An exploration of the nature and meaning of informal communities in cancer treatment

Matthew Grant

MBBS, MBioethics, FAChPM, FRACGP

Supervisors:

Prof Paul Komesaroff, Prof Jennifer Philip, Prof Luc Deliens

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School of Primary Health Care

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Abstract

In hospital settings patients, visitors and staff engage in many interactions outside the formal clinical encounter. While many of these are inconsequential, other encounters are of significant importance to the manner in which patients and their caregivers experience cancer and its treatment and staff engage in care provision. There is evidence that these 'informal interactions' in cancer treatment settings exhibit consistent and stable social processes. This study proposes that these interactions and the relationships that form as a result constitute social systems within hospital settings, as 'informal communities', composed of patients, staff and visitors.

This thesis proposes the existence of informal communities in cancer treatment settings as collective social processes developed outside formal clinical interactions. It explores their nature, meanings and outcomes in order to develop a model that provides a systematic account of both their structures and their functions.

A multimethod approach is employed that encompasses theoretical and empirical studies. The first study sets out the conceptual basis of informal communities and proposes a theoretical model. This is followed by two empirical studies to test the model, elaborate its internal structures and to identify previously unrecognised variables. An ethnographic study and a phenomenological interview study are conducted, in which participants are observed engaging in informal interactions in cancer treatment settings of a tertiary hospital, and interviews are performed with cancer patients, staff and family members.

Informal communities in cancer treatment settings are important, fluid and complex social entities that exhibit patterned structures and functions, indicating that they exist as specific social systems. In contrast to the formal clinical interactions that occur alongside them, informal communities exhibit characteristics, reflective of post- or late modernity, of fluidity and heterogeneity of participation, knowledge and focus.

A structural functionalist theoretical framework is employed to describe the structures and the functions of the informal communities. The structures—that is, the patterned arrangements that allow them to operate as systems—are marked by relationships characterised by fluidity, lack of organisational hierarchies and roles, use of local and concrete language, and broad fields of content shared within them. The knowledge employed draws on

many sources and is open to questioning and interpretation. The functions - that is, the processes or outcomes that both result from and maintain the system - embrace mutual caring, building of personal relationships, and making sense of health issues and processes.

A focus on interpersonal relationships is an invariant attribute that drives these communities and enables their broad range of outcomes. All their functions are directed towards strengthening these relational bonds, and in doing so reinforcing the impetus to provide care for others, share experiences and personal narratives, and access support. Thereby informal communities present opportunities unavailable to formal health systems that can be utilised in the processes of care by staff, carers and patients.

Declaration

This thesis contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution and that, to the best of my knowledge and belief, this thesis contains no material previously published or written by another person, except where due reference is made in the text of the thesis.

Matthew Grant

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Prologue

Me: *Can you tell me about the people you meet here in the hospital?*

Jackie: Yeah. Just the ones that have been here. We meet. We all meet up.

Yeah. We still have coffee dates, and we meet up here for appointments. If one's got an appointment, everybody else rocks up for that appointment, so we still meet up and have coffees and do all that sort of stuff.

And just talk about where we're going and how we're going and how far we've got. We do all that still. My phone's full of hospital patients. We still all meet up. We've got mates in Albury, Wodonga, who've been here, but we still talk.

Col was here last year, but we still hang out. At the moment, it's room-to-room because he's in isolation. But we still hang out. Yeah, I still go do his shopping and shit like that.*

Me: And what do you talk about?

Jackie: Oh, it's just general. How are you? How are you feeling? How's your sickness going? Have they worked out the right meds for you now? And just how's your day? Have you seen the kids? Have you been out to a big restaurant? I mean, it's just all ... a bit of medical and general stuff in between. Mostly, how they feel and what they're up to, where they're going and what they've got planned for the weekend. It's all just like a normal group, but they're all hospital patients.

Shirley seems to get a lot ... she gets a lot of knowledge, because she's got ... Oh, shit. What has she got? Yeah, whatever's she got, plus a mental illness, so she's not a very easy learner. She'll ask me a lot of just general questions. Just about the weather sometimes, or ... How could you put it with Shirley?*

She'll ask you anything and everything. Whatever you teach her or tell her, she writes down. Then she'll go home and she'll learn what you've taught her. Then she'll come back and tell you what you've taught her. That's how I do it with her. Pen and paper. Because she really can't remember. Her depression and all that is very, very, high. But that's how I work with her.

She just went one day and got pen and paper and said, "Right. Let's go. This is what I need to know. Can you help?" I'll help with whatever she asks. Who knows what it's going to be. If I can answer it, I'll answer it. If not, I'll go find out for her, then I'll come back and tell her. That's how we do that.

Johan just gets friendship because he lives in Shepparton*. He just gets friendship, and a bit of knowledge. "With your medications and that, go easy on it. Don't OD on that stuff. Don't take too much."Because he might say, "Oh, I took six of those," and I'll go, "Why for?" "Oh, the buzz." "Yeah, but when the buzz runs out, you run out, don't you?" Just stuff like that. Just your general stuff. Be careful. But he gets the friendship. A little bit of learning knowledge. That's how he goes.*

Dan is pretty much the same. He's on a learning curve because he's only a pup. Yeah, so pretty much, we just all learn off each other. We try and learn off each other, so we can help each other next time around. That's about it.*

Yeah, it's a big support group. That's what it is. It's just an in-house support group. Then we go home, within a week or two of everybody getting better, then we start our out-house support group. That's when we start meeting up.

Me: *How did this all start?*

Jackie: *Just coming in here (the hospital), going down to the fishpond for a smoke, and that was it.*

> *That was it. Simple as walk out the door, sit on the fishpond, and someone will say, "G'day." You say g'day back, and that's it.*
>
> \- Jackie*, patient, palliative care ward, participant #1, interview study
>
> (* all names have been altered)

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Chapter 1

Introduction

1.1 Project Beginnings

This project started the day when I met Gwen.

Gwen was a lady in her 60's, with whom I came into contact with through my work as a Palliative Medicine Physician. She was always cheerful and enthusiastic, taking an interest in those people around her. Every morning when I walked into the hospital, I would see Gwen chatting with the smokers outside the hospital, even though she didn't smoke. Throughout the day she was equally occupied with talking with other patients on the ward, either in the corridors or their rooms.

Some days later I was sitting with Gwen talking about a clinical matter. I asked her about these other people in the hospital and what these relationships meant to her.

"Those other people are the most important part of coming to hospital." She replied. Gwen told me about life at home, where she was often too tired or short of breath to leave the house, and when she did see friends or family the conversations were superficial, evading talk of her illness and treatment. She said: "Here I talk to people, and we all talk about our cancer, which medications to take, what chemo you are on, all the struggles we have. Sometimes, it's nice to know that you aren't the only one hurting."

Her response made me reflect on many other patients I had known and the relationships they had formed with other patients and family members. Over the coming months I met new patients and relatives, and witnessed similar bonds forming.

One unforgettable memory involved three patients in a shared room on the palliative care ward, each of them from differing cultural and social backgrounds. None of these patients had a great deal of social support, and the few family members that did visit became increasingly entrenched in this small community. They spent their days together, talking and sharing meals, helping each other with practical tasks, and celebrating small milestones. The patients made a promise to each other, that they would not leave each other. Over the coming month they all died, one by one. Each of them refused to leave the room in their final days, at a time where we would usually offer them the option of a private room. Instead, they died together in this shared space, supporting and caring for each other.

1.2 Background

This work was motivated by phenomena witnessed in clinical practice, the meaningful and often enduring relationships that developed between individuals through cancer treatment. The project began as an exploration of these phenomena, to understand these interactions and relationships.

As the research progressed, it became apparent that this was not an isolated phenomenon, but recurring and patterned social processes. A review of the published literature examining informal interactions in cancer care further supported my hypothesis (presented in Chapter four), demonstrating consistent and repeated social processes within these interactions (Album, 1989, Larsen, 2013, Larsen et al., 2013, Andersen et al., 2015, Isaksen and Gjengedal, 2000). These considerations re-defined the project. The focus was shifted from describing the experiences of these individual or singular personal phenomena to detailing them as collective social processes.

These recurring social processes are described in sociological theory as social systems (McDonnell et al., 2009). As the focus shifted to understand these systems, which I refer to as “informal communities”, the object of study moved to these group processes. To engage in this study, I utilised theoretical resources not commonly applied to the medical field: structural functionalism, organisational theory, and communicative action (Habermas et al., 1984, Parsons, 1991, Snowden, 2000). These resources enabled the systematic description of these social systems: their functions, contents, outcomes and significance.

This study hypothesised that ‘Informal Communities’ in hospital cancer treatment settings exist as social systems, adjacent to formal health care systems. Furthermore, I propose they (informal communities) make important contributions to social connectedness, information sharing and care provision.

This is a radical and potentially subversive proposition. It suggests that there are existing communities functioning alongside formal health care systems that are engaged in provision of information, social support and health care. The experiences of Jackie and Gwen articulate the importance of these relationships, and they reflect many of the elements and outcomes of formal care processes. Jackie's community shared information about medication and proffered advice regarding its use. Gwen described many outcomes, most importantly the significance of these relationships for her ability to connect with others who shared the same challenges through cancer. Such a proposition has widespread implications for formal health care systems. Yet to appreciate these ramifications we were first required to understand informal communities and their relationship to formal health systems.

1.3 Theoretical Approach

This study proposed the novel concept of 'informal communities' as social systems in hospital cancer treatment settings. 'Communities' defines these groups as being social systems, rather than independent social processes. The theoretical basis for these communities is influenced by postmodern thinkers, particularly Zygmund Bauman, who identifies late modern communities as evolving, fluid and dispensable, whilst others may be enduring and immovable (Bauman, 2013b). The term 'informal' is used to describe that which occurs outside the formal or deliberate clinical encounter.

The theoretical approach of this thesis is broad, comprising of a range of sociological and ontological traditions. It draws upon theory from phenomenology, structural functionalism, symbolic interactionism, ethnography and feminist philosophy. To explore informal communities has demanded the use of different theoretical positions and bodies of knowledge. It is an approach that is postmodern, supporting examination of assumptions and structural norms, whilst allowing for the individual and the community to be viewed in a fluid context. This postmodern ontology was important in the exploration of how the individual related to the formal hospital setting, society and community. Central to this exploration was the notion of health as a discourse dominated by power imbalances of professionalism, rationalisation of illness and exclusionary language (McKnight and McKnight, 1995). Michel Foucault's examination of the use of institutional and societal power dynamics further enlightened this concept(Foucault, 2007). Section II of this thesis develops this theoretical approach in greater detail.

This thesis contains numerous terms that may not be immediately recognisable to the reader, and thus I offer a series of definitions. These terms are further elaborated upon in the ‘theoretical chapters’ (Section II). The terms ‘informal’ used in the context of this thesis differentiates that which is outside of formal provision of health care and its clinical discourse. ‘Interaction’ describes a temporally circumscribed event of social engagement between two or more persons (Goffman, 1961). Relationships are normally comprised of many instances of interaction, or, reflective of postmodern times, possibly only a single episode. Additionally, I employ the terminology of ‘domains’ of communication, describing institutionally relevant spheres of social interaction and discourse (Fishman, 1971). In the hospital setting I have articulated two separate communicative domains: the formal domain grounded in the clinical or medical discourse, and the informal domain which occurs outside of the formal.

1.4 Aims

This thesis proposes the existence of informal communities in cancer treatment settings, being collective social processes developed outside the formal clinical consultation. Its primary aim is to explore this social system, to provide a systematic account of these social systems. In order to meet this aim, its primary objective is to construct a model of informal communities, describing their structures and functions.

In order to conduct this examination, I will be focusing on a number of specific research questions:

- *Question 1.* What is the theoretical basis of informal communities?
- *Question 2.* What are the behaviours and dynamics of informal communities?
- *Question 3.* What is the communicative content of informal communities?
- *Question 4.* What is the significance of involvement in these communities?
- *Question 5.* What outcomes are realised through these communities?
- *Question 6.* How do these informal communities engage with the formal health system?

1.5 A Project Map

Informal communities are a novel concept that, to the best of our knowledge, have not previously been described in the medical literature. To develop this concept, I have begun with a hypothesis describing their existence, importance and irreducibility. To prove this hypothesis, the first challenge was to articulate the concept of informal communities, defining their constitute components and relationships to the formal health care system and then to develop a theoretical model describing their structures. In order to test this hypothesis I have engaged two empirical studies that sought to add important data to this model and to describe variables that were not known. The final task was to use these data to support my hypothesis, to construct a model that describes the many structures and functions of informal communities.

I employed an approach that incorporates multiple methods, theoretical positions and perspectives. This approach drew upon important positions from postmodernism, phenomenology and structural functionalism, and incorporated empirical studies utilising hermeneutic phenomenology and ethnography. Figure 1 provides a diagrammatic representation of the research approach.

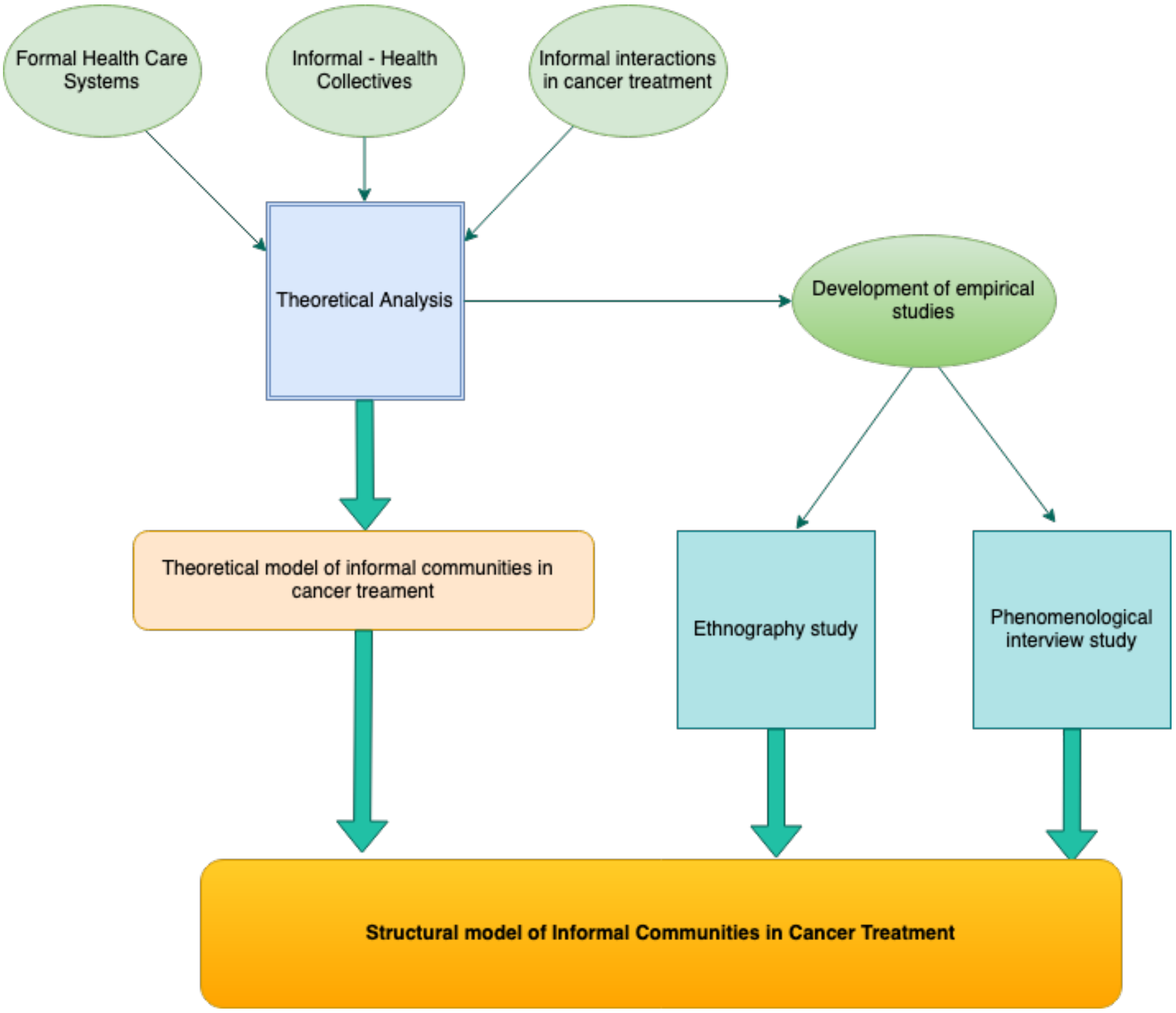
This thesis begins with an exploration of the literature relating to formal and informal health, to understand the structure and functions of these systems. A specific focus upon describing informal interactions in cancer treatment settings was taken, and the potential structural elements of informal communities was proposed.

The first study was theoretical in nature. As a novel concept, informal communities have not been defined, and there was not an existing conceptual basis to interpret their functioning. Based on the initial data described in the background section and a thorough examination of the sociological and philosophical literature, a theoretical model of informal communities was developed. This model proposed a framework through which informal communities could be interpreted, addressing Research Question one. The development of this theoretical framework informed the research methods employed in the empirical studies.

The empirical component of this project comprises of two studies: employing ethnographic observation and phenomenological interviews. The ethnographic study observed informal communities in cancer treatment settings, and explored their behaviours, roles, and dynamics. This addresses Research Questions two and three. A phenomenological interview study explored the experiences of participants of informal communities, describing the personal experiences, significance, and outcomes. This addresses Research Questions three, four and five. These two empirical studies accessed informal communities through differing perspectives, providing data that focused on contrasting aspects of these systems.

The final step of this thesis is to propose a model of informal communities.

Figure 1: Diagrammatic representation of project



1.6 Content of Thesis

The first section of this thesis is focused on examining the available literature relating to social systems in health care. It sought to provide an understanding of social and care systems in formal and informal health care processes, and to review the literature applicable to informal communities in cancer. Chapter two discusses formal health systems, and the manner in which they are ordered, regulate and are regulated through knowledge, power and other means, built upon the work of Michel Foucault and Talcott Parsons (Foucault, 2012, Parsons, 1991). Chapter three shifts to informal care provision, describing the impact and organisation of informal care organisations, known as ‘health collectives’ (Grant et al., 2019). In Chapter four, I focus on the literature that examines informal interactions in cancer treatment settings, discussing potential social structures.

Section II is focused on developing the theoretical basis to this thesis and to propose a model of informal communities. Chapter five discusses the theoretical framework that forms the background to this thesis - postmodernism, phenomenology and structural functionalism - and outlines a coherent theoretical approach. Using this approach, I propose a theoretical model of informal communities in Chapter six. This model forms the initial construct that was tested in the empirical studies. Chapter seven outlines additional theoretical resources that informed the empirical studies, namely qualitative methods, ethnography and symbolic interactionism.

Section III contains the empirical components of this thesis. These aimed to systematically describe informal communities of cancer treatment through two differing perspectives. Chapter eight outlines the empirical methods for both studies, and the ethical considerations in conducting this research. Chapter nine describes the results of the ethnographic observational study, which is scaffolded through the use of vignettes. This study intricately describes informal interactions in hospital cancer treatment settings, and how they relate to formal interactions and tasks. Chapter ten presents the results of the phenomenological interview study. In this study I explored the content, outcomes and meaning of these interactions, constructing a systematic understanding of how these communities are experienced.

Section IV develops the theorical (section II) and empirical (section III) results to form a model of informal communities. Chapter eleven presents this model and contrasts it with the structure of formal health care systems. Chapter twelve engages in a discussion of this thesis, presenting the major findings, implications and methodological considerations. Finally, Chapter thirteen concludes the thesis.

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Section I

Background

Chapter 2

Formal Health Care Provision: Systems and Structures

> *The institutions, as historical and objective facticities, confront the individual as undeniable facts. The institutions are there, external to him, persistent in their reality, whether he likes it or not. (Berger et al., 1967) p.78)*
>
> - Peter Berger and Thomas Luckman, *The Social Construction of Reality*

The focus of the existing health literature is on the formal structures and domains of care provision. Understanding the informal domain (or domains) is far more difficult, owing to a lack of literature and the wide variations inherent in how informal health care may occur, including, whether they should they exist, the variations in any systems, and structures of care. In order to explore and understand the informal ways in which health care occurs I will, firstly seek to establish and delineate the formal systems of health care provision. This chapter therefore focuses on describing formal health care systems: their structures, functions, institutions and knowledge. It examines the historical developments that have been instrumental to the current systems and divisions of health care.

This chapter aims to provide a systematic description of the formal domain of health care provision. The description of formal health systems will enable a framework for informal communities to be understood and their structures articulated.

The framework employed to describe formal health care systems was developed from the work of Talcott Parsons and Structural Functionalism. This theoretical approach provides a systematic framework to explore health care provision as a complex of structures, functions and institutions (Parsons, 1991). In addition, modern theorists of health care will be discussed, such as Michel Foucault and Anne-Mei Mol (Foucault, 2012, Mol, 2002). Structural Functionalism proposes that society is structured according to a set or sets of norms or values, which allow it to function as a cohesive whole (McDonnell et al., 2009). It has been widely used to appreciate society from a 'macro' perspective, and has notably been applied to understand health care in Parson's most noted work, *The Social System* (Parsons, 1991). I employ this existing approach to systematically describe the formal systems of health care. In this approach, social systems are defined by their structures and institutions of care delivery, and engage in functions in order to maintain the system (Mol, 2002). A more elaborate description of Structural Functionalism is provided in Chapter five.

Parsons describes *structures* as representing patterned relations: the scaffold within which systems operate. *Functions* are actions, processes or outcomes that result from these systems, and may play an important role in maintaining those systems (McDonnell et al., 2009). *Institutions* refer to those parts of society focused on meeting social needs, such as government, education, family, religion and the economy (Spencer, 1898). I have added *knowledge* as an additional category. This refers to the central role of knowledge in developing the current structure and institutions of health care provision. Understood in this way, knowledge is interwoven and embedded with the systems of health care provision (McDonnell et al., 2009). Additionally, knowledge in medicine has been a critical focus of Michel Foucault's and other modern theorists' conceptions of health care (Foucault, 2012).

Before the hospital, the doctor, the nurses, and the diagnosis there was illness, disability and death. The current state of health care provision, the formal system and our perceptions of this were constructed through societal, cultural and technical responses to illness. The institutions and structures of health are a product of their historical development, constructed through prevailing understandings of illness and treatments at the time. I begin the description from this historical viewpoint, focused on the development of Western medical systems, in order to appreciate the development of the knowledge and structures of formal systems of health care in the Australian context.

2.1 The Development of Medicine

Prior to the age of modern medicine there were numerous frameworks to interpret and treat illness: some based upon early forms of empiricism (ie. Hippocrates); others in religious or spiritual dogma such as voodoo, witchcraft, or religious interpretations of illness and relatedness to sin. The individuals who provided health care services were from diverse backgrounds, representing different theoretical approaches often reflective of local cultural beliefs. These ‘health care providers’ were for the most part active in other forms of labour and did not derive their livelihoods wholly from these care services. For example, in a medieval European village, childbirth may have been managed by an experienced local woman, surgery performed by the barber, and serious illness the domain of the clergy (Bagwell, 2005). There were physicians, healers and shamans whose sole focus was health care provision, but much of the population did not have the financial means to access their services and they were few in number (Wolf, 1992). These health providers were not subject to a standardised approach to training and education, leading to diverging interpretations and treatments of illness; and thus, the provision of health care differed widely. For most people and for most of the time, health care was provided by the family.

It is widely regarded that modern medicine evolved from changes in society and approaches to knowledge at the end of the eighteenth century (Foucault, 2012). The Enlightenment prompted existing approaches to the construction of knowledge and reason to be re-examined. At this time there were numerous societal shifts: economic changes causing growth of the middle class, professionalisation of occupations, and the increasing influence of institutions of higher education. Komesaroff identifies three factors that have facilitated the transition towards modern medicine: (i) the development of a structured approach to illness, (ii) formation of a structured medical profession and its institutions, and (iii) the rise of the voice of the patient (Komesaroff, 2020).

Influenced by Enlightenment scholars at the end of the eighteenth century, doctors engaged in questioning the traditional frameworks used to interpret disease, and rationalising approaches to medical knowledge and illness. The development of what Foucault termed ‘the medical gaze’ introduced a set of highly disciplined procedures to interpret the body and to obtain information (Komesaroff, 2008). The source of medical knowledge was focused upon the encounter between the patient and doctor, which Foucault described as ‘The Clinic’ (Foucault, 2012). Within this encounter, doctors applied an increasingly rigorous, formalised and systematic mode of enquiry, observation and documentation (Komesaroff, 2008).

At this time there were significant shifts towards the professionalisation of medicine, through standardisation of qualifications, training and the emergence of medical institutions. This is best reflected in the grand institution of modern medicine: the hospital. Hospitals had existed since the Ancient Greek period, yet, up until the Enlightenment period they were few in number and predominantly operated by religious communities with shared medical, social and religious objectives (Risse, 1999). They served populations with a wide range of needs extending beyond what we may now call the medical, to include those who were the poor and destitute. In the eighteenth century, the modern hospital emerged with the singular focus of the treatment of medical needs through the developing scientific approaches to illness. The modern hospital was staffed by trained surgeons and physicians, with formal divisions of care from those untrained workers who performed clerical and carer roles. As a result, hospitals became the centre of medical innovation, knowledge, education and training (Risse, 1999). The reform of medical training assumed a wider significance; it reorganised medical knowledge to congruent curricula taught through its institutions and organised stringent criteria for entering the medical profession (Foucault, 2012). A homogenous set of approaches to symptoms, signs, classification and treatment was developed, and a dominant episteme of medicine began to form (Mol, 2002). One example of this is Thomas Percival's 1802 treatise *Medical Ethics*: a comprehensive approach to conduct for the medical profession, with guidance around the approach to the clinical encounter and subsequent formation of behavioural norms (Percival, 1803).

A third factor that fashioned modern medicine was the rise of the voice of the patient. This has been an incremental development, which has progressively gained prominence over the past two centuries. This term reflects the knowledge of illness and health that is conveyed in and through the patient: their understandings of disease, coping strategies, mechanisms to enact care, and experiences of illness, disability and loss (Komesaroff, 2020). John Wiltshire identifies the writings of Frances Burney describing her 1811 mastectomy without anaesthetic as the first account of illness and medicine described entirely through the experiences of the patient (Wiltshire, 1993). Whilst the voice of the patient is recognised as a focal point for health policy through rhetoric such as patient-centred care, recognition of its value in practice remains imperfectly enacted (Komesaroff, 2020). This shift towards recognising the value of patient knowledge has had dramatic effects on health care provision, most prominently to engage the medical profession in critically reflecting on and reassessing its practices. As a result, treatments such as institutionalised psychiatry, routine mastectomy for breast cancer, and pregnancy terminations have been drastically altered (Grant et al., 2019). Numerous scholars including Frank and Mol have identified the full integration of the patient voice and knowledge into clinical care as being the next step towards the practice of a postmodern medicine, that reflects and embraces the differing understandings and knowledge embodied by the health professional, the patient and their carers (Mol, 2002, Frank, 2013).

2.2 Knowledge in Health Care

This period in the development of health care was highly significant for the formative basis for medical knowledge. It defined the approach and frameworks to understanding and treating illness that are visible in our health care systems today (Foucault, 2012). Through having a structured approach to understanding and interrogating illness, examination, normalised expectations of conduct, formalised education and training, and agreement to the terms under which new knowledge could be formed, medicine formed what Foucault termed an episteme - a logical coherent body of knowledge (Mol, 2002). The concept of the episteme as used by Foucault describes knowledge and its discourses at a temporal point. Knowledge, societal attitudes and technological advances are not static, and thus as these alter, there is a shift between epistemes. Foucault's proposal aligns somewhat with Thomas Kuhn's concept of the 'paradigm': shared ideas and concepts that guide members and their activities in a particular scientific field (Goldstein, 2012). "The paradigm designates connectiveness, but (also) makes it possible to articulate difference" (Mol, 2002) p.73). Both concepts – the episteme and the paradigm - articulate medical practice as evolving and operating in multiple discourses.

The rise of modern medicine signifies the development of the dominance of the medical discourse over matters regarding health and prominence in our society. The 'medical gaze' penetrated beyond the realms of the clinic, and, under the auspices of public health, "instilled a generalised medical consciousness about the role of health and good living" (McDonnell et al., 2009) p.7). The discourses of medicine formed a dominant narrative, one with global significance that is reflected in the prominent role of medical institutions in society (Lyotard, 1984). Prior to this, health was made up of many competing frameworks of understanding of illness derived from many differing conceptual backgrounds. Most health care was provisioned by the family, and the medical events of birth and death presided over by non-professionals. The era of modern medicine altered this dramatically, as health care transitioned from the home to the clinic and the hospital, from the family members to the health professional. The medical discourses formed a dominant position regarding health care, that rationalised and anatomised understandings of illness, limiting the involvement of the non-professional in health care.

The knowledge that relates to health care is vast and evolving, and to reflect this, I will use the term discourse to relate to this concept. Komesaroff describes clinical medicine as a complex of contending discourses born from science, anatomy, physiology, sociology, ethics and many other influences (Komesaroff, 2008). I have employed the term medical discourse as used by Foucault, reflective of the dominant and historically constructed epistemes of medical practice, research and health care provision. These are the dominant narratives of health to which the researcher, the nurse, the medical administrator and the doctor contribute, the narratives that dominate public discourse and understandings of illness. These terms of narrative and discourse are utilised to reflect the position of medicine as occupying a historical and structural position in society that has been described by many commentators as reflective of modernist concepts of knowledge, yet embedded within a society whose relationship to knowledge is likely better articulated by postmodern literature (Frank, 2013, McDonnell et al., 2009). These discourses are the result of many contributors: the patients, carers, family members of those affected by illness, and the ordinary citizens for whom health influences many facets of their lives.

The discourses of health are embedded throughout its practices, institutions, structures, functions, training, education and the conduct of its professionals. And the discourse of health shapes and orders the provision of health care.

2.3 The Institutions of Health

Formal health care in the Australian setting is comprised of many governmental, private and individual institutions existing under a centralised regulatory system which bestows the ‘rights’ and titles to provide health services. It is commonly termed ‘a system’, but in reality is comprised of many complex and interacting organisations and providers with aligning foci around health care services (Palmer and Short, 2000). Nevertheless, for the purpose of this thesis, I will refer to it as a system, which consists of multiple interacting networks of organisations and actors. It is the product of a diverse range of historical, economic, political and social factors. What is presented in this section references the Australian context, though is a reflection of a broader literature (Palmer and Short, 2000).

The Australian health care system is formed of a number of distinct domains of care: hospital, residential care, community, and public health services. The hospital system – comprising both public and private institutions – provide inpatient, emergency and specialist outpatient services. Nursing home facilities provide long term residential care for people with chronic care needs, mostly an older patient cohort. Community health services are provided by a range of health professionals, many (or most) who are subject to professional registration requirements, and they include providers of what might be considered alternative or complementary medical services (Palmer and Short, 2000). Public health services are involved predominantly in health promotion, education and environmental management. Commonwealth and state governments are responsible for guiding the provision of the majority of services, either through direct relationships, funding health providers, or in partnership with private entities (Palmer and Short, 2000). Additionally, governments administer the legal frameworks governing formal health service provision.

The normative representations of health care provision is decidedly narrow, reflected in the current national literature describing the subject, which provides little reference to organisations and providers outside of the formal health care system (Willis et al., 2016, Australia and Economics, 2015). Public discourse also focuses primarily on health care as the domain of the formal system, with conversations led by the health professionals and researchers. In his critique of the Australian health system, George Palmer describes it as an ‘illness system’ that is focused on illness and its treatment, which may neglect many aspects of health and wellness that fall outside of this modernist paradigm (Palmer and Short, 2000). There are many entities acting outside of the formal system that contribute to health care and its prevention. This is particularly relevant within developed societies with high rates of lifestyle diseases, where many of the potential contributors to better health outcomes are non-health care entities, that instead focus on improving diet, social support and smoking cessation. In conjunction with the institutions of the formal health care system there are other external stakeholders that also contribute to care provision, consisting of civil society groups, informal caregivers and interested citizens (Timmermans and Oh, 2010). As these groups reside external to the formal system and its knowledge constructs, they may reflect differing conceptual understandings of illness. This field is vast and is difficult to delineate, however, I shall discuss some of the cohorts that may be represented in these institutional bodies.

The formal health system and its institutions are supported by external entities and actors. Civil society organisations form an important, yet frequently unrecognised domain of health care provision (Grant et al., 2019). There are groups that may be aligned or supported by formal institutions or health professionals. A recent report published by Carers Australia suggests that one out of eight Australians (2.8 million) are providers of informal health care (Australia and Economics, 2015). Informal carers occupy a unique position, as they are independent yet work alongside formal care processes and may receive (small amounts) of government funding, health care training and support for their work. The definition used for informal carers in this report is decidedly narrow in that it only accounts for care provided for people with disability and chronic conditions who have regular and ongoing needs for care provision. It therefore is likely to significantly underestimate the number of those involved in informal care. It does not take into account many activities that may have significant and identifiable impacts on health such as the breastfeeding mother, the supportive friends of a depressed student, the housemate who cares for her friend with the flu, or the children who visit their elderly mother every few days in an aged care facility. Chapter three focuses on the domain of informal care provision and describes these actors in greater detail.

2.4 Structures of Health

There are numerous structures that order health care provision within the formal realm. These structures exist across all levels of society, from shaping societal and cultural understanding of health and illness, to framing the discourse in the clinical encounter between the doctor and patient.

Regulatory Structures

The majority of health professionals who work within this system are governed by regulatory frameworks, defining scope of practice and guiding conduct. The Australian Health Practitioner Regulation Agency licenses the majority of health care providers including nurses, doctors, physiotherapists, psychologists, occupational therapists and dentists (Wardle et al., 2016). There are some practitioner groups that sit outside this framework but are nonetheless part of formal professional groups through national member associations and education qualifications. For the purpose of this thesis I refer to health practitioners as those who are employed or engaged in the provision of formal health care services.

The professional status of these domains of practice has an important influence on the frameworks of knowledge through which health care is practised. Timmermans describes the distinguishing characteristic of a profession as a successful claim for specialised and valued skills, in return for state-sanctioned economic and legal privileges (Timmermans and Oh, 2010). This monopoly over a specific scope of practice provides economic advantage and exerts control over the knowledge related to those practices. The scientific evidence in this field is constructed in collaboration with these practitioners, influenced by their understandings and frameworks for interpreting the specific condition. Students and practitioners of this profession are trained and certified, and operate within the scope defined by the profession. Operating outside, or in conflict with these norms of practice can lead to exclusion from the profession, or legal ramifications.

Education and training of future practitioners occurs within these regulatory structures. The institutions that provide training – hospitals, community health services, universities and other higher education providers – enact a curriculum that is regulated by the profession. Teaching is conducted primarily by members of that profession. This results in professional training occurring within a structured environment and a curriculum that imparts the knowledge, conduct and functions of that profession.

Organisational structures

Modern health care systems are ordered around biomedical models of illness, focused on the body as a composition of physical components that medicine seeks to repair (Wade and Halligan, 2004). In the hospital, care provision is organised around physiological systems in relation to which medical specialities are ordered, such as cardiology, oncology, orthopaedics or speech therapy. Modern health practice reflects an increasing need for hyper-specialised knowledge, of numerous specialties that deal with intricate yet confined domains of practice (Mol, 2002, McDonnell et al., 2009). Such an approach is imbued with a modernist approach to knowledge (Frank, 2013). It reflects the focus of much of scientific and medical endeavour which involves applying rapidly developing technology to analyse and find solutions to illness. The structures of medical organisation mirror a modernist society, with health systems and professionals each engaged in their own specialised fields of knowledge, their own paradigms. In this modernist approach, the individual patient, a person with understandings, experiences, relationships, passions and fears can become marginalised within a framework of interpretation that limits the profundity of these phenomena. Eric Cassel detailed the dehumanising impact of the medical approach, in which the richness of experience is reduced to symptoms, and the embeddedness of the individual becomes a body of organs (Cassell, 1991, Michael and Rosengarten, 2012).

In practice, illness and its treatment do not always fit comfortably within these modernist frameworks. Health care systems function as seemingly aligned and coherent structures designed around health care provision, yet they comprise many differing discourses. In the modern tertiary hospital, a cancer patient may be treated by many different health professionals. The oncologist, the surgeon, the speech therapist, the psychologist and the nurse each has a different approach to the patient, with divergent priorities, interpretations and outcomes that might all be achievable under their care. However, the practitioners and their varying conceptual approaches nevertheless function together, their discourses joining at points of common reference. In addition, the voice of the patient continues to increase in prominence, not only influencing the discourses of medicine, but creating its own paradigm. From a systemic viewpoint, the bodies of knowledge that inform clinical practice are informed by differing approaches and theoretical frameworks (ie. patient-centred care, evidence-based medicine), each accessing the data of health care in a different manner and arriving at a, sometimes diverse, range of interpretations and recommendations.

John Law proposed that large organisations such as health systems act within ‘modes of organising’ (Law, 1994). His work was developed from ethnography conducted within scientific organisations, in which he identified the staff focusing on different fields of endeavour (Law, 2009). He suggested these modes of ordering pervade organisations, buildings, professional groups, practices and systems (Mol, 2002). They consist of multiple facets related to health care: scientific knowledge, the ethical domain, cultural and societal influences, and personal perspectives. Law suggested that his framework be compared to Foucault’s discourses, yet on a micro-level:

> *We should treat it as a set of patterns that might be imputed to the networks of the social; second, we should look for discourses in the plural, not discourse in the singular; third, we should treat discourses as ordering attempts, not orders; fourth, we should explore how they are performed, embodied and told in different materials; and fifth, we should consider the ways in which they interact, change, or indeed face extinction. (Law, 1994) p.95)*

Such an interpretation places Law's framework for interpreting organisations within a postmodern paradigm (Knox et al., 2008). It articulates the complexity and dynamic nature of the organisation and its participants, relating to each other across multiple discourses. The hospital is not a singular system, but is comprised of many networks that function in complex and fluid relationships to and with each other, relating in many different fields of influence in health care (Mol, 2002). Such an understanding positions the health professional as active and constructive within organisational processes and provision of care. It facilitates an understanding of the health system, the hospital, or the local clinic as components of larger networks of health provision, reactive and engaged in the discourses of medicine, and, many individuals with their own fields of interest and knowledge.

