997). Creative processes can unexpectedly open doors of communication and facilitate understanding, enabling expression of the inexpressible (Bolton 2008). In particular I take my inspiration from the film 'Hospice in Amsterdam' and its director Steef Meyknecht (2005). I am moved by the way in which Steef together with the four residents of the 'Hospice Veerhuis' present death and dying honestly yet sensitively. The profound relationship between film-maker, residents, families and volunteers of the 'Veerhuis' is evident as the final

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[17] According to Seale (2007) asking important rather than trivial research questions and commitment to rigorous argument determines research quality. In particular, he argues that making links between claims and evidence and consideration of all viewpoints are necessary before taking any particular stance.

journeys of residents and the life of the 'Veerhuis' is shared with the viewer. The power of this work is its visual medium.

We live in a visual and auditory world with many visual and auditory stimuli. The visual can "jar people into seeing things differently" and can propel people to look at something in a different way (Leavy 2009, p220). Critically, many realities craft themselves into semioses other than the linguistic (Law 2004). Thus, representing social realities through written narrative can go only so far and even miss the point by suggesting that such realities are fitted into a particular order (Law 2004). I look to the visual as an alternative mode of expression. Engagement in a 'participatory mode of consciousness', or "an awareness of a deeper level of kinship between the knower and the known" (Heshusius 1994, p16) requires methods that are capable of "distributing agency more generously and less parsimoniously" (Law 2004, p151). I explore more fully in Chapter 5 how the visual can account for joint knowing in a way not possible through writings and texts, democratising the research process.

Video ethnography

Historically ethnography has its roots in cultural anthropology and sociology (Delamont 2007). Ethnography studies social interactions, behaviours, and perceptions that occur within teams, organisations, and communities (Reeves, Kuper & Hodges 2008). Ethnographic methods describe the setting, the activities, and the meanings attributed to them from the perspectives of the actors. It is a method that asks the researcher to the extent that it is possible, to share with those actors the environment, worldviews, activities and meanings. Ethnographers typically gather participant observations and interviews and immerse themselves in field settings to generate understanding of the social action that occurs (Anspach & Mizrachi 2006; Costello 2001; Kaufman 2005; Reeves, Kuper & Hodges 2008). Rather than seeing my observations as an 'objective' or comprehensive account of the palliative care day hospital or the acute hospital setting, the knowledge produced is co-constructed with participants and pertains to their specific cases. In other words, I recognise that my presence as the researcher inherently effects change in what is described. Accordingly, the research is an "interventionist ethnography"(Cassell 2005, p187-189), necessitating researcher reflexivity throughout all stages of the research process and requiring me to convey, as I have attempted to do thus far, my own 'voice' (Delamont 2007).

I combine ‘interventionist ethnography’ with visual methods. Video that is used alongside ethnographic methods is termed ‘video-ethnography’ (Carroll, Iedema & Kerridge 2008; Iedema et al. 2006c). The ethnographic use of video is a technique that records the complexity of healthcare practices. It allows exploration of how data are created socially (Carroll 2009). Video ethnography can interrupt the social landscape creating a “local interactional space” (Mesman 2007, p281). Chapter 5 explores how these interruptions take place.

Participant video accounts

Video diaries or ‘participant-generated video accounts’ are digitised diaries used for the collection of data that reflect participant experiences over an agreed time period (Buchwald, Schantz-Laursen & Delmar 2009; Chalfen & Rich 2007; Gibson 2005). Video accounts ask people living with illness to teach others caring for them about their illness experience providing a reflexive medium to facilitate mutual understanding among patients, families and clinicians. This has the possibility of promoting care that is responsive, sensitive and effective (Rich & Patashnick 2002). I use video as a medium so that patients and families as well as healthcare professionals have the opportunity to access their own stories directly for their own purposes rather than indirectly via me, as the researcher. I investigate health issues from the perspective of the patient, their family and clinicians.

I ask people living with illness and their families to teach healthcare workers caring for them about their illness experience, based on the idea that exposure to such experiences mediated through video provides healthcare workers with understanding otherwise not available to them. Furthermore, video gives control to participants to provide information about their own experiences, feelings and needs in their own time and when they feel physically and emotionally able to do so. Experience of other researchers of ‘handing over the camera’ is that people engage powerfully with the creation of their illness narratives (Chalfen & Rich 2007; Rich & Patashnick 2002; Rich, Patashnick & Chalfen 2002). I recognise that the nature of life-limiting illness may limit the capacity for individuals to ‘always have the camera’. The co-construction of knowledge as a product of my research process, however, means that participants are able to request my assistance with filming (Gibson 2005). I describe the operational processes involved in these negotiations in the next chapter (Chapter 4).

Video reflexivity

Video reflexivity and video ethnography are intrinsically linked. Video reflexivity describes a process where video footage is played back to participants for review and discussion. Uniquely, video footage can challenge the taken for granted and attune people to dimensions of practice that they might not otherwise have considered (Iedema 2011a). These characteristics of video reflexivity are brought about by the simultaneous presencing and distancing of the viewer (Carroll, Iedema & Kerridge 2008). Reflexivity, distinct from reflection, positions the subject contextually in relation to him or herself and to others as well as the broader influences that shape actions and behaviour (Iedema 2011a).

Video reflexivity and video feedback do not detach the researcher from participants or seek to objectify the complexity of caring for people with a life-limiting illness (Carroll 2009). Rather, the crossing of roles and boundaries creates opportunities for the co-construction of meaning that can challenge and impact the assumptions of all parties (Carroll 2009; Gibson 2005; Iedema et al. 2006c; Iedema et al. 2009). Visual communication as a research tool can provide a powerful channel for the sharing of knowledge (Iedema et al. 2006c; Pink 2007a, 2007b). Video footage is able to capture the context and psychological, social, cultural and spiritual elements of the patient's narrative (Goopy & Lloyd 2006). Video footage is able to integrate face-to-face communication within the lived experience of the care process, a necessary component in exploring healing environments (Frankel, Hee Sung & Hsu 2005). How these combined methods were enacted will be conveyed in more detail in Chapters 4 and 5. First, however, I turn to the ethical context in which they are situated.

Indigenous research ethics framework

Of central importance to indigenous scholars is connection with each other and a world viewed in historical as well as spiritual and physical terms (Mertens 2009). Indigenous methods have arisen from the inadequacy of established scientific methods to attend to intuitive, spiritual and personal ways of knowing (Bishop 2005). In this paradigm the researcher and participants set out in a general direction rather than selecting a specific destination. The central aim of indigenous methodologies is to ensure that research is carried out in a participatory, respectful, ethical and beneficial manner seen from the point of view of Indigenous peoples (Botha 2011). This overarching philosophical approach is set out in the introductory paragraphs of the Australian Guidelines for Ethical Research in Australian Indigenous Studies:

> *"It is essential that Indigenous people are full participants in research projects that concern them, share an understanding of the aims and methods of the research, and share the results of this work. At every stage, research with and about Indigenous peoples must be founded on a process of meaningful engagement and reciprocity between the researcher and Indigenous people. It should also be recognised that there is no sharp distinction between researchers and Indigenous people. Indigenous people are also researchers, and all participants must be regarded as equal participants in a research engagement" (Australian Institute of Aboriginal and Torres Strait Islander Studies 2011, p4).*

While acknowledging the necessity of this approach and ethical guidelines specifically for 'doing research' with Indigenous peoples, I take this a step further arguing for application of the principles outlined in this document to my own research and arguing for replacement of 'Indigenous peoples' with 'dying people'[18] in the following listed principles as follows:

- "Principle 1: Recognition of the diversity and uniqueness of peoples (dying people), as well as of individuals, is essential".
- "Principle 2: The rights of Indigenous peoples (dying people) to self-determination must be recognised".
- "Principle 3: The rights of Indigenous peoples (dying people) to their intangible heritage must be recognised".
- "Principle 4: Rights in the traditional knowledge and traditional cultural expressions of Indigenous peoples (dying people) must be respected, protected and maintained".
- "Principle 5: Indigenous knowledge (dying people), practices and innovations must be respected, protected and maintained".

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[18] I prefer not to label people as dying seeing them as living. I use the term here however for practical reasons to underscore my argument of engagement and reciprocity.

- “Principle 6: Consultation, negotiation and free, prior and informed consent are the foundations for research with or about Indigenous peoples (dying people)”.
- “Principle 7: Responsibility for consultation and negotiation is ongoing”.
- “Principle 8: Consultation and negotiation should achieve mutual understanding about the proposed research”.
- “Principle 9: Negotiation should result in a formal agreement for the conduct of a research project”.
- “Principle 10: Indigenous people (dying people) have the right to full participation appropriate to their skills and experiences in research projects and processes”.
- “Principle 11: Indigenous people (dying people) involved in research, or who may be affected by research, should benefit from, and not be disadvantaged by, the research project”.
- “Principle 12: Research outcomes should include specific results that respond to the needs and interests of Indigenous people (dying people)”.
- “Principle 13: Plans should be agreed for managing use of, and access to, research results”.
- “Principle 14: Research projects should include appropriate mechanisms and procedures for reporting on ethical aspects of the research and complying with these guidelines”.

I look to this indigenous research ethics framework including the above guiding principles to provide me with a foundation on which to base my methodology. This translates as a need to develop reciprocal relationships with participants based on openness, trust and engagement. What is of most importance is the need to position the voices of participants centrally in the research. Accordingly, I endeavoured to remain reflexively aware of power imbalances throughout all stages of the research. Further consideration of my own positioning in the research and relationships with participants is explored in Chapter 5.

Section 3.5 Conclusion

In conclusion, this chapter has positioned the positive and creative philosophy offered by Deleuze and Guattari as the theoretical foundation and methodological framework for understanding end-of-life care space(s) and within which the empirical research can embrace complexity, uncertainty and transformation. This mode of enquiry engages with and respects unstable and dynamic ‘realities’. It allows for mess in the form of non-linear research planning and entangled relationships. As nomadic researcher, seeking new possibilities, I do not embrace theories as means to delimit my research and legitimise my approach, but instead to use theories to make connections serving to inform and extend the thesis. Critically, and encouraged in this by Deleuze, getting close to the mess and engaging with it has the creative potential to uncover what is otherwise invisible: As Deleuze and Guattari put it:

> *“The rhizome is altogether different, a map and not a tracing. Make a map, not a tracing. The orchid does not reproduce the tracing of the wasp; it forms a map with the wasp, in a rhizome. What distinguishes the map from the tracing is that it is entirely oriented toward an experimentation in contact with the real. The map does not reproduce an unconscious closed in upon itself; it constructs the unconscious. It fosters connections between fields, the removal of blockages on bodies without organs, the maximum opening of bodies without organs onto a plane of consistency. It is itself a part of the rhizome. The map is open and connectable in all of its dimensions; it is detachable, reversible, susceptible to constant modification. It can be torn, reversed, adapted to any kind of mounting, reworked by a individual, group, or social formation” (Deleuze & Guattari 1987, p12).*

The present research, by removing the boundary between the researcher and the researched, acknowledges methodology, ethics and epistemology to be inseparable. I now outline in the next chapter, Chapter 4 (Methods), the technical and practical elements of the methodology before providing a more in-depth discussion of how the methodology that emerged from this approach was lived in practice in Chapter 5.

Chapter 4 Methods

Section 4.1 Introduction

This chapter continues to describe the background of the research. It begins to detail how the methodological philosophy and approach outlined in the previous chapter (Chapter 3) were realised practically in the field by outlining the research design. Technical and practical aspects of methods are the foci of this chapter. The next chapter (Chapter 5) provides an in-depth discussion of how the methodology that emerged from this approach was lived in practice as the research unfolded.

This thesis employs an ethnographic method to collect data incorporating ethnographic field observations, field interviews, semi-structured interviews, participant generated video accounts, and video reflexivity. It was inevitable that 'on the ground' research strategies evolved and changed as the research progressed. In collaboration with participants, they remained however, informed by Indigenous research philosophy of building relationships and reciprocity and seeking out agency. This chapter details the practical and technical components of the research methods foreshadowing an extended critique of how these relationships were formed and built in the next chapter (Chapter 5). Section 4.2 titled 'Field Sites' describes the study sites, locating the research in context. It outlines the recruitment and data collection processes. Section 4.3 is titled 'Equipment and Process' and details apparatus and operational processes of data management. Finally, Section 4.4 titled 'Data Analysis' presents the approach to data analysis including video reflexivity foreshadowing the empirical chapters of the thesis (Chapters 5, 6, 7 and 8).

Section 4.2 Field Sites

As it is concerned with space and affect and inspired by Deleuze and Guattari's philosophy of fluidity, emergence and unfolding, this thesis considers 'the field' as non-static. Thus positioned and as I have already argued in Chapter 3 (Theoretical Perspectives), methods were needed to account for these dynamics and emergences. Practically, however, fieldwork required entry points. This section describes these located entry points and how methods including recruitment and data collection evolved from these locations. I begin the research journey at a specialist palliative care day hospital.

Locating the palliative care day hospital

Palliative Care Services form a part of a 72 bed public hospital that specialises in rehabilitation, palliative care and older persons' mental health and provides inpatient, outpatient and community services. These services include a 20-bed inpatient unit, a day hospital, outpatient clinics and after-hours telephone advice service for people diagnosed with a life-limiting illness. To access these services patients are required to be registered with the area specialist palliative care service.

Entry to the field (the palliative care day hospital)

I drew upon existing relationships and contact circles to gain access to field sites. Having previously worked in the healthcare context, I had access to both the palliative care day hospital and acute hospital. While some of the palliative care day hospital staff knew me from having previously worked as a community palliative care nurse, I had never worked directly in the palliative care day hospital. This meant that day hospital staff knew me from within the area palliative care service and that they trusted me enough to allow me into the palliative care day hospital. As I had never worked directly with them in a nursing role, however, I was still able to establish myself in the new role of ethnographer.

I was also employed on a part-time basis one day a week on another project based in another department of the palliative care hospital. This legitimised my presence in the hospital one day a week, fostering relationships with staff and engendering serendipitous encounters. However, I never took this privileged access to or presence in the hospital for granted and took formal as well as informal steps to introduce myself as the researcher. I describe these steps more explicitly in the next chapter (Chapter 5).

The palliative care day hospital provided what I deemed an appropriate place from which to launch the research. It was a place that advertised itself as ‘a safe healing place’ evident from its information brochure:

> *“The palliative care day hospital aims to give social, spiritual, emotional and physical support to our patients and their carers. The atmosphere is both friendly and life affirming”.*

Ensuring ‘safety’ for patients and staff was the principal reason for commencing the research in the palliative care day hospital. It was also, however, a safe place from my own point of view as the researcher. In this early stage of the research, I was uncertain whether participants would accept visual methods as feasible or worthwhile, and indeed ‘safe’. Further, establishing whether or not visual methods have a place in palliative and end-of-life care research was a significant aim of the study. Thus, I regarded this phase of the research as a ‘pilot’ phase and initially presented as such. Initiating fieldwork in the palliative care day hospital allowed me to develop effective research processes, to identify barriers to the method and generate feedback about the method from participants so that I could refine them for the subsequent phase of the study. However, it became apparent that the palliative care day hospital, as a place that portrayed itself as a safe healing space, would provide much more than a testing ground for methods. Rather, it provided a significant and profound source of insight and knowledge through my interactions with participants, observations, and experiences there. What I initially considered as a ‘pilot’ phase became a central and critical part of the research. As a consequence, I later abandoned the label ‘pilot’ to reflect this change of view. I will discuss this further in Chapter 8 of the thesis. Here, however, I locate the palliative care day hospital within the research more broadly.

Data collection (palliative care day hospital)

The palliative care day hospital service took place twice weekly on Tuesdays and Thursdays from 9:30 am until 2pm. I attended one or both days weekly over a period of four months from May 2010 until August 2010 culminating in eighteen days of attendance. This resulted in fifty-four hours of ethnographic observations and field interviews.

Participant recruitment (palliative care day hospital)

People diagnosed with a life limiting illness and a poor prognosis, their families and healthcare workers caring for them were included in the study. That is, there were three categories of participants: patients living with a life-limiting illness; family member(s) or significant other(s) nominated by the patient, and healthcare workers. Participants in these three categories were involved contemporaneously or sequentially, depending on each individual participant. Healthcare professionals were asked to identify potential patient participants from both the palliative care day hospital and out-patient clinic for referral using the ‘surprise’ question: ‘It wouldn’t be a surprise if this person dies in the next six months’ (Lynn 2004). Adults over the age of eighteen and who were able to converse in English[19] and to give informed consent were provided the opportunity to participate.

The number of patients attending day hospital on any one day ranged from between three and twelve. Occasionally, patients would come through from the adjoining in-patient palliative care ward to join in day hospital activities. Family members would sometimes accompany patients for all or some of the time. I engaged in informal conversations with day hospital patients, families and staff throughout the course of my attendance there.

Initially I requested a ‘formal’ semi-structured interview from palliative care day hospital patients who members of the palliative care multidisciplinary team had identified as potential participants. Following several visits to the palliative care day hospital and in collaboration with staff, it became apparent to me that all patients attending the palliative care day hospital met the study criteria. An increase in my own comfort levels in the role of researcher as well a realisation that I was gate-keeping who might want to participate led me to extend an invitation to all palliative care day hospital attendees. I critique this issue of gate-keeping in the context of my relationships with participants in Chapter 5.

Video accounts

The study was designed to reflect the need to ‘follow’ what happens to patients and their families over time and in different contexts. Depending on their wishes and whether they were able to, patients and/or families kept the camera to ‘film’ what, if, and when they wished. I sought to ‘meet participants’ on their grounds. To this end, the use of video accounts sought to enable patients and carers to express their stories, in their own time and in their own way without the research method creating an added burden for them. This resulted in some people wishing to tell me their stories ‘in the palliative care day hospital’ ‘at the bedside’, ‘in the outpatients department’ or in ‘their home’ with or without being filmed. For some people this involved a ‘one off’ interview. For others it entailed several visits on or off camera depending on their

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[19] Participants were not required to have to be able to read in English to take part. The information and consent could be read to them and their consent video recorded.

wishes. For several patients and families, this entailed leaving the camera with them and me ‘following’ them over a period of months.

I provided potential participants with an information sheet (Appendix 1). Interviews occurred in the place(s) and times most convenient to participants. These initial participant interviews took between approximately ten minutes and one hour. The amount of time spent on video accounts was determined by what participants regarded as important. I used a semi-structured interview schedule with prompt questions (Appendix 3 and Appendix 4). As a precursor to being present in day hospital, I interviewed all members (twelve in total) of the palliative day care interdisciplinary team. I provided the option for staff to be interviewed on film or audio-recorded. Of the twelve healthcare staff, I filmed seven and audio-recorded the remaining five interviews. I interviewed three patients formally; I filmed two of these interviews and audio-taped one. I interviewed one patient’s family member using videotape.

Along with the palliative care day hospital team I arranged two meetings to reflexively examine video-recordings. These meetings were pre-arranged at a mutually convenient time, and lasted an hour. I held a third video reflexive meeting at the invitation of the palliative day hospital team for the palliative care in-patient team.

I proceeded between periods of fieldwork and reflection and analysis of data. I did not use film ethnographically in the day hospital and explain the reasons for this decision in the next chapter (Chapter 5). I invited the three patient participants I formally interviewed to be involved in generating further video accounts of their experiences of safety and healing in a variety of settings. One day-hospital attendee and her husband consented to these ongoing video accounts of their experiences. This resulted in me having a continuing relationship with them for the duration of the study (twelve months). Contingent on their preferences and together with participants I produced video material for healthcare participants and other audiences to view reflexively.

The research method including video accounts did not necessitate that I film patients and families as people could convey their stories in any way that they wished. Participants could participate in the ‘language’ of communication of their choosing. For example one participant chose to articulate her message through the sharing of her poems. I made regular contact with patients and families in collaboration with them to inquire about and assist with any issues they may have regarding the research. Patients, healthcare professionals and family members determined the timing of contact and amount of time I spent with them.

Locating the acute hospital

The acute hospital is a large metropolitan tertiary referral hospital and a major trauma centre for the state, with approximately 855 beds and providing medical, surgical, emergency medicine, intensive care, oncology, mental health, women's health and new-born care services.

The general manager of the acute hospital recruitment site knew of me from having worked on a previous end-of-life care project there. Once again I capitalised on previous relationships I had gained there to establish trust with the senior executives and gain access to the site. Hoping to be able to ‘follow’ patient participants and families into other neighbouring hospital facilities, ethics and site specific approval was also obtained for two other metropolitan hospitals in the same district. Endorsement of the study by the area palliative care medical director paved the way for me to access all three acute hospital sites. I wrote to all relevant general managers and directors of nursing at the sites involved to explain the project and reassure them that filming would only occur in close collaboration with clinical staff on the ground. I also provided them the opportunity to meet with me in person to discuss the project in more detail. Two of the three general managers approved access without a meeting. I met with the third in person along with the director of nursing of that particular hospital to discuss the project further and invite questions and or concerns.

I was well known by the specialist palliative care team at the primary acute hospital recruitment site. Again, their professional respect and trust of me was critical in their acceptance of me into their department, attendance at their meetings and initial referral of participants. At the time of fieldwork commencement, the person holding position of general manager had changed. Consequently, I advised both the new post-holder and the director of nursing that ethics and access approval had been obtained inviting them to provide me with instructions as to any particular process they wished me to follow. As a result, I was provided with site identification in the form of an identification badge. The hospital palliative care clinical nurse consultant was directed by the director of nursing to act as a key person on her behalf should I have any concerns or issues for the duration of fieldwork.

Data collection (the acute hospital)

I attended the acute hospital site over a period of ten months from November 2010 until September 2011. I responded to patient referrals. Not confining myself to any particular inpatient or outpatient section or ward of the hospital, I engaged in shadowing[20] patients and clinicians. This involved a combination of observation of routine communication practices as well as ‘shadowing’ of participants. Shadowing included members of the specialist palliative care team, oncology specialists, ward observation, informal patient, family and staff conversations and attendance at clinical handover meetings. The process was iterative and included observation, semi-structured interviews, informal interviews, video ethnography including participant-generated video accounts and video reflexivity.

In negotiation with the hospital palliative care team, I initially attended the hospital two days a week ‘stationed’ in their department as a base from which to launch fieldwork and liaise with non-specialist palliative care providers about the study. The number of days that I attended the hospital increased to four days a week throughout the fieldwork period as networks expanded and number of referrals increased and gradually decreased towards the latter phase of fieldwork. While recruitment of patient participants took place at this, the main hospital site, in negotiation with participants and their families, I also ‘followed’ them to other care sites. These sites included the local palliative care unit, another acute hospital and a local hostel.[21] This culminated in 68 days of attendance for ethnographic observations written as field notes or sketched in diagrams.

Participant recruitment (acute hospital)

Again, I invited people diagnosed with a life-limiting illness and a poor prognosis, their families and healthcare workers caring for them to take part in the study. Initially I received referrals for eligible participants from the specialist palliative care team. I attended the team handover where hospital patients referred to the hospital palliative care service were discussed. Those patients considered to meet the study criteria were referred to me. I explicitly chose not to include any particular disease or diagnosis in the study criteria. Based on what I had read in the literature, my own ethics and values

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[20] Czarniawska, B. 2007, Shadowing and Other Techniques for Doing Fieldwork in Modern Societies, Korotan Ljubljana, Slovenien.

[21] A low level aged care facility.

together with an Indigenous ethics research framework, as far as was possible, I wanted to avoid categorising or labelling people as a disease or diagnosis. It was not my intention to recruit any particular patient group, nor to recruit those patients already referred to the palliative care service. To this end I approached several other specialties and arranged meetings with senior medical and nursing staff from those specialties to tell them about the project. Specialties included medical and radiation oncology, respiratory, haematology and cardiology. I asked healthcare staff to identify potential patient participants for referral to the researcher again, using the surprise question: ‘It wouldn’t be a surprise if this person died in the next six months’ (Lynn 2004).

I used a process of convenience sampling to recruit healthcare professionals gathering broad and preliminary information initially as I had done in the day hospital, and again making the most of fortuitous meetings and unfolding opportunities presenting to me. I recruited and interviewed on film sixteen individual healthcare staff this way. Four of them were medical specialists, eleven were nurses, and one was a receptionist. Through a process of snowball sampling, I interviewed hospital social workers and speech pathologists as a group at their request. This did not include those healthcare staff recruited purposively and interviewed as part of the video reflexive process that I describe later in the chapter. As the research progressed, it became clear to me that non-professional healthcare staff are key people within assemblages. Thus, from this point of the thesis forward, I use the term healthcare worker instead of professional healthcare staff to include non-professionals such as receptionists.

I followed the same process of recruitment of participants as I had for the palliative day hospital. I undertook interviews and observations in the place(s) and times most convenient to participants including patients’ homes and in both inpatient and outpatient healthcare settings. A total of forty-five patient referrals were received. Sixteen of those patients wished to be interviewed informally at the bedside without being recorded or filmed. Thirteen patients consented to being interviewed formally on film. However, two of these patients deteriorated and died prior to filming taking place. Of the thirteen who formally consented, five were followed over several visits and into other care settings. Five family members formally consented to filmed interviews. Two participants ‘kept’ the camera over a mutually agreed timeframe. While these field interviews were unstructured, I found that as soon as I explained to patients what I was interested in and why I was there, they shared narratives and disclosed themes that showed great affinity to my more refined semi-structured interview schedule.

Section 4.3 Equipment and Process

The camera

I used a small user-friendly consumer level video camera of mini-DV tape format for the duration of the study. Patients and families used the same camera as I did. I made this decision on the basis of practicality and ease of use. Later in the research, however, I came to view this decision as much more significant than I initially realised. First, this was symbolic of putting relationships on an equal footing. Secondly, the limited audio function of the camera[22] meant that it picked up background noise that became meaningful for viewers of the footage and I discuss this further in the next chapter (Chapter 5). Participants who requested to keep the camera were trained in the basics of making the camera work. After seeking the advice of others and giving significant thought to what kind of camera to use, I opted for mini-DV tape. First, recording tape rather than digital footage allowed me to provide patients and families with a solid artefact that was tangible. This enabled me to provide patients and or family participants who ‘held’ the camera with two tapes at a time; one tape for recordings pertaining to the study and a second tape to do whatever they liked with and could keep if they wished. Second, it was less likely that taped footage would be recorded over. The optimal number of tapes, frequency of my visits as well as the duration of the video accounts was negotiated with each participant.

I asked participants to document what it means to them to live with their or their family member’s illness, using the questions: *If you were to make visible what it is like to live with your illness, what would you make visible to others? What would you want them to know and what would you want them to see?* In this way, I sought to become an apprentice of participants, seeking to ‘see’ and understand phenomena in the way that they do (Grasseni 2004). In particular, I asked them to record the kind of places and situations where they thought they were most safe or not so safe including places where they received care. I negotiated with participants as to how often I would contact them

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[22] The decision to use a simple consumer camera was driven by the research. Ease of use for participants as well as myself as researcher took priority over the need for professional media quality footage.

on an individual basis. This became more of a joint process than I had initially anticipated. I learnt that handing over the camera completely to patient participants, as was my initial intention was not only unrealistic, but did not take account of my own key argument of the necessity for close collaboration in producing video accounts. I, therefore discussed with participants what they had recorded or what they wanted help with recording and its significance.

The editing process

I captured visual data from mini-DV tapes into an editing software programme called Final Cut Pro. I catalogued and time-coded the footage for ease of retrieval and editing. I also transcribed video-recorded interview accounts as well as video feedback meetings verbatim. I downloaded footage onto my laptop so that it was accessible to participants should they wish to view it themselves. If participants wished to show footage to others i.e. their family member(s) and/or healthcare worker(s) caring for them, I provided them the opportunity to choose footage. Further, I explained to participants that should they wish, I would provide them with a copy of their footage at the completion of their involvement in the study.

Data storage

The data I collected for each participant is held in a participant study file. Data took the form of field notes, audio recordings and visual recordings. My field notes remained in my possession throughout the duration of fieldwork and analysis. I stored all data electronically on a password-protected computer and locked up back-up drives in filing cabinets. It will be securely stored for a period of seven years, after which all data will be destroyed using appropriate secure disposal methods in accordance with university standards. I outlined to participants that their footage may be used in several different forms and that unexpected dissemination opportunities may arise that were not anticipated. Where patients made it explicitly clear to me before they died who they wanted to view footage, I will continue to honour their wishes in this regard, using my own judgement while also taking account of the wishes of family members.

Section 4.4 Data Analysis

The theoretical framework of the thesis informs the analytical approach. In preparation for the analysis and discussion of the findings of the research, it is important to note: First, findings remain fluid and second that the ‘mess driven’ ethnographic methods contextualise data obtained in a relationship-centered way. That is to say, visual research materials are inseparable from and comprehensible only in terms of other research materials with visual, verbal and textual data informing each other. That is, my field notes informing the visual and vice versa or what Collier and Collier (1996, p189) describe as “Building a bridge between the visual and the verbal”, warning against a goal of “decoding” visual data into verbal data. Analysis continued throughout the entire process of the research taking account of the fact that visual images are never one thing but rather have their own biographies, changing and evolving depending on the conditions in which they are viewed (Pink 2007a). In other words, my analytical approach involves examining how both participant producers and viewers of images give meaning to their content and form. I view visual data as jointly constructed images or meaning-making events, recognising that both participants and myself as the researcher were engaged in deciding what to present (Carroll 2009; Gibson 2005; Sullivan 2005). Critically, affect and emotion play a crucial role in the thesis and as such accessing the visual alongside the text allows the ‘reader’ to connect with and experience these affective elements in a way that would not be possible by reading them. Presenting the visual allows the ‘mirroring’ of concepts that the thesis has invoked. However, the clips are not viewed as images that need to be somehow ‘translated’ into the text but rather as a “Contribution to social argument in their own right” (Chaplin 1994, p3).

Capitalising on the recent neuroscientific and social neuroscientific evidence highlighting the role of emotion in cognition, integrating the visual with the written text provides a platform for the reader’s “emotion, cognition, body and mind to work together” in processing the thesis, as well as those of myself as the writer (Immordino-Yang 2011a, p102). Moreover, narratives can create connections between people in ways that circumvent cognition (Connolly 2002). Film can be especially effective at producing “movements of affect” (Roelvink 2010, p117). Viewing of visual stories can, according to Connolly:

> *"Open a new round of intrasubjective communication between your virtual register and a conscious line of reflection allowing new thoughts to stroll or run onto stage, now and then setting an internal dialogue into motion that brings something new or exciting into being" (Connolly 2002, p71).*

As such, 'viewing' as well as 'reading' the thesis provides the 'reader' (and myself as the writer) with a vehicle for accessing one's own affective responses. Assimilating psychosocial and neural evidence, Immordino-Yang (2011b, p313) posits that accessing such emotion-related bodily sensations in this way may play a facilitative role in reflection of one's own social behaviour and perhaps even one's own awareness of what "motivates moral sentiments and actions toward others".

Integrating visual narratives into the thesis is also my attempt to make them accessible to a wider audience than would otherwise be possible with text alone. In doing so, I make the thesis available to a greater diversity and number of stakeholders, meeting participant objectives as well as my own. This is an important ethical and methodological underpinning of the thesis. It is one that I have referred to already and one to which I will return again in the next chapter (Chapter 5). Finally and importantly, in retaining the visual narratives in this way, I attempt to honour the voices of the people who have chosen to participate. I continually heard from individuals that they did not wish to be 'objectified' but rather be treated as human beings in the context of their healthcare. This translated into the expressed wishes of participants not to be anonymous. Thus in re-presenting them, it was imperative that I attempt to preserve their faces and voices including their views and dilemmas holistically and centrally within the thesis.

While 'anchoring' to individual stories provides the scaffolding for each chapter, the individuals I will introduce tell their stories in the wider context of the research more broadly. Thus categorising them within chapters serves only as a heuristic device when in fact they interact across the thesis as a whole. The individuals' stories that follow in Chapters 6, 7 and 8, while 'anchored' to visual narratives for the purposes of these chapters are representative of the overall analysis. In other 'words' they speak on behalf of the data. I also embed extracts from formal and informal interviews, field notes and reflexive meetings into the text to complement the 'visual' and as a further means to make my case. As such, there are several analytical layers of the thesis; the analytical process that I as the researcher have engaged in from the outset; the analysis of participants themselves, and the reader/viewer's analysis.

Video reflexivity

Video reflexivity forms the basis of data analysis focusing on the meanings different individuals and groups of individuals give to images in different contexts and examining how visual content is informed by the subjectivities and intentions of the individuals involved (Pink 2007a). In this way visual material reflexively viewed by participants produces a further layer of knowledge (Grasseni 2004). By inviting participants themselves to become involved as stakeholders in the analytical process, reflexive viewers of footage provided critique of my own thoughts, promoting transparency as my observations and my positioning in making them are made visible in the video data (Pink 2006). Critical to the analysis, therefore, is an understanding of 'data' as flexible and open to possible change and emerging perspectives. It becomes necessary to speak of 'data' not as if it is somehow static but as something that emerges, thus resisting limitation and final categorisation. In this way how persons present themselves for the research camera provides a resource for analysis and is in itself data (Gibson 2005). For example, participant Joe who I introduce in Chapter 6 requests that his daughter take part jointly in the filmed research interview, indicating an interconnected view of what is safe and what is unsafe.

In the context of trusting relationships, I asked patient participants what they wanted me to do with footage and how they wanted it used after they died. Consent was ongoing and was gained from all participants[23] featured on film in advance of specific reflexive meetings. Ongoing consent for specific viewings will continue after the research has concluded.

For analysis purposes I provided the opportunity for participants to review material before others viewed it. I arranged for participants to view their footage on my laptop at a time and place of their choosing. Giving participants this opportunity resulted in a collaborative analysis process and was also critical within the relationship of trust I had with them. What was shown in reflexive sessions was also a joint process. Some participants were clear and specific about which footage they deemed most important and who they wanted to view their video clips. Others appreciated the opportunity to

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[23] Here participant refers to patients, families and healthcare workers

preview material but declined this opportunity. Some participants expressed that they wished their footage to be seen by ‘anyone’ involved in the provision of healthcare at the point of care and/or at a managerial or policy level.

Footage was edited into narrative-governed themes and scenes. This was an iterative process depending on patients, families and clinicians analysis of their own footage. Along with the participants’ analyses, I used my own clinical judgement, experience, contextual knowledge, and non-visual data to decide which footage was most relevant to present at video reflexive meetings. Footage selected for a group audience depended on the audience and the amount of time I was given.

I selected themed footage that demonstrated the complimentary perspectives of patients, families and healthcare workers and footage that I regarded as ‘representative’ of participant voices as a whole and would stimulate discussion and reflexivity. This process was never ‘clear cut’. I used my own ethics and experience seeking to portray a balanced view of selected visual narratives. Where participants were particularly critical of their care, I tried to balance this with more positive accounts when showing footage to clinicians. The reflexive healthcare worker focus groups commenced with a brief overview about the research project. There were three styles of reflexive meetings, as I will discuss next. These reflexive meetings provided the opportunity for immanent critique of analysis as I will go on to discuss.

Small group meetings-reflexive # 1

Two specific group meetings were held for the multidisciplinary team at the palliative care day hospital. In the acute hospital, group meetings were offered and held for specialties where the majority of footage pertained to those specialties. That is, oncology and haematology. However, these meetings resulted in a snowball effect with other invitations arising from these groups. For example, a meeting was run specifically for the Cancer Therapy Centre administration team. Meetings were either held in already-structured timeslots such as departmental ‘journal club’ or specifically set up for the purposes of the research. There were four meetings in total.

With the consent of participants, I filmed feedback meetings. In the first phase of the study, and not wishing to affect the level of trust by bringing someone ‘new’ into the group, I filmed these meetings by placing the camera on a stationary tripod in the corner of the room. However, I discovered that it was operationally difficult to run the meeting and also manage the camera myself. In later meetings therefore, I requested assistance with filming. This assistance came either from a member of the group and, in the case of the palliative care setting, from one of the palliative care nurses in the acute hospital or from one of my PhD colleagues.

In these group meetings, I contextualised the footage shown by providing a brief background to the research, where video reflexivity was positioned in the broader scope of ethnography and explaining the role of the participant group in viewing the footage. For group meetings I showed up to three vignettes of about six minutes in length. Participants were encouraged to note any particular thoughts or feelings they would like to share. Using metaphors from the film industry, Gibson uses questions that she argues are able to reveal different aspects of how participants locate themselves (Gibson 2005). The screening of footage was prefaced by the following questions inspired by the 'movie method' (Gibson 2005):

- What does the sequence say to you? What do you see, hear, in the footage?
- To whom do you think the footage is directed?
- Is there anything that is 'hidden from view' that the footage doesn't tell? Why?
- How and where else would you like the footage to be used if at all?

One-on-one meetings-reflexive #2

For patients and family members who had participated in filmed interviews and who consented to doing so, the specialists involved in their care were offered the opportunity to engage in a one-on-one reflexive meeting. They received an initial email invitation describing the study with a follow up phone call after they'd had time to digest the email. Nine specialists in total were given this opportunity. One specialist declined the invitation and there was one non-respondent.

I provided a similar background context to the individual meetings and put the same questions to individual clinicians. However, one-on-one meetings were inclined towards a more informal conversational style and dialogue between myself and the specialist. These meetings were also filmed with the consent of the participant. All specialists consented to the meeting being filmed with the exception of one.

Large group meetings-reflexive #3

The snowball effect resulted in invitations from larger internal groups as well as external groups. These meetings, outlined in Appendix 7, fall into the following categories:

- Healthcare Community: several other metropolitan hospitals as well as the field site provided the opportunity to present at their 'grand rounds' or equivalent forums.
- Policy related: including the executive of the national framework for quality improvement of specialist palliative care.
- Professional bodies: such as state palliative care institutions for presentation to their membership.
- Educational forums: the presentation was used as the focus for a workshop to setup a hospital-wide generalist nurse resource program at one of the satellite field sites in collaboration with clinicians.
- Consumer groups: carer groups have used example narrative vignettes as a focus for discussion for informal carer strategies when caring for someone who is dying.
- Research community: footage used as the focus for dialogue and critique with service providers and academic peers.

I experimented with the structure of these meetings, presenting footage in the same way as I would for smaller groups, providing audiences the opportunity to respond reflexively with the aid of roving microphones. I sought the consent of participants prior to use of footage at these meetings. The specific format of these meetings was dependent on the time allocated. They followed a similar format to small group meetings, however, incorporating a brief overview of the research project followed by presentation of footage of up to three short vignettes. Footage was framed in the same way as it was for small group meetings prefaced by the adapted 'movie method' questions accompanied with an invitation to the audience to note any particular thoughts or feelings they would like to share.

Section 4.5 Conclusion

This chapter has detailed the practical and technical components of the research methods employed. I have already established (Chapter 3) that methods themselves participate in the enactment of the social realities that are the subject of the research (Law 2004). That is to say, the visual methods I have outlined in this chapter not only provide and convey social realities but also help to create them (Law 2004). What I mean by this is that methods are themselves implicated in producing assemblages that would not otherwise exist. Thus, the process of co-producing video accounts, as well as video accounts themselves, is the subject of analysis. For example, included in my analysis is how participants present themselves and how they choose to co-create and structure their videos, who participants see as their audience, as well as the iterative ‘snowballing’ effect of showing footage driven by participants. In this way, data are flexible, open and dynamic. Visual images, as ‘never one thing’, change and evolve depending on the context of the collaborative and reciprocal relationships within which they are both produced and viewed. Thus, as inseparable from the research findings, enacting of relationships becomes data itself. The next chapter addresses such data by examining these interconnections and relationships and the outcomes they produce. Acknowledging methodology, including ethics, as inextricably linked with findings, the next chapter (Chapter 5) provides a critical appraisal of these relationships. This foreshadows empirical analysis of video method assemblages entangled within “an awareness of a deeper level of kinship between the researcher and the researched” (Heshusius 1994, p16).

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Chapter 5 Methodological Findings: Forming communities and building agency

Section 5.1 Introduction

This chapter presents what I refer to as ‘methodological findings’. That is to say, Questions 3[24], 4[25] and 5[26] of this thesis are concerned with the role of visual methods in end-of-life care research. This chapter begins to address these questions. In broad terms the chapter explores the role of visual methods in creating the rhizomatic interconnected networks I referred to in Chapter 1. Examining research relationships and how they are built, this chapter is concerned with the description of how community/ies developed around the research. I do this by scrutinising the ethics of the research to appraise relationships between patients, families and healthcare workers and other stakeholders.

I apply a three-layer model of reflexivity as the focus of my analysis. I explore self-reflexivity, interpersonal reflexivity and collective reflexivity (Nicholls 2009). In the first section of this chapter (Section 5.2) titled ‘Self-reflexivity: Establishing myself in the field’, I examine the foundations on which relationships with participants are built, engaging with the question of what right I have as the researcher to represent others. This transparent reflexivity requires that I identify my assumptions underpinning the research as I did in Chapter 3 (Theoretical Perspectives). Importantly, this transparent reflexivity is not about accounting for my own subjectivity but rather about being receptive to “the relational; the spaces in-between or that which connects those working in collaboration” (Nicholls 2009, p122). In other words, as nomadic researcher, self-reflexivity equates with awareness of my own capacity to affect and be affected; which means, in turn, my capacity to be moved; moved from where and what I am to somewhere else and someone else.

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[24] Do collaborative practice-oriented feedback and reflexivity approaches utilising visual methods contribute to end of life care research?

[25] Can visual methods promote the stories of research participants and advance a more meaningful death and dying experience?

[26] Can visual methods communicate principles, strategies and systems to facilitate improved end of life care to consumers, clinicians, service providers, administrators, designers, planners and policy makers?

Interpersonal reflexivity requires an evaluation of my collaborative abilities as opposed to my abilities to know or lead or take control as authority (Nicholls 2009). The second section (Section 5.3) is titled 'Interpersonal Reflexivity: Field examples'. I demonstrate the kind of ethical challenges I faced and decisions I made as I enacted the research in collaboration with participants.

The third section (Section 5.4) titled 'Collective Reflexivity'. Collective reflexivity or catalytic validity[27] is concerned with the process of how collaborative relationships determine the frames of inquiry, who participated, the terms of that participation in addition to its practical knowing for participants (Nicholls 2009). Its focus is on how the research creates new assemblages bringing forth new storylines through creative collaborations. This section describes the role of video as a tangible device with which patient and family expertise as well as healthcare worker expertise could be recognised. It highlights the reach of video within and beyond the research study and includes: Video: A disruptive innovation; Video: A mechanism to recognise patient expertise; Video: making 'Hospital Dying' affectively tangible; Video: A Sustainable camera eye; and, lastly, Video: Producing legacy.

Section 5.2 Self-Reflexivity: Establishing myself in the field

I have already detailed in Chapter 3 (Theoretical Perspectives) the underpinning personal values and ethics that frame the thesis as well as a brief overview of entry to the field in Chapter 4. This section provides critical analyses of how these values manifest in relationship with others as I entered the field and took on the role of researcher. I sought to build on relationships that already existed and to enter into relationships with participants on their terms.

The palliative care day hospital

This section describes the steps I took to initiate and build relationships with staff and patients in the palliative care day hospital. I give examples from my field notes and diary reflections to illustrate the extent of self-reflexivity in which I engaged as I took on the role of ethnographer. Not only did I record critical reflections about my conduct,

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[27] *"Catalytic validity refers to the degree to which the research process re-orients, focuses, and energises participants in what Freire (1973) terms 'conscientisation', knowing reality in order to better transform it" (Lather 1986, p67).*

I also documented my feelings as I settled into the environment reflecting on atmosphere(s) and noted them alongside observations in my field notes, talking with others formally and informally and noticing what was going on around me even when I was 'officially' at work.

I attended a day hospital team meeting to introduce the project and answer questions. In anticipation of possible staff concerns about my intrusion into the therapeutic space of the day hospital, I interviewed individual members of the specialist palliative multidisciplinary team prior to establishing myself in day hospital proper. This provided an opportunity to refine my interview questions as well as highlighting any issues that healthcare workers deemed important. Most importantly, it gave individual team members the opportunity to get to know and trust me and to discuss any potential concerns they had about having a researcher in the palliative care day hospital. The extract that follows provides an example of how I reflected on the concerns of healthcare workers and my own positioning as researcher:

> Extract 5.1 (RD, Palliative care day hospital, Chaplain, 28th April 2010).
>
> She (chaplain) expressed her concern for the project and challenged me on my use of language. She suggested that there was a danger of people feeling pressured to take part in the project. This personal challenge 'threw' me, challenging my view of 'self'. I reflected later with a senior colleague on this. In enacting my role as researcher I did not want to lose my ability to put people at ease or to become unreflective of my behaviour.

The extract above shows an example of the discomfort of those that question whether dying patients should be involved in research at all given that people are so burdened by the dying process and vulnerable to subjugation (Lee & Kristjanson 2003). I contest this position throughout the thesis. While this extract highlights the challenge to my motivations and conduct, it also brings to light the agency of healthcare worker participants in being able to express their concerns and challenge me in this regard. Initially I was upset by the fact that, I may, in my enthusiasm for the research, be at risk of coercing participants. Later, however, I viewed the situation described in the extract above as a positive sign that I had created circumstances conducive to being challenged by participants. Concerns such as these led me to continually critique my positioning as researcher. Later, in this chapter, however, I reflect on my own impact on the research process as a result of being overly conscious of not burdening patients. First though, I turn to my initial entry into the palliative care day hospital proper. My first day in the day hospital was an anxious one, expressed by the following extract:

> Extract 5.2 (RD, Palliative care day hospital, 25th May 2010).
>
> Initially when I walk into the room I feel anxious, not sure where to sit, what to say, how to introduce myself and how to explain what I am doing. The diversional therapist introduced me as Aileen the researcher. I tell the patients that I am a researcher, but have a background as a palliative care nurse, and that I am investigating what it is in the environment that helps patients most (or least). I joke that they (patients) can "throw me out whenever they like".

Although the diversional therapist introduced me to the people around the table, I felt it necessary to extend her introduction by revealing to those present more about myself and why I was there. By articulating that my presence may not always be welcome, I hoped to ground relationships in a way that would allow people to make known either to me or a member of staff should they wish me to leave.

The research design was intentionally 'overt'. All members of the palliative care day hospital team and patients knew I was a researcher and that I was making observations. If I came across someone who I had not previously met, whether a member of staff or a patient, I endeavored to introduce myself in a timely manner. While always taking an open and honest approach, I defined my research in a flexible manner depending on who I was talking to and the context in which I was talking to them. The manner in which I explained the research tended toward a more practical and concrete framing when I was talking to patients and families or healthcare workers. It took on a more abstract or sometimes organisational frame when discussing it with my peers or when provided the opportunity in formal presentations to provide a more theoretical explanation. Thus, the distinction between overt and covert could become blurred. If or when researchers 'hold back' information, participants may not have a complete picture of what they have consented to (Dingwall 1980). The 'blurring' of the line between overt and covert presented a much greater challenge in the acute hospital setting and I discuss this under the heading 'The acute hospital'.

Such was the intimacy of relationships within the palliative care day hospital; I did not feel able to be solely sitting with my notepad taking field notes. Instead, I sometimes engaged in ‘table activities’ just as others did, including staff as well as patients. I found that the most practical way to do this was to join in group activities or games and by taking on the task of knitting a scarf. This allowed me to be ‘doing something’ but at the same time still be observing and interacting with others. Not only did engagement in activities such as exercise time or knitting foster conversations with the rest of the group, it provided me with a ‘side task’ that meant I was less self-conscious of attending the group solely as an observer.

As I was to later realise and go on to discuss in Chapter 8, such activities were instrumental in producing safety and were conducive to sometimes deep and profound conversations taking place. What seemed at the time a banal involvement in a knitting task proved no exception. On further reflection, I view knitting as an activity that reinstates the body as the site of affective encounter or, in other words, the ‘medium for critical information’ which I refer to in Chapter 3. As a bodily activity, knitting affectively connected me with the group. Involvement in activities meant that I would make only short rough notes in my notebook during the time of the palliative care day hospital. These short notes provided the scaffolding from which I wrote expanded notes after I had left for the day. Alongside these notes I kept a reflexive journal of my thoughts, feelings, any problems that arose and initial analysis and interpretation (Spradley 1979).

In all the time I spent in the palliative care day hospital, I never ‘filmed’ interactions or practices there. Although I always took the camera with me, I trusted my ‘gut feelings’ during this early phase of the research, concerned that the unique therapeutic space of the day hospital may be rendered ‘unsafe’ if I used the camera. On reflection, and towards the final stages of the research, I felt it would have been appropriate to ‘film’ at times during the latter stages of my time there, when I felt I had developed significant trust with participants. In the early stage of the project, I chose to trust my instincts, inclining to err on the side of caution. Yet, several weeks after commencing fieldwork, my own ‘protection’ of research participants was exposed as the following entry from my field notes highlights:

> Extract 5.3 (RD, Palliative care day hospital, 29th June 2010).
>
> I was struck by the stark contrast of demands on me to articulate theory for the PhD at my recent doctoral assessment while the previous day had been spent sitting in the day hospital alongside patients facing the reality of their life's end. I commented that the whole philosophy of my project seemed to be in conflict with the individualised nature of the PhD. However, the medical director of the hospital encouraged me: "Patients are adults, and often have great resilience having already had to endure much in the health system and throughout the course of their illness. They appreciate choices and are able to say no". Perhaps, dying patients, far from being vulnerable, are more capable of making decisions and exercising choice than patients who have not been through what they have. In my endeavour not to create a burden, was I prejudging who may or may not want to take part? In doing so, was I denying a voice to patients who might want to participate? What would be the effect on those patients who had observed me asking others to participate?

This realisation was significant, resulting in a repositioning of patient and family participants as people with a desire to continue life, striving to continue to engage with their aspirations and to reciprocate in relationship with others. Positioning myself as co-researcher with participants, I sought to avoid privileging my 'authoritative voice' but rather to let participants' voices speak for themselves and their own lived experiences through the entirety of the research process. Relational collectives are about learning to know one another as people rather than reducing relations to on-off descriptions or facts. Learning in this way is central to the present research (Bishop 2005). Thus, participants' stories merge with my own stories to create new ones.

As I entered into these reciprocal relationships with participants my own concerns, interests and agendas became entangled with those of participants resulting in "an awareness of a deeper level of kinship between the knower and the known" (Heshusius 1994, p16). I take a strength-based perspective. Namely, one that recognises human beings as having capacities and strengths, and the ability to grow (Saleebey 2009) and emphasising the agency of people involved in research (Mertens 2009). I characterise participants as 'Indigenous peoples' being able to and having a right to make decisions about the research agenda and methodologies for themselves and having understandings and competencies in their lives.

There is evidence that many patients not only wish to participate in research, but that a research priority for them is helping clinicians to understand what they are saying and feeling (Perkins 2008). Reciprocation is important to patients. There is a need for them to participate in the same human interactions that are important throughout all of life. Patients, as people, have a need to contribute to others, just as in any other relationship (Burr 1996; Kavanaugh et al. 2006; Steinhauser et al. 2001).

Of course, there are some who challenge these arguments. Particularly noteworthy and of relevance to my own work is De Raeve (1994) who, taking a deliberately provocative stance, cautions that the researcher-participant relationship can make it difficult for participants to withdraw from the research, risking harm. In this research, however, relationships are formed long before and continue long after the actual research process is occurring (Bishop 2005). This makes the need to recognise the ethical complexities surrounding the relationship with participants all the more necessary (Lawton 2001). The therapeutic benefit of qualitative research is a contested area (Eide & Kahn 2008). That is to say, the explicit purpose of the qualitative research interview is not one of therapeutic intent. Yet the nature of the interview is often one of active listening contributing to the transformation of both participant and researcher (Eide & Kahn 2008). This can leave qualitative researchers feeling uncertain about how much of themselves to disclose and the kind of relationships they develop with participants as well as exposing them to emotional burnout (Dickson-Swift et al. 2006). Importantly however, there can be unintended positive outcomes of research relationships for both participants and the researcher (Frank 2000; Priya 2010). Moreover, giving people the opportunity to tell their story can contribute to finding meaning and hope in what is happening to them (Casarett & Karlawish 2000; Mount et al. 1995). Most importantly, though, is that people do want to take part in palliative care research (Barnett 2001).

The acute hospital

This section describes the steps taken to establish myself in the acute hospital. Although I was well known by the specialist palliative care team at the primary acute hospital, I did not presume to have immediate access to the team. As I had done for healthcare workers in the palliative care day hospital, I attended a team meeting to introduce the project, answer questions and respond to concerns such as ‘who would own the footage’?; ‘how would it be protected’?; and ‘how would the hospital be de-identified’?

With the collaboration and permission of hospital staff and patients, I observed daily practices and interactions in a variety of contexts and settings. I adopted the same style of field note taking as I had done in the day hospital expanding my rough notes at the end of each day. I augmented my note taking with audio-recordings of my thoughts and feelings.

As I have already stated, the research design was intentionally ‘overt’. Enacting this in the palliative care day hospital was almost always attainable. In the complex and unwieldy environment of the acute hospital I found this to be much more of a challenge than it was in the palliative care day hospital. For example, I would often be sitting with a patient when an entourage of medical staff entered the room. On occasions such as these I would always ask the patient if they wanted me to leave. If and when they asked me to stay, I tried to take the opportunity to introduce myself. I also wore a hospital identity badge. Despite this, the nature of the ‘entourage’ often involved a brisk interaction led by a senior doctor supported by the rest of the medical hierarchy. On these occasions I found it difficult to interrupt them to explain who I was and why I was there.

I introduced myself every time I entered a new department. I would present myself to the nurse responsible for that person’s care on that particular shift checking my visit was appropriate. Nevertheless, it was impossible for every nurse to know who I was and why I was there. There were also occasions when despite introducing myself I was assumed to be a patient’s relative. I used my own ethics to decide whether or not I ‘documented’ situations where my presence was clearly covert. That is to say, when I did not have the opportunity to introduce myself to people I was observing. Notwithstanding the uncertainty of whether to record my observations or not when these circumstances arose, I often found them extremely insightful and impossible to eradicate from my experience; serving to inform the research as a whole. There were occasions, for example, when I would be sitting with a patient in a shared room of the ward and be witness to interactions healthcare staff had with other people in the room.

I attempted to let patient participants ‘lead’ the research. That is to say, they determined the frequency of visits in combination with my own assessment of their level of ‘wellness’ to participate. I responded to whether it ‘felt right’ to stay and talk at the bedside or not and used my intuition in combination with my extensive clinical assessment skills to determine whether a person was well enough to talk with me or not. In other words, I applied a blended knowing that encompasses the skills of my professional craft along with personal and pre-cognitive knowing. Namely, I applied knowing that is unable to be described explicitly and is referred to by Titchen as "professional artistry" (Titchen & Higgs 2001; Titchen & Manley 2006, p341-342). For example, some participants I met in hospital wanted to wait until discharge home to be interviewed, while others were adamant that I set up the camera at their hospital bedside there and then. At other times, I said 'hello' and introduced myself quietly, excusing myself if it was clear a participant was unwell or wished to be left alone. On occasion, when I 'felt' my presence to be 'intrusive', I would say a brief 'hello' before slipping away quietly.

On other occasions, I would follow my sense that I should call into the palliative care unit to visit someone. Whether I followed patients there was determined by a combination of patient and family wishes as well as acting on my instincts. In other words, I recognised myself as being somatically involved in the research. To illustrate how this is enacted I share an extract from a meeting with participant Greg:

> Extract 5.4 (EFN, Palliative Care Unit, patient, 30th May, 2011).
>
> Intuitively I wanted to say hello to Greg or perhaps a goodbye. While I was in the hospital working, I called into the ward. As I approached his bedside it was clear he had deteriorated significantly since my last visit. He sat on his bed, legs crossed. I was unsure if he was 'awake', his eyes rolling back in his head, as if at any moment he were about to drop off. It was clear to me that he was approaching death now. Unsure as to how coherent he was, I asked if I could sit down beside him for a while. He responded clearly with "yeah sure". I joked with Greg that he was famous now as I informed him of his inclusion in a video clip that I'd shown to healthcare workers as part of video feedback meetings. A large grin took over the whole of his face. I was surprised when his eyes opened widely and he asked me gleefully if anyone involved in his current care in the palliative care unit had had the opportunity to view his footage.

This account shows how enacting professional artistry enabled me to act on my instincts to visit Greg one last time before he died. I was able to reassure Greg that his wisdom had been shared through his footage and he was able to confirm his request to me that it would be shown to the healthcare community he was now part of. There was an unexplainable connection between us at that moment when both Greg and I realised the significance of his footage.

My relationships with participants are what underpin this research. Thus the decisions I made along with participants, including decisions pertaining to informed consent and the use of footage require critical appraisal in their own right. The section that follows attempts this critique recognising that representing the scenarios as text has removed the emotional, spiritual and, in part, the moral elements of the decisions arrived at in ‘real time’. Resolving and responding to ethical dilemmas in the field occurs contextually and often spontaneously rendering it difficult to “capture the fine distinctions arising at the level of interaction” (Ryen 2007, p220).

Section 5.3 Interpersonal Reflexivity: Field examples

As researcher I was conscious of not contributing to patients or healthcare workers becoming unsafe. Filming took place only when I considered it safe to do so within the context of relationships of accountability, reciprocity and trust. The purpose of the following section is to describe and critique how I enacted this safety in the field, and in so doing address the ethical complexities with which I was faced on a day-to-day basis in relationship(s) with participants. I will illustrate these by giving examples and using extracts from my field notes and reflexive diary. In order to fulfil this aim, I outline several themes: negotiating consent (Heather); role conflict (Madge); footage dilemmas (Gloria). Although I have separated these examples for the purpose of illustrating these themes, in reality, the scenarios overlap across themes, serving to highlight the ethical complexity with which I was embroiled. Finally, in this section I deal with the challenge of exiting the field and what that meant for collaborative relationships.

Negotiating consent

Inherent in the philosophy of ‘doing with’ as opposed to ‘doing to’ is a view of informants as active participants rather than research subjects, requiring protection from harm. Further, a participatory approach recognises mutuality between researcher and participants and the transformative potential for all involved.

Participants were provided with an information sheet detailing the project in simple language. I ensured my availability to explain anything that was unclear about the project in person. Participants were given time and opportunity to consider the study. The amount of time needed varied from a few minutes to a few weeks. Once a participant had the opportunity to have their questions addressed and answered fully and they wished to participate, they were provided with the consent form (Appendix 5) for signature. However, the notion of 'informed consent' evidenced by a signature on an institutionally-approved form was problematic. It was unlikely that the understanding I held as the researcher would coincide exactly with that of the participants. Participants may not be in a position to read information or necessarily speak the same 'language' as I do. That is, they did not necessarily have access to the same understanding of the research that I did.

Further, the feelings a participant has about the use of their footage or what they wish to express can differ from setting to setting and time to time. There are different ways of understanding harm and causing it with footage (Pink 2007a). Harm, rather than a fixed concept is dynamic and is culturally and contextually determined. A participant may be happy for footage to be shown to one group of people and not to another. However, Pink (2007a) further contends that the notion of research and/or images as distressing is often based on the premise that participants are having the research done on them. As does Pink (2007a), I saw visual materials as 'jointly owned'. Thus the ethical agenda was one of mutual investment in the research where both parties are rewarded. This is opposed to an act of taking something away from participants (Pink 2007a). In this way there is co-creation between researcher and participants and agency may be shared (Pink 2007a).

I therefore viewed consent as a continual process of exchange through dialogue with participants and any other person the participant believed should be included in the discussion. Although written consent was obtained, verbal consent was ongoing and sensitive to the emerging needs of participants, in recognition that the unpredictability of events and uncertainty meant that decisions could change.[28]

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[28] See for example the case of Heather and her family in Extract 5.5.

Participants themselves decided along with me as the researcher what footage would be used through a process of negotiation and collaboration in which their objectives could be met as well as my own.

Given that patient participants would not necessarily be alive to give ongoing consent, I used my expertise as a palliative care nurse to ask about their wishes for future use of footage in situations when it was clear participants were aware of their poor prognosis and spoke openly of their dying. For some participants, their footage became an ongoing legacy and I discuss this again later in the chapter. Participants were given the opportunity to withdraw from the study at any time, have any footage they wished destroyed and reassured that this would not affect their care.

Footage was edited into various forms. Consent from participants was sought in advance prior to any footage being shown in a group video feedback meeting. Opportunity was provided for participants to preview footage prior to it being shown. As well as being edited into a form for the benefit of participants, with their permission it was also disseminated and continues to be for conference presentation, publication and visual media. Additional consent was and will continue to be gained for this kind of dissemination of footage.

Participants were advised that any filming would occur only in close collaboration with them, and that, if they so wished, the resulting footage could be made visible for feedback purposes. This was within agreed ground rules and contingent on written participant consent and *verbal* consent in each instance. Informed consent is based on a principle of *individual* rights, however, and this is problematic when participation reveals *collective* information or knowledge (Tuhiwai Smith 2005). These issues are highlighted in the following extract:

> Extract 5.5 (EFN, Palliative Care Day Hospital, patient and family 13th July 2010).
>
> Heather’s sister asked about how the video footage would be used. I explained that this was dependent on Heather and her family and gave examples of how it might be used. I emphasised that it would be Heather that would direct this and that I was only a facilitator. I explained what kind of issues I was interested in such as patients’ safety. Diane (Heather’s sister) asked questions such as, “Are you

> interested in things like medications?" Then she shared a story about Heather being given the wrong drugs in hospital. Heather expressed a strong desire to participate in the research, as it was important to try and 'fix things'. Both women suggested that Heather's other sister Jane would be really interested in helping out. Diane joked that Jane fancied herself as a bit of a movie person and that she and Heather would have a chat with her. Both Diane and Heather expressed enthusiastically that "This could be a really good thing".
>
> I was very conscious of not tiring Heather out all at once and suggested that we could leave it there for today and do the formal interview another time. Both Heather and her sister agreed. I explained that as well as the study tape, I would give Heather a tape for the camera to do anything she liked with, such as film the grandchildren. As I said this, I could see that she became 'choked' holding back tears. There was a silence … but the moment felt a positive one rather than a negative one. There was a moment of intimacy in the dialogue when all three of us seemed to recognise the finality of Heather's future loss of her grandchildren.

Barnard describes such episodes of intimacy as moments of "enormous promise" because they "Open patient and caregiver to possibilities for feeling connected to others, for meaning, hope and even joy in the midst of great suffering" (Barnard 1995, p22). I drew upon my intuition as well as my experience and professional skills to apply ethical responsibility in my relationship with Heather. Her rapidly changing situation and the deterioration associated with her terminal illness meant that while she felt able to consent on the 13th July she did not two weeks later. Heather never formally signed a consent form to participate in the research as an interviewee or diary subject. However, she and her sisters made it clear on several occasions that they wanted their story to be heard and wanted to contribute to the research. Even when Heather was in the final days of her illness, her sisters sought to continue their relationship with me as the researcher. Many patients and families exercise their agency and competency if they feel they need to decline to take part or agree to participate. Arguably, any participant's decision occurs in the context of ongoing dialogue marking a relationship of mutual trust between researcher and participant.

Role conflict

The ethical imperative of the International Code for Nurses highlights the nurse’s primary responsibility to people requiring nursing care (International Council of Nurses 2006). As an experienced palliative care nurse and a fellow human being it was impossible for me to be dispassionate in my role as researcher. Moreover, a philosophy of ‘doing with’ rather than ‘doing on’ did not exonerate me from questions of accountability and moral responsibility given the knowledge, experience, and professional skills available to me. On the contrary, such philosophy intensified these questions for me. I was not a ‘neutral’ observer or interviewer, just as participants were not objective machines that yield data.

In addition, as ethnographer, I was tentative about how I would ‘enter’ the day hospital and how I would establish myself there. I had an embodied ‘way of being’ as a palliative care nurse. In other words, my habit was to respond to patients and staff as a nurse, assessing their concerns and patients’ symptoms etc. I was anxious about how to relate to both patients and staff in my new and different role as researcher. This was further compounded by the fact that I was also employed, one day a week, as a project nurse for another section of the organisation. These identity tensions were forever present and are highlighted in the next extract:

> Extract 5.6 (EFN, Palliative Care Day Hospital, 8th July 2010).
>
> On my way out, I glanced fleetingly into the treatment room to say goodbye. It was clear that I had interrupted the RN during an intervention with Madge (a patient). Madge swiftly covered herself up and the RN quickly closed the door. I was jolted into remembering that I was the ‘researcher’. I became aware of my privileged view of ‘the body’ as a nurse. It is strange that when I am sitting upstairs in the clinical trials room I am very much viewed as a nurse, yet downstairs, I am something different. Yet as I begin to feel more comfortable in the day hospital, I feel more able to contribute in some ways, but in other ways I am excluded from the group. I am neither patient, staff member, or volunteer. This feels quite uncomfortable and confusing at times. I am observing the behaviours and actions of team members as they interact with patients; what I call ‘person to person levelling’ while at the same time myself feeling like an ‘alien’.

Yet, at the same time, as someone who 'sat' at the table alongside other patients, I became entangled in interactions and conversations. I made a point of introducing myself explicitly as a researcher, particularly if someone new who I hadn't previously met was there, explaining why I was there and what I was doing. Later, I became more confident in negotiating these tensions making it clear to participants that I was there as researcher while at the same time ensuring that immediate care needs were met by the appropriate team member when the need arose. Using an Indigenous research ethics framework provided the basis for the relationships I had with participants. I avoided assuming an explicitly therapeutic role outside the boundary of the research. I was continually aware that my observations were filtered through my eyes as nurse, while at the same time, my background as a palliative care nurse combined with responding just as 'one human being to another' ensured sensitivity towards participants. In this way the research process became meaningful for participants and myself as the researcher:

> Extract 5.7 (RD, Palliative Care Day Hospital, 26th August 2010).
>
> There was a uniqueness in how people related to me that perhaps wouldn't be present if I was there as a nurse. I became aware of this when the day hospital doctor made a comment after viewing some video footage. "They (patients) don't share those kind of things with me", she said. I was aware that, on the one hand, I felt useless at times, while at the same time it was clear that patients and staff alike had come to see me as a vehicle for telling their stories as a 'partial outsider'.[29]

Critically, I came to realise that instead of it being problematic, it was precisely because I avoided fitting into any particular identity, that I was able to become *nomadic* and thus function in 'in-betweens' where I could remain open to possibilities, tensions and opportunities.

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[29] I used the term 'partial outsider' in my field notes to convey that I was party to communication around the communal day hospital table. As I was not a core and permanent team member, however, I was not party to 'insider' team communications behind the scenes.

Footage dilemmas

I interviewed Gloria on film in her single room on the renal ward. As had become my convention, I asked her what she would want me to do with her footage if anything happened to her. Gloria was clear that I needed to give it to her niece:

> Extract 5.8 (FI, Acute Hospital, Patient, 24th March 2011).
>
> “Give it to my niece”, she said, “Give it to my niece”.

I downloaded Gloria’s footage onto the laptop. Watching it back, I realised that Gloria consciously or unconsciously had used the filmed interview to talk about her life. She told stories of her youth and early life. There were tales of family relationships and dynamics. A few days later, Gloria deteriorated much more quickly than expected and went into renal failure. I hadn’t met Gloria’s niece and therefore had no relationship with her. However, Gloria’s words had been clear. I remember repeating them back to her for clarification. “So you want me to give it to your niece?” However, I felt uneasy. Was Gloria fully aware of the family stories she had told on camera? Did she really want her family to be party to these tales and opinions when she had gone? What would I say to her niece as I handed over the DVD? Was I underestimating Gloria? Did she know exactly what she was doing? Was this indeed part of Gloria’s legacy? I was in a quandary. Gloria was in renal failure. Was she still well enough now to speak to me? Not wishing to intrude into Gloria’s final days with her family, I put my dilemma to the palliative medicine doctor. “Why don’t you just ask her” was the response. I returned to see Gloria:

> Extract 5.9 (FI, Acute Hospital, Patient, 27th March 2011).
>
> She (Gloria) said, “They’ve just told me I don’t have very long now”. In between her fluctuating levels of coherent and non-coherent talk she was able to express her distress at being given the news of her deterioration. And so I just sat down beside her, not as the researcher in that moment but simply as a ‘listening companion’ hearing Gloria’s distress. She began to relax and I knew that she knew exactly who I was and that she’d spoken to me on film the other day. I reminded her that she’d spoken about her family on film and so I asked her again what she wanted me to do with the footage when she dies. She was definitively clear: “Give it to my niece”.

Despite Gloria's deterioration, her delirium and accompanying distress, I sensed the clarity of her instructions and took her at her word. She died a few days later. I let several weeks pass before contacting Gloria's niece. I did so tentatively, as having not met her previously I was unaware if Gloria had informed her about the research and was unsure of her response. Gloria's niece, however, was pleased to hear from me. Affirming Gloria's participation in the research, she talked of her own views about end-of-life care and thanked me for the DVD.

In this example, I deal with messiness by reflecting on both my understanding of the situation as well as interpersonally, responding to Gloria's request by checking with the palliative care doctor and re-checking with Gloria before finally delivering the DVD to her niece at her request. In this way, the video footage became an object which foregrounded patient and family expertise as well as healthcare worker expertise in the negotiation of its purpose and use.

Gloria's story concludes this section and has highlighted the messiness involved in relationships between researcher and participants and their social networks. Additional questions arise about how to terminate such relationships. Abrupt endings to such relationships can be distressing (de Raeve 1994). The next section deals with such endings.

Exiting the palliative care day hospital

Once accepted into field sites, it is not uncommon for researchers to experience difficulty leaving, as they become 'friends' with actors (Delamont 2007). My increasing 'comfort' was an indication that it was time to depart. The time to leave is when the field site "feels like home" (Delamont 2007, p214). I initiated the process of disengagement from the palliative care day hospital:

> Extract 5.10 (RD, Palliative Care Day Hospital, 26th August 2010).
>
> I experienced a mixture of feelings. On the one hand I felt very content in the day hospital today, enjoying being with the patients and chatting to people and realising that I had become very comfortable and had found my place. I would miss it. In many ways it would be difficult to leave. I found myself wondering whether my place was with patients. But perhaps I was comfortable because I was there as the researcher.

I felt it important that my disengagement was carried out appropriately and effectively. Loss was not unfamiliar to the day hospital and its attendees. For example, rotating allied health workers came and went; doctors would move onto other sectors of the service, and most significantly, fellow patients would die. I discussed my own leaving with the diversional therapist. A plan was implemented as it was with any other 'leaver' and the day hospital leaving ritual was enacted:

> Extract 5.11 (EFN, Palliative Care Day Hospital, 26th August 2010).
>
> When most people were present, Joyce (the diversional therapist) presented the leaving banner to me. The social worker brought in a cake, which I cut and social worker Joan handed it around. There was an exchange of gifts as I handed over my small contribution to the 'craft box'. Brian (patient Liz's husband) suggested that Joyce open it. I remember feeling surprised, reflecting and comparing the experience to just a normal social occasion. I reflected back that this was quite different from when I first arrived at day hospital, anxious, not quite sure where to sit, feeling awkward and wondering if anyone would speak to me. I wondered if this reflected anyone new coming into the space that was the day hospital! I said goodbye to everyone and then departed.

Exiting the acute hospital

My withdrawal from the acute hospital occurred organically. I became increasingly aware, (as I had done in the palliative care day hospital) of my 'comfort' in the specialist palliative care office. My withdrawal happened over a period of several weeks. As I stopped taking referrals, the frequency of visits organically decreased and came to a conclusion when I had completed reflexive meetings.

Section 5.4 Collective Reflexivity

This section is concerned with the process of how collaborative relationships determine the frames of inquiry, who participated, the terms of that participation and its practical knowing for participants (Nicholls 2009). First, I illustrate the inseparability of 'data' from collaborative research relationships. This foreshadows analysis of the part played by video in bringing forth knowledge through creative collaborations. Introducing visual methods into the complexity of end-of-life care settings produced a way of 'seeing' in different ways and at different angles:

> Extract 5.12 (RD, patient and family 22nd December 2010).
>
> Len was bright and awake today. I was slightly taken aback when he asked me how I was and if I was happy. I found myself letting down my own mask of professionalism. Despite my reservations, not wishing to burden Helen and Len, I informed him honestly what he had picked up intuitively; that I had indeed had a few concerns lately regarding my husband's health, but that yes, overall I was quite content. Curiously, I found myself being personally more open with Helen and Len than I would have been had I been visiting in a nursing role. I reflected on why this might be. Was it that I didn't feel so encumbered to maintain the boundaries incumbent on me in a nursing role? Or was it that having read and reflected in great depth that I was now challenging this position and felt more comfortable in letting my guard down? Perhaps it was because in my role as researcher I was freed from any particular agenda; making assessments, completing tasks and paperwork? I expressed this to Len, expressing how much I valued learning from him and his experiences without having 'nursing tasks' to attend to. "Yes," he said, "often people are just too busy. Here, for example there is just not enough staff". Len asked me "Can you come and visit again before I die?" I was struck by his openness in talking about his impending death. Again, on my way out, he said, "Don't make it too long before you come back again. Come back again, come back and see the pommy bastard." I replied that I would plan to come back and see him again.

This extract demonstrates what Nicholls refers to as "reflexive determination of positionality" (Nicholls 2009, p123). As researcher, I juggle transparency of my own vulnerabilities with my concern about 'burdening' Len and Helen by my personal sharing. By ceding control to Len, however, I was able to become more open, allowing Len's attunement with me to come to the fore and responding transparently to his concern for my wellbeing. This transparency results in a mutual trust, producing agency that meant Len was able to invite me back again.

Video: A mechanism to recognise patient expertise

This section describes the role of video as a tangible device with which patient and family expertise as well as healthcare worker expertise could be recognised. The camera, at times, was instrumental in creating assemblages[30] that didn't otherwise exist. These assemblages manifested in a variety of ways. For example patients and families often expressed feeling singled out or 'special' in the way that Joe expresses below:

> Extract 5.13 (FI, Acute Hospital, Joe, 15th February 2011).
>
> "No one has ever asked me to do anything like this before, I really feel pretty important".

I gave all participants the opportunity to view their own footage and 'control' over whom, if anyone, should have the opportunity to see it. Mostly participants chose not to view their own footage, entrusting me to (re)present their stories as I felt appropriate on the basis of the research aims, my experience and clinical judgement. However, I asked for consent for specific viewing events even if 'blanket' permission was given for footage to be used in other forums. Participants who opted to view their own footage articulated that it had given them insights that they were previously unaware of:

> Extract 5.14 (FI, Palliative care day hospital, 3rd August 2010).
>
> Malcolm beckoned me to say that the tape had finished. He took the headphones off. What did you think? I asked. "Fantastic", he said, "That's a fantastic interview". I asked him if he could explain what he thought was good about it. "Everything" he said. "Yes, I said much more than I thought I did. It's just great". "If you could show it to anyone, who would you want to show it to?" I asked. "Well, I think shown in the right place it could be beneficial", he said. "I would like to share it with other people who are going through a similar thing to me. 100 people could watch it and have 100 different things to say. But there's nothing false, it's all true. Truth is the best thing out. Everyone is entitled to an opinion. It's something anyone could listen to. It gives an insight into what one person thinks and is going

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[30] Remember, assemblages are agencements or enablements: people acting in creative and productive ways in response to others, and often outside of prescribed behavioural regimes.

> through, passing on thoughts, voicing things. Mostly I think it would benefit those going through a similar thing".

I had reservations about showing Malcolm his footage for fear that he might find it too confronting or upsetting. We remained in the room of the day hospital, only off to the side. I made sure that the diversional therapist was aware of what was happening. In this way she could keep Malcolm within her supportive sights. Yet, these fears were unfounded and Malcolm's response was one of positive surprise. Through the medium of film, he could now position himself as 'expert' with important matters to voice and share. In Malcolm's view, these were matters that would be of benefit to patients in similar circumstances.

During the first phase of the study in the palliative care day hospital, I myself drew upon the expertise of patients and families as well as healthcare workers as researcher advisors. At the outset, I explained to participants that, secondary to the main purpose of the research, I sought their guidance in an advisory capacity to inform research processes and the feasibility of methods moving into the second phase of the study. One particular participant, Liz and her husband Brian became key informants in this respect, and I introduce them and describe their contributions further in Chapter 8.

Reflexive examinations of video-recordings further brought to light the extent of patient and family 'expertise',[31] challenging healthcare workers to reconsider the degree to which those they cared for had made sense of their environment and situations. The following extract from my field notes typifies this kind of response:

> Extract 5.15 (VRM #2, Acute Hospital, Staff Specialist, Haematologist, 24th August 2011).
>
> "Joe and his daughter had much more insight than I (staff specialist, haematology) probably gave them credit for. There were a couple of places I think where there was a lack of understanding like with the resuscitation. Perhaps he thought that was about antibiotics. But they are right about everything else".

When patients positioned themselves, on film, as knowledge holders, healthcare workers often expressed a level of surprise. Even in the palliative care hospital where

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[31] I explore patient and family expertise in depth in Chapter 7.

agency is promoted as integral to the philosophy of care, the interdisciplinary team were struck by the extent to which patients had expertise to voice issues:

> Extract 5.16 (VRM #1, Palliative Care Day Hospital, 13th January 2011).
>
> Diversional therapist: "The thing that strikes me most is that there's just no hesitation with their answers. You ask the question and the answers are just right there".
>
> Occupational therapist: "They feel very comfortable. Yes, when Liz (patient) was answering the trust one, she was so clear. Yes, because that is quite powerful, the lack of hesitation".

With the aid of the camera a powerful medium was created through which patients and/or their family members could engage creatively with illness narratives and impress clinicians with their knowledge and insight into their illness and related care issues. It provided a medium for the voices of participants to be heard opening up dialogue about hospital death and dying. Further, when asked how they wanted footage to be used following their death, patients requested it continue to be used for the purpose of 'helping others'. Critically, I came to realise that, in the main, patients and families were not merely giving me permission to show their footage to stakeholders including clinicians, administrators and policy makers, but that they *expected* it to be used in this way. The next extract demonstrates Helen's expectations of how footage would be used:

> Extract 5.17 (PC, Helen, 28th April 2011).
>
> When I asked Helen (daughter of patient Len) for permission to use footage for a conference presentation she emphasised how important it was to her that the footage was used in this way and stressed yet again how grateful she was to have a visual 'record' of her father's final weeks.

Charging me with the responsibility of making sure others hear their 'voices' further challenged me to consider the ethical approach to the research. If the 'terms' of participation are negotiated on the basis that these voices will continue to be 'relayed' at the request of participants, even after they have died, then making these voices anonymous may need to be called into question. Anonymity would render participants' objectives unmet. On this basis, I take the decision within this thesis not to give pseudonyms to participants who made explicit these objectives. Where this is not the case or is ambiguous I have changed the names of participants.

Video: Making 'hospital dying' tangible (internal stakeholders)

This section is concerned with video's capacity to affect bodies, making tangible what is otherwise not. Most medical specialists, when given the opportunity, accepted the offer of 'seeing' care delivery from the patient's and or family's perspective and valued the opportunity to do so. On an individual basis those specialists who did accept the offer to view footage expressed anxiety about being confronted with what patients under their care had to say on film. Mediated by video, healthcare workers were able to identify closely with patients' and families' stories as well as the actors and events in these stories. Patients and family video narratives watched by the doctor(s) responsible for their care created an impact, where, without exception, specialists responded in terms of being moved.

At one level, healthcare workers conveyed that patients' stories did not surprise them. They expressed feelings of powerless to respond to what they saw as safety issues beyond their control or the responsibility of the 'health system'. Footage, however, also revealed to healthcare workers, patient and family understandings that they had not heretofore considered. Video narratives brought healthcare workers 'up close' yet created distance at the same time, revealing to them a previously 'unseen' hospital environment and challenging their assumptions about care of dying people and their families in hospital. For example, two specialists recalled that footage had brought to light the extent of frailty and poor prognosis of patients they had cared for. The narrative that follows demonstrates the extent to which the medium of film made 'hospital dying' tangible for one particular specialist in a moment of intimacy when he recognised the reciprocal nature of his relationship with Esmereldo:

> Extract 5.18 (VRM #2, Acute Hospital, Staff Specialist, 10th March 2011).
>
> He (staff specialist, oncology) choked up with tears and quickly pressed the space bar to pause the footage. After giving him a moment "What is it that has touched you"? I asked. "Well it's that he is in such a noisy, terrible environment in a four-bedded bay, when at the very least, I would expect, for me, to be in a single room several days

> before I die. But he is more concerned about us, us clinicians, not himself. He's expressing his understanding and empathy for us, and it's just a few days before he died".

The potential of video narratives to make tangible what was otherwise intangible in day-to-day practice became evident during group reflexive meetings as well as individual reflexive meetings. In this way visual narratives provided an impetus for different ways of thinking and acting to be explored and providing immediate feedback for action. Through the localised interpretation of video images healthcare workers themselves begin to problem solve issues of end-of-life care previously intangible. In the extract that follows, a service director conveys planned strategies to work around organisational bureaucracy so that healthcare workers and patients can contribute to the design of their new department:

> Extract 5.19 (VRM #1, Acute Hospital, Cancer Therapy Centre, 7th June 2011).
>
> Service director: "But there's a whole lot of differences between outpatient and inpatient care. I think inpatient care is more protocolised. It's more sterile just by its nature and I've been reflecting on this when listening to this about the design of the hospital. It's very protocolised. So you get presented with what a bed looks like and the bed doesn't have anywhere for photographs or room to move with regard to any paraphernalia around the bed because the department of health standard code is 'that' and even when I heard about your research and suggested that we might have input into the painting it was like I created world war three".
>
> Researcher: "Yeah"?
>
> Service director: "Yes, because the reaction was 'no'. A committee decides that. You know like a committee decides the colour of the paint".
>
> Researcher: "I mean, I have to say, I didn't really know how to respond to your email".
>
> Service director: "Well no, in actual fact, I achieved what I wanted to, which was to cause a little bit of agitation and then I'll pull my head

> back in now and just let things happen. They'll paint it any damn colour they like and then once we take the space over and have a little bit more free rein then I think we go in and make some changes. Now, I've got some changes planned. I don't have all the changes planned because I'd like input from lots of other people and I think we have the possibility of doing that in the new palliative care ward".

This extract demonstrates how footage prompts the service director to reflexively examine why patients and families feel more connected with service providers as outpatients. As service lead, he takes the opportunity to view footage on numerous occasions interrogating the 'taken for granted' view of what a bed looks like and the possible role of policy and protocol in preventing personalisation of the bed-space. Further, bound by standard processes for redesign of his department despite his seniority, he uses the research process to his own advantage enacting 'deviant innovation'.[32] He is prepared to go along with the standard processes temporarily. Yet, he considers strategies to work around the procedures he is bound by. Reflexive meetings provided otherwise unavailable opportunities where creative solutions and 'out of the box' possibilities could be explored:

> Extract 5.20 (VRM #1, Acute Hospital, Cancer Therapy Centre Administrative Staff, 1st July 2011).
>
> "Why not have more volunteers and you've got people, you've got a ward with four sick people in there. Why not have volunteers there all the time, you know, they've got someone there all the time".

Administrative healthcare workers in the extract above use the reflexive meeting as the means to generate possible solutions to what they see as the need for patients to be able to connect with others while in hospital.

Patient and family participants were not alone in wanting their 'voices' heard. Healthcare worker participants, despite being initially tentative about me interviewing them on film, often expressed satisfaction at being provided with opportunities to discuss and express their experiences, opinions and feelings in relation to caring for dying people. In the following instance, such was the strength of this nurse's feelings

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[32] A term coined by Legge (1978) to describe how personnel managers achieve change by actively promoting new values in an organisation by challenging the predominant frame of reference.

that she uses the research interview as a means to ‘voice’ what she saw as the need for hospital administrators to account for the needs of dying patients:

> Extract 5.21 (SSI, RN, acute hospital, 25th March 2011).
>
> “Give them the time. Give them the respect. Because all of us are going to go there. Because all of us are going to be in that position one day and of course you have to do that. Be a person even though you’re in a hierarchy position or be on whatever position you got in a top-notch position. Be a person. Be human that’s all”.

This nurse, like the service director sees the research process as providing an opportunity that did not otherwise exist for her. With the aid of the camera, she expresses her frustration about what she views as ‘loss of sight’ of the human needs of bereaved families when there is an administrative imperative to free up beds. Critically, with the camera acting as mediator, group reflexive feedback meetings could reveal what was ‘lost from sight’ making what was previously intangible tangible. In the next extract, footage makes the otherwise invisible visible to admin workers prompting a proposal that footage be shown more widely:

> Extract 5.22 (VRM #1, Acute Hospital, Cancer Therapy Centre Administrative Staff, 1st July 2011).
>
> Participant 1: “Should more of these videos go around? I don’t know. What would you say? Right around the whole hospital? Every department where nurses and admin and allied health are all viewing this and actually seeing the other side?”
>
> Participant 5: “The hierarchies. They should be seeing it”.