Relational Structures

On an individual level, health care is structured through the behavioural norms, roles and discourses of the clinical encounter. These are the relational structures of medicine. It is a relationship that "links between the micro- and macro-politics of health care since it is bound up with public trust in medicine and the authority that is invested in professional values and expert knowledge" (McDonnell et al., 2009) p.26). These structures order how health professionals enact their roles, their choice of language, their lines of questioning. The clinical consultation begins with greetings, and then frequently and immediately delves into intimate subject matter, before finally unmasking the physical body. The language is often foreign, in which phenomena of experience are reclassified to potentialities of illness or of health. The 'medical gaze' described by Foucault is a powerful analytic tool for health practitioners to question and interpret illness, and it exposes the patient, their suffering and their vulnerabilities. It imposes expectations on behaviours, the willingness to receive tests and medications, to submit to enquiry about their body, and to accept the medical knowledge. "The clinical relation is not an ordinary relations: it is asymmetrical and non-reciprocal…its processes involve not just the integration of experience, but disintegration, critical questioning, anatomising" (Komesaroff, 2008) p.131).

Patients and their family are subject to their own historically and culturally embedded patterns of behaviour, which are frequently reinforced by the institutional environments, including the sterile waiting room or the large desk of the doctor. It is not a normal relationship, but it is not unfamiliar. It is serious, has clinical significance and is not mere 'talk' (Mishler, 1984). The patient willingly submits to questioning, offering intimate details of their body, their relationships, their fears and suffering. The role of the patient and carers in this encounter is a socialised role, learnt through childhood encounters with the child maternal health nurse, the general practitioner and the school vaccination nurse. The medical encounter is equally influenced by the socialisation of the patient role and their individual perceptions of expected behaviour and course of the consultation.

As a medical student, I worked in a rural region of Ecuador, visiting Quechuan farming villages. The patients would enter the consulting room, sit quietly answering questions, and then move to the examination bench once questioning had finished. The doctor I worked with would always provide a prescription at the end of each consultation, even though he admitted that he knew the medications were often of no utility. When I questioned the doctor about his practice, he replied that he perceived that the patients expected a prescription as the outcome of the consultation, such that it became the concluding act of every consultation. The clinical encounter was thus fashioned as much by his medical discourse as it was by the socialised behaviour of the patients.

It is undoubted that the interactions that form health care provision are influenced by personal, societal and health system factors (Parsons, 1991). The current interpretation of this relationship details the complex and fluid interaction between practitioner, patient and carers. In a recent study, Druss and Mishler studied numerous clinical consultations, demonstrating that the majority of interactions proceed as a negotiated discourse between professional and patient following a particular structure (Mishler, 1984). The interaction occurs with familiar elements: the sequence, order and structure of discourse, the clinical examination, the hierarchy of knowledge; and, the recommendations of the practitioner (Drass, 1982). Druss described this structure as being imposed from both parties, as they negotiate these linked 'units of discourse' together.

2.5 Functions of Formal Health Care Systems

Health care systems engage in a range of functions that enable health to be provisioned and realised. Institutions provide services which are focused on improving health, ameliorating the effects of poor health, or preventing adverse health outcomes. Health is realised through individual and social behaviour, in addition to health care provision. As mentioned earlier in the discussion of institutions, a significant portion of the formal health care system is focused solely on the treatment of illness rather than on the broader goals of societal health promotion and prevention. The treatment and prevention of most health conditions occur in the home: eating well, taking medications, exercise, following management plans, and engaging with health services when issues arise. In considering the functions of health care systems we must consider how they engage not only with the tasks of formal health care such as writing prescriptions and taking blood, but also how these systems engage in enabling health on a societal level.

From a functional structuralist perspective, functions denote the way in which systems maintain stability and order within themselves (McDonnell et al., 2009). In health care systems, these are activities that allow the systems to function and provide care effectively, in addition to those activities that preserve authority over the domain of health. In many instances these functions may coincide, such as the medical profession exerting authority over a particular health issue, in order to ensure that credible and useful information is available to the public, whilst also maintaining their position as the experts in this field. It is through such activities including, and how they intersect, that order is maintained within systems (Parsons, 1991).

The prevailing thesis on this matter is provided by Michel Foucault, describing the relationships between knowledge and power in health care (Foucault, 1979). The basis of Foucault’s claim is the understanding that knowledge is inseparable from power as it defines the norms by which its subjects define themselves (McDonnell et al., 2009). In health care this knowledge is embedded within its discourses, practices and techniques, and thus the relationships that form the basis of health care provision are defined by relations of power. It is present at all levels of health care including: our societal and cultural norms of health and illness; the manner in which the differing systems and institutions of health interact; and, our personal, professional and health care relationships that deal with the knowledge of health and illness.

Health holds a crucial position in our society, as it is delineates the boundaries between normality and deviance, and between wellness and illness (Mol, 2002). “It lies on an indivisible boundary between the public and the private, between personal freedom and social control, between the intractable demands of nature and the historically conditioned effects of culture" (Komesaroff, 2008) p.101). Foucault described how modern medicine turned the clinical outward to the social sphere, as physical health became an object that could be realised through social and societal measures. "Medicine must no longer be confined to a body of techniques for curing ills and of the knowledge that they require…which authorises it not only to distribute advice as to health life, but also to dictate the standards for physical and moral relations of the individual and of the society in which he lives" (Foucault, 2012) p.34). Simultaneously, governments shifted focus towards the well-being of their populace, and thus became aligned with the objectives of health care (McDonnell et al., 2009).

Foucault described the influence of medicine in establishing societal 'normality', in establishing conventions for what is considered healthy or abnormal from biological, psychological and social perspectives (Foucault, 2013). The normality imposed by medicine traverses beyond the scope of illness:

> *The normal is established as a principle of coercion in teaching…it is established in the effort to organise a national medical professional and a hospital system capable of operating general norms of health; it is established in the standardisation of industrial processes and products…With it, normalisation becomes one of the great instruments of power at the end of the classical era. (Foucault, 1979) p.184).*

According to Foucault, the discourses of health function as exercising a disciplinary power that establishes itself through defining norms of conduct and engages society in their maintenance (McDonnell et al., 2009). This power is not specifically negative: the patient is not obligated to stay in hospital (except in limited circumstances when there are identifiable risks to self, such as suicidal ideation) or go back to work. However, expectations are articulated of expected behaviours, symptoms and outcomes (Mol, 2002). It is society that manages the surveillance and maintenance of these norms through socialisation.

Eliot Friedson described the increasingly broad effects of the discourses of health in establishing societal norms in domains of social life beyond the realm of health: in particular issues of moral personal identities and preferences (Calnan, 2015). This has been most notably described by Foucault in his work on sexuality (Foucault, 2019). Characteristics and activities associated with negative health outcomes are afforded labels of, and thus societal recognition as evidence of aberrance, such as homosexuality, young motherhood, and rock and roll music. This influence extends to the individual's understanding of their own body, and thus perception of self. Foucault describes this as the 'anatomo-politics' of the human body (McDonnell et al., 2009).

The clinical interactions are shaped by these dynamics of power and knowledge. Foucault describes how the power of the norm appears through its disciplines, through the health professionals who engage in care provision (Foucault, 1979). It is present in the clinical discourse, the language used to describe the objects of medicine, the expected outcomes of a treatment, and the nuances of body language and behaviour as the health professional and patient interact. In his work on psychiatric wards, Goffman described the interactions between staff and patients as a key component of the function of the institution and system (Goffman, 1968). He identified that patients and staff members act within patterns of behaviour related to their formal roles. Talcott Parsons famously described the ‘sick role’ of the patient, which sheltered the patient from certain social obligations in exchange for submission to medical controls (Parsons, 1991). The understanding of the health care interactions has evolved beyond that of formalised roles and behaviours enacted only within the boundaries of each profession, to expected norms of behaviours as described by Foucault. In the clinical interaction these influences on behaviours are omnipresent, in the buildings, uniforms, language, objects and dynamics of engagement.

Power and knowledge are not unidirectional. Within Foucault’s framework, power is not limited only to the system and its institutions: “within this disciplinary matrix, people can exert power, be the subjects of power, and may resist it, for in this model individuals are neither ‘empowered’ nor ‘disempowered’ but are active mediators of the gaze” (Heaton, 1999) p.771). Heaton has detailed shifts in medical practice over the preceding decades, in which the patient and now the informal carer, have incrementally sought and gained more control in the clinical encounter. Underlying this shift is the recognition of the voice of the patient: the knowledge embedded within the experience of illness that cannot be found in the discourse of the professional. Mol claims a key factor influencing this shift has been an understanding of health as being perceived differently according to the individual, with patient preferences and care needs becoming increasingly focal in current frameworks of care provision (Mol, 2002):

> *The professional, or professional knowledge, is no longer the sure authority able to differentiate between what is and isn’t a problem in a person’s life. Is this a problem for you, Mrs Sanges? This is the new trope; that patients are being elicited to articulate norms about and for themselves. (Mol, 2002) p.128)*

The recognition of this knowledge of health and the body from the viewpoint of the patient in the clinical interaction is reflected on a societal level. There is an increasing awareness of the economic advantages of informal care arrangements, expertise on matters relating to the embodiment of illness, and the power of non-professional discourses in influencing health policy and public awareness (Heaton, 1999). These are discourses related to experiences and alternative understandings of illness, disability, suffering and caring; and thus constitute their own bodies of knowledge with accompanying expertise of those with such knowledge. These discourses have evolved over time, frequently in parallel with the health professions, and aspects of them are being adopted in the medical discourses. This will be discussed in greater detail in the following chapters on informal care (Chapters three and four).

The health system uses power to realise its functions in two key domains: to enable health on a societal level and to maintain the systems of health care provision. Health systems influence health in multiple ways, through contributing to public discourse, economic measures, education, public health campaigns, maintenance of public reserves, and many other facets of our lives. Foucault described how this power is most effective when it is not disciplinary or negative in its actions. For the most part the power exercised is positive, in that is produces better health outcomes for its society:

> *What makes power hold good, what makes it accepted, is simply the fact that it doesn't only weigh on us as a force that says no, but traverses and produces things, it induces pleasure, forms of knowledge, produces discourse. It needs to be considered as a productive network which runs through the whole social body, much more than as a negative instance whose function is repression. (Foucault, 1980) p.119)*

Chapter 3

Informal Health Collectives

Ill people may subsequently find communities comprising those who have similar losses and support each other in imagining new possibilities for their lives. But these illness communities must invent themselves. (Frank, 2013)

- Arthur Frank, *The Wounded Storyteller*

The informal domain of health care is comprised of many actors and entities, and contains many perspectives and approaches to illness and health. It lacks the visibility and awareness of formal care provision. Perhaps because of this, when compared with formal health care the literature examining this domain is small, and is focused on those entities that are more conspicuous or have developed their own organisational structures, such as charitable foundations, formal support and advocacy groups. Beneath these organisations, there are many independent actors who engage in care provision, advocacy and support. The boundaries of informal care are often fluid, as individuals interact with numerous systems of care, potentially operating in different manners in each.

The nature of this domain, its dynamism and indistinct boundaries mean that it is not possible to review the entirety of this field in depth. This background of informal health care is essential towards understanding the structure of health care beyond the scope of the formal. Through this, we are able to develop an understanding of the functioning and organisation of informal care, to be applied to constructing the model of informal communities.

The exploration of informal health care will take place on two sociological levels. This chapter will address this on a group level, introducing the concept of health collectives, which are structured groups external to the formal health care system. Three cases studies of health collectives in the Australian context will be explored, detailing their impact of health care provision and policy. I will then consider the functioning of these groups as sociological systems. Given health collectives are structured groups, I will not be pursuing the discussion of their structural elements in depth. Chapter four will then focus on informal interactions in cancer treatment, and examine their potential structures and functions.

3.1 Communal Responsibility: A History of Health Collectives in Australia[1]

The manner in which health care is provided in Australia has been shaped by professionals, patients, administrators and government. The public perception of care is predominantly determined by the structures and processes of the formal health system. Beneath this, however, are layers of informal health care provision, including family caregivers, parents nursing children, and everyday sharing of non-professional advice. Professionals and academics frequently lead public discourse regarding health care, in the media or with government. The experiences of patients and the complexity of the networks of participants that stand behind and extend beyond professional led health provision receives minimal exposure (Timmermans and Oh, 2010).

The role played by informal health providers is already great but is likely to increase rapidly. Australia has an aging population with rising rates of chronic diseases, and to meet these future challenges massive support external to the formal health system will be required that incorporates non-professional participation and responsibility (Kellehear, 2012). The aim of this essay is to formulate the concept of the ‘health collective’, to describe and explore its key role in the provision of health care, and to offer an understanding of its significance, potential and complexities.

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[1] [1] This first section is an article published in the *Internal Medicine Journal* by the researchers which is included in its original form. It was published as: Grant M, Philip J, Deliens L, Komesaroff PA. Communal responsibility: a history of health collectives in Australia,. *Internal Medicine Journal* (2019), 49; 9; pp.1177-80.

Defining Health Collectives

It is becoming increasingly recognised that non-professionals are important components of care networks and are not simply passive recipients of health care (Kellehear, 2012). While the current popular concern with ‘person centred care’ recognises the importance of individual patients as the focus of care, a role for other non-professionals as providers of care is less explicit (Richards et al., 2015). However, patients and carers do actively participate in advocacy, awareness campaigns and direct provision of support and expertise. Health professionals are trained to engage with illness in relation to frameworks arising from science and its concepts of causality. Patients encounter the same phenomena through the lenses of their personal impact, illness and disability. Accordingly, a single illness may produce contrasting understandings among the different participants. This may generate opposing narratives with divergent meanings and different interpretations of the outcomes (Timmermans and Oh, 2010). While this complexity may occasionally prove challenging to health practitioners, inclusion of the perspectives and experiences of patients may offer considerable benefits to patients and the health system (Brown and Zavestoski, 2004).

It is important to acknowledge that patients do not experience their illnesses in isolation. Though it is not well recognised, narratives of illness are widely disseminated and shared within hospitals, waiting rooms, existing social structures, and through social and internet media (Timmermans and Oh, 2010). The relationships formed between patients and other interested individuals constitute active communities that may play important, sometimes decisive, roles in relation to health care outcomes (Brown and Zavestoski, 2004). Such communities may vary markedly in terms of whom they comprise, their temporality, their formal structures and their specified aims. Nonetheless, despite this variety, they serve a common, constant function by providing forums through which shared understandings and identities are constructed and collective actions in response to specific health issues are developed (Brown and Zavestoski, 2004). While the existence of such communities is not a new phenomenon, their roles and impact have been poorly appreciated.

I propose to refer to these groups broadly by the term ‘health collectives’, which I employ to include structured communities external to the formal health system, comprised primarily of patients and non-professionals. The most easily recognisable health collectives are those that work in parallel with the formal health system: for example, Alcoholics Anonymous and cancer support groups. But there are many other collectives that are less formalised and which interact with each other and the health system in multiple ways, including via a range of electronic media, may involve little or no face to face contact, and may engage in activities, such as policy, fund-raising and research, that extend beyond internal support (Brown and Zavestoski, 2004).

Three examples of health collectives will be described that have had a profound effect on health care in Australia.

Cancer Support Groups

Cancer support groups in their current form are a relatively recent phenomenon. The pioneering group in the cancer field was ‘Reach to Recovery’, founded in 1954 in the USA by Terese Lasser in response to a lack of support following her mastectomy for breast cancer (Cantor, 2014). It was originally a patient-led collective focusing on post-mastectomy rehabilitation and support. Owing to its success, in 1969 ‘Reach to Recovery’ became incorporated into the American Cancer Society, formalising the program and placing it under the auspices of professional leadership (Osuch et al., 2012). In response to this reduced control over group processes and purpose, many breast cancer patients initiated their own communities. These ensuing groups focused on community level information, emotional support, and wider activism, encouraging women who choose to question their ‘passive’ role within the doctor-patient relationship where mastectomy was the singular surgical treatment for breast cancer (Borkman, 1999) (Osuch et al., 2012). The advocacy of these groups was instrumental in the development of breast conserving techniques, and advancing lymphoedema management (Osuch et al., 2012).

There is little documented evidence of Australian health collectives for cancer until the decade following 1980. These initial groups were small self-formed communities of cancer patients aiming to share information and provide mutual support, primarily initiated by those experiencing breast or prostate cancer. As these collectives became more widespread, networks were formed to create avenues between groups for advocacy and dissemination of knowledge, culminating in groups such as the Prostate Cancer Foundation of Australia (1996) and Breast Cancer Network Australia (1998) (Grassi and Riba, 2012). The past two decades have seen a proliferation of collectives across all types of cancer: from patient-driven mutual support groups to large-scale networks of consumers who are prominent advocates in research and health policy.

Parent Groups

Parent groups form an integral component of post-partum care in Australia, which is one of the few countries where such groups exist as part of routine care. They represent a unique phenomenon which emerged from collective action by new mothers to become incorporated into the formal health system. In their present form these groups are initiated by the local health system but continue beyond this involvement, and remain participant controlled.

The decade of 1940 saw a shift in a series of medical and social factors surrounding child-birth (O'Connor, 1989). The infant mortality rate had improved vastly over previous decades, an influx of post-war migration and increased mobility, with young families often isolated from traditional social supports (Brown, 1995). Birth practices shifted, with the majority of births occurring in the hospital setting, and support in the post-partum period became specialised and short in duration (Hodnett et al., 2007). New mothers with limited family supports started forming their own communities in New South Wales, often meeting in the waiting rooms of local infant welfare centres or making contact through community notice boards. These groups served as forums to share information and frustrations, for support, and an environment that accepted infants and breastfeeding (O'Connor, 1989). In 1963, some Sydney-based centres started formally organising these ‘mothercraft groups’, combining education sessions facilitated by midwives with communities of new mothers who were able to set their own directions and activities (O'Connor, 1989). These groups were an immediate success and spread rapidly to become a routine component of post-partum care. They have, in succeeding years been re-named ‘parent groups’ in recognition of the important involvement of partners in raising infants and supporting mothers.

In 1964, one such parent collective in Melbourne became increasingly interested in breastfeeding. At this time breastfeeding rates were low, with just 20% of mothers feeding at three months, and recommendations for breastfeeding were highly regimented (Karen Twigg, 2012). What was originally structured as a peer support and education network evolved over the coming decade into a broad movement focusing on support, information and national advocacy for breast-feeding. This formed the basis for what eventually in term became the Australian Breastfeeding Association, an organisation which has been instrumental in promoting breastfeeding as an aspect of normal care—with current rates of 70% at 3 months—adaptive to the needs of mothers and children.

HIV Collectives

Australia is one of the few countries that can claim success in effectively limiting the early spread of HIV transmission (Plummer and Irwin, 2006). Following an early peak in 1984, the rates of new HIV infections declined for the next decade, prior to the institution of government health policy interventions in mid-1985, (Plummer and Irwin, 2006). As the cohort most affected, the gay community was at the forefront of the response to HIV and played a key role both in organising the community response and directing the formulation and implementation of public policy.

After the first Australian case of HIV in late 1982, early the following year a number of informal public forums were organised by members of the gay community to promote understanding of HIV and of safe-sex as a preventive measure. From these forums, the NSW AIDS Action Committee and the Alternative Lifestyle

Organisation (ALSO) arose (Bowtell, 2005). These communities quickly demonstrated a willingness and capacity to engage with experts from within the formal health systems to promote their objectives:

> *Basically we were able to draw together very quickly a nucleus of very intelligent, articulate and committed, passionate people, men and women, who had experience in the law, in health, in social marketing and advertising, political activism, community organisation, psychology and medicine.* (Council, 2017)

HIV collectives were formed from within existing gay communities, promoting immediate and active strategies to address HIV as a health issue. They worked together with community groups, health systems and government organisations with a range of purposes: to educate those at risk (especially around safe sex practices), to disseminate new research, to advocate for public awareness and reduce stigmatisation of HIV, and to influence health policy (Plummer and Irwin, 2006). In an analysis of the Australian response to HIV, Plummer concludes that "grassroots and informal activities were vital to Australia's early and effective response to AIDs… [including] community mobilisation and the timely intervention of front-line clinical services alerted by early reports in the press, and activism in the gay community" (Plummer and Irwin, 2006) p.792).

During this period, homosexual intercourse continued to be illegal in some States, and the appearance of HIV exacerbated a pre-existing negative public perception of homosexuality. Individuals with HIV were often disconnected from their families and more orthodox social networks. Their systems of support were frequently grounded within the gay community and became of increasing importance as people navigated the terminal stages of their disease. Small collectives developed to provide care for those dying from HIV, comprised of volunteers, friends, and members of the gay community, to provide support of all kinds, including allowing them to live and die at home (Wiseman, 2015).

> *We went in and did all the cleaning up, whether people had soiled themselves or vomited... When people did have friends and family around to support them, it meant that we could do all of those mundane but exhausting things, so loved ones could have quality time and offer emotional support.* (Wiseman, 2015)

As HIV became a chronic illness, for the most part these communities dissolved. Other groups, such as the Bobby Goldsmith Foundation, have evolved from a collective focused on providing care, towards HIV advocacy and education.

Implications

The three collectives associated with these examples have had profound effects on health care in Australia, constituting substantial networks of informal care—that is, outside the boundaries of the institutions of the conventional health care system. All have represented a response to, and arisen out of the knowledge of, experiences of change in health status at the community level. The outcomes health collectives generate are complex and sometimes radical, ranging from direct contributions to daily care, to precipitating changes in social policy, to challenging extant medical frameworks of interpreting illness. Often, their democratic roots and organisation have supported ongoing, fertile public debates and the emergence of alternative viewpoints, which have sometimes eventually been incorporated into the mainstream.

This essay has focused on an illustrative overview to foster an appreciation of the wider roles and implications of health collectives. I suggest that their importance justifies further detailed study, covering their internal structures and dynamics, to examine how their promise may be mobilised more systematically in the service of community-based health care. If this proves to be possible, health collectives may contribute to a more differentiated, responsive, democratic and cost-effective health care system.

3.2 The Social Systems of Health Collectives

Health collectives exist as a broad category of groups, and occur outside, yet adjacent to and frequently interacting with the formal structures of the health system. This section examines the literature describing their functioning as social systems, and whilst it will be informed by the same structural functionalist approach, I will not be enlisting the same scaffold to this discussion as in Chapter two. This is not a conclusive description, but rather a broad examination of how these entities that can be used to inform the development of a structural understanding of informal communities. The aim of this section is to elicit structural elements from the literature, and to identify gaps in our current understanding.

Thomasina Borkman, in her empirical studies of women's conscious raising, stuttering and other self-help groups, proposed that these groups are a response to the postmodern evolution of community or communities (Borkman, 1999). Health has become increasingly professionalised and over-institutionalised, "turning society into a group of providers (the professionals) giving services to the dependent clients, labelling more and more people with conditions that are defective or need treatment" (Borkman, 1999) p.xi). In this setting, Borkman suggests that these health collectives exist as entities that enable individuals to promote and redefine their skills and capabilities, through shared responsibility.

Organisation and Participation

There is a broad range of health collectives and terms used to describe them: including self-help, advocacy, consumer, mutual aid, conscious raising, or support groups (Brown et al., 2004, Brown and Zavestoski, 2004). These groups may range from small, loosely organised entities, comprised of a small number of interested participants, whose relationships and interests focus on particular health issues. On the other end of the scale, health collectives may be formalised, with participants functioning in specific roles and having key relationships with formal institutions and health professionals.

The participants within the collectives may consist of people suffering from health conditions, affected by them as carers or family members, or interested individuals. They may relate to the particular health issue in differing ways, based on their own personal experiences of illness, contacts with the formal health system, knowledge, and cultural viewpoints. Importantly, in contrast to the formal health system, the individual does not gain entry into these groups through a structured process of education or training. Instead, they may arrive to become a participant in these collectives through a broad background of experiences and understandings of the particular health issue. Being personally afflicted by the health issue was not necessary for participation, as many of the participants were carers, family members, or interested members of society (Grant et al., 2019).

Health collectives are an expansive group, with heterogeneous practices and norms of interaction. In her work on support groups, Thomassina Borkman proposed that there are five key characteristics of these groups, influencing the structure of these relationships (Borkman, 1999). These characteristics provide an overview of the potential structures and principles upon which these collectives are constructed (Geertz, 1973):

1. Participation is free and uncoerced
2. Participants share a commonality of purpose
3. There is joint ownership of group processes and discourse
4. Mutuality exists in the group as evidenced through interconnected and reciprocal relationships
5. Social relations are characterised by fairness.

For the most part these characteristics described by Borkman enable a flat hierarchy of actors, who interact on equal terms. The organisation of relational roles ranges from those groups with semi-formalised organisational structures, in which there are designated roles such as chairperson, treasurer and secretary, to other collectives where such structures are absent, or openly opposed. One well-known example of such a group that rejects organisational structure is Alcoholics Anonymous, founded as a non-hierarchical community where there is no leader and no set proforma of topics for discussion. This creates its own relational structure which aims to maintain equality of knowledge and control of group processes. In other settings, health collectives take on characteristics of formal organisations, such as the Australian Breastfeeding Association, which has implemented a formal professionalised organisation structure (Grant et al., 2019).

There are often underlying norms of conduct of the groups that serve as relational structures to preserve the fairness and joint ownership of the group. In Alcoholic Anonymous such norms include: no interrupting or criticising, members may not present direct advice or furnish causal explanations of others' behaviour, and must speak honestly and only about their own experiences (Mäkelä, 1996). Such modes of conduct allow the individual to focus on subjects of personal relevance and for group processes to be shared. These structures of conduct may differ widely between health collectives, and may be explicit or implicit.

Care occurs through and is manifested within these supportive relationships. The provision of care is inseparable from the relationships. Unlike formal care relationships, the participants act as both providers and recipients of care (Riessman, 1990). Yet the provision of care is but one outcome of these relationships; as the individuals construct new social identities, networks of support, and opportunities to form new knowledge, and through such communities, collective meanings related to their health issues. Care is not specific to the biological illness, but focused on the person and what they determine to be their needs (Rappaport, 1993). The individual decides his or her own requirements, whether it be for information, social or emotional support. Thus, the same fairness, equality and self-determination that orders relationships also provides the structures through which care is provided.

Relating to Knowledge

> *The problem is integrated with life; the treated is the treater and the treatment is to find a new way of living, incorporating the problem into one's everyday experience. This is done by providing a continuous form of care and concern through a network of friendship that itself permeates everyday living and closes the distance between normal everyday living and having problems ((Robinson and Stuart, 1977), p121).*

- David Robinson and Henry Stuart, *Self-help and Health, Mutual Aid for Modern Problems*

The participants within health collectives may have many different educational and cultural backgrounds, and varied experiences and perceptions of illness. Borkman has suggested that a key feature of health collectives is the ability to construct a different health narrative, both collective and individual (Borkman, 1999). It can be a safe space where innovation and experimentation may occur, in which individuals can learn others' experiences on similar phenomena. Through this process of questioning, exploring and sharing, individuals and groups may be able to construct their own narratives in which they may find particular elements of their illnesses which are subject to change. This not only occurs through group discourse, but also through observation, listening to others, and role-modelling. The experiences and perspectives of others may also challenge existing perceptions, and enable the individual to embark upon a process of self-evaluation. This process of self-directed learning facilitates responsibility as each person arrives at their own conclusions and actions (Bandura, 1977).

Borkman and Rappaport describe these group processes of knowledge construction as 'experiential learning' (Borkman, 1999, Rappaport, 1993). This term first described by John Dewey and later developed by David Kolb, refers to a process by which an individual is able to construct a knowledge based on a range of information and interpretations within his (or her) own frame of reference (Fry and Kolb, 1979, Borkman, 1999). It begins with concrete experience, usually through the experience of illness or treatment. The second phase – 'reflective learning' – is when the individual applies the knowledge to his own particular situation: "pieces together and guides his action by taking account of different things and interpreting their significance for his prospective action" (Rose, 1962) p.81). The 'testing' (the third) phase is where the individual uses these novel concepts or generalisations about the knowledge, and applies them to his own actions. Within the health collective, this is often done in tandem with other members, such as trying new behaviours in the public space for those with phobias. The fourth phase is 'active experimentation', where the individual chooses to discard or integrate the learning, thus altering behaviours. This is where the cyclical nature of learning re-starts, as if chosen to be utilised for the future, the individual engages in an ongoing process of refinement and re-evaluation. These phases may occur simultaneously or there may be other individuals who have a particular favoured learning and coping manner which predisposes them to a particular phase. This may be seen in the individual who is fixed in the use of concrete information and cannot interpret their own and others' experiences to modify learning or behaviour.

The use of communication within health collectives occurs largely through narrative expression. Polner and Stein, in their work on Alcoholics Anonymous, described the use of narrative language in these groups as both a means of expression, a formal medium in which to converse, and a manner in which to demonstrate qualification (Pollner and Stein, 1996). They employ a metaphor of a cartographer mapping the terrain, using their 'voice of experience' to instruct the other members through the social world of the illness, the potential paths of treatment and their pitfalls, the people and environments they may encounter, the history of the support community, and an awareness of how the path onwards may appear (Borkman, 1999). Borkman describes similar uses of narrative discourse across many forms of support groups. This storytelling is important for the experienced and new members, and through this they may reinterpret past experiences and perceptions. The connection may also evoke stronger connections, allowing for role-modelling upon another person's actions, or forming of relationships as mentor/mentee. Narrative provides the framework to assemble experiences, social history, beliefs, to reveal assumptions and meaning that may allow other individuals to relate and reflect (Borkman, 1999).

This use of narrative as a manner of exchanging information appears as a form of knowledge - a knowledge that is based on personal experience, what illness, its treatments, investigations and expectations feel like. In the medical discourses, health practitioners use specialised language and knowledge to convey meaning, to demonstrate professional status, and authority (McDonnell et al., 2009). It could be interpreted that the use of narrative languages in health collectives communicate similar meanings, placing prominence on these lived experiences. Most importantly, it validates the individual's position as an expert in the experience of illness, and the significance of those experiences (Borkman, 1999, Mol, 2002). It forms an experiential discourse: a discourse that is readily accessible to patients and carers in which they are they experts, and can construct and evaluate new knowledge.

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Chapter 4

Informal Interactions in Cancer Treatment

> *I just meet people in here, and I just chat to them. It just helps to pass the time. It's nice to see them and touch base with them, that's it about it usually. You might not talk about too much, I could talk to people more, as they are going through similar things. It's nice to have people here to have a chat to.*
>
> - Jill*, patient, chemotherapy day centre, participant #8, interview study

Allan Kellehear, in his work on palliative care and public health, describes how hospitalised patients spend about five percent of their time in the presence of health care professionals at the end of life (Smith, 2019). He poses the question to the reader: What occurs during the other ninety-five percent of the time?

Social research within the hospital setting has primarily focused on the formalised clinical interactions between nurse and patient and doctor and patient, or within health professional groups. It has concentrated upon the formal clinical consultation, occurring within the medical discourse, with little attention given to the informal elements of clinical interactions that may not constitute formal care processes. These "informal elements" may include social chatter in the elevator, a quick acknowledgement in the corridor, or a jocular discussion about football whilst performing a chemotherapy check. Most research has largely overlooked the wealth and breadth of interactions that occur within the clinical setting, many which occur outside of the medical or clinical discourse. To paraphrase Kellaher, research has focused on the five percent of time patients are with health care professionals, and even then, only that portion of the five percent that occurs within the boundaries of the clinical discourse.

The focus of this project is the other ninety-five percent, that which occurs outside the formal clinical discourse. These informal interactions are commonplace, as can be witnessed on any hospital ward or chemotherapy unit, yet the roles and meanings of these contacts are not well understood. How they contribute to, and collaborate with the delivery of hospital care is yet to be appreciated, but it is possible they may address a number of needs not provisioned formally.

This chapter continues the focus on the informal domain of health care, but here is narrowed to the key phenomenon of interest to this thesis: informal communities in cancer treatment. The first section of this chapter describes the scientific literature relating to informal interactions in hospital cancer care. This is not, however, a broad literature; rather, it consists of a small number of mostly qualitative studies. The aim of this section is to describe the existing literature regarding the experiences of informal interactions in cancer care and the significance to participants. The second section analyses the data presented in the first section through the structural functionalist scaffold applied in Chapter two, to propose from this emergent literature potential structural elements that will enable the appreciation of these interactions as representative of social systems. This work will identify concepts for further development through the theoretical and empirical work.

4.1 Beyond Formal Care Provision

This section provides a narrative review of the literature relating to the informal domain of hospital cancer care, to describe their experiences and significance of the interactions. A scoping literature review was performed, which identified 2266 articles, of which 12 articles were found to meet inclusion criteria: describing informal interactions occurring in the hospital setting, in environments where cancer was commonly treated. A narrative approach to data synthesis was adopted, informed by the work of Popay et al, specifically concept mapping (Popay et al., 2006).

Five themes emerged from the data synthesis: the hospital setting, relating, learning, support, and the roles of visitors, family and staff.

Table 1 - Overview of themes from data synthesis describing experiences and significance of informal interactions in cancer treatment settings.

The experience and significance of informal interactions in cancer treatment settings
• The hospital setting • Relating o Sharing o Intimacy o Not engaging • Learning • Support • The roles of visitors, family and staff

The Hospital Setting

Many of the hospital spaces were communal, in particular the hospital wards where patients slept and occupied shared rooms. The majority of studies explored primarily those interactions that occurred in shared wards. This setting creates an atmosphere where interactions with other patients are seemingly unavoidable (Larsen et al., 2013). Single rooms may provide patients with a quieter and more confidential surroundings, whilst the shared rooms allowed for interaction, distraction, and a more social environment (Larsen et al., 2014, Larsen, 2013). In these shared spaces it was possible to visualise others at any time, overhearing conversations and medical consultations(Larsen et al., 2013). These shared spaces caused difficulties in negotiating privacy or periods of respite with the other occupants; however, patients also reported strategies that helped them successfully navigate these issues. Interestingly, most patients (18/20) who were questioned regarding their preferences for room type preferred the shared rooms, owing to the opportunity they afforded to interact with other individuals (Larsen et al., 2014).

“Equality” was a key concept in the hospital environment. Album et al quoted a patient stating: “In the hospital all are equals” (Album, 1989) p.296). Certain pre-existing social determinants such as culture, religion, education level and class are seemingly less relevant in this setting (Ludvigsen, 2009, McCaughan et al., 2011). This equality was partly structural, as care provision is such that treatment is provided according to medical need rather than economic or social class (Larsen, 2013). Patients are placed in rooms according to this need, dressed in identical garments, and provided with identical meals. This equality was present in the interactions that occurred within the shared ward space, as patients seldom discussed their education, income or jobs. The main topic of discussion – the illness – demonstrated the similarities these individuals shared (Isaksen and Gjengedal, 2000). Sex was however a major discriminating factor, as segregation tended to occur upon gender lines in the shared rooms, thus often leading to gender specific social groupings (Album, 1989).

The space of the shared room was somewhat ambiguous, as a shared domain that also contained areas of privacy (Ludvigsen, 2009). The bed and bedside table of the patient was a private space (Larsen et al., 2014). Many of the patients used objects to create privacy, such as curtains and chairs to block the space, or books or headphones to convey inaccessibility (Ludvigsen, 2009). Patients found it easier to negotiate interactions in other spaces in the hospital wards, such as lounges and kitchens, as these were perceived as public spaces where interaction was expected (Larsen et al., 2014). In these settings the individual could choose to attend and then retreat to the 'private' space of the room when conversation was not sought.

Being in hospital space was a time of significant inactivity for those patients, some who were too unwell to engage in activities, or others who had no activity to conduct (Ludvigsen, 2009). Being with fellow patients created distraction to relieve feelings of loneliness and boredom, which encouraged them to converse (Isaksen and Gjengedal, 2006, Isaksen and Gjengedal, 2000). A sense of continual waiting was described as particularly tiresome and was improved by sharing of this task through waiting together (Larsen et al., 2014).

Relating

The theme of relating was divided into three subthemes: sharing, intimacy, and not engaging.

Sharing

The proximity of space, the lack of privacy, and similarities of disease course and treatment encouraged sharing. Patients gained expansive knowledge of those around them, being exposed to their daily routines, medical care, personal conversations and details of their medical treatment (Ludvigsen, 2009, Isaksen and Gjengedal, 2006). This intimacy could be intrusive, especially when needing to share intimate details in the confines of the room which could be readily overheard (Ludvigsen, 2009).

A number of studies described emotional intimacy developing through such enforced sharing - in particular in the setting of cancer (Larsen et al., 2014). A diagnosis of cancer was identified as a facilitating influence in many of these interactions, as a similar event that could openly be discussed among fellow patients (McCaughan et al., 2011). Participants described this as having a "cancer badge" which enabled them to converse with other patients or offer support (McCaughan et al., 2011). The experience of life with cancer formed the basis for many conversations (Andersen et al., 2015). These were often filled with humour, stories of life, or observations regarding the hospital and its routines (Larsen et al., 2013). Patients described these discussions as allowing them respite from the seriousness of cancer and treatment, even though these topics were infrequently the subject of conversation (Egestad, 2013).

Sharing of the experiences of cancer allowed for a normalisation of illness (Egestad, 2013). A number of participants reported that these interactions engendered a perception of solidarity and community between the patients (Ludvigsen, 2009, Egestad, 2013). Cancer, and discussion of its effects and treatment, became a social norm. The patients reported that this enabled them to express their own feelings, distress, symptom issues, and allowed for a greater empathy towards others in similar situations (Isaksen and Gjengedal, 2000, Egestad, 2013).

Such sharing with fellow patients also, at times created negative associations. Intensity of contact could be very demanding for the patients, so that there was a need to withdraw from contact for certain periods (Isaksen and Gjengedal, 2000). Other patients could be disrespectful of the shared space, being noisy, odorous, having too many guests, or transgressing the shared rules of the space, thus, causing disharmony (Isaksen and Gjengedal, 2000, Larsen et al., 2013). There were patients who chose to minimise interaction and exclude themselves from the community of patients, which was viewed as rude (Ludvigsen, 2009). Those patients who did choose to exclude themselves from contact were few (Andersen et al., 2015, McCaughan et al., 2011). One patient described fear at sharing and interacting with others with cancer: "If I go and sit with other people who are maybe a lot worse than me, am I going to come out feeling any better? I don't think so. I think I'm going to take their troubles home with me" (McCaughan et al., 2011) p.2691).

Intimacy

The intimacy shared between patients created bonds that could cause negative emotions when others suffered hardship or loss (Ludvigsen, 2009, Isaksen and Gjengedal, 2000). One patient stated: "Really understanding and caring for someone was painful, and it hurts to see the fellow patient suffer" (Larsen et al., 2013) p.501). The other patients engendered reciprocity, where they offered support or care for each other, which was often difficult when individuals became increasingly unwell. This difficulty could be due to their own physical frailties, or self-identification with that person's illness as a situation they may themselves face in the future (Isaksen and Gjengedal, 2000, Isaksen and Gjengedal, 2006). Patients described feeling sad, sorry, and depressed by these experiences of suffering in fellow patients (Egestad, 2013). Despite these negative emotions, many believed they had a responsibility to offer ongoing support and care to these patients, and found this to be rewarding though emotionally challenging (Larsen et al., 2013). This reciprocity was viewed as important, and added to their own feelings of self-esteem and personal respect (Isaksen and Gjengedal, 2006).

The intimacy of these interactions often created enduring relationships between patients (Egestad, 2013). Ongoing contact took the form of telephone calls, Christmas cards, or social outings outside of the hospital environment (Isaksen and Gjengedal, 2000). Patients often reported feeling sorrowful after returning home and leaving the community of patients. They reported the progression of these relationships as different to many normal social relationships due to their sudden intimacy, which often subsided or ceased upon discharge, despite a wish for it to continue (Album, 1989). As a result, these communities may be intense yet short-lived, or instead may be enduring and form more formalised relationships.

Not engaging

Not all patients chose to associate with the patient community. These outsiders were more likely to be of a younger age, recent or lack of certainty regarding cancer diagnosis, viewing cancer as a transient disease, and or having other comorbidities, particularly psychological (Andersen et al., 2015). They described not identifying with the other patients, especially those who were older, physically impaired, or had long-term diagnoses of cancer. They often had strong social identities firmly determined by membership to other social groupings (Wilson and Luker, 2006). Their self-perception was often reinforced by their cancer as an acute diagnosis that would be cured, and thus forming relationships with other cancer patients had little relevance to their long-term goals.

For these individuals the experience of interaction with fellow patients in the hospital setting was at times overwhelming, intrusive, or unwarranted. As stated by Andersen et al: “They experienced interaction with fellow patients from the spectator’s point of view and felt sorry for them” (Andersen et al., 2015) p.277). They did not perceive a need for information relating to others’ experiences of cancer, because they did not believe it related to them. The physical environment of the wards exacerbated their unease, as the shared intimacy of the space forced contact with other patients. As a result, these patients often engaged in avoidance behaviours to limit interaction, such as leaving the room and drawing the curtains. As time progressed a number of these patients did become part of the patient community, whilst others continued to exclude themselves (Andersen et al., 2015).

Learning

Information was shared on a variety of topics and experiences. Treatment information was commonly discussed, especially regarding different chemotherapy agents, medications and their side effects (McCaughan et al., 2011). Patients often conversed regarding prognosis and the future. Instead of focusing on the scientific facts such as months of survival after a particular chemotherapy, they were interested in how other people had responded to treatments, what it would be like if cancer recurred or progressed and how people experienced this (McCaughan et al., 2011). Coping mechanisms were shared, such as how individuals dealt with bad news, colostomies and other treatment effects, as well as cancer-related symptoms. Patients utilised all these types of information to reflect upon and consider their own situations, chances of recovery, or potential for worsening of condition. Comparisons with other patients based on conversations of their experiences and observations of physical condition allowed patients to form their own perceptions as to their own health status, independent of health professionals (McCaughan et al., 2011).

"There was a recognition that the only people who know are people who have been through it before" (McCaughan et al., 2011) p.2690). The patients described the generous nature of fellow patients sharing their knowledge and experiences (Ludvigsen, 2009, Andersen et al., 2015). This knowledge was viewed as being complementary to the scientific knowledge conveyed by the health professional, giving it further clarity by providing context and personal experience (Andersen et al., 2015). Patients did not expect that staff would meet all their requirements for experiential knowledge, nor did they believe that staff had the legitimacy to provide such information. "I think the nurses have told me these things, but it's as if I didn't hear what she said. Things are clearer to me now, because my fellow patient has told me about her experiences. I understand it now" (Andersen et al., 2015) p.276). The information shared by fellow patients was expressed in relatable language and described the intricacies of treatment and illness, and their personal effects (Album, 1989). The patients often employed a process of communal validation among the others in their room to make sense of medical information together.

Patients described self-identified roles of 'newcomer' and 'experienced' patients (Andersen et al., 2015). The newcomers were often initially cautious in their interactions with fellow patients, instead relying on listening and observing to gain information. The role of the patient was often foreign to them, and thus learnt from the behaviours of the more experienced patient or patients, especially in the manner in which the experienced patient interacted with and questioned the health professionals (Larsen et al., 2013, Isaksen and Gjengedal, 2006). The time spent in the role of the newcomer was brief, as they quickly gained knowledge, met other less experienced patients and transitioned to becoming an information provider. The 'experienced patients' provided information on the illness, treatments, symptoms, tests, and practical information about the experience of particular procedures (Andersen et al., 2015, Egestad, 2013). These individuals possessed knowledge that differed from the knowledge or information given by health professionals, based on the personal experience of illness, being able to detail the emotive and physical perception of illness and treatment (Larsen et al., 2013, Ludvigsen, 2009, McCaughan et al., 2011).

The hospital represented a unique life situation that required new learning in order to negotiate the challenges of treatment and a foreign environment (Andersen et al., 2015). The patients did not necessarily perceive a need for this new knowledge at the beginning, and its transfer appeared to occur osmotically rather than being purposefully sought. Those newcomer patients were able to copy and modify the behaviours learnt from experienced patients (Andersen et al., 2015). The knowledge learnt from conversations with fellow patients enabled them to better engage with health professionals and other patients, and potentially informed their acceptance of medication and treatments. Another learning method involved using fellow patients as comparators or reinforcers of knowledge. Patients would compare the information gained from health professionals between them, in an effort to dissect and question this information (Egestad, 2013).

Support

Patients provided and received care from other patients (Isaksen and Gjengedal, 2000, Isaksen and Gjengedal, 2006). Compassion was often visible in these interactions, whether it be assistance with practical matters, or providing social or psychological support (Larsen et al., 2013). They were described as reciprocal relationships, with patients receiving similar amounts of care as they provided to others (Isaksen and Gjengedal, 2006, Wilson and Luker, 2006). Support was mostly offered through the provision of information, sympathy and forms of psychological encouragement, and social support. Conversations were the primary medium through which support was provided. Physical assistance, sharing items, or small gifts such as food were also often exchanged.

One study by Isaksen et al aimed to quantify the significance of supportive offerings from fellow patients (Isaksen et al., 2003). The most supportive element was the ability of other patients to provide hope, with most patients (74%) experiencing this. The majority also detailed feeling encouraged and supported (69%) and gained knowledge about illness and treatment through these interactions (66%). Negative emotions were also described, with painful and sad feelings (59%), and anxiety (46%) associated with this contact. Interestingly, those patients who described those negative emotions were those most likely to also detail positive consequences, such as hope, support and comfort. This would suggest that such interactions can lead to a variety of emotional responses which often coexist (Isaksen et al., 2003).

Humour was an instrument commonly utilised when addressing sad or tragic issues, and was often self-depreciating (Larsen et al., 2013). The use of comedy as a coping strategy through cancer treatment was a theme throughout many of the studies, and was detailed as providing solidarity and fellowship within the patient community, enabling them to address difficult topics (Ludvigsen, 2009, Isaksen and Gjengedal, 2000, Isaksen and Gjengedal, 2006, Egestad, 2013, Wilson and Luker, 2006). It was often employed to 'break down barriers', especially on initial contact with new patients. Staff employed similar methods of humour, particularly as a response to perceived anxiety or distress (Petri and Berthelsen, 2015).

Within the hospital environment, those affected with cancer had the opportunity to face similar challenges (Egestad, 2013, Wilson and Luker, 2006). "I thought it was just me (having panic attacks) but when people in Barton's (the hospital) told me themselves that they'd gone through similar things… then I was quite cheerful because I wasn't on my own" (Wilson and Luker, 2006) p.1622). Normalisation of suffering or frailty was a common feature of these conversations, which was greatly appreciated. Wilson describes a stoical yet sympathetic culture in the community of patients: "If I can do it, you can do it" (Wilson and Luker, 2006) p.1622). This was described as promoting resilience whilst being a forum to share suffering. "Let's get on with it and let's enjoy ourselves as far as you can" (Wilson and Luker, 2006) p.1622). Negative emotions were frequently openly discussed. The experience of being a cancer patient gave credibility into understanding these emotions, and to any suggestions to address these feelings. The community of cancer patients enabled patients to function in a manner that was continuous with, rather than in opposition to cancer (Egestad, 2013). The interactions allowed patients to share their meanings of the events they experienced, and to create purpose in their new role as a 'cancer patient'.

The Roles of Visitors, Family and Staff

There were limited studies exploring the role of visitors or family members in the hospital setting (Wilson and Luker, 2006). They were often perceived as being part of the patient community, due to their frequent presence and interaction with many other people in the hospital. They participated in similar supportive activities as patients and often provided practical assistance for other patients such as making warm drinks, helping with meals, and assisting other patients with walking (McCaughan et al., 2011). Family members often had a close personal experience with the physical and emotional effect of cancer and its treatment, and thus were seen as having validity in engaging in conversations and creating humour based around these events (Wilson and Luker, 2006).

Staff were aware that the patients and family caregivers frequently talked with or assisted each other, though this was generally not considered to be of significant importance or value (Isaksen and Gjengedal, 2000, Larsen et al., 2014). These interactions were often perceived as a means to reduce boredom. A negative view was described by some staff, who believed that these conversations spread medical misinformation (Album, 1989). There were other staff who described positive attitudes to these communities, describing a complex understanding in keeping with the discussed literature: “Fellow patients understand each other, we think we understand, but we can’t feel the pain” (Isaksen and Gjengedal, 2000) p.386). This literature did not examine the role of the staff within these informal communities.

4.2 Informal Interactions as Social Systems

The previous section provided a synthesis of the empirical data describing informal interactions in cancer treatment settings. This consisted of a number of themes describing the experiences and meanings related to these interactions. It is apparent that there are patterns to these relations, that these data from different hospitals and countries displayed similarities. I propose that they are not only a loosely affiliated set of phenomena, but that these interactions exist as part of patterned social relations: a social system.

This section uses a structural functionalist framework to propose a structural understanding of the informal interactions in cancer treatment settings. It will be based on the literature presented in the narrative review featured in the previous section. The presentation of data will utilise the same framework as Chapter two: describing their institutions, structures, knowledge and functions. Due to the limited available literature, it is a rudimentary description, which will be developed further through the theoretical analysis to develop a model of informal communities presented in Chapter six.

Institutions

These interactions occur at the level of the individual. There are discernible institutions that are focused on meeting the needs of informal interactions. Yet, the institution of the hospital plays a pivotal role in regulating behaviours, and thus the interactions themselves. These influences are discussed in Chapter two in relation to the use of knowledge, social conditioning and formal roles. The formal roles within the hospital (those of patient, visitor, and staff member) influence and shape these interactions, yet does not seem to define their interactions (Larsen et al., 2013, Isaksen and Gjengedal, 2000).

Structures

There are a number of findings detailed in the previous section that represent patterned social relations, in particular the manner in which the patients shared information and developed norms of behaviour appropriate to the interactions.

The participants engaged in sharing many aspects of their lives: medical information, life stories, and the space of the hospital room (Egestad, 2013). This was described as facilitating reciprocity and equality amongst the patients. This literature suggested a collective identity, that the patients identified with and bear a shared responsibility for others within their group. The participants used names to describe this bond, such as ‘group’, ‘community’, and ‘companionship’ (Larsen et al., 2013). They also used identifiers within their community: e.g. of the ‘newcomers’ and the ‘experienced patients’ (Andersen et al., 2015). They engaged in group activities such as exercise or outings beyond the hospital environment. In general, the findings from informal interactions described in the literature examined bear similarity to what is reported in the literature on health collectives, and strongly suggest these interactions are collective social entities.

There are important external influences that may engender differences between the informal interactions and health collectives. Health collectives and the informal interactions in the hospital occur within different contexts and structures. An individual purposefully chooses to involve themselves in a health collective and the group processes routinely occur as a delineated encounter, with a set time, place, and often, purpose. Informal interactions in hospital frequently lack this structure. As described in these studies, interactions often occur organically, with less participant control around entry, or how these engagements progress. The purpose and outcomes related to these interactions may be unclear, or differ between participants. The literature describes the evolving nature of these interactions, as new patients enter the room and others are discharged. They are not static, but evolve in relation to the different participants and their individual wants.

The informal interactions in hospital occur alongside the structures of the formal care provision. As discussed, the formal roles delineating patients from staff and visitors continue to be influencing factors in the informal domain. These roles regulate tasks and behaviours that occur in the hospital, implicitly shaping who the individuals interact with and, the content, language, power dynamics and nature of the engagement. These influences and relationships between the formal and informal domains require further exploration, and will feature in the empirical studies.

Knowledge

There was a variety of knowledge forms shared within these informal interactions. Participants detailed medical, social, and experiential data. From the descriptions provided, no one form of knowledge appeared to take prominence. This was reflected in the manner through which the differing forms were perceived as being of relatively equal importance, showing that patients' experiences were as valued as that provided by health care professionals. Instead, the patients described these types of knowledge as complementing each other (Andersen et al., 2015). Furthermore, knowledge was communal. With discussions readily overheard, the participants described a lack of control over the sharing, and therefore a lack of ownership, of information.

Interestingly, situational knowledge was prominent in these engagements; as patients outlined how to act within the medical system, and how to make best use of their contacts with health professionals. This was a form of knowledge not detailed in health collectives. This form of knowledge served as the divider between those who identified as 'newcomers' and 'experienced patients', the former category being the receiver of this information, the latter disseminating this advice.

Functions

The literature reviewed describes a number of functions related to these informal interactions that supported and maintained these social systems. In particular, patients engaged in learning with and supporting each other, which facilitated the development and strengthening of these relationships.

The participants described learning through observation of, and discussions with other patients. The data that prompted this learning were the actions, experiences or information derived from other patients, which were reflected upon by the individual. Learning has numerous outcomes, beyond that of acquiring and utilising new information (Girvan et al., 2016, Ng et al., 2009). Importantly, it enables development of new skills, meanings and relationships. In this manner, learning can enrich the capacity of the individual, strengthen relationships, and enable the participants to find common meanings in their experiences. Whilst it cannot be assumed that all these processes are occurring within these interactions from the literature described, learning remains an important function that has the potential to develop group cohesion and relationships, thus leading to the strengthening of the relationship between individuals.

Support is discussed as a key outcome of these relationships, which took on many forms: through humour, offering hope, an emotional release, a forum to share their concerns, and guidance for the unfamiliar hospital environment (Larsen et al., 2013). As with learning, the acts of support may address important needs whilst developing the relationships between the participants. This is evident from the reciprocal nature of these relationships discussed by the patients, demonstrating that there may be enduring bonds that result from these interactions.

It is likely that there are other outcomes and processes that result from these interactions, that were not articulated in the literature. This formed the focus of the empirical work, which will seek to appreciate the functions of these interactions, and how they may enable maintenance of these relationships.

4.3 Concluding and Beginning

The examination of this literature present herein strongly suggests that informal interactions that occur between individuals in hospital cancer care exhibit patterned relations. They are not merely individuals coming together as random or haphazard engagements. The interactions may be fluid and heterogeneous, and may vary greatly in many aspects; however, they demonstrate consistent underlying structural elements. The participants themselves described these interactions using many words that indicate such coherence, such as: “community”, “reciprocity”, “support”, and “friendship”. Taken together, the interactions exhibit structures, forms of knowledge, and functions; even though the exact nature of these often remain to be elaborated. These groups are social entities, which I will refer to as “informal communities”.

This hypothesis that, taken together, the informal interactions within cancer hospital treatment settings may be understood as constituting a social system that is structured and incorporates precise and definable functional elements is core to this thesis. However, the details of the structures and functions of these collections of informal interactions, which I refer to as "informal communities", requires further elaboration. Unlike health collectives, these communities are subject to change, evolution, dissolution and renewal. In addition, these arise and operate within the peculiar social environment of the hospital, which itself operates as a formal social system. To pursue these ideas further I will first seek to explore somewhat more rigorously the theoretical basis of these communities in Section II. The theoretical understanding will then be tested in the subsequent empirical work.

Section II

Towards a Theory of Informal Communities

Chapter 5

A Theoretical Framework

You talk about family and friends in here and a little bit of the medical stuff. "What have you got? What are you doing? What are you doing?" and stuff like that, but when you go out and do talk to your outside friends, it's totally different. It's like, "What do you get up to at home?" and "How's the weather?" and "How's this?," and "How's the house?," and da-da-da. It's all just different. You don't really bring up the medical side of it.

Nah, it just goes to the back, because you're home. You're out. Once you're out, unless someone rings you from here, which they quite often do ... One of the guys will give me a ring because they're not well or something. The conversation just goes out the door when you're home. You just get back on with your daily everyday life, so you don't worry about the medical side of it. You throw it out the door 'til it happens again.

A lot of them will ... If you're talking about what they've got, they'll get a bit teary, so the only thing you do is go and give them a cuddle. I find that with a cuddle, within a couple of minutes, they're as good as gold and then they'll have a cackle, and then we'll have another chat about something else. We'll make a cup of tea, and that's the end of it. That cuddle. It's that two-minute cuddle what changes everything. Just a cuddle or a kiss on the cheek or a hug. That just stops the whole lot. It just gives them a little bit to think about. Yeah. It's not so bad after all because someone does care. Yeah, and they're all right with that. They'll just sit there and smile, and we go on about our daily stuff. It's that cuddle. It's the hug, and just being there to listen.

- Jackie*, patient, palliative care ward, participant #1, interview study

Section II of this thesis focuses on the theoretical components that underpin this research. It aims to provide an understanding of the conceptual background to this work and the methodological frameworks applied to the empirical studies. Importantly, it considers the concept of 'informal communities', to develop a theoretical basis through which they can be understood and studied. Through this process, I aim to develop a theoretical model of informal communities, that will be tested in the empirical studies. A broad range of resources has been accessed, each of which contribute important understandings to the research. This approach embraces the use of contrasting theoretical frameworks and the possibilities afforded by incorporating these differences.

The first chapter (Chapter five) focuses on the theoretical frameworks that form the background to this work; presenting a discussion of postmodernism, phenomenology and structural functionalism, all key concepts to this research, and which have been referenced throughout this thesis, supporting the theoretical and empirical analysis. The second chapter (Chapter six) details how these theoretical traditions are applied to the concept of informal communities to develop a model to understand these communities. The third chapter (Chapter seven) provides an overview of qualitative methods, and relevant theoretical positions and tools that were employed in the empirical components of the research.

5.1 Developing a Theoretical Approach

To appreciate the concept of informal communities requires an approach that is broad and interpretative. As described above by Jackie*, these communities are complex, displaying multiple functions and outcomes, and existing adjacent to existing social networks. Jackie describes social banality, intimacy, connectedness, fluidity, humour and distance in her short description. It is apparent that the significance of the 'cuddle' for Jackie may differ from that of the recipient, as may the outcomes that this cuddle potentiates.

The result is a theoretical approach that incorporates multiple positions, to appreciate difference and contradiction. This is of particular importance in the hospital space, where these informal communities are embedded within systems of health care provision, and may challenge or subvert existing approaches to social relations and the exchange of knowledge.

5.2 Postmodernism

Postmodern philosophy is a broad philosophical perspective. At its core of this epistemology is scepticism of dominant or institutionalised forms of knowledge, such as scientific or medical knowledge, as outlined by Jean-Francois Lyotard. “Scientific knowledge requires that one stream of discourse be retained and others excluded, and that the acceptability of the statements are weighed according to the parameters of the presupposed scientific truths” (Lyotard, 1984) p.25). Postmodernism questions the dominant ‘grand narratives’ comprised of the positivist assumptions of science, and cultural and societal constructions of knowledge and truth (Komesaroff, 2008). Additionally, it recognises the value of knowledge arising through alternative frameworks of understanding, in particular those which reflect personal history, societal beliefs, and the nuances of communication and personal understandings (Lyotard, 1984). Postmodernism portrays knowledge as comprised of numerous discourses that may conflict and differ in their frameworks and interpretations, resulting in multiple outcomes and understandings.

The position of informal communities in the hospital setting reflects many of the concerns that lead to the development of postmodernism. Hospitals are institutions that house the grand narrative of medicine. The medical discourse and socialised hierarchy of its practice reinforce its dominance as an episteme of knowledge and power (Foucault, 1980). Yet, in this community, alternative elements of social relations, knowledge and care provision are seemingly also enacted. Joan comforts her fellow patient with cuddles, not with advice or medication. The patients in the cancer ward described in Chapter four tell personal stories about chemotherapy, in contrast to describing its role and likely side effects. Postmodernism is ideally placed as a philosophical perspective to appreciate these alternative and co-existing systems and approaches to knowledge. Additionally, from an empirical perspective postmodernism supports the application of multiple research methods and theoretical approaches, in order to develop a multifocal understanding of informal communities.

One of the important elements of postmodern epistemology is the use of language, in particular the notion of ‘language games’. Originally described by Wittgenstein, these are various categories of utterances occurring within an interaction and which occur according to predetermined rules of engagement as defined by the actors (Wittgenstein, 2009). Lyotard interprets language games to suggest that every utterance is a move in the game in which the terms of references and frameworks are constantly evolving (Lyotard, 1984). Legitimation comes “only from their own linguistic practice and communicational interaction” (Lyotard, 1984) p.41). Knowledge is generated through and as a result of these back-and-forth utterances. This implies that knowledge is actively engaged in a continual process of development and renewal, in which the boundaries of understanding are questioned. In questioning these boundaries of what is known, science can create innovation and progress through the disruption of existing knowledge.

The understanding of language games as central to the development of knowledge recognises the importance of the interaction in knowledge generation. Language games are dynamic and unstable. Within language games the participants engage in processes of negotiating and renegotiating the rules of the encounter (Lyotard, 1984). It is an unstable process, and this instability is a core element that allows for new knowledge formation, as opposed to knowledge formed within the historical grand narratives of positivist science. Lyotard views the participants as 'nodal points' within a network of communication in which they are constantly altering, disrupting and being changed by the message (Lyotard, 1984). Of particular relevance for this work, this concept places emphasis on the active role of the individuals and the act of interaction as central to knowledge processes.

Derrida suggested the process of 'deconstruction' occurred within these language games, to enabled new meanings and knowledge to be formed (Derrida, 1982a). This process is not conceived as a destructive one, but one that allows clarification and uncovering of meaning through the articulation of underlying assumptions. Derrida perceived that this movement for change occurred from without the system. He suggested that the processes of deconstruction enable us "to transform concepts, to displace them, to turn them against their presuppositions…and thereby produce new configurations" (Derrida, 1982b) p.24). Deconstruction alludes to numerous processes, in which existing constructs are taken apart, followed by a period of creative disorganisation. At this point we may choose to reconstruct old systems or we may choose to break it apart, and allow new terrain to develop (Derrida, 1982a).

These concepts have important ramifications for the interpretation of the encounters in hospital. Within the formal clinical encounter, the dominant frameworks of medicine and scientific discourse dominate the clinical exchange (Grant et al., 2019). The encounters occur primarily between those who occupy the historically and clinically defined roles of the patient, visitor and health professional. The roles regulate the forms and foci of discourse, and are simultaneously subject to the instability of language processes. Through the changes that language exchanges bring about within these interactions, the dominance of the medical and scientific discourse may be disrupted, and new approaches or systems developed. The language brings about change through questioning or the introduction of other narratives. The players or nodes in the interaction may vary as other roles of the participants enter the conversation, as the individuals reveal elements of their lives as a father, sports enthusiast, farmer or cooking expert. Komesaroff identifies roles as being both liberating and limiting (Komesaroff, 2008). A role may confer increasing scope for action and capacity, yet at the same time, limits are imposed by the competing interests each role confers.

Equally, postmodernism has important implications for the use of knowledge in social relationships.

Medical knowledge "is not based upon, nor reinforces social bonds. The basis of this knowledge is institutional or professional groups, and thus retains no direct or common bonds between the participants" (Lyotard, 1984) p.26). Frank comments upon the hospital as being an institution of modernist knowledge, in which each specialist visits the patient to interrogate the medical condition through their own paradigm of interpreting the body (Frank, 2013). In this encounter, the lay individual inhabits a passive role, in which their body is deconstructed into the sum of its physical components and systems (Lyotard, 1984). Frank terms this a 'narrative surrender', as the illness story and the interpretation of the patient's own physical body is told in medical terms (Frank, 2013). The formal medical discourse can thus have dehumanising qualities, limiting the ability to express other aspects of personhood and the formation of social bonds with others.

This focus on the social bond has important implications for the status of narratives as a form of knowledge. Lyotard and Frank describe narrative as the dominant form of knowledge used to establish and communicate within social relationships (Frank, 2013). Within the narrative are the influences of personal history, societal norms and beliefs, and the nuances of communication and personal understandings. A social group that uses narratives as its form of knowledge "finds the raw materials for its social bond not only in the meaning of the narratives it recounts, but also in the act of reciting them" (Lyotard, 1984) p.22). Arthur Frank develops this concept of Lyotard further to describe narrative as an ethical act (Frank, 2013). The act of sharing of narratives defines social bonds and shapes them as dynamic processes. This implicates the use of differing forms of knowledge as being central to the construction of relationships and communities.

The context to this body of research involves multiple potentially conflictual influences and differing discourses related to health, and enacted alongside the discourse of medicine and science. Postmodernism is well suited to recognising and interpreting these influences, and in doing so, requires that the cultural and structural contexts be fully explored. The informal interactions in the hospital occur adjacent to the dominant forms of medical knowledge, the processes of cancer treatment and the structural hierarchy of clinical roles. In the informal domain the individuals – nurses, doctors, visitors, volunteers, administrators and patients – form complex networks where the influence of roles, behaviours, discourses and meanings are potentially altered. The formal role that provided structure for the individuals in the formal system is likely to have differing characteristics in the informal interaction. I seek to make sense of these multiple influences and the interplay between the different discourses and interpretive frameworks of illness. The informal domain presents an unexplored domain of research that requires a thorough exploration from many perspectives, and most importantly, through the perspectives of individuals who experienced it. Language games are a useful concept towards understanding these processes, as the participants negotiate the content and dynamics of the encounter.

5.3 Phenomenology

Martin Heidegger described phenomenology as “to let that which shows itself be seen from itself in the very way in which it shows itself from itself” (Heidegger, 1996) p.58). Put simply, it is the study of lived experience (Laverty, 2003). Edmund Husserl, viewed as the founder of phenomenology, described it as knowledge of existence arising through examining conscious experience (Husserl, 1999). The manner in which we experience the world assumes relationships between what we believe to be objectively real and what we perceive. The broad purpose of phenomenology is to describe the experience of phenomena, or the appearance of things, through exploring the lived experiences of the individual (Penner and McClement, 2008). The goal of phenomenology is not to discover causes, but to interpret the meaning of phenomena attributed to experience by the individual (van Manen, 2017).

The historical tradition of phenomenology developed in continental Europe in the late 19th century. Edmund Husserl was critical of current approaches to human research that ignored the fact that people do not simply react to external stimuli, but rather, are responding through their own situational perception of the meaning of those stimuli (Laverty, 2003). Husserl called for a fresh look at our world and ourselves (Jones, 1975). To explore this, he placed experience as the focus through which existence could be understood and explored.

An important concept described by Husserl that has continued to be prominent in contemporary philosophy is ‘the lifeworld’. The lifeworld is understood as the *a priori* or pre-reflective framework through which we experience life, and is constructed upon our existing beliefs, social and cultural understandings (Laverty, 2003). It is the subconscious manner in which the individual interprets and structures the world around them into different objects and categorisations (Moran and Cohen, 2012). The lifeworld of Husserl was inherently social and cultural, developed upon meanings and constructed through language and other social processes. The lifeworld is developed by and is the framework through which communication occurs, structuring the meanings and senses for mutual translation of language and social practices (Moran and Cohen, 2012). Komesaroff offers a contemporary description of the lifeworld as being the “intimate and private realm of experience within which we live and construct realms of meaning and value” (Komesaroff, 1995) p.1).

Maurice Merleau-Ponty stated that being phenomenologically aware is “ a question of replacing habitual concepts to which we pay no careful attention, by concepts which are consciously clarified” (Merleau-Ponty, 1964) p.61). To enable this understanding, Husserl proposed the method of phenomenological reduction. He proposed that we should bracket out individual biases, suspend judgement, and explore social and cultural influences on understandings in order to view phenomena clearly (Laverty, 2003). Klein and Wescott describe this as a three-step process including intuition, imaginative variation, and synthesis (Klein and Westcott, 1994). Osbourne presented a simplified view of this process as identifying one's presuppositions about the phenomenon and then attempting to re-evaluate the phenomena as it really is (Laverty, 2003).

Hermeneutic Phenomenology

Hermeneutic phenomenology developed from the phenomenological method of Husserl, with some important epistemological differences. Like phenomenology, its focus is the lifeworld of experience and interpreting meaning. Whilst these approaches have more similarities than differences, there are important contrasts, most notably relating to the individual's embeddedness in the world. Martin Heidegger and Hans-Georg Gadamer are its most noted proponents.

Heidegger emphasised the importance of personal history and background in interpreting the world, and in constituting meaning. He described a view that people and the world were indissolubly related in cultural, social and historical contexts (Laverty, 2003). Thus, one can never fully extricate oneself from one's cultural and historical background. These pre-understandings are our structure of being in this world - a concept he named *dasien* – and cannot be cast aside. Gadamer described that "understanding and interpretation are bound together and interpretation is always an evolving process, thus a definitive interpretation is likely never possible" (Laverty, 2003) p.24).

Gadamer furthered this view, in particular noting the role of language in shaping these conditions through which experience occurs. " Language is the universal medium in which understanding occurs" (Gadamer, 1989) p.390). Words each carry their own significance for the writer and reader, and thus the manner in which data are communicated is laden with implicit meanings. He proposed that understanding was not a structured process but arose through dialogue and contextual embeddedness. Questioning and dialogue open up the possibilities of meaning, and this meaning is passed between subjects, into their own thinking (Laverty, 2003). From an empirical viewpoint, this hypothesis rejected the use of a singular scientific method as being able to describe understanding. Instead, Gadamer proposed that meaning could be understood through dialectical processes, using experience as the fore-structure to understanding (Ginev, 1999). Through dialogue can we engage with the historical and cultural positions through which we interpret the world, question them, and re-interpret them.

To engage in these dialectical processes, the ‘hermeneutic circle’ was proposed. It hypothesised that understanding occurs through interpreting individual aspects of phenomena, which are all informed by our historical and social being in the world. The resultant understanding of the ‘whole’ is determined by the individual elements, and our past and potential relationships to these elements (Debesay et al., 2008). The hermeneutic circle involves assessing individual aspects of understanding and at each point reflecting on our own prejudices and influences. Thus, the understanding of the ‘whole’ occurs through interpreting the prejudices of each aspect and how they relate to each other, and the emergence of new meanings (Debesay et al., 2008). Hermeneutics rejects the notion that it is able to arrive at a conclusive understanding through employing the hermeneutic circle, but through these processes the individuals are able to engage with different understandings that may challenge their pre-conceptions. The hermeneutic circle is not a defined methodological process. Tina Koch describes that it “invites participants into an ongoing conversation, but does not provide a set methodology. Understanding occurs through the a fusion of horizons, which is a dialectic between the pre-understandings of the research process, the interpretive framework and the sources of information” (Koch, 1995) p.835).

Phenomenology and hermeneutics represent important frameworks to develop the theoretical concept of informal communities and to be applied to the empirical work. The existing literature describing patient-patient interactions through cancer treatment discussed in Chapter four highlights the role of these interactions as being filled with significance and meaning for the participants. Phenomenology is ideally situated to facilitate exploration and understanding in this setting. Phenomenology and postmodernism represent differing philosophical traditions that are conceptually aligned, but focus on differing aspects of existence. Both perspectives are sceptical of positivist knowledge, instead advocating for critical understanding and the engagement of multiple theoretical positions. Phenomenology contains important empirical methodological tools that are particularly focused on understanding individual social processes and behaviour, and thus represents an ideal framework to be applied to the empirical work.

5.4 Structural Functionalism

My central hypothesis assumes that informal communities exist not only as phenomenological entities, but also as parts of social systems. The perspectives of phenomenology provide important understandings of the perceptual lifeworld yet lack the theoretical tools to describe social systems and structures. Structural functionalism represents an alternative framework to those previously mentioned, one that describes society from a structural perspective (McDonnell et al., 2009). Previously in Chapter two and four, I have employed structural functionalism to frame the description of formal and informal health care provision. Although originating from different theoretical traditions, the positions of structural functionalism, phenomenology and postmodernism are not fundamentally opposed. The work of Jürgen Habermas on communicative actions has demonstrated that these approaches can be theoretically consistent and complementary (Habermas et al., 1984).

Structural functionalism has been used extensively as a perspective to describe systems of health care, most notably in the work of Talcott Parsons in ‘The Social System’ (Parsons, 1991). It has been a significant influence in organisational theory, which has developed theoretical perspectives of informal communities in other environments. I have utilised the toolbox and terminology developed within structural functionalism to explore the domain of health care provision and to construct a theoretical perspective of informal communities as a social entity, existing within a social system. However, the theoretical position for this work remains postmodern, and I have sought a position that incorporates these differences of theoretical perspectives.

Structural functionalism proposes that society is structured according to sets of norms or values which allow it to function as a cohesive whole (McDonnell et al., 2009). Society is comprised of many interconnected parts that attempt to support the functions of the system and its own existence (McDonnell et al., 2009). The work of Emile Durkheim, whilst predating structural functionalism, was an important foundation for this theoretical position. Durkheim was concerned with how societies function through collective systems of beliefs and behaviour. His work was influenced by the changing nature of society at the end of the nineteenth century, where industrialisation and urbanisation had altered social formations. In this modern society, he identified specialised divisions of labour, increasing power of societal institutions and decentralisation of relational networks; of a society that was more mobile and with more, but weaker, social ties (McDonnell et al., 2009). Durkheim saw social integration as being developed upon the dependency of the individuals’ needs and the mutual relationships between functions (Allan, 2005).

Talcott Parsons, likely the most noted theorist of structural functionalism, identified these shared values and norms as being structures that enabled social order to be maintained (McDonnell et al., 2009). He proposed that social practices and processes were mechanisms through which social control can be maintained. Importantly, he provided a taxonomy to interpret social systems, as constituting institutions, structures and functions. ‘Structures’ represent values, norms and roles, which enable social systems to act cohesively. ‘Functions’ are actions, processes or outcomes that maintain the system and enable it to achieve its objectives (McDonnell et al., 2009). ‘Institutions’ refer to those parts of the system which embody the structures or knowledge of the system, such as government, university, or religion (Spencer, 1898).

Parson’s most famous work – ‘The Social System’ - bears similarity to the focus of this thesis (Parsons, 1991). It addressed the interactions between staff and patients in the hospital environment, notably describing the ‘sick role’ adopted by patients. This terms describes the manner in which the patient is sanctioned from their usual social obligations as a result of a medical diagnosis, but are subject to obligations to follow medical treatment and engage in behaviours to improve their health (Mol, 2002). The health professional exerts social control through sanctioning their illness, as does society in upholding behavioural expectations of the sick. Whilst sociological understandings of illness have evolved beyond Parsons’ conception of the sick role, it has important implications for understanding the health care system and the health professional-patient relationship (Mol, 2002). It identified the health professional-patient interaction as central to health care provision, through establishing expectations and norms related to illness and treatment. These demonstrate the relationship between micro-relations (the interaction between individuals or groups of individuals) and macro-politics in health care, and how these influence larger social processes such as illness behaviour and knowledge in medicine. It places informal communities as embedded within, and potentially reflective of systemic social structures.

Jürgen Habermas’ work on communicative action proposed a theory of social order that aligned many of the underlying premises of structural functionalism with phenomenological theory (Gaines et al., 1991). His theory detailed a two-level concept of society that incorporated structural and perceptual paradigms. He borrowed Husserl’s concept of the lifeworld, identifying society as consisting of the ‘system’ and the ‘lifeworld’ (Habermas et al., 1984). Habermas described social order being comprised of the perceptual lifeworld and economic and administrative systems (Baxter, 1987). These levels of society are interdependent, as the actions and meanings of communication are embedded with structural and lifeworld elements, and enable these two levels of social order to coexist. Social entities function within these two levels or domains of action, “according to how they specify the goal-directed actions of different participants: as the interlacing of egocentric calculations of utility, as a socially integrating consensus of norms and values instilled through cultural tradition and socialization, or as reaching understanding in the sense of a cooperative process of interpretation” (Habermas et al., 1984).