This group saw themselves as being limited in their ability to influence the service and to improve the care of dying people in hospital. At the same meeting described in the extract above, admin staff articulated a significant gulf between their goals of care delivery as workers at a ‘grass roots’ level, and the goals of hospital administrators who they frequently positioned as ‘being out of touch’:

> Extract 5.23 (VRM #1, Acute Hospital, Cancer Therapy Centre Administrative Staff, 1st July 2011).
>
> Participant 5: "Up there'[33] don't want to know".
>
> Participant 1: "I think sometimes they don't get to see so much because they're just drowning in so much paperwork and not so much they don't want to see it. They just hear it and think 'Oh well it couldn't be that bad sort of thing or they're just over exaggerating'. But actually be there and see what goes on, you know. Don't tell anybody you're coming otherwise everybody puts on a bit of a show".

Every reflexive group asked that footage be shown to the senior administrators of their organisation and more widely. First, this was seen, in part, as a critical opportunity to make tangible the 'extraordinary' work that they do in caring for dying people. Secondly, it was seen as an advocacy mechanism for both patients and healthcare workers to create further 'lines of flight' in forums that had the potential and/or the political power to influence care. A cancer specialist in the acute hospital proposed that the expertise demonstrated by patients and families should be employed for the benefit of all. In other words, he proposed that patients could become advocates for advancement of cancer services goals. Another senior cancer specialist extended this to suggest specific forums where participants' 'voices' could or should be heard:

> Extract 5.24 (VRM #1, staff specialist (Radiotherapy), Acute Hospital, Cancer Therapy Centre, 7th June 2011).
>
> "Patient advocate groups are clearly one so presenting this stuff to people like (names a contact) and so forth because they do have influence. It would be interesting to see what response you would get by offering to meet with the chief cancer officer and just show him, I think you know, the fact that he is a palliative care physician, may actually be a significant advantage to you and then I think it's influencing politicians, key politicians, the current minister".

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[33] Referring to Senior Hospital Administrators.

At different levels of the ‘hierarchy’ video narratives were seen as providing a language for senior hospital administrators to communicate and influence those responsible for health policy as the staff specialist in the next extract expresses:

> Extract 5.25 (VRM #1, staff specialist, Palliative Care Day Hospital, 13th January 2011).
>
> “My sense of the forum is that it wouldn’t be telling them (the hospital executive) anything that they intuitively don’t understand. I think it will assist them, in giving them a language that, because they are at political strategic interfaces, that none of us are, it will give them an idea of some of the really powerful language that they can use that would facilitate them advocating for the things that they have a strong belief in. So I don’t think it’s something that … It would give them a richness that would help crystallise the message”.

Through a snowball effect, the research produced ‘spaces of engagement’ beyond the study sites themselves. Film acted as an affective connector between various different external parties as I outlined in the previous chapter (Chapter 4). It is to these ‘external’ reflexive meetings that I now turn.

Video: Making ‘hospital dying’ tangible (external stakeholders)

‘Communities’ concerned with care of dying people more broadly were also exposed to reflexive examination of footage. Unlike healthcare workers attending site reflexive meetings, other stakeholders (Appendix 7) – as groups external to the research – did not *‘know’* participants. Despite not *knowing* participants, these audiences[34] were still able to identify with the actors and events in the visual narratives. They connected ‘affectively’ to actors and events and stories and settings as they resonated with their own experiences and contexts:

> Extract 5.26 (VRM #3 Service Director, 20th Annual Symposium of the Sydney Institute of Palliative Medicine, Thursday, 7th April 2011).
>
> “It’s not quite a solution at all. It’s actually another challenge. The problem is, as palliative care clinicians; once again end-of-life care is

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[34] Healthcare Community; Policy makers; Professional bodies; Educational Forums; Consumer groups; Research Community.

> not just the responsibility of palliative care. Somehow we (Specialist Palliative Care community) need to get other services to take this on. It[35] not only needs to come from down up. It needs to come from top-down in terms of policy development. It does have to appear in NSAP (National Standards Framework). It does have to appear in NSW Health but it needs to be a cultural change and so often palliative care is seen as the ambassadors for this, but we can't accept ultimate responsibility".

This extract shows how footage provoked debate among specialist palliative care providers on the role of the sector in improving end-of-life care more broadly. The service director in the extract above posits that safe end-of-life care extends beyond the remit of the specialist palliative care sector to include the wider healthcare community and even the community more generally. These forums prompted discussion at a policy level. For example, the aforementioned forum led to an invitation for me to present at a meeting of the executive of the national peak body for palliative care. The group debated quality measures of end-of-life care led by the filmed perspectives of research participants.

Showing the footage in this way also opened up critical spaces of engagement providing critique of the research. For example, on one occasion, concern was expressed that exposing healthcare workers to video narratives may be harmful to them, provoking unnecessary guilt for those employed in a 'broken' health system. On a second occasion at a 'grand rounds' event, a medical specialist suggested that I had explicitly chosen to show footage that was controversial and aimed at stirring emotion, accompanied by a suggestion that patients and families viewed were not 'representative' of the majority. Deciding what will and will not cause offence or upset to viewers is not straightforward (Murphy & Dingwall 2001, p342). In both cases I reflexively considered my positioning along with participants. First, these critiques came from external stakeholders. Thus I re-emphasise my earlier point that harm is dynamically and contextually defined. That is to say, the meaning made of footage is not fixed or independent of the viewer. Importantly, healthcare worker participants positioned as having understandings, agencies and competencies, for the most part welcomed and valued the opportunity to 'see' care from the perspective of those they care for. Further, the assumption that

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[35] Improvements in end of life care that take account of patients' and families' experiences.

emotion and offense provoked by footage may be harmful is, of itself, open to interrogation. First, this position assumes that healthcare workers do not have capacities, resources and agencies to respond to footage. Second, emotion and offense may, in fact, be necessary to unsettle habitual patterns of being and responses to the world (Dewey 1922; Tamsin 2005). In other words, causing offence, rather than being problematic, may in fact have positive effects.

Video: The camera eye

This section considers the consequences of embedding myself along with the camera within the specialist palliative care team in the acute hospital. As key informants in the acute hospital, the palliative care team considered me an ally and resource within the team. They were aware of my research interests and were particularly acquainted with the research taking on the role of principal referrers of participants to the study and advocates of the research with other specialist teams. As a result, my presence within the team brought issues of patient safety into consciousness as the following field-note extract conveys:

> Extract 5.27 (FI, staff specialist (palliative care), acute hospital, 2nd March 2011).
>
> One of the specialists returned from seeing patients saying, “You know I don’t know if it’s just because you are here, but there seem to be lots of patients who talk about safety. Mr Christie (patient) said ‘I just don’t feel safe to be at home’. If the patient doesn’t feel safe to be at home, then we shouldn’t send him home should we”?

Safety language was foregrounded in the everyday work of the team in relationship with the research. Further to this, the camera took on an unexpected prominence; it became commonplace for team members to view their day-to-day work through the lens of the camera. For instance, I was frequently told “I wish you were there with the camera when …”, and as is evident from the following extract from a conversation with a palliative care staff specialist:

> Extract 5.28 a (FI, staff specialist (palliative care), acute hospital, 31st February 2011).
>
> “I wish I had had the camera today” she (the palliative care doctor) exclaimed. “And you know, I was sitting there and thinking what else is he (patient) going to say? And it was forty-five minutes and the next patient was waiting”. He (patient) said, “You know if it wasn’t for palliative care I think I would be dead by now. You listen and you fix things. You know I (the patient) haven’t spoken to anyone else like that before”.

This doctor expresses a desire to have the camera present in the consultation. She wants non-specialist palliative care providers to witness this patient’s testimony. Critically this doctor wants to demonstrate to other healthcare workers that the philosophy of the specialist palliative care service is to promote living rather than death and dying. She goes on to tell me:

> Extract 5.28 b (FI, staff specialist (palliative care), acute hospital, 31st February 2011).
>
> “This would be good for my colleagues to see; especially those colleagues who say things like ‘the patient is not ready to accept palliative care’ or those who are afraid that referring to palliative care implies a reduced life span or loss of hope”.

In addition, the specialist, by imagining the presence of the camera, reflexively views her own encounter with a patient. She applies critical analysis of the consultation, holding the tension of her concern for the present alongside her concern for the next patient in the waiting room. This imagined, or what I call ‘third-eye’ camera view, outlasted the duration of my fieldwork and was applied in various settings.

Video: A legacy

This section describes how video created a profound mechanism by which individuals who knew the closeness of death could impart something of themselves that would continue beyond the conclusion of their very *earthly* existence. Filmed narratives transcend time producing a means for the persons to continue. This was profoundly so not only for patients but also for their families. It is difficult to express in words what happened during an encounter with Helen when she realised I was able to leave her with the camera. Emotionally she expresses:

> Extract 5.29 (FI, Helen, Hostel, 22nd December 2010).
>
> "You won't believe how hard I have been trying to get my hands on a video camera so that I can document Dad's wisdom and experiences, especially for other family members and to keep for the future. It is a Godsend".

There was a moment of intimacy when both of us recognised an unspeakable spiritual synergy. Emotional and spiritual elements of a good death are closely associated with end-of-life preparation and completion incorporating both the need to reflect on the life lived as well as looking forward to prepare oneself and one's family for whatever time remains (Steinhauser et al. 2000a). Furthermore, there is a body of literature demonstrating an association between expressing emotionally laden experiences and positive outcomes (Niederhoffer & Pennebaker 2002). Filmed stories produced wisdom to be shared and lessons learned and provided participants with a tangible legacy, making an important contribution to other people and practices including other recipients of end-of-life care and those caring for them.

Section 5.5 Conclusion

I argue for research that foregrounds affect and the letting go of boundaries between self and other decreasing the distance between participants and myself. Here what is produced is what Heshusius calls a "participatory mode of consciousness" (Heshusius 1994, p15). I tried to enact a spirit of humility turning toward the other in an attitude of openness and receptivity in the manner I describe at length in Chapter 3. Primarily, this meant me being open to affecting and being affected. I enacted this way of being as the creative means to be open to new possibilities. This nomadic way of being resists fixed identities, practices and methodologies. In other words, I am open to 'becoming'. Critically, nomadic subjectivity requires self-awareness. This chapter presents a case for interpersonal and collective reflexivity as well as self-reflexivity as the means to self-awareness. Reflexivity was needed for the duration of the research process including data collection and analysis, and extends to the effects of the research into the future (Nicholls 2009). Collective reflexivity, that is, nomadic research, required me, as researcher, to relinquish control, allowing collaboratively determined and enacted methods to unfold. To do so however was messy, as this chapter has shown. It required that I negotiate uncertainties and respond to ethical challenges as they unfolded. The effects of this openness, however, allowed for experimentation and creative capacities to be brought to the fore. Filmed narratives revealed the otherwise ‘intangible’, creating new thoughts and possibilities, challenging normative end-of-life care practices. In other words, with the aid of the camera and the visual narratives it produced, I, as researcher became a research instrument or mediator to provoke ‘lines of flight’ helping to take ‘things’[36] elsewhere.

In the context of research enacted in this way and as I have thus far advocated, some patients want to share their wisdom with others. These others include healthcare workers as well as people who are recipients of care, including future patients. Sometimes this wisdom sharing was focused on patients’ own families and future generations. Critically, filmed stories provided a tangible means to preserve such wisdom.

I have enacted methodologies and method inspired by the philosophy of Deleuze and Guattari. That is to say, my overarching ethical position of humility and receptivity drives desire and openness. This openness is what underpins all stages of the research and creates new and tangible ways of seeing and being. I endeavour to continue this process of discovery in the chapters that follow. The next three chapters of the thesis (Chapters 6, 7 and 8) explore what these new and tangible ways of being and seeing bring to light.

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[36] For example: end-of-life care, hospital care, patient safety, research methodology.

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Chapter 6 Safeties and Un-safeties

Section 6.1 Introduction

This and the next two chapters address the scarcity of empirical research on patient safety and end-of-life care. This chapter begins to define safety and harm from the perspectives of patients, families and healthcare workers. In this and the two chapters that follow, patients' and families' visual narratives are woven together with the written word to convey the chapter's message. The reasoning for each chapter is realised by presenting patient participants at significant points in each chapter requesting that the reader view the corresponding visual vignette as the anchor point for the 'reading' of key sections.

The chapter is structured in three main sections. Section 6.2, titled 'Redefining Patient Safety' considers matters of safety from the point of view of patients. Section 6.3, titled 'Normalisation of Inattentiveness to Patient Safety' continues to define safety matters from the perspective of participants. I discuss how sensitivities to patient safety are diminished and analyse the extent to which patients, their families and healthcare workers are exposed to harm in healthcare settings. Section 6.4, titled 'Contradictions of Patient Safeties' reveals incompatible 'safeties'. In this final section, I demonstrate how safety and harms are contested, meaning different things at the same time. The chapter concludes by arguing for a reconceptualising of safety that accounts for these multiplicities of patient safety.

Section 6.2 Re-defining Patient Safety

This section addresses how safety is articulated from the perspective of participants. First, I examine the manner in which patients view their own safety. Second, I begin to explore the relationships between technical safety, physical safety and feeling safe. I begin this section by introducing Esmereldo[37].

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[37] See Chapter 5 for my rationale for using real names or pseudonyms.

Introducing Esmereldo

> *Esmereldo was in the four-bed bay beside the window. The curtain was pulled between him and the next bed. He was in bed and I was struck how white everything looked as I approached the bedside: the white walls; the crisp white sheets; Esmereldo's white gown; his frail white face. He appeared frail and thin, yet this quickly paled into the background as I sat down beside him and introduced myself. As I shook his hand he kept hold of it and I didn't get very far into my introduction and explanation when Esmereldo indicated that he was expecting me. He told me that his specialist had told him that I was coming and that she had introduced the research. It was easy to be with Esmereldo. I found myself having an instant rapport with him. His attractive features and his large eyelashes struck me while at the same time I became quickly aware that talking was a significant effort for him and I let him know that I recognised this. Yet, Esmereldo seemed to appreciate my presence. He made it clear that he wanted to participate on film, seeing himself as a 'teacher'. He spoke of his life's work, indicating that he came from a background of both science and art. An interesting mix, he commented. I appreciated the intellectual nature of our conversation, reflecting on where scientific method and the social sciences might converge. He expressed a wish to proceed with the interview then and there.*

(View DVD)

Esmereldo articulates safety as interpersonal safety. Critically, even in his final days of life, Esmereldo identifies himself as having a key role in his own safety and healing. For Esmereldo, healing means being as ‘fit as he can be’ with ‘mental reserve and strength’. In other words, remaining ‘well’ remains important to him even in the final days of his life. Further, Esmereldo considers himself just as important as any member of the healthcare team in achieving this aim. A safe environment for Esmereldo is one that enables expression of his feelings and opinions and takes account of his knowledge. In this way, Esmereldo anticipates being proactive in his encounters with healthcare workers. As this story shows, he is not a passive recipient of care even in his last days of life.

Patients’ articulations of ‘safety’

Matters of patient safety prioritised by hospital clinical governance departments[38] are also matters of concern for patients and families. For instance, the following extracts highlight the importance placed by patients on receiving their medication correctly and on infection control measures:

> Extract 6.1 (FI, patient, palliative care day hospital, 15th June 2010).
>
> “It was awful. I (patient) am sure they didn’t give me the correct medication”.
>
> Extract 6.2 (FI, patient, acute hospital, 6th December 2010).
>
> “And, about safety in hospital; infection control; the doctors come around and they go from person to person and they don’t wash their hands. I (patient) always wipe things, handles on doors etc. And their stethoscopes; surely they have something to clean them with in between patients. I think that’s wrong (referring to stethoscopes)”.

The first extract demonstrates the importance a patient places on receiving the right medicine. She is unable to trust whether or not she is receiving the correct drugs. In the second extract, a patient articulates awareness of infection control measures. She is aware that not washing hands and cleaning their stethoscopes between patients implicates doctors in the spread of infection. This patient responds by wiping down

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[38] Matters of concern for clinical governance departments: healthcare associated infection; medication safety; clinical handover; recognising and responding to clinical deterioration; falls prevention (Australian Commission for Safety and Quality in Healthcare 2012).

common areas in an attempt to minimise her risk of infection. These extracts show that even in their final months and weeks of life the importance of infection control measures in hospital and receiving the correct treatments still matter to patients. Patients are concerned with staying as well as possible even when they are dying.

Further, they are, to some degree, aware of whether or not healthcare workers are delivering safe care. Importantly, they are active participants in their care. To some extent, patients define safety as clinical technical safety in the same way that healthcare organisations do. However, matters of technical safety are dependent on trusting healthcare workers. Whether or not patients feel safe is related to having their needs met. The patient speaking below expresses this point as follows:

> Extract 6.3 (SSI, patient, palliative care day hospital, 3rd August 2010).
>
> “At all times I (patient) don’t think I’ve ever felt safe because in an environment the nurses, you know, they haven’t got the time. They leave you waiting and when you can’t walk and you want to go to the toilet or something and they leave you. They just leave you hanging and then they finally come. It is very frustrating and worrying you know when you’re sick”.

This patient defines hospital as a place that he has never felt safe. Safety matters, as far as he is concerned, are not simply related to clinical technical interventions and medical error. Here, safety is determined by whether or not healthcare workers can be trusted to meet immediate and essential needs such as assisting him to get to the toilet. It is important to patients that physical and technical needs are met but this is intertwined with what I term interpersonal safety. The implication of this extract is that physical safety is inextricably linked with interpersonal safety. These safety matters are not accounted for in hospital clinical governance guidelines and safety structures.

This section has shown how patients’ safety needs, to some extent, are consistent with organisational safety needs. Yet the physical safety needs of patients are inseparable from interpersonal safety. Most significant is that safety matters are important to patients. Rather than passive recipients, patients actively evaluate the quality and safety of their care. Further, the way in which patients articulate safety suggests that they enact safety measures in response to their own evaluations. The next chapter (Chapter 7) examines more closely the place of patients and families in enacting safety. Here, in this chapter, I continue to examine how safety is defined. In order to do so, I first need to analyse safety by examining what is unsafe. This foreshadows my examination of what predisposes people to harm. I term these predispositions to harm as ‘becoming-harms’.

Section 6.3 Normalisation of Inattentiveness to Patient Safety

This section addresses what I term ‘normalisation of inattentiveness to patient safety’. This inattentiveness is related to habitual care patterns that expose dying patients and their families to harm. I investigate what these harms are; and the context in which they manifest. I consider ‘adverse events’ from the perspective of patients and families. This foreshadows discussion of the place of healthcare workers in relation to harm. I consider healthcare workers’ own articulations of ‘safety’. Further, I discover that healthcare workers are themselves exposed to harm, and explore what these harms are under the heading ‘Are healthcare workers unsafe’? Lastly, I investigate what I term becoming-harms and discuss the predisposing factors implicated in these harms. I begin this section by introducing Joe and Tara.

Introducing Joe and Tara

> *I met Joe for the first time on the 7th February 2011. I visited him on the new oncology/haematology ward. He was in a single room. The room appeared spacious with a window outlook overlooking the school. Joe was sitting in a chair at the window side of his bed. He was attached to a drip and the machine was beeping. He had his bed-table next to him. There was a small device sitting on it that appeared to be a DVD player. I sat down next to him and explained who I was. He immediately recognised my accent, “And you’re a Scot he said” and “You’re an Irish”, I retorted. “You never lose your accent”, he said. “How long have you been here?” I asked, “Oh about 30 odd years”, he replied. I asked him what he liked to be called. “Joe”, he said. “I am Ignatious Joseph but at school I got everything and so finally settled on Joe. My wife didn’t know I was Ignatious until we got to the alter and the priest called me Ignatius”, he chortled.*
>
> *He switched a button on his drip machine (“That usually works”, he said, “but not this time”). “Do you need to press the buzzer”? I asked. “No, I’ll go out and get them to do it” he said, “It’s quicker”.*

When I told him why I was there and what the research was about he said to me, "Well, I just want to get out of here, I have been in here since November, the 11th of the 11th. I don't remember much about it but my family and other patients have told me, 'You died several times''. "So you must have been very ill"? I asked. "Yes, but I don't remember much about it", he said. "I remember more than they expected me to. I just want to go home. They (the medical team) keep telling me, 'In 2 weeks' and then when that comes they say, 'Just another 2 weeks'. My wife died seven years ago, that is why they are worried about me going home. But I have been independent for seven years. I don't mind being in hospital for a couple of weeks but I have been here since November. It's easy to get into these places but not so easy to get out again".

He started telling me about his involvement on a local committee and that he had reports to sort and write and needed access to his computer. "Can you do it in here"? I asked. "I don't have a laptop", he said, and "I'd rather do it in my own home. They are taking me home today or tomorrow for a visit to see how I go".

When I told him more about the project and what it involved, he said that he would like his daughter to be involved. I said that was absolutely fine and I would give him a chance to read the information and talk it over with his daughter. Then we could arrange a time. He wrote down his daughter's details for me and asked me to contact her to explain the project. He told me about his other children, a son and his other daughter. He said that they all tried to visit regularly and they took him down in the wheelchair to the front of the hospital. "You are confined in here", he said. "(names other daughter) finds it difficult to come, she works at (names other local hospital). It's more difficult for her to visit". "Is she a nurse"? I asked. "No, she works in the ED reception, but she knows everything", he said, "knows more than some of the nurses. In fact she got onto the nurse here the other day because of my eardrops and infection". I summed up about contacting his daughter and the project. "It sounds very interesting", he said. "And if it's not going to do me any harm, then I might as well do it". I wished him good luck with the home visit and said that I would catch up with him next time.

(View DVD)

For Joe and Tara, the camera provides an important medium through which unsafe care can be communicated to those responsible for providing care. Organisational processes for dealing with adverse events do not provide the means for Joe and Tara, and many other participants like them, to voice their expressions of unsafe care. Joe and Tara's visual narrative has a special place in this thesis. Further, they speak on behalf of other participants who concurred with their articulations of patient safety but were either unable to or did not wish to speak on film.

In short, Joe and Tara's account encapsulates 'normalisation of inattentiveness to patient safety'. For Joe, patient safety is more likely to be realised at home than in what he considers the unsafe environment of the hospital. He has been a patient in hospital for a number of months. Just as Myers and Lynn (2001) suggest, continuous hospitalisation over a period of many months is likely to involve patients in errors that harm them. Importantly, unsafe care for Joe and Tara is not defined as a discrete event, but rather as an unfolding series of events. For Joe and Tara adverse events include: unmanaged pain and other symptoms, overruling of Joe's expressed wish not to be resuscitated and delivery of bad news without the presence of family support. Critically, for Joe and Tara these incidents occur as a result of ineffective communication both at the point of healthcare workers' interaction with them and at the level of team communication between different disciplines and between medical specialists themselves. In other words, clinical technical safety is inextricably linked with interpersonal safety. Furthermore it is the ‘camera’ that enables the unveiling of these harms. I now consider further what adverse events are and how they are revealed.

Adverse events

Even when articulated solely in terms of clinical technical safety and according to organisation definitions of patient safety, adverse events were pervasive. They were brought to my attention in several ways. Adverse events were discussed explicitly by the specialist palliative care team in their weekly meeting under the heading of ‘alerts’; a reporting mechanism where specialist palliative care staff recorded issues and events as they applied to a list of agreed criteria that were deemed contrary to best quality palliative care. I provide an example of the kind of incidents recorded as ‘alerts’ in the extract below from my field notes:

> Extract 6.4 (EFN, specialist palliative care team meeting, acute hospital, 21st Feb 2011).
>
> A renal patient had been given 20mg instead of 2mg of Hydromorphone (a strong opiate drug) in the emergency department. The patient subsequently died on the ward. One of the staff specialists expressed that the patient was already dying. However, a root cause analysis was underway and the case was now with the coroner. The second patient was discharged home on the wrong dose of Hydromorphone and also subsequently died. It was noted that the patient had gone home without a discharge summary (including a list of discharge medications). A Hydromorphone committee has been set up to address process and strategies that minimise risk of overdose for this particular drug.

In the above account, two significant adverse events concerning opiate drugs and resulting in formally reported incidents were recorded as ‘alerts’. Adverse events such as these drug errors were made explicit and defined within hospital clinical governance structures. This account shows that the organisational response to significant errors is to try to ‘fix’ processes. The underlying assumption of the response to adverse events is that the fixing of these processes will reduce risk and prevent further errors concerning the opiate drug Hydromorphone. The patient safety movement “tends to accept without question" that the elimination of error will result in safe practices (Jerak-Zuiderent 2012 p733). This is the machine metaphor at work: we fix the broken component, and safety has been restored. I will go on to show, in this and the next two chapters why this assumption may be problematic.

Adverse events were not necessarily always recognised or formally acknowledged or reported. Further, by their omission, adverse events were a normal part of everyday care. For instance, drug omissions were a common occurrence for patients admitted through the hospital emergency department. This was evidenced by the status of drug omissions as a regular standing agenda item on the weekly 'alerts list' and as I noted in my field notes from attendance at a weekly clinical team meeting:

> Extract 6.5 (EFN, acute hospital, 26th August 2010).
>
> "Meds not charted (prescribed or administered) in Emergency Department".

This item on the 'alert list' referred to occasions where patients known to the area palliative care service and prescribed a known regimen of drugs to manage symptoms such as pain or nausea, did not have their regular medication prescribed or administered while in the emergency department. This could result in uncontrolled symptoms including symptoms associated with drug withdrawal.

Potential for adverse events relating to prescription of opiate drugs was revealed through day-to-day encounters and observations in the hospital. For instance, ward doctors of various specialties articulated a lack of confidence in their own opiate prescribing. They were often fearful about prescribing drugs, evident from the following field note extract from an informal conversation with a small group of medical registrars:

> Extract 6.7 (EFN, acute hospital, junior doctors, 12th January 2011).
>
> Doctor 1: "The only thing that I get anxious about is prescribing large doses of opiate".
>
> Researcher: "What do you mean by a large dose"?
>
> Doctor 1: "Well, when the patient hasn't had an opiate before and they need a larger than normal starting dose".

> Doctor 2: "I don't know what to do with my patient. He's on 20mg of Oxycontin and he's still needing lots of Endone. I am worried about increasing the Oxycontin".
>
> Doctor 3: "Well you can increase the Oxycontin if he's needing lots of Endone. Why was he started on Oxycontin in the first place, why not MS Contin"?
>
> Doctor 2: "Why MS Contin"?
>
> Doctor 3: "Well we use Oxycontin if the patient has chronic renal failure".
>
> Doctor 1: (laughing) "It was me that started the Oxycontin".

The above account reveals that doctors express uncertainty about prescribing opiate drugs. Doctor 1 is unaware of the 'criteria' for selecting a particular opiate and conveys his embarrassment in response to what Doctor 3 regards as the 'wrong' selection. This extract reveals how junior doctors rely on their peers for learning how to prescribe medication. There is a risk of harm if opiate drugs are not appropriately prescribed. First, by omission, patients can suffer unnecessary pain without adequate pain relief. Second, if an inappropriate opiate drug or the wrong dose of opiate is prescribed, patients are placed at risk of significant harms including opiate toxicity and/or renal failure (Palliative Care Expert Group 2010). Importantly, the doctors in this account do not learn how to prescribe opiates from therapeutic guidelines. Instead, they learn to prescribe through an informal process of peer support in the hospital cafeteria. This challenges the idea that prescribing guidelines and protocols will, alone, lead to medication safety. The assumption that healthcare settings can be made safe by reducing adverse events with protocols and other safety devices is open to question.

In the course of daily ethnographic interactions and at other clinical meetings, I came across evidence of adverse events in areas of the hospital where protocols were prolific. For example, I witnessed the following corridor conversation between a nurse, oncologist and a palliative care specialist:

> Extract 6.8 (EFN, acute hospital, 14th January 2011).
>
> "She (patient) was there (ED) for four hours," the nurse told the oncologist; the nurse continued "No work up. No nothing: Ordine

> (painkiller) and fluids and fine to go. Several hours later the patient was dead on arrival at (names another acute hospital)". In response, the staff specialist (Palliative Care) said that she would try and discuss the incident at the morbidity and mortality meeting[39] (implying that this would be difficult).

Several aspects of unsafe care are contained in this account. The emergency department deems the patient 'palliative' and thus unworthy of a 'full work up'. In other words, the patient is viewed as someone for whom emergency saving care is inappropriate. As 'palliative', the patient is not considered a candidate for a complete clinical assessment. Despite considering the patient to be 'palliative', the patient's deterioration and the fact that he is imminently dying goes unrecognised. As a result, the patient dies on route to a second emergency department. The emergency department is a place where rigorous criteria, protocols and guidelines are in place to address the immediate clinical needs of seriously ill patients. Protocols and guidelines, however, do not prevent harm for this dying patient and his family.

The morbidity and mortality meeting is an organisational process set up to discuss management decisions and improve patient safety and quality of care (NSW Health Department 2001). The doctor quoted above indicates that it is difficult for her to raise issues pertaining to the safety and quality of end-of-life care in these meetings. The focus of the morbidity and mortality meeting is the *'why'* of death rather than the *'how'* of dying. In other words morbidity and mortality meetings are privileged towards the goals of cure and repair; not towards the goals of appreciation and understanding. The positioning of the patient as unimportant in this extract resonates with the theme of abandonment in the literature. Non-abandonment is espoused as a core value of end-of-life care (Periyakoil 2007) and has been defined as "open-ended, long-term, caring commitment to joint problem-solving" (Quill & Cassell 1995, p368). The emergency department fails to assess the patient and ensure the correct medication is administered, in effect abandoning the patient discussed in the abstract above, resulting in an unsafe death. Further, organisational inertia and complacency compound this abandonment by failing to effect reflective learning.

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[39] *"A meeting held on a regular basis to review deaths and adverse outcomes in patients of a specific clinical group or specialty" (NSW Health Department 2001 p12).*

The evidence I have provided so far demonstrates that patients' and families' experiences and articulations of adverse events are not always acknowledged, defined or addressed by healthcare workers or organisationally. Even when technically defined, harms are normalised despite the presence of policy, protocols and clinical governance structures.

Clinical technical adverse events are assumed to have a linear or 'root' cause, that when fixed will prevent further adverse events (Jerak-Zuiderent 2012). Further, organisational processes assume that adverse events will be defined as adverse events and that they will be reported. Defining a care episode as an adverse event does not necessarily translate into reporting. For example, healthcare workers frequently conveyed their contempt for the administrative safety processes put in place for the reporting of adverse events. The next extract demonstrates the views of a specialist towards the electronic reporting system in response to viewing footage:

> Extract 6.9 (VRM #2, staff specialist (haematology), acute hospital 24th August 2011).
>
> "I don't do IMMS[40] or anything like that, waste of time, nothing ever happens, they come back with some platitude or something. I don't bother with it. This hospital is run by d********. All they are interested in is getting people in and out of beds and keeping themselves out of the newspapers. I don't bother with them at all. They're not interested in patient care. All I do is just come in and look after my patients. I treat them and try and keep them alive with the best quality of life for as long as possible. But the hospital doesn't care about patient care, nor do most doctors on the ward. And the doctors looking after patients on the ward don't have the skills to look after patients like Joe and that bit about not writing it in the book (he puts his hands over his face). I can just see it". I (researcher) asked him (the specialist) how he maintained the safety of his patients. "Well I do the best I can, but I'm sure patients get the wrong drugs and wrong treatments all the time. Joe and his daughter are right. Hospital is a dangerous place".

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[40] Online incident reporting system.

The doctor affirms Joe and Tara's view of the hospital as a place that is unsafe and even dangerous. In other words, a place so normalised to inattentiveness to patient safety that incidents are insidious and patients 'get the wrong drugs and wrong treatments all the time'. This doctor does not trust those responsible for hospital clinical governance structures to act on the formalised reporting of adverse events. He questions the motives of hospital administration. He also questions the skills and motives of junior doctors at the bedside. In doing so, this doctor effectively disengages from his accountability as a senior specialist in these matters. He regards the formal reporting of error or harm via the electronic reporting system as a waste of his time. Instead of seeing clinical governance and clinical supervision as something he is, in part, responsible for, he positions hospital wide safety as the domain of others and responds 'doing the best he can' at an individual level. The individual efforts of this specialist, however, do not produce safety. In other words, safety does not simply materialise from individual accountability. Further, the inaction of the specialist renders him complicit in becoming-harms. The account above demonstrates that patient safety is, to a large extent, dependent on the specialist's relationships with junior members of his medical team and hospital managers. That is to say, clinical technical safety is inextricably linked with interpersonal safety.

Importantly, the general assumption that adverse events will be reported and acted upon to address patient safety is erroneous. Further, when deemed adverse, events are not necessarily discussed and investigated, let alone disclosed. If adverse events are not recognised and/or reported, then I suggest it becomes critical to understand what healthcare workers do recognise as adverse and harmful. Thus, I now turn my focus towards healthcare workers conceptualisations of safety and harm. This foreshadows analyses of what harms they are exposed to on their terms.

Healthcare workers' articulations of 'safety'

Healthcare workers, to some extent, equate patient safety with clinical technical safety just as patients do. Organisational matters of patient safety prioritised by hospital clinical governance departments are for some healthcare workers, and to some degree, congruent with their own safety priorities. In other words, they consider safety in terms of safe administration of medicines and matters of infection control as expressed by the nurse in the following extract:

> Extract 6.10 (SSI, student nurse, acute hospital, 15th February 2011).
>
> "Safety to me (student nurse) means, you know the obvious things, performing our roles within legislations. So obviously not giving the wrong medication. You know, taking a cannula out three days after it's supposed to come out and all that sort of stuff. Patient safety to me also means prevention of any infections and what not".

For this nurse, safety equates with technical safety and is related to the correct administration of drugs and prevention of infection according to policies and protocols. About to become a registered practitioner, this student nurse articulates the accountabilities required of her to deliver technically safe care.

Are healthcare workers unsafe?

More experienced nurses articulate safety more broadly to encompass interpersonal safety. The registered nurse in the following account expresses her anger and disappointment when another nurse reprimands her in front of a patient for the way she has carried out a chemotherapy specific procedure:

> Extract 6.11 (SSI, RN, acute hospital, 11th March 2011).
>
> "The next day one of my colleagues (a senior nurse) came out to the radiation bay and said, 'Did you do such and such?' and I said, 'Yes'. 'Well come here' (quoting the senior nurse's direction). I said, 'What's wrong'?, 'Come here and have a look at this' (quoting the senior nurse). So I went in there and the patient was in there and, 'Well did you do this?' (quoting the senior nurse) 'Well yes', 'Well why did you do it like that'? (quoting the senior nurse) And I said, 'Well there's nothing wrong with it being done that way, that's the way it's done on the wards and I did it under supervision'. But the patient and her daughter are sitting there and the looks that I was getting from them! It was just dreadful and you know I had to get someone senior to come in and go and reassure them but I have since felt that that daughter and patient have absolutely no faith in me and it was wrong and it was unprofessional to do that. I can get over how it made me feel but can they (patient and family) ever get over that? Do they trust me to treat her"?

A hospital protocol is in place for the safe access of a central line. Another nurse contests the way the procedure is carried out in front of the patient. This demonstrates that despite standard hospital protocols for procedures, safety can still be called into question. In other words the protocol itself does not ensure procedures are carried out safely. It is not only how the procedure is carried out but also the breaking down of trust between nurse and patient that undermines safety. This extract reveals several 'becoming-harms': other patients in the room witness the nurses' altercation. Hence, trust breaks down, not only between the nurse and the recipient of the procedure, but also between the nurse and other patients. Finally, the nurse also feels unsafe as a result of being admonished. Thus, I suggest that healthcare workers also have safety needs and these safety needs are closely related to the safety of patient and families. Critically, technical safety is again not discrete from interpersonal safety. In the extract that follows, a group of nurses makes reference to their own safety with respect to their accountabilities as registered nurses.

> Extract 6.12 (FI, RNs, acute hospital, 11th February 2011).
>
> RN 1: "You are lucky if you manage to document anything at all".
>
> RN 2: "It's just not safe".
>
> RN 3: "I just don't feel safe, you are worried you will get sued or something, make a mistake, because you forget to do something because you are trying to do too much".

The three nurses engaged in this dialogue designate the acute hospital as an unsafe place of care delivery. The nurses describe multiple risks to safety. One nurse expresses an inability to document the care she delivers, a task she sees as integral to her role and an imperative for safe care. Another of the nurses concludes that operating in what she sees as an unsafe environment increases the likelihood of an incident that she will be held responsible for, placing her at professional as well as personal risk of litigation. Further, these nurses talk from a position of being without agency to alter the unsafe care delivery described in what they view as an overstretched public health system that makes extraordinary and unrealistic demands on them. Critically, what matters to these nurses is not only the safety of patients but risks to their own safety. They emphasise that safety extends beyond key areas defined in policies and procedures and feel powerless to improve safety. Further, they suggest that the organisation does not recognise these risks or take account of these safety needs. Like the specialist in Extract 6.9, the nurses defer accountability for clinical governance to others. In other words, they too become complicit in unsafe care. The nurses' account shows how patient safety is inextricably linked with the safety of healthcare workers.

Caring for dying people brings the safety of healthcare workers into sharp focus. When given the opportunity to do so, staff of all grades and disciplines spoke openly and frankly about their experiences, both positive and negative, of looking after dying people. Often they expressed the cathartic nature of the research interaction, commenting that they did not usually have the opportunity or the time to reflect on issues of death and dying. Most healthcare workers were able to easily recall the memories of early death experiences and often described feeling ill-prepared for caring for dying people. Experiences such as these can have a significant impact on healthcare workers as the next extract from an interview with a specialist reveals:

> Extract 6.13 (SSI, staff specialist (Radiation Oncology), acute hospital, 25th March 2011).
>
> "I think as an intern I used to dread having to (certify a death)...my first rotation as an intern was just nuts, it was just dreadful, you know because there would be deaths and you'd have to go up to a ward where you didn't know the nursing staff, the lights were sometimes right off. You know, you knew no one. Here's this dead body and you've got a torch and you shine another torch in their eyes and have a listen to their chest and out you go and write on the bits of paper or there's still a whole lot of family around and it's like well you have no relationship with this family and you've never met them before and you're fearful. The reality is you probably can't help them very much and I certainly didn't know how I could and didn't know what to say and you know I think I just went in and out as quickly as possible as avoidance".

This extract demonstrates how as an intern, this doctor is faced with declaring a person dead in circumstances where the environment is unfamiliar to him and he does not know the patient, his or her family or even the nurses caring for the patient. This doctor's feelings of fear and unsafety are compounded by having to carry out certification of the death at night when there is no senior medical support in proximity.

The doctor knows that bereaved families have expressed needs at the time of death. He feels isolated without appropriate skills and importantly the social support of other team members to respond to these needs. This doctor feels forced to cut himself from the situation as soon as possible in order to feel safe. As a result, the certification of the death is reduced to a technical task performed on a dead body rather than a relational encounter with the family of a person who has died.

Healthcare workers across all disciplines and care settings articulated the kind of effects that caring for people at the end of life can have on them. In the next extract a social worker conveys how she feels complicit in causing harm to a patient and his son:

> Extract 6.14 (SSI, social worker (palliative care), 20th April 2010).
>
> "Because I felt that I was damaging people as a social worker, as a person. And even when they (patients) didn't get to a nursing home because they'd died, I put them through it. And as a person, it was awful. Now, the system. That's what was driving the whole thing. But I'm in the system. It was not good. And I can remember once this guy eventually agreed to put his father in the nursing home. I think he lived maybe not quite a week. And I did a follow-up bereavement call because I'd heard that this gentleman had died. I had complicated his bereavement like you wouldn't believe. And he said to me, 'I wish to Christ I'd never agreed to it.' And you think to yourself, now that's just the stuff that you cart around".

This account demonstrates how a social worker is implicated in creating unsafety and how she knows and regrets it. The social worker directly links what she views as the inappropriate transfer of a patient to a nursing home as being implicated in the future complex grief of the patient's son. The social worker, experienced and skilled in bereavement, anticipates the past being carried forward into the present at the level of lived experience (Boston Change Process Study Group 2007). As the key team member involved in arranging the transfer, the social worker feels personally responsible for causing harm, not only to the patient but also to the patient's son. Although the social worker identifies the role of system processes and the cause of the harm as exceeding her contribution to the harm, she positions herself as a part of the system and thus implicated in the outcome. As a result, the social worker expresses her distress and names the residual memories of this and similar incidents as 'just the stuff that you cart around'. In other words, the social worker is exposed to becoming-harms. These harms are not something she can prevent as an autonomous individual. Rather, whether or not she suffers harm is inextricably linked with the system she is a part of.

Harms suffered by healthcare workers do not occur in isolation of their surroundings and the organisations they are a part of. Thus, I now want to examine further how harms are brought into being within these assemblages. I propose that becoming-harms arise as a result of healthcare workers divorcing themselves from affective exchanges or what I term 'learning not-to-be affected'. Learning not-to-be affected is learning not to be moved by the collective or individual body. Healthcare workers learn how to disengage from the wider human and nonhuman world of which they are apart. Further, I argue that learning not-to-be affected, to a large extent, arises from constructing people as 'body singular'.

The 'Body Singular' and 'Learning not-to-be affected'

Learning not-to-be affected means closing oneself down to possibilities of openness and humility. I argue that it is through cutting off from these possibilities that harms come into being and 'normalisation of inattentiveness to patient safety' is cultivated. Further, learning not-to-be affected is fostered by the construction of people as 'body singular'. The view of the person patient as body singular reduces the person to an object to be treated. This can manifest as the metonymic substitution of patients for bed number or disease. In the extract that follows from an interview with a nurse, the patient is metonymically substituted as the physical space:

> Extract 6.15 (SSI, RN, acute hospital, 25th March 2011).
>
> "You get a room there who's a dying patient, then next to that is a patient who's well and good and it's actually in your hands for her to get better".

This nurse dichotomises dying patients and 'well' patients. By substituting 'patient' for 'room' she disengages from the person as a living acting subject. The idea that one should not get emotionally attached to patients and families was prevalent among healthcare workers. Emotional attachment is seen as jeopardising the application of clinical knowledge and technical competency, and thus reducing the objectivity necessary to perform one's professional role (Lavoie, Blondeau & Koninck 2008). This stance is one that presumes an ability to separate cognitive understanding from emotional response (Liben 2011) and is based on a traditional mind-body separation. The idea that doctors should be “sufficiently detached or objective toward the patient to exercise sound medical judgment and maintain his equanimity” while simultaneously being “sufficiently concerned about the welfare of the patient to give him compassionate care” (Fox 1998, p86), has been termed ‘detached concern’ (Lief & Fox 1963) in what is now a seminal work. The term has been used since to invoke some form of detachment: “and it is viewed critically as representative of a traditional medical stance that places greater emphasis on cognitive detachment from patients’ feelings than on empathic emotional attunement to them” (Fox 1998, p101-102). In the course of fieldwork I came across the belief that doctors could and should maintain an objective, unemotional stance such that professional ‘distance’ and ‘boundaries’ are retained. This professional mask is one that is supposed to protect the healthcare worker from emotional burnout and the patient from non-objective unscientific intervention (Marcum 2008a) and is revealed in the next extract from an interview with a specialist discussing his own spirituality in relation to the spirituality of one of his patients:

> Extract 6.16 (VRM #2, staff specialist, (radiation oncology), acute hospital, 11th July 2011).
>
> “I think the issue is much bigger than just the fact that it’s a clinical issue. He’s (patient) passing from life into death. Again, depending on faith, but according to his faith then onto a new life, a real life. So it’s just a passing over to his real life and for me those are the real issues and I feel sometimes with other patients as their doctor, I’m dealing with, let’s say, half the story which is just their physical suffering and I don’t in any way address the spiritual side. I’m unable to do that but with Donald (patient) that was very easy. Now you know that’s a real taboo, taboo to speak to someone about your beliefs so I (specialist) almost really never do it unless asked by patients and then I will”.