This brief description of some aspects of Habermas’ work reveal important implications for this study. It provides a theoretical scaffold that links the structural functional and phenomenological traditions. Not only does it indicate that theoretical positions have conceptual coherence in relation to this work, but it also yields a method to negotiate between them. Through establishing that both domains are present within accounts of social actions, it implies that empirical research that accesses these accounts contains data relating to the system and the lifeworld. Thus a phenomenological study can detail important data regarding social structures. The aim of this work was to construct a systematic understanding of informal communities in cancer. The work of Habermas has enabled the translation of the empirical findings focused on the interactionalist perspective to the systemic domain, to describe the structure and functions of informal communities.

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Chapter 6

Proposing a Model of Informal Communities

> *Culture is interpreted "as purely a symbolic system, by isolating its elements, specifying the internal relationships among those elements, and then characterising the whole system in some general way – according to the core symbols around which it is organised, the underlying structures of which it is a surface expression or the ideological principles upon which it is based* (Geertz, 1973) p.17).
>
> \- Clifford Geertz, *The Interpretation of Cultures*

To construct a theoretical model of informal communities I have used aspects of the aforementioned theoretical approaches. This chapter discusses the application of these differing theoretical positions to form a coherent approach. It then aims to construct a theoretical model of informal communities.

Informal communities are social entities functioning within existing social systems which exhibit structural elements. These communities are equally a product of the lifeworld, developed from individuals, their relations and personal meanings. This model takes both accounts into consideration, defining the structural and phenomenological terms through which informal communities are constructed.

6.1 Outlining the Theoretical Position

The theoretical approaches of phenomenology, postmodernism and structural functionalism provide important theoretical positions to underpin and progress this research. I identified these epistemological approaches as complementary, each possessing significant theoretical contributions to the model. The aim was to construct a systematic theoretical account of informal communities, and to do so required consideration of their structures, significance, and functioning from an individual and societal perspective.

Phenomenology and postmodernism are schools of thought that reject positivist approaches to knowledge, instead embracing ambiguity, difference, and multiple meanings and frameworks for interpretation (Unah, 2000). Neither approach is prescriptive, instead encouraging the individual to engage with multiple frames for interpretation, whilst simultaneously being critically engaged in questioning these approaches. In the descriptions provided in the preceding chapter, there are marked similarities apparent in the theoretical basis of key concepts. For example, Jacque Derrida's early works were focused on Husserl's phenomenology, and his subsequent work on deconstruction was substantially influenced by phenomenological reduction (Lawlor, 2002). Wittgenstein was another scholar whose work links these philosophical traditions, although only posthumously with postmodernism (Munson, 1962). Whilst I do not intend to engage in a comparative analysis of these theoretical perspectives, I am keen to demonstrate that they are epistemologically congruent and therefore do not require any significant conceptual differences to be resolved.

The place of structural functionalism within this theoretical approach is also complementary. It provides powerful descriptive tools to understand social and health care systems, and to describe informal communities on an organisational level. Additionally, it develops the theoretical approach of informal communities as social entities embedded within these existing systems of relationships and care provision. The work of Jürgen Habermas has demonstrated that the positions of phenomenology and structural functionalism can be theoretically consistent, and when applied to the study of the social world can develop systematic accounts of phenomena that traverse the system and lifeworld (Habermas et al., 1984).

The decision to use phenomenology, postmodernism and structural functionalism as the theoretical framework for this thesis was developed through careful consideration of the research domain and literature review as presented in Section I. Postmodernism offers powerful tools to appreciate knowledge and social shifts, to identify how informal communities are embedded within dominant discourses and social structures. Phenomenology provides a framework to appreciate these phenomena from an individual perspective, and the many differing meanings and roles that these communities may play for the individual. Structural functionalism enables a social system perspective to be constructed in order to identify the structure and functions of these communities and how they engage with those other social systems (i.e. the health care system) in which they are embedded. Reflective of the postmodern approach, I have borrowed methodological and interpretive tools from other philosophical traditions to inform the empirical and theoretical work – qualitative research, ethnography and symbolic interactionism – which will be discussed in Chapter seven.

6.2 A Postmodern Community

There are many different ways to understand the notion of community. The traditional concept is based on pre-modern life of family, the home and place of work, all of which were usually in close proximity. In this understanding, the individual exists within networks of interconnected communities all formed in close proximity, and which were durable and longstanding. The circumstances of modern and postmodern life have changed considerably, as witnessed by a geographical and relational spread in the locations of families, friendships, education, workplaces and homes. The networks of relationships through which we enact our lives have expanded exponentially, to be increasingly fractured but equally more connected to the vast world in which we reside. The physical self is arguably of lessened importance in social interaction, which is readily accessible through electronic or telephonic means. The greater connectivity of the current age allows individuals to be connected through multiple communities that may be geographically and culturally diverse, and take place through a range of relationships and media (Bauman, 1996). This connectivity not only allows the individual to be part of many different communities, but seamlessly and instantaneously transition between or remain within these networks.

Late modernity illustrates the changes inherent in twenty-first century society in which those structural bonds that define and support have lost their same relevance (Bauman, 2013b). Bauman describes how the strong ties of family, marriage, religion and class are less fixed, and their desirability is lessened (Bauman, 1996). Within this lies tensions between opposing desires for freedom and security, autonomy and support. Relationships exist as part of this tension, as we participate in complex networks of relationships through all our various activities and environments that are in states of flux. These relational ties are dynamic, are constantly being formed, strengthened, loosened or severed. Community exists within these networks, constructed in the many differing and interstitial spaces where the individual exists. It is just as present, albeit in different forms, at the family Christmas dinner as it is in the internet chat room. In place of the fixed and predetermined communities described by Max Weber prior to industrialisation, in which identity and physical self were enmeshed within family, class, religion and the profession of our forebears; the individual is offered freedom in exchange for impermanence

(Neuwirth, 1969). In this dynamism they are easily created and extinguished, in need of constant replenishment, and represented in increments of closeness and intimacy. The late modernity of Bauman poses these challenges for us, telling "of the pleasures of togetherness in one breath with the horrors of enclosure" (Bauman, 2013b) p.xi).

I wish to take an example from a different space to illustrate these concepts. A university student is sitting in a chemistry lecture listening to the lecturer. She occasionally jokes with her two friends sitting beside her, whilst periodically replying to a conversation with her mother through text message and flirting with a young man through a dating app. The student is engaged in multiple interactions and communities all seemingly occurring at the same time: that of a student in chemistry class, a daughter, a friend, an undergraduate on campus and a potential suitor. She seamlessly transitions between these groupings, being within all these in those same instances, but relating to each in differing manners. The roles, boundaries, discourses and purposes of these interactions all differ. Yet these relations are not all distinct, being interconnected through many of the relationships around her, as her two friends are integral to the communities of friends, chemistry class and university student, and are removed yet interested observers of her conversations through the dating app.

The university student in her lecture is embedded within many communities, with varying degrees of importance, strength, reciprocity, and disposability. The interaction with her mother may be of little current importance compared to the potential suitor on the dating app, yet is likely to be a far more enduring and profound relationship. She is embedded within the larger diffuse community of university students with which she may have few personal ties but which is an important element in her life narrative and manner of self-presentation.

The notion of 'community' incorporated in this analysis seeks to be inclusive of both the structured and the ephemeral, building upon Bauman's late modernity work (Bauman, 2013a). This definition builds upon earlier sociological literature in which community is identified as a socially constructed process, derived from social interaction and negotiation, in which individuals are members of multiple communities each of them fulfilling specific needs, even contradictory ones (Abner, 1985). Community in the current age may be a fragile and evolving state that encompasses those ephemeral and loosely affiliated individuals who coexist within a particular moment, in addition to those structured groupings that are central to identity and meaning, such as family. They may be dispensable or indestructible, fleeting or endure. This notion of community is an important construct through which we may interpret the dynamic nature of the group, its differing meaning and roles for the individuals who inhabit it, and the manner in which communal discourse may relate to personal meaning and development.

The hospital environment contains complex networks of relationships and communities. Similar to the university student described, the patient in the chemotherapy centre is embedded within multiple communities. Some may be within formal roles, such as being a patient of the hospital, or a longstanding relationship with the treating oncologist as her patient. Other communities may be well recognised: the partnerships with her husband who attends with her every chemotherapy session, and the two patients with breast cancer who have their chemotherapy at the same time each fortnight and with who she always converses. Additionally, there may be many other less visible communities: such as being a breast cancer patient; having a familiar relationship with a favourite nurse with whom she exchanges stories of grandchildren; a passionate supporter of her football team; the group of patients who shared a room with after her mastectomy; and, the occupants of the chemotherapy room around her (many of who she recognises and shares an occasional smile). Her behaviours and the subsequent manner in which she interacts with these communities' affect the other individuals in the space, and their engagement with these and other communities.

The qualities of these communities are challenging to define, and their definition seeks to accommodate relationships that may be either enduring or ephemeral, and of significant personal importance or serving momentary purposes. The structures and dynamics of these communities are many. Within informal communities there may be a lack of defined community structures, roles, purposes, and goals. External status (such as doctor, patient) may be of differing significance within the community or may serve as an important qualifying or identifying factor.

To develop an empirical understanding of these communities I have applied symbolic interactionism to support the analytical framework. Symbolic interactionism contains important analytic tools to assist in understanding the functioning of these interactions and will be described in greater detail in Chapter seven. Erving Goffman presents a binary understanding of interactions, as being either focused or unfocused. The focused engagement has a single focus, where the participants openly engage with communication, and will often employ acts of entrance and departure (Goffman, 1961). The unfocused encounter occurs when people may be present in the same environment and whilst not mutually interacting in shared activity, they do engage in the surrounding milieu and alter their behaviours accordingly (Jacobsen and Kristiansen, 2014). This unfocused engagement is afferent and efferent, in that they alter personal behaviours while at the same time affecting those around them.

These unfocused interactions are important to these representations of community. Individuals may passively engage and through this, absorb medical information, experiential narratives, behavioural expectations, and thus create interpretations as how they might act in the space. Such passive interaction may be observed in the unwell patient, who may lack ability or energy to engage fully in focused interaction but gain satisfaction through being and observing. From my professional experience, I have witnessed this behaviour in palliative care units, where unwell patients may sit passively as conversations occur around them. This behaviour may also be common in internet cancer groups or message boards, where many individuals may take on passive roles as collectors of information and find engagement suitable to their needs (Yli-Uotila et al., 2014). In many respects the unfocused interaction is an extension of the postmodern condition, enabling freedom of engagement while lessening the potential for entanglement (Goffman, 1961).

The interpretation of community incorporates both the focused and unfocused interactions. It is a broad definition seeking to encompass the transient and permanent relationships that shape and contribute to the evolving self which may have needs of all forms of interaction at different times. The current sociological literature illustrates community as an evolving concept, and this definition embraces their dynamic nature, focusing on the commonalities of shared meanings, spaces and narratives.

6.3 An Informal Community

The term ‘informal’ was originally applied to these communities to differentiate those which were not part of the formal provision of health care or its structures. This definition supported the empirical studies, as it allowed the participants to readily identify which interactions and communities may be considered to be informal. Yet this notion of informality requires further consideration from a conceptual viewpoint, as to their nature and dynamics. I have approached this from two aspects: the organisational and the discursive.

Organisational theorists have elaborated on ‘informal communities’, predominantly within business environments. The theoretical background of organisational research is heavily influenced by structural functionalism, and for the purpose of the work I have assumed alignment of these theoretical positions. The dominant hierarchy and rigid structural environment of corporations and bureaucracy bears significant resemblance to the hospital organisation. These organisations contain dominant professional discourses, rationalisation of tasks, and common frameworks through which knowledge and success are interpreted. Informal communities are described as arising spontaneously from within these formal organisations, generally in response to stimuli such as a common experience, values or beliefs, or shared goals or organisational inadequacies (Snowden, 2000). Around this stimulus the community construct social relations and meanings that are appropriated by the participants (Cox, 2005). They are formed around voluntary and authentic relationships, and the perceived existence of a shared community is frequently not recognised (Wenger, 1998). The nature of these groups is ambiguous and ephemeral, and thus may quickly form or dissipate (Snowden, 2000). Within the groups the participants take on many differing roles, in contrast to the highly structured hierarchy and task rationalisation present in professional practice.

An interesting quality of these informal groups as noted in the organisational literature is their capacity for data exchange and use of language. They act as rapid disseminators of information and ideas, far more so than occurs through more rigid formal relationships (Sorenson and Stuart, 2008). Snowden's work examined how formal and informal groupings within an organisation relate to professional knowledge and language (Snowden, 2000). In business organisations, formal groups predominantly engaged in professional or bureaucratic language to interpret and share information. In contrast, informal communities communicate through symbolic or emergent language. Snowden describes symbolic language being used when participants who are well known to each other can engage through pre-existent understandings and commonalities, in which many concepts do not require discussion as they have agreed upon meanings shared between participants. This enables the dissemination of a large amount of information in a succinct manner (Cox, 2005). Frequently, stories are used as the medium to convey such information. Emergent language occurs when the participants are presented with new situations and must construct a way in which it may be understood and communicated. This enables learning, construction of new meanings shared between the participants, and through these processes strengthens the relational bonds between individuals.

Reflecting upon the informal communities described in cancer treatment, these descriptions seem to hold significance. In cancer treatment, informal communities are characterised by their ambiguous and fluid organisation, situated within existing bureaucratic structures. The discursive qualities described by Snowden reflect processes that occur in the existing research on patient-patient interactions in health settings and in the support group literature (Andersen et al., 2015, Larsen et al., 2013, Borkman, 1999). The language observed in these groups is primarily narrative in form and utilises shared experiences to convey meaning, which can be complex and of emotional value. The emergent language is well described by Borkman as a component of the experiential learning processes of support groups (Borkman, 1999).

Chapter four described significant differences within informal relationships between patients on a discursive level. In the hospital environment, professional medical discourses and frameworks for interpreting illness are a powerful influence on the interactions occurring within these spaces. It is a discourse involving hierarchy and assumed role behaviours that are constantly reinforced through the use of language, role privileges (such as the doctor prescribing medications) and tasks (Foucault, 2012). Its language is exclusionary to the non-professional, limiting their ability to interpret and meaningful contribute (Mol, 2002). Additionally, it is reductive of their lived experiences of illness, instead categorising these complex experiences to technical terms, and in turn, separating these events from the physical body and individual who experienced them (Frank, 2013). As described by Arthur Frank, it is a discourse that diminishes the role of the patient (and to a lesser extent the visitor) to be the subject of a foreign discourse in which they have little control over authorship, one which is recorded in medical notes and which she (the patient) is expected to accept (Frank, 2013). Howard Waitzkin described that the “language of medicine leaves few options for action…such tensions that derive from troubling social issues erupt into the discourse…and create a contextual reality that cannot be resolved in the framework of the medical encounter” (Waitzkin, 1991).

A consistent theme to emerge from the literature presented in Chapter four was the use of experiential or narrative discourses within patient interactions. These different forms of discourse suggest alternative methods of communication, language and interpretive frameworks to what is presented within the medical discourse. These relate to similar objects of reference and contain aspirations of understanding health and illness. However, this similarity may also create forms of tension. These other discourses are potentially shaped by the dominant medical discourse, in particular the exclusionary nature of its language, hierarchy, and specialist knowledge. By contrast, many of the aspects of narrative discourses engage with points of reference familiar to the patient, that of the experience of illness or personal history, which can easily be accessed by all patients. Through placing experience as the focal element, it moves the patient to the centre of the narrative. However, this narrative discourse may be exclusionary to those who have yet to experience illness, in particular the health professional. This is an exploration I have engaged through the empirical studies.

The concept of informal communities that has been developed is closely aligned with the theory of postmodernity. It is evolving and dynamic, and occurs in multiple forms, with the potential for many differing outcomes. Equally, it is not defined by what it is, but by what it is not. It is not centred upon the relationship that develops through the clinical dialogue and consultation. It is what happens outside of this. It is how a nurse and patient relate to each other when the structures of the medical discourse recede; when they are forced to find their own mutually agreed-upon terms of reference, to find similarities in their life stories and interests. It is two patients talking about cancer without mention of metastases, organs and chemotherapy medications. At its base are people communing, in all shapes and forms, with the potential for a simple greeting or for more meaningful contact. This broad definition is the basis for this thesis.

It is useful to consider how the formal and informal groups in health care settings can be delineated. From an organisational perspective formal groups act with set purposes and goals, the participants act within set positions, tasks are rationalised, and there is an identifiable group existence. The discourse of the group is formed, potentially reflecting existing professional or bureaucratic language and subject knowledge. This classification may fit many developed cancer support groups, who have developed a fixed identity and purpose, with a relational hierarchy, tasks that are directed towards members with specific skill sets, and a set language of interaction. Borkman describes these groups as having a set ‘meaning perspective’, having developed agreement between members around major issues, and instead are focused on addressing solutions (Borkman, 1999). In contrast, the informal groups lack these ordering structures of discourse, relations and outcomes. The members act to fulfill a variety of tasks that are not conducted in a set role, the language is emergent and dependant on the individual, the group lacks a fixed purpose, and potentially lacks a common identity. Additionally, these informal groups are dynamic, with participants moving in and out of the community, and relationships evolving as new meanings and discourses are entered into. These qualities describe the patient-patient interactions through cancer treatment detailed in Chapter four. They also apply to many of the health collectives described in Chapter three, particularly those in their early stages of existence, such as early incarnations of mothers' groups and HIV care. Borkman names these the 'fledgling groups', that are yet to form set processes and meaning perspectives, where the purpose is driven by the individual needs of the participants (Borkman, 1999).

From a discursive perspective, the informal nature of these communities is evident through interacting outside the formal clinical consultation processes and discourse. Throughout this thesis I have employed the terminology of 'domains' of communication, which describes institutionally relevant spheres of social interaction and discourse (Fishman, 1971). The formal health consultation is a confined process, and occurs within boundaries of framework, roles, narrative and dynamics of power (Mishler, 1984). The formal clinical encounter is defined as "the point at which transactions between patients and professionals take place; it is the point at which decisions about diagnosis and treatment are made, and during which caring takes place" (Dieppe et al., 2002) p.279). On a practical level, these are the formal interactions between health professionals and patients and their families in the clinic, the private practice, the hospital ward, or through telephone or video-link, occurring largely within the formal domain. They are deliberate and enact a set agenda focused on a medical concern or issue. The term 'informal domain' is used to describe that which occurs outside the formal or deliberate clinical encounter. Informal interactions may occur within the clinical consultation but do so outside of the formalised dialogue and agenda of clinical investigation and management.

It is worthwhile to consider how the outcomes related to these communities may differ. In the hospital setting, outcomes of formal relationships are often focused on identifiable outcomes related to health care, such as giving a medication, taking blood, or providing a medical opinion. However, beneath this level of attributable care provision, there are other, less tangible outcomes resulting from these relationships. Patients and their families may feel supported, encouraged, frightened, or empowered through these formal health interactions, and access their owns forms of information and treatment (such an complementary therapies) as a result of these relationships(Mead and Bower, 2002). From my experience as a doctor it is presumed that health professionals are subject to a similar, yet differing array of less perceptible outcomes, from feeling self-validation through these caring interactions, to our own emotional responses and concerns around structural inadequacies of the health system as it seeks to respond to the patient's situation. These outcomes are notably both structural and phenomenological, reinforcing our broad approach in constructing this model of informal communities. Reflecting on the literature discussed in Section I, there appears to be significant overlap with the outcomes of these formal relationships and the patient-patient interactions discussed. This is an important consideration that will be explored in the empirical work, to consider how the outcomes and modalities of care differ within informal communities.

6.4 Informal Communities and Care

The theoretical position of this project identifies informal communities as providing care. This is an important distinction from being only a social entity. It posits them as being active constituents in health care, complementary to formal care providers. This is a conclusion that the current literature exploring informal interactions discussed in Chapter four suggests but does not make explicit. The empirical work began from this theoretical position. However, this position has implications, in particular, for the nature of care and what is implicit in its provision.

In cancer treatment, care is focused on observable processes and procedures: hospitalisation, chemotherapy, clinic appointments, scans, radiotherapy, surgery and pathology tests. Yet, there are many additional aspects that contribute to the health of the individual. As discussed in the Chapter two, health care occurs in many guises and through many actors, its provision not only signified by a prescription, tablet, or visit to the clinic. Through cancer treatment patients and their families access care in many forms from the formal health system. Information is provided from staff, visitors, volunteers and fellow patients, covering the medical facts of drug side effects and overall survival rates, and those personal experiences of treatment and life with cancer. Emotional and social support are provided in everyday conversations that may normalise the individual’s current predicament or provide encouragement. Patients and their families describe a wide range of benefits and offerings of care in the hospital environment that extend beyond the formal medicalised treatment (Isaksen et al., 2003).

Such a representation of care in health as being embodied by the formal system alone fails on many accounts. It denies the layers of informal health care provision present within the system, including family caregivers, parents nursing children and everyday sharing of non-professional advice (Grant et al., 2019). It imbues the patient as a passive self, a recipient of care, a body of illness but not of action. For the health professional it is also limiting, relegating their role to within these narrow structures of potential action, and failing to recognise the importance of all that occurs outside of this framework of care: the inquiry about the family, the jokes, the cup of tea, and the conversation about football that are instrumental to caring.

Care is a broad notion. Its philosophical origins date back at least to the time of the stoics, where Seneca described care as a force that could impose burden, yet enables humans to do good, reflecting the will of the divine (Reich, 1995). Care entailed attentiveness, devotion and conscientiousness. Martin Heidegger developed the notion that care was a central concern of phenomenology (Heidegger, 1996). Our being in this world and the meaning we derive from it is based upon our ability to care and be cared for. "It predates, underpins, and makes possible all other mental, physical, and social operations… bringing about the very possibility of mind and body" (Tomkins and Eatough, 2013) p.4). In other words, caring about ourselves and others is what enables us to form relationships with our physical body and the world around us. Caring for and being cared for by others is the basis for coexistence and relating to the other. Heidegger claimed that we are care, and care is what we call the human being (Gelven, 1989).

A modern account by Milton Mayeroff provides a strong empirical perspective to the concept of care. He described care as an act to help the other grow (Milton, 1971). It is a mutual act, one that is not defined by its outcomes, but through the processes of caring. It may entail trust, patience, humility, honesty, knowing the other, respect, and hope (Reich, 1995). Mayeroff identifies caring and the provision of care as an inherently moral act, in which the participants enact their owns values and relate to the ideals of the other.

These acts of care or caring have important implications. As described by Mayeroff, acts of care are implicitly moral acts. This is reinforced by the work of Komesaroff and Frank, who describe the inherent ethical nature of relating to the other in the context of illness, be it through formal acts of care or sharing stories and experiences of illness (Frank, 2013, Komesaroff, 2008). These acts of care are inextricably linked to the moral relationship to the other. It also identifies the broad nature of care, as being innate to the processes of relating to the other.

In conclusion, I propose that care is present within, and an outcome of, informal communities in cancer treatment. These communities are providers of care: that which improves health, facilitates understanding, provides support, gives to the other, and through these processes, develops and enriches the individual. This care is inherently ethical, and acts of caring cannot be separated from the moral actions.

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Chapter 7

Empirical Resources

Research occurring within a postmodern epistemology is challenged to question the validity of its methods and conclusions. It is apparent that uncovering the ‘answer’ to our questions is impossible. However, engaging in a deconstructive process of learning, interpretation and reflection may allow greater understanding and the formation of knowledge or multiple forms of knowledge. The methodological approach must manage these instabilities and engage in this process of reflection upon its own biases, boundaries of interpretation and vulnerability. Thus, the use of a hermeneutic approach to data analysis is well suited to these explorative processes. This chapter describes the theoretical resources that supported the empirical studies.

7.1 Qualitative Research

This work is focused on social processes and human experience. It is exploratory, theorising and describing a domain of social interaction within the hospital space that has not been the focus of existing literature. As such, qualitative methods were deemed to be most appropriate to this research work.

Qualitative research includes a broad array of methodological approaches and theoretical traditions (Lingard et al., 2008). It employs a variety of theoretical perspectives and tools, each with individual strengths and limitations. Qualitative research has been defined as including empirical methods that do not seek to provide quantified answers, but instead employ non-numerical data to focus on social phenomena and individual meaning (Pope and Mays, 1995). These methods have a long tradition of use within the social sciences, where they have focused on understanding human behaviour, experiences, perceptions, functioning and culture. Their application in health research continues to increase, as they are ideally suited to understanding how individuals relate to and participate in health, and interact with health processes and technologies.

Within the domain of qualitative research there are a large number of methodological approaches, including but not limited to: grounded theory, phenomenological, ethnographic and action research approaches. These approaches are developed upon a constructionist perspective, which views knowledge as being socially constructed and situated (Goodson and Vassar, 2011, Pope and Mays, 1995). Qualitative methods in general employ malleable approaches to research practice, promoting methods that are flexible to the needs of the research and avoiding fixed dogma.

There has been a range of criticisms directed towards qualitative methods, in particular the ‘reliability’ and ‘validity’ of its results. Qualitative research typically addresses practices and perceptions within defined social contexts, and does not seek to identify to what extent these phenomena occur or how they might be generalised to society. Thus, qualitative research may not address issues of reliability and validity in the same manner as positivist research. Clive Searle describes these terms as unhelpful given the uniqueness of each social context, and instead focuses on addressing the quality and trustworthiness of research. He suggests the trustworthiness of qualitative research “lies at the heart of issues conventionally discussed as validity and reliability so that four questions have, from within the modernist paradigm, been asked of research reports, namely their truth value, applicability, consistency, and neutrality” (Seale, 1999) p.467). This may be enhanced through attending to specific research practices, such as cross-checking data, establishing data coding and analysis processes, and enlisting multiple researchers in data analysis.

The term ‘triangulation’ is frequently mentioned as a manner to improve the trustworthiness of qualitative research. It involves applying multiple forms of data collection, methods or theoretical frameworks to the same research question (Carter et al., 2014). Triangulation can be used for a number of different outcomes. Perhaps the most frequent is its application to develop a deeper understanding of the phenomena in question, through exploring it using differing perspectives. Silverman described triangulation as a way to reveal multiple realities and expose difference (Silverman, 1993). The difference Silverman mentions is not a comparator, but an exploratory notion, in which the researcher can access data through another frame. In this essence it may be comparable to Derrida’s notion of ‘differance’, as an interruption of the structural connections through which the data were originally interpreted (Derrida, 1973). Flick suggests triangulation in this manner may hold even further possibilities, to expand the scope, depth and consistency of the interpretations (Seale, 1999). Thus, triangulation promotes quality in qualitative research through enhancing trustworthiness and broadening understandings arising from the data.

The methods employed in the empirical work are based upon these fundamental considerations. This is most apparent in the overall research design, that access informal communities through two contrasting and complementary methods, ethnography (study 1) and phenomenology (study 2), each contributing their own perspectives and understandings to the final concept. These approaches to data analysis utilise differing theoretical perspectives, including feminist and hermeneutic frameworks, in order to enhance the depth, breadth and trustworthiness of the results.

7.2 Ethnography

Ethnography is a domain of research arising from sociology, directed towards undertaking first-hand observation and participation in the natural setting of the participants (Hammersley, 1990, Geertz, 1973). Its epistemological basis is constructionist: that knowledge is socially constructed and embedded (Goodson and Vassar, 2011). It is underpinned by the fundamental premises that (i) behaviours have meanings, (ii) actions make sense in context, and (iii) actors are knowledgeable in their own culture and actions (Goodson and Vassar, 2011, LeCompte and Schensul, 2010). This places particular emphasis on the research context, in particular accessing the ‘natural setting’ of the participants, and thus the ‘real’ behaviours within the social processes that they occur.

The value of ethnography in this program of work is its ability to understand the processes and relationships that constitute and influence the provision of health care (Walshe et al., 2012). In observational research, the researcher is able to see health care being enacted, to identify how these processes occur in their natural setting. This is in contrast to interview methods, where participants reflect upon their experiences, which may identify particular only particular aspects of these phenomena. For example, a study of district nurses providing palliative care demonstrated that they engaged in many differing care tasks, roles and behaviours, but they were unable to describe many of these through interviews (Griffiths et al., 2007, Griffiths et al., 2010).

The research methods applied in ethnography are broad, focusing on the collection of data from the natural world of the participants through observation and participation in their environment (Goodson and Vassar, 2011). Historically, ethnography has been characterised by complete immersion in the research environment over long time periods, yet modern applications have placed greater emphasis on accessing the natural setting through a variety of means (Reeves et al., 2008). This may result in the researcher occupying a passive role in the environment (such as a visitor sitting on a chair) or immersion within an existing role, which in the hospital environment is frequently performed as a staff member (Gijsberts et al., 2013).

The hospital environment is unlike the outside world, in that it has its own systems of bureaucracy, language and role behaviours that are distinct from broader societal norms (Van der Geest and Finkler, 2004). This presents a significant opportunity, as many of the behaviours and practices of a culture are enacted within a differing set of structures. “The study of health, illness, and medicine provides us with one of the most revealing mirrors of the relationship between individuals, society and culture” (Lock and Gordon, 1986) p.8). The importance of hospital ethnography is that is enables exploration of the experiences, meanings, processes and social complexities that are an inescapable component of illness. It provides data that are richly contextualised, and that cannot be collected or understood through quantitative means.

7.3 Symbolic Interactionism

Symbolic interactionism, in particular the work of Erving Goffman, describes human interactions in intricate detail (Goffman, 1961). It provides a valuable methodological toolbox to describe and understand the informal interactions of the hospital space. In the ethnography study, symbolic interactionism has been applied as a descriptive tool with important terminology to describe and advance theoretical perspectives to inform the research. The literature arising from symbolic interactionism has additionally informed the theoretical model of informal communities.

“Interaction is a complex process in which people form, sustain and change the world to create meaning” (Blumer, 1986) p.2). Symbolic interactionism is focused on promoting the methodology of direct observation to describe the manner in which individuals relate, negotiate difference, and form meaning through those relations (Frank, 2015, Denzin, 2008).

Herbert Blumer, one of symbolic interactionism’s key thinkers, proposed three fundamental assertions underlying its epistemology (Blumer, 1986). Firstly, the individual has a self: a perception of oneself; can make judgements about objects, others, and our own goals; and, can make determinations based upon this. Secondly, action is both rational and irrational - the actor may define their own actions, is influenced by forces external to their control, yet can redefine the interpretation of the events and outcomes (Blumer, 1994). Thirdly, actors do not build up meaning on their own, but do so by taking the role of others, by seeing other’s situations from others’ perspectives (Frank, 2015). “Meaning is a question of mutual alignment, not an individual construction. In this alignment actors seek not self-interest but community affiliation” (Frank, 2015).

Symbolic interactionism identifies the distinctive character of interaction (both with other individuals, objects, and concepts), in that "human beings interpret or 'define' each other's actions instead of merely reaction to each other's actions" (Rose, 1962) p.79). The interaction which occurs is thus mediated by interpretation of symbols, meanings, and concepts as an ongoing process in which the individual makes determinations over their behaviours and actions (Rose, 1962). This perception is influenced by the past, world views, cultural considerations, environmental and personal stimuli, all of which influence both afferent and efferent behaviours. In contrast to the 'top-down' approach of much sociological theorem of the time explaining how structures influence the individual, symbolic interactionism takes an inverse approach, focusing on how the micro-ethical perspectives of the individual influence interactions and group behaviour.

Erving Goffman's works on dramaturgy have significantly informed the ethnography work (Goffman, 1978). Behaviours may reveal, hide or explicitly mislead important aspects of the individual's self. Goffman uses the metaphor of an actor in a play, presenting themself to the audience, engaging in different presentations of the self. They behave and dress differently in each context: a frontstage and a backstage (Goffman, 1974). The individual defines the forms of self to portray to their audience based on their values and belief, but these forms are additionally shaped by the perceptions of the other participants. Individuals present differing aspects of their self and activity to others, and guide the impressions they wish to create (Goffman, 1978). This expression intentionally or unintentionally reveals differing aspects of the self. Whilst they may involve hyperbole, negation, or falsity, these are nonetheless important aspects of the self. For example, Arthur Frank wrote about the many narratives of illness he read, declaring: "I have read personal accounts I considered evasive, but that evasion was their truth" (Frank, 2013) p.22). Interactional behaviour involves many influences and discourses, and this concept allows an understanding of the complex and often performative nature of individuals as revealing important data reflecting aspects of the person.

The concept of dramaturgy bears important relevance to the hospital setting, where individuals are asked to detail intimate personal details and stories, whilst also being influenced by the socially conditioned role of 'the patient'. Arthur Frank writes that "Goffman shows that they (patients) are responsible for how they present themselves and manifest the signs of illness" (Frank, 2013) p.31). In one sense, the individual may be subject to influences to present what they perceive to be 'the good patient', to follow the advice and agenda of the health professional (Kaba and Sooriakumaran, 2007). Additionally, the presentation and others' perceptions of the self are shaped by the individual's functional ability, the objects and clothes they carry, the hospital environment, the people they engage with, and the areas they access. Appreciating these influences and how they may reveal and reflect differing aspects of the individual's backstage self is an important theoretical perspective to inform the empirical work.

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Section III

Informal Communities – System and Lifeworld

Chapter 8

Empirical Methods

I think it was a few weeks ago talking to a guy. His first time in here. Trying to think of what ... I think he had bowel cancer. He was saying how he wasn't sure just what was going to happen with him. I think they told him he had 12 months to live. I mean young buck too.

I sort of try and pep him up a bit, and say, "Well, whatever they're doing here, hopefully it'll prolong the situation. You know? It can't be any worse. You know your situation. You know there's 5 to 12 months. Whatever they give you now, you can get next here, you're doing well. As long as you still to a certain extent healthy enough."

Poor bloke, he could hardly walk. He had problem with his legs too because he had lost so much weight. Didn't have any strength in his legs. Walking with a walking stick. Like I said, he was only a young bloke. He happened to be German as well. Didn't even know that until I started talking to him. It's the accent, you know?*

But, I thought I'd say to him, "Look, just don't be too hard on yourself. Just think to yourself, or tell yourself, I'm here. I'm in the best place. I'm getting the right treatment. People looking after me, and just suck it in. Just go with it." That's first thing that you have in your head, really. He wasn't that with it when we were talking, but he sort of listened to what I had to say a bit more than ... I explained my situation to him, and, "Oh, shoot, you know. You sort of know a little bit what you're talking about."

- Georgio*, chemotherapy day unit, participant #13, interview study

This chapter details the empirical methods. It discusses how the theoretical positions and methods informing data analysis outlined in Section II were applied to the research fieldwork. The focus is practical, to explain how this research was conducted. Additionally, I explore the methodological and ethical considerations that arose through this research.

As noted, the empirical study design includes two studies focusing on informal communities: an ethnographic observational and a phenomenological interview study. These studies are independent of the other, and thus I have described the methods of each separately.

Ethnographic observation was the method chosen for the first study, in order to observe informal communities in their natural setting of the hospital. Ethnographic methods enable exploration of the complex realities of social practices, through interpreting the nuances of individual behaviour, and the roles and dynamics of social interaction (Walshe et al., 2012). Informal communities have previously not been described in the hospital setting, and ethnographic methods provided access to the hospital space to collect vivid descriptive data describing many such interactions. It enabled a detailed study of the contents, behaviours, roles and dynamics of these interactions as they occurred in reality.

For the second study, a phenomenological approach was employed. This method facilitated access to informal communities through a differing perspective focusing on personal meaning. It enabled an understanding of the diversity of personal experiences of informal communities and the outcomes related to involvement in such communities. Accessing these lifeworld accounts of informal communities would enable us to additionally form an understanding of the structures of these entities, their system elements, as described by Habermas (Habermas et al., 1984). Due to these empirical and theoretical considerations, a phenomenological methodological approach was deemed ideally suited and complementary to the ethnography work.

8.1 Ethnography Methods

The aim of this study was to describe informal interactions in hospital cancer treatment settings: to provide a descriptive account of their contents, dynamics, and the actors, objects and tasks that shaped them.

Design and Procedure

This study was designed as an ethnographical observational study based within a single health service, across a variety of settings where patients with cancer were commonly treated.

Population

This study examined the informal interactions that occurred in cancer treatment settings. It involved patients, staff members, volunteers, family members, and other individuals present in this setting. All participants present in this space were thus the focus of this study. The inclusion criteria involved any of these participants who were involved in interactions that occurred outside of the formal clinical consultation.

The exclusion criteria for this research were any patients or visitors with who the researcher (MG), a doctor, had a clinical relationship. At the beginning of each session of data collection, the researcher toured the space to identify any individuals with who he shared a clinical relationship, with a plan to absent himself if this was the case. These occurrences did not eventuate.

Consent

A waiver of consent was granted by the research ethics committee for this study. All data collected were de-identified and no information from medical records was collected. To inform those participants who were regularly in the spaces, I addressed the staff meeting of each research site prior to commencement of the research. On each observation period, I would greet the available staff members in the staff area to make them aware of my presence and provided time for any questioning. I identified myself as a researcher when engaged in conversation by any individual. This proposal was submitted to the St Vincent’s Hospital Melbourne Human Research Ethics Committee and was granted approval #LNR/17/SVHM/59 (see Appendix 4). This ethics approval application covered both empirical studies.

Setting

St. Vincent’s Hospital Melbourne is a 504-bed tertiary facility in inner Melbourne with a particular focus on oncology, haematology and palliative medicine provision. This hospital does not treat paediatric patients. It operates an oncology and haematology ward, a chemotherapy day unit, a cancer outpatient centre, a radiation oncology centre, and two palliative care wards across two separate sites. It services a particularly diverse population of Melbourne, covering a large proportion of social housing, recent migrants, and both high and low socioeconomic regions.