In the above extract a specialist comments on the professional taboo of sharing his spiritual beliefs with a patient. The medical taboo of not being able to speak about his own spirituality unless asked creates a palpable tension for this specialist. He articulates a view of patients as existential beings until their death and of the profound nature of caring for dying patients. In other words, he is not individually ‘detached’. Instead, he conveys that the social context of the discipline of medicine prevents him from revealing his ‘true’ self and thus affectively attuning with most patients. He shuts off from possible transformations avoiding articulation of his own spirituality unless he is asked outright about his personal beliefs. This leaves him with the conundrum of only dealing with what he describes as ‘half the story’.

Further, the normalised value of maintaining professional ‘distance’ and ‘boundaries’ extends beyond doctors to include nurses and other healthcare workers. In the next extract a receptionist expresses frustration at being reprimanded for relating to patients in a manner regarded by her line manager as inappropriate:

> Extract 6.17 (VRM #1, receptionist, CTC, 7th June 2011).
>
> “I (receptionist) got told I’m too personal with the patients, that I shouldn’t become involved with the patients that I need to keep it professional (shrugs shoulders). I said, ‘Sorry, that’s my personality. If you can’t handle it bad luck’. I believed I was doing the right thing but I kept getting in trouble for it. I kept getting into trouble”.

This receptionist expresses her frustration at being reprimanded for relating in what she regards as a friendly manner with patients as they enter the cancer therapy outpatients department. Not only is revealing oneself to patients considered taboo, relating to people in this way is regarded as unprofessional. She expresses what she regards as the dissonance between what patients want and need, conveyed to her on film, and the behaviour required of her by her line manager. This extract demonstrates that it is not a problem of detached concern that prevents her from affectively attuning with patients. To the contrary, she resists attempts by her manager to prevent her from doing so.

Therefore, my argument extends beyond the notion of ‘detached concern’ to suggest that closing off to creative possibilities and transformations is cultivated within the social context of healthcare settings and intra and inter-professional relationships. In this case the receptionist resists attempts to shut down these possibilities. I suggest, however, that learning not-to-be affected is partially determined by habituated social patterns and rituals within the collective body that help to justify affective disengagement among stakeholders generally and pervasively and that these rituals and habits are hard to resist. The next extract shows how the hospital ward round acts as a ritual to foster affective disengagement:

> Extract 6.18 (VRM #2, staff specialist (radiation oncology), acute hospital, 11th July 2011).
>
> "Time is an issue, in the sense that you have a number of patients to see on a ward round and there are clinical questions you're trying to address and sometimes the answer to that clinical question can take seconds not even minutes".

This extract reveals the doctor's view of the purpose of the ward round as one of principally answering 'clinical questions' for the benefit of the medical team. In other words, the modus operandi of the medical ward round configures the person as a fixed set of physiological processes that require technical assessment and intervention. The person as doctor is there to draw conclusions about this fixed set of processes. He is not there to reveal anything of his 'true' self, nor is he open to being moved. In other words he too is configured as body singular just as patients are.

Acute healthcare settings, largely clinical technical assemblages, favour medical authority and reason. I argue that this reduces the capacity for healthcare workers to affect and be affected. By having a set agenda driven by the clinical question, healthcare workers can close themselves off to other possibilities that might increase the potential for action, meeting the safety needs of healthcare workers as well as patients. In the context of the traditional mind-body split, connecting with patients affectively is seen as having a discrete subjective and therefore optional/discretionary purpose. Thus, time becomes a more significant issue and causes tensions for healthcare workers trying to balance how they best spend their time to maximise benefit for those they care for. The nurse in the next extract provides an example from her own experience:

> Extract 6.19 (SSI, RN, acute hospital, 25th March 2011).
>
> "When they're on the ward it's hard to explain because the staff shortage. We don't have time. We can only be there for five minutes. I've just got a new lady who's actually newly diagnosed with young kids. I want to spend time with her, explaining and basically trying to reassure her but time is your enemy and you just, you just can't".

Nurses like this one often describe time as the 'enemy'. In the churn of a busy health system, and as I will continue to demonstrate in the next chapter (Chapter 7), communication becomes a means solely to deliver information and answer clinical questions. Healthcare workers, to a large extent, set the agenda of these clinical questions. This is in contrast to affective exchanges in which both patient and healthcare worker are embodied subjects in space and time occupying a lived context in a world of social interactions.

When people are constructed as 'body singular' in the palliative care unit, the very care of dying people is at risk of becoming a habituated routine. In the next extract a healthcare worker suggests that continually caring for dying people and their families can result in 'learning not-to-be affected':

> Extract 6.20 (FI, secretary, palliative care unit, 22nd December, 2011).
>
> "They (healthcare workers) become so familiar with dying that it can become 'just another dying person'. But these are people with a story, with a life, with a history", she (secretary) emphasised. "Even as I (secretary) am sitting at my desk, I (secretary) read the green sheets (death notification documents for case notes) and wonder about who that person was, what their life was like, what their story was, whether they had a family. Sometimes I (secretary) think that's just forgotten, that these are people (families) with lives that continue after they leave the unit. Those people who have been bereaved have lives and when someone they love, their light goes out, there is a profound mystery surrounding it that I think the workers here forget".

This secretary reflects on how dying people and their families are cared for in the palliative care unit. She constructs the task of filing the green form, not as a simple administrative task but representative of the loss of a living, feeling person who has died, leaving behind family and friends for whom the death can have profound and lasting effects. Drawing from her personal experience of bereavement, she expresses concern that care of dying people can be reduced to a normative set of tasks. This healthcare worker draws from her personal as well as professional experiences to suggest that palliative care healthcare workers can learn not-to-be affected. Learning-not-be-affected is concerned with learned habituated patterns of being that close down awareness to patients and families and colleagues as living acting creative beings and blunting attentiveness to safety. Further, learning not-to-be affected occurs in the context of collective bodies. To illustrate this further I provide two extracts drawn from my field notes. The first of these extracts is from a lunchtime discussion between specialists concerning the issue of mixed sex wards and the effect on one patient's safety from having to share her room with men:

> Extract 6.21 (EFN, specialist palliative care team weekly meeting, acute Hospital, 28th March 2011).
>
> The staff specialist (Palliative Care) said: "I've just been to see Mrs Roberts. She doesn't want the curtains open because there's a man opposite but having the curtains around seems to be upsetting her. There are two areas where there are two women sharing with two men and so I asked the acting nurse unit manager why he couldn't change them over so that the men were sharing and the women sharing; so I asked the ANUM if she could be moved". The staff specialist (palliative care) expressed her frustration and disappointment with the response; and continued "The ANUM said that even if they move her she'll find something else to complain about. I can see she's been labelled but the ANUM said that, 'It's just how they come in and it's hospital policy'. Another other staff specialist (Palliative Care) responds: "I think they hide behind hospital policy".

This extract shows how a doctor suggests a possible solution to meet the needs of a distressed patient. The nurse unit manager is unable to respond in the way that the specialist hopes. He accounts for his inability to do so by constructing the patient as the source of the problem and by citing hospital policy as a reason for not being able to alter the bed configuration. The second doctor in the extract considers the use of hospital policy an ordering device used by the nurse to avoid meeting the needs of the patient. This example demonstrates how the nurse divorces himself from an affective exchange and thus the patients' safety. This nurse's capacity to act (or not) is inseparable from the habituated patterns of the healthcare setting of which he is a part. In this case inattentiveness to safety is, to some extent, normalised through the application of hospital policy and protocols. In other words the 'bed policy' provides a mechanism to justify learning not-to-be affected.

The second extract from a field interview records a discussion that took place at a palliative care team meeting. The team discuss a new hospital practice of writing the expected date of discharge (EDD) on a white board at the head of patients' beds:

> Extract 6.22 (EFN, specialist palliative care team, acute hospital, 21st January 2011).
>
> It seems that all patients in the new respiratory ward have the letters EDD with a date written above their beds. The junior doctor told of being asked by a family member what the date EDD meant, mistaking it to represent expected date of death. Following her (the doctor's) attempts to explain otherwise, she (the doctor) noted that the family asked, "But won't he stay here to die? Why does he have a discharge date? What if he doesn't die? Will he be discharged?" Natalie (palliative care nurse) interjected in the conversation noting that while she was in discussion with a patient she became aware of 'the date' written above the bed. Apparently she rubbed it out discreetly, only to later be rebuked by the Nurse Unit Manager for doing so. In response to this discussion the staff specialist (Palliative Care) adds, "If I was the NUM, I'd just say not on my ward. Wouldn't you be concerned as the date is getting nearer and they probably don't update the date? Imagine if you're there and not getting better. You'd be worried that you don't feel welcome".

The writing of the expected date of discharge on the white board above a patient's bed results in unintended consequences: A patient's relative interprets the white board acronym as expected date of *death* instead of expected date of discharge, leading to distress. Even when the acronym is explained, family members remain distressed. They are concerned that unnecessary pressure will be placed upon them to look after their dying relative at home. The NUM, nevertheless, adopts the newly adopted ritual as routine practice. This shows again how bed policy and the ritual of writing EDD are implicated in learning not-to-be affected. The routine of writing the EDD is also implicated in constructing the person as a 'bed to be discharged' rather than a living, feeling, acting person.

Construction of the person as 'a bed' is disrupted when the palliative care nurse rubs the EDD from the white board. This action interrupts the ordering device and its enforcement by the nurse in charge of the ward returning the patient to a feeling acting person. Further, this newly adopted ritual, based on false assumptions and applied inflexibly can produce harm in other ways. The writing of EDD assumes that patients are admitted to hospital for a short time, and are returned home once they have been ‘fixed up’. We saw from Joe’s situation that this view of hospitalisation is misguided. Paradoxically, it is the very characteristics of clinical technical assemblages that keep people like Joe in hospital for protracted periods.

Thus, I argue, healthcare settings as clinical technical assemblages are implicated in becoming-harms. I assert that healthcare workers, just like patients, can be constructed as body singular by removal of ‘self’ from interactions in the context of assemblages and their associated habituated patterns. Unable to be disentangled from assemblages, healthcare workers are not immune from harms. As soon as an ‘other’ maps someone out a priori and reduces him or her to body singular they have stopped being affected and are thus deprived of the power to move and be moved. The effects of this are to lose one’s ability to be attentive and receptive to safety risks, to close down learning and rule out creative possibilities opening up for the collective body. I argue that to stop being affected in this way increases the likelihood of becoming-harms.

In sum, this section has shown that habitual care patterns expose not only dying patients and their families to harms but also those healthcare workers caring for them. I have shown that healthcare professionals as well as patients and families have safety needs. Further, the safety needs of patients and families are unable to be disentangled from the safety needs of healthcare workers. Policies and procedures, however, are focused towards the safety of patients and to organisational needs. I have demonstrated that unsafe care pertains not to individual patients and discrete episodes of their treatment and/or care but rather to multiple un-safeties involving interacting bodies[41] that produce unfolding harms. I argue that it is a misnomer to refer to safety matters simply as patient safety. Accordingly, from this point of the thesis forward, I refer to safety matters not as patient safety but as healthcare safeties and un-safeties. The final section of this chapter continues to explore these multiplicities of safety.

Section 6.4 Contradictions of Healthcare Safeties

Section 6.3 concludes that there are multiplicities of safety. These safeties or un-safeties often are in tension and collide when the safety concerns of healthcare workers and organisations are in opposition with those determined by patients and families,

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[41] Bodies emerging from the physical and social world inter-related with their surroundings and always becoming affecting and being affected (See Chapter 3).

especially when clinical technical safeties compete with interpersonal or social safeties. I refer to this problem as the 'contradictions of healthcare safeties.' It is to these contradictions that I now turn. I begin this section by introducing June.

Introducing June

> *I arrived on the respiratory ward. June was in the four-bed bay beside the window. She was sitting in her chair beside the bed. She 'wore' nasal prongs and was attached to oxygen. There were two young guys, perhaps in their twenty's, lying on the bed beside her. One of who turned out to be June's son. I introduced myself and June asked me to call her by her first name. As soon as I explained what I was doing June launched into her healthcare experiences (as was the case when I sat down at the bedside with most participants who were able to talk). She told me that her cancer was originally diagnosed more than 20 years ago. "You know, back in the days when they used cobalt". June told me, "Back then I didn't know that any of those things were available, cancer council, help and support with things". Then June told me several stories about her interactions with medical staff: "Doctors aren't always right you know", she exclaimed. "Then another time", she (June) goes on "A surgeon came up and said to me after the op; 'I have never seen such a mangled mess on the operating table'". I (June) said, "Excuse me; I am June Barrat, just as you are Professor (names professor). 'Oh, I'm sorry', he said to me". Then she (June) told me about when she was in hospital before Christmas, and that the respiratory specialist had sent her home without any 'back up'. "I (June) said to him, 'If you are sending me home on warfarin, then you better tell me how I am going to get more medication and followed up as no-one is open'. He gave me nothing and there was no back up. I didn't realise you could get oxygen at home. You see it was Christmas, and they just tried to get people out. And that's me after 20 years of having cancer. If I don't know the support that's available, then what about first timers who come in here. And you know Dr (names respiratory specialist) has come and apologised. He said, 'I am very sorry that happened to you'. I accepted his apology, but I told him, 'Do you realise what effect that had on me and on (names her son) for the few weeks after'". June's son interjected saying, "I rang the social worker to get some help and she told me, 'I can't help you now that she's (June's) not an inpatient', but she gave me numbers to call to get home care. And I had to phone around to get everything sorted".*

> *June continues; "There are so many mistakes you know. I see them all around me. You have to count your tablets. Make sure you have the right number, keep an eye on the oxygen. You see they come along and change things. These hospitals are making thousands of mistakes ... I see them, I see them all the time".*
>
> *When I told her about the filmed interview, and why I was using film, June responded, "Well I probably won't be here. They told me years ago that I was going to die". "But you're still here" I (researcher) interjected. I smile (by now appreciating June's feisty talk in the face of her adversity, and feeling a connection with her that I am unable to articulate) "Yes, they don't know really do they, they're not God" she (June) states. I respond with another wry smile. June responds, "They told (names son) again recently that they think I only have a few weeks to live". I (researcher) asked her, if she decided to take part, what would she want me to do with the footage when she died? She replied, "If it's going to help improve the health system, then just use it". I responded, "Well I can't promise you that, but I will use it to give a voice to your wisdom and insights.*

(View DVD)

For June, just like Joe and Tara, the camera provides a medium to communicate what she regards as healthcare safeties and un-safeties. Once again organisational processes for dealing with adverse events do not provide the means for un-safeties to be communicated and acted upon in terms of how they are defined by June. For June, un-safeties include medication errors, oxygen errors, and a lack of compassion, unplanned and unsafe discharge and focusing on her as 'disease' rather than 'person'. Importantly, June’s vignette conveys multiplicities of un-safeties. That is to say, footage highlights that what June regards as safe and unsafe, both for herself and other patients in her proximity, is not necessarily consistent with how safety is seen and enacted by healthcare workers.

The principal response to patient safety and eliminating risk has been to design systems according to evidence-based practice produced by scientific research such as scientifically validated policies, guidelines, and protocols to reduce uncertainty and minimise errors (Jerak-Zuiderent 2012). These attempts to eliminate risk are intrinsic to the hospital setting. For the dying person, however, these very policies can result in adverse events. The extract below reveals a situation where the protocol for treating an acute neurological condition and directed towards those for whom a cure is expected fails to meet the safety needs of a man who is dying:

> Extract 6.23 (EFN, specialist palliative care team weekly meeting, acute hospital, 28th March 2011).
>
> The registrar said, “The neurosurgical team told me we don’t send our patients home on benzodiazepines”. The palliative medicine staff specialist responded: “But this is a patient with a GBM (Glioblastoma multiforme – an aggressive type of brain tumour) who is dying”.

This extract shows how a treatment that poses a risk for someone with a head injury is a necessary treatment for the dying person. It characterises the paradoxical effects of safety when a blanket policy put in place by a specialty team to minimise risk for people with an acute neurological condition results in a possible adverse event for the dying person. The overriding of protocol for this particular patient was necessary for the prevention of further seizures and thus for his safety. In this case, it becomes necessary for the palliative care specialist, using her clinical expertise and judgement to contravene the safety protocol. That is to say, the breaching of guidelines is not always wrong and may actually protect the patient from harm (Rowley 2011). This extract demonstrates that for safety to happen, the doctor has to remain open and be prepared to improvise according to the specific safety needs of a patient.

In the acute hospital setting it was not uncommon for the safety needs of acutely ill patients to be incompatible with the safety needs of dying patients and their families. For example, in the haematology oncology ward, Joe’s safety need to have his grandchildren visit poses a risk to acutely ill haematology patients who are significantly immuno-compromised and thus at risk of acquiring a life-threatening infection. This is brought to light when Joe's specialist watches Joe and Tara's footage. Tara comments on film:

> Extract 6.24 (SSI (filmed), patient and daughter, acute hospital, 15th February, 2011).
>
> Tara: "Bit more relaxation when it comes to grandkids coming in."
>
> Joe: "Yeah". (Joe agrees)
>
> Tara: "Because when we were allowed to bring them in, that made his day and he was much more cooperative with the nurses and the doctors and everything. Because they have to understand, like I know this is their job (healthcare workers) and I know that there's a lot of infections and stuff but if the patient is willing to forgo that for their grandkids and their kids, they should be allowed to".

In response, the specialist promptly presses pause (as requested to do so if he wished to make a comment):

> Extract 6.25 (VRM #2, staff specialist (haematology), acute hospital, 24th August 2011).
>
> "That's (Tara's proposition to allow Joe's grandchildren to visit) not right. We have other patients. Actually I think that's quite selfish".

The specialist is immediately moved in response to footage. That is to say he responds angrily and with frustration. In making the assumption that Joe's daughter has access to the same knowledge of the needs of immuno-compromised patients as he does the specialist judges Joe's daughter as selfish. Joe's specialist is accountable for the treatment and care of both acutely ill patients and dying patients like Joe. He is left with little choice but to prioritise the needs of acutely ill patients. Later, having watched the full piece, and on reflection, the same specialist moderates his expression, reflexively taking account of the perspectives from Joe and Tara's position:

> Extract 6.26 (VRM #2, staff specialist (haematology), acute hospital, 24th August 2011).
>
> "Most of what he and his daughter are saying is so right. I think I often talk over people's heads. I try not to but I probably do. They're right about the white walls. It is very depressing and I think they should be able to bring their own things in. I'm not averse to that. The place isn't set up for people like Joe. He should be in a separate place where the palliative care service is looking after him, where we manage the care jointly".

For this specialist, footage makes tangible un-safeties previously unnoticed. In particular the doctor picks up on Joe and Tara's critique of the manner in which doctors have a tendency to talk in medical language that is difficult to understand and to communicate 'at them' rather than 'with them'. The specialist relates what Joe and Tara are saying directly to his own communication with patients. Further, the specialist makes reference to Joe's critique of his physical surroundings and the expressed need to bring in small artefacts that connect Joe with home. Overall the doctor concludes that the oncology haematology ward does not meet Joe and Tara's needs.

Critically, as a result of engaging with footage in this way, the haematology specialist makes a significant proposition. The footage opens him up to being moved and makes visible Joe and Tara's articulation of un-safeties. This allows the specialist to be open to alternative and creative possibilities. Not only does he consider the need for a more suitable physical environment for people like Joe, but suggests the need for a shared care arrangement between Haematology and Specialist Palliative Care Specialists. The specialist's relationship with Joe is typical of the often very long relationships that develop between haematologists and their patients (Manitta, Philip & Cole-Sinclair 2010). Other haematology specialists conveyed to me in their video reflexive meeting the significant complexities involved in the care of patients like Joe, including difficulty in prognostication and the uncertainty of reversibility of recurrent events such as infection including rapid deterioration to death. The response of Joe's specialist is particularly significant since people with a diagnosis of haematological malignancy are more than twice as likely to die in hospital as those with other cancer diagnoses (Howell et al. 2010). Importantly, in this case, footage enabled the specialist to 'see' safety contradictions and thus to consider possible strategies to negotiate them.

The conflicting care goals of acutely ill patients and dying patients also posed significant challenges for nurses on the oncology haematology ward. Nurses were frequently faced with, what appears to be, competing safeties. The next extract shows again how contested safeties arise:

> Extract 6.27 (SSI, acting nurse unit manager, acute hospital, 21st March 2011).
>
> "I (nurse unit manager) know it sounds really horrible but someone (patient) that's dying does not have a clinical preference over someone (patient) that has an infection or is clinically unwell. So that can be difficult, so they (dying patients) kind of get pushed back a little bit. We do try to give patients single rooms as much as we can but sometimes it's just impossible".

The safety needs of dying patients are regarded as secondary to the safety needs of those for whom a 'cure' is expected and in particular to minimising the risk of hospital-acquired infection. The nurse is forced into making decisions about competing safeties. Responding to multiple safeties requires healthcare workers to negotiate and renegotiate with others what safety means and what is required to produce safety at any particular time for particular patients and in context of the kind of care goals I have described above. In the extract that follows a group of oncologists in the acute hospital participate in these safety negotiations debating an end of life decision:

> Extract 6.28 (EFN, weekly clinical meeting (Medical Oncology), acute hospital, 25th March 2011).
>
> Doctor 1: "It's not an oncology issue really".
>
> Doctor 2: "He's not suitable for METs (medical emergency team call) or ICU".
>
> Doctor 1: "We'll manage him conservatively".
>
> Doctor 3: "So we're saying not for ICU"?
>
> Doctor 1: "No, I'm not really, it depends on reversibility".

When there is uncertainty over whether or not a patient should be actively resuscitated, highlighted in the above account, safeties are not fixed or dependent on scientifically-validated protocols but, rather, are contingent on emergent and affective clinical judgements. That is to say safeties rely, to a large extent, on the oncologists drawing from their experience in dialogue with each other localising their concerns in context of a specific situation (Jerak-Zuiderent 2012). In doing so they try to determine whether or not the patient's deterioration is reversible or not and decide whether or not to accept that the patient is dying. In the liminal space between life and death, goals of care are continually negotiated and re-negotiated and decision-making is complex (Anspach 1987; Cassell 2003; Iedema et al. 2005; Iedema et al. 2004; Seymour 1999).

Contradictions of patient safeties in the palliative care day hospital

The palliative care day hospital was also a place in flux where safeties were continually negotiated and re-negotiated. Safeties accounted for by the hospital governance structures were sometimes in opposition with the safeties of individual day hospital patients. The next extract from an interview with a specialist shows how infection control protocols put in place to prevent the spread of antibiotic resistant infections dictate that patients, known to be carriers of these organisms, are not permitted entry to the palliative care day hospital:

> Extract 6.29 (SSI, staff specialist (palliative care), palliative care day Hospital, 22nd July 2010).
>
> "We've had a big problem with a lot of multi-resistant organisms, meaning that people can't come to the day hospital. So they can be referred and often during the first consultation, that's when we realise there's a problem. So they've just come for the first time and loved it and we have to say, 'You can't come anymore'. And one service we've provided those people so they don't feel abandoned is to provide a sort of outpatients where they can come as often as they need to, to know that there's still somebody supporting them".

The palliative care day hospital is a place that defines itself as providing a safe space. Even in the palliative care day hospital, however, safeties are never fully determined. Infection control measures put in place for the safety of the majority of patients means that some patients are unable to access the safe space of the palliative care day hospital. However, the safety of infected patients is threatened by denying them access to the therapeutic environment of the palliative care day hospital. There is potential for harm to patients, families and healthcare workers as a result of possible spread of antibiotic resistant bacteria as well as potential harm to patients, who as carriers, are told they cannot attend. This demonstrates how safeties are often in tension and there is always a potential for harm. Rather than closing off to becoming-harms however, the palliative care day hospital healthcare workers remain open to creative and temporary solutions for patients infected with antibiotic resistant bacteria such as MRSA and unable to attend the palliative care day hospital.

I have demonstrated in this section that safeties and un-safeties are in continual flux and never fully determined. I have used this section to show that healthcare workers are required to juggle these safeties. This section reveals that safeties become possible and aligned when healthcare workers are open to improvisation and are attentive to the context of a specific situation.

Section 6.5 Conclusion

Patient safety is currently seen as a state brought into being by individual clinicians and hospital systems to limit the risk of adverse events. This chapter challenges this approach to patient safety in several ways. I have established that safety according to patients, families and healthcare workers is unable to be isolated as a ‘state’ of clinical technical safety, and rather encompasses the constant unfolding and enactment of interpersonal and social safeties. The safety needs of dying patients and families need to be redefined to take account of how they themselves define safeties and un-safeties.

There is also a widely held assumption that dying patients are not vulnerable to harm and that because they are dying, safe practices become less relevant to them. This chapter refutes these assumptions. To the contrary, patients continue to be concerned with staying as well as possible even when they are dying. Further, I have described what I term ‘normalised inattentiveness to patient safety.’ In other words, dying patients and their families as well as the healthcare workers caring for them are exposed to habitual patterns of harm and adverse events. Rules, regulations and protocols put in place to prevent isolated technical incidents do not necessarily prevent harm and can have unintended consequences, including un-safeties, if applied unattentively and unaffectively.

I have shown how habitual patterns of un-safeties are associated with healthcare workers’ learning-not-to be-affected. Importantly healthcare workers as well as patients articulate a need for safety. They too are exposed to becoming-harms. Importantly, these safety needs are not accounted for by the organisations they are a part of on their terms. I propose that for patients to be safe, the safety of healthcare workers needs to be addressed more fully.

Finally, safeties and harms are never fully determined. Protocols and policies rely on static, fixed and generalised circumstances yet safeties are multiple, dynamic and contested. Clinical technical safeties end up competing with social and interpersonal safeties when, in fact, they are inextricably linked. This means that healthcare workers are forced to make safety compromises. In other words, addressing the safety of one patient and their family may mean compromising the safety of others. When healthcare workers are aware and open to this juggling, however, they are able to attend to safeties contextually and dynamically according to the safety needs of specific patients and particular circumstances.

I have shown in this chapter that patients view themselves as active participants in their care and may even participate in safeties. In order to analyse further how safeties are brought into being in Chapter 8, I must first investigate more closely how patients and families participate in their own safety and how healthcare workers respond to them when they do. The following empirical chapter, (Chapter 7) extends the arguments of this chapter by examining the place of patients and families in bringing safeties into being.

Chapter 7 Finding Patients and Families in Patient Safety

Section 7.1 Introduction

This chapter explores the ways in which patients and families participate in safeties and un-safeties. I have shown that patients, even though dying, are not passive recipients of their care. In this chapter, I analyse the active engagement of patients and families in safeties and/or un-safeties in greater depth. This chapter is structured in two sections: Section 7.2, ‘Patient and Family Expertise?’ explores the role of patients and families in producing safety. I bring to light the knowledge, expertise and agency of patients and families in healthcare safeties and how healthcare workers, to a large extent, do not recognise this expertise and how to take it into account. Section 7.3, titled ‘The safety work of patients and families’ extends Section 7.2. In this section, I explore further the kind of resources and strategies used by patients and families to stay safe. I discuss what healthcare workers can do, in response, in order to improve safety. This foreshadows my in-depth discussion of how healthcare settings can be made safer for dying patients and their families in the next chapter (Chapter 8).

Section 7.2 Patient and Family Expertise?

I pose the title of this section as a question to acknowledge the critical debate that the notion of ‘expert’ patient has raised among scholars (Fox, Ward & O'Rourke 2005). Patient choice and autonomy have become the dominant approach to healthcare in order to overcome the paternalism of the traditional doctor patient relationship where the doctor knows best and the patient complies (Calne, Calne & Calne 2009). Mol (2008, p7) refers to this approach as the “logic of choice”. The idea of patient expertise has established itself in health policy within the context of the ‘logic of choice’. The notion of patient expertise in this context is one of enabling patients to manage their own illness to maintain health (Shaw & Baker 2004).

This view is crystallised in notions like ‘self-management’ and ‘self-directed care’. This view of patients as able to manage their own care is open to critique. For example, Wilson (2001) has argued that patient expertise assumes compliance with taking control of one’s health and thus merely serves to further the Foucauldian medical gaze I discussed in Chapter 2. Additionally, and as I have already argued, the notion of patients as self-managers of care charges patients with staying well. Thus, self-care, framed in this way, does not give recognition to patients who are dying (Price & Cheek 2007). Moreover, framing patients as ‘experts’ does not necessarily translate into the acceptance of their expertise by healthcare workers who to a large extent seek to hold onto power (Henwood et al. 2003). Further, patients do not necessarily wish to take on the role of expert (Fox, Ward & O'Rourke 2005).

In this chapter I propose to extend the work that critiques patients’ capacity as experts. I do so by problematising the concept of expert patient and the dominant approach of patient choice in the context of end-of-life care. Patients and families enact expertise towards the end of life and are actively engaged in safety work. I show that for patients and families, safety work is not a simple task nor is it enacted in isolation from their social networks and surroundings. I begin by introducing Shane.

Introducing Shane

> *I met Shane for the first time in hospital. He was in the cardiothoracic ward. I found him in a single room, in one of the new hospital wards. There was a note on the door requesting that visitors consult with a nurse before entering. I took this as a signal that Shane was in a single room as an infection control measure. I approached an RN who very politely told me that I could visit Shane but that I would need to dress in the appropriate clothing i.e. gown and gloves. I observed the request, and dressed in the appropriate attire and knocked on the door. I found the gown and gloves uncomfortable. Not only were they extremely hot, I found them altering of my identity into someone very clinical. I found it awkward to shake Shane’s hand with hospital gloves on, as though it was positioning him as ‘untouchable’. However, he didn’t seem to mind and invited me to sit down.*
>
> *I explained who I was and why I was there. As was often the case, Shane started to tell me some of his stories there and then. Rather than seeing himself ‘shut off’ from the rest of the ward, Shane expressed that he was fortunate to require a single room. Here he could do his own thing. “I have my music player and I have made myself comfortable”, he told me. I told him more about the project and what was required. He asked what would happen to the footage and what it would be used for. I answered his questions as openly as I could. Shane told me that he hoped to get home in*

> *the next few days and that he had a preference to be interviewed there. He asked me to call him the following week once he'd had a chance to settle in at home.*

(View DVD)

Shane positions himself as a central member of the healthcare team even if healthcare workers do not always see it that way. His visual narrative demonstrates a view of himself as an active participant in his treatment and care. He regards this positioning as critical to his safety. His story shows that even in the final months and weeks of life, it is possible for people to evaluate what is safe and what is not. Even when patients are acutely ill, elderly, 'vulnerable', and dying, they are not disconnected from their life experiences, wisdoms and social networks as the following extract highlights:

> Extract 7.1 (FI, patient, acute hospital, 14th November 2010).
>
> She (patient) told me (researcher) that she had told 'them' (the medical team) "Look, I don't want any of that chemotherapy stuff (non-verbally she (patient) indicates having drips and tubes). You're not going to do any of that to me unless I decide and after I talk with my family. I just want to go peacefully and with some dignity. This is about ME and MY body and I'm going to discuss this with my family." It struck me (researcher) that she (patient) had agency to

> make decisions and I asked her why she thought she was able to speak up. She talked of her early years as an eighteen-year-old and indicated that her personality was such that she had always made decisions independently. In particular, she mentioned her role in the army during the war.

This patient draws on past experiences and current resources and the support of her family to retain agency over her life and death. She does not position herself as a passive subject at the mercy of the healthcare team. Filtered through a biomedical lens, her body may be reduced to set of organs (Brown & Webster 2004), one or more of which have come under the attack of cancer requiring chemotherapy. However, this patient is explicit in claiming her body as her own and as being made up of more than a collection of organs. She actively determines what happens to her body with the assistance of others. Thus, even in the final days and weeks of life creativity is a possibility.

Patients are frequently attuned to changes in their own bodies. Yet, this attuning often goes unrecognised and is undervalued. I offer Amy’s story to demonstrate how patient expertise often goes unheard. Healthcare workers do not account for Amy’s expertise of her own body, resulting in harms. The doctor’s account of what happens in Extract 7.2 provides the context to Amy’s narrative in Extract 7.3 and 7.4:

> Extract 7.2 (FI, staff specialist (palliative care), acute hospital 10th January 2011).
>
> As the staff specialist (Palliative Care) relays it to me (researcher), Amy had a palliative operation for a bowel fistula secondary to metastatic ovarian cancer three weeks ago in a private hospital. She (Amy) has been readmitted to ICU following a second operation for the same reason. After the first operation, Amy tried to explain to the healthcare workers looking after her that she was still passing faeces and that there was nothing in her colostomy bag. This went on for five days. The staff specialist exclaims, “No one, not even the nursing staff had examined her during that time. Instead they tried to reassure her that a small amount of discharge was to be expected and that everything would settle down. Eventually, Amy was operated on for a second time”.

This account shows how Amy’s reports of her own body and symptoms are largely ignored by the nursing staff following the first surgery. In essence, evidence of the surgical procedure is considered more authoritative than Amy’s self-reported evidence. Not having her expertise acknowledged and accounted for is not new to Amy. When I meet her for the first time, she conveys the extent of her anger in this regard:

> Extract 7.3 (FI, patient, acute hospital, 10th January 2011).
>
> “Isn’t it a solicitor I need to do this”, Amy responds angrily. I (researcher) briefly explain again the purpose of the research. Again, she expresses in an angry tone “Document my experiences, isn’t that a solicitor’s job? You should have been here five weeks ago”, she exclaims, “Seeing me in excruciating pain; doctors who won’t listen to you and speak to me as though I am an idiot; nurses who don’t believe you are in pain, when you are sitting in excruciating pain”. She breaks down in tears.

Amy’s reports of pain, continued passing of faeces and empty colostomy bag are invalidated until they become severe, necessitating a second operation. Amy expresses anger, as she relays how her pain is not taken seriously and left untreated. Amy’s articulations of her body are not considered reliable or valid. Her expertise is disregarded and her safety becomes significantly compromised as a result. She is exposed to unmanaged pain, other symptoms and is significantly distressed. Amy constructs her care in terms of harmful and unremitting adverse events that for her justify legislative action. However, her care is not considered or defined in these terms by the professional team or healthcare organisation caring for her.

The next extract traces Amy’s story back to just prior to the first operation. Amy chooses not to have a CT scan and the surgeon accepts this choice. Amy has an ultrasound scan rather than a CT scan. As a result of this decision the higher fistula is missed. Subsequently Amy has an operation to palliate the symptoms of the fistulae. Higher fistulae are missed requiring the second operation. I return to the specialist’s narrative from my field-notes concerning Amy:

> Extract 7.4 (FI, staff specialist (palliative care), acute hospital, 10th January 2011).
>
> Amy has been seeing a Chinese medicine doctor. His advice to her was to avoid having CT scans. Amy had clinical symptoms indicating malignant fistulae. Her surgeon respected her choice not to have a CT scan with contrast (optimal pre-surgical planning) and made a clinical assessment based on ultrasound. Amy proceeded to surgery on the basis of fistulae located with the aid of the ultrasound. The ultrasound did not locate the higher fistulae (as a CT scan would have done) resulting in continued symptoms significantly affecting Amy's quality of life and eventually her requirement of a second surgical procedure.

Of most importance to Amy was not the right to decide for herself but attentiveness to making her day-to-day life as liveable as possible without disregarding her own expertise. It is overly simplistic to suggest that patient and/or family expertise in isolation leads to patient safety or, as the palliative care specialist implies (Extract 7.4), that patient choice leads to unsafety.

Taking account of Amy's expertise did not mean taking account of her decision not to have a CT scan. Instead, it meant attuning to Amy, taking the reports of her body and symptoms seriously and drawing from medical expertise to relieve these symptoms. Without this combined expertise, Amy instead, endures a protracted period of unrelieved symptoms. As would Mol, I contend that Amy's care is contingent on democratisation of expertise reconfiguring the subject as affectively connected with others and not discretely separate from the 'other'. This requires an alliance whereby Amy and those caring for her continually "experiment, tinker and attune together" in order to cultivate safeties (Mol 2008, p56). This would have meant Amy's symptoms were addressed and acted upon in a timely manner to maximise her quality of life and minimise time spent in hospital for whatever time Amy had left to live.

Patient choice, instead of producing patient safety, leads to adverse events detrimental to Amy's safety. Critically, Amy spoke not of the fact that she had or had not been given choices but rather of neglect of those caring for her (Mol 2008). Critical to my argument is that taking account of patient and/or family expertise is not synonymous with taking account of patient autonomy and choice.

Thus, patient expertise alone does not necessarily produce safety. Further, when patients are forced to take safety into their own hands, risks to safety can occur. For example, Joe, with the assistance of his daughter, resorts to keeping extra supplies of opiate pain-killers (in the biscuit tin), brought in from home for self-administration when his need for adequate pain control goes unmet. The actual amount of opiate medicine he takes therefore becomes unclear, placing him at risk of the effects of overdosing or under-dosing. Yet, Joe is left with no choice but to take charge of his own analgesic requirements. Joe and Tara's actions were necessary to compensate for the un-safety created by the lack of responsiveness of healthcare workers to his pain.

As part of a kind of all-or-nothing game patients are, for the most part, expected to devolve their expertise to healthcare workers, even when expertise is framed as enabling patients to manage their own illness to maintain health (Shaw & Baker 2004). Sometimes patients develop significant expertise in managing their chronic health conditions. In the next extract a patient relays how this expertise is unaccounted for when he is hospitalised:

> Extract 7.5 (FI, patient, acute hospital, 12th January 2011).
>
> "I manage my own insulin at home. It is very frightening when you have a hypo and you wake up and there are five people around you. I have control over my insulin and alter the dose according to what I need, but in here they can only give me what the doctor has written on the chart and when I tell them that's not the right dose, they tell me that's what we have to give you because that's what's written on the chart; they have control. Well that's fine if they give me the correct dose but when I wake up in the middle of the night and I am having a hypo, it's very frightening. You know, I have discharged myself several times from here. They have told me that I wouldn't be able to do that if I have the stem cell transplant because there is a risk that that would kill me. Then I have to take a drug before my meals, and they never know when the meal is going to come, so I never get it at the right time and they give me into trouble if I keep it myself, because they want to be in control of everything".

This extract shows how a patient is expected to hand over management of his medication to doctors and nurses when in hospital. He is expected to place his trust in those caring for him to administer the correct dose of insulin. Under these circumstances patients are forced to defer to the healthcare professional who has command of decision-making (Fox 1999). When trust is broken, however, this patient takes matters into his own hands, storing medication himself and discharging himself from hospital. This makes him unpopular, a phenomenon described in the seminal report; *'The Unpopular Patient'* (Stockwell 1972). Further, he is threatened that his behaviour may have implications for his future treatment. In other words, doing safety comes at a cost. Not only is his expertise unaccounted for; he is chastised for applying it. Despite the rhetoric of informed consent and patient choice in healthcare, healthcare workers frequently strive to retain power in their engagements with patients (Fox, Ward & O'Rourke 2005).

As self-managers of care, patients are charged with staying well (Price & Cheek 2007). On the one hand, patients are expected to comply with medical interventions and are often blamed when treatment is unsuccessful and yet on the other hand, doctors want to retain control. In the next extract, two specialist chronic care management nurses articulate their frustrations about this paradox:

> Extract 7.6 (FI, specialist RNs (respiratory and cardiology), acute hospital, 19th January 2011).
>
> “We (specialist cardiac nurses) get frustrated when they (specialists) say ‘Oh the patient is admitted again because they’re non-compliant’. No! It’s because they (patients) have a deteriorating cardiac disease, that’s why they’re unwell. We know the patients. We see them at home and in their own clothes. They (patients) know what they’re doing. They do their fluid restriction and take their tablets. They don’t take their tablets when they’re not feeling well. They (specialists) wouldn’t take their tablets if they weren’t feeling well either. Sometimes, yes, it’s that they’re just not taking them, but most of the time it’s just that they are unwell”.

When a person is unresponsive to treatment or when complications arise that require someone who is chronically ill to be readmitted to the acute hospital, blame for the readmission is often placed with the patient as a result of their ‘non-compliance’, as above. The nurses in the above account critique this use of medical language. They contrast the medical view of patients as bodies that don’t comply with prescribed treatment with their own view of patients as people with home lives doing the best they can to stay well. This kind of language norm, an accepted component of clinical technical assemblages, assigns agency to the patient when interventions fail. I suggest that through these language norms the body, constructed as ‘body singular’, or a body made up with ‘a set of organs’ is one that is required to comply with medical treatment. Fuks (2011) has pointed out that the power of medical words and language norms can serve to harm or to heal evidenced by nocebo[42] effects. Thus, I argue that such language serves to deny the significant expertise of patients undermining the relationships between healthcare workers and patients. The significance of nocebo effects resulting from medical language are not recognised in everyday care providing further evidence of ‘normalised inattentiveness to patient safety’.

The nurses in the above account verbally articulate their critique of negative medical language and critique the behaviour of the cardiologists. They espouse values of patient-centred care and recognition of the ‘body multiple’. Yet, the evidence I have provided in Chapter 6 and so far in this chapter suggests that this does not necessarily translate into attention to real patients and specific situations when it matters. Sometimes this is directly articulated by nurses evidenced by the nurses’ account of safety and their expressed lack of agency in Extract 6.12 (Chapter 6). At other times it is symbolised in terms of ‘being too busy’ or not legitimising patients’ pain and/or other symptoms or other concerns. Here, my findings resonate with those of Wicks (1999) who discovered that nurses’ can have insight into their own marginalised position but can also repress this marginalisation.

Further, when patients are dying, expertise is not only disease or treatment related but takes in all that encompasses what is important to a person in their social context and in the context of knowledge about their illness. This expertise is inaccessible to healthcare workers but can still be met with their resistance when end-of-life decisions are made. The palliative care doctor in the next extract discusses a patient’s decision not to have a bone marrow transplant:

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[42] *“The nocebo effect is a phenomenon that is opposite to the placebo effect, whereby expectation of a negative outcome may lead to the worsening of a symptom” (Benedetti, Lanotte & Lopiano 2007, p260).*

> Extract 7.7 (FI, staff specialist (palliative care), acute hospital, 12th January 2011).
>
> "He (patient) has decided not to have the transplant and he is happy with the decision but the Haematologists are not. He (patient) said to me (palliative medicine doctor), 'I am going to die whether or not I have the transplant, and I just wanted to spend whatever time I have left with my mother. If I have the transplant, I will get sick and my blood sugars will be all over the place'".

This patient applies his own expertise to weigh up whether to have a stem cell transplant. He makes a significant end-of-life decision drawing from his past experiences, knowledge of his own body and disease processes as well as his desire and hopefulness for a future that means he can spend whatever time he has left with his mother.[43] His specialists, however, have difficulty with this decision and position him as a deviant patient, and one who does not conform to medical expertise. As their care shows, despite the rhetoric of patient choice, healthcare workers may have trouble with collaborative decision-making. The following extract traces the sources of some of these difficulties. For instance, haematologists, taking part in a group reflexive meeting, expressed their difficulties in talking to patients about changes from curative to palliative goals of care:

> Extract 7.8 (VRM #1 (haematology team), 19th October 2011).
>
> Doctor 1: "I do find it difficult, I find it difficult to have conversations about stopping treatment, especially when it's borderline".
>
> Doctor 2: "You need to have these sorts of discussions with the patient, in collaboration with the patient".
>
> Doctor 1: "Yes, but what do I do when the patient says, 'You decide, you are the doctor'".

Doctors in this group reflexive meeting express their feelings of uncertainty around decision-making, particularly with regard to stopping anticancer treatments. This extract also demonstrates that not all patients want to collaborate in the decision-making process, preferring instead to refer decisions to the doctor. Other doctors also expressed

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[43] See also Extract 7.24 (Section 2).

difficulty in taking account of patient expertise in collaboration with patients, especially when the decisions pertain to end-of-life care as this palliative care doctor suggests:

> Extract 7.9 (SSI, staff specialist (palliative care), palliative care day hospital, 4th May 2010).
>
> "Well I think most areas of medicine, the doctor decides what he thinks is the best treatment and they tell the patient what they think they should have, and informed consent just means that you agree to do what the doctor wants to do. And it's hard when a patient decides to reject a life-prolonging treatment, as a doctor. But you need to have a very strong belief in patient autonomy to say, 'That's ok. You're not doing what I think is best, but I'll support you anyway'. That's just what I've observed. There are individuals who do things differently, but I think most people aren't happy to let a patient knock back a treatment they really think is best for them. And most patients tend to just go along with what a doctor recommends".

The palliative care doctor in this extract points out that doctors find it difficult when patients decline life-prolonging treatment. This extract again highlights the rhetoric of patient choice and autonomy. Although she claims to support patient choice and autonomy within her own practice, this doctor expresses that most specialists are reluctant to let patients decline treatments. The doctor quoted above suggests, 'Most patients tend to just go along with what a doctor recommends'. As this chapter will go on to show however, this belief is problematic.

The very research process itself extended patient expertise to include expertise about healthcare communication and processes, the healthcare care environment and patient safety. In the same way that the research process made this expertise visible on the part of the patient, it also demonstrated how patient expertise was dismissed. In the following extract from a telephone discussion with a respiratory specialist, a patient is denied recognition of his expertise:

> Extract 7.10 (PC, staff specialist (respiratory), acute hospital, 19th April 2011).
>
> "I (doctor) do know the patient you are talking about. Unfortunately he (patient) was delirious at the time and didn't know what he was

> talking about and he didn't know which doctor was which, so I'm not sure how scientifically rigorous it (the research interview with the patient) would be. I read your email and I'm just not sure how rigorous it would be. It's not objective and so I'm not sure how useful it (taking part in the research) would be. How long would it (the research interview) take? An hour? No, I couldn't afford a whole hour. I have so many commitments I just couldn't fit that in. He's (patient) probably marked me out as I was involved early in his care and he did get very confused".

This extract shows a doctor arguing that she is unable to trust a patient's claims and assertions. Here the doctor, by positioning a patient as mentally unreliable, reconstructs this participant's research account as invalid. She makes a clear differentiation between the patient's internal abnormal psyche and external 'clinical realities'. The doctor, placing herself squarely in the realm of scientific rigour, imagines truth as existing only for those who are able to separate themselves from the world and produce knowledge from the point of *"View from Nowhere"* (Nagel 1986). In my interpretation, the doctor becomes defensive and avoids confronting the footage by positioning the patient's account as well as the research as invalid. This suggests that some doctors are not used to being questioned, may be fearful of what patients have to say about them and do not know how to deal with being shown their patients' accounts about the outcomes of their care. On several occasions, I came across similar displays of defensiveness by doctors at group reflexive meetings. For example, when I showed footage to the acute hospital community at a grand rounds event, one specialist put the following to me:

> Extract 7.11 (VRM #3, staff specialist, (respiratory), grand rounds, acute hospital, 28th March 2011).
>
> "It is clear that you have chosen footage with the intention of making us emotional. These are clearly just a minority of patients with a grievance. In my experience, most patients are satisfied with their care".

For this grand rounds presentation, I had compiled vignettes that I considered to be locally relevant. Footage represented patients from a variety of the hospital's specialties and was representative of common themes incorporating feedback from small group video reflexive meetings. The respiratory staff specialist who spoke up in response to my presentation speculated that my choice of visual data was deliberately designed to make the audience emotional, using specific vignettes that represent outlier experiences. He invalidated patient and families' video accounts as non-truths. Thus, he argued that footage has nothing valid to say about patient safety.

Other instances of where doctors discounted patients' knowledge and expertise were revealed during video reflexive meetings. The following extract is from a video reflexive discussion with the haematology team:

> Extract 7.12 (VRM #3, haematology team, acute hospital, 19th October 2011).
>
> "I (staff specialist, Haematology) wonder how much of what he (Joe) is saying is just that he is depressed! It is hard to get psychiatric consults. I mean he probably said all of that because you (researcher) were asking him those specific questions".

This doctor in a group video reflexive meeting dismisses Joe's assertions on the assumption that he is depressed. Further, Joe's comments about the built environment and colour of the walls are considered a further indicator of his distorted perceptions given the hospital ward is brand new. Whether or not Joe is depressed however, his expertise as a painter/decorator of many years is discounted. Joe is, according to the doctor, unable to access the reality of the situation as determined by rational others; namely the healthcare team.

Doctors' disregard for participant accounts was made evident in other ways. For instance, it was common in both small group and larger forums for doctors to discount elements of patient and family talk that pertained to interpersonal encounters and focus instead on organisational aspects. For instance, in the next extract, the doctor focuses on the issue of mixed gender wards as being one that is beyond his remit and the responsibility of hospital executives and government to fix:

> Extract 7.13 (VRM #3, grand rounds, acute hospital, 28th March 2011).
>
> "You need to show this to the general manager and to politicians. I mean we have been trying to tell them about the issue of mixed wards for a long time but it never changes".

In larger group meetings, it was common for doctors, such as the one quoted in the extract above, to filter out issues that directly relate to care at the bedside. That is to say, the focus of their comments was on issues that defined 'system matters' as being outside of their responsibility and agency. In other words, healthcare workers would sometimes avoid taking responsibility for patient safety by regarding patients' accounts as the responsibility of 'the system'. Prominent reports such as *"To Err is Human: Building a Safer Health System"* argue that adverse events originate in systems and therefore error should be seen as system failure (Commitee on the Quality of Health Care in America 2000). The focus of the patient safety movement has been to develop safe healthcare systems. However, a problem with this focus on systems is that it can promote artificial distinctions between 'the system' and the people, the artefacts, and their interrelations that constitute and enact the system (Hor et al. 2013). I argue that it is only by addressing the safety of people in relation to these artefacts and their inter-relations that healthcare safeties become possible and that includes health care workers taking an active role in responding to patients' concerns and preferences, without relegating such response to others.

In sum, this section has shown that patients and families have expertise that, to a large extent, is not valued by healthcare workers. Doctors can distance themselves from being affected by challenging patients' insights and views on the strength of their claimed adherence to science. Nurses can also discount patients' views and experiences on the strength of a similar distancing but symbolised differently. Other research also found that healthcare professionals have a tendency to dismiss efforts by patients to theorise and explain their illness (Henwood et al. 2003; Iedema et al. 2012; Thorne, Ternulf Nyhlin & Paterson 2000). As I go on to argue, however, to conceptualise doctors and/or nurses, as an undifferentiated collection of passive beings does not take account of the creativity and dynamic features of assemblages. In the next section of this chapter I illuminate further how patients and families use their expertise and articulate their needs despite their frequent dismissal. I describe how patients are actively involved in safety work contrary to what healthcare workers believe.

Section 7.3 The Safety Work of Patients and Families

This section builds on Section 7.2 by investigating how patients and families actively participate in care to help produce safeties. I examine the various approaches that patients use to work out if they are safe. Further, I consider what resources and strategies patients apply to increase the likelihood of their own safety before discussing the specific contribution of family members to patient safety. This foreshadows my discussion of what healthcare workers do in response to the safety work carried out by patients and families. In so doing, I begin to address how healthcare settings can improve safety. I begin this section by introducing Gloria.

Introducing Gloria

> *I found my way to another of the brand new hospital wards. This time I visited the renal ward. I found Gloria in a single room. The window overlooked the school and local park. The room was large and spacious with its own toilet and shower room. Gloria sat in a recliner chair beside the bed with her legs resting on a footstool. She was dressed in a hospital gown. I sensed her authority as I walked into the room and introduced myself. Perhaps Gloria picked this up in me, wasting little time in telling me she was a bit of a 'trouble maker', smiling wryly. I asked her permission to sit down beside her and she invited me to do so. I explained who I was and why I was there. Gloria, as well as telling me about herself asked me about myself: Where was I from? Was I married? I took an immediate liking to her as we chatted. She asked me some questions about the project and what was expected of her. I took time to answer her questions. "Yes, ok, let's get on with it now", she exclaimed. Her immediate consent was unusual and I was slightly taken aback. It concerned me: did Gloria fully understand what I proposed? Should I agree to her request to "Let's get on with it now"?*
>
> *I put it to Gloria that perhaps this was something she might wish to think about and discuss with her family first. However, Gloria was adamant, almost slightly offended that I should suggest she needed anyone else's 'permission' to make such a decision. Given her request to set up the camera there and then, I suggested to her that, out of courtesy, I notify the nursing team. The RN informed me that it would soon be lunchtime and requested that I return after lunch. When I returned to Gloria's room the meal tray had arrived. I suggested to Gloria, I return later. She looked at me intently and asked me what time it was? "You be back here in an hour", she asserted. "Don't forget now, an hour".*

(View DVD)

Gloria creatively enacts a number of strategies in order to meet her safety needs. First, she draws on her life experiences. For example, she tells me she has been an organiser at the catholic club and city mission and has always been someone who speaks up for herself. Second, she utilises the resources of her niece, a midwife, to facilitate understanding and as a translator of jargon. Gloria affectively senses who, as part of the healthcare team, is trustworthy. She actively seeks to 'fit in' by abiding with organisational rules and by taking on what she describes as a 'medical personality'. This she sees as a means to voicing her concerns and the differences of opinion she encounters with the healthcare team. However, this is not a straightforward task for Gloria, clearly referring to previous experiences of being regarded as 'a difficult patient'; she suggests that the voicing of differences in this way comes with the risk of being labeled 'unpopular'.

Patients and families judge situations to be safe (or unsafe) when a number of social and material factors coalesce, rather than when a single specific protocol is enacted or a single technological resource is deftly applied. Patients and families observe and sense what is going on around them. They watch how healthcare workers interact with other patients and colleagues working out whom they can trust. Mary, a palliative care day hospital attendee, was admitted to the in-patient palliative care unit for a blood transfusion. As well as observing the physical environment and its impact on care, she makes her assessment by watching the manner in which care is delivered to those around her, especially patients she knows from the palliative care day hospital. In particular, she evaluates the quality of the care delivered to the patient in the bed opposite:

> Extract 7.15 (FI, patient, palliative care day hospital, 12th August 2010).
>
> “Well, it just looks different. Like in my four-bedded bay, there’s me and Brenda opposite and another Indian lady and Robyn in the corner, but there’s a sun-room, and Robyn’s family can use that” (Mary is aware that Robyn is dying). Then she (patient Mary) spoke about the lady (patient opposite), “They try to feed her and her daughter brought her in some Indian food. They come to clean the teeth of everyone who can’t eat regularly, but I noticed that when they came in the evening to her, she had all the food still in her mouth”.

Mary is attuned not only to how Robyn and her family are cared for, but also to the physical environment available to them. Furthermore, she evaluates her own safety, based not only on the individual interactions she has with healthcare workers, but also by the manner in which care is delivered to other patients in her proximity. When patients and families are in a care environment, they are not confronted by a discrete set of separate one-on-one interactions. Instead, they are part of a milieu comprising multiple bodies interacting, affecting and being affected by one another. Like Mary, as with June in the previous chapter, patients see and pick up on what is going on around them. I recall June’s words here: ‘I watch everything, everything that’s going on and I see it’. June, like Mary, assesses the quality and safety of care provided to those around her. Despite being unwell, they are both affectively attuned to their surroundings and the safety gradients they embody.

The premise of current approaches to healthcare is that patients, families and healthcare workers are autonomous individuals (Mol 2008). However autonomy is predicated on self-determination whereby one has the capacity to make reasoned decisions without interference from others, and then only when there is mental capacity to do so. This premise assumes the position of a ‘body singular’, a clearly bounded individual in which decision-making occurs in isolation from social networks, social context, and the bodily condition (Mol 2008). This is in contrast to the view advocated here, regarding decisions as made in the flux of assemblages (‘agencements’; or weaves of agency and commitment). This is to say that both Mary and June are a part of a collective subjectivity that exceeds the boundaries of one-on-one patient/healthcare worker encounters. Picking up the argument I started in the previous chapter, this means that simply eliminating discrete technical errors cannot prevent harm and produce safeties. Instead, the state of assemblages is what determines whether harms or safeties come into being. Importantly, Mary and June play an important role in the collective body. They are not separate from it. I discuss the characteristics of assemblages and what healthcare workers can do to contribute to the collective body and help produce safety more fully in the next chapter. First, I consider the place of non-human elements of assemblages or the collective body considered by patients as part of their evaluations of whether they are safe or not. In the next extract a patient describes how she decides if she is safe and what she does in response:

> Extract 7.16 (FI, patient, acute hospital, 14th November 2010).
>
> “But I have been in terrible wards. There was a ward I was in before that I hated. The toilets were dirty. There were no nurses or doctors to be seen. I couldn’t find anyone to talk to and I hated it. In fact I woke up one morning and said I am leaving and checked myself out. I got up that morning and I thought, I am out of here and I signed myself out … I just got this removed (gestures to intravenous cannula) and went home”.

This patient makes her evaluation of safety based on the cleanliness of the toilets as well as the availability of healthcare workers. In other words she determines whether she is safe by assessing the physical as well as social environment. Applying her own expertise, she judges safety to be absent, and she takes matters into her own hands and discharges herself. In other words, for this patient, safety is determined on the basis of assemblages that encompass material as well as social elements.

For some patients these safety evaluations become critical in making significant end-of-life care decisions as the next extract from my conversation with another patient, Pete, at the bedside shows:

> Extract 7.17 (FI, patient, acute hospital, 12th January 2011).
>
> “You (patient) don’t know where you are safe these days. I have to make a decision about having a bone marrow transplant but I don’t

> think they have the capability to do it here. I am a poor man and I can't afford private health insurance or anything like that". I (researcher) asked Pete (patient) what he thought would be different if he had private health insurance. "Yes, I would get better care," he said. I asked him what better care would look like. "What would it look like?" he pondered. "Well, I would have a single room, there would be enough nurses to look after me and I would get the correct medicines at the correct time. And it would be clean. They make mistakes all the time with my medicines". I (researcher) asked him how he knew this and he replied that he knew what medicine he takes so he knows when they get it wrong. "I (patient) even called 000 one time from my bed because I was at the end of my tether. I just wanted the ambulance to come and take me home. The thing that's stopping me from having the transplant is my concerns, whether they will be able to look after me properly".

Pete assesses whether he is safe or not in a number of ways. He too, like the patient in the previous extract is concerned with the physical environment including whether he is allocated a single room as well as cleanliness. Further, he considers safety in terms of whether he gets the correct medicine, not only at the time it has been prescribed but also in accordance with his expertise as a long-term diabetic. All of these elements of the assemblage, together, play a part, in assessing whether the healthcare team responsible for his care has the professional expertise and capability to perform the medical intervention. In the end, it is this assessment along with Pete's own knowhow, hopes, values, and desires that are instrumental in his critical life decision not to have a bone marrow transplant.

Patients like Pete often find ways of resisting medical expertise. They are actively involved in safeties and apply their own knowhow and expertise even when their claims and assertions are dismissed or discounted. Here, expertise includes: knowing medications; judging whether staff can be trusted or not; judging whether the physical environment is clean and free of infection, and resisting intervention.

Further, I discussed in the last chapter that safeties are sometimes incompatible. The next extract from my conversation with the specialist cardiac/respiratory nurses brings these threads together to demonstrate how a patient resists an intervention to produce what is safe from her perspective but unsafe for the specialist caring for her:

> Extract 7.18 (FI, specialist RNs (respiratory and cardiology), 19th January 2011).
>
> RN 1: “At first they (referring to the heart specialists) thought it was great because they diagnosed a pulmonary embolism, then she (the patient) was anti-coagulated, so then she had bleeding from haemorrhoids and had to have surgery, then her albumin was low and she is severely oedematous, so she’s unable to eat and drink on her own, but she’s said no to having a PEG tube (feeding tube placed in the stomach). She was self-caring before she came in. The OT is saying she can’t eat because she is physically unable to eat. She’s 74. Now they are saying she will die if she doesn’t eat or get a PEG”.
>
> RN 2: “And he (referring to the cardiologist), won’t go up there today because he doesn’t want to speak with her, he doesn’t know what to do with her”.
>
> RN 1: “It would be interesting to see what she would say about patient safety”.

Multiplicities of patient safety are evident from this extract. The medical team determines patient safety as a singularity of purpose: we need to treat the pulmonary embolism. This medical approach is articulated within the framework of the ‘body singular’. After the pulmonary embolism has been treated, however, an unanticipated series of complications arise and are further compounded by resistance from the patient to agree to a feeding tube. For the cardiologist, safety is rooted in the application of evidence-based medical procedures and the certainty of agreement by the patient to have the tube. The specialist nurses in this account suggest that the cardiologist is uncomfortable with the uncertainty of knowing what to do when faced with the patient’s resistance to having a feeding tube. Further, they propose that the patient’s view of her own safety would be different from or extend beyond that of the cardiology team. As we saw in Chapter 6, harm is not an isolated discrete and ‘easily delineated’ adverse event. The patient is situated within a nexus of relations and affective connections with other bodies both past and present. By declining the insertion of the PEG tube, she is active, as part of the collective, in making sure that she is safe. What the patient views as safe, and what the cardiology team view as safe, however, is not necessarily compatible.

The active engagement of patients and families in safety work was evident across all my field sites. In the next extract, a non-English speaking patient and her brother draw on resources placed before them for their own safety:

> Extract 7.19 (EFN, patient, acute hospital, 2nd March 2011).
>
> Ms Tran turned to me exclaiming "It was fine when I was just letting them care for me but now that I need to know more and ask questions I need an interpreter". The surgeon, backing away from the bedside, explained that the oncologist would probably become Ms Tran's main doctor but that he (the surgeon) would still be around in the background. Continuing to edge away and backing towards the door of the room, the surgeon tried to say that he would see her (Ms Tran) later, however, Ms Tran's brother continued to ask questions, through the Vietnamese speaking junior doctor forcing the surgeon to remain in the room.

The patient and her brother in this extract actively utilise the resource of the Vietnamese speaking junior surgeon. Ms Tran and her brother continue to ask questions of the surgeon in their own language and make an explicit request for an interpreter. I note an observable discomfort of the junior doctor as Ms Tran and her brother direct their difficult questions to her. The junior doctor defers the questions to the surgeon. In turn, the surgeon attempts to defer to the oncologist. I sense a clear tension between the surgeon and junior doctor. In other words, the normalised hierarchical flow of team communication is disrupted. In her active desire for knowing about her illness, Ms Tran is creatively engaged in a dynamic encounter rather than being "passively inscribed" by biomedicine (Fox 2002, p362). In other words, Ms Tran and her brother make it impossible for the surgeon to reduce her to a surgical task to be reviewed. She intervenes as part of the collective body, preventing the surgeon from leaving the room until their needs have been met.

Even in the last weeks of life, some patients are able to actively engage with their surroundings. When time becomes short and death draws nearer patients often continue to exercise their creative agency in a number of ways in order to be and feel safe. For instance, it was not unusual for people to talk in metaphorical language associated with 'journeying' and symbolical meanings of home as they approached death; endeavouring to create feelings of safety towards the end of life:

> Extract 7.20 (FI, patient, acute hospital, 2nd March 2011).
>
> She (patient) told us (referring to the palliative care nurse, the palliative care doctor and myself as we sat at the bedside) "You three are with me on my journey." Then she turned directly to the staff specialist (Palliative Care); "You get on the train at my carriage and you stay there for a while on my carriage with me, then you go around all the other carriages and eventually you come back to mine".
>
> "I (specialist) wish I could spend more time with you on your carriage." Then she (patient) talked about the bedside curtains around her, telling us that she created her own art out of the patterns on the curtains. "Today, I am seeing a garden, a beautiful garden with beautiful flowers". After we left the bedside the staff specialist (Palliative Care) commented, "Isn't it interesting, Mrs Roberts is creating her own space".

Using the metaphor of the train carriage, Mrs Roberts symbolically creates her own spaces of companionship. Having previously visited her at home, I knew Mrs Roberts to be particularly creative. She had given me a tour of her lounge room telling me the stories behind her craftworks and paintings and sharing her poetry with me. Here she draws on her creative capacity to produce artwork from the bedside curtains. The doctor, relating back to the research, reflects on how Mrs Roberts imagines her own space. In other words, Mrs Roberts and others like her use their creative capacities to create their own safe assemblages. This account demonstrates not a reactive body, but a creative 'becoming' one with an unfolding capacity to determine itself in engagement with the world around it (Fox 2002).

Finding families in patient safety

Family members bring a particular expertise to end-of-life care and safety of their relatives especially when they have 'cared' over a protracted time period. Often they develop know-how that can surpass the most experienced or skilled of healthcare workers. To further illuminate how families enact their expertise I introduce Len and his daughter Helen.

Introducing Len and Helen

> *I went over to the main hospital to find Mr Rushton. He was in a side room, just off the nurses' station in a surgical ward. His daughter, Helen was with him. They were both expecting me as the palliative care doctor had already told them a bit about the project. As soon as I explained who I was, why I was there and the purpose of the study, they started to tell me their story. Len made it clear that he wanted to participate in the research and that he would like to do so in his hospital room. His daughter took out his comb, tidying his hair and distinctive eyebrows.*
>
> *As they talked and talked, I pondered the value of the research process. Perhaps the research itself was instrumental in creating a 'safe space'. I was struck at how quickly a rapport developed with Len and Helen. Perhaps their trust in me resulted from the trusting relationship they already had with the palliative care doctor.*
>
> *I must have been in the room with Len and his daughter Helen for at least an hour. I didn't say much, just listened. Helen told me of their difficulties over the past year. In the back of my mind, I questioned whether it was appropriate for me to be there as 'listener'. Was this in the scope of my role as researcher? Afterwards, I reflected again about my positioning as the 'researcher'. Yet, at the same time, it would have been impossible for me to imagine that I could just get up and take leave, narrowly defining myself as 'data collector' given that the research sits within a relationship of accountability (see Chapter five). I resigned myself that I am nurse, a person as well as researcher. At one point in the conversation Helen commented that the surgeon was only concerned with the operation. "The palliative care team are more sympathetic", she said. "They are concerned with everything. It was (names doctor) who suggested that Dad could do his own eulogy"! In documenting the journey forward, I wondered how things would play out into the future. How I would cope with the emotional entanglements that would come about as a result of 'travelling' with Len and Helen. As I left the room and out of ear shot of Len, Helen exclaimed, "If I hadn't been here caring for Dad I think he would have been dead by now". She went on to tell me that at times she had had to help out with clinical tasks because there weren't enough nurses.*

(View DVD)

Len and Helen's visual narrative demonstrates that Helen attends not only to Len's personal care, but also to clinical tasks usually carried out by professional healthcare workers such as dressing of his wounds. Finally, it is Helen who initiates Len's transfer back to hospital when he is dying, not the nursing home staff. Helen positions herself as critical to Len's safety. Critically, Helen takes on safety roles herself to compensate for the lack of healthcare safety. She posits that without her interventions throughout Len's illness trajectory he would already be dead.

Helen was not alone in articulating what she saw as a critical role in keeping her father safe and thus preventing his premature death. For example, in Joe and Tara's video narrative in the previous chapter, Tara also articulates the necessity of having to mediate safeties for her father:

> Extract 7.21 (SSI, Joe and Tara, acute Hospital, 15th February 2011).
>
> "There was one day there a few weeks ago, because of lack of communication; he went 24 hours without insulin. If that had been the week before he would have been dead because he went really loopy on me one day and I had no idea what was going on. I walked in and he goes; 'Oh hello', and I went, 'Oh hello. How are you? You're a bit chirpy'. And he goes, 'Are you here to give me my medicine now'? I'm like, 'hmmm' … and then a couple of hours later he's like;

> 'Where am I, how'd I get here, who am I?', and it was because his sugars had dropped too low and if that had of been that day it would have been critical".

Tara identifies Joe's symptoms as being the result of a drug error and suggests that if the error had occurred when Joe's condition was unstable, he might have died. Like Helen, Tara is actively engaged in ensuring her father's safety in hospital. As for patients, it is important for family members that patients stay safe and well even when they are approaching death.

At the same time, both Helen's and Tara's narratives show how they occupy the ambiguous position of both provider and recipient of care. The next extract, from an interview with a nurse from the coronary care unit provides further evidence of the ambiguous position of patients' families. Further, it highlights how safety is not fixed and determined but relies on the nurse's responsiveness to an unfolding situation:

> Extract 7.22 a (SSI, RN, CCU, acute hospital, 7th February 2011).
>
> "Because of the lady (patient) on the other side, her family don't let us wash her. But it's like the daughter's job. When she comes in, the daughter wants to wash. The son is very good". Acting out the patient son she says, "'Excuse me nurse, can I please have your blood pressure machine? Because she's a dialysis patient, and I (patient's son) do peritoneal dialysis. Excuse me; can we go take her blood pressure'?And because the son's very knowledgeable and another daughter's really knowledgeable. And they like to help make her bed, and they are very involved and so we stand back. Here's her tablets. Here's what the doctors want. Oh she's got some pain. Oh here you go".
>
> "She actually had haematemasis (vomiting blood). They (patient's family) didn't really tell us until … They were trying to make it better, and you're like, 'What's going on in there'? And when we saw it, 'Oh! Oh!' And she (patient) actually needed blood transfusions and everything. We didn't really know. So because they (patient's family) do handle her dialysis … But all of her (patient) bags were, they (patient and family) actually kept all of her post-dialysis bags in a box,

> beside her bed. And they (patient's family) didn't actually give it to us to empty. And, we didn't actually go in and ask her (patient) either. That's because they (patient's family) just look after her (patient) and they don't complain of anything and they don't want to disturb you. It gets very interesting that way".

The family members in the account above take on tasks that exceed personal care to include the technical tasks of blood pressure monitoring and dialysis. The role of care provider, however, quickly changes into care recipient when their mother experiences a haematemasis; a potentially life threatening and critical event. The nurse above recognises the family's expertise and ability in caring for their mother, allowing them to carry out tasks ordinarily held in the professional domain. Yet this is not straightforward. The nurse is required to manage the competing risks evident from the critical event of the life threatening bleed. She demonstrates dynamic responsiveness to a quickly unfolding situation. In other words, she displays 'deviant innovation', a term used by Rowley (2011, p95) to describe behaviour when the goal of patient safety is internalised but is not realised according to normative professional practices. The above account provides evidence that nurses frequently have to 'juggle' competing safety demands. Nurses like the one above, find themselves continually negotiating complexity. In other words, safeties and un-safeties are not static but are continuously being negotiated and contested.

Further, I was curious to know what it was about the nurse quoted above that enabled her to defer professional tasks to a patient's family. Later in the interview the same nurse relays to me how she learns to hand over tasks that she previously regards as being in her domain:

> Extract 7.22 b (SSI, RN, CCU, acute hospital, 7th February 2011).
>
> "I think it's just part of this ward's environment, because before I would never have allowed somebody to go and take the towels off the linen trolley and go and wash their relative, because I was a bit, 'oh no that's my job! Don't do that'! But now I've accepted that they (families) just want time with their loved one and they want to be with them and do whatever. And I think you have got to allow them to show their love to that person. But here because it is in the open and it was already done, I just joined in and said, okay then. Help yourself"!

This nurse expresses how she previously regards particular tasks and particular areas and artefacts of the ward as being in her professional domain. Her decision to allow families to help themselves to towels from the linen trolley is not made autonomously and independently, however. Instead she adapts her behaviour according to accepted practices of the ward. That is to say, her capacity to collaborate with families in the care process is determined in part by features of the ward assemblage.

When healthcare workers acknowledge patient and family expertise, safeties are made possible, as I show in the next extract from a conversation that took place with Helen ‘off film’ one day as she walked me out of the building following my visit to her and her father:

> Extract 7.23 (FI, Helen, hostel, 22nd December 2010).
>
> On the way out Helen walked me (researcher) to the door as usual. She commented about one of the nurses as we passed their room: “That one there is very good”, she said. “She came to change his patch and I asked, ‘Are you an RN’? She replied, ‘Yes, I have been an RN for 20 years, but you know your father and his needs best; so I’ve seen these (stoma) and what to do but how about you do it and show me how he likes it done and then I shall take over from there’?” Helen expressed that this was the first time that her expertise had been recognised in attending to her father’s care and how much she appreciated the nurse acknowledging her *know-how.*

When Helen’s expertise is recognised by nursing home staff she feels valued as a member of the team, working in collaboration with the nurse to provide individualised care to ensure her father Len’s comfort. Recognition of patient and family expertise, combined with professional expertise, I contend co-produce safety, by allowing the negotiation of multiple safeties and un-safeties.

This section has shown that patients and families actively evaluate what is safe and what is not. They have significant knowledge and use that knowledge and expertise to help produce safeties through weighing up and trading off risks and agency and so forth. Importantly, safeties and un-safeties are never fixed or determined by a guideline or protocol alone. Rather, they are produced through living and acting together. Critically, patients and families themselves are actively engaged in this living and acting to produce safeties even when a person is dying.

Section 7.4 Conclusion

Current approaches to patient safety are focused on system strategies and system solutions to reduce errors such as guidelines or protocols (Australian Commission for Safety and Quality in Healthcare). This approach to patient safety assumes that such systems will automatically produce safe care and that harms will be prevented if errors are minimised and evidence-based guidelines are followed. I discussed in the previous chapter how this approach to patient safety does not address multiple and at times competing safeties from the perspective of patients, families and healthcare workers themselves frequently necessitating delicate negotiations and trade-offs. This chapter extends these findings. I have shown that patients and families have unique knowhow and expertise. Importantly, patients apply their knowhow and expertise even when they are dying. They use their expertise for their own safety, and to some extent, the safety of others. This expertise often goes unrecognised by healthcare workers and organisations. When healthcare workers do acknowledge and accommodate patients' and families' expertise, safeties are made possible. Taking account of patient and family expertise does not simply equate with allowing patient choice, however.

The next chapter will more fully explore the conditions that increase the likelihood patient and family expertise is not only recognised but, in collaboration with healthcare workers, also acted upon. It examines how patients, families and healthcare workers can co-operate more successfully, to increase the potential for safeties, to be brought into being.

Chapter 8 Becoming-safe Assemblages

Section 8.1 Introduction

This chapter is the third and final empirical chapter. It extends the findings of the previous two Chapters (Chapters 6 and 7) by describing the conditions that foster healthcare safeties. I examine how patients, families and healthcare workers can co-operate to create safety, analysing the conditions that facilitate experimentation and creative engagement to enable new possibilities that make safe dying possible. I have argued thus far in the thesis that healthcare safeties are never fully determined and often contested. In other words, there are multiplicities of patient safety. Further, assemblages are never static and are always becoming. Thus I argue that safeties be reconceptualised contextually in terms of 'becoming-safe assemblages' rather than as isolated technical events or practices deemed safe because they are modeled on science, policy or protocol.

This chapter is divided in four main sections. Section 8.2 is titled 'Affective Atmospheres'. It defines what 'affective atmospheres' are, exploring the place and role of healthcare workers in bringing such atmospheres into being. Section 8.3, titled 'Designing Becoming-safe assemblages' explores whether or not there is a conscious element to producing safeties. Section 8.4, titled 'The Built Environment' investigates the place of material surroundings in producing safeties. Finally, Section 8.5, titled 'Connections with Home', explores the relationship of home and safeties.

Section 8.2 Affective Atmospheres

Affective atmospheres are "singular affective qualities that emanate from but exceed the assembling of bodies" (Anderson 2009, p77) or what Thrift (2006, p143) calls "swirls of affects"[44] In other words, affective atmospheres are the prepersonal and transpersonal intensities that emerge when bodies affect and are affected by one another (Massumi 2002). It is clear that they arise from something exceeding any one body and by their very nature are ambiguous (Anderson 2009). Immediately noticeable about the palliative care hospital whenever I arrive is that it 'feels different'. Most significant,

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[44] I also use this quote in Chapter 3 where I define affect and space.

however, were the often-stark differences observable in patients when I followed them from the acute hospital to the palliative care unit. I was purposeful in trying to find out what might contribute to these different intensities. What follows is my attempt to communicate these findings. Nevertheless it is important to reemphasise that my text representing ‘affective atmospheres’ is limited in its capacity to convey the characteristics of these realities which “craft themselves into materials other than or as well as the linguistic” (Law 2004, p147). Visual data, as in the previous chapter, allow me to present the findings of this section in a sensory way, complementing the text. Thus, I begin this section by introducing Greg.

Introducing Greg

> *As I entered the hospital ward to see Greg, I met the junior doctor attached to the palliative care team at the nurses’ station. She had just been to see him and told me that Greg was feeling very down today. She put it down to an incident overnight when an intern came to see him because of a fall and had, and apparently accused Greg of ‘just acting’. “All I (doctor) could tell him was that people speak rubbish at night, what else could I say? And I think that the endocrinologists have been in and told him that his BSL (blood sugar level) needs to be better managed”, she said.*
>
> *I approached the bed where Greg was sitting. He was beside the window on the right hand side, dressed in his own clothes, sitting on the bed. His mood appeared very low. I felt that he might burst into tears at any moment. I asked if it was ok if I sat down beside him. He said yes and I shook his hand. I explained who I was and why I was there. I commented that he looked very down today. He said “Yes, I won’t be here”, he said, “the doctors want to send me home, I think the doctors and nurses have had enough of me. I am confused about it all”, he said.*
>
> *I asked him if he had told anyone, any of the doctors and nurses how he was feeling. “No, I can’t speak to doctors and nurses”, he said. “I just don’t know what to do with myself”. I asked him if he would prefer to be left alone. “Yes, it’s not personal”, he said and “I’m sorry that I’m in such a bad mood today”. I said that I thought it was ok to be in a bad mood and perhaps I would come back and see him when/if he was feeling better.*
>
> *The next time I saw Greg was when I ‘bumped’ into him in the hospital foyer. He stopped me to say hello and seemed a bit brighter, introducing me to the friend he was with. A couple of days later I ‘bumped’ into him yet again. I was making my way from the office across to the main hospital building. Greg was sitting on the wall with the palliative care nurse. I was uncertain whether to say hello, not wishing to interrupt the conversation.*

> *However, rightly or wrongly I decided to do so, not wishing to ignore them. The nurse explained that Greg had just received some bad news. I responded that I was sorry to hear this. Greg expressed that he had been thinking about the research and wanted to take part. However, he said that he also wanted to use the camera to film some 'words of wisdom' to leave behind for his grandchildren. I emphasised to Greg that he didn't need to take part in the research in order to 'borrow' the camera. But Greg stressed that he wanted to do both. We agreed that the palliative care nurse would help him to leave a message on the camera when he felt ready to do so. He informed me of his planned transfer to the palliative care unit the following day and we agreed that I would visit him there to carry out a filmed interview.*

(View DVD)

Greg contrasts the atmosphere of the acute hospital with that of the palliative care unit. He characterises the palliative care unit atmosphere as conducive to expressing his feelings safely and as a place in which he feels safe. He contrasts this with his experience of the acute hospital. Most powerfully perhaps is his expression of feeling more 'alive' in the palliative care unit, a place designated to look after people who are dying. Greg, rather than being restored to a healthy former self consistent with the acute hospital goal of cure, is able to discover a new self despite his poor prognosis (Buchanan 1997). As Greg deteriorates, his creative capacities for doing so are able to continue.

This section is concerned with the characteristics of affective atmospheres that help or hinder the safety of people like Greg. I foreground the remaining findings of this chapter by quoting following extract spoken by the palliative care massage therapist:

> Extract 8.1 (SSI, massage therapist, palliative care hospital, 15th April 2010).
>
> "It permeates. When it's working it permeates. You know, of course they're (families) talking about the nurses but in the end they're almost talking about this amorphous edifice. This amorphous system that is about caring for their loved one, when their caring for him or her isn't enough to save them. But they can feel it's a gift coming from … yeah. So being involved in that when that happens is, I'm happy to use the word spiritually, a spiritual experience".

The massage therapist makes reference to the spiritual nature of what she calls the 'amorphous edifice'. Although she finds it difficult to articulate, she seems to conceive of the amorphous edifice as something closely related to care and to safeties. It is the permeating amorphous edifice spoken of by this participant that is the key theme of this chapter and one that I wish to interrogate more closely. As this chapter proceeds, I attempt to convey its elements more fully in order to try to arrive at an explanation of how it is brought into being. I begin by looking at how I myself articulate atmospheres. For example, I affectively sensed the differences moving from one area or unit of the acute hospital to another:

> Extract 8.2 (EFN, acute hospital, 17th January 2011).
>
> I (researcher) was struck by the palpable difference in the atmosphere. We (the PCN and I) crossed from a surgical ward, where there was lots of bustle, lots of people around and lots of equipment in the corridors into the coronary care unit, where I was struck by an absence of equipment in the corridors and an atmosphere of calm. I heard the odd beep from a monitor, but other than that it appeared quiet, calm and peaceful.

I was struck how it was possible even in the coronary care unit, a place where critically ill people are cared for in a highly technological environment, that it was possible to sense an air of calm. In accordance with the findings of Chapter 6, I show how impressions of the care setting exceed one-on-one interactions to affect collective interactions that take place in the context of these surroundings and encompassing all relationships with those surroundings. I turn now to explore affective atmospheres in greater depth. I begin by considering the relationship of healthcare workers with affective atmospheres and how the way in which they live and act might contribute to how those atmospheres are sensed through 'learning to be affected'. Learning to be affected is the obverse of what I term 'learning not-to-be affected' in Chapter 6. 'Learning to be affected' means "effectuated, moved, put into motion by other entities, humans or non-humans" (Latour 2004, p205). Latour argues that for a body to be alive in the world, it must be able to be moved by its relationships with the collective body. When healthcare workers 'learn to be affected' they are moved by their material surroundings and those around them and to be moved is the precondition for safety.

Healthcare workers and affective atmospheres

I encountered nurses who were cognisant that what they do and how they are is related to whether patients and families trust them. The next extract from an interview with an enrolled nurse demonstrates the importance of this relationship from the nurse's perspective:

> Extract 8.3 (SSI, EN, acute hospital, 8th April 2011).
>
> "If they (patients and families) feel comfortable with you (healthcare workers) then it's a lot easier to do your work. If they have that distrust or they're not sure of who's caring for them it can make it quite difficult and I think if you don't have that empathy and that caring nature then it's going to show when you do your work and patients will pick up on it".

The nurse in this extract articulates that it is not only patients that benefit from feeling safe but that she as the nurse also benefits. When this nurse is connected with patients and families in a relationship of mutual respect and trust, care delivery becomes more satisfying. The nurse suggests a need for what I term 'affectively attuning'. Affectively attuning is what Jerak calls knowing through living and acting or "opening oneself up with all the sensory doors of perception to whatever manifests during the encounter" (Jerak-Zuiderent 2012, p741). Rather than a 'soft extra', affectively attuning with others creates conditions that are more likely to address the needs of healthcare workers as well as those of patients and families. I demonstrated in Chapter 6 how the prevalent approach to the healthcare worker/patient relationships is one where the professional mask is applied to protect the healthcare worker from emotional burnout and the patient from non-objective, unscientific intervention (Marcum 2008a). Yet, hidden beneath this discourse of professional distance nurses frequently conveyed the ‘realities’ of relationships with patients and families as the next extract from an interview with a registered nurse shows:

> Extract 8.4 (SSI, RN, acute hospital, 11th March 2011).
>
> “We (nursing staff) all get attached to patients when the philosophy is ‘Don’t get attached to patients’ **(**makes inverted commas with hands**)**. The day I don’t have that rapport with my patients is the day that I walk away from nursing because I think if you don’t have that then you can’t be the best person that you can be”.

This nurse determines ‘attachment’ with those she cares for as a central tenet of her identity as nurse. At the same time however, this extract demonstrates her awareness of the normalised value of detachment. For this individual her capacity to be ‘the best person that she can be’ is closely associated with becoming affectively attuned with patients. In other words, the nurse is open to learning and transformation: or to becoming ‘nomadic’.

Removal of the professional ‘mask’ was implicitly sanctioned in the palliative care hospital. In this setting, healthcare workers viewed the reciprocal nature of the healthcare worker/patient relationship as integral to their work:

> Extract 8.5 (VRM #1, RN, palliative care hospital, 27th August 2010).
>
> “You (the nurse) have to give of yourself here. In other places you’re just the nurse, but here you have to be a person as well as a nurse. You have to be everything: a counsellor; a shoulder to cry on. We talk about ourselves, share our own experiences, our own lives, because they (patients) give so much to us; their confessions, their fears and anxieties”.

For this nurse, bringing herself into the professional role is seen as critical to a fulfilling encounter for both parties. She talks of the need to be open in response to the openness of patients. The criticality of bringing self into relationships with patients was illuminated during group reflexive meetings where healthcare workers reflected on the nature of the patient/healthcare worker relationship as the next extract spoken by the radiology director shows:

> Extract 8.6 (VRM #1, radiology director, CTC, acute hospital, 7th June 2011).
>
> "It's actually give and take. It's two human beings interacting. Not a uniform interacting with a patient and that I (radiology director) think came across there as much as with the two gentlemen we (radiology staff) spoke to over the past couple of weeks. It's back to personalising the care".