The study was set in cancer treatment settings in the hospital. This includes the chemotherapy day unit, cancer outpatient centre, oncology and haematology ward, and palliative care wards. The researcher was situated in the 'public spaces' of these settings. This entailed not being within the private spaces of the patients – such as patient rooms or bathrooms. I was able to enter 'staff only' spaces, yet this was done to communicate with staff members about research activity rather than being a vantage point for data collection. From these 'public spaces' in the cancer treatment settings, I was able to observe many of the interactions and activities taking place.

Cancer Centre

The cancer centre comprises of the cancer clinic and the chemotherapy day unit.

Chemotherapy day unit – is a 28-bed open-plan chemotherapy centre adjoined to the main hospital. There are dividers between each patient space, however other patients remain visible, as do any other people walking past. There are also 6 private rooms, though these are rarely used. Each patient space usually consists of a reclining chair or bed, a few chairs for relatives and friends, a television and a small table. Nurses, doctors, administration staff, catering staff, pharmacists, allied health and volunteers are usually present on the unit. It is a busy environment, filled with people and medical equipment. The unit opens at 0800hrs every morning with a staff meeting, with the first patients arriving at 0830hrs. Patients attend the unit at a specified time during the day for their treatment, which may be brief (approximately one hour) or the entire day in duration. The unit closes at 1700hrs daily. I sat observing from two vantage points in the unit: on a couch in the centre of the unit and on a chair next to the window.

Cancer Clinic - This is located next to the chemotherapy unit and is the site for clinic visits for the Oncologists, Haematologists, Radiation Oncologists and Palliative Care Physicians. It has a large waiting room with televisions, a small kitchenette, and a large reception desk for two or three clerical staff. There are six consulting rooms. There is a large central waiting room with seating space for 40 people. Patients and visitors wait in this space for clinic appointments and to be admitted into the chemotherapy day unit. I sat on a chair in the waiting room where other patients and visitors congregated.

Hospital Wards

The sixth floor of the hospital is dedicated towards cancer treatment. It comprises of an Oncology and Haematology ward on the west side, and a Palliative Care ward on the east. There is a large central elevator and reception desk where a ward clerk is often seated from 0830 – 1600 hours. Visiting hours are 1200-2000hrs, but this is not strictly enforced. Primary caregivers are usually allowed on the ward at any time, and will occasionally spend the night with patients, especially those who are particularly unwell or dying.

Oncology and Haematology Ward – is a 26-bed ward comprising of three 2-bed rooms, four 4-bed rooms, and four private rooms. It is situated on the 6th floor of the acute hospital site. Outside the rooms is a large corridor and a series of staff desks, but there is no designated patient space outside of the rooms. This is quite a sterile space, with medical equipment scattered throughout, and patient rooms appearing focused on clinical care rather than patient comfort. During working hours the corridors are filled with staff (nurses, doctors, allied health, cleaners, catering and administration staff), patients and families. On the other side of the corridor are staff specific rooms for storage, medications, utilities, and pharmacy. At the far end of the corridor there is a small couch area and a meeting room with tables and couches. These are often used by staff for meetings or family discussions but may also be used by patients and visitors outside of business hours. I observed from two benches in the middle of the corridor, chairs in the corridor that were situated outside the patient rooms, and non-clinical space at the end of the ward with four couches that was frequently used by patients and visitors.

Palliative Care Ward – is an 8-bed unit adjacent to the oncology and haematology ward on the acute-hospital site, comprising of 3 private rooms, a double room, and a three-bed room. A large corridor with staff desks connects the rooms, and there is an adjoining patient and visitor lounge. I conducted observations from chairs in the corridor.

Hospice

The hospice is a ‘stand-alone’ palliative care unit located 4km away from the main hospital. It is a 28-bed unit, comprising of 6 double rooms, and 16 private rooms. The ward is shaped as a rectangular structure, with a central outdoor courtyard and common area around which rooms are organised. There is a large kitchen and social area at the front of the building where patients and families often convene. There is an adjoining art room and chapel used for daily art activities, church services and as spaces where visitors and patients may congregate or seek solitude. It is situated in surrounding parkland, and to the front and rear of the building there are gardens with outdoor seating and tables. Each room has windows overlooking the outside gardens. Observations were collected whilst sitting in the kitchen area or on chairs situated in the corridor near the central staff area.

Data Collection

Data collection for the study took place from May 2017 until July 2018. Data collection was conducted separately to the interview study. The researcher was present during all periods of the day, on all days of the week. This was only possible on the chemotherapy day unit from Monday until Friday, 0800 – 1700 hours, as the unit was closed outside of these hours. As the focus of the study was interactions, there was a greater focus on those busier times of time when interactions were more frequent. Direct observation periods were mostly short in duration (usually 2-4 hours), as after this time the researcher perceived a diminishing level of concentration and awareness.

Observational data focused on the interactions that occurred, including the context and contents of interactions. This was collected through field-notes: a “gnomic, shorthand reconstruction of events, observations, and conversations that took place in the field” (Van Maanen, 2011) (p.223). This was conducted using a comprehensive note-taking strategy, as described by Lofland and Lofland, in which field-notes are recorded systematically and comprehensively (Lofland and Lofland, 2006). This was to ensure that not only the most noteworthy and interesting interactions are captured, but also the routine and mundane.

Recording of data was influenced by Spradley’s field-note list (Spradley, 2016). This allowed a framework for interpreting the hospital environment, and to classify observations according to the particular categories of data present:

1. Space – the physical place or places
2. Actor – the people involved
3. Activity – a set of related acts people do
4. Object – the physical things that are present
5. Act – single actions that people do
6. Event – a set of related activities that people carry out
7. Time – the sequencing that takes place over time
8. Goal – the things that people are trying to accomplish
9. Feeling – the emotions felt and expressed

Due to the large number of individuals present in many of the treatment settings, observations focused on one or two individuals at one period to ensure that data were recorded systematically. The behaviour and actions of the individuals were observed, with a particular focus on the interactions. In addition to observations, I recorded distinct reflective data to report my perceptions, emotions and interpretations as an ongoing process during data collection and analysis.

The term ‘informal interaction’ was defined to describe that which occurs outside the formal or deliberate discourse of the clinical encounter. On a practical level, there were the formal elements of consultations between health professionals and patients and their families in the clinic, the private practice, the hospital ward; that focused on discussing illness and its consequences through medical frameworks of interpreting health. They were deliberate and enacted a set agenda focused on a medical concern or issue. Informal interactions may occur within the clinical consultation but do so outside of the formalised dialogue and agenda of clinical assessment, investigation and management.

My research positionality was that of a ‘complete observer’ or ‘passive observer’ as described by Gold and Spradley (Gold, 1958, Spradley, 2016). This involved observing and listening, but not purposefully participating or interacting with participants to any great extent. I remained reactive to the environment and responded to interactions from other individuals when prompted. I aligned myself with the role of a ‘visitor’ in the hospital, not actively participating in tasks or interactions, and remaining within public spaces of the hospital. I was dressed in smart casual attire, wore a hospital name badge, and identified as a researcher when asked.

Data Analysis

The fieldnotes were transcribed from paper to word processor software (MS Word v16). Data were collated for each particular timeframe and group of individuals observed, to form vignettes. A vignette comprised of data referring to a specific group of actors at a specific period in time. This definition was based upon the work of Miles and Huberman, who describe a vignette as a dataset with a narrative structure bounded by time, actors or space (Miles et al., 1994) (Labov and Waletzky, 2003). The data were arranged in chronological order and structured to form this narrative flow of events. They were a ‘plain ethnography’, comprised only of the observed account of what took place. It contains the data from the initial fieldnote account organised into a coherent and related report of the events.

Analysis was conducted by all the research team (MG, PK, JP, LD). The analysis was performed over four phases involving all the researchers and performed as a continual and iterative process. We interrogated the data through varying analytical frameworks, in order to question interpretations and identify differing meanings emerging from the data. This approach was influenced by modern qualitative methods, most notably hermeneutics (Coffey and Atkinson, 1996, Carter et al., 2014, Palmer, 1969). The data were interrogated from differing positions, eliciting contrasting interpretations of the data, engaging in a hermeneutic process of iterative meaning constructive (Packer and Addison, 1989).

In the first phase, I presented the vignette to another of the research team (PK, JP, or LD). We discussed possible meanings present in the data and summarised the key ideas at hand. This was a dialectical process, in which assumptions and differing perceptions were questioned and dissected. These processes were cyclical, in which the research team discussed their assumptions, pre-conceptions, and interpretations, which then became the focus of analysis (Laverty, 2003). These discussions were all noted, with this comprising the initial data analysis results. Prominent ideas and meanings were noted and data coded in accordance with interpretations.

The second phase involved analysing the data through an adapted I-poem framework. I-poems are a qualitative research methodology originating from feminist epistemology, in which the data are interrogated through sequential readings to interpret differing aspects of understanding (Edwards and Weller, 2012). It was developed to better interpret the relationships between the participants, researchers and their social realities (Edwards and Weller, 2012). It has been applied to interview data to construct portrayals of the participants' representation of their selves and relationships to social structures (Brown and Gilligan, 1993). It comprised of two phases, the first which constructs a text from the interview transcripts based upon the participants' use of the pronoun "I". As the data did not contain participants' personal representations through interviews, I omitted this phase. The second phase comprised of a four-step process described below, in which the data were explored isolating differing foci. This was conducted by me and the interpretations at each step discussed with one of the supervisory team (Edwards and Weller, 2012).

i. Interpretation of the content and narrative of the vignette. In this step the researchers documented their own intellectual and emotional response.
ii. Interpretation of how the participants present themselves through their behaviours, actions and words
iii. Interpretation of how relationships are represented within the vignette
iv. Interpretation of the structural influences on the context and interactions

In the third phase, the coded data were arranged by the research team into a broad thematic structure. The coding developed from the data were continuous through both frameworks used for data analysis. These formed four broad themes of results. The fourth and final phase involved writing the results. The majority of the data analysis was conducted by myself, with the other researchers being involved at all stages of the analysis processes. Data were predominantly arranged and coded manually on paper. NVivo software (version 12) was used to catalogue data.

8.2 Phenomenological Interview Methods

This study was designed as a phenomenological interview study, aiming to explore the personal experiences, significance and outcomes of informal communities in cancer treatment settings.

Design and Procedure

The population for this study consisted of participants who were patients, staff, and caregivers / family members. These participants were recruited from the cancer treatment settings of the hospital and cancer support groups. Data collection for the study took place from May 2017 until September 2018. This study included participants over the age of eighteen years, able to speak English and provide consent. Potential participants were excluded if they were a patient of the researcher, or staff members who had a direct hierarchical relationship with the researcher.

The participants were recruited from two settings: (i) the cancer treatment settings of a hospital, and (ii) cancer support groups.

- Patients and caregivers – were initially sampled via a convenience sampling, with subsequent purposive sampling based on curative intent of cancer (curative, chronic, or palliative). I approached the clinical staff of the aforementioned treatment settings, requesting if there were potential participants who might be willing to be interviewed. I then approached potential participants to introduce the research, my role, and to gauge interest.

- Staff – were sampled purposefully, to ensure a spread of role (i.e. doctors / nurses / allied health / administrative) and site of work (chemotherapy day unit, oncology ward, PCU). I initially approached individuals to introduce the research and gauge interest in participation. If they demonstrated interest and availability, a suitable time was found for the interview to take place and the PICF provided.

- Support group members – the researcher contacted known cancer support groups via email, and information about the research project was disseminated. I was invited to one cancer support group to speak about my project. Sampling was conducted as a convenience sample. I approached individuals and described the project, and if interested, arranged a suitable time to conduct the interview either in person or via telephone.

A copy of the PICF form was provided and consent obtained. This was written consent for patients, visitors and staff members. For participants from cancer support groups, verbal consent was obtained to facilitate interview over the phone and through email. Ethics approval for both empirical studies was included in the one application. It was submitted to the St Vincent's Hospital Melbourne Human Research Ethics Committee and was granted approval #LNR/17/SVHM/59 (See Appendix 4).

Setting

This study was also conducted at St Vincent's Hospital as described in 2.3.2. The study was predominantly conducted in the cancer treatment settings of the hospital, which have been described in detail in the ethnography methodology.

Data collection

Basic demographic data were collected regarding the participants. For cancer patients, age, gender, type of cancer, and treatment intent were collected. Carers were asked their relationship to the person with cancer and gender. Demographics for staff members included gender and clinical role. Cancer support group member's cancer type and gender was collected.

I conducted all interviews which were semi-structured in nature, adaptive to the conversation and experiences of the participants. An interview guide for patients, staff and carers / family members, and support group members are attached in Appendix 1, 2 and 3. The interviews were audiotaped and transcribed verbatim. These were supplemented by the researcher's field-notes, which were reflective in nature, focusing on the content and context of the interview. These reflections included details of the physical environment and interactions that occurred during the period of the interview. Interviews were not limited to a single person. This allowed for multiple perspectives on a singular interaction, and the varied meanings that participants attributed to these conversations.

The interview focused on the participant's most recent experience of interactions within the cancer treatment setting. The participant was asked to recount this experience, and explore its significance, purposes and outcomes. This was followed by more general questions focusing on the perceptions of these interactions, outcomes, and relation to existing social networks and support. Questioning followed eight lines of enquiry. The data related to each line of enquiry were reviewed throughout the study, and once data saturation was reached on each line of questioning it was no longer included. As a result, interviews in the latter stages of the study were frequently shorter. Data saturation was deemed to be reached when all eight lines of enquiry had been saturated.

Data Analysis

I analysed the data in conjunction with all of the research team. It was conducted as an iterative and multiphase process alongside data collection (van Manen, 2017). The approach was informed by hermeneutic phenomenology, examining the experiences shared by the participants as communicating meaning that was reflective of social and environmental context, and could be appreciated on multiple levels (Laverty, 2003, Penner and McClement, 2008).

Initially, the research team familiarised ourselves with the data. This was performed through listening to and transcribing the interviews, reading and re-reading these transcriptions. All interviews were analysed together, as from an epistemological viewpoint it was uncertain the relevance of these formal role categories in the informal domain. From this initial familiarisation with the data, initial codes were generated. Codes were compared and arranged into groups that shared similarities. The research team then attempted to construct thematic categories that reflected the content of the data. The research discussions and coding arrangements were documented and reflected upon throughout the analysis processes. These processes were cyclical, in which the research team discussed their assumptions, pre-conceptions, and interpretations, which then became the focus of analysis (Laverty, 2003). These processes of interpretation and categorisation of the data were repeated until a structure was formed that represented the data. The resultant structure of the data focused on how participants accessed and experienced the phenomena of informal interactions: the environment, people, content and meanings they derived.

The final stage of the interpretation was the writing of the results. The majority of the data analysis was conducted by myself, with my supervisors being involved at all stages of the analysis processes. Data were predominantly arranged and coded manually on paper. NVivo software (version 12) was employed to catalogue data in the initial coding phase.

8.3 Methodological Considerations

Ethnography and Positionality

Medical ethnography has paid particular attention to the issue of positionality within the hospital environment. In this formalised social system there are few roles available to the researcher: that of the staff member, patient or visitor (Long et al., 2008, Van der Geest and Finkler, 2004). A ‘researcher’ is not a specific role within the social system of the hospital, and thus must fit within one of these recognised social groupings. Whilst an interview study enables clear boundaries to the research process (the interview and consent process), ethnography challenges the researcher to be embedded within the social structures of the hospital.

The role of the researcher must be carefully considered to be appropriate to the phenomena of interest to the research. The interactions which were the focus of this study are often ephemeral, short in duration, and reactive to the environmental and actors around them. It was hypothesised that to best appreciate these encounters the researcher would ideally be fully attentive to the interactions, and presence would least likely influence the surrounding interactions. Spradley’s ‘participant observer’ was described as being present without taking on a particular tasks, allowing the researcher to observe and interact closely enough with individuals without participating in those activities (Adler and Adler, 1994). The role of the visitor confers these advantages to the researcher in the hospital setting and was chosen as most appropriate to the methodology. To take on a ‘staff’ role entails participation in tasks or accompanying those performing these tasks, and thus of formal care provision. It was in this ‘visitor’ positionality that I was able to best observe and record these informal interactions in the space.

The visitor role presents a number of challenges in the hospital space. Access is limited to public spaces, and when in those spaces they are present in a predominantly passive role (Long et al., 2008). The public area is often inadequately purposed for visitors to stay for any period of time, lacking space to occupy, or that does not obstruct clinical care provision. Interactions with other actors in the space are mostly infrequent, as the visitor has no formal purpose in the provision or receipt of health care. Staff have little reason to interact with the visitor unless prompted by the medical needs of the patient. For these reasons the ‘passive observer’ is the natural fit for the visitor role in the hospital space.

Ethnography and Dual Roles in the Research Setting

I chose to conduct this study in a hospital setting where I was also employed as a Palliative Medicine Physician. This was chosen as my position and existing relationships facilitated acceptance of this study by management and clinical staff. My knowledge of the space and clinical procedures of the hospital space enabled a more comprehensive understanding of this environment and the interactions that occurred. It was recognised that conducting research in an environment where I had (i) dual roles and (ii) a pre-existing relationship to the space and (some of) the people had implications. To address these, the study design focused on ways to limit these influences, from practical measures through to data analysis.

As a clinician, my interpretation and classification of the hospital and the people within has developed from my previous exposure, training and frameworks for interpreting illness. It influences many aspects of this research, just as our life history, education and relationships shape our interpretation of the world. This needs to be recognised, however does not diminish the validity of the research. These factors should not be interpreted as only barriers and conflicts, but as part of the rich tapestry through which the life world is experienced. When a cultural anthropologist enters a remote tribal village, their perception is framed through their feelings, personal experience and expectations. Like any researcher, I brought my own personal history to this work. “Feminist anthropology has taught us that we have to be acutely aware of the personal background of the field-worker, and the differences of gender, age, looks and former experience may make when the field-worker tries to find a suitable place and role in the field” (Wind, 2008) p.80). Having such an identifiable personal history and association with the hospital in my role as a Palliative Care Physician challenged me to place greater awareness on the implications of this throughout data collection and analysis (Downs, 2012). The methods employed in data collection and analysis for both studies paid particular attention to these personal influences, to minimise their impact on interpretation.

These relationships and knowledge of the medical language acted as significant facilitators to gaining access to the research setting and trust of the staff members. An understanding of the clinical context of the patients, the interactions, objects and language is facilitated by the researcher's experience as a clinician. Additionally, to place the researcher outside of their usual role invites a new set of perspectives, and to question those perceptions formed through their primary role.

Ethnography and Postmodernism

> *Postmodernists are concerned about the anthropologist's control over the text – the means by which they establish legitimacy as authorities who are describing exotic but nonetheless existing realities. The postmodernist goal is, I take it, to encourage the author to present a less tidy picture… and to encourage the reader to take more responsibility for puzzling out what is really going on (Wolf, 1992) p.53).*
>
> - Margery Wolf, *A Thrice-Told Tale: Feminism, postmodernism, and ethnographic responsibility*

In her book 'A Thrice-Told Tale', ethnographer Margery Wolf presented three different accounts of the same set of events in Taiwan (Wolf, 1992). Each account presented the data in a different manner, and the analysis varied accordingly. Wolf initially first described a fictionalised ethnographic account, followed by a presentation of the 'raw' fieldnotes, and then a more conventional modern ethnography consisting of a refined narrative of events with interwoven analysis and interpretations. Each account detailed narratives that revealed differing discourses regarding the events and uncovered important meanings present in the data. The challenge of ethnographic data is yet another tension between retaining the richness, preserving the methodological rigour, and allowing transmission of the narrative and results to the reader. This is of increasing relevance given our postmodern theoretical framework, to find an approach that illustrates the complexity of the data and the many meanings that it invokes. In consideration of the methodological approach to the ethnographic data analysis, I aimed to maximise transparency of the source data and analysis process, and interrogate these data from differing positions. This section describes the theoretical justification of the methodological approach.

Observational research entails large volumes of data, with likely hundreds of pages of fieldnotes, reflections, interim analyses, and supplementary materials. In qualitative interview research the datasets of words have a set order, temporality, and relationship to each other. This is less clear in observational data, as events and people may be contextually or environmentally linked, yet these are not readily apparent to the reader. Observational data are a rich network of inter-related data as the actors, objects, acts and spaces exist in constant relationship to each other. Organising the data into units that will preserve these relationships is vital for analysis. Observational data are not discrete, and creating groups or subsets are important steps to proceed through analysis.

Observational data “ cannot be pure descriptions of reality no matter who collects them or writes them down” (Wolf, 1992) p.91). Fieldnotes are further informed by other observations, reflections, occurrences that transpire later in the chronology of events, and what is termed ‘headnotes’ – the iterative process of meaning attribution performed by the researcher (Sanjek, 1990). Most commonly in cultural anthropology the various data sources are combined in a narrative form, arranged according to temporal events. There has been considerable and unresolved debate regarding the degree of interpretation and contextualisation in arrangement of these data (Humphreys and Watson, 2009).

There are varying approaches to the analysis of ethnographic data. One such approach is ‘thick description’ as named by Gilbert Ryle (Gilbert, 1971). It is an iterative and interpretive process, aimed at detailing the web of meanings perceived by the participants (Geertz, 1973). This and other constructionist approaches generally favoured by cultural anthropologists seemingly focus on the narrative as an extended dataset that is analysed as a whole, rather than broken down into small ‘data units’. Small sections of data are usually presented to the reader (as quotes or short narratives) that represent analytical themes. For the reader, the process of data analysis from the large dataset and the resulting themes and presented data, is often not transparent nor clearly defined.

On the opposite end of the spectrum is a more targeted approach to the data analysis, with sources (fieldnotes, reflections, interim analyses) analysed separately, with the base ‘data unit’ for theme development being words, phrases, or sentences. These methods may add a perceived rigour of process, however loses much of the contextuality of the data, and diminishes the ease of transmission to the reader. Relying on the source data as an ordered and objective account of events is conceptually discrepant, as the representations made through the words are done so by the researcher and remain subjective representations. The data are systematically coded using phrases or strings of words as the core ‘data unit’, as is common practice in thematic coding of interview transcripts. This approach allows for rigour to be applied to the data analysis process, yet in my opinion diminishes the richness and contextuality of observational data.

In applying these approaches to analysis and presentation of the data, I found both these aforementioned methods ill-suited to the data and theoretical approach. I wished to find an approach that conveyed the richness of the data to the reader whilst allowing for transparency of the data analysis processes. Ethnography has often struggled for validity in the domain of medical research, and I wished for the rich narratives of the data to be communicated to the audience with a consistent and transparent method of data analysis (Van der Geest and Finkler, 2004). The subject matter and epistemology underlying the research is substantially postmodern, and I hope to engage the reader to through exposure to source data, analyses, and to immerse themselves in their own interpretations.

The aim throughout analysis was to retain continuity with the original data, to preserve the temporal, environmental and personal relationships, to facilitate full contextualisation of the phenomena undergoing analysis by the reader. Vignettes were chosen by the research team as the medium to explore, analyse, and present the data.

Vignettes

A vignette has “a narrative, story-like structure that preserves chronological flow and that normally is limited to a brief time space, to one or a few key actors, to a bounded space, or all three” (Miles et al., 1994) p.81). The vignette is a narrative form, and thus comprising of structural elements consistent with a narrative structure (Labov and Waletzky, 2003). To inform this definition I referenced the work of William Labov on narrative analysis, describing a narrative as consisting of a number of elements that provide the reader overview, orientation, complication, summation, and evaluation of an occurrence (Labov and Waletzky, 2003). They enabled the transmission of “rich pockets of especially representative, meaningful data” (Miles et al., 1994) p.81). Vignettes have a long history of being utilised in ethnography as a way to present data to the reader, but to my knowledge not as the data unit for analysis (Huberman and Miles, 1994). The vignettes present a raw and unprocessed depiction of events whilst conveying the rich complexity of the data. Below is an example of a vignette from the ethnography study.

> *A lady walks into the cancer centre waiting room accompanied by two companions and they sit together on the chairs. They enter the room together as a group, with the companions helping the lady to a chair. She is likely in her seventies, dressed in smart clothing, and walks slowly with a mobility frame. She is a patient. Accompanying her is a female translator and a female nurse from the complex care team. The*

nurse walks to the administration desk to announce the arrival of the group to the clerical staff. She then returns to sit next to the lady.

They all sit down together. The nurse says that "It shouldn't be too long", which is translated to the patient in a Chinese dialect. They all then sit in silence and disengage from each other's attention immediately. The patient searches around the waiting room looking at the people within it but does not pay attention to the others in her group. The translator appears quite happy but distracted, looking around the room. The nurse looks at her notes, her phone, appearing preoccupied with other issues and tasks.

They are soon escorted into the chemotherapy day unit.

The ethnography methods section in this chapter describes the data analysis processes applied to the data. For this process we analysed each vignette as a separate dataset and interrogated this through different theoretical perspectives and positionalities. The vignette, formed through the observations of the researcher is conveyed to the reader in its original form, as are the results derived through data analysis. This approach challenges the reader to engage with the data and analysis processes. It invites her to question and challenge interpretations of the data, in recognition of the vital role she, the reader performs in the research process. It is a postmodern approach that invites critical engagement and contradiction.

8.4 Ethics and Approach

The practice of research in the medical domain occurs with many competing priorities, or tensions (Anspach and Mizrachi, 2006). These tensions are heightened in ethnography, when the researcher's aim is to embed themselves into the hospital culture. In an ideal world, the researcher is able to build up strong relationships to support their research: access compelling stories, conversations and interactions; enable the participants to be engaged with the research; eliminate risks for the participants; and, engage in a deep and critical examination of the subject. However, ethnography engages with the messy nature of what occurs in reality (Walshe et al., 2012). It attempts to make sense of life, with the complexity of relationships, differing understandings and actions. It is not a science practised at a distance. The ethnographic researcher embeds themself within the cultural context, shaping the research through their presence within the field and forming relationships with the participants. There are many tensions that may develop through the course of ethnographic research. There were two major tensions that developed through the course of study design and fieldwork, which I will describe in detail: consent in the data collection process and managing my dual roles within the hospital space.

Consent in Observational Research

A considerable tension arising in observational research is regarding consent processes. Firstly, I wish to make clear that I strongly support the underlying principles that consent seeks to promote, such as: involvement in research processes, individual choice, harm limitation, and participation free from coercion. As a process, informed consent is often poorly suited towards ethnographic research. It was originally developed primarily for interventional research, where it is possible to reasonably describe the processes and expected outcomes(Murphy and Dingwall, 2007). It is an individual process, framing research as a set of processes that are limited to the individual, rather than the wider community. However, ethnographic research involves accessing many relationships, and the effects of involvement may radiate beyond the domain of the individual. Ethnography often occurs over long periods of time, in which the focus of the research and the nature of the relationship between participants and researcher may have substantially altered; and, it is unclear how such processes of consent should be applied when the initial terms of engagement in research have evolved. Thus, the processes of informed consent may not be achievable nor be the optimal manner in which to promote ethical conduct in ethnographic research (Bell, 2014).

An additional challenge posed by the consent process in ethnography is the effect on research outcomes. There is considerable literature demonstrating that the behaviour of individuals is altered when they are aware of being observed, known as the Hawthorne effect (Kohli et al., 2009). This was originally observed in factory workers, whose behaviours altered when they were knowingly observed. It has been widely documented in ethnographic research, prompting questioning of the informed consent processes utility and applicability (Lipson, 1994).

This study involved observation of many interactions involving many individuals. It concerned spaces that were publicly accessible, often with many people leaving and entering the space in short periods of time. From a practical perspective, it was not possible to consent every person who came into the space.

The resultant approach resides in this tension. I decided that informed consent was practically not possible, due to the number of people in the spaces who were often there only transiently. Additionally, to consent all these people was expected to alter their behaviours. It was chosen to apply for a waiver of consent for this project. Whilst there was not a specific consent procedure, I aimed to facilitate informing the participants where possible and minimise potential harms related from the collection of data.

To inform those participants who were regularly in the spaces, I addressed the staff meeting of each research site prior to commencement of the research. This initial introduction detailed the research project, methods, providing an opportunity to ask questions, and how individuals could exclude themselves from involvement. On each observation period, I would greet the available staff members in the staff area to make them aware of my presence and provided time for any questioning. At all times during the data collection I wore my identification badge, identifying me as a staff member.

The interactions I observed occurred in the public spaces of the hospital and the data collected were those which were open to witness by any other person in that space. Whilst it was publicly available information, we applied safeguards to it to minimise potential risks related to sharing of that information. The data I collected through field notes contained detailed information regarding the interaction that could be readily observed. I collected very limited data describing the individuals, limited to their identifiable role (patient, staff or visitor), gender, and estimated aged group (expressed according to the decade). For staff members, I omitted the age range, as this had the potential to aid identification. I recorded no potentially identifying data from the conversations, such as dates, personal information, and the names of persons, groups, or specific places. The resultant data richly described the environment, objects, behaviours, dynamics and acts that constituted interactions. It accomplished the aims of the research whilst at the same time, engaging in minimising any identifiable risks to the individuals.

Dual Roles in the Research Space

The role of a health care professional in the hospital is very different from a researcher. This has never been more apparent than our current predicament during the coronavirus pandemic, where most researchers have been excluded from clinical spaces. Health professionals perform tasks that are closely aligned with the primary objectives of the health service, namely the treatment of patients. Researchers occupy a differing status in the hospital wards, as their actions are not focused on short-term clinical outcomes. As such, researchers often occupy a peripheral position in treatment settings, and may find it challenging to gain approval for clinical research or to engage with health professionals. As described in Chapter two, formal health systems operate with dynamics of power structuring the relationships between individuals. The role of a doctor has been reported in many countries to hold significant status, influencing the relational dynamics with other health professionals (Crowe et al., 2017).

I am aware that my role as a palliative care physician at the health service facilitated the acceptance of the project with clinical and management staff.

In the process of data collection in the hospital settings, I implemented criteria to minimise the influence of this dual role. This was important so that individuals: (i) did not feel compelled to comply with the research; (ii) their behaviour was minimally influenced by my clinical role or existing relationships; and, (iii) I was not present in a dual role for patients with whom I had clinical relationship. I was not present in any of the treatment settings where I was currently working, or had worked in the previous two months. If there was a patient I had been involved with in a clinical capacity, I would immediately exit the space. Upon entering the research settings, I presented myself to the staff area, stating my purpose during this period and requested permission to be in the space. In addition, I was reactive to the current circumstances of circumstances of clinical care, exiting the space if there was significant conflict or emotions expressed. For the most part, these circumstances never eventuated, and due to these measures I did not come into contact with patients for whom I had provided care. On one occasion I entered into the clinical space and introduced myself to a staff member who was quite emotional due to a clinical event. I promptly exited the space after asking about their wellbeing.

The staff interviews necessarily took place in the cancer treatment settings of the hospital. Through my periods of ethnography data collection and clinical work, I was known to almost all of the staff who worked regularly in these treatment settings. Thus, I was approaching these individuals with pre-existing perceptions and relationships that likely influenced their decisions to participate and the dynamics of the interview. These were not necessarily negative influences, as familiarity and context knowledge may have facilitated the discussions in the interviews. However, I was attentive that these relational dynamics were not perceived to be coercive in affecting participation or shaping responses through the interview. For this reason, I did not seek the participation of those with who I had a formal hierarchical relationship, or were currently engaged in some form of ongoing clinical relationships that may be influenced these dynamics, such as: those I had directly supervised, or currently worked with routinely in delivering clinical care.

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Chapter 9

An Ethnography of Informal Communities

This chapter details the results of the ethnography study. The first section focuses on the 'research field', describing the environment and the place of the researcher within. This is a familiar approach to ethnography research, as the environment and individuals who occupy it provide the context to interpreting the research results. The following four sections discuss the major themes which emerged as the results of this work: roles in the hospital space, multiple discourse, presentations of self and fluid communities.

As noted, the presentation of the results employs vignettes to present the observational data and frame the results. Accompanying these vignettes are our interpretations based on these data. In this manner, I am hopeful that this manner of presentation of results will engage you – the reader - to challenge or disagree with our interpretations, or engage in your own analysis, thus contributing to the hermeneutic research processes.

9.1 The Hospital Space

The space of the hospital is unique in our cultural context. Social identity and signifiers are stripped from the individual patients, and their treatment and location of care is assigned according to disease status. Staff and visitors are similarly affected, confined by uniforms, hierarchies, and restrictions on behaviour and access. The hospital is focused on illness, and care processes deal with it methodically, through a range of formalised tasks.

I am sitting on a bench in the corridor on the oncology-haematology ward. The bench is in the centre of the ward, adjacent to a number of patient rooms (both private and shared), two staff desks, and the pharmacy room. The corridors are busy with nurses, cleaners, groups of doctors, a few nursing students, and the odd clerical staff member walking around checking odd things. Patients remain mostly in their rooms, except to emerge to visit the bathroom, physiotherapy or a self-directed walk around the ward.

The corridors are wide, sparse, decorated with harsh and sterile colours – cream and grey, with some indiscriminate use of wood. Large bright florescent lights are everywhere, creating the sense that it could be day or night outside. The patient's rooms are semi-camouflaged, with obscuring blinds hiding most of their inner contents.

The bench I sit on is very uncomfortable, made of linoleum with minimal cushioning. The linoleum is unfriendly to touch, similar to the other surfaces in the space, however they share a similarity of being easy to clean. There is little that is soft or comforting to touch. The bench is the only place to sit in this corridor, however I still perceive being in the way of the staff.

There is the constant drone of purposeful chatter and the hammering of keyboards, which create an aura of utility to this space. I can hear dry-retching which seems natural in this environment – no one notices. It is in fact a cleaner, not a patient. A group of cleaners audibly complain about the horribleness of the smell that caused it – from the patient bathroom – from what appears to be a large faeculent event in the toilet. I smell a faint odour of faeces after a few minutes, and by this time no one seems obviously perturbed, or to notice. This smell is in stark contrast to the more powerful fake-floral/chemical smell of cleaning products that is similarly offensive.

This study occurred within three distinct areas of the hospital as previously described in Chapter eight: the cancer outpatient centre, an off-site hospice, and the acute hospital: containing the oncology, haematology and palliative care wards. These environments are all distinctive, but the general appearances are in many ways interchangeable, with the same colours, textures, objects, uniforms, signage and medical jargon filling the space. The elements that provide distinction are partially related to the design, and partly to what fills the space: the objects and people.

The acute hospital spaces are all relatively modern, having been built or renovated around the same period in the last twenty years. Whilst there are differences between the specific hospital spaces, their elements that are homogenous throughout. The colours that adorn the space are mild and inoffensive shades of light blue, grey, yellow and off-white. The floor is covered with thick linoleum or industrial carpet squares, and is cleaned at minimum daily. Light fills the spaces, yet much of this is artificial from the large number of fluorescent lights on the ceilings. There are windows, which are primarily adjacent to the patient spaces, which may look out over a variety of scenes, from parklands to an adjacent building wall. The walls are mostly bare, except for the occasional notice board, and the patient cubicles and rooms that have fixtures for oxygen and electricity points. The spaces are sparsely filled with clinical objects. The rooms and spaces are large, yet there is minimal space for people to coalesce, apart from the busy corridor, a small lounge area at the end of the corridor, and two rooms that are frequently used by the staff for meetings.

> *I am in the hospice, sitting in the lounge area next to the central courtyard. There are many visitors most of whom reside in the rooms of the patients, as I understand a few patients are in the terminal phase.*
>
> *A man in his 60's, casually dressed, meanders from one of those rooms around the lounge area. He is apparently lost in thought, taking little notice of the nurses and other people who walk past him. There is a large unfinished jigsaw puzzle next to the couch on a table, which catches his attention. He wanders over and examines it, then starts to pick up the pieces and attempt to add to the unfinished work. It is a communal work, where each person may contribute their piece. The jigsaw stands out as an object that has no medical value, yet occupies prime position in the ward.*

The off-site hospice inverses the distribution of space, with narrow routes of access and larger patient and public spaces. It is designed in a rectangular shape, with a central courtyard in the middle, and gardens to the exterior. There is a wealth of public spaces including a central courtyard, a kitchen, a large multipurpose room, a chapel, a lounge area and outside gardens. The majority of patient rooms are private and much larger than the acute hospital, allowing more space for visitors and personal objects. The hospice is not austere in its presentation despite a similarity in colour pallets and interior design. Paintings hang on walls, a radio plays music softly, and importantly patients and visitors are visibly occupying the public spaces.

The cancer centre is a contrasting space, in that the divisions between public and private spaces are less apparent, allowing for public flow of conversation and interactions. The chemotherapy chairs are arranged in open-plan design that allow for the easy flow of conversation between cubicles, yet with the option of being able to draw curtains to limit involvement. Public spaces include two kitchens, a lounge area and waiting room. There are a small number of private rooms for clinic appointments and in the chemotherapy centre. It is a densely busy space during operating hours, as the majority of cubicles are permanently occupied by patients and accompanying visitors, and nurses, doctors, allied health, administration, catering and volunteers are in constant motion traversing the milieu.

Divisions of Space

> *A lady in her 30's and small toddler wander around the oncology ward. He is very happy and inquisitive, as he searches around the spaces of the ward. He is unaware of the divides in space and his status as a visitor in the environment, as he enters patient and staff rooms, and attempts to grab medical objects. His mother attempts to control his wandering, chasing after him into the patient and staff rooms, directing him back to the corridors. The patients in the rooms he invades are seemingly delighted by his presence, waving, saying hello and smiling. The mother is far less enthusiastic, somewhat embarrassed by his transgressions.*
>
> *The mother is acting as a guide, restraining him to the 'visitor space' of the corridor and the patient lounge. Throughout the evening they occasionally do a lap of the ward, and then retreat to the patient lounge – a safe space, away from objects and environments they should not access.*

The spaces in each area of care can be roughly divided into three types: the public space, the staff space, and the patient space. This division is evident throughout the entire hospital. Staff have access to all areas, and patients to their own and public space. Visitors are the most confined, able only to access public areas during certain times of the day, and requiring the accompaniment of a patient when accessing their (the patient's) area. This public space was where I was present for the duration of this project.