This healthcare worker connects what she sees on film with interactions she has recently had with radiotherapy patients as part of a focus group to discuss service improvements. These experiences combine to make tangible what is for her a need to loosen one's identity beyond that of professional. Loosening of one's identity translates as a willingness to open up and put oneself at risk of being moved.

The same openness and willingness to be affected became evident to me during the initial phase of fieldwork in the palliative care day hospital. Whatever their professional discipline within the team, healthcare workers were openly attentive to the concerns and needs of patients and families. I observed this happening in the way described by the massage therapist in the following extract:

> Extract 8.7 (SSI, massage therapist, palliative care day hospital, 15th April 2010).
>
> "This is the time and this is the place of the day hospital and we (day hospital staff) are here for you. But we are not so very different from you. You sit down, staff participate in the activities. If we all sit down at the one table we are all (staff and patients) at the one table. When clinicians do do this, they hear a whole lot of new stuff. Because of course it's a different footing".

When healthcare workers are open and practice humility, sitting at the table alongside patients, new understandings and ways of knowing can come to light in the way the massage therapist describes. This extract shows how 'the table' provides a physical locale where healthcare workers can meet patients as fellow human beings, providing a safe place for patients to express their needs and concerns. The table, in this extract, also provides a strong metaphor to express the shared humanity of the collective body. Being prepared to sit at the same table is 'learning to be affected'. Sitting at the same table acknowledges the embodied interdependency of patients and healthcare workers. This interdependency allows for learning and transformations that create knowledge increasing the possibilities for collective action.

This kind of embodied interdependency was not confined to the palliative care hospital however, and there was evidence of healthcare workers affectively attuning to one another in the cancer centre of the acute hospital. In the next extract, an enrolled nurse describes how the strengths and weaknesses of each person are tacitly recognised to enable the team to affectively commit to each other:

> Extract 8.8 (SSI, EN, acute hospital, 11th March 2011).
>
> "I (enrolled nurse) think that we've got a really good team of people that we work really well together, I think that allows us to do it, we're pretty clear on all our policies and protocols and if we need help we ask for help and it's there, so I think that's what really helps us get along and making sure that our patients are safe and it is by working together as a team as opposed to all individuals in one area. I think that, I know it's going to sound a bit terrible but we all kind of know where we fit in the scheme of things".

This extract shows how team members get to know each other's strengths and weaknesses and acknowledge their limitations. This nurse articulates the importance of healthcare workers negotiating a common understanding of policies and protocols in the delivery of cancer treatment. These policies and protocols are only properly enacted when team members understand each other as members of a weave of commitment. In other words, safeties are produced as a result of collectives rather than the actions of individuals in isolation and according to the protocol alone.

The manner in which numerous bodies affect and are affected iteratively influencing each other within collective networks was evident 'behind the scenes'. Medical specialists, just like patients, are not autonomous individuals making clinical decisions independent of their social networks. The following extract from my field notes traces a discussion about a particular patient at the oncology inpatient weekly meeting:

Extract 8.9 (EFN, Acute Hospital, Medical Oncology weekly team meeting 11th February 2011).

Cancer doctor (Doctor 1) articulated that the patient was having episodes when she could not be roused. She (the doctor) questioned if it would be worthwhile carrying out a bone marrow aspiration to confirm bone marrow infiltration (an indicator of poor prognosis) rather than continue to actively treat (the patient) with platelets and antibiotics and have the patient deteriorate and die while on active treatment. She makes a case for carrying out the bone marrow test to provide clarity thus allowing her to communicate that to family members that the patient is dying. The doctor also indicates that she has already involved ICU doctors in the decision-making process and a discussion had taken place that the patient wasn't suitable for intubation or for admission to the ICU.

I (researcher) pick up the conversation and dictate it as it happens:

Doctor 1: "I have discussed with the family several times that she may take a turn for the worse. I am just putting it out there".

Doctor 2: "Can't we have the conversation with the family on the basis of the haematologists' opinion"?

Doctor 3: "Have you given GCSF"? (a growth factor that stimulates the bone marrow to make more white blood cells)

Doctor 1: "I have implemented both of those already".

Doctor 2: (Tells a story about a patient in similar circumstances he treated in his previous job in another hospital to make a case for not carrying out the bone marrow test).

Doctor 1: "Do I just keep treating this woman and she stays in hospital on IV antibiotics? Or do I accept that she is going to die"? (She adds that the patient herself had indicated that she doesn't wish to pursue active treatment).

Doctor 2: "We shouldn't do it if it's not going to add anything".

> Doctor 4: (palliative care doctor arrives in the meeting) She contributes by adding what treatment(s) would be available in the palliative care unit.
>
> Doctor 3: “But the overall picture of GBM, (Glioblastoma multiforme, an aggressive brain tumour) the prognosis is very poor”.
>
> Doctor 1: “But the difference may be days if I don’t do anything and months if I do and that could make the difference to them” (patient’s family).
>
> Doctor 3: “You need to sit down with the family and put it on the table”.
>
> Doctor 1: “I’ve done that a couple of times”.
>
> Following a lengthy discussion there was a general consensus that the bone marrow test was not appropriate. I (researcher) noted the willingness of the oncologists to express their uncertainty.

The dialogue above demonstrates that ‘knowing’ is not a discrete decision hidden in the head of a doctor. Rather, knowing is a collaborative endeavour where the planning of the most appropriate care for the patient results from a democratised and dynamic decision-making process that enacts relational accountability. The cancer specialist is able to express uncertainty with her peers about the care of a patient she is responsible for. She demonstrates humility and openness and is prepared to take account of the experience and opinions of other members of the medical team. This account demonstrates that when doctors are able to affectively attune to one another, a weave of commitment becomes possible and operates so that safeties can unfold. In this way, safeties are not predetermined but rather are continually being made and remade.

Furthermore, learning to be affected and becoming affectively attuned plays a critical role in responding to situations of possible harm. Becoming affectively attuned can raise the possibility that something is ‘not quite right’, having the potential to avert adverse events and harm, as indicated by a registered nurse working in the cancer therapy centre:

> Extract 8.10 (SSI, RN, acute hospital, 11th March 2011).
>
> "So you (nursing staff) get to know them (patients and families) and so you can't necessarily find something wrong with them medically but you know that they're not right, you know that something's not right and I think it's just by being open yourself".

By being open and engaging affectively, healthcare workers are sensitive to knowing what cannot necessarily be described formally. This knowledge is only held within the context of collective affective connections. The criticality of these connections to healthcare safeties was made tangible for healthcare workers in reflexive meetings. The following extract traces elements of these connections with the aid of one healthcare worker's narrative response to footage:

> Extract 8.11 (VRM #1, CTC, acute hospital, 7th June 2011).
>
> "What the people there (on film) are saying is that they want to feel connected, but if the staff don't know how to connect or are too afraid to connect, then they're (patients and families) not going to be able to feel connected to the hospital system and to their own care and that. That's how I (receptionist) feel about it. It comes down to us (healthcare workers) being able to connect with them (patient and families) and feeling comfortable connecting with them".

Critically, this extract emphasises affectively connecting not as a problem of the intellect to be solved by a cognitive device, but rather a relational issue to be dynamically and constantly negotiated anew. It is through feeling connected with healthcare workers that patients and families also feel connected to the 'bigger system'. The same healthcare worker extends her reflection to suggest that the connections of which she talks might be promoted by getting to know patients by name:

> Extract 8.12 (VRM #1, CTC, acute hospital, 7th June 2011).
>
> "I (receptionist) knew every patient by name. If I didn't know them I'd have photo ID. It was when photo ID started coming in. I would flick it (photo) up (on the screen) because I'd have basic recollection of who they were because I saw everybody coming through. Ok, so when you greet someone by name, most important thing in the world

> when they think that you know them and then they feel an instant connection to you".

What this extract points towards is the possible immediacy of 'getting to know' or the potentiality of the 'encounter' and in this case, made possible, by paying special attention to peoples' names. Further, the receptionist is clearly an important member of the team. She plays a significant role in determining whether patients and families feel respected and connected with the 'system' and therefore safe as the enrolled nurse in the next extract stresses:

> Extract 8.13 (SSI, EN, acute hospital, 8th April 2011).
>
> "I (enrolled nurse) think they (patients) have to feel secure when they walk through the front door, the first people our patients actually come across are administration staff then from there, they're directed to the nursing staff, the radiation therapist. So they go through a few chains of people before they get to their treatment and I think if they have a bad experience at the front or with us before they get to radiation it sort of has a knock on effect".

The impression patients have when they enter the department can have an impact on their overall radiotherapy treatment experience. If patients have a bad experience at the reception desk this can continue to have an impact on them even when they reach the treatment bay. In other words, the receptionist's role in contributing to 'affective atmospheres' is a critical one. Even the briefest of encounters can leave an affective impression on others as the chaplain conveys:

> Extract 8.14 (SSI, chaplain, palliative care hospital, 22nd July 2010).
>
> "Sometimes you're that lifeline for that person in that moment and that might be the only contact you ever have with them. Like you might go back again and there's not that same intimate contact".

These extracts show that every encounter matters and can contribute to the overall safety or unsafety of assemblages. In other words, it is how one is that matters rather than verbal communication alone (Dobkin 2011). Using a musical metaphor Shotter asserts that:

> *"At each particular moment a new tone is added to the previous ones, or more accurately, each new moment is constituted by the creation of a new musical quality and the irreducible individuality of each new tone, is 'tinged' or 'coloured' by the whole preceding musical context into which it 'strikes,' and which in turn, it retroactively changes by contributing to the emergence of a new musical quality" (Shotter 2003, p20).*

When healthcare workers recognise themselves as bringing 'new tones' to encounters, the issue of time takes on a different meaning. Every encounter, no matter how momentary can communicate to patients or families whether they are safe or not. That is, the kind of communication that patients and families expect does not necessarily demand additional time. For example, experienced nurses acquire strategies that enable them to perform the recommendations made by Joe's daughter, Tara; "They (healthcare workers) talk to him (Joe) while they are doing it (nurse or medical intervention or task)". The following extract demonstrates how significant communication occurs as a result of the manner in which nursing tasks are carried out:

> Extract 8.15 (FI, RNs, acute hospital, 22nd November 2010).
>
> One of the RNs relayed how a patient had expressed concerns over their (family's) request for her to make a will. The nurse commented that she'd spent about an hour with this particular patient today. I (researcher) asked the nurses if they could explain how they fitted this kind of conversation into their time schedules. The nurses replied: "We do it when we are hanging the chemo. That's how we talk to them. We talk to them while we are doing the tasks".

Critically the extracts above show how healthcare workers can circumvent the problem of insufficient time. These nurses perform communication as care while providing technical care. Rather than seeing tasks and the 'therapeutic' relationship as separate or distinct pursuits, nursing care is embodied in 'affective connections' that are made at the moment where bodies meet. The intent of these nurses is conveyed not through words alone, but embodied in the way that personal and technical care is delivered. Importantly the expert nurse intuitively knows this and enacts care delivery accordingly:

> Extract 8.16 (SSI, RN, acute hospital, 28th February 2011.
>
> “I (registered nurse) come on and the patient looks all messed up in the bed or you know really in a lot of pain and miserable and by the end of the day they look comfortable. Just those simple body, like full body, full sponge, cream all over head to toe, straighten the sheets and that’s it, you know, that’s physically, that’s it. Mentally I might not make them feel any better but physically they look better, they feel better and you know that’s what counts and that’s why I come back all the time”.

This nurse differentiates care in terms of the traditional mind-body separation. Her use of language indicates a normalised Cartesian dualism in which the mind is separate from the physical body. Alongside this language of dualism, however, the nurse suggests that care of patients’ physical bodies is inseparable from their emotional self. She thereby intimates that the brain is not dissociable from the body and its surroundings, including the ‘affective atmosphere’. Patients themselves also understand to some extent the inextricable connection between ‘mind’ and body in this way. For instance, even in his final weeks of life the following patient stresses the significance of this inseparability to his wellbeing:

> Extract 8.17 (FI, patient, palliative care day hospital, 3rd June 2010).
>
> He (patient) told me that he thought the brain and physical body were inextricably linked and that because his brain was active, his body hadn’t yet ‘stopped’. He told me how the art and painting helped his ‘brain’; how the nurses put a plastic sheet on his bed so that he could paint in bed and not make a mess.

For this patient, the bodily activity of art gives recognition to the relationship between the body and its surroundings. The nurses, by facilitating painting, help to foster his creative capacities. The hospital bed is configured as a painting easel. The nurse and patient as a collective with other bodies practise being affected.

Becoming affectively attuned benefits patients and fosters teamwork, increasing the likelihood of safeties. For healthcare workers, learning to be affected also provides benefits. It is the affective connections with those they care for that can give healthcare workers job satisfaction and is often at the core of their work. ‘Learning to be affected’ can help create resilience to keep going when times get tough in the way an enrolled nurse describes:

> Extract 8.18 (SSI, EN, acute hospital, 11th March 2011).
>
> "I (enrolled nurse) love the patients. Yeah, I think that's what keeps me here (Cancer Therapy Centre). Even if there are dramas you know professionally, it's the patients ultimately. They give you cards and they give you letters and you know telling you that you've made a difference. Things like that make you want to come back".

The reciprocity of relationships is just as important for healthcare workers as it is for patients and families. Sobel applies the term engagement for these reciprocal connections where an intermeshing between individuals leads to something of consequence for both parties (Sobel 2008). This mutuality is what the healthcare workers – quoted thus far in this chapter – were able and willing to achieve.

This section has shown that it is the milieu comprising multiple bodies affected and affecting, interacting and resonating with each other that shape impressions and responses, creating affective atmospheres. I argue that it is 'learning to be affected' that enlarges the capacity of assemblages to achieve safeties by extending what bodies can do and increasing connections and new compositions in response to the needs of others (Buchanan 1997). The next section discusses further what healthcare workers do to affectively attune, and how they can 'learn to be affected'.

Section 8.3 Designing Becoming-safe assemblages

This section extends the previous discussion by examining the 'design' components of 'becoming-safe assemblages.' I use the term 'design' not to suggest that these assemblages are 'fixed' or 'concrete' in any way or that they are attainable by attending to architecture, or organisational planning or strategy, but rather to imply their partially conscious make-up. As a casual observer, one could be forgiven for thinking that the palliative care hospital atmosphere was something that 'naturally occurred', or in the words of the service director: "That the atmosphere is simply piped around the building". However, it became clear that 'becoming-safe assemblages' are partially constructed. They are constructed in the sense that they require attentiveness, a particular kind of interdisciplinary teamwork, and most critically openness to affect and be affected. I begin by introducing Liz and her husband, Brian.

Introducing Liz and Brian

> *I met Liz for the first time on my first time at day hospital. I'd heard a lot about her. Liz was well known. She had been attending the day hospital for some time. Whenever I introduced the research to staff, she seemed to be the person who first 'sprung' to mind when they thought of potential participants. Liz was one of a three-member team of patients who 'inducted' me to 'day hospital'. She, along with two other women was instrumental in 'showing me the ropes' and making me feel comfortable in the space. On that first day of day hospital the 'team of three' were involved in a joint project of making a birthday banner for Liz's husband Brian.*
>
> *I expanded on the introduction to the day hospital group given by the diversional therapist, explaining whom I was and why I was there. Turning to the group of three I added, "You chuck me out at any time". (The potency of their presence in the space is palpable). Later, Liz's husband enters the room. He greets the whole group, saying hello and he is met like an old friend. Friendly chat ensues between the doctor, Brian and the rest of the group. Liz presented a delighted Brian with his birthday banner.*
>
> *On my second visit to day hospital, I had the opportunity to chat with Liz alone. She told me about her diagnosis. I noticed her claddah ring and earrings and she told me about her Irish connections and talked a little about her family. She also told me on that day about a particular dream she'd had the previous night, not knowing quite what to make of it. As she tells me I recall the dream work that Michael Kearney has written about and I reflect on my 'natural' function as a nurse in palliative care turned researcher wondering about my role in day hospital and where I fitted.*
>
> *Meanwhile, Liz said that she'd forgotten to bring her anti-sickness medication and made a request to the enrolled nurse to get her one from the ward. I noticed the EN putting this request into action immediately. Liz told me that she was forever fearful of becoming as symptomatic as she was when she had required admission to the ward as a result of nausea and vomiting.*
>
> *I interviewed Liz for the first time on the 28th July 2010. She agreed to 'take the camera'. I suggested we go over it with Brian her husband as well. I went over the purpose of the research with Brian and explained the camera. He was very enthusiastic and thanked me for 'choosing' them. I was struck by the fact that he felt 'special'. He said that we should make the most of technology to teach others and thought it was a great idea.*

> *As the weeks passed I got to know Liz and her husband Brian well. They became key participants over the course of the research. I came to regard Liz as an 'expert'. As the 'inaugural' participant in the project, I regarded Liz as my 'guide' of what was possible. She helped me to calibrate my approach with other patients. Our relationship was such that she provided me with feedback, allowing me to move forward on the research journey. Moreover, Liz was also an expert advisor of 'healthcare' in another capacity. She had worked as a receptionist in hospitals. She had been on the 'other side'.*

(View DVD)

Liz and Brian's vignette conveys the importance of looking beyond the body as disease to one of a living acting person with creative capacities and purpose. For Liz, safety requires that all team members commit to her by listening, caring and acting. She provides an example of how a nurse responsible for carrying out a wound dressing affectively attunes with her recognising needs that extend beyond the task. In other words, a weave of commitment operates to meet Liz and Brian's needs. Liz's final recommendation is simple yet profound: "Talk to each other".

What follows is a further analysis of conditions created in the palliative care day hospital that makes the weave of commitment that Liz describes possible. I begin by interrogating the expertise of the diversional therapist:

> Extract 8.19 (SSI, diversional therapist, palliative care day hospital, 12th April 2010).
>
> "There's a physical environmental component to that, which is, who needs what chair? Whether people have wheelchairs; whether people have oxygen. And that will depend on where they're sat in the room. So some of it is just a matter of physiological needs first, and then after that there'll be people who I can observe need more space than others. And they do. When people first come, I sort of watch how they are and how they react to that. And so sometimes I'll see people actually be up walking around. They won't be sitting or they'll sit somewhere else, and I'll say to them, 'Are you not comfortable with there'? Sometimes they're not aware that that is happening and it's nerves or whatever. Some people will be very direct, 'I can't sit with my back to the door, I have to face it'. So I try to assess those things from people either by talking to them or just visually observing them. And then try and fit them into the room. So the space that we have, I can fit, I can accommodate some things and I can't accommodate others. But mostly I try and assess what the needs are and then try and make that happen if I can".

The diversional therapist makes deliberate moves within the palliative care day hospital to account for the needs of both individuals and the collective. Unseen by the majority, she continually manipulates both social and physical elements of the assemblage to attend to the group as well as individuals. Importantly, she is attuned to bodies affecting and being affected. In the next example she narrates how the limitations of the physical environment are compensated for to ensure safeties:

> Extract 8.20 (SSI, diversional therapist, palliative care day hospital, 12th April 2010).
>
> "If everybody's (patients) a little bit anxious today or the bus broke down, I (diversional therapist) might put on some relaxation music and we'll have, maybe we'll have a special drink. We'll do something as a distraction or as a therapeutic tool to kind of get everybody back to being safe again. So I might put the music on, or I'll turn everything off and we'll just have a chat about what happened, you

> know. But then a grieving family might be sharing the same room. So there might be children running around, babies crying, people changing children, or just families distressed in the same room. So it's not always just possible to do exactly what I want or how I want to do it because that's a shared environment".

This account shows how the diversional therapist employs music, social activities as well as group facilitation skills actively seeking to influence the affective atmosphere in order for palliative care day hospital attendees to be safe. Yet, her capability to do so is limited by factors in the room beyond her control. I became most aware of the critical leadership role of the diversional therapist in creating safe assemblages in her absence and as I noted in my reflective field notes:

> Extract 8.21 (RD, palliative care day hospital, 19th August 2010).
>
> Today felt different when I (researcher) walked into the day hospital. I felt an unease and wasn't sure exactly why. I didn't think my discomfort was solely Mary's (patient) emotional state. However, I did notice the diversional therapist wasn't around and I wondered whether it was because she wasn't there to 'contain' things.

My own sense of unease brings me to an awareness of the anxious atmosphere within the palliative care day hospital. The importance of the diversional therapist's attentiveness to the atmosphere only became visible through her absence. That is to say, becoming-safe assemblages are partially constructed as a result of interdisciplinary team working through the diversional therapist's attentiveness to safeties.

The physical environment as one shared with the in-patient palliative care unit was exploited for the benefit of all. I set out to study the day hospital on the basis that it was a discrete place where people would be less unwell than they would be in the in-patient unit. However, my assumptions were challenged in two ways. First, I realised that the in-patient unit and day hospital were inextricably linked. In other words assemblages are dispersed, always "multidimensional, resonant, open to other spaces and never fully enclosed" (Macgregor Wise 2000, p298). The palliative care day hospital was open to the assemblages of the palliative care in-patient unit and vice versa. Second, early in the study my assumptions about in-patients being less able to participate were exposed and later confirmed (as I discussed in Chapter 3). The next two extracts trace these entanglements. The first extract from an interview with the diversional therapist highlights that the palliative care day hospital has an explicit purpose:

> Extract 8.22 (SSI, diversional therapist, palliative care day hospital, 12th April 2010).
>
> "And one of the overt considerations in setting up the day hospital is it provides an environment where people can mentally move from being in an acute care environment to a terminal care environment, and just have that halfway house where they can get their head around the fact that their disease isn't curable, that they have to expect to deteriorate, and that the end is in sight."
>
> Extract 8.23 (EFN, patient, palliative care day hospital, 3rd August 2011).
>
> There was a patient in a hospital bed facing towards the window but positioned to be part of the group. She had a portable oxygen bottle beside the bed. The sun was bathing her and she was facing towards the window. I (researcher) hadn't met her so I introduced myself and explained why I was there. She smiled, told me her name was Annie and asked "Are you from Europe too"? (in a German accent) She told me that she was enjoying being in the day hospital as she hadn't been out of the ward for some time and was fed up 'looking at the four walls'.

The extract shows, that to some degree, interactions between in-patients and day hospital patients were purposeful. In-patients accessed the day hospital and its activities even when confined to bed. Families of patients from the in-patient unit accessed the lounge and kitchen facilities in the room where the palliative care day hospital took place. In other words, the palliative care day hospital and the palliative care unit are inextricably connected spatially. The exchanges that result from these spatial entanglements are exploited for the perceived benefit of both day hospital patients and in-patients. Coming into contact with in-patients challenged patients attending day hospital to confront death. This is seen as positive by the specialist palliative care hospital team who operate in a paradigm of 'open awareness'[45]. For in-patients, like Annie, spending time in day hospital could temporarily free one from the confines of the ward.

Becoming-safe assemblages are always a possibility whatever the care setting or the characteristics of the physical environment. I observed and sensed what I considered 'affectively attuned' encounters between healthcare workers and those they care for resulting in becoming-safeties in the acute hospital as well as the palliative care hospital. The following narrative extracts illustrate such encounters. In the first, the palliative care chaplain shares one such 'encounter'. In the second, as ethnographer, I am witness to the interaction that occurs between an elderly woman, her daughter and the palliative care nurse in the acute hospital:

> Extract 8.24 (SSI, chaplain, palliative care hospital, 22nd July 2010).
>
> "I (chaplain) hadn't met Diane (patient), so I went and introduced myself and she grabbed hold of my hand and as hard as she could and she was shaking and she was crying and I'm not, with three daughters, I'm not someone who's put off by tears, I can handle it (except if it's me-laughing) but I don't reach for the tissue box and give them a tissue box. If they are crying, I let them express those tears because I think it's a good thing at times and she started, just holding my hand. We didn't talk, I just said, 'I'm Jim I'm the chaplain here', and that's about all, didn't say anything. I think I said, 'Would you like me just to sit with you?' and she just nodded her head and she held my hand and after about ten minutes she sort of settled down and she started to talk and one of the things she said to me was, 'I don't like crying', and I said, 'Look if you're embarrassed about crying in front of me Diane you don't have to be', I said, 'Because I don't think anything less of that, I think it's sometimes good for us to cry', and she said, 'No, no, I don't like crying in front of other people', and I said, 'Well ok, so you feel embarrassed not because of me but because I was here?' She said, 'Yes'. And I said to her, 'Well you know Diane that's one thing that you can control', and she said, 'What do you mean'? And I said,

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[45] See Chapter 2 under heading 'The hospice and palliative care movement' for my critique of 'open awareness.

> ‘Well you can’t control anything else here at the moment, can you? You’ve been in here’, I think she’d been in here for two weeks, ‘Everything’s orchestrated for you, you can’t even get out of bed, can you?’ She said, ‘No’ and I said, ‘But the one thing you can do is you can choose when you want to cry and when you don’t want to cry’, and I just sort of said that just to encourage her and she looked at me and she said, ‘Thanks for that!’ And I said, ‘Thanks for what?’ And she said, ‘I didn’t realise that. You’ve given me one thing that I can do while I’m here, I can cry when I want to cry and I’ll choose not to when people are here’, and not every time we met but from then on I’d say to her, ‘So how’s your crying going’? And she’d say to me and she’d wink sometimes and she’d say ‘It’s going fine thank you, Jim’. She never cried in front of me again, but I knew she used to cry and it just empowered her and that created for her a healing place and definitely a safe place”.

This account demonstrates how the chaplain does not solely apply a cognitively framed skill or technique but rather allows an affective presence to transpire. The chaplain retains body-self in the encounter, reflecting, ‘I’m not someone who’s put off by tears, I can handle it’ and retains his character and humour in recognising his limitations; (‘except if it’s me-laughing’). He remains affectively receptive; ‘I just said I’m Jim, I’m the chaplain here and that’s about all, didn’t say anything. After about ten minutes she sort of settled down’. In turn, this provides the conditions necessary for Diane’s creative capacities to emerge. Through learning to be affected, the chaplain is affectively receptive to uncertainties and to Diane’s suffering. That is to say, the extract demonstrates the chaplain and Diane collaboratively affecting and learning to be affected. In doing so, the chaplain and Diane co-create safeties, thus opening up and making tangible new possibilities for Diane even though she is dying.

Becoming-safe assemblages were possible even in the four-bed room of the acute hospital ward. This was evident from my ethnographic field note entry describing one particular experience when I shadowed a palliative care nurse as she interacted with a dying patient and her daughter:

> Extract 8.25 (EFN, PCN, acute hospital, 28th January 2011).
>
> We (researcher and palliative care nurse) entered the four-bed bay where the elderly patient who the palliative care nurse (PCN) had come to see was in the corner beside the window. The curtain between her and the next patient was closed. It was evident that she was dying. The patient’s daughter sat on the table beside the window and the PCN sat down beside her and asked how she was. The PCN introduced me and asked permission for me to be present during the consultation. There was what I would describe as a tender directiveness in the interaction. The nurse sprayed some water gently into the lady’s mouth with a plastic spray bottle as she gently stroked her head. It was obvious the water was appreciated. At the same time she (the patient) appeared agitated trying to remove the bed covers. The PCN, proposing that she (the patient) may just be too hot, removed the blanket. The patient’s daughter expressed that she thought her mother could be itchy. “If she is itchy then we can use this”, the PCN said reaching for the moisturizer. I watched on as she dispensed some into her hand and handed the container across the bed to the patient’s daughter to do the same. In mirror image they stood at either side of the bed rubbing the cream gently into the lady’s arms. I was touched as I watched the actions of the patient’s daughter and the nurse in what appeared a moment of intimacy.

First, the nurse asks permission for us to approach the bedside and enter into what she views as the private space of the patient and her daughter. Second, she does not separate physical, emotional and spiritual care, but rather by her attentiveness to the physical body she cares for the whole person. When the brain is positioned as inseparable from body, the patient’s body as well as the nurse’s body affects and is affected. The nurse takes account of this, respectfully talking to the patient despite the fact that she is moribund. Lastly, she is open to the suggestion by the patient’s daughter that her mother may be itchy and responds accordingly in collaboration with the daughter. The nurse is affectively attuned. With an attitude of humility, she opens up all of her perceptory senses to what manifests in the encounter with a dying patient and her daughter. She senses, hears and listens to words, not only with conscious and cognitive elements but also unconscious elements (Jerak-Zuiderent 2012) or what Hutchinson and Brawer call “analogic communication” (Hutchinson & Brawer 2011, p40). This extract demonstrates again the patient, her daughter and the nurse using such communication and collaboratively affecting and learning to be affected, co-producing safeties.

When healthcare workers are learning to be affected safeties become possible. Affective atmospheres that bring becoming-safe assemblages into being were more notable in the palliative care unit but are possible whatever the care setting. Becoming-safe assemblages are ambiguous and uncertain and yet are made possible when healthcare workers both as individuals and as teams are affectively attuned and actively engage in making them possible. I now turn to consider the place of non-human bodies in fostering learning to be affected.

Section 8.4 The Built Environment

I explicate physical space here merely as a heuristic device. It is overly simplistic to separate the physicality and non-physicality of assemblages. As I have argued thus far, living bodies are body multiples becoming in relationship with their surroundings. This complicates the idea that the physiological body is distinct from its spatial surroundings or from the cultural body and thus from other bodies in assemblages (Blackman 2008).

Put more simply, bodies, care and space are all mutually implicated in creating safeties. As I intimate in the previous section, it is possible, at least to some degree, for safeties to come into being when the physical environment is less than optimal. This is evidenced from the day hospital where the becoming-safe assemblages are foregrounded against a material environment that is suboptimal as well as being contested. That is, day hospital takes place in the room that also functions as a lounge room and small kitchen space for the in-patient unit. It also serves as a storage space for the in-patient unit and it was not uncommon for me to walk into the room to see a hospital bed with a pressure-relieving mattress positioned in the corner of the room. Yet despite its physical limitations, day hospital enacts becoming-safe assemblages in a manner that is, at times, profound. I now wish to explore the relationship of physical environment and safeties further. Particularly remarkable was the difference I noted in Ken (patient) who, like Greg (patient), I visited in both the acute and palliative care hospitals:

> Extract 8.26 (EFN, patient, palliative care unit, 13th January 2011).
>
> Ken (patient) was in a large single room at the back of the ward with a large window that looks out onto gum trees and the golf course. The room was large, bright, and airy. I (researcher) was struck by how much cleaner and well cared for he looked compared than when I saw him before his transfer. Perhaps it was because he was well shaven now. His eyes were closed, but he was smiling and he welcomed me into the room. I sat down beside him and asked him how he was. He said chirpily, "If I knew you were coming I would have got you to bring me the paper." I chortled, responding that I would see what I could do. I asked him how he was settling in. "Beautiful, he said, I just hope I get the opportunity to enjoy this place."

Not only did Ken look different when I visited him for the final time in the palliative care unit, he was also in good humour and, despite his apparent coming to terms with his dying, he viewed the palliative care ward as somewhere to be enjoyed. While the importance of architecture to wellbeing has been recognised (Sternberg 2009) and the significance of the environment is recognised in some clinical settings,[46] in the main, acute hospitals are assembled and enacted as functional clinical technical environments. Healthcare workers felt that the limitations of the physical space could, to some degree, be overcome if other matters were attended to as the next extract from a conversation with a ward clerk conveys:

> Extract 8.27 (FI, ward receptionist, acute hospital, 15th February 2011).
>
> "There's an atmosphere on the ward, a different atmosphere to other wards"; she (ward clerk) stressed. "When 'our' (cancer patients) are admitted into another ward they always want to come back here. They feel safer here"; she said. "Even though that ward downstairs was dingy and horrible and old, they still wanted to come down there. Patients would ask to get back there".

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[46] See for example, hospices (Worpole 2009), specialist dementia care units (Fleming, Crookes & Sum 2010) and children's hospitals (Queensland Government 2012).

The ward clerk in this account describes how the oncology ward has a particular atmosphere that patients find safe despite a poor physical environment. This suggests that an 'atmosphere of safety' may be possible despite the physical state of the ward. Yet for patients, physical elements of the ward were indicators of safeties and un-safeties. For example, for Pete, who I quoted back in Chapter 7, the physical environment is indicative of whether he is safe. He takes account of the stains on the ceiling when considering infection risk and thus whether he will agree to a stem cell transplant. Likewise Joe (Chapter 6) comments how the colour of the walls impacts on his wellbeing. For both, the physical environment of the acute hospital space(s) is implicated in producing safeties, or to use my terms, becoming-safe assemblages.

The built environment is designated, in the main, for clinical technical functions. The following extract, spoken by an enrolled nurse shows how clinical technical function is privileged over social function within the built environment of the acute hospital. The nurse relays the effect of 'losing' the ward lounge room on her as well as on a patient and the patient's family:

> Extract 8.33 (SSI, EN, acute hospital, 11th March 2011).
>
> "It was set up and it had beautiful big comfy couches and a TV and it had a big eight seater dining table and it had a little kitchenette area and it was fantastic because the patients that couldn't go home, their family could come in and they could have their dinner together just like normal or they could sit and watch TV, as a homely experience. When that room got taken away and was needed for a clinical space, the patients then had nothing and it was literally bare walls with a TV and a bed in their room. They had nowhere to go to escape to and when someone passed away in a four bedded room we would take the patient into that lounge room area, close it off with the family and then they had a massive room to be there with their family member who had just died. There was this one family that I'll (enrolled nurse) never forget because they were the same age as me when my step father passed away. They all wanted to come and stay so we put the kids up in the lounge room and they just laid in the lounge and slept overnight until the week leading up to their mums passing and it's things like that. Once that room was taken away that couldn't happen.

> Those kids would have missed out. It's got to be really homely. Like at home but in hospital".

Setting aside a physical place for this family means that children are able to accompany their mother until her death. Additionally, setting aside this room creates the conditions for nursing staff to care in a way that is satisfying. Furthermore, the emotion of the nurse in telling her story was palpable as she related personally to the significance of what this meant, not only for the patient and her family at the time, but just as critically, for the children into the future as they grieve the loss of their mother. This extract highlights the inseparability of the physical and the social components of assemblages both inextricably linked in fostering safeties.

Further, the removal of a room set aside for dying patients and their families, privileges clinical technical space over social space and is an additional symbol of the abandonment of dying patients. This removal is further a testimony to the lack of recognition of affective relationship practices contributing both to patients' safety and to healthcare workers' well-being.

I capitalised on the acute hospital's redevelopment to investigate how the physical environment relates to the social environment in terms of producing safeties. I was able to do this because during the period of fieldwork, several hospital wards moved into a new building. This move to new wards brought the workspace into nurses' consciousness. In particular, nurses commented on the importance of being able to see patients and patients being able to see them. Lines of sight were regarded as important not only between patients and nurses, but also among nurses themselves:

> Extract 8.28 (SSI, RN, acute hospital, 7th February 2011).
>
> "Like when there used to be, I (registered nurse) love four-bedded rooms. And I want more of them, because they (patients) can see you. And they (patients) can easily just go, 'Excuse me, can I have this?' And I like them just being able to say, 'Excuse me'! And just to be able to approach and to talk to you. But also because you can see them all the time. It's also that I've got more interaction in a four-bedded room. I can build up a rapport with them (patients) and once you have that rapport people do talk to you a lot more and, they're not so afraid to ask you. Whereas in single rooms, they (patients) don't see you

> either. And it's that part that upsets most of us (nursing staff), because they don't know if you are busy. They don't know that you are there to help them".

For this nurse, proximity to patients including being able to see them makes being able to develop relationships easier. In turn, this makes her more available to patients and able to affectively attune to their needs. From the point of view of some patients as well as staff, the four-bedded room affords accessibility to the nurse as well as social interaction (see Gloria and Joe).[47] What is safe for one patient and family in terms of bed configuration is not necessarily safe for others. Most important is the need for flexibility so that the physical environment can, as far as possible meet the particular needs of an individual and their family. Critically, patients, where able, were instrumental in creating their own 'space'. This was assisted, in part, by the material surroundings as demonstrated in the extract that follows:

> Extract 8.29 (SSI, diversional therapist, palliative care day hospital, 12th April 2010).
>
> "Those (patients) that are mobile can actually go and find a space. It only takes two or three days to realise oh, that's where he (patient) likes to be, so that would be a space, whether it's in the sun, whether it's in the shade, whether it's where they can smoke, or wherever that is, in having that space, people (patients) tend to go back to what's familiar".

What this extract shows is that patients seek out areas of the hospital according to their needs and the kind of places with which they have an affinity. In other words, they attune with the non-human as well as the human elements of assemblages.

This section has established that becoming-safe assemblages are not necessarily reliant on the built environment. Yet, as a component of assemblages the material environment, while unable to compensate for social elements of the assemblage, can help foster affective atmospheres and thus make becoming-safe assemblages more likely. In other words affective atmospheres come into being as a result of both material and non-material components of assemblages. As Anderson has put it; "Affective atmospheres

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[47] This is consistent with the findings from a recent study carried out by (Gardiner et al. 2011): i.e. that a single room was important for many people but that shared rooms can lead to social interaction (See Chapter 2, Literature Review).

are a class of experience that occur before and alongside the formation of subjectivity, across human and non-human materialities, and in-between subject/object distinctions" (Anderson 2009, p78). The next section further analyses the entanglements between the material and social by exploring the relationship between safeties and connections with home.

Section 8.5 Connections with 'Home'

> *"A man's self is the sum total of all he can call his; not only his body and his psychic powers but his clothes and his house, his wife and children, his ancestors and friends, his reputation and works, his lands and horses and yacht and bank account" (James 2007, p291).*

I have already discussed in Chapter 2 (Literature Review) that home as an outcome measure for palliative care and its association with a 'good death' is open to question. This section interrogates the meaning of home, the significance of connections with home and the implications for safety of dying people in hospital and those caring for them. Patients and family members, in the course of conversations, often raised the topic of home. However I also explicitly asked the question 'If you are unable to be at home, what would it take for you to 'be' at home or 'feel at home' here in this place'? Thus, I wish to take a deeper analytical approach to the meaning of home than I have done thus far in the thesis. Dovey (2005), herself drawing from Deleuze and Guattari, argues that the meaning of home is 'fluid', 'becoming' rather than being. I extend this debate, exploring the meaning of 'home' for dying people and their families. I intentionally chose not to produce a definition of home for the purposes of my question to participants, viewing it, like Dovey, as having symbolic meanings as well as the more concrete meaning of one's dwelling place.

Patients frequently mentioned home as the environment where they felt most safe. Here, safety relates to a place of security where individuals have more control over the environment, retain close connections with loved ones, and where one's individual rhythm can be maintained with the ability to carry out activities at one's own pace. There is no doubt that for many people home is the place they would choose to be cared for if at all possible and anything other than home is unimaginable:

> Extract 8.30 (SSI, patient, palliative care day hospital, 3rd August 2010).
>
> "I find for me (patient) that I'm actually able to be out of hospital and be looked after at home. I think is the greatest. Well it's a Godsend. It's a real blessing because the environment of your home and your family, nothing can beat that. Because when you're in your own home and you've got your family around you and no one looks after you like your family".

The participant above alludes to 'home' as partially crafted by the people he is closest with. Thus produced, home is something that healthcare professionals are unable to provide. Patients commonly responded to my home question in terms of their relationships with others, that is "One can be at home simply in the presence of a significant other" (Macgregor Wise 2000, p299). This was heard from Gloria back in Chapter 6 and again from Liz, here in the current chapter.

The arguments that now follow are anchored in participant articulations of home. First, I suggest that for people in the final stages of life, home is brought into sharp focus. I contend that the meaning of home, when given to be an elusive concept with slippages in meaning between place of dwelling and ontological security, assumes a particularly heightened meaning for those who are dying and particularly so when in hospital. Connections with home can become particularly potent when death is imminent, as was the case for Patricia who died one day after transfer to the palliative care unit:

> Extract 8.31 (FI, patient, acute hospital, 14th November 2010).
>
> Patricia (patient) said that all she wanted to do was, "Get back to my Croyden, to my own place, to palliative care (unit) there. There (the palliative care unit), my poodle will be able to visit me and all my friends who are in their nineties you know. I want to be able to be myself. I need my nails done and my hair done. I have always taken pride in my appearance", she told me. She gestured with her hand repeating, "I just want to get back over the hill to Croyden, where I can relax, where I can be less anxious". She talked in terms of Croyden refreshing her soul as it is what she called 'her place'.

For Patricia, who knew her life was coming to an end what she identifies as her 'soul' is inextricably linked with home. If home is as Cooper Marcus (1995) proposes, *a mirror of self*, and associated with a deep sense of identity and a place where identities are expressed socially and culturally, then it follows that being 'disconnected' from home is problematic. This is profoundly so for Patricia. Despite closeness to death, being able to connect with home means that she continues to become a creative nomadic self. Patricia was not alone in this respect; for Joe having his grandchildren in his midst during his final weeks was important to him; June had a need to retain a close connection with her Father via a phone-line next to her bed, and Shane had a requirement for his family to be kept well-informed of what was happening to him and to know that his elderly mother's needs were being met back at home. Furthermore, the gathering of meaningful material objects around oneself and personalising the bedside also helped to strengthen connections with home. For Joe, it was having his flag and photographs around him that yielded a 'more homely' space. For Greg, it was having his favourite music. For Mrs. Roberts, it was having a large photograph of her son at the bottom of her bed.

When conceptualisations and enactments of home are allowed, 'slippage' where meaning is entangled with but much more than the physical properties of assemblages, they become critical for the dying person in hospital. Thus, the enabling of connections with home, wherever the person is cared for, is crucial. The doctor below was prepared to put himself 'on the line' in order to meet such needs:

> Extract 8.32 (VRM #2, staff specialist (respiratory), acute hospital, 2nd June 2011).
>
> "I (staff specialist, respiratory) mean hospitals are the most filthy environments anyway so I really can't see the occupational health and safety problems of bringing a dog, who's probably much better looked after and cleaner than most of the people in the hospital, into the ward. So I didn't think there was any risk to anybody else (patients) and clearly this is one of the most important things in June's life. So not that I've got any authority but again being 'the doctor' I can say, 'Aw, she (June) can have her dog in'. I was more worried about the nursing staff finding out (smiling) and taking me to task. So you know, if it was my parents and there was a small thing that would make a big

> difference and you were bending a rule to do it I wouldn't think twice and I would 'cop the flack' for that".

This doctor rationalises his decision by suggesting that the hospital is already unclean. He uses his authority as 'the doctor' to justify breaking the rules. He does so in the context of being affectively attuned to June's needs by putting himself and his own family in the same position. His willingness to break the rules in this way is not without risk. His account demonstrates again how healthcare workers juggle safeties. Furthermore, this account shows how difficult it can be to foster connections with home in the acute hospital environment where clinical technical safeties are given priority.

A further argument I want to make is that the very 'slippage' of the meaning of home, its never 'fixed' character, always becoming, means that the dichotomisation between hospital and home as a place of death may be misguided. For Greg, as for others, home was not a safe place to be. Greg made it clear that even if he was well enough to return home for a short time he wanted to return to die in the palliative care unit where he felt 'at home', safe and cared for. Likewise for Patricia, the necessity to return home was not to return to her place of 'dwelling', but rather 'home' to Croyden, where she could connect closely to her friends and family, her dog, and to be surrounded by a natural and familiar environment connected with her birthplace. Magat (1999, p120) refers to this as 'Big Home' making the distinction between 'Little Home', the place of dwelling and 'Big Home', the home country or homeland. In the following excerpt, the significance of 'Big Home' takes on particular significance to me as well as Patricia as our homeland narratives serendipitously bond us in a seemingly timely manner:

> Extract 8.34 (RD, acute hospital, 14th November 2010).
>
> She (patient Patricia) shared her memories and reminisced of the special moments in her life. She told me (researcher) that despite living in Australia for 50 years she still got homesick. Again she gestured with her hands the rolling hills, that she missed the greenery and the 'brightness' of her homeland and 'the familiar'. This struck a strong cord with me resulting in a moment of intimacy. I had been having almost exactly the same feelings this week about my own identity as an immigrant. I reflected on the "shared dimension to the healing encounter" that Kearney (2000, p24) talks about as I considered my own situation and what 'home' means to me as I took

> the step to becoming an Australian citizen this week. I was reminded of the mayor's words at the ceremony; "the gap between living in one country and being the citizen of another creates a vacuum". I too could relate to missing the physical environment of my homeland, the green, the colours, and the quality of the daylight. We (Patricia and researcher) laughed together as she told me that when she had returned home, she didn't want to be there, wanting to return to Australia. I related to her sentiment.

The vacuum of living in one country and being the citizen of another perhaps serves as a powerful metaphor for the 'vacuum' created when dying patients are disconnected from 'Home', whether 'Little Home', 'Big Home' or at their points of convergence. In the palliative care hospital where the goals and philosophy of care are compatible with connections with home, healthcare workers sought to give these connections precedence. The creative capacities of patients continue to be recognised even in the final weeks or months of life. Furthermore, when the physical body is unable to return home artifacts connecting patients to home are able to populate the bedside. The scenario below is a poignant one as the wife of a patient attempts to verbalise the characteristics of the palliative care hospital's affective atmosphere:

> Extract 8.35 (FI, patient's wife, palliative care day hospital, 27th May 2010).
>
> Madge (patient's wife) tells me (researcher) about Norman's (patient) stroke and how he has learnt to paint with his left hand. She tells me that he is on his third painting and that she has laminated them and put them on the wall in his room in the ward. She wells up with tears as she conveys that it has brightened up the room. Unprompted she expresses how good the staff (palliative care team) are, nothing too much trouble for them, how good the doctors are and that none of their other hospital experiences compare to here (palliative care hospital). She articulates that she thinks it because they are trained to deal with 'this sort of thing'. She tells me that they have experience of two other hospitals. "I especially didn't like one of the hospitals", she says. "I (Madge) cannot put my finger on exactly why".

As Madge tells me about Norman's paintings, she appears to convey something much more symbolically important about having them displayed than simply brightening up the hospital room. Madge connects Norman's paintings with her wider experience of the palliative care unit, including the relationships she has with healthcare workers and her affective experience of the hospital, in comparison with other experiences. In other words, it is both the human and non-human components of the assemblage that combine to produce safeties. Connections with home, including material artefacts, as well as social connections are of particular significance to patients when they are in hospital. Physical elements of assemblages are unable to compensate for deficiencies of the social environment (Morgan & Stewart 1997).

Section 8.6 Conclusion

This chapter has provided an account of the elements of assemblages that when brought together make normalised un-safeties less likely and increase the likelihood of healthcare safeties. The findings of this chapter reveal that much of what is experienced by patients, families and healthcare workers occurs as pre-verbal as well as through verbal language and the conscious in relationships of co-affection. In other words, agency extends beyond the 'body singular' to the 'body multiple' or a combination of agencies that are irreducible to one another. Importantly, no one 'body' creates an atmosphere of safety and security. Rather safe assemblages arise from the collective of bodies. Further, clinical judgement and affective knowing are interdependent. Safeties only arise when healthcare workers are affectively engaged with the implications of the task and operate in a weave of commitment with others. Becoming safe-assemblages are contingent on healthcare workers becoming affectively attuned and open to patient and family expertise in relationships of trust. Safeties become possible where experimentation and creative engagement are fostered to enable new knowledge making safe dying a possibility. Critically, 'learning to be affected' is not a 'soft option' but central to collaboratively producing safeties.

Chapter 9 Conclusion

Section 9.1 Introduction

In Chapter 1, I indicated that this thesis is written at three levels. First, I give an empirical account of 'patient safety' relating specifically to dying patients, their families and healthcare workers. Second, I provide a reflexive account of emergent and visual methodologies. Third, I offer a critical account of 'space' in relation to patient safety and end-of-life care inspired by French philosophers Deleuze and Guattari. This final chapter addresses all three levels at which this thesis is written. Collectively, it articulates the unique contribution of the research to extending empirical and theoretical literature, making specific recommendations for further research.

This thesis celebrates the movement of life as it unfolds, making new connections and lines of flight. Thus, even as it is being completed, it is already continuing and expanding. As such, the thesis is not so much about coming to a certain understanding of the world but rather expressing it differently (Dewsbury & Thrift 2005, p91, 92). I do not come to a definitive interpretation and a certain conclusion. In keeping with rhizomatic thinking and writing, I respond to the research questions leaving room for them to remain open. In this way, I hope that other interested parties will continue to construct useful meanings from my own accounts as well as those of participants. This research acknowledges that the people's lives and healthcare settings I interrupt with the help of a camera, and the safeties and harms I write about, emerged in specific settings and times producing their own realities. In this thesis, I have sought to find a balance between what is common and what is immeasurable; "between universality and multiplicity" (Despret 2004a, p222). I have attempted to enact an account of humility. I have found this to be an uncomfortable task. As Dickson (2011, p11) pointed out:

> *"Humility stands alone among the virtues in that as soon as you think you have it, you probably don't. And, yet, the reverse does not follow. Not thinking yourself humble is no indication that you are. You might be right! Both the arrogant and the humble are unlikely to think of themselves as humble. So, how could you ever know if you have attained the virtue"?*

Yet, my account is a compelling one nonetheless. In this final chapter I convey the significance of what this account might mean in relation to the wider debates surrounding end-of-life care and patient safety. This chapter is structured into four sections. Section 9.2 is titled ‘Addressing the Research Questions. I respond to each of the research question in turn. Section 9.3 titled ‘Thesis Limitations’ outlines the limitations of the thesis; Section 9.4 is titled ‘Future Research’ and articulates new questions that the research raises. Finally, Section 9.5, the ‘Conclusion’ draws the research together.

Section 9.2 Addressing the Research Questions

Research Question 1: What are safe healing spaces towards the end of life?

There is a dearth of extant literature addressing patient safety and end-of-life care. This thesis contributes to redressing this gap. I have explored safety empirically, redefining data as inseparable from research relationships. I am guided by a notion of space, not as a static and uniform void inhabited by a shared reality but rather as a moving phenomenon that resists categorisation (Dewsbury & Thrift 2005, p89). I address this research question by first considering the antithesis of safe healing spaces.

This thesis has uncovered what I term ‘normalisation of inattentiveness to healthcare safeties’. Habitual care patterns expose dying patients and their families to harms along with those healthcare professionals caring for them. The findings of this thesis support the findings of other studies. That is, participants are subjected to unremitting harms including unrecognised and untreated symptoms, poor continuity of care and planning, and a lack of family support (Myers & Lynn 2001). These unremitting harms are for the most part, unaccounted for by organisational clinical governance structures.

The field of patient safety has to date, dealt with iatrogenic harm by focusing on the individual actions of healthcare professionals and more recently on a systems approach to deliver safe healthcare. Patient safety, as currently conceptualised, is principally assumed to be achieved through the application of evidence-based guidelines and protocols (Runciman et al. 2012). Here, safety is a technical achievement.

Instead I advocate new expressions of patient safety towards the end of life. Importantly, these new expressions have arisen from patients, families and healthcare workers thinking about these issues themselves. For participants, technical safety is critical but cannot be disentangled from interpersonal safeties. Most critical is that patients and families are central to establishing meanings of patient safety and of what is deemed ‘adverse’. As demonstrated in Chapter 6, harms for the most part accepted as normal inside the hospital walls are not considered ‘normal’ by patients and families. As Mol (2002, p142) pointed out, outside of the operating theatre cutting into someone else’s flesh would be regarded as a violent matter rather than a technical one and considered a serious transgression. As Wicks puts it, “there are disturbing parallels in the history of scientific medicine, where observation becomes the first stage in a process of objectification which can lead to cruelty and sadism” (Wicks 1999, p59). I argue that, for dying patients and families and, at times, for healthcare workers caring for them, what is considered as ‘treatment’, can be a serious transgression, even within the walls of healthcare settings. When the goals of care are aimed at quality of life and dying becomes a reality, these transgressions become most salient. Patients’ and families’ meanings of safety are what matters most at the end of life. In the context of this research, these meanings have been made visible and tangible through the medium of visual methods.

Current approaches to safe practice, geared towards a systems approach, assume that safety will occur if predetermined and previously agreed norms are followed, such as specific protocols (Jerak-Zuiderent 2012). Instead, and based on how participants articulate safety, I argue that for the need to move past current conceptualisations of ‘patient safety’ to a new theoretical framework of ‘becoming-safe assemblages’ and ‘healthcare safeties.’ This has several effects: I propose the term ‘becoming-safe assemblages’ to emphasise that safeties do not arise from predetermined or fixed guidelines mechanically enacted by individual healthcare workers. Rather, safeties are dynamic and emergent in nature. I argue that safeties require the kind of openness and creativity that I demonstrated in Chapter 8. Multiplicities of safeties mean that safeties are often contested and have to be continually negotiated. The term ‘becoming-safe assemblages’ recognises safeties as being contingent on an entangled web of social interactions in the context of material surroundings. Defined in this way, safeties are recognised as incorporating emergent and adaptive interdependent behaviour. Further, I propose the term ‘healthcare safeties’ to highlight that the safety of patients and families is inseparable from the safety of healthcare workers. Whether or not safeties are brought into being is as much determined by patients' and families' expertise as much as by healthcare workers in relation to their colleagues and surroundings.

The findings of this study therefore, contribute to emerging research in the broader healthcare field showing that safety depends on the ongoing interactions of people with one another and with their surroundings (Iedema et al. 2006a). I showed in Chapters 6, 7 and 8 that safeties do not arise as a result of system devices such as protocols and policies. Instead, safeties rely on healthcare workers, in collaboration with patients, responding to emergent and situated events. Healthcare workers are continually and contingently defining, redefining and negotiating safety in situ (Bosk 2003; Hor et al. 2010; Mesman 2011). This thesis builds on these findings by showing that patients and families are not merely the recipients of these negotiations but rather, are actively involved in them. Thus, healthcare safeties are contingent on bringing together healthcare worker expertise and patient/family expertise to co-produce safety.

Research Question 2: How can healthcare space(s) enhance safety and healing?[48]

I have now found the term 'healing,' initially used in the first and second research questions a misnomer. The concept of healing in the context of its definition as I initially use it above is problematic for two reasons. First, this thesis, by defining the body as body multiple[49], considers the domains of the definition as falsely discrete entities. Thus, to directly address the question: How can healthcare space(s) enhance safety and healing? I suggest that siphoning off care according to particular entities such as the psyche or spirit does not account for the inseparability or, at the very least, the intimacy of connections between body, mind and soul, a conception supported by emerging neuroscience (Damasio 1994, 2008; Immordino-Yang 2011a), psychology (Cacioppo & Decety 2009), theology (Murphy 2006) and philosophy (Shusterman 2006). Yet, Cartesian dualism pervades care processes. Even the World Health Organisation definition[50] of palliative care separates physical, psychosocial and spiritual problems as distinct entities. Damasio, coining the phrase "Descartes' error," considers

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[48] Where healing is defined as 'the physical, psychological, social, and spiritual processes of transformation that increase resilience and coherence and where wholeness is cultivated'.

[49] And without reworking intractable debates on the relationship between mind and body (Warner & Szubka 1994).

[50] *Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (World Health Organisation 2012).*

this distorted view “a spiritual crisis of Western society” and one that infuses research as well as practice condemning matters of affect and feelings as inconsequential (Damasio 1994, p257). I argue that we are at one and the same time physical and spiritual beings, or in the words of Damasio (1994, pxvii), “The soul breathes through the body, and suffering, whether it starts in the skin or in mental image happens in the flesh”. In other words, the power to be affected applies equally to the mind and body involving both reason and passion. As Hardt (2007, p ix) puts it, “The mind’s power to think corresponds to its receptivity to external ideas and the body’s power to act corresponds to its sensitivity to other bodies”. Thus, the construction of the ‘psyche’ or spirit as separate entities is problematic. Separation of care and skills leads to disregard for affectively attuning as the domain of particular experts such as psychologists or social workers (Liben 2011). As Chapters 6, 7 and 8 demonstrated, practical and technical needs matter to patients and families but these needs are not divorced from desires and fears. As Mol[51] posits, one can be a body in physical pain, a dying body, and at the same time, a body with creative desires. Instead of constructing the body as different objects, body multiple acknowledges the “hanging together” of object aspects as “more than one but less than many” (Mol 2002, p55). This requires a paradigm shift to one of re-embodied care as integral to healthcare safeties rather than viewing care of the ‘psyche’ or ‘spirit’ as ‘soft’ extras supplied if, and when there are available resources or time.

Further, I have discovered that ‘healing’, does not reside in the individual but within dynamic encounters arising from bodies affecting and being affected by others. Chapter 8 conveyed that much of what is experienced by patients, families and healthcare workers within encounters locates something greater than any one party. This chapter showed the entwined nature of the social dynamic. This view is prominent in philosophy (Shotter 1993; Wittgenstein 1953), and in psychoanalysis (Beebe 2004), and is now corroborated by neuro-scientific research (Ledoux 1996; Libet 1985), demonstrating individuals to be connected in an unconscious, pre-personal, bio-physiological way (Iedema 2009).

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[51] Mol (2002) describes the various ways that atherosclerosis is ‘enacted’: in the pathology department, atherosclerosis gets defined as a ‘thickening of the blood vessel wall’. in the clinic, the disease is performed as ‘walking pain’, Mol asserts that these different ways that atherosclerosis is articulated enact a different version of the object.

Importantly, Chapters 6 and 8 established that communication is not simply an exchange of information or of meaning but one of resonance. Resonances, vibrations and rhythms form the basis of communication, opening up one milieu onto another (Macgregor Wise 2000). Moreover, such milieus are, simultaneously, the result of connections to elsewhere and are always permeable. In other words, agency extends beyond the ‘body singular’ to the ‘body multiple’ or to a combination of agencies that are irreducible to one another. Shotter (2004, p443) describes this as “living bodily embeddedness in a ceaseless, pulsating flow of spontaneously unfolding reciprocally responsive intercorporeal interactivity between us and our surroundings”.

This thesis articulates a non-static dispersed notion of healing that resonates back to the affective atmospheres that participants describe in Chapter 8. It is only within unique entanglements of the life worlds of both patient and healthcare worker that healing can occur (Pellegrino 1999). That is to say, the power to affect and be affected gives way to safety and healing: “The greater our power to be affected the greater our power to act. Every increase of the power to act and think corresponds to an increased power to be affected” (Hardt 2007, p ix).

In a review of Cicely Saunders’ writings, Thoresen (2003) identified that individualism was a strong feature even within hospice philosophy. Self-control and autonomy and metaphors of individual journeys are strongly represented. To fulfil one’s life is connected to independence and control (Saunders 1998). I argue, like Thoresen (2003), that Saunder’s recognition of the importance of relationships to the dying person does not go far enough, and I argue for a reframing of care that recognises that people are interconnected with each other and act in creative and productive ways in response to one another as part of assemblages.

Chapter 7 provided evidence that healthcare assemblages are driven by a kind of “sticky web of medical power” (Peterson & Bunton 1997, p101) whereby patients’ and families’ knowhow and expertise is often disregarded. This, in part, resonates with Foucault’s (1975) notion of the ‘clinical gaze’ that I describe in Chapter 2 and that the specialty of palliative care is now charged with (Kearney 1992). Zimmerman (2012), drawing from Foucault, argues that the discourse of ‘acceptance’ is one that legitimates a new form of social control over dying people who are made to conform with a correct way to die: “The players appear to be caught in a disciplinary web, where acceptance is rewarded and resistance results in the label of ‘denial’ and an offer of psychological assistance" (Zimmerman 2012, p223). Foucault alleges that what he calls 'confession' is the new medical bio-power of "interrogation", and even though it has a compassionate intent, bio power is nonetheless a kind of technological power that serves to control people as a group (Sandstrom 2005, p67). I could suggest that these effects of the ideology of a 'good death' can lead to un-safeties. This is to oversimplify my argument, however. I have shown, in this thesis, how patients are not simply at the mercy of a 'web of power'. This thesis challenges the view of patients and families as passive subjects at the mercy of medical bio-power. Chapter 7 showed that patients and families are actively engaged with their care, creatively responding and improvising. The argument that patients are simply at the mercy of this web fails to take account of their creative capacities for resistance to medical intervention and the knowhow patients and families enact. Patients mobilise their own resources, carving out their own becoming-safe assemblages. Even when positioned as dying, patients are very much alive:

> *"One opens the circle, a crack, one launches forth, hazards and improvisation. But to improvise is to join the world or meld with it. One ventures from home on the thread of a tune" (Deleuze & Guattari 1987, p311).*

So what is it that healthcare workers can do and how might healthcare settings look to foster opening of the circle and launching forth, and the kind of openness and humility that by now has become a familiar argument? The conditions that foster individuals to sustain their power to affect and be affected are conditions that help maintain connections or 'familiar and comforting rhythms' and at the same time leave them open to becoming-other. This requires a creative understanding of what safety means in a specific event and what it means to specific patients, families and healthcare workers collaborating together or living and acting safety (Jerak-Zuiderent 2012).

In Chapter 6 I discussed how learning not-to-be affected puts healthcare workers at risk of harm as well as patients and families. As Lavoie, Blondeau, & Koninck, (2008) quoting (De Hennezel & Leloup 1997, p114) put it:

> *"If a certain 'professional' distance proves to be necessary to remain available and helpful for a person, it consists, at most, of an interior distance with respect to our feelings, a distance between me and myself and not between me and the other".*

This distance between 'me and myself' is associated with 'learning not-to-be affected' and leads to the un-safeties revealed in Chapter 6. That is to say, the stakes of 'learning not-to-be affected' are high, potentially leading to burnout and depression for healthcare workers and healthcare un-safeties. Removing 'self' denies the healthcare worker what Michael Barbato calls the 'brittle paths of oneself' (Barbato 2012). This leads to disengaging affectively, leading one to become "insensitive, dumb, you drop dead" (Latour 2004, p205). Healthcare workers engage in defence strategies in response to burn out such as detachment, denial and depersonalization (Obholzer 2005; Sorensen & Iedema 2009). When these become embedded within the organisational culture, they are perpetuated and become accepted as normal, leading to negative culture in the workplace (Hinshelwood & Skogstad 2000; Menzies 1960).

'Learning not-to-be affected' combined with a reliance on a protocol and checklist approach to patient safety can further lead to un-safeties. "One cannot 'engineer' the human work of creating a culture of attentiveness, care and self-correction" (Benner, Hooper & Kyriakididis 1999, p443). I argue instead that in order to meet the needs of dying patients, their families and healthcare workers, the body needs not to be solely reconstituted into a holistic entity but as a becoming body, one 'learning to be affected' meaning to be moved or activated by other bodies both subjectively and objectively (Latour 2004). Bodies are moved in relationships with the wider collective. In other words, the body is moved or transformed, not only through interaction with other human bodies but also through engagement with non-human entities vis-a-vis the physical environment:

> *"Bodies learning to be affected are bodies willing to harmonize with*
> *the beats and vitality of what is no longer or not yet entirely oneself*
> *nor entirely the world" (Despret 2004a, p219).*

In so doing, healthcare workers would accept that clinical technical competence and knowledge do not oppose humanity (de Konink 1999). Thus, the self is retained in encounters with patients and families. This is only possible when one becomes affectively attuned: "Care of the self is improved when keener somatic awareness advises it of problems and remedies before the onset of pains damage" (Shusterman 2006, p12).

When self remains within encounters, healthcare workers are able to be open to uncertainties and the suffering of others, while also opening up creative possibilities.

Critically, it is only through such attunement that relationships of trust emerge. Safeties are possible where experimentation and creative engagement are fostered to enable new potentials that make safe dying achievable for all concerned. The power of affecting and being affected gives way to what Shotter (2004, p443) describes as “real presences”: “These presences are external to us and outside of our individual agency to control but we are participants in them and have our being in them”.

This has further implications for healthcare organisations, healthcare workers in practice and for the education of healthcare professionals. For example, there are implications for the pedagogical approaches to teaching healthcare communication. I argue, like Barnard (1995), that neither moral theories nor skills techniques of interviewing and communication are sufficient to address the need for such encounters. When clinical and technical skills are separated from affective knowing, ‘learning to be affected’ is reduced to skills of empathy and communication and, in turn, to ‘detached concern’. Most models of communication focus on equipping individual healthcare workers to communicate in a stepwise manner, guiding them through an ordered process. Teaching empathy as a skill risks trivialising the experience of the other by the reciting of lines that have been memorised leading to dissatisfaction for all parties and further un-safeties. This is particularly so when healthcare workers are unable to identify with a patient but continue to have a professional accountability for care (Liben 2011).

Rather than teaching the skills of empathy and thus ‘detached concern’, I propose that healthcare workers need to know how to ‘learn to be affected.’ While I do not argue for relinquishment of rational skills-based models as tools, I argue for a more encompassing approach that brings affect to the fore. Bringing ‘becoming-safe assemblages’ into being is as much about the receptionist being attuned to the visitor at the desk as it is about the surgeon’s encounter with the nurse, influencing and being influenced by their surroundings and mindful of the overall quality of those surroundings, the atmosphere and ‘the feel’ of the place.

Thus, improvements in communication should be focused on assisting healthcare workers, both practicing and in-training to know how to be, rather than on knowing what to say. Chapter 8 established that lack of time as justification for not being able to address safeties is based on the premise that it is what people say and how they communicate verbally that matters. This chapter showed how communication is seen as a discrete task whereby therapeutic interactions require dedicated linear time slots. I contend, like Dobkin (2011, p76) that the idea of limited time is based on the misconception that it is verbal communication alone that matters when in fact it is “how one is” that matters.

If healthcare safeties are to be addressed for dying patients and their families then contemporary health systems and healthcare organisations must address the safety of its workforce. Innovative approaches to workforce development and new pedagogies are required that support healthcare workers in ‘learning to be affected’. This requires a significant paradigm shift that fosters the dissolving of hierarchical and disciplinary boundaries helping to: “relinquish our attempts to embody the power of life as individuals and mutate our lines of flight in keeping with the improvisations around us” (Tamsin 2005, p174).

Only when living and acting are shared and distributed or what I term becoming ‘affectively attuned’ is experienced can safeties begin to be addressed. The patient safety movement separates abstract knowledge from practical action (Jerak-Zuiderent 2012). Instead, I propose, as an alternative a flexible guideline approach that allows healthcare professionals to improvise in collaboration with patients and families to account for specificities of safety.

The final empirical chapter, Chapter 8 conveyed how patients’ and families’ creative capacities as well as those of healthcare workers might be fostered and what renders affective attunement more likely. Facing the symptoms and bodily assaults that result from having a life-limiting illness can lead to what Nelms (1996, p372) calls “ontological homelessness”, when one’s very place in the world is under threat. Drawing on Heidegger (1977), Nelms (1996, p373), identifies a need to feel comfortable with “being in the world” and to try to make the world home. Connections with home and connections with family and friends become issues of critical importance, supporting previous work framing these connections in terms of spirituality (McGrath 2004). Connections with home delimit the body as body singular, extending its creative capacities and building agency. When attempts are made to maintain and create these connections, where symbols are identified with home, it is possible to maintain a sense of connectedness. Findings support the previous work of others in this regard. For example, personal artefacts kept at the bedside can become important symbols of home (Jordens, Lewis & Kerridge 2009; Kellehear, Pugh & Atter 2009; Rasmussen & Edvardsson 2007; Wiliams, Dawson & Krisjanson 2008).

Furthermore, the built environment and materialities of healthcare settings inextricably form a part of assemblages and are implicated in healthcare safeties. Some healthcare settings lend themselves to ‘learning to be affected’ more than others. Extrapolating from other disciplines underscores the significance of this. For example, there is a significant body of work exploring the environment in the area of dementia care that highlights the inseparable features of the human and physical environment(s) in managing agitation in Alzheimer’s disease (Sloan et al. 1998). This thesis has shown that these inseparable features of the human and physical environment are no less important for healthcare workers as they are for patients.

Despite the limitations of the hospital environment becoming-safe assemblages are possible as Chapter 8 established. This supports findings from other settings. For example, Mesman (2012) established that the built environment was not essential to safety measures in a neonatal intensive care unit. Above all, what may be of utmost importance is that the “material environment cannot compensate for deficits of the social environment” (Morgan & Stewart 1997, p747).

In sum, healthcare settings are seen as a place or simply a ‘container’ where clinical interventions take place. Instead, I contend that rather than a place where interventions happen healthcare settings *are* clinical interventions. That is, healthcare settings, as clinical interventions in and of themselves, are implicated in the safety of patients and their families and healthcare workers caring for them. This has significant implications for the way in which healthcare settings are designed, how healthcare workers deliver care and how the organisations they work in support them in doing so. When healthcare settings are viewed as interventions there are also implications for education and professional training.

Adult hospital design tends to be influenced by clinical functionality rather than creating environments that foster affective attuning. Hospitals are currently designed to respond to acute care episodes based on short discrete episodes of care. Yet, throughout the course of their illness dying patients experience substantial suffering, multiple and sometimes lengthy hospitalizations, with associated high costs (Myers & Lynn 2001).

Defining healthcare settings as clinical interventions requires radical reform if safety and quality of end-of-life care is to be taken seriously. If we are to accept hospitals as a place where dying people are cared for, then there is a need for radical re-design to meet the needs of those who most need it (Myers & Lynn 2001). Examples of this can be extrapolated from other areas where the need for patients to feel safe in the context of ‘family-centred care’ is recognised and service users are co-designers of care delivery. For example, a new children’s hospital in Australia is “designed with the needs of children, young people and families in mind” (Queensland Government 2012).I argue for a paradigm shift that recognises the necessity for hospitals to be designed with the needs of adults and families as a central focus. Alternatively, innovative healthcare settings are required to meet the safety needs of dying people and their families such as the “Re-creation of community hospitals; ultra-local home hospices with a handful of beds; and shared housing schemes” (Leadbeater & Garber 2010, p15). An example of where this has been realised is the ‘Veerhuis’, a ‘normal’ residential house at the end of a ‘normal’ street in Amsterdam with room for four residents where people go to die (Hospice Veerhuis 2012; Meyknecht 2005).

Research Question 3: How can visual methods promote the stories of research participants and advance a more meaningful death and dying experience?

Filmed contextual narratives revealed otherwise ‘intangible’ safeties and harms. Findings coincide with those of other studies that have highlighted these contributions as central to fostering quality at the end life (Chochinov et al. 2005; Steinhauser et al. 2008). For instance, a patient’s perception of how they are ‘seen and heard’ is closely associated with perceptions of dignity. Having opinions heard and concerns validated can foster hope (Chochinov 2004). This thesis has shown that the importance of providing the opportunity for patients and families to ascribe meaning to their experiences through the medium of film extends far beyond the primary purpose of the research itself. Chochinov’s body of work highlights that:

> *“the reflection that patients see of themselves in the eye of the care provider must ultimately affirm their sense of dignity. At least in part, it would appear, dignity resides in the eye of the beholder” (Chochinov 2004, p1339).*

Potentiality is only actualised in conjunction with other bodies (Manning 2010). The camera acted on behalf of participants to enable them to be viewed as they wished and a way that could continue after death. A sense that nothing of one's life will transcend beyond death is associated with loss of dignity (Hall et al.). Significantly, through film, patients and families could reveal of themselves what they wanted others to see.

Critically, patients and families could convey safeties and harm otherwise not possible. Profoundly, patients with the aid of film endure beyond their physical life providing a tangible legacy for those left behind.

Research Question 4: How do collaborative practice-oriented feedback and reflexivity approaches utilising visual methods contribute to end-of-life care research?

Drawing from an indigenous research ethics framework, I engaged multiple methods, not with the aim of triangulating towards definitive certainties, but as part of creative experimentation that acknowledges collective subjectivities and participatory modes of consciousness (Heshusius 1994). Chapter 5 established that the stories of research participants and those of others, including my own, intertwine, crafting and re-crafting new stories and thus creating and re-creating new space of which this thesis is a part. As the product of interrelations and always under construction "perhaps we could imagine space as a simultaneity of stories-so-far" (Massey 2005, p9). These stories are non-linear, requiring me not to control or predict emergent events and to embrace the inevitable messiness of method, and importantly, the 'messiness' of dying. These continually negotiated and re-negotiated relationships between the researcher, participants and other stakeholders in the research are central to indigenous research ethics framework and to video ethnography. This required not only self-reflexivity but also interpersonal and collective reflexivity.

Importantly, my own safeties were inseparable from the safety of others. Doing research in the way I have described required me to continually question my thoughts, decision-making, actions and identities negotiating research 'troubles' and working out different ways of doing things. As Chapter 5 established, this is not a straightforward ethical task. Chapter 5 emphasises ethics not as a prescribed task to be done or procedures to be followed but instead thinking of 'ethics' as emergent and unfolding. An institutional ethics framework attempts to "protect the vulnerable" but is unable to prevent a "hopelessly predetermined and finished off" participant (Bakhtin 1984, p58). Tensions arise when the institutional ethics process comes into conflict with the ethical frameworks of the research and myself as the researcher. This has implications for 'doing' sensitive research as well as for institutional ethics frameworks. By seeking to 'protect' patients, there is a danger of paternalism and even marginalising those individuals institutional ethics procedures seek to protect (Mount et al. 1995). The ethics of potentially depriving patients' opportunity to participate in research is questionable in and of itself. Defining inclusion of vulnerable subjects as immediately unethical can put people at a disadvantage when the result is missed opportunities to gain knowledge that is useful to them and others (Agrawal 2003). Labelled as ‘dying hospital patients’ and ‘vulnerable’ research subjects, participants are often positioned as what Bishop (2005, p110) describes as “minoritised peoples”. Bishop (2005, p114), draws from an indigenous research ethics framework and more specifically Kaupapa[52] Māori, to challenge the dominance of conventional research approaches. He rejects what he terms “Māori can’t cope” discourses. Drawing from Kaupapa Māori and oriented toward benefiting research participants and addressing their objectives and agendas, the need to reject what I shall term ‘dying patients can’t cope’ discourses, became increasingly clear to me. That is to say, it is untenable to decide on behalf of patients whether they wish to participate in research and how they wish to participate.

Given the challenges presented by serious illness including fluctuating symptoms and poor function, this required a flexible approach leaving room for patients to decide what, when and how they contributed rather than ‘boxing’ them into a predetermined fixed process. This meant I needed to let go of previously held habitual ways of being, and become open to alternatives. In other words, I needed to be prepared to let go of self and be open to becoming other. This uncertainty was often challenging but also transforming as I took on nomadic subjectivity. It required me to be open to being affectively attuned with participants myself. By embracing mess, I was able to collaborate with individuals on negotiated terms even when they were extremely sick and, for some, in their final days and weeks of life. Critically, this was only possible through professional artistry (Titchen & Higgs 2001), as the necessary foundation for ‘transformative potential’ for both participant and researcher, attuning with participants and a preparedness to be nomadic. That is, open to alternative ways of thinking and perceiving, being and acting as I took on the role of researcher:

> *“That is not something you can do in your head: but then where these days are the seeds of a new way of existing, communally and individually, beginning to appear; and are there any of these seeds in me?” (Deleuze 1995, p106).*

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[52] Agenda/philosophy of the Māori.

Chapter 5 established that 'the seeds of a new way of existing' were made possible through 'collaborative practice-oriented feedback and reflexivity approaches utilising visual methods' The visual brings the unconscious into consciousness revealing habitual rhythms hitherto unknown. Video fosters nomadic subjectivity by fostering what Shusterman (2006) calls better somatic knowledge and greater awareness to improve understanding and performance:

> *"Bodily habits and their attendant consciousness need to be examined before they can be properly transformed. We must know what we actually do in order to correct it reliably into doing what we want" (Shusterman 2006, p13).*

Video reflexivity provides a possible route to examining these 'bodily habits and their attendant consciousness'. Casting the world in a new light, filmed contextual narratives revealed otherwise 'intangible' safeties and harms, creating lines of flight by challenging normative end-of-life care. If normalisation of inattentiveness to safeties is to be confronted, awareness of habitual modes of behaviour is necessary (Shusterman 2008). 'Learning to be affected' requires awareness of habitual and comforting rhythms to bring normalisation of inattentiveness to safeties into consciousness. Together with the camera, *we*, just like the 'artist's act', acted as the conduit of the virtual and immanent (May 2004):

> *"Mediators are fundamental. Creation's all about mediators. Without them nothing happens. They can be people-for a philosopher, artists or scientists, but things too, even plants or animals, as in Castaneda. Whether they're real or imaginary, animate or inanimate, you have to form your mediators" (Deleuze 1995, p125).*

Video reflexivity offered creative potentialities or what Deleuze and Guattari call "lines of flight",[53] challenging the boundaries and constraints that limit what can be done in the highly regulated hospital and disrupting the normalised logic of care.

The implications of doing research and the indigenous research ethics I espouse have implications for the way in which end-of-life care research is carried out and perhaps even for the way that research is carried out in the western university. "A focus on

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[53] Lines of flight free order and categorisation providing the potential for "cutting edges of de-territorialisation," opening up alternatives to territorialisation and to becoming-other (Deleuze & Guattari 1987, p88).

affects illuminates both our power to affect the world around us and our power to be affected by it along with the relationship between these two powers" (Hardt 2007, p ix). Thus, if the bodies of researchers are bound to affect and be affected just as patients, families and healthcare workers are, then, as researchers "we are obliged to attune ourselves to emergent life as becoming, unsettling ourselves from normative spatial practices to collective spaces of unfolding" (Tamsin 2005, p174). Paradoxically, affective engagement might better place us to deal with mess in a way that holding onto predetermined fixed plans is unable to do. In other words, predetermined fixed plans can cut the researcher off from learning to be affected and thus open to new learning and transformation. As Despret writes, "to 'de-passion' knowledge does not give us a more objective world, it just gives us a world 'without us' and therefore 'without them' … in other words, a poorly articulated (and poorly articulating) world" (Despret 2004b, p131). Furthermore, by applying Deleuze and Guattari's understanding of space, critique of doing research framed in terms of its ability to generalise may be a moot one. This understanding of space dissolves boundaries of local and global. There is no here, there, only everywhere (Dewsbury & Thrift 2005).

Research Question 5: How can visual methods communicate principles, strategies and systems that would facilitate improved end-of-life care to consumers, clinicians, service providers, administrators, designers, planners and policy makers?

The patient, family and healthcare voices that most need to be heard are often those least likely to speak (Browning 2010). Chapter 7 established that the expertise and knowing of patients and their families is frequently ignored and undervalued. This expertise is utilised by patients for their own safety and, to some extent, the safety of those around them. In turn, healthcare worker expertise and knowing is also frequently undervalued and the safety needs of healthcare workers largely ignored. This thesis argues that denying people opportunities to speak can itself lead to un-safeties. To directly answer the question: How can visual methods communicate principles, strategies and systems that would facilitate improved end-of-life care to consumers, clinicians, service providers, administrators, designers, planners and policy makers? Chapter 5 established that film provides a medium for people to address a variety of audiences that they would otherwise not have the opportunity to speak to. The visual provides an aid to democratisation of research from obscure and abstract texts and writings to the common language of the visual, enlarging conversations about death and dying heretofore not possible. Video provides access to a 'different sensation' between the actual and the virtual (Dewsbury & Thrift 2005) providing a powerful channel for building social capital. Chapter 8 established how conditions are created for becoming safe where experimentation and creative engagement are fostered to enable new possibilities that make safe dying possible. This research, through visual methods as a vehicle of creative engagement contributes, to creating these conditions by "disrupting edges-opening spaces" making the research accessible to people outside of academia and its associated language (Horsfall & Titchen 2009, p158). Visual methods can act as a tool to open up creative and different possibilities.

Section 9.3 Thesis Limitations

I have articulated how the research journey has rhizomatically arisen and thus where it might lead. I have not set out to guarantee that my findings are 'trustworthy' nor have I sought to be in control, sticking to a predetermined plan (Mann et al. 2011). Instead, I have attempted to celebrate mess, seeking to keep pleasure, sadness, joy, complexities, ambiguities, and tensions alive in the thesis (Mann et al. 2011). In so doing, I have attempted to leave room to welcome, not only dying people and their families who might otherwise have been unable to contribute to the research process, but healthcare workers also, who, to a large extent, are not provided the opportunity to reflexively consider death and dying. Yet, to borrow the metaphor of Mann et al, the experimental meal has to at some point, be over. Thus, I will only ever have partially succeeded. Further, in doing research in the way I espouse, the experimental meal could have turned out differently. Here, my thoughts and feelings resonate with those of John Law (1994, p47):

> *"I missed out on many important events during my fieldwork. Sometimes I could not be there. Sometimes it just seemed inappropriate. Sometimes I just happened to be in the wrong place at the wrong time. And certainly, I did not collect materials that might have attracted other ethnographers with different interests. But, though I know, even by my own increasingly modest standards, that the study is incomplete, I now see things differently: since there are discontinuities in place, and discontinuities in ordering, it follows that*

> *the largest part of the action is always being generated elsewhere" (Law 1994, p47).*

Despite efforts to engage non-cancer medical specialties and the patients and families they care for, participants were largely drawn from cancer and palliative care specialists. While patients with chronic and complex diseases such as end stage renal failure, or chronic obstructive pulmonary disease, are found to experience similar issues as cancer patients, the illness trajectories involving long progressive deterioration in health and function may require different approaches, particularly as it is difficult to decide when the move to palliative treatment goals should occur (Skilbeck & Payne 2005). My lack of success in engaging this group of patients is perhaps characteristic of a particular reluctance of medical teams to discuss end-of-life issues with this particular group (Fitzsimmons et al. 2007). Furthermore, models of care for people with chronic and complex diseases are predicated on the notion of 'self-care'. This self-determining approach demands patients be responsible for staying healthy and keeping themselves out of hospital. In this paradigm of self-care and prevention, the inevitability that patients will die of their illness and require care goes largely unrecognised (Price & Cheek 2007).

Another important limitation of this study is that meeting the criteria of human research ethics committees required clear parameters at the outset, making negotiation of objectives with participants impossible prior to the ethics application thus privileging my goals as the researcher. Furthermore, the majority of patients I had the privilege of meeting 'knew', at least to some degree, that their prognosis was poor. That is, they were in 'open awareness'. In addition, while I met many patients and families who did not speak English as their first language, my conversations were privileged towards those who could converse in my own tongue. On one hand, I could argue that those participants I have introduced on film are those most able to speak. Arguably, however, by not sticking to a rigid process of excluding participants should they choose not to be filmed, the voices of those individuals remain prominent in the thesis. Moreover, as I have already conveyed to this point, as part of a nomadic system, this thesis continues to be open to the movement of life, finding new connections and 'lines of flight'.

Responding to the twists and turns of emergent mess means that there are, of course, alternative routes that I could have taken. For example, I learnt that handing over the camera completely to patient participants, as was my initial intention, was not only unrealistic but did not take account of my own key argument of the necessity for close collaboration in producing video accounts. Furthermore, ethical issues remain murky requiring ongoing consideration of participants and their families in terms of what to show and to whom, despite the expiry of formal Institutional Human Research Ethics approval. Moreover, engaging with mess means that as nomadic researcher, I too need to be open to transformation. Departing from conventional methodologies on my own journey to professional artistry was itself messy. Even as this research reaches conclusion, I now see things differently. For example, I could have taken greater risk in the very writing of this thesis by completely departing from the traditional conventions of a standard thesis format.

Chapter 5 established that decision-making is never straightforward. Functioning nomadically, finding new connections and lines of flight and embarking into the unknown is not without threat or risk. Their potentiality means that ‘lines of flight’ are inherently unpredictable and thus always have a possibility of turning into lines of despair and destruction:

> *“Inherent in any line that escapes, in any line of flight or creative deterritorialization: the danger of veering toward destruction, toward abolition” (Deleuze & Guattari 1987, p299).*

In this respect, risk and harm always remain possible. If I am to accept that harms and risk are always possible in healthcare settings, then I also accept that the research is implicated in ‘forever possible’ risks and harm. By deliberately using video reflexivity as a tool to disrupt habitual patterns and create lines of flight, I run the risk of ‘veering toward destruction’. Yet paradoxically, this does not take account of the capacity of others to counter such risk, a key argument of this thesis.

Section 9.4 Future Research

Continuing the metaphor of the rhizome, this thesis gives rise to a number of projects for future research. I advocate a research agenda specifically focused on healthcare safeties relating to dying patients and their families and healthcare workers caring for them. If healthcare safeties are to be redefined according to the empirical findings of this thesis and the suggestion of others, for example (Dietz et al. 2010; Myers & Lynn 2001), then it will be important to address how specific safeties towards the end of life can be incorporated into health system clinical governance structures (Myers & Lynn 2001). It may be, for example, that the extent of harms requires to be quantified as well as qualified to establish the economic implications of investment in healthcare safeties pertaining to dying patients and their families. In particular, establishing the enduring effects of harm at the end of life for bereaved families will be important. Different or additional methodologies, however, should not exclude the voices of patients and families as well as healthcare workers. Thus, further research could include visual methods. Investigation of the use of visual methods as a tool in other circumstances and care settings will also be important. For example, residential care settings, home care settings and private hospitals. In this regard, it would be useful to further explore the use of film for end of life care research in two important ways: First, as a generative device for the benefit of patients and families and second the filming of healthcare practices in collaboration with healthcare workers.