> *A man in his forties sits in the kitchen area of the hospice. It is late morning on a Wednesday, with the early morning busy period having finished as the staff occasionally visit the kitchen for a cup of tea. The man is a visitor, and sits behind a computer at his table.*

He walks over to the kitchen bench to warm up his lunch in the microwave. A female nurse who is known to him comes over to the bench and says hello as she makes a warm drink. They start discussing the patient who the man is visiting, who appears to be under the care of the nurse this morning. The visitor controls the focus of the discussion, and asks about what care and food was provided to the patient, No medical information is disclosed. The conversation ends amiably after a minute, when the nurses drink is complete.

The nurse unit manager wanders into the kitchen shortly after to also make a warm drink. She and the male visitor start talking, asking about each other's days. It remains a superficial social conversation, lasting a further minute.

The man returns to his table to eat his lunch. He makes a phone call, in which he details the recent developments regarding the patient, relaying some of the information conveyed by the nurse. During this conversation other staff and visitors enter and exit the kitchen area, exchanging greetings with each other.

The public areas of the hospital represent the environment where the unplanned and informal intersect with formal care tasks. Whereas formal consultations and planned care tasks occur in the clinic and patient rooms, and staff engage with each other in the staff offices, the public space does not have the same direction of purpose apparent. It includes the transition spaces of the hospital, the corridors, entrances and elevators that are used as access routes by everyone. During daytime hours, these areas are busy with many individuals comprising many roles, and are in many ways are chaotic and disorganised. People do not move linearly through these spaces. Rather each moves according to their own functional ability and purpose. Others are stationary. These are unavoidable spaces that allow, and at times enforce, unplanned interactions. In more colloquial terms, they represent the 'melting pots' of the hospital.

The divide between the public and patient space is frequently ambiguous. This is most apparent in the chemotherapy day unit, which is unique in the lack of barriers between the private and public. There are curtains surrounding each cubicle, yet these are rarely drawn. Curtains are limited barriers, as they do little to diminish transmission of sound and when open are not readily visible as a boundary. The cubicles are small and close to each other, so that conversations are conducted across the hallway, and private interactions are readily overheard. The nurses move through the space engaging in multiple conversations with the patients and visitors, entering many patients' areas. The same behaviours visible when entering a patient room are not followed, such as knocking or requesting permission to enter, possibly due to the lack of physical barriers.

This ambiguity is present in the other spaces of the hospital, yet not as readily apparent. There are physical barriers, yet few of the rules of the space are explicit, such as who can access the space, and the rights they may have to use of objects (i.e. use a microwave to warm food, of occupying a desk in the corridor). For the individuals new to the space, this can be difficult to navigate, as it is not specified which areas they are able to access. Other actors are unaware of these divisions of space, and mistakenly transgress. The space and its division contribute to order behaviour in an implicit fashion.

Objects

The objects that adorn the spaces are similar in design and uniformity. Even the objects without a clear medical purpose, such as couches, chairs and tables, are designed according to the practicality of the environment. They are designed with the exacting sameness, use of beige and off-white colour tones, and an ease with which they can be cleansed and moved. Each allotted 'patient space' in the inpatient unit, whether it be a private or shared room, is fitted with the same objects: a motorised hospital bed, a bedside table, curtains surrounding the bed, a chair, a built-in cupboard, a table on wheels, and wall fittings for oxygen and power points. The chemotherapy unit uses these same objects, but in most chemotherapy cubicles a red reclining armchair replaces the bed.

Dress is an object of similar conformity in the hospital spaces. Patients in the inpatient units are invited to dress in hospital attire, which are unflattering and purposeful in design. They are light blue, green or white in colour, and sit on large shelves around the wards next to the sheets. This attire is transient, inhabited by patient after patient, and without identifying features to distinguish differences. The hospital dress is not required dress, and many patients choose to dress in their own clothes, in particular those who have been admitted for longer periods. There are other signifiers of patienthood that are apparent, those more obvious being intravenous cannuli, wheelchairs and mobility aids, dressings and bandages, and the 'IV pole'. There are those less apparent signifiers such as the compulsory wrist-tag or the wearing of slippers, that allow the staff and those more familiar with the hospital to identify patients.

> *I am sitting at the hospice in the kitchen. From here I can see into one of the patient's room which is open. Inside there are a number of people, the patient is on the bed but I cannot see her fully, A young man in his 20's, a female in her 20's, and another lady in her 60's all sitting on chair arranged around the bed and a*

table. All are dressed casually, in jeans and jumpers. A cat jumps all over the chairs and table. The table is covered by food, books, and the usual objects that would be expected scattered across a kitchen table.

It is a scene that appears transported from a suburban kitchen. the visitors dress and act as if they sit in that kitchen. They move through the space, interacting with and rearranging the objects, rather than being stagnant. They slouch in the chairs, play with the cat, open the door to the outside garden, and pick at the snacks.

The visitors come out to the kitchen a half hour later, sitting around a table next to me. Their demeanour is altered from the laid-back affect seen whilst in the patient room. They talk in hushed tones about how the patient is currently: "She is barely awake, not talking." they convey a worried and sad affect, conversing slowly and sparingly – seemingly preoccupied.

The few personal or non-clinical objects in the space are mostly owned by patients, consisting of clothes, books, magazines, photos, drawings, flowers, and electronic devices such as phones and computers. There is minimal space for these objects in most rooms in the acute hospital, as personal belongings are given little space to fit within a bedside table and a small cupboard. These objects are transient, disappearing as patients are discharged. These personal objects are important elements of the space, providing differentiation in the environment, and are representations of the social identities of the inhabitants. It is common to see scarves of football teams, drawings by grandchildren, hand-made quilts with historical significance, and favourite and well-worn dressing gowns adorning the rooms and patients. Staff exhibit similar yet more modest exhibitions of self-identity, in the forms of a small badge devoted to a particular cause, a small piece of jewellery, or a minor yet not insignificant alteration in the way they present themselves in uniform.

There is malleability to the space. All the objects are able to be rearranged, repurposed and redesigned. This malleability is furthered by the transient nature of its inhabitants, who temporally occupy the rooms and cubicles. The patient rooms are the most evident in this regard, as they change in accordance to the occupants, family members and visitors, and the medical and social factors. The medical purpose of the rooms may have its clinical qualities moderated through changes of the space and objects. Beds are covered with homely quilts, friends and family occupy chairs and the bed, walls become decorated with photographs and children's pictures, and music and laughter fill the quiet surrounds. The bland aesthetics of the space enable this, as those unique elements present in the space – the people and the personal objects – assert themselves and the influence of the people who own them over the space.

Time

Time in the hospital space is significantly altered. During both day and night the corridors are filled with the same objects, the constancy of people (even staff who change as individuals yet are omnipresent as a cohort), and acts are repeated through the same tasks. Whilst the lights in the rooms turn off overnight, the corridors of the hospital are constantly illuminated by the abundance of fluorescent lights, creating an atmosphere of eternal daytime. Clinical tasks continue irrespective of time: the patients woken for observations and medications, nurses writing notes and assisting patients with transfers, and the scene of a dozing patient is present during both business and resting hours. These are constants, yet they are constants that are distanced from the rhythm of life at home. The routine of life on the hospital ward is structured by health care provision, with set times for meals, ablutions, visiting, sleep and medications.

Time influences the actors in a variety of ways. Patients have an over-abundance of time, and limited numbers of activities to fill it. Staff have a shortage of time, seemingly rushing from task to task, yet limited control of how this time is spent. The visitors are constrained by the time they are able to spend in the hospital, yet once in the environment this time is devoted to the patient. Time is a significant influence on the behaviours in the hospital space, and instrumental towards facilitating or negating interactions. For patients, considerable time is spent in the act of waiting, unable to leave the area as they may be shortly summoned or be attended to by staff, yet lacking any substantial activities to occupy them other than a television, an old magazine, or the company of others. Staff are predominantly focused on accomplishing their set clinical tasks, their actions and interactions mostly purposeful with a desired outcome, in order to maximise efficiency of that time. Like the patients, they do not own this time. There is limited autonomy over what activity they may conduct, as they are guided by their functioning as part of the care team.

While patients seemingly have an abundance of time and few activities to fill their days, this is frequently in contrast to the temporal reality for the patients. For many, due to the effects of cancer, time may be very limited, in particular for those on the palliative care wards. Time is an increasingly valuable commodity for these people, yet the hospital system fills this time with few elements of value. This similarly affects visitors, in particular those who attend their family or friend at the end of life. These people frequently spend many days waiting by the patient in the knowledge that death could occur at any time, yet it does not.

The Position of the Researcher

> *I am sitting on a couch in the chemotherapy day unit with a book in my hands. An art therapist who I know sits down opposite me and begins to place her knitting supplies on the coffee table. We talk briefly about her impromptu knitting classes she has begun here.*
>
> *A lady in her 50's or 60's, dressed in smart casual attire comes over to look at the knitting. She doesn't appear to be a patient. She starts talking to both of us, sits down, and begins knitting with the supplies lying on the coffee table. She displays a mastery of knitting, and takes on the role of a teacher as she demonstrates to the art therapy student a few tips and tricks.*
>
> *The lady starts discussing her family, in particular her grandchildren. She displays a very happy affect and is obviously proud of her family and her skill in knitting. She pulls out her phone and shows us some of her knitting creations whilst telling us the stories of who and what inspired them. They are all stories of the lives of her family and friends, and the gifts she knits for them. I look at the pictures of the intricate toys and garments she has made and we talk for about 20 minutes about them and her family. After this time she departs happily. None of the conversation detailed anything about cancer nor did it touch on why she was in the chemotherapy centre.*

The role of the ethnographer in the space is not static. The researcher is both observant and participant in this space. I was situated as a passive observer, however interacted with the space and actors consistently throughout my time in the environments. These interactions were predominantly brief and non-verbal, but through my presence in the space I was likely an influencer of the events that occurred within it. This was a reciprocal relationship, as I was inversely affected by the surrounding environment. This complex relationship between researcher and the researched in ethnography is well established and of significant importance. It places the researcher beyond the role of data collector and analyser, to be also a data source and influence. This is a relationship of complexity yet does not diminish the rigour of the data. It emphasises the requirements for clarity and transparency of research processes, and examination of the complexity of these influencing relationships.

In the knitting circle described above I became an active participant. The lady changed her actions as a result of my presence, describing stories of her experiences and showing photos of her creations. She shared intimate details about her family members. She shared these details of her volition, as I did not actively pursue any line of questioning. Despite this aim of passivity, I was actively altering what occurred around me.

The ethnographic researcher is immersed within the research data and remains an active force despite whatever degree of passivity is aimed for. Even in those vignettes where I was situated on the periphery of the space, I remained an influence. Despite how small that influence over other actors may be, the relationship remained. It is a complex relationship, acting not only as a barrier to the use of objects (i.e. the chair I sat in) or to intimate conversations in my vicinity, but potentially a facilitator of other visitors or patients feeling more comfortable, occupying the spaces and filling them with their own interactions.

9.2 Roles in the Hospital

The cancer treatment centres of a hospital are visited by many individuals: patients, doctors, nurses, visitors, volunteers, allied health, administration staff and many others. The structural elements of the hospital system further reinforce these role behaviours. The environment is divided between areas over which different roles have varied degrees of access. Uniforms and implicit standard of dress provide readily interpretable role identities and denote expected behaviours relative to that identity. This is further enforced for patients with noticeable stigmata of illness, such as IV poles or wheelchairs, who may be further limited in their activities: by staff, physical environment or illness factors. Language and knowledge exaggerate these role differences, enabling those with command of the medical dialect and scientific terminologies to actively engage in the medical discourse.

Roles are a set of patterned and characteristic social behaviours which are assumed by participants in a particular social situation (Biddle, 1986). Structural functionalism views roles as being systemically enforced through shared, normative expectations of conduct for the individual. The individuals within the social system are expected to interact within a set of constrained behaviours towards a common standard, in order to maintain the structure of the system (Parsons, 1991). Thus, roles are the product of the social system rather than the individual, who may be socially conditioned to act within such a role. In the hospital environment, ethnographic literature has described three broad roles each with their own tasks, responsibility, levels of access and use of discourse: staff, patients and visitors (Van der Geest and Finkler, 2004). Within these broader groupings there are more specific roles available, such as the senior doctor, the nurse, or the cleaner.

This theme describes how the individuals in cancer treatment settings enact informal interactions with respect to their formal roles. These roles may have a limiting effect, potentiate informal discourse, or individuals may choose to act entirely outside of these roles. It encompasses four subthemes: adherence to formal roles, negotiating role and influences, assuming other roles, and acting outside of roles.

Adherence to Formal Roles

> *Mr C, a man in his sixties dressed in smart casual attire is sitting in a cubicle of the chemotherapy day unit. He sits on the reclining chair whilst eating some food. When I arrive he is having a long chat with a female nurse who is sitting in the chair beside him – Nurse A. It is obvious this is his first time here by the content and tone of conversation. The nurse is providing the 'introduction talk', starting with an introduction about the chemotherapy centre. She progresses to talk about practical issues about the chemotherapy treatment: what to expect as effects of the chemotherapy treatment, who to contact if issues develop, and phone numbers for cancer centre and after-hours.*
>
> *The nurse then describes what might be expected over the coming few months and the issues that other people frequently face. It is not a medical discussion but more focused upon personal challenges that might be expected or possible in the months to come. She attempts to integrate this information to be personally relevant for Mr C. The man is quite passive in discussion, affirming the points made by the nurse with simple answers of "ok", and "yes". He has a nervous affect throughout these discussions, constantly moving around in the chair. He does not ask any questions of the nurse, or direct the conversation in any way. The discussion concludes after approximately thirty minutes, and the nurse leaves.*
>
> *Shortly afterward, a female catering assistant walks past Mr C to offer snacks. The man declines politely and offers no further conversation.*
>
> *Nurse A returns to start the chemotherapy. It seems that the patient has thought over some of the contents of the previous discussion, and asks a few questions around practical matters. "What will it feel like? What happens if I need to go to the toilet?"*
>
> *The nurse unit manager walks past and introduces herself to the patient. "How are you? Where are you from? Did you have any questions about your chemotherapy?" she asks. The man keeps all the answers*

> *very brief and factual, and does not volunteer any questions of his own. He appears nervous during the exchange, fidgeting in his seat.*
>
> *Once the chemotherapy is running, after ten minutes he rings the 'call bell', and another nurse attends. "Can I go to the toilet?". She disconnects him, and he tentatively walks to the toilet.*
>
> *He returns to the cubicle and is reconnected to the chemotherapy. However, in a further fifteen minutes he requests again to go to the toilet. Nurse A attends and disconnects him, asking how he is going. His reply is short, saying "I am alright." He ambles tentatively again to the toilet, avoiding eye contact with the other individuals in the room on his way to the bathrooms.*

The strict adherence to formal role behaviours is most visible in the newcomers to the space. They are frequently more accepting of the conventions and dress of role, the use of space, and less likely to engage in interactions with other actors beyond those that occur as part of care provision. Individuals new to the space explore and interpret the environment and meanings present around them. The language of the hospital presents challenges, as new patients may struggle to understand the medical discourse, may be unsure how to respond to social interactions, and lack the experience and etiquette to request further explanation. This may be amplified by a range of other factors, such as a recent diagnosis of cancer, the physical effects of cancer (which may potentially include fatigue, nausea, anorexia or pain), and perceptions of the effects of chemotherapy. Mr C acts passively in most of the interactions, unsure of the rules of the space and the other people who inhabit it.

After delivering the information about the practical and medical aspects of treatment, the nurse discusses its experiential effects - what might be expected of his lived experience over the coming months, adopting the same colloquial language Mr C uses in his questions. These may be attempts by Nurse A to minimise imbalances in power: the nurse sits next to Mr C at the same height, medical information is delivered in common language when possible, and relates the information to his personal situation. Whilst she does not venture outside of her role as a nurse, there are elements of her behaviours that are malleable in response to the patient. This flexibility is likely in response to the nervous and anxious affect demonstrated by Mr C. The delivery of information is done in an approachable form, kept quite simple to be easily interpreted. This might provide an opportunity for Mr C to participate in this discourse and reduce uncertainties regarding the large quantity of information that he likely received on his first day in the chemotherapy unit. The demeanour of the nurse portrays calmness and reassurance, in direct contrast to that of Mr C who is visibly nervous. The relatable nature of the narrative and behaviours communicated by Nurse A offers Mr C a common ground in which to interact. Mr C remains anxious and fixed within the limitations of his role as a recipient of care. He remains mostly passive in conversation, and the questions he asks convey this uncertainty.

A female nurse enters a single room on the palliative care ward at the acute hospital. Inside, a male patient in his seventies is lying in bed in his hospital gown, covered by sheets and a blanket. She announces her intent to measure the patient's blood sugar levels and uses a small device to 'prick' his finger to test the level. She does this quite briskly and purposefully, without any social discussion.

Five minutes later she re-enters his room, telling the patient about the need for him to order his meals. She hurriedly reads out the menu options and fills the order form with his assistance. The patient seems to struggle to grasp all the menu options due to her speed.

Once the menu form is complete the nurse attempts to exit the room. However, the patient has a number of questions about how he is feeling, his medications, and what to expect in the coming days. These questions are quite indirect and vague, delivered in colloquial language. The nurse becomes somewhat bothered by these questions. She dismissed them, stating that she has other tasks to finish, and leaves the room. The patient remains in his bed, appearing both uncertain and annoyed.

This encounter occurs with the nurse enacting fixed role behaviours, focused on the resolution of formal care tasks. There is a disconnect between the ability of the patient to engage as a participant in the ordering from the menu and the nurse's intentions for this to be completed. The patient initiates a discourse to clarify a number of issues, and delivers these queries in an indirect manner, using non-medical terms. He describes how he is feeling as a narrative - a story of his symptoms.

The nurse is unable to interpret the narrative presentation of symptoms and questions of the patient. The patient is unable to address these concerns in a manner that is accessible to her medical frameworks of understanding. As a result, there is a conflict in discourses, culminating in annoyance of both parties. The nurse appears unable to engage outside of her formal frameworks of interpretation and task-focused behaviours. The nurse in this scenario was not a novice, however, her behaviours appeared fixed to her formal role and terms of engagement.

Negotiating Roles and Influences

> *A young man in 30-40's (Mr J) lies on a hospital bed in the chemotherapy day unit. He is bald, covered by the sheets, with seemingly little energy. He creates the impression of someone who is very unwell.*
>
> *Mr J grabs the attention of a passing staff member, a female administrative staff, asking about his medical treatment. This woman is unable to answer his questions, and he appears visibly displeased and anxious.*
>
> *A female nurse then shortly attends to the man and apologises at the delay. The man expresses his concerns about the lack of information and disorganisation. Another female nurse then joins at this point, and both nurses become firmly focused on medical needs: taking his blood pressure, temperature, and looking at his notes. The patient seems relieved by this attention, and the nurses question his recent symptom issues.*
>
> *His temperature is high. The nurses call a doctor, who attends within a few minutes. The female doctor enters and immediately asks a multitude of directed and short questions about specific health issues. There is a further flurry of activity, as another female doctor and nurse join in the encounter. Each has their own task: writing notes, taking blood pressure, taking blood, asking questions and examining the patient. Throughout this intense activity the man plays a mostly passive role, answering directed questions or being involved only in a physical sense in the activity (i.e. taking blood).*
>
> *As these events progress, he becomes noticeably calmer. His initial line of questioning has yielded the desired result. This is despite him gaining less attention throughout the interaction, as the staff become increasingly focused on their tasks.*
>
> *After approximately fifteen minutes, the two doctors then address him again, telling him he needs to be admitted, and then disappear. The nurses continue to write notes and organise paperwork, continuing to be in his physical space but not interacting with him. Mr J is now calm, relaxing underneath the sheets, and does not seem to be inviting interaction.*

In this vignette medical issues suddenly took precedence, each individual focusing on their specified tasks: a doctor examined and directed treatment, one nurse took blood, another scribed notes, and another organised practical aspects of care via the telephone. The informal interactions that predominate the chemotherapy day unit were suspended, replaced by an overwhelming focus on formal tasks. In this scenario, the patient became increasingly passive in this interaction. His physical body was the focus of the emergency: it was measured, examined, punctured, and was the topic of conversation and decisions. The patient as a social being was of limited relevance.

This shift to formal role behaviours involved changes in content, roles and context occurring within the framework of the interaction (Goffman, 1961). The patient was a participant of the situation he confronted, and his behaviours adapted in response. The reduction of the patient to a physical body is not solely a consequence of the medical frameworks of illness and formal role behaviours of the staff. The patient played a key role within this encounter in bringing attention to his health concerns. This may have been achieved through enacting a more formalised patient role, or illness behaviours. Through his interactions, he was able to cause a shift to establish or re-establish the focus on the formal domain, to focus on his physical body and its symptoms. This was reinforced by the staff, who further instrumentalised his self and confirmed the validity of these concerns through further assessment and tests. The resulting outcome was positive for Mr J, in that his affect becomes calm and satisfied, and he was no longer requesting the attention of the staff.

Approximately 20 minutes later Mr J remains lying in bed, as the nurses around him organise practical tasks. He is visibly relaxed now, but somewhat disengaged from what is happening around him, almost dozing in bed.

A male nurse attends him to place an intravenous cannula, and there is little conversation. After the cannula has been placed, Mr J starts talking to the nurse. He sits up in the bed and becomes quite lively. Both the men are of similar ages and appear to be quite friendly with each other. I cannot hear all the specific words of the conversation but it appears these involve discussions about their families.

The nurse lends Mr J his mobile phone so he can call his family to explain what is occurring.

Before calling them, the conversation becomes more serious. Mr J's affect changes from the friendly and social demeanour, to one of worry and concern. He asks the nurse what this illness might mean: "I'm not well though?"

> *The nurse replies to him using colloquial language, describing that it is uncertain what it means. Mr J appears to appreciate his candour, looking slightly more relaxed. He makes the phone call using the nurse's phone and talks softly to his family.*

The acute episode of care had concluded with the instigation of an appropriate management plan for Mr J involving admission to the hospital. He was noticeably relieved, and his physical health status was of decreasing focus. Mr J engaged with the nurse, who shared a number of similarities of age, gender and a young family. The interaction shifted in focus, and as the need for medical attention receded, the personal impacts of his illness became more apparent.

The narrative of Mr J evolved throughout this vignette, and through it the role behaviours and relationship with the nurse. The interaction was initially formalised, in which Mr J played a more passive role as the intravenous cannula was placed. Superficial social engagement then developed, which soon became more substantial. Their shared social identifiers and narratives were likely catalysts for this development, as they both shared similar stories of their young children. The language was in narrative form, relating to their experiences and the lives of their families. For the most part it was an exploratory discussion, with neither participant controlling the flow. The roles these two men inhabited transitioned outside of the formal behaviours of their status, to an interaction that is social in nature and lacking medical frameworks of interpretation.

The conclusion to the vignette demonstrated a further development of the relationship, beyond normative social interaction. Mr J described his concerns, which were now focused on the effects on his social self and family. He attempted to make sense of the medical information provided earlier and apply it through his frameworks of interpretation, focused on meaning for himself, his family and his future. The following discussion was of significant intensity, in which Mr J revealed his distress. The nurse replied to this distress by communicating openly and in the language of the patient, recognising this same uncertainty. The nurse did not attempt to medicalise or solve this distress. Such attempts would have risked reinstating formalised role behaviours and medical frameworks of interpretation. The nurse's response provided the answers Mr J required for the phone call to communicate to his family, even if that response was neither positive nor definite. This interaction occurred outside of formal role behaviours, and it is likely that if these were employed they may have been an impediment to finding a satisfactory resolution.

Assuming Other Roles

> *It is a quiet evening at the hospice. A man in his seventies emerges from a patient room, wearing jeans and a polo top – Mr CC. He has been at the hospice for the majority of the day. He enters the staff area where three nurses are sitting on chairs talking about social events. All the nurses know him, greet him and continue with their conversation as before, now with Mr CC included.*
>
> *He tells them he is departing for the evening, and the current condition of the patient – his partner. He gives a brief summary of how she has been over the past few hours. "Thanks CC, safe travels home." the nurses reply.*
>
> *He leaves the building, after saying goodbye to the nurses. It is similar to the manner in which the nurses depart at the end of a shift, handing over responsibility for care of the patient to the next nurse. His interaction with the nurses was purposeful in the way Mr CC delivered it and contained factual information with a set end-point.*

Many individuals in the hospital existed between roles. The male visitor was taking on much of the formal roles of the nursing staff, potentially a similar role to what he inhabited at home. He was engaged in providing care, monitored the patient's needs, acted as an advocate, and reported her progress to the nurses. The man joined the nursing staff within their space and the information he provided to the nurses was perceived as valuable by the nursing staff. The interaction mirrored the 'hand-over' procedure that occurs between the nurses at the end of each shift, conveying useful clinical information and change-over of responsibility for patient care.

Interestingly, it was Mr CC who was the more purposeful in the interaction, while the nurses focused on social topics of engagement. It likely signifies Mr CC as being different in this community. His purpose and tasks focused primarily on his partner - the patient – differing to the roles of the nurses who exist in professional distance to the patient. His ability to function as part of this community was likely dependent on the context, and that he would not be welcome if discussing the care of other patients, or personal matters of the staff. Like the community, the individuals within were fluid, having both formal and social roles with identities outside of the hospital. It appears Mr CC was the person least focused on this social persona, instead concentrating in these interactions on his role in providing care for his partner.

It is mid-morning at the hospice. Mr CC enters the staff area where the nurses are all gathered. They all know him and welcome him in the space. "I am going to go, she looks quite peaceful." He provides a report on how the patient has been and the care he has provided. His language is very factual, similar to what a nurse would report during handover.

"Do you want to give her a kiss?" The nurse looking after this patient asks as he leaves.

"I won't be that long" the man says as he walks away. As he walks away he becomes uncertain, and visibly saddened. After some contemplation he turns around and walks back to the room. His affect changes noticeably, from the purposeful carer to the emotional and frightened partner.

A minute later he leaves the building briskly, a look of discomfort on his face.

This second vignette involving Mr CC demonstrated a similar interaction, in which he 'hands over' care to the nursing staff. He delivered his 'handover' using the language of the nurses, using the word 'peaceful', a term common to the medical personnel.

The question of the nurse prompted Mr CC to query his competing demands: that of the caregiver and someone who might be expected to receive care - a partner of a patient who is dying. He functioned in the space within both roles yet was focused on the former. It was likely the nurse's question regarding the kiss was a reminder of his role as partner. This identified the complexity of his roles in this space. This may have been to encourage his emotional comprehension of her deteriorating state, or in response to his encroaching role behaviours. The nurse may also have done so instinctively, recognising that it may be his last opportunity given her death was soon to be expected. These vignettes of Mr CC illustrated the complexities of roles in the hospital, and the communities that the individuals exist between.

Acting Outside of Roles

> *In the cancer centre waiting room, an elderly male patient stands at the small kitchenette. He appears very frail, with a significant limp. He makes a cup of tea with difficultly, finding it challenging to balance and use his hands. He looks as though he is unwell, with all his attention concentrated on the task at hand.*
>
> *A male nurse walks past and says hello. The demeanour of the patient changes dramatically, as he smiles broadly and stands upright. It appears they know each other well. The man replies with a joke, which is slightly sarcastic at the expense of the nurse. They engage warmly in a conversation full of humour, in which they talk about football and their life outside of the hospital. They continue talking in the waiting room for about 5 minutes without any sign of time pressures. They then walk out together to the chemotherapy day unit. The frailty of the man seems far less evident, as he talks enthusiastically and smiles.*

The elderly gentleman initially appeared unwell, yet through engagement with the nurse demonstrated a self that was not frail. He was lively, humorous and engaged, a social being rather than an unwell patient. The nurse similarly demonstrated his social self, disengaging from task-focused behaviours ruled by time pressures and openly discussed elements of his life external to the hospital. Both individuals noticeably enjoyed and gained pleasure from this relationship, one that appeared to have developed over a substantial period of time. This exchange occurred in the middle of a waiting room, overheard by many.

There appeared to be a performative aspect to the patient's behaviours, potentially in defiance or rejection of his physical state. The expectations of the role of the unwell patient were in contrast to his social and lively affect. He did not require or ask for assistance, or talk about his illness and health concerns. Through rejection of expected role behaviours, the social identity of the man was seemingly more explicit. His positive and exuberant affect was exaggerated by the physical fragility.

This could be interpreted in two ways. Firstly, it may be a rejection of his failing health status and wish to exhibit that this is not the case. Secondly, it may occur in continuum with physical frailty, but as a readjustment of priorities. Those friendly, caring and joyful relationships may have been of greater importance to the individual than the focus on the physical self.

9.3 Multiple Discourses

Conversations form the most apparent aspects of interactions. The words and the language, context and frameworks within which they occur are thus of particular importance. These are not homogenous. Due to the vastly differing experiences, training and roles of the individuals in the hospital the use of language varies significantly. The differing patterns of use of communicated language occur in association with related constructs and context: a discourse. The work of Michel Foucault outlines this premise of discourse as “ways of constituting knowledge, together with the social practices, forms of subjectivity and power relations which inhere in such knowledges and relations between them” (Weedon, 1997) p.108). This definition informed the understandings of the use of language within informal interactions (Foucault, 1972).

In medicine, commonalities of language and frameworks of meanings are used to convey information and knowledge, thus resulting in the medical discourses (Wilce, 2009). Arthur Frank writes that “folk now go to the paid professionals who re-interpret their pains as symptoms, using a specialised language that is unfamiliar and strange” (Frank, 2013) p.5). Multiple other discourses also occur in this setting, constructed upon cultural history, spirituality, personal history, frameworks of understanding, and experiences of cancer. Within a single interaction there may be multiple discourses involving the same topics, yet differing considerably in the way these topics are perceived and the meanings interpreted by the individuals involved. Cancer as a subject may have many parallel and opposing discourses, based on experiences of culture, knowledge, medicine and personal history.

Narrative is a form of discourse, defined by William Labov as the acts relating to the communication of past events (Labov, 1997). Roland Barthes presents a more diffuse understanding, incorporating all those communication forms and compositions which detail elements of experiences (Barthes and Duisit, 1975). Narrative may relate to events, real or fictitious, and frequently is structured by the chronology of events and the relationship of these events to the storyteller. As with human experience, the meanings inherent within the narrative may be unclear, yet to be dissected, or evolving (Genette, 1983). Narrative is an important form of discourse, as the major medium used by participants in the informal domain as described in Chapter four.

This theme is divided into three sub-themes: mismatches of discourse, complementary discourses and connecting through personal experience.

Mismatches of Discourse

Mr JK - a man in his early fifties sits on a hospital bed in the chemotherapy centre. He is of African descent, and sits on the bed in casual clothes appearing relaxed and interactive. He is accompanied by another man of African heritage who sits next to him, talking in a foreign language. They have the television turned on, with the programming in English.

A female nurse introduces herself to the men and discusses what the treatment today will involve. The interaction is pleasant and purposeful, as the nurse directs the conversation. A male nurse joins to help set up with chemotherapy. He doesn't converse with the men, instead talking with the other nurse. The topic of their conversation is recent social occurrences, and the men appear to listen to the conversation between the nurses.

A catering assistant offers food to the men, who politely decline. Mr JK's visitor soon leaves, so that he remains alone in the cubicle. The television remains on, but his attention is drawn to watching the interactions occurring around the room. He begins to rearrange his bed and asks one of the nurses for a blanket.

A second female nurse approaches Mr JK shortly afterwards. She asks about his financial situation. This is not well received, and he becomes defensive: appearing concerned and uncertain, retreating behind the blanket. He provides sparse factual information to the nurse. The nurse continues her line of questioning, asking specific details about sources of income. Mr JK evades this line of questioning, instead telling a story of his desires to return to work. The nurse interrupts the story, attempting to gain specific answers to her questions. At this point Mr JK dismisses the questions and concludes the conversation through lying down in the bed under the blanket. Both he and the nurse do not appear happy with the result of the interaction, Mr JK appearing somewhat angry as he lies in bed.

The interaction between Mr JK and the last nurse occurred in differing discourses. The conversation focused on Mr's JK's finances, a potentially delicate topic. The nurse focused on the task of gathering the specific information that was important for her role, which targeted objective information about income, savings and employment. She did not provide a background context to these discussions to support her reasons for questioning, leading to ambiguity as to her intentions and the consequences of the discussion. Employment, professional roles and income may be a significant influence upon self-worth and image. During cancer this self-perception may be significantly altered, as normal activities are disrupted through cancer treatment (Frank, 2013). This may be more pronounced in cultures where the masculine role is closely associated with financial provision and security for the family. The interaction occurred in a public area, which many other people including myself could readily overhear, covering a topic that is frequently of a private nature.

The discourses of Mr JK and the nurse occurred in relation to each other, yet they failed to find commonality. The initial purposeful questioning of the nurse was met with a defensive affect from Mr JK, as he appeared uncertain of the reasons to discuss his financial situation. In many contexts, health care is not by provided a public system, and finances may be the major factor in determining care provision. To engage in discussions regarding finances may be perceived as oppositional, asking the other participant to defend their financial position and their ability to provide for family. Mr JK attempted to provide a contextualisation of his finances, through a narrative form which took into account other related elements, such as employment, relationships and the cancer treatment. This form allowed Mr JK to display the continuance between the financial queries and his identities as cancer patient, provider and professional. The nurse was unable to comprehend this narrative account to her questions and instead returned to her discourse, interrupting his narrative in the process. The discursive mismatch appeared to become conflictual at this point, as Mr JK appeared unhappy, and disengaged from the conversation.

The narrative relayed by Mr JK was an unhappy one. A diagnosis of cancer and subsequent treatment, lack of employment, possible financial hardship and related psychosocial sequelae was likely to be markedly affecting his perceptions of self, mood and relationships. Such a theme of conversation might have provoked unhappy or protective attitudes that reflected the current situation. As such, providing a context as to the reason for discussion and other influences on his personal situation may have allowed for an understanding of his predicament, enabling the participants to find convergences in their purposes and meanings.

Complementary Discourses

> *A lady in her late sixties walks around the oncology ward with a physiotherapist. She looks unwell, appearing quite fatigued as she noticeably struggles for breath whilst walking slowly. Her face and arms are covered with dry and loose skin, with several dry lesions covering the arms. She is dressed in a mixture of hospital and personal clothes, covered by a tracksuit top that is far too large for her thin frame. The physiotherapist is a young man and walks beside her through the corridor of the ward.*

After walking approximately fifty metres she stops to catch her breath, and then sits down on the bench. The physiotherapist congratulates her on the walking and asks about how her legs and breathing feel. He receives no response as she focuses on her breathing. After a minute, he sits down beside her having noticed it is taking her a while to recover.

Once he is seated, she starts telling him a story. She remains short of breath and talks in short phrases. She talks about how her breathing feels when she does certain activities, and how this makes her feel: scared, anxious, helpless. She talks about how she deals with this. The conversation occurs as a story, and she controls it, performing it in her time. She smiles and appears relaxed as she tells the story, in contrast to the issues she describes.

This vignette involved two differing discourses focusing on the same issue of breathlessness. The physiotherapist initially enquired about the lady's breathing difficulties but failed to receive an answer. Her functional ability was a significant influence upon this, as it was likely that she was unable to converse at this time due to her breathing. When she was able to engage with the physiotherapist, it was on her terms and in her words that she described her experiences. In contrast to the somewhat impoverished account of breathlessness that may be available through the medical discourse, she provided an account that described the complex nature of her bodily and emotional experiences, suffering and social effects. The description was in narrative form, in which she was at the centre of the story and its meanings. Through story telling the woman was able to convey how her breathing and body felt as a result of her illness, and how exertion affected her further. Her discourse described the experience of illness as inseparable from her personal story and physical body. These two discourses did not appear conflictual.

Interestingly, the patient expressed an affect that was contrasting with the content of her narrative and physical status. She smiled throughout her story and engaged warmly with the physiotherapist as they sit together on the bench. Meanwhile, the content of the narrative described disability, and physical and emotional distress. Within this interaction there were a number of aspects that might have influenced her cheerful affect. The physiotherapist interacted warmly with her, sitting next to her, and provided her ample time to describe her experiences with interruption. 'Feeling listened to' – particularly in the acute hospital environment – can be of significant value when many of the interactions occurring are brief and task-oriented. The interaction was on her terms, and she was able to construct a narrative as a complex and social individual. The narrative she presented was one of perseverance despite the challenges, enabling her to demonstrate that her struggles with breathlessness engendered both positive and negative outcomes that were linked to her own personal narrative. It suggested that the act of interaction provided value beyond the conversing of words and information.

Connecting Through Personal Experience

> *In the hospice, a man sits in one of the common spaces on a chair – Mr P. He is a patient, likely in his late sixties, and dressed in hospital clothes. He does not appear obviously unwell, as he energetically watches the interactions occurring around him.*
>
> *A female social worker enters the room and says hello. She introduces herself and he immediately recognises she is Greek. He starts speaking a bit of broken Greek and they both laugh. He talks about how he spent some time living in Greece many years ago. The social worker sits down and they both share tales about their lives and families in Greece.*
>
> *Mr P starts to talk about his wife and family in Greece. These are sad stories and he is crying as he recounts them. He describes his sadness from these stories of the past, his regret, and how this impacts his current state of mind. The social worker keeps listening as he tells these stories, not trying to steer his story in any particular way. He talks about his current predicaments and his cancer, and how he feels in response to this.*
>
> *He soon comes to conclude his stories. By now Mr P's sadness has gone and he is noticeably smiling. His affect is not happy, yet is warm in the manner in which he interacts with the social worker. As he concludes, the social worker offers him a cup of coffee. She quickly leaves the room, then returns with the cup of coffee and says 'thank you' as she departs. Mr P replies to thank her, and looks content and relaxed as she departs.*
>
> *She walks past the nurse looking after Mr P, saying "what an interesting man". She similarly appears affected by the interaction, smiling and content. The entire interaction occurred with the social worker saying very little apart from responding to the man's story. The interaction took approximately fifteen minutes.*

This interaction was short in duration, yet conveyed a significant amount of personal and emotional information. It occurred all within the use of narrative discourses from both parties. Mr P and the social worker began the conversation through sharing stories of their lives and families in relation to Greece. The shared similarities of their personal stories allowed a commonality of meaning. They established a number of personal commonalities: their Greek ancestry, language, food, culture, family and children. The conversation quickly progressed to a very intimate one, as Mr P detailed profound insights and regrets. This intimacy was likely made possible through the sharing of personal narratives by the social worker.

Narrative offers the opportunity to convey the personal and the social, and find convergence with other individuals. It allows the sharing of selves to form deeper bonds. The medical discourse does not facilitate such sharing of personal meanings, and actually mitigates against doing so. The sharing of personal stories enables the construction of shared meaning and commonalities, and creates the possibility for the interaction to progress to something more profound.

It appeared a positive emotional response came from this interaction, as witnessed through the warm and relaxed manner visible at the conclusion of the interaction. This was evident in both individuals. This was likely facilitated by the commonality of meaning, that allowed them to convey emotions within the construct of the stories. In the medical discourse, this might be termed a ‘therapeutic benefit’. The social worker makes a statement summarising the encounter to the nurse: “what an interesting man”. It conveyed her respect and recognition for Mr P as a person rather that only a patient, and her pleasure at sharing in and being a part of his story.

> *Sitting in the chemotherapy centre, a conversation occurs behind on a wall which I hear but cannot see. A female patient is talking to a female nurse. The patient seems somewhat apprehensive in initial conversation as she describes how she has been feeling lately.*
>
> *The nurse mentions the symptom of diarrhoea. The nurse describes a recent experience of illness to the patient. She describes a detailed story of her recent bout of diarrhoea, how unwell she felt, and how it affected her ability to function as a parent. The story is quite embarrassing.*
>
> *The patient laughs at the story and shares her own similarly embarrassing diarrhoea story. They continue laughing through the patient’s story. They continue talking about their respective lives as mothers – trying to look after children and work. The conversation is relaxed, warm and funny, as they talk about their similar lives and challenges.*

The patient is relaxed as the conversation becomes more social then concludes. The nurse leaves to check on another patient.

This vignette demonstrated a convergence of discourse through the use of narrative. The patient appeared somewhat anxious and not keen to fully engage with the nurse. The nurse changed her approach, sharing her own personal story. In sharing an embarrassing tale regarding her diarrhoea, the nurse placed herself outside of the expected role behaviours of her position. It demonstrated vulnerability and portrayed her other roles as wife, mother and occasional patient. It was well received by the patient, who responded in kind with her own personal experiences. These narratives allowed a sharing of common meanings, identities, and engender a positive emotional response.

When health professionals engage in a narrative discourse it may take them beyond the expected behaviours for their role. This was seen in the behaviours of the nurse, who shared a very embarrassing story. This may have been a positive contributor to engagement, diminishing the barriers of role constructs and conveying similarities of personal identities with non-professionals. It also may present challenges. Behavioural expectations for health professionals exist in tension between the safety of professional distance and the perceived need for connection and solidarity with patients and visitors. However, engaging in the narrative discourse is not synonymous with boundary transgression. The preceding vignette of Mr P and the social worker detailed a profound interaction where personal histories were shared respectfully in the context of the interaction.

9.4 Presentations of Self

Individual engage in interactions through enacting a self, comprising of both the physical body and a social being (Merleau-Ponty, 2006). Symbolic interactionism has highlighted the active nature of the individual in controlling the presentation and enactment of the self in accordance with social circumstances (Goffman, 1978, Blumer, 1994). This is of particular importance in hospital environments, where structural influences have an impact upon the physical body, role behaviours, methods and contents of discourse. In illness, the physical body receives increasing attention and may be of greater influence on the discourse and the manner in which individuals present themselves.

Behaviours may reveal, hide or explicitly mislead important aspects of the individual’s self. Erving Goffman’s works on symbolic interactionism (see Chapter seven) informs this interpretation, describing that individuals present differing aspects of their self and activity to others, and guide the impressions that are formed about themselves (Goffman, 1978).

This section takes a different focus from the previous theme describing roles. Roles are expected norms of behaviours and manners of presentation within a social system, as a structural element to allow these systems to function (Baker, 2006). They do not describe the individual but the social system. Presentation of self is the manner in which the individual presents themselves through their interactions. These may be aligned with a specific role (i.e. a nurse), but may also demonstrate subtitles reflecting a personal history, as well as understandings and significance of the actions of those around them.

It is important to address the notion of identity in this work. I have not engaged with this term as observational data are likely insufficient to engage with a concept that encompasses deep personal history, social and cultural development, understandings and relationships (Bauman, 2001). The literature focusing on the concept of identity is broad, with numerous postmodern theorists questioning whether such a notion reflects the evolving and multiple nature of self in society (Bauman, 2001, Schachter, 2005). Instead, I have focused on the manner in which the individuals present their self through their actions, behaviour, affect, words, dress and the manner in which they are situated in the world.

This section describes three subthemes that emerged from the results: the normal self, the self with cancer, and the potentialities of cancer.

A Normal Self

> *A young man - Mr SW - in his thirties walks into the cancer centre waiting room. He is tall, very skinny, and looks somewhat unkempt in a tracksuit and a wispy beard. He walks slowly with a painful limp, using a single-point stick as support. He looks tired and in discomfort, but he smiles at the people around him as he takes a seat. He is accompanied by a female in her thirties – his partner (Miss SW) - dressed colourfully in a smart summer dress. She talks loudly to Mr SW, and appears outwardly full of energy and a positive affect as she smiles.*
>
> *Mr SW walks over in my direction to collect something to read. He slowly walks past me, and I realise that my leg is obstructing the way through. "Excuse me", he says politely. "Oh, sorry" I reply. "Can I help you mate?" I ask as I see him beginning to collect the newspaper.*
>
> *"No, it'll all be good" Mr SW replies. He slowly bends down on one knee, unsteady and in obvious discomfort. He can barely reach low enough to grab the newspaper. After about 10 seconds he manages to grasp the paper, and slowly rises back to his feet, still in pain. He walks back to his chair with a pronounced painful limp. He intermittently scans the newspaper without turning the page and occasionally talks to Miss SW.*
>
> *A lady sitting next to Mr SW drops all her papers – which appear to contain medical documentation. She is sitting in a wheelchair and is likely in her late sixties. Miss SW immediately jumps up to help. She bends down to pick up all the papers, and talks loudly to the lady whilst doing so. They laugh about all the paperwork at the hospital, appointments and transport issues. The lady is very thankful to Miss SW, and keen to keep on talking.*
>
> *Miss SW disengages from the conversation to ask how Mr SW is. He provides a minimal answer. They both sit in silence appearing pensive and concerned for the next twenty minutes until their name is called by the doctor. Their affects changed markedly since their entry into the room. In particular Miss SW, who changed from a positive and energetic affect to tense and worried.*

Mr and Miss SW portrayed juxtaposing behaviours in this vignette. These demonstrated differing aspects of their selves: well and unwell, able and disabled, exuberant and concerned. Mr SW appeared physically unwell with his cachectic frame, antalgic gait, and use of a walking frame, which was matched by his unkempt appearance. This appearance contrasted with Miss SW, who was wearing a bright stylish dress that matched her portrayed energy and smile. Mr SW's affect demonstrated conflicting realities, as he engaged in loud social conversation and read a newspaper, yet struggled to walk. Miss SW continued similar behaviours as she interacted with the lady in the wheelchair.

These behaviours displayed by Mr and Miss SW appeared to have a significant performative aspect. The context of their situation was serious, a young couple, one of them with cancer significantly altering his function and appearance. This illness was disabling and pain invoking, yet Mr SW attempted to maintain activities of his pre-morbid state, despite my offers of assistance. The act of reading a newspaper appeared largely symbolic, an act associated with wellness and potentially his 'healthy self', rather than 'the unwell'. Mr SW's portrayal was marked by the limitations of his physical self and appearance, which he was unable to alter. Miss SW's smart and vibrant appearance complemented her energetic interactions. As the vignette progressed, it become increasingly apparent that these were front stage representations. These presentations may be further influenced by their age appropriate behavioural norms of wellness, independence and sociality.

The conclusion of the vignette demonstrated acts from both Mr and Miss SW that are more in keeping with the context of their situation. They sat together in silence, with only small amounts of rather tense conversation as they waited for their appointment. The time waiting likely exacerbated this consternation, with the possibility of bad news being delivered this consultation.

Mr and Miss SW portrayed conflicts in the manner in which they presented their selves, behaviours that were embedded in their youth, health and potential, disrupted by the realities of cancer. Mr SW bore the physical stigmata of his illness, which he was unable to hide, further interrupting his portrayal of his independence. Miss SW's portrayal of exuberance and sociality was in tension with the context of the hospital visit. In her work on identity in spinal cord injury, Yoshida presented this tension as the view of 'the former self' (Yoshida, 1993). It "represents patterns of action, conviction and habits built up over the years…after illness, resuming these patterns becomes the person's major objectives" (Charmaz, 1987) p.302). These were common presentations in younger patients with sudden alterations imposed by illness, such as in spinal cord injury (Yoshida, 1993). For Mr SW, the continuation of these activities of his previous self may have allowed this continuance, and portrayed to others that he remained able, in continuance with his youth and masculinity. The influences of Miss SW behaviour were complex, as she was entangled in Mr SW's portrayal, wanting to present a strong and young self, to have control over her future, yet constantly reminded of his serious illness.

A Self with Cancer

> *Mrs Z lies in a bed in the chemotherapy day unit, receiving chemotherapy. She is likely in her late sixties, dressed in casual clothes, and appears to be an outpatient. She appears quite tired, lying semi-reclined in her bed supported by pillows. Mrs Z doesn't read or watch television, but occasionally scans the room to watch the people around her.*
>
> *After approximately half an hour by herself, a female nurse comes over to disconnect Mrs Z's chemotherapy, and asks how she is. Mrs Z starts talking slowly. She talks about food, detailing her recent experiences through the difficulties she faces with eating and preparing food. These stories describe her love of food, favourite meals, relating these to current issues of cancer and chemotherapy. They involve her family, describing how they have helped her lately: "I get my son-in-law to make up little kebabs for me."*
>
> *The nurse listens to Mrs Z's stories and replies sympathetically: "Everything's a learning experience at the start." The conversation soon ends as Mrs Z ceases her stories about food. Once disconnected she rises slowly from the bed and collects her belongings.*
>
> *The patient next door and a companion walk past Mrs Z's cubicle. They all say goodbye to each other. Mrs Z walks in a fatigued manner towards the door, with all her focus on her ambulation. She passes the nurse, and with effort says "See you tomorrow", as she leaves.*

This lady was unwell, as was evidenced by her affect, fatigue, use of a bed instead of a chair, and slow verbalisation and ambulation. She was able to engage with the environment according to her abilities, mostly through passive means as she watched the occurrences around her. Yet she engaged actively with those around her when able, and controlled the discourse when interacting with the nurse. Her illness was apparent through those interactions, in the affect she presented and their content.

Mrs Z’s portrayal appeared to have little frontstage component. Fatigue, functional limitation and illness stigma were visible in her affect, and she made no attempts to hide or diminish them. Her behaviours portrayed elements of a social being, through her interest in watching and interacting with others. It may be interpreted that in the ‘unwell patient’ the ability to engage in frontstage behaviour is reduced. Those performative aspects of behaviour may become increasingly difficult to maintain due to the fatigue or the imposition of physical signs of illness into their affect. The ill person may have diminished control over the physical body and increased stigmata of illness, through medical attachments, mobility aids, clothing, disfigurements and physical signs. Yet, these tensions between the illness and the presentation of the self may be more subtle. As seen with Mr SW in the first vignette in this theme, it may limit activities they might engage in, or lead others around them to assist in this portrayal.

The lack of a performative aspect to Mrs Z’s behaviour was supported by the narrative she presented to the nurse. The narrative focused on food engaged with many aspects of her being. It was a topic in which she expressed significant interest and likely some expert knowledge of. Through this she discussed her recent issues with eating, their relationship to the chemotherapy, and her symptom issues. The topic of food connected her illness, aspects of her culture, social self, relationships, and personal history. It encompassed a continuity between all these elements of her being that related to her current self-expression.

Mrs Z presented a self that was congruent with her diagnosis of cancer. This interpretation was formed through two aspects of her behaviour. Firstly, the expressive behaviours she presented, in which there was a continuity between her active and passive selves. Secondly, and likely of greater importance was the relationship of cancer to current narrative of self. Mrs Z illustrated many meaningful aspects of her life in her family, her love of food, her expertise as a cook, and her culture. Cancer was embedded and related to these notions. She presented a self which was congruent with her diagnosis of cancer through these behaviours and use of discourse.

Potentialities of Cancer

> *A young male patient in his thirties walks along the oncology ward corridor. He is dressed in hospital clothes, with an intravenous infusion running and attached to a mobile stand that he walks with. He walks briskly down the corridor, appearing somewhat agitated.*

He approaches a male nurse on the ward. "Is there somewhere I can do yoga here? I am feeling trapped here." The nurse replies positively, and quickly goes to check the spaces where this may be possible. Unfortunately they are both occupied at the present time. The nurse communicates this to the man expressing his sympathy.

"I am trapped in a room with a guy with half a face", the man exclaims. The nurse talks to the man about the other options at the moment, and when the rooms might be available. They talk in colloquial language. He doesn't attempt to probe the man's distress or use medical language.

The male patient appears happy with these options discussed with the nurse. He leaves the conversation with a far calmer affect, walking down the corridor at a relaxed pace.

The individual's experience of cancer comprises of the past and present, and the potentialities that may occur from cancer. Within the hospital environment, the individual comes into contact with many other people with cancer. Through witnessing and learning of others' experiences of cancer, this opens up potentialities, some positive and others negative. These experiences may evoke re-evaluation of concepts and understandings of cancer, and how it relates to their self. This may instil new knowledge and create disruptions as to their perceptions of cancer and relatedness to the self.

In this vignette the young man had cancer. Whilst he carried many of the physical stigma of illness in his dress and intravenous appendage, he did not appear physically unwell and was still able to participate in yoga. He vocalised and exhibited distress at being in the hospital environment – 'feeling trapped'. A major influence was the appearance of another cancer patient 'with half a face'. This appearance was likely distressing due to a number of factors: the sympathy he may have felt for this other person, and the sight and potential odour of such physical disfigurement. There was potentially a significant reflexive component to this distress, in that both he and this other man were afflicted by cancer which manifests in differing ways. Thus, these phenomena disrupted his own understandings of cancer as it related to himself, provoking potentialities of cancer that seem in conflict with, and more distressing than his current conceptions.

The notion of 'feeling trapped' suggested a current loss of control. The act of yoga was likely an enabler of control, a manner by which he was able to bring elements of his life external of the hospital into this environment. He recognised his own distress and engaged in health promoting behaviours in response. He was able to articulate the causative factors, the condition, and presented a management plan to the nurse. The yoga was his treatment, his manner of engaging with and managing his distress. This behaviour suggested significant insight into his condition.

In this respect, yoga represented a bridge between the formal and informal provision of health care. It is a practice which has outcomes aligned with health (and is used for a range of health issues), yet in this scenario was practiced independently by the patient but within the hospital environment. The response of the nurse recognised the distress of the man but did not medicalise it. Presentations of psychological distress in the hospital would commonly lead to further questioning through medical frameworks, and classification of depression, anxiety or suicidal risks. The nurse instead reacted sympathetically and assisted the man in accomplishing his informal management plan. The man reacted positively to the nurse's approach, appearing noticeably calmed after the exchange.

This vignette is illustrative of the tensions that cancer may manifest upon perceptions of self, exacerbated by the hospital environment. Many cancer patients may find connection with other patients in the manner in which they present their selves as individuals with cancer. Cancer may be a central narrative in their relations to other individuals and the hospital space. For some, it may comprise elements that are central to their perceptions and presentations of self: as a cancer survivor, 'a fighter', or a non-professional who is very knowledgeable about cancer and shares that knowledge with other patients. Yet the concept of cancer and its relation to the self is in constant evolution, as the cancer is removed, goes into remission, recurs and progresses. The experiential learning that all patients engage in as they occupy the hospital environment presents the cancer of others in many forms. Thus, the perception of a familiar cancer may be instantly disrupted in this environment, filled with distressing potentialities.

9.5 Fluid Communities

The research has thus far focused on individuals engaging independently in interactions, and the particular influences and behaviours that occur in these actions. The presentation of the resultant themes has focused how individuals enact roles, discourses and presentations of the self. This may have suggested that these experiences as individualistic, comprised of people acting as distinct entities however influenced by the behaviours of others. I hope to shift this perception, and through this final theme complete the picture, describing how these phenomena occur within networks of relationships, of communities.

This theme describes results fitting within three subthemes: social communities, communities of learning, and communities of support.

Social Communities

> *It is mid-morning at the hospice, and three female nurses are gathered in the staff area. They are focused on clinical activities. As one of the nurses reads the medical notes of a patient, she realises that it is the patient's birthday. She tells the other nurses, and they decide to all visit the patient together. They tell a few other staff who are nearby: a physiotherapist and an administration assistant. They all go to the room of the patient.*
>
> *A female patient in her eighties sits on the side of the bed in hospital clothes. She is surprised as the group of five staff members enter her room and start singing 'happy birthday' loudly. The singing is loud and can be heard throughout much of the hospice. A few staff members and visitors walk past to check on the situation, and all seem to react happily.*
>
> *The patient sings along and smiles broadly, once overcoming her initial slight embarrassment. Once the song finishes the staff all stay in the room and asks her familiar birthday questions. Who is coming to visit? What presents does she hope she will get? They make jokes about looking far younger than her age. They all laugh together as they engage in these familiar acts. The patient engages enthusiastically with the birthday rituals, smiling as she enjoys being the centre of attention.*
>
> *The staff slowly leave after about ten minutes. The patient sits on her bed, smiling happily. I overhear a few volunteers talking in the background about baking her a birthday cake for lunch.*

The familiar cultural ritual of 'happy birthday' is commonplace around the world. The act of singing together and associated high jinks are a routine experience within family, work and social networks. In this vignette the staff members and patient were all immersed in this familiar interaction, and in doing so engaged outside of their usual roles in the hospital. The patient became the focus, the social epicentre of the interaction, and expressed her shared embarrassment and delight at the attention. It was a significant shift from her usual daily activities and interactions of being a patient. The interaction followed a familiar structure which enabled the individuals to disengage from the serious nature of their work and engage in the silliness that can be the ‘happy birthday’ ritual. This interaction shifted the frames of reference, as all were immersed in the activity as “some kind of exclusive solidarity and permits them to express relatedness, psychic closeness, and mutual respect” (Goffman, 1961) p.37).

The effect of this engagement on the patient was substantial, as she demonstrated a change in affect and behaviours. She shared this moment of cultural celebration with individuals who related to her in formal provision roles, yet she was the centre of attention for non-medical reasons. There was a juxtaposition between the serious nature of the hospice environment, and the ritualistic high-jinx and poor singing involved in the traditional birthday celebration.

The delight demonstrated by this lady was difficult to translate through an observational account. A patient sitting on a hospital bed seemed suddenly transformed into young exuberant birthday girl, who sang, laughed and smiled in abundance. She discussed thoughts of presents and birthdays past with a childlike enthusiasm. There was perhaps an added poignancy in that it was implicitly understood to be her last birthday. Her delight may have been influenced by the historical nature of the interaction, reminding her of many other birthday celebrations. For this period, the external influences appeared to diminish in importance, and the lady was able to fully engage with these familiar elements of her life that obviously bring her joy.

Engaging together within this shared encounter was representative of many aspects of community. These liquid relationships, like the evolving roles the actors inhabit, enabled this transient yet poignant community to appear(Bauman, 2013b). It was a community that existed only in transition, as the actors were likely to never assemble again in the same form or terms of reference. Yet for those moments, these people created something that transitioned away from their pre-existing roles and meaning frameworks.

> *Sitting in the waiting room of the chemotherapy centre, a couple in their sixties – a male and female - sit opposite me. They talk happily and quietly amongst themselves in a Chinese dialect, smiling on occasions. They are both dressed in smart casual attire and appear physically well.*
>
> *A lady in her sixties who also appears to have Asian origins sits nearby and joins in the conversation after about five minutes. They talk together in the shared language. The conversation becomes louder and more*

> *animated, with all three people laughing and smiling. I cannot interpret what is being said, but it appears to be social and all participants are enjoying the interaction.*
>
> *After about five minutes the couple are called into the consulting room by the doctor. They bid farewell to the lady happily. The lady remains in the waiting room, waiting for her own appointment, returning to silently watching the room.*

The individuals who inhabit the hospital may share many commonalities: of experience, cultural history, or personal interest. This may not seem immediately apparent, as the inhabitants of hospital rooms are determined primarily by their pathology and disease status. In the cancer centre and on the oncology ward, the diagnosis of cancer is an a priori influencer of the inhabitants, either as a personal status through being a patient, or as a carer or relative who have been affected by it. Cancer's effects disperse beyond pathological status, comprising of commonalities of experience, knowledge, and potential challenges. Additionally, it embeds all these individuals within common spaces and practices, and networks of relationships with the staff members. It was likely that two differing patients in the waiting room have attended the same computerised tomography (CT) machine for their scan, talked to the same administrative staff at the reception desk, eaten the same hospital biscuits, worn the same patient wristbands, and answered the same questionnaire when being admitted. These shared experiences and frames of reference may enable relationships to form. The waiting room or any other hospital space is one comprised of individuals who are influenced and confronted by a similar set of experiences.

This vignette described a brief interaction that occurs in the public space of the waiting room. It was friendly and cheerful, occurring between two groups of people who seemingly had no previous knowledge of the other. They shared the commonality of language, and likely shared cultural understandings and history. Underlying these identifiable traits were the implicit illness and treatment factors. The milieu within which they were embedded contains many commonalities and influences that may facilitate interaction and provide meaning through which to converse. Goffman describes the presence of multiple similarities as enabling interactions to take place, which he describes as the "flooding in" aspect of the engagement; a facilitator bridging the different parties to engage over a commonality (Goffman, 1961). In this setting, the shared language allowed the opening of dialogue, in addition to the shared environmental and illness influences. There may have been other local and personal facilitators: a prolonged waiting time, an anticipated good result on a test on behalf of one of the patients, or a friendly staff member. These interactions were far from random, constructed upon the many influences of personal, environmental and structural factors.

This brief encounter did not exhibit any profound qualities or functions. The ensuing conversation was likely of a social nature. It may have formed the initial step of relationship development as they continued to meet through treatment, or it may have been their only interaction. It illustrated an interaction that occurred within the milieu of many influences and networks of relationships. Whilst language and culture may have served as the spark to facilitate the conversation, these individuals were a priori embedded within a relational and meaning structure. In their interaction these three individuals formed a community constructed upon commonalities of culture and illness. However, prior to this interaction they equally existed with a larger community connected by the shared relations and meanings of cancer treatment.

Communities of Support

> *It is Sunday morning at the hospice. I stand next to the front desk and start talking to a female administrator behind the front desk who I have known for many years. We initially talk about recent social and work-related events. I have not seen her since starting my research, so I describe what I am doing and why I am here.*
>
> *She describes a number of recent experiences where she has had quite close relationships with a number of people. Being at the front desk, she describes being the social contact for people who visit, and often developing quite close relationships, particularly with the longer-term patients and families. This happens despite not having a role a direct role in patient care.*
>
> *A man in his seventies walks into the hospice. She greets the man kindly by name, and they both smile and ask how each other has been. After a short and pleasant exchange, he walks past the desk towards the chapel. As he leaves the space she says: "That man comes in here every Sunday. His wife died here a few years ago, and still every Sunday he comes in here for the church service to remember her."*

The network of relationships in the hospital is complex. This complexity is influenced by the number of individuals, the variety of roles which they undertake, the situational seriousness and emotional profundity of the interactional content, and the differing dynamics present in these encounters.

This vignette demonstrated a longstanding relationship, yet one that had remained on a superficial level for many years. The man walked straight from the entrance to the chapel, and the administrative staff member would have been the only person he would have seen on most visits to the hospice, apart from the celebrant. Due to the relatively high changeover of nursing staff, it is likely that many of the nurses who had cared for his wife were no longer working at the hospice. Yet, this staff member, who worked every Sunday and had done so for many years, is the constant. Potentially she was the only person who remained from his wife's time in the hospice, the only person who may have known his story and reason for visit. It was likely that this small community of people with whom he interacted every Sunday (the administrative staff and the celebrant) constituted important elements in his remembrance of his wife. Their relationships were constructed through her illness and death, and remained continuities of her existence, despite her physical self being non-existent. Thus, these relationships and the environment of the hospice, could be viewed as continuations of her lifeworld (Komesaroff, 2008).

This interaction was brief, yet the relationship enduring. Their exchange was very pleasant, in the manner they both looked each other in the eye, addressed the other by first names, smiled, and enquired about their lives. In this relationship the staff member recognised the narrative of this man's connection to the hospice and his wishes for engagement. There was nothing more required from this interaction at this time than a friendly greeting and acknowledgement that he is welcome at the hospice. Yet, this could change, for in this relationship there was potential for his weekly visits to manifest in displays of distress or complicated bereavement. Equally, this potential may never eventuate. This relationship seemingly allowed for this man to feel welcome, supported, and feel connected to the place where his wife died, whilst was reactive to his needs, which appeared to be realised through these engagements. This may have appeared as a superficial interaction, yet it conveyed a profound history, the continuation of his wife's being, and offered a myriad of unrealised potentials.

Communities of Learning

> *A man in his sixties – Mr N – sits in a cubicle in the chemotherapy centre, with chemotherapy running through a drip. He is dressed casually in jeans, a flannelette shirt and a vest, and appears quite healthy. He sits in his chair and watches other people in the room, not requiring the distraction of the television or reading material.*
>
> *A male nurse attends to him to check the chemotherapy. They exchange pleasantries, but otherwise have limited social interaction.*
>
> *A male patient sitting opposite Mr N starts talking to him. The conversation begins talking about "how they are going". They soon start talking about what treatment they are each on and the side effects. The*

interaction takes on a friendly tone, with both men laughing and sharing stories, despite detailing serious medical issues. The conversation is short, only about five minutes, in which they share a significant amount of personal information with each other. It ends with them both talking about the future: "You never know", they both say and nod in agreement.

The other patient starts packing up his belongings to leave, and says goodbye to Mr N. "Will see you next time."

Shortly afterwards Mr N hails the attention of a female nurse walking past, asking to be disconnected from his chemotherapy so to visit the bathroom. They have a friendly social chat while she does this.

He returns about five minutes later and grabs the attention of the original male nurse to re-connect the chemotherapy. Mr N directs a purposeful conversation, during which he asks about the particular side effects of his chemotherapy. Much of this seems to have developed from his discussion with the other patient, as he asks about these side effects discussed. The discussion is very factual, using medical words. After Mr N's questions are answered he concludes the conversation and the nurse departs. Mr N looks around however there are few people in his vicinity. He switches on the television, paying little attention to it.

The male nurse returns with some written information about the chemotherapy. They both talk briefly about the information. The nurse is distracted by a colleague who asks for assistance. He remains in the vicinity as they check chemotherapy contents together.

As the male nurse is finishing his task, Mr N gains his attention to ask a series of further questions. On this occasion Mr N poses his questions as stories of how he has recently been feeling. He relates how he has been feeling to the side effects of the chemotherapy.

The nurse asks: "What is your main concern?" "To get through the next 12 months" Mr N replies. He continues to ask more questions of the nurse, who replies mostly with medical language and medication. The nurse briefly disappears, only to return with more printed information. Mr N thanks the nurse as he departs but seems to be somewhat unsure of the information he has received.

At the beginning of this vignette, Mr N and another male patient initiated a conversation, one that promptly progressed to medical matters. Within a short five-minute timeframe, they had discussed their personal experiences of treatment and side effects, their current medical situation, and lack of clarity as to the future. The information was shared through narrative, allowing each to express elements of their personal story with the accompanying medical data. Each individual confronted a future - "You never know" – as being uncertain. It did not have an answer, and they were able to embrace this shared uncertainty rather than provide solutions. They shared this commonality, of two people with similar experiences who faced comparable challenges ahead. This interaction between the two men ceased shortly after this, as the other man departed the chemotherapy centre. However, in their departure there was also potential for continuance, perhaps at another time in the chemotherapy centre or the waiting room.

The series of interactions between Mr N and the male nurse contrasted in the manner of their progression and discursive style. The exchanges were initially based around care tasks, such as checking and reconnecting chemotherapy, and printing of medical information. The language and content employed in these exchanges was primarily medical and delivered in a factual manner. The latter portion of these interactions demonstrated a shift in the discourse, as Mr N detailed his experiences in a narrative form. The nurse initially appeared to respond as the conversation progressed through Mr N detailing his existential concerns: "To get through the next 12 months." The response of the nurse contrasted markedly with the fellow patient. In this interaction, this statement was instrumentalised by the nurse, who sought to engage with this statement through medicalised frameworks of interpretation. The resultant 'printed information' was procured as a solution for his problem, yet poorly engaged with the concerns of Mr N. The interaction concluded with both parties disengaging. Mr N appeared uncertain and dissatisfied, with his concerns not fully understood nor addressed. From a purely medical viewpoint, the nurse had identified and provided information regarding Mr N's concerns, and likely perceived the resolution to be satisfactory.

Contrasting these two interactions illustrates the importance of shared discourses to the construction of relationships. Both relationships were confronted by issues of uncertainty of the future. One relationship allowed the sharing and construction of knowledge, the other resulted in tensions between two differing frameworks that failed to converge. In the interactions with the nurse, there was an exchange of a considerable amount of data, yet little that was seemingly related to the circumstances and concerns of Mr N.

The community formed between Mr N and the fellow patient allowed the construction of knowledge. This was evidenced through the following interaction with the nurse, in which Mr N referenced the side effects discussed in his previous interaction. These can be interpreted through the processes of experiential learning, described in four steps by Dewey and Kolb. Mr N had related his own concrete experiences of learning, and expanded these data through hearing the narrative of the others patient's account (Miettinen, 2000). He then engaged in a reflective observation process, applying this information to his own situation through comparison with the fellow patient (Borkman, 1999). Through these dialectical processes they engaged with interpreting the significance of the data to their own personal situations, the abstract conceptualisation (Rose, 1962). The final stage – active experimentation – occurred with the nurse, when Mr N utilised these new concepts in his discussions with the nurse, to question how these effects of the chemotherapy would apply to him (Ord, 2012). He interacted with this knowledge through differing interfaces, firstly presenting it through a medical discourse, and then again in narrative terms.

9.6 Reflections on an Ethnography

In conclusion, these informal communities were subject to many influences, as individuals negotiated the hospital environment, role expectations, and differing forms of knowledge. Outside of the formal domain individuals expressed differing aspects of their selves, engaged in other discourses, and communed with others. These informal communities were evolving and dynamic, took on an array of meanings, and realised many outcomes.

To conclude this chapter, I have focused on a single vignette that demonstrates the breadth and significance of these communities. Within this single interaction there were many foci of interaction, changing dynamics, multiple outcomes and processes; an interaction that evolved in accordance with the participant, offering many potential outcomes rather than being confined to a singular set of meanings and knowledge.

> *Two male patients sit in cubicles opposite each other in the chemotherapy centre. A man in his sixties – Mr X - is dressed casually in an oversize flannelette shirt and tracksuit pants, displaying a relaxed attitude. He talks loudly to the nurses about current affairs as I enter.*
>
> *Mr Z is younger, likely in his early fifties, and is accompanied by his wife – Mrs Z - of a similar age. He is smartly dressed in a polo shirt, jeans and dress shoes. He appears slightly anxious, unfamiliar in his surroundings. As his chemotherapy is being organised Mr X starts talking to him and his wife, despite being separated by a corridor. This is facilitated by a nurse, who has been conversing with all of them.*

The conversation initially revolves around Australian football, as they all discuss the recent form of their clubs. Both Mr X and Z seem passionate about football, as they talk about recent matches.

These two men came from quite different backgrounds, apparent from their accents, use of language, and appearance. Mr X's stories described a working-class background, whilst Mr and Mrs Z were quite well educated, presumably middle class.

Their discussion demonstrated a shared passion in football and the unspoken commonality of cancer. The social interaction allowed a distraction from the boredom of inactivity. It also provided connection with another who faces similar challenges, a shared narrative.

After about five minutes the conversation changes to a more personal nature. "How long have you been on treatment?" Mr Z asks. They both talk about their experiences of cancer diagnosis and subsequent treatment. For him, this is his first cycle of chemotherapy.

"What treatments have you been on?" he asks. Mr X tells him about the various chemotherapies he has been on, and future options for his cancer including trials. They talk about where they get their information about cancer, including the internet, attending seminars, and other people.

"Everybody's got a story. Some do it holistically, but me I do as they say. Because psychologically, it can get to you." Mr X says.

What was a social conversation about football had evolved. Together they shared their personal stories of cancer, finding greater commonality in shared experiences and identities. The conversation occurred using narrative as the means of detailing information. The story was their experiences of cancer, the meanings of which constituted their knowledge of the condition.

Through sharing their experiences, they were able to question and refine their understandings. They engaged in a process of experiential learning, sharing narratives, conceptualising and applying the knowledge to their own situations through contrasting their experiences (Kolb, 1984). Mr X, the more experienced of the two, provided some guiding hypothesis for this knowledge based on his and others' experiences.

> *A female volunteer enters the space and says hello to the group. She offers to show Mr and Mrs Z around, as it is their first time at the chemotherapy centre. They politely decline and she departs.*

> *The men keep chatting about football, and Mrs Z becomes increasingly disengaged from the conversation. After a few minutes, the men start comparing the types and doses of medications they are on. "What are steroids for?" Mr Z asks. Mr X details how they can affect sleep, and they compare stories of how their sleep has been.*

Both men communicated aspects of their selves beyond that as recipient of care. The conversation enabled them to broadcast this complexity, as social beings, and individuals knowledgeable and active in the management of their cancer. Through these narratives they described the many communities that they identified with: football supporter, family, friends, and cancer patient.

Mr X demonstrated his expertise in the experience of cancer, and took on a teaching role, despite likely disparities in formal education. His credibility was demonstrated through his own experiences. He delivered that knowledge in a form that was readily understood by Mr Z – through narrative. In the support group literature this is described in those individuals who are able to proactively engage with illness, through assembling knowledge and providing support: from cancer victim, to survivor, to thrivor (Borkman, 1999). The declined offer of assistance from the volunteer may be a reflection of Mr X's expertise.

> *The conversation then drifts back to football. A male nurse joins in, as he checks the men's chemotherapy. Both Mr X and Z make jokes at the expense of the nurse's football team, all laughing together. The conversation with the nurse alternates between the serious and the jocular. Mr X describes his experiences of the last cycle of chemotherapy, they talk about hair styles, and more football.*

> *Mr X begins to recount stories of the difficulties he has faced since diagnosis, and Mr Z shares his. They relate stories of other people they know with cancer, both positive and negative.*

This conversation occurred within and through acknowledging the network of relationships in which they were embedded. Mrs Z and the nurse engaged fluidly as they drift in and out of conversation. This was not only an interaction, but a web of longitudinal relationships – a community. These communities involved many people (staff, patients and visitors), contributing social connectivity, mutual offerings of support and shared understandings.

Through detailing the experiences of others, they were able to draw upon a communal body of knowledge outside of their own experiences. It supports the importance of community in this process: as the construct in which knowledge can be conveyed, and the key space where learning occurs.

Chapter 10

The System of the Phenomenological Lifeworld

The informal interactions that occur in cancer treatment settings of the hospital are a domain of interaction that has received limited attention. The ethnography study described, in detail, the breadth and variability of these interactions. This approach enabled a rich exploration of how these interactions occur within the influences of illness experiences, cancer treatment, and the hospital environment, and in particular, the presence of these interactions alongside formal systems of health care provision.

The next step was to systematically describe these communities through the structure which individuals experienced them. Whilst the ethnographic observational methods used in the former study have many strengths, they lack the potential to understand the personal meanings and outcomes derived from these encounters by the participants. To develop this understanding I engaged the people who occupied the hospital cancer treatment environments in semi-structured interviews. These interviews were phenomenological in design, focusing on the participants' recent encounters that occurred outside of the formal domain of the clinical consultation. The participants were asked to reflect on the interactions: their significance, content, precipitants, the nature of the relationships, and the potential consequences of the engagement. The questions that guided the interviews are listed in Appendix 1, 2 and 3. This chapter describes the results of this interview study.

10.1 Overview of Results

Participants

31 participants were interviewed for this study: including 18 people with cancer, of whom five were recruited

through cancer support groups, four carers, and nine staff members. 18 of the participants were female. Participant's demographics and characteristics are described in Appendix 5.

Clinical characteristics were collected of the 13 cancer patients having treatment at the hospital. Age ranged from 34 – 84 years, with a mean age of 63.6 years. Two participants were undergoing curative treatment, four had chronic disease, and seven were having palliative-intent treatment. These individuals had breast (4), colorectal (3), haematological (4), ovarian (1) and renal-cell (1) cancers. The cancer support group participants included four individuals with prostate cancer, and an individual with breast cancer. The staff participants included two nurses, three doctors, two allied health professionals, and two administrative officers.

Interviews ranged in length from 18 to 93 minutes, with a mean time of 37.5 minutes. Four of the interviews involved two participants (both patient and carer) and there was a group interview with four participants from a cancer support group. Interviews took place in many locations of the hospital, at a cancer support group meeting, and one interview via telephone.

Quotations of the participants from the interviews are employed to describe the various categories of results. The participant number described in Appendix 5 is listed for each quotation.

Categorical Mapping

The results reflect the phenomenological description of these interactions, the manner in which the participants experienced them. These categories resulted from the many descriptors of informal interactions provided to us by the participants. In simple terms, the data were grouped according to the manner in which the participants described the interactions, and structured them as experiences. The representation of the data in this manner was a response to the complexity of the phenomenology of the interactions described in the data. In contrast to a normative thematic description, the data presented by the participants detailed important elements that did not fit 'neatly' into such an analysis framework. Developing such a representation of the data allows these important structural elements of the interactions to be explored in detail, in addition to predominantly phenomenological domains such as significance. These categories represent descriptors of informal communities that could be considered lifeworld and system elements.

The following categories described in Table 2 arose through the process of data analysis, through questioning and interrogating the data. It comprises of five major categories: person and place, interactional prompts, content and context, outcomes and significance. Within this categorisation there are elements of formal health systems, such as the formal roles of the participants, or some outcomes that are related to formal care provision. Yet, these interactions are 'different' to the formal consultation, remaining intrinsically inter-related to these formal structures and dynamics through this difference.

Table 2 – Categorical representation of informal interactions

Category	Descriptors	Variables
Person and place	Actors	○ Staff ○ Patient ○ Visitor
	Location	○ Cancer centre ○ Acute hospital ○ Hospice ○ Other hospital spaces ○ Outside hospital
Interactional prompts	Environment	○ Shared space ○ Atmosphere
	Tasks	○ Formal tasks ○ Informal tasks
Content and context	Field of content	○ Greetings ○ Social ○ Personal ○ Emotional ○ Illness
	Disclosure of information	○ Mutual self-disclosure ○ Lack of mutual disclosure
	Temporality of relationships	○ Singular ○ Continuous
Outcomes	Mood and perceptions	○ Entertainment ○ Distraction and comfort ○ Positivity ○ Negativity
	Care Provision	○ Information ○ Emotional support ○ Anticipatory care ○ Practical assistance
	Experiences of support	○ Connection ○ Demonstrating appreciation

		○ Understanding
Significance	Connecting	○ Belonging ○ Commonality ○ Differences ○ Feeling valued ○ Being normal
	Making sense	○ Sharing experiences ○ Comparing ○ Unpredictability
	Helping others	○ Emotional and social support ○ Teaching and learning

10.2 Person and Place

Actors

When describing the informal interactions, participants invariably included descriptions of the other participants. The formal role of the participants in the hospital was habitually described, often accompanied by other descriptive details to further illustrate that person. It was this formal role that was a constant, detailing if that person was a staff member, a patient, or a carer/family member.

Staff

There were many categories of staff described in the interactions: nurses, doctors, physiotherapy, speech pathology, pastoral care, volunteers, administration, cleaning and catering staff.

- *Starting with the cleaning guy, the food service, and the nurses who would come and see us.* (patient, palliative care ward, participant #14)

Patients

The category of patient was attributed to those participants who been in receipt of treatment. In these descriptions there was no differentiation based upon diagnosis or stage of illness, they were all patients. This term was used by all the participants, patients describing themselves as patients, including those in the support groups who were outside of the hospital.

- *Bit of a catch-up, not really a staff patient thing.* (patient, chemotherapy day unit, #6)

Visitors

The category of visitor was frequently a category of exclusion; these were people who were not staff or patients, and thus did not have a readily identifiable role. They were often described in relation to the person they were visiting.

- *One bloke sat there who was a civil engineer. I don't think he was a patient, I think he was visiting someone.* (patient, chemotherapy day unit, #2)

Location

The location of the interactions was constantly specified by the participants, providing additional detail regarding the environment of the interaction. The focus of this study was the hospital environment and the interactions were initiated in this space. A detailed description of these hospital spaces can be found in the methods and ethnography chapters (Chapters eight and nine). However, in this study the participants also referred to these interactions with others outside of the hospital space, particularly those people with whom they had formed closer relationships.

Cancer Centre

This was the centre for outpatient cancer treatment, located adjacent to the main hospital building. It included the chemotherapy day unit, the clinic, and the waiting room.

- *It was actually in the waiting room, in the reception* (patient, chemotherapy day unit, #6)

Hospital Wards

This included the hospital wards of the acute hospital. Predominantly this referred to the haematology, oncology and palliative care wards, where most patients with cancer were treated and were located next to each other.

However, on occasions patients were admitted to other wards, especially if they were undergoing a surgical procedure.

- *Yeah, sometimes when you sit in the (patient) lounge there are a couple of people* (patient, palliative care unit, #10)

Other Spaces

Participants described many other spaces in the hospital environment where interactions occurred. These were commonly in places used for transit (i.e. corridors, elevators) or for socialising (i.e. cafes, the smoking area outside the hospital).

- *Just coming in here, going down to the fishpond (smoking area) for a smoke, and that was it.* (patient, palliative care unit, #1)

Hospice

The hospice was an offsite hospital run by the department of palliative medicine for inpatient palliative care. It was situated adjacent to parkland and had large garden areas on site.

- *They will be taken outside the garden here or outside the front there or if they can, they'll walk outside and just sit there.* (staff, administration, #16)

Outside the Hospital

Participants described interactions that initially occurred in the hospital, and over time evolved into relationships that lead to engagements outside of the hospital space. These outside environments included neutral spaces such as cafes, football matches and restaurants, or more personal spaces such as the participants homes.

- *We still have coffee dates* (patient, palliative care unit, #1)
- *He is a bloke that, when he got it, he came down to my house* (patient, chemotherapy day unit, #3)

10.3 Interactional Prompts

In their descriptions of the informal interactions, participants recounted how they came into being. Within these descriptions were frequent references to aspects of the environment and tasks which influenced the participant's engagement. These factors fitted within two themes: those related to the physical and social environment, and others related to the tasks performed by the participants.

Environmental Prompts

Shared Space

Many of the environments in the hospital were described as conducive to interacting. These were primarily spaces where the territory was shared by many actors, with proximity of space and action. The participants described the shared patient rooms, the chemotherapy day unit, and the shared spaces of the ward such as the kitchens, lifts and lounges as particularly conducive to informal interactions.

- *Yesterday I had an interaction in a lift. The lift is a common bumping ground into informal space, and it was the son of a patient.* (staff, palliative care physician, #29)
- *There are a lot of people who wouldn't want to go into a four-bed ward, It didn't mind me. I've met people that I would have never met before, with amazing stories* (patient, palliative care ward, #14)

Atmosphere

The atmosphere within some of the hospital spaces was remarked by the participants as promoting engagement. The two places that were the focus of many of these remarks were the chemotherapy day unit and the patient rooms. The patients and visitors described the attitudes of the staff as being very positive and friendly, and witnessed other people engaging in social conversations in the space. They felt comfortable to engage themselves in non-formal interactions. The staff were perceived as being mostly open to engaging in these, often being the initiators.

- *I could walk in here and everybody knew me. All the female nurses – 'Ok Greg*, you're back. Give us a hug.'* (patient, chemotherapy day unit, #13)

Task Prompts

Formal Care Tasks

The hospital environment is focused on health care provision, realised through the formal care tasks of the many staff members. As they move through the space to perform these tasks, they frequently engage in discussions not related to the formal provision of care. The formal tasks that are frequently associated with informal interactions are practical, such as dispensing medications, checking chemotherapy, taking observations (i.e. blood pressure), and functional (washing, toileting) and physical (changing dressings, walking assessments) care. Care tasks conducted through the medium of conversation, such as the medical consultation, do not offer the same opportunity to engage in informal interactions, as the engagement remains focused on the formal domain.

- *If the (chemotherapy) machine goes off, and they come and fix you, and have a bit of a joke.* (patient, chemotherapy day unit, #13)
- *If I was in the room looking after them and I offered a cup of tea, she (patient) would always interject, saying, "You need to give her the special cup (Nurse)* (staff, nurse, #23)

Informal Tasks

Being a patient or visitor in the hospital requires these actors to engage in their own activities or tasks. Whilst outside of the formal provision of care, these tasks are a necessary component of being in the hospital. The most commonly described task was waiting: for appointments, recovery, tests, chemotherapy treatment or as a caregiver of someone who is undergoing these procedures. The lack of stimulation while waiting was described by many of the participants as a contributor factor to initiating engagements. Other tasks for patients and visitors involved using the kitchen, having a smoke outside, taking a walk around the wards, and having a coffee, all brought them into contact with other individuals.

- *I just meet people in here, and I just chat to them. It just helps to pass the time.* (patient, chemotherapy day unit, #8)
- *They've all brought in food. They asked me how to use the oven.* (staff, administration, #16)

10.4 Content and Context

The content and context provide an understanding of the field of discussion, how information was shared between the participants, and their relationship. In the formal clinical consultation, the field of conversation is well established, focusing on the medical condition and related events. In the informal domain the engagement is open to negotiation between the participants. Three categories arose to explain the conversations or engagements described: the field of content, disclosure of information and temporality of relationships.

Field of Content

The interactions covered a number of specific fields of content, with the majority of interactions covering multiple fields of content.

Greetings

Greetings frequently were the first exchanges of the interactions. Some interactions remained limited to this field of content.

- *We say 'Hello, how's it?' And then it's the end of the conversation and that's it.* (patient, chemotherapy day unit, #5)

Social

Social topics were commonly discussed between the participants. The content of these interactions related to general events related to the society: such as sport, television programs, holiday destinations, events in the news, restaurants. These were often related as a personal experience (such as attending a football match) but did not focus on their personal self.

- *We spoke about football, we spoke about cricket, and everything else.* (patient, chemotherapy day unit, #3)
- *I ask her how her holiday was because you hear them talking amongst themselves.* (patient, chemotherapy day unit, #13)

Personal

Personal stories and information were frequently shared in these discussions. Common fields of content included narratives of growing-up, work, children, life achievements, and recent events at home. Staff often shared these details of their families and the regions they came from.

- *I hear about their (staff) families which is nice to know.* (patient, chemotherapy day unit, #3)
- *Where they came from, where they live, where they're going* (patient, palliative care unit, #1)

Emotional

Content often included emotional subjects detailing uncertainty, distress and ability to cope. Patients would often 'check-in' with other patients as to how they were bearing treatment and health related issues. Whilst this field of content focused on topics of an emotional nature, they did not necessarily result in an emotional response from the participants. However, they did provide a forum to discuss mental, spiritual and existential issues.

- *He was saying he wasn't sure what was going to happen with him. I think they told him he had 12 months to live.* (patient, chemotherapy day unit, #13)
- *How you are faring in the whole system? How you are coping psychological or otherwise?* (patient, chemotherapy day unit #3)

Illness

The experiences of illness, treatment and diagnosis were frequently discussed. They were predominantly relayed as first-person narratives, in which patients and family members reflected upon events through their personal stories of being affected by cancer. This was a field of content in which most staff members did not have personal experiences. Occasionally they might contribute experiences that had been shared by other patients, relaying these in the third person.

- *Most of the other people I've met had other complaints and illnesses.* (patient, chemotherapy day unit, #9)
- *I was in touch with every single patient. To find out – how they were progressing?* (support group member, #22)

Disclosure of Information

The participants described differences in the manner in which they shared their personal information and experiences in these interactions. Disclosure is defined as the revealing of information that is personally relevant (Greene et al., 2006). The notion of mutual self- disclosure in communication is developed from social penetration theory. This theoretical perspective has been applied in numerous empirical studies, demonstrating associations between self-disclosure and relationship formation (Hargittai and Hsieh, 2010, Trepte and Reinecke, 2013).

Mutual Disclosure

Participants described frequently sharing personal information in these interactions, dependant on the nature and topics of conversation.

- *Yeah. Everybody just says what they've got or what they think they've got that they've been told they might have, and we just take it from there, so it could end up anywhere.* (patient, palliative care ward, #1)

In the above quote the participant describes a group of patients who regularly meet up while at the hospital and shared their experiences and stories, with the expectation that everyone shared their personal experiences of care.

Lack of Mutual Disclosure

Many interactions involved disparities in the information that was shared by participants. This may be due to unwillingness to share this information, or due to a lack of content knowledge in the particular field, such as staff members who had no personal experience of cancer treatment.

For example, this patient details her perceptions on the exchange of information with a series of other patients on the wards. In these interactions she had learnt a substantial amount of information about their lives and illnesses yet, as highlighted in the quote, revealed little about herself.

- *I didn't give much away about myself...sometimes it's just not being inquisitive, it's just asking a question… I was just someone they didn't know. Just a patient.* (patient, palliative care ward, #14)

Temporality of Relationships

The temporality of the relationships was a feature of the descriptions; whether these interactions existed as part of an ongoing, continuous relationship, or as a single engagement that began and was completed on a single occasion. The majority of the interactions described in the interviews were part of continuous relationships.

Singular

These were solitary interactions, occurring at a single period in time.

- *But then she got called and I never saw her again.* (patient, chemotherapy day unit, #2)

Continuous

A continuous relationship was defined as multiple interactions over different time periods. Examples of this could be patients who shared the same room for three days in hospital, or a nurse seeing a patient and carer a number of occasions in the CDU.

- *Where you come in here for five or six hours or whatever, intermingle with them, and then you say, "See you later. See you next week." Then after next week, you say, "See you in two weeks time."* (patient, chemotherapy day unit, #13)
- *They always ask about how I am going. Fine, terrific. Haven't had nausea, everything fine, good. There's not much. When I met this lady, she not a friend, she's just an acquaintance. I don't have too much conversation, but it is a happy connection.* (patient, chemotherapy day unit, #6)

10.5 Outcomes

The participants described many outcomes resulting from the interactions. These outcomes were defined by the participants, who discussed acts being performed, and changes in behaviour and perception resulting from the interactions. The categories of outcomes fitted within three broad themes: mood and perceptions, care provision, and experiences of support.

Mood and Perception

Entertainment

The interactions were described by many participants as having an entertaining quality: through joking, laughing, or engrossing them through stories and conversation.

- *They all get on really well together, just having a laugh. We stir them up.* (patient, chemotherapy day unit, #3)
- *I did actually meet some really incredible people while I was in there. One of them recited Roald Dahl's poem with [inaudible 00:06:19] and theatrically as well, so it was really enjoyable.* (patient, chemotherapy day unit, #9)

Comfort and Distraction

Participants reported feeling relaxed and comfortable through the interactions, often being distracted by the treatment at hand.

- *Mainly, I find unwinding with N (nurse) a bit about her son.* (patient, chemotherapy day unit, #2)
- *It's a bit of comfort, I suppose, to choose a word for it, being comfortable, because you are used to the place and the people. Because it could be pretty horrible if you didn't know anyone.* (patient, chemotherapy day unit, #8)

Positivity

Engaging with others was reported as frequently having positive effects on the participant's mood. This was noted commonly in the CDU, which was reported as an atmosphere which was friendly and sociable.

- *They are always just really bubbly which is nice. Cause that is lifting to everyone as well. I'm sure that when you have your treatment you can feel like crap, so when someone is bubbly and happy around you its gotta lift you.* (carer, chemotherapy day unit, #4)
- *One of the joys of it. As you say, it's nice to talk to other patients* (patient, chemotherapy day unit, #3)

Negativity

There were also negative outcomes related to the interactions. One domain of conversation that frequently prompted such a response was hearing the illness experiences of others where there were complications, unexpected outcomes or progressive cancer.

- *It concerned me quite a bit when she (other patient) was talking through all the side effects… All so negative.* (carer, chemotherapy day unit, #7)

In one instance a couple (a patient and their carer) perceived the same interaction as having differing effects on each of them.

- *She was negative to such an extreme extent… Sort of fatalistic* (patient, chemotherapy day unit, #7)
  I disagree with that. She was talking about the hard things that we have to go to. She even didn't accept the fact that everything was under control, you know (patient, chemotherapy day unit, #6)

Care Provision

Information

Information was readily exchanged through informal interactions, with this information contributing to care provision. It was commonly information about illness experiences. Additionally, other types of information (including social information, such as good local restaurants) was exchanged that contributed to the participants' personal and social care.

- *We'll recommend food to each other and where to go* (patient, chemotherapy day unit, #3)

These informal exchanges were also utilised to gather information about the participants. This was commonly used by the staff, to learn more about the patients and their families, and thus provide personalised care.

- *And it's those informal chats where you pick up most information, generally speaking. It might be an odd comment here and there that gives you an extra insight* (staff, haematologist, #25)

Emotional Support

Participants frequently described the provision and receipt of emotional support through these interactions.

- *And she said to me one day that that's been part of my process of bereavement and grieving and feeling better and dealing with the loss of her husband and that sort of thing.* (staff, nurse, #26)
- *I find that with a cuddle, within a couple of minutes, they're as good as gold and we'll have a cackle (a laugh).* (patient, palliative care ward, #1)

Anticipatory Care

Participants described the potential for future support as an outcome of their relationships. This was in particular expressed by those patients who were currently well and identified that this may change in the future.

- *They've always been covering me, and they're always saying, "Well, you know, can just come back next week again."* (patient, chemotherapy day unit, #13)
- *Someone she can touch base with every now and then. She knows there's support here or I'm here to listen if she needs it, sort of thing.* (patient, chemotherapy day unit, #8)

Practical Assistance

The interactions frequently resulted in the provision of practical assistance. Examples of this were getting another person coffee, cigarettes, ringing the 'call bell' or adjusting their pillow in bed. Some of these actions might be considered a formal care task (such as assisting a patient with eating their food or walking), yet were accessed outside of the formal domain of care provision, often provided by other patients or visitors.

- *"Would you like me to go and get you some cigarettes?" She said, "Would you, darling?" And I said…"Oh, I can get you some cigarettes"* (staff, psychologist, #31)
- *Someone needs a cup of tea or a cup of coffee. Off you go to the coffee shop, you make the coffee, you come back.* (patient, palliative care unit, #1)

Experiences of Support

Connection

Many of the participants described the connections that developed through these interactions as being important. These were described using words such as friendship, support network, family or a community. These descriptions identified the social and supportive roles of these relationships.

- *You develop friendships there, so you feel like you are part of it all.* (patient, chemotherapy day unit, #8)
- *In a way, it's a funny thing to say, but you miss coming in here because you've got this network of people, and when you're at home, like all right, I've got my family, got my wife, and got my kids and things like that, but it's not quite the same because it's just me and the Missus. most of the time, 24/7.* (patient, chemotherapy day unit, #13)
- *Outside of her own social circle, family circle. We're a second family I suppose, in a sense.* (staff, administration, #17)

Demonstrating Appreciation

Through these informal interactions the participants described the conversations as enabling them to show interests in others and also to feel valued themselves. This frequently occurred through taking interest in the personal lives of the other participants. Staff described that through learning more about the personal lives of the patients and their families they derived an understanding of the impacts of care provision and identified the value of their work.

- *Ask them about holidays. If I remember, how was your holiday? That's about it. Yeah. Yeah its alright. One nurse at a time.* (patient, chemotherapy day unit, #12)
- *It's a matter that the patient's husband felt appreciated for what he was doing as well...... He was very nice and very chatty and he started telling me about the wife.* (staff, administration, #16)

Understanding

Participants described the interactions as resulting in greater understanding. Through sharing information, stories and experiences they frequently identified commonalities with other people, especially between the patients undergoing treatment. They identified that in their family and social networks there was often limited understanding of what they were experiencing. Thus, meeting other people with common experiences and challenges, and feeling understood by others were viewed as significant outcomes.

- *Yeah, they know that you understand, because you are in the same boat. When you go and talk to someone outside, they have no idea.* (carer, chemotherapy day unit, #4)
- *Being quite open about what is going on, and what your medical situation is, and what you are doing about it or what you propose to do or what treatment you have - and telling other people who understand.* (support group member, #18)

Other participants detailed the importance of the longitudinal nature of these relationships, that other people understood and had been a part of their experiences over time.

- *And they have seen me all from like the day I was here. So they know how I've progressed through these this time.* (patient, palliative care ward, #10)

10.6 Significance

The significance of these interactions for the individuals involved was markedly different to the outcomes resulting from the interactions, and thus comprises a separate category. Whilst outcomes focused on what the participants described as actions or potentialities resulting from the interactions, the category of significance was based on the phenomenological description, the personal meaning of the interaction. Their significance was understood through three themes: connecting, making sense and helping others.

Connecting

Belonging

Participants described feeling connected to many of the other participants. They used metaphors to describe these connections such as family, support group, network, and referred to the relationships as friendships or being 'mates'. Being connected to others enabled them to feel supported and their personal situation understood.

- *It's the sort of thing that maybe in ten years time, if you met up with them you'd make a celebration out of it, because you learnt a lot about them.* (patient, chemotherapy day unit, #9)

- *That nurse, she's alright. She's my mate.* (patient, chemotherapy day unit, #5)
- *It's a big support group.* (patient, palliative care unit, #1)

Commonality

The participants, in particular the patients, described many common elements they shared with other people in the informal domain. These commonalities were frequently related to the illness, their experiences of treatment, or attending the same environment. However, further common interests were often found. These commonalities were often an important factor in the development of the relationships.

- *There's a commonality that happens here...you're here for a reason.* (staff, pastoral care, #24)
- *When you meet another patient, it is definitely a support group. When someone comments about my hat or something, its communication between the people who are going through the same thing. It is a positive thing we go through, but because of a negative event.* (patient, chemotherapy day unit, #6)

Difference

These interactions also provided fora for the participants to discuss or demonstrate difference. These differences were not necessarily a barrier to interactions. For some participants these differences stimulated the interactions, enabling them to access information and concepts that they would not have otherwise been exposed to.

- *It's like any social group. I mean, some people you like, some you like very much. Some you don't like at all.* (patient, hospice, #27)
- *Us city people have different things to talk about than them. But it's interesting to find out what other people do and what they're up to.* (patient, chemotherapy day unit, #9)

Other participants perceived that they were different to the others in the hospital environment, on a range of personal, illness or social factors. They identified this as a reason why they did not engage with others in interactions, or only in a superficial manner.

- *A lot of people are different to me, because I just got the cancer and it took off, and that was it. But a lot of them are sad sacks. I can't be a sad sack, so I didn't stay. Yeah, nah. Nah. I get sad days, don't get me wrong, but I can't be a sad sack. Nup.* (patient, palliative care unit, #1)
- *I want peace and quiet, I want to be an individual.* (patient, chemotherapy day unit, #12)

Feeling Valued

Connecting with others allowed the participants to feel valued and appreciated. Sharing personal stories and information with another person seemed to establish this perception of value, as people felt respected as a result of both being listened to, and having personal information shared with them.

- *I feel respected that they wish to tell something that's intimate as their illness or what's happened with their family member.* (staff, administration, #16)
- *It's valuable to be just to be recognised as: oh, he's not just my doctor, he's another human being.* (patient, haematologist, #25)
- *Well, a sense of connection, obviously. Yes, they're good to have, those kind of conversations. I like talking about books and movies a lot…I don't need to say anything because they pick it up. They come in with a pile of books.* (patient, hospice, #27)

Being Normal

The informal interactions frequently took the focus away from cancer, instead concentrating on other aspects of the participants' lives. In these conversations, the focus was frequently social events, food, amusing narratives, and special interests or life experiences. These interactions inserted elements of social and personal identity into the hospital space, beyond being a cancer patient or nurse. Participants described this as allowing them to feel normal, forget about their cancer, and bring the outside world into the hospital environment.

- *All of a sudden they weren't so reduced to their symptoms. In this dynamic, they could be themselves, how they were outside of our hospital walls.* (staff, psychologist, #31)
- *It's a bit easier to talk to people that've got the same problems as you. When they said talk to somebody that's so-called normal, of course they don't have a clue what you're talking about because they haven't been through that experience.* (patient, chemotherapy day unit, #13)

Making Sense

Sharing Experiences

Experiences were shared: of illness, stories of life and personal history. These discussions frequently focused on the experiences of cancer, often conveyed in narrative form. Meanwhile, staff did not have their own personal experience of cancer, they might relay the narratives they had heard from patients to other patients. Visitors shared their own stories as a carer, and the effects of cancer diagnosis and treatment on their life and health.

- *If you find people in a relatively small area and they were getting the right treatment, and at night-time 'cause you're sitting there for an hour. "Oh, where are you from? How many treatments have you had?" Before you know it, "Do you mind giving me a number and we can swap notes." Before you know it, you talked about it.* (cancer support group member, #22)
- *I think lived experience brings a lot to health care in general. I suppose in a lot of ways, you know that those girls understand how shit the chemo really is 'cause they've had it.* (patient, oncology ward, #30)
- *I am happy to talk to anyone with it. You can tell other people what I went through. It might not be quite the same, but at least they get a bit of an idea with what's involved.* (patient, chemotherapy day unit, #3)

Comparing

The participants engaged in the sharing of experiences through contrasting and comparing. This could be done as an individual, comparing others' experiences to their personal situation.

- *If that person can survive for a longer time why can't you survive.* (patient, palliative care ward, #10)
- *It's always nice to know what's happening with other people – to compare yourself and see where they are at. It gives you a bit of an idea of where you are. Sometimes you are passing on the goods, you know.* (carer, chemotherapy day unit, #4)
- *You sometimes see the families drifting back into the shared room, and then they just talk to other family members about how things are changing.* (staff, nurse, #23)

One participant described a group of patients that frequently met whilst at the hospital to engage in making sense and comparing their experiences.

- *Then you sit there and think, "Jeez, we're on a lot of stuff," or "What does what?" "I don't know. Do you know?" "I don't know." It just goes round and round and round.* (patient, palliative care ward, #1)

Unpredictability

Cancer was viewed as unpredictable, and this unpredictability was shared through these discussions. The participants reported that the medical discourse around cancer was quite narrow, and didn't explore the uncertainty that was part of the experience of diagnosis and treatment. Through sharing personal experiences, the participants explored the potential outcomes related to cancer and how it may affect their future. A number of the participants perceived the uncertainty in these discussions as being confronting, making them feel scared and more pessimistic about their future. For others, these experiences allowed them a greater understanding, and as a result greater control of their personal situation.

- *The people you are meeting are often in the middle of their treatment and their own shit…the stuff that sticks in your head is the stuff where it's gone badly.* (patient, oncology ward, #30)
- *I find a lot of times, people will go and say I've had that drug and they didn't like it and that's fine. That's good for them to be informed because that shows to me that they actually want to be involved. But, at the same time, it's a bit of a double edge sword.* (staff, haematologist, #25)

One important domain described by the participants was the experience of loss and dying. This topic was perceived as confronting, but also one they explored, noting that understanding others' experiences could inform their own approach. One participant described how she now identified death as a possible good outcome for her fellow patients, and potentially herself.

- *He's in a better place. That's it. He's home now. He's better. He can't hurt anymore, so he's happy. We're happy.* (patient, palliative care ward, #1)

Helping Others

Emotional and Social Support

Through these interactions the participants perceived that they supported others, emotionally and socially. This might be achieved through listening to them, trying to make them feel supported or displaying empathy.

- *But if we make it a good day, like if we make it positive, they'll go away happy.* (staff, administration, #17)
- *I think it was a few weeks ago talking to a guy. His first time in here...I think they told him he had 12 months to live. I mean young buck too. I sort of try and pep him up a bit.* (patient, chemotherapy day unit, #13)
- *As I said, to meet other people with metastatic cancer and how they're coping with it, what they do, what they kind of think…. I still find it so supportive, as I did. Good for my emotional and mental health, in having that context.* (patient, hospice, #27)

Teaching and Learning

A number of participants described using information and experience to provide advice to others within these interactions. They could thus engage in helping other participants by being an advisor or teacher, particularly the less experienced patients and carers.

- *Some will ask about different medications that they've seen, read, or heard of, or they've got but they don't fully understand 'em, so you try and find some way to help them understand what they do and what they're going to do for you.* (patient, palliative care ward, #1)
- *I am not entirely at the mercy of the medical people who – they do have success and they do cure people, but there are lots of consequences along the way. There is also that feeling of self-determination that I can, I don't have to just put myself in the hands of other people – I can do something about it.* (support group member, #18)

Advice was also provided on subjects not related to cancer. Participants described teaching or learning about topics such as: finding the best local restaurants, learning about other cultures, sharing football tips, and through exchanging life stories. Participants described the process of learning and teaching as valuable to expanding their own knowledge and helping others.

- *Last week there was, or last treatment, there was a gentleman and he was Mexican. I have never in my life met a Mexican. A genuine, native Mexican, which was quite a privilege.* (patient, chemotherapy day unit, #9)

10.7 Reflections

The results of this study propose that informal communities are experienced by the participants according to a structure. This structure was derived from the phenomenological description of the participants. In describing and reflecting upon these interactions, there were consistent elements that were present in these characterisations, focusing on a broad array of elements: the physical location, the formal roles of the participants, the speech content and context, the interactional prompts, personal significance, and the resulting outcomes. It is suggestive of larger social processes that are present within these communities, such as providing care, connecting with others and the use of content and role of context in facilitating these interactions. Importantly, this structure describes elements of the formal clinical domain as key components of informal communities: the formal role of the participants, formal care tasks, and physical location.

Reflecting upon these results from a methodological viewpoint, I would like to highlight the relationship between these results and the hermeneutic phenomenological analysis methods that were employed. A common approach used in qualitative methods is the use of themes to order the categories of results. I have elected not to use this term, as it does not seem fitting for these results. The categories described are heterogenous, independent and occurring on differing levels, referring to categories describing physical location alongside significance, lacking the conceptual congruence that would be expected when describing inter-related themes. Within these categories, in particular those of outcomes or significance, this thematic structure is present, as the data forms linked and dependant concepts. My answer to this unorthodox representation of the data is that it reflects the phenomena of informal communities as structured by the individuals. It does not seek to minimise this incongruence, instead ordering the data in accordance with the manner in which they were experienced.

It is worthwhile to consider the relationship between this study and the ethnography. From a stylistic viewpoint, the presentation of results differs significantly, taking a far more structured form. This was intended, in recognition of the strengths and limitations of these complementary research methods. Ethnography provides rich textured descriptions of culture and environment, and phenomenological interview methods enabled access to the experience of individual participation and its resultant structures. As a result, I focused the aims accordingly. The ethnography study aimed to understand the content, behaviours and dynamics of these interactions, thus taking a more descriptive nature. The aim for this study was more focused, to describe the experiences and meanings of participation in these interactions. Despite this focused presentation of the results, the data presented in this study are expansive, covering many informal interactions of the 31 participants, who occupied differing roles in the hospital setting.

How do these results relate to, or represent a structure of informal communities? They propose a categorical description of informal communities formed through phenomenological means, and thus remain focused on the experience of the individual. It is thus a structure, but one focused on the individual. Whilst it highlights important data to contribute to our understanding of group processes, relational organisation and wider use of knowledge, it does not propose a structure that is generalisable to informal communities. That task will be the focus of the following chapter, where we will construct such a model based on a synthesis of the results from the theoretical work and empirical studies.

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Section IV

A Model of Informal Communities

Chapter 11

A Model of Informal Communities

This thesis seeks to understand the social interactions that occur outside formal clinical consultations, to explain them as a social entity. This understanding has been developed through exploring informal communities from differing perspectives, using differing bodies of knowledge from sociology and philosophy, and research methodologies in observational and interview studies. Our theoretical position has been developed from multiple philosophical traditions, including postmodernism, phenomenology, and functional structuralism, each approach highlighting aspects of community functioning. Whilst these differing theoretical and methodological positions have limitations, their combination allows a full understanding, and thus the development of a multifaceted model of informal communities.

The previous section has described the results from the empirical studies, from which I aim to develop into a comprehensive model of informal communities. This model establishes the structures and functions that enable these communities to act as social systems. The model was developed based upon the earlier literature review, theoretical model and empirical work, and employed a functional structuralist framework, consistent with the previous theoretical position.

This chapter focuses on the description of the model of informal communities.

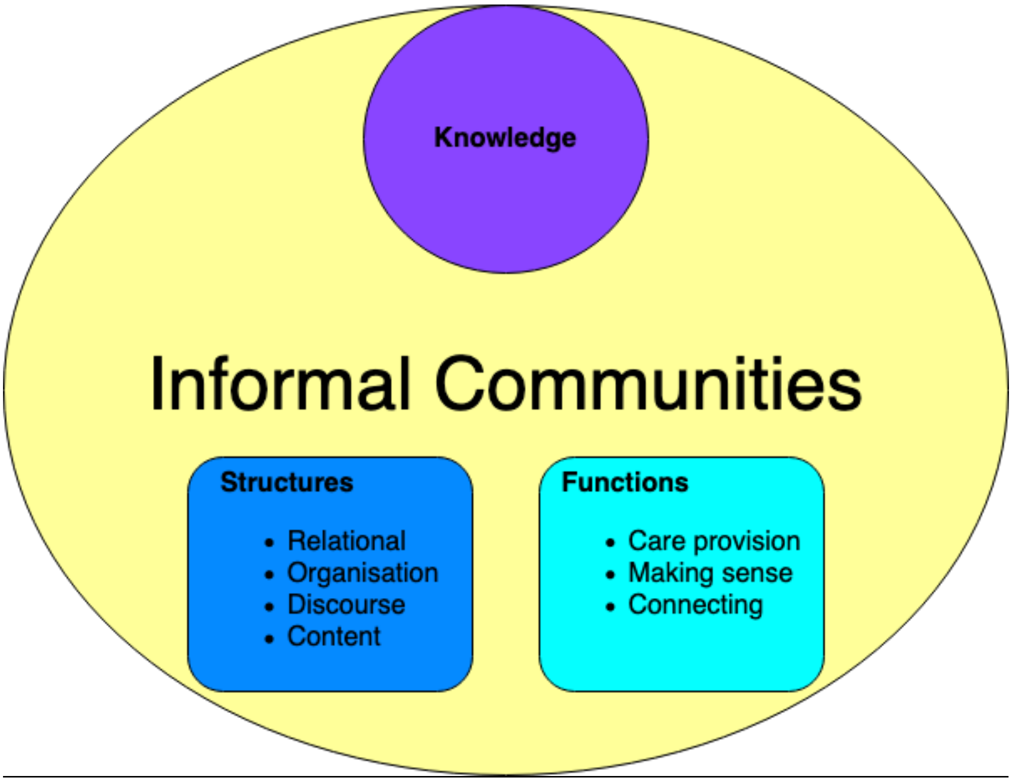
11.1 Constructing the Model

I propose at this point that informal communities exist as a structural entity, and thus can be defined in relation to their structures, functions and knowledge. The structure of informal communities is dynamic, evolving, and open to inconsistencies, but it is a structure nonetheless. The results from the empirical studies demonstrate significant alignment to the background literature and results from the theoretical model, discussed in Sections I and II. This empirical work enabled many of the unknown variables from the theoretical model to be populated, to create a model that reflects the nature of these communities.

The model of informal communities was developed based on our theoretical model of informal communities presented in Chapter six. The empirical studies in Chapter nine and ten provided data to describe the variables of this model – the structures, knowledge and functions. Figure 1 from Chapter one described this process.

The model of informal communities is presented below in Figure 2. The descriptions of formal health systems provided in this chapter is derived from Chapter two. Later in the chapter, Table 3 contrasts these differing structures and functions of informal communities with the formal health system.

Figure 2 – A Model of Informal Communities



11.2 Institutions

The institutions of formal health care systems are readily identifiable: the hospital, universities, professional colleges, regulatory bodies, and government departments. There are no such institutions of informal communities. This domain is comprised of individuals, who come together to form self-determining communities. This is not to state that these communities operate without external pressures; as they are still influenced by the hospital, and societal expectations and understandings of illness.

In our theoretical model of informal communities, the organisational aspects of informal communities were discussed. These informal groups do not usually self-identify as organisational groups: the members do not have specific names for their communities or recognise them as being linked to specific outcomes. There are understood in relational terms, as a friendship or a group of like-minded acquaintances. This was reflected in the empirical studies, where the participants of the informal communities described these relationships as: friendship, mates, or a community. On the few occasions when these communities were identified by the participant as an identifiable group they were classified according to the social qualities of the members. ‘The dutchies’ was a group that referenced the personal background of the members, and ‘the pondies’ described another group’s preferred meeting place. These groups were not associated with specific needs nor were they defined by these outcomes.

11.3 Knowledge

The knowledge held within informal communities is diverse and dynamic. It relates to many aspects of understanding, including social etiquette, personal history, experiences of illness, medical treatments and emotionality. Unlike the formal domain it is not fixed within a singular discourse, but navigates differing fields of content and interpretative frameworks. This can be seen in the ethnography study, where the interactions frequently navigated multiple domains of content and knowledge. This content was navigated dynamically, seamlessly shifting from one topic of conversation to the next, as the participants negotiated together the course of the interaction.

The knowledge was derived from many sources: from websites, television, and conversations with staff members, friends and other patients. This knowledge was often focused on personal experiences and perceptions - whether the participants were discussing football, chemotherapy or sharing a story of their life.

It is a knowledge that is not fixed or explicit, but is instead an emergent knowledge, one that is dependent on the specific experiences and understandings of the participants. It is a transient knowledge, as it is not enshrined in guidelines or textbooks, but transferred through socialisation. The relatedness of this knowledge reinforces its transience, as it is embedded within this community, and loses its relevance and utility once outside of this community. The impermanence of this knowledge is central, as it necessitates new knowledge creation, rather than the fixed forms of knowledge found in the formal domain.

The transient and dynamic nature of knowledge in informal communities minimises the potential for knowledge dominance. There is no technical jargon or specialist education needed to access the knowledge, it is relatable and maintains an ease of interpretability. It is not controlled by a single person or professional