Paramount to a safety agenda concerning dying patients is the consideration of the safety of those who are not openly aware of their prognosis or are unable to articulate their own safety needs including people with dementia, other cognitively impaired, or indeed those too unwell to do so. In addition, the safety needs of dying people and their families for whom English is a second language are of critical importance. Importantly, the continued safety needs of the healthcare workforce, needs to be addressed. For example, questions concerning how to enable healthcare workers to 'learn to be affected' are paramount. For instance, it will be important to finding out whether specific interventions such as mindfulness programs foster healthcare safeties and when these should be implemented including implications for pre-registration education, including the education of non-professional healthcare workers.

Section 9.5 Conclusion

This thesis has theoretically and empirically applied a lens inspired by French Philosophers Deleuze and Guattari to critically examine the links between where dying people are and the extent to which spaces contribute to their safeties and enable or constrain their agency. This lens has enabled me to see that healthcare safeties are more likely when healthcare workers are affectively attuned and thus able to account for patient specific safeties that are critical to end-of-life care. Five main conclusions emerge from this research:

First, habitual care patterns expose dying patients and their families to harm along with those healthcare workers caring for them.

Second, safety and ‘healing’, do not reside in the individual but rather within dynamic assemblages arising from bodies affecting and being affected by others. Healthcare safeties are contingent on attuned weaves of commitment that foster relationships of trust and bring together healthcare worker expertise and the expertise of patients and their families to co-produce safety.

Third, ‘learning not-to-be affected’ is untenable, placing healthcare workers at risk of inattentiveness to their own safety along with those they care for. Conversely, when healthcare workers ‘learn to be affected’ and thus attuned to the implication of the task healthcare safeties are possible.

Fourth, healthcare settings are viewed as a place where clinical interventions take place. This thesis shows that healthcare settings *are* clinical interventions rather than simply providing a container for them in which to occur.

Lastly, visual methods provide a device to disrupt normative and habitual rhythms of inattentiveness to healthcare safeties. Further, just as healthcare settings are not simply venues for care, research field sites are not simply research laboratories able to be viewed objectively by the researcher and emerging in isolation from the research methods and myself as researcher. Thus, we, as researchers, need also to disorientate from our conventional and habitual patterns as a part of open-ended collaborative communities unfolding together and attuning to life as ‘becoming’.

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Appendices

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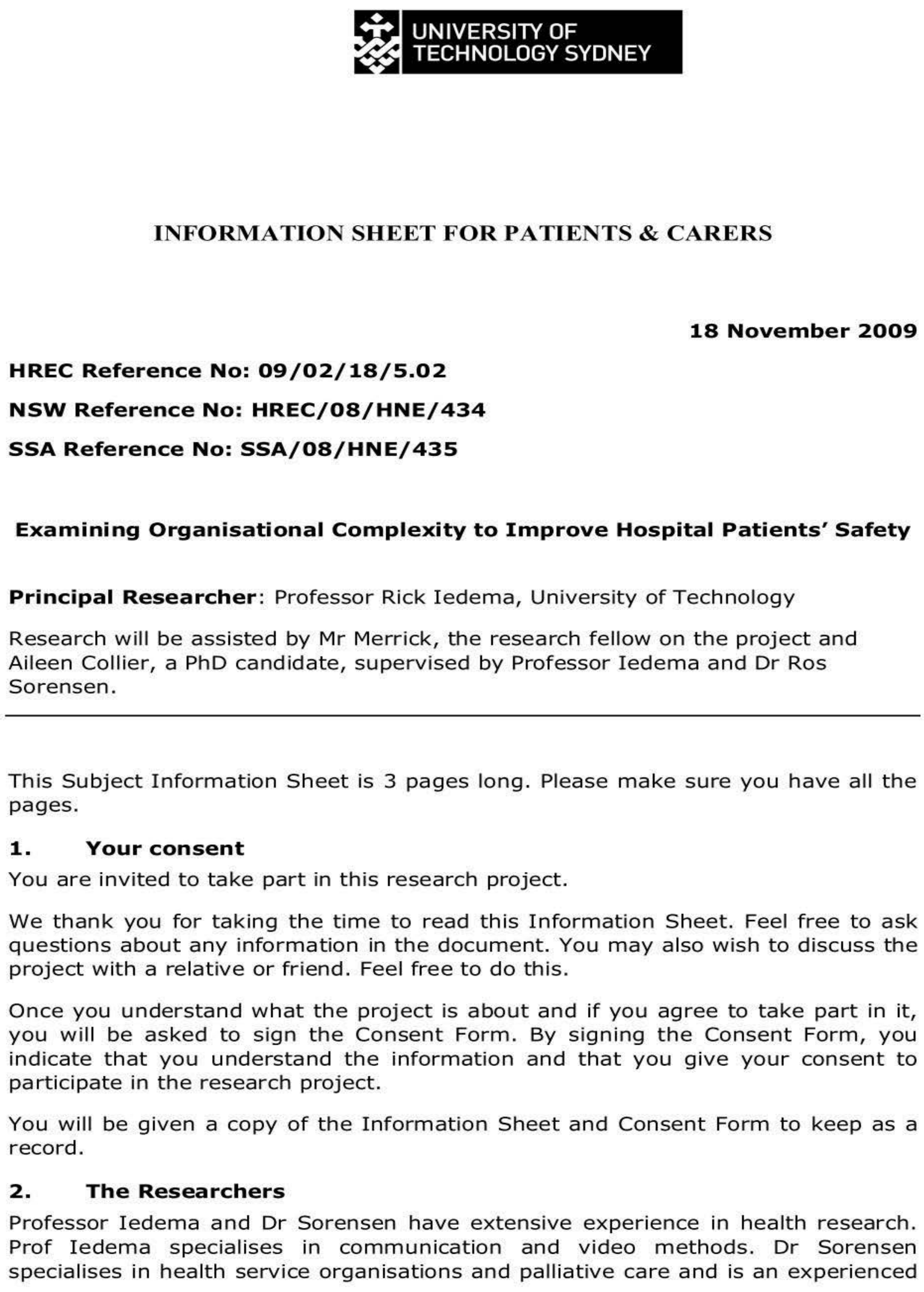
Appendix 1 Information sheet for patients & carers



UNIVERSITY OF TECHNOLOGY SYDNEY

INFORMATION SHEET FOR PATIENTS & CARERS

18 November 2009

HREC Reference No: 09/02/18/5.02

NSW Reference No: HREC/08/HNE/434

SSA Reference No: SSA/08/HNE/435

Examining Organisational Complexity to Improve Hospital Patients' Safety

Principal Researcher: Professor Rick Iedema, University of Technology

Research will be assisted by Mr Merrick, the research fellow on the project and Aileen Collier, a PhD candidate, supervised by Professor Iedema and Dr Ros Sorensen.

This Subject Information Sheet is 3 pages long. Please make sure you have all the pages.

1. Your consent

You are invited to take part in this research project.

We thank you for taking the time to read this Information Sheet. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Information Sheet and Consent Form to keep as a record.

2. The Researchers

Professor Iedema and Dr Sorensen have extensive experience in health research. Prof Iedema specialises in communication and video methods. Dr Sorensen specialises in health service organisations and palliative care and is an experienced social worker. Mr Merrick is an experienced nurse and the research fellow on the project. Ms Collier is a PhD student at the Centre for Health Communication. She is an experienced nurse and has led a number of previous health projects.

3. Aim of the study

The purpose of this study is to look at how the healthcare environment affects the way that health care workers relate to each other. It will identify links between the environment, health care workers interactions and patient safety. It will provide a means for health care workers in practice to improve the safety of patients. It is hoped that the study will enhance our understanding of what minimises risks to patients and their families and makes healthcare environments safe.

The project is funded by the Australian Research Council.

You are invited to participate in this research project because you are a patient and/or carer experiencing the healthcare environment and participating in communication practices that are of interest to this study.

4. Who will be invited to enter the study?

It is anticipated that up to 30 patients and 30 carers will be recruited to participate in this study.

5. What will happen on the study?

Pending consent, your participation may involve:

- An interview of about an hour during which you will be asked about your experiences views and beliefs about patient safety and positive healing environments. The interview will be video-recorded.

- You may also be given the opportunity, using a simple camera, to keep a video diary of your experiences. You will be able to view the recordings in order to help select footage that may be used, only with your consent, to help health care professionals and other people caring for you to understand your experiences of the environment.

- Only with your consent, participation may involve being observed and/or filmed in the healthcare environment and in interactions with health care professionals.

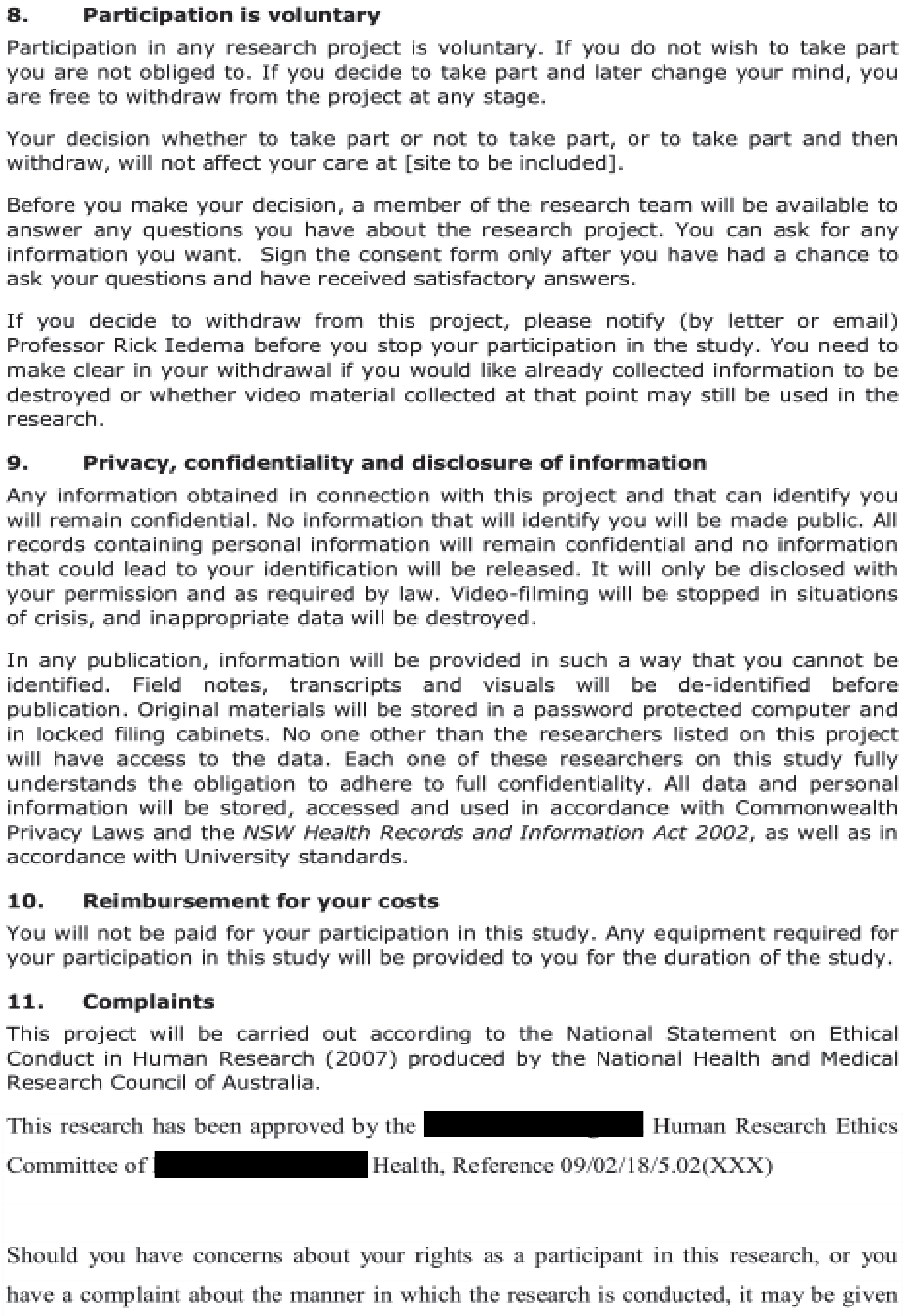
6. What are possible benefits?

We cannot guarantee or promise that you will personally receive any benefits from this project, however previous participants in research of this kind have found it beneficial and have experienced a positive impact.

7. What are possible risks?

Possible risks, side effects and discomforts include psychological risks: There may be some issues that, as a result of being observed and filmed, cause personal concern. Participants experiencing such concerns have the opportunity to access appropriate counselling or support as required.

You can suspend or end your participation in the project at any time.



8. Participation is voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your care at [site to be included].

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the consent form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please notify (by letter or email) Professor Rick Iedema before you stop your participation in the study. You need to make clear in your withdrawal if you would like already collected information to be destroyed or whether video material collected at that point may still be used in the research.

9. Privacy, confidentiality and disclosure of information

Any information obtained in connection with this project and that can identify you will remain confidential. No information that will identify you will be made public. All records containing personal information will remain confidential and no information that could lead to your identification will be released. It will only be disclosed with your permission and as required by law. Video-filming will be stopped in situations of crisis, and inappropriate data will be destroyed.

In any publication, information will be provided in such a way that you cannot be identified. Field notes, transcripts and visuals will be de-identified before publication. Original materials will be stored in a password protected computer and in locked filing cabinets. No one other than the researchers listed on this project will have access to the data. Each one of these researchers on this study fully understands the obligation to adhere to full confidentiality. All data and personal information will be stored, accessed and used in accordance with Commonwealth Privacy Laws and the *NSW Health Records and Information Act 2002*, as well as in accordance with University standards.

10. Reimbursement for your costs

You will not be paid for your participation in this study. Any equipment required for your participation in this study will be provided to you for the duration of the study.

11. Complaints

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia.

This research has been approved by the [redacted] Human Research Ethics Committee of [redacted] Health, Reference 09/02/18/5.02(XXX)

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr [redacted] Professional Officer (Research Governance and Ethics), [redacted] Human Research Ethics Committee, [redacted] Health, Locked Bag 1, [redacted] NSW [redacted]

12. Contact details

Should you require further details about the project, either before, during or after the study, you may contact Professor Rick Iedema on (02) 9514 3833, mobile 0414 553 742, email: r.iedema@uts.edu.au from the University of Technology Sydney, PO BOX 123, Broadway NSW 2007.

We would like to thank for your time and interest in taking part in this study!

Appendix 2 Information sheet for clinicians

UNIVERSITY OF TECHNOLOGY SYDNEY

INFORMATION SHEET FOR CLINICIANS

March 3rd 2009

HREC Reference No: 09/02/18/5.02

NSW Reference No: HREC/08/HNE/434

SSA Reference No:

Examining Organisational Complexity to Improve Hospital Patients' Safety

Principal Researcher: Professor Rick Iedema, University of Technology

Research will be assisted by Aileen Collier, a PhD candidate to be supervised by Professor Iedema.

This Subject Information Sheet is 3 pages long. Please make sure you have all the pages.

1. Your consent

You are invited to take part in this research project.

This Information Sheet contains detailed information about the research project. Its purpose is to explain to you as openly and clearly as possible all the procedures involved in this project before you decide whether or not to take part in it.

Please read this Information Sheet carefully. Feel free to ask questions about any information in the document. You may also wish to discuss the project with a relative or friend. Feel free to do this.

Once you understand what the project is about and if you agree to take part in it, you will be asked to sign the Consent Form. By signing the Consent Form, you indicate that you understand the information and that you give your consent to participate in the research project.

You will be given a copy of the Information Sheet and Consent Form to keep as a record.

2. Aim of the study

1. Use experience based enquiry to articulate the influence of the built hospital environment on inter-professional interaction
2. To conceptualise and articulate the causal links between inter-professional collaboration and clinical risk
3. To use experienced base enquiry for participant led redesign of work practices to enhance patient safety
4.

The project is funded by the Australian Research Council.

You are invited to participate in this research project because you are a clinician who participates in communication practices that are of a kind of interest to this study.

3. Who will be invited to enter the study?

It is anticipated that between 50-100 clinicians across 2 sites [redacted] will be involved in this project.

4. What will happen on the study?

Participation in this project will involve:

- An interview/focus group of about an hour to an hour and a half during which you will be asked about your views on improving communication practices in your part of the hospital (participants in the focus groups will be given the opportunity to review and edit their contributions). You will also be asked to discuss what you see as the opportunities of using video footage of communication practices on medication management/infection control for reflecting on practices and for improving these. We will explain how video footage can be generated and used for this purpose without compromising trust between clinicians and researchers. When and only if you consent to this, your answers will be video-recorded.

- You will then be asked to participate in focusing on one communication process. This will occur through observation of that process, video-ing of that process and attending reflexive-feedback meetings to discuss the footage thus created. In these meetings questions about existing processes and relationships are raised and alternative solutions explored.

5. What are possible benefits?

We cannot guarantee or promise that you will personally receive any benefits from this project.

6. What are possible risks?

Possible risks, side effects and discomforts include psychological risks: There may be some issues that, as a result of being observed and filmed, cause personal concern. Participants whom experience such concerns have the opportunity to contact the Site details to be included) if they experience distress. Previous research of this kind has had a positive impact on participants as staff have had the chance to review their own ways of working in a trustful environment.

Participants can suspend or even end their participation in the project if distress occurs. The video materials will be de-identified through blurring of footage and appropriate editing.

7. Participation is voluntary

Participation in any research project is voluntary. If you do not wish to take part you are not obliged to. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your employment at [redacted] Area Health Service.

Before you make your decision, a member of the research team will be available to answer any questions you have about the research project. You can ask for any information you want. Sign the Consent Form only after you have had a chance to ask your questions and have received satisfactory answers.

If you decide to withdraw from this project, please formally notify (by letter or email) Professor Rick Iedema before you stop your participation in the study. You should make clear in your correspondence whether your withdrawal means already collected data needs to be destroyed, or whether your withdrawal only pertains to future data collection and participation.

8. Privacy, confidentiality and disclosure of information

Any information obtained in connection with this project and that can identify you will remain confidential. No information that will identify you will be made public. All records containing personal information will remain confidential and no information that could lead to your identification will be released. It will only be disclosed with your permission and as required by law. Video-filming will be stopped in situations of crisis, and inappropriate data will be destroyed.

In any publication, information will be provided in such a way that you cannot be identified. Field notes, transcripts and visuals will be de-identified before publication. Original materials will be stored in a password protected computer and in locked filing cabinets. No one other than the researchers listed on this project will have access to the data. Each one of these researchers on this study fully understands the obligation to adhere to full confidentiality. All data and personal information will be stored, accessed and used in accordance with Commonwealth Privacy Laws and the *NSW Health Records and Information Act 2002*, as well as in accordance with University standards.

9. Reimbursement for your costs

You will not be paid for your participation in this study.

10. Complaints

This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2007) produced by the National Health and Medical Research Council of Australia.

This research has been approved by the [redacted] Human Research Ethics Committee of [redacted]

This research has been approved by the [redacted] Human Research Ethics Committee of [redacted]

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to [redacted] Professional Officer (Research Governance and Ethics), [redacted] Human Research Ethics Committee, [redacted]

11. Contact details

Should you require further details about the project, either before, during or after the study, you may contact Professor Rick Iedema on (02) 9514 3833, [redacted] email: r.iedema@uts.edu.au from the University of Technology Sydney, PO BOX 123, Broadway NSW 2007.

We would like to thank for your time and interest in taking part in this study!

Appendix 3 Anticipated semi-structured interview questions - patients and family

Would you mind giving me some demographic information?

Is there a difference between healing and curing do you think? What might that difference be for you?

What sorts of things most contribute to your healing? Is it a place, person, memories?

Can you tell me about the kind of things you do, places you go, to help with ‘healing’?

What kind of things, what you do, where you go to feel most ‘yourself’?

I wonder if you are able to tell me in what kind of ways healthcare workers contribute to your healing?

What do you think helps you to have satisfying and rewarding relationships with your healthcare workers?

What do you think would be needed here, in this place, for you to be able to express yourself best when you are talking with the healthcare team?

What do you think of as a ‘healing environment’? What would be needed for this environment to be ‘healing’?

Do you think you could try and describe for me the kind of place that is most likely to lead to your healing? What would it look like, who would be there, what would it feel like?

What kind of things do you think get in the way of your healing?

What kind of things do you think help you to feel safe when you visit the hospital, your healthcare team, when you are in hospital?

What kind of things help you to feel most ‘at home’ and most ‘yourself’ when you visit the hospital, healthcare team, when you are in hospital?

What kind of things do you think healthcare workers could do to make you feel safe and at home, to create a healing environment?

What kind of things do you think would make it more likely that healing would happen in these surroundings, in the hospital that you visit, in the hospital that you have been an in-patient in?

Appendix 4 Anticipated semi-structured interview questions - healthcare workers

Is there a difference between healing and curing do you think? What might that difference be for you?

How do you think about, describe, conceive, healing and your role in healing?

What type of expectations do you find patients and families have of you? How do they generally express these expectations?

What kind of things maximise your therapeutic effect with patients and families?

What kinds of things would be needed here to help you to respond in the best way you feel able, and have the most satisfying and rewarding interactions with patients, families and your colleagues?

What are the times/events you find most difficult to deal with? Why? What are the strategies that you have developed to get through these difficult times?

What do you think of as ‘healing environment’?

What kind of things do you think are needed to facilitate a ‘healing’ environment here?

Is there room, do you think, for a healing space? What would it look like to you?

Do you feel able to contribute to ‘healing’ in this environment? If so, how?

What sorts of things get in the way of this healing environment?

What do you think contributes most to your morale in this environment?

What do you think would make healing more likely in this environment?

Can you describe for me what it felt like the first time you experienced a death?

Has this affected the way you deal with death and dying?

How has it done so?

Do staff support each other when they have experienced a particularly difficult death/death of a patient whom they have cared for for a long time, formed a bond with?

How do they support each other?

Are there other types of support that you might need on particular occasions?

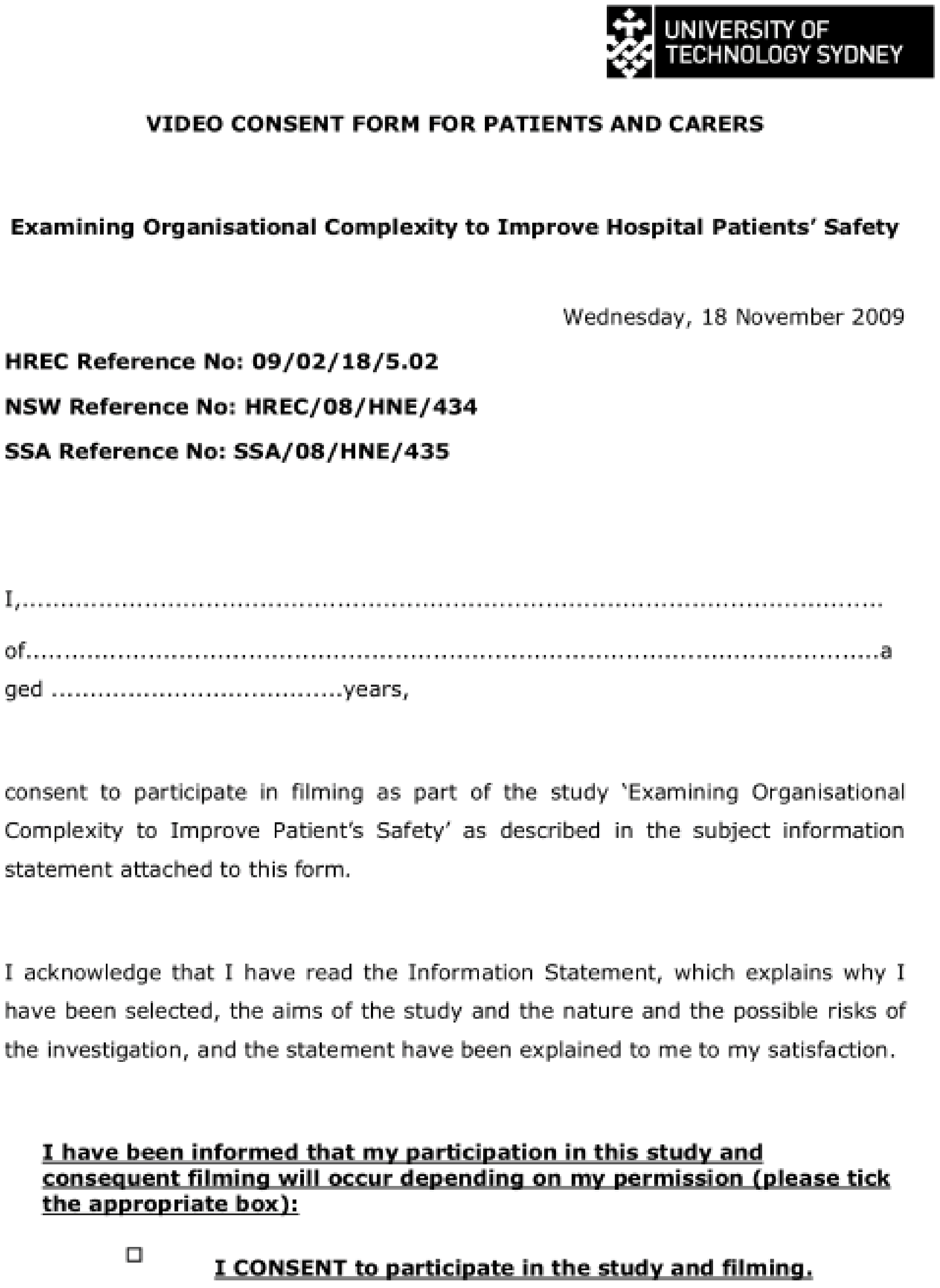
What might they be and when might they occur?

Is there a difference between the ways that different professionals deal with death as a part of their work?

Can you tell me about those differences?

Are there other things that you would like to add about the care of dying patients here?

Appendix 5 Video consent form for patients and carers



UNIVERSITY OF TECHNOLOGY SYDNEY

VIDEO CONSENT FORM FOR PATIENTS AND CARERS

Examining Organisational Complexity to Improve Hospital Patients' Safety

Wednesday, 18 November 2009

HREC Reference No: 09/02/18/5.02

NSW Reference No: HREC/08/HNE/434

SSA Reference No: SSA/08/HNE/435

I,……………………………………………………………………………………………………

of……………………………………………………………………………………………………a
ged ………………………………….years,

consent to participate in filming as part of the study 'Examining Organisational Complexity to Improve Patient's Safety' as described in the subject information statement attached to this form.

I acknowledge that I have read the Information Statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement have been explained to me to my satisfaction.

I have been informed that my participation in this study and consequent filming will occur depending on my permission (please tick the appropriate box):

☐ **I CONSENT to participate in the study and filming.**

Before signing this Consent Form, I have been given the opportunity to ask any questions relating to any possible physical and mental harm I might suffer as a result of my participation. I have received satisfactory answers to any questions that I have asked.

I understand that my participation in this study is entirely voluntary and I may withdraw at any stage. If I withdraw, this decision will not affect my future treatment or care. If I decide to participate, I am free to withdraw my consent and to discontinue my participation at any time without prejudice.

I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

I understand that if I have any questions relating to my participation in this research, I may contact the principal researcher, Professor Rick Iedema on (02) 9514 2709, who will be happy to answer them.

I acknowledge receipt of a copy of this Consent Form and the Subject Information Statement.

The conduct of this study at [name of site] has been authorised by the [name of organization]. Any person with concerns or complaints about the conduct of this study may also contact the [Research Governance Officer] on [telephone number] and quote the reference number 09/02/18/5.02.

Further to this, any complaints or concerns about this research project may be made to the UTS Ethics Secretariat through the Research Ethics Officer as follows: Research Ethics Officer, UTS Human Research Ethics Committee, PO Box 123, Broadway NSW 2007.

Tel: (02) 9514 9615

Fax: (02) 9514 1244

Email: Research.Ethics@uts.edu.au

Signature of subject ____________________ Signature of witness __

Please PRINT name ____________________ Please PRINT name __

Date ____________________ Date ________________

Signature(s) of investigator(s) _

Please PRINT Name ____________________________________

Date: ____________________________________

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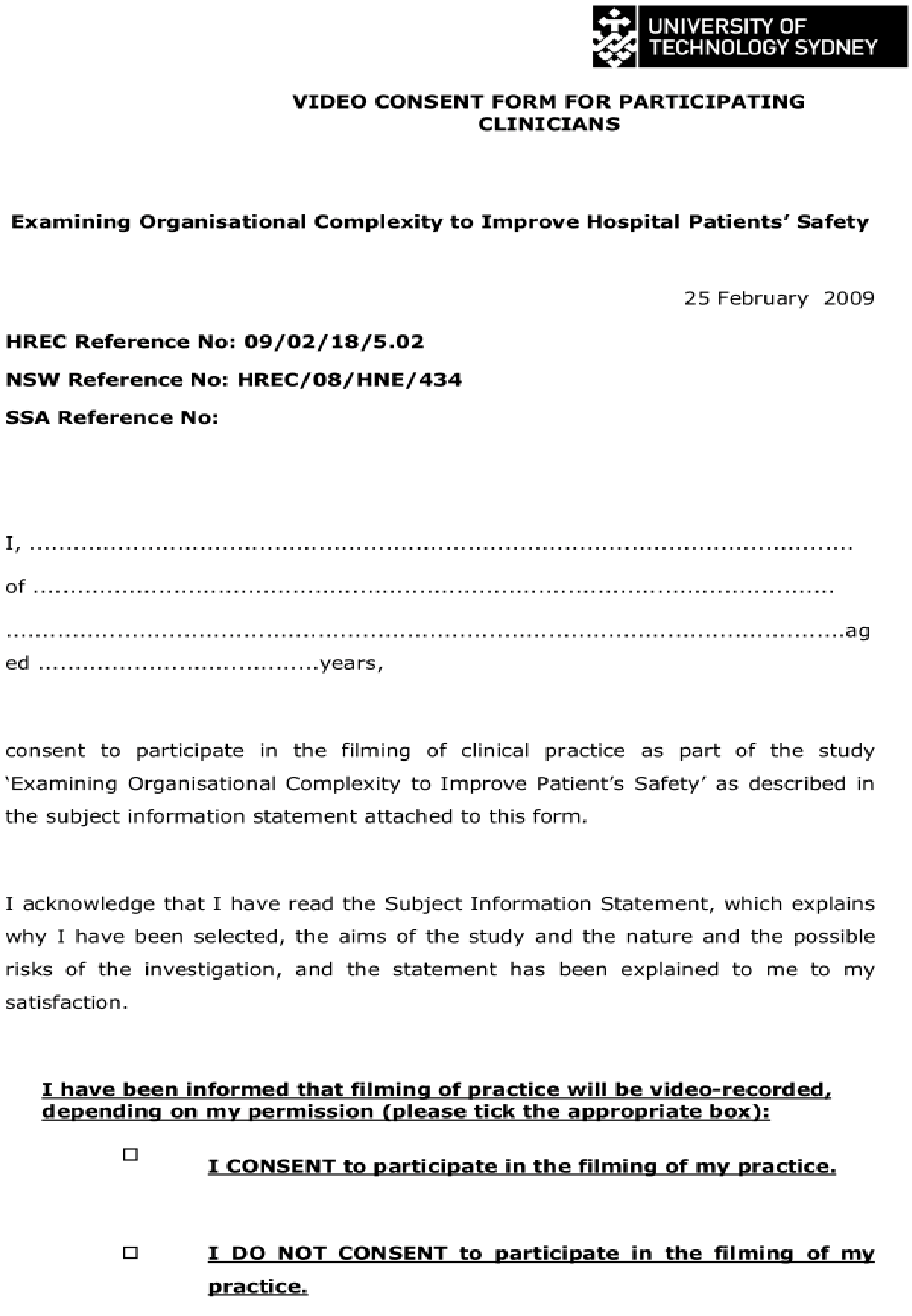
Appendix 6 Video consent form for participating clinicians



UNIVERSITY OF TECHNOLOGY SYDNEY

VIDEO CONSENT FORM FOR PARTICIPATING CLINICIANS

Examining Organisational Complexity to Improve Hospital Patients' Safety

25 February 2009

HREC Reference No: 09/02/18/5.02
NSW Reference No: HREC/08/HNE/434
SSA Reference No:

I, ...
of ....
....aged ....years,

consent to participate in the filming of clinical practice as part of the study 'Examining Organisational Complexity to Improve Patient's Safety' as described in the subject information statement attached to this form.

I acknowledge that I have read the Subject Information Statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

I have been informed that filming of practice will be video-recorded, depending on my permission (please tick the appropriate box):

☐ **I CONSENT to participate in the filming of my practice.**

☐ **I DO NOT CONSENT to participate in the filming of my practice.**

Before signing this Consent Form, I have been given the opportunity to ask any questions relating to any possible physical and mental harm I might suffer as a result of my participation. I have received satisfactory answers to any questions that I have asked.

My decision whether or not to participate will not prejudice my present or future employment with (site to be inserted) or any other institution cooperating in this study. If I decide to participate, I am free to withdraw my consent and to discontinue my participation at any time without prejudice.

I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

I understand that if I have any questions relating to my participation in this research, I may contact the principal researcher, Professor Rick Iedema on (02) 9514 2709, who will be happy to answer them.

I acknowledge receipt of a copy of this Consent Form and the Subject Information Statement.

The conduct of this study at the (insert site) has been authorised by the [redacted] [redacted] Area Health Service. Any person with concerns or complaints about the conduct of this study may also contact the Research Governance Officer on (02) 9515 6766 and quote protocol number 09/02/18/5.02, SSA (insert #).

Signature of subject ____________________ Signature of witness

Please PRINT name ____________________ Please PRINT name

Date ______________________ Date __________________

Signature(s) of investigator(s) _

Please PRINT Name ________________________________

Date: ________________________________

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Appendix 7 External Stakeholders (Large Group Meetings)

Healthcare Community

- Collier, A 2012, Hospital Dying: Video accounts of patient safety, Sacred Heart Hospice, 10th September
- Collier, A 2011, A Video Narrative of Patients, Families and Clinicians' Experience of Dying in Hospital, Westmead Association Hospital Week, 2011.
- Collier, A 2012, Liverpool Hospital Dying: Video accounts of patient safety, Liverpool Hospital Grand Rounds, 29th March 2012.
- Collier, A 2012, Conversations at the End of Life: Video Accounts of 'Patient Safety, Concord Hospital Physician's Workshop, 7th July 2012.

Policy related

- Collier, A 2011, Using Participatory Video with Palliative Patients, Families and Clinicians to Investigate Patient Safety, Executive of the national framework for quality improvement of specialist palliative care, June 2011.

Professional bodies

- Collier, A 2011 'Hospital Dying': Video narratives of patients, families and clinicans' experiences, Palliative Care NSW, Professional Development, Education Forum, 27th May 2011.
- Collier, A 2011 Using Participatory Video with Palliative Patients, Families and Clinicians to Investigate Safe Healing Spaces, Sydney Institute of Palliative Medicine, 2011.

Educational Fora

- Collier, A 2012, Dying in Campbelltown Hospital: A Video Narrative of the Hospital Experience, Campbelltown Hospital, Palliative Care Hospital Resource Nurse Program, 2011.
- Collier, A 2012, Safety in Palliative Care: Patient and family perspectives. Third Year Student Nurse Cohort, Notredame University, Sydney, 25th September 2011.

- Collier, A 2012, Palliative Care in Practice, Third Year Student Nurse Elective, Faculty of Health, University of Technology Sydney, 25th October 2012.

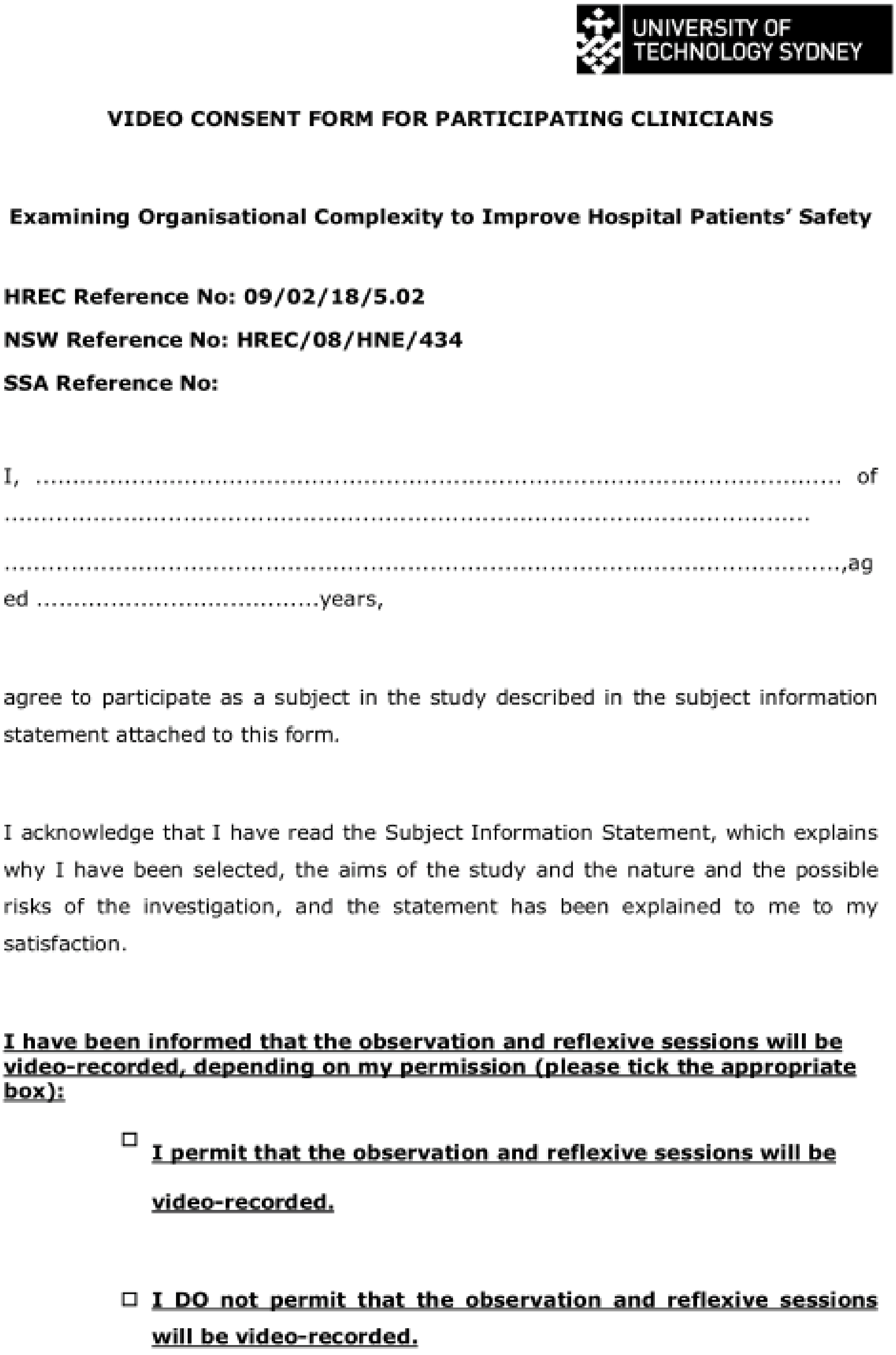
Consumer groups

- Collier, A 2012, Looking After Yourself: Making Your Voice Heard, South West Sydney Area Palliative Care Service Carer's Forum, Bankstown Trotting Club,

Research Community

- Collier, A 2012, The Patient Journey Towards the End of Life: Patient and family accounts of 'patient safety', ASCEPT-APSA, Medication Safety, December 3rd 2012.
- Collier, A 2011, Strengthening Quality Care Towards the End of Life in the Acute Hospital-Patient and Family Accounts of 'Patient Safety' paper presented to Diversity 2011,11th Australian Palliative Care Conference, Cairns Convention Centre, 30 August - 2 September 2011.
- Collier A. 2011, 'Exploring Death and Dying Down Under Using Participatory Video-A Case Study' paper presented to the Inaugural Death Down Under Conference 2011, Sydney, Australia, 27 and 28th June 2011.
- Collier A. 2010, 'How People with Life-Limiting Illness and those Caring for Them Construct 'Safety'- Results of a Pilot Study To Explore Safe Healing Spaces' paper presented to 'Hands on in the Hunter'- Innovation, Inclusiveness and Integration, NSW State Palliative Care Conference, 3-5 November, Hunter Valley.
- Collier, A. 2010, 'How People with Life-Limiting Illness Construct 'Safety' and 'Healing'-Results of a Pilot Study to Explore Safe Healing Environments Using Visual Methods', paper presented to the Making Sense of Health, Illness and Disease 9th annual meeting, Oxford, UK, 11-13 September 2010.
- Collier, A. 2010, 'A pilot study utilising participatory video with palliative patients and their carers to investigate safe healing spaces. 'Paper presented to the International Conference on Communication in Healthcare 2010, 5-8 September 2010, Verona, Italy.

Appendix 8 Video consent form for participating clinicians



UNIVERSITY OF TECHNOLOGY SYDNEY

VIDEO CONSENT FORM FOR PARTICIPATING CLINICIANS

Examining Organisational Complexity to Improve Hospital Patients' Safety

HREC Reference No: 09/02/18/5.02
NSW Reference No: HREC/08/HNE/434
SSA Reference No:

I, ………………………………………………………………………………………………… of
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ed …………………………………years,

agree to participate as a subject in the study described in the subject information statement attached to this form.

I acknowledge that I have read the Subject Information Statement, which explains why I have been selected, the aims of the study and the nature and the possible risks of the investigation, and the statement has been explained to me to my satisfaction.

I have been informed that the observation and reflexive sessions will be video-recorded, depending on my permission (please tick the appropriate box):

☐ **I permit that the observation and reflexive sessions will be video-recorded.**

☐ **I DO not permit that the observation and reflexive sessions will be video-recorded.**

Before signing this Consent Form, I have been given the opportunity to ask any questions relating to any possible physical and mental harm I might suffer as a result of my participation. I have received satisfactory answers to any questions that I have asked.

Before signing this Consent Form, I have been given the opportunity to ask any questions relating to any possible physical and mental harm patients might suffer as a result of participating in this research. I have received satisfactory answers to any questions that I have asked.

My decision whether or not to participate will not prejudice my present or future employment with (insert site) or any other institution cooperating in this study. If I decide to participate, I am free to withdraw my consent and to discontinue my participation at any time without prejudice.

I agree that research data gathered from the results of the study may be published, provided that I cannot be identified.

I understand that if I have any questions relating to my participation in this research, I may contact the principal researcher, Professor Rick Iedema on (02) 9514 2709, who will be happy to answer them.

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Signature of subject ____________________ Signature of witness

Please PRINT name ____________________ Please PRINT name

Date ____________________ Date ____________________

Signature(s) of investigator(s)

Please PRINT Name ____________________

Date: ____________________

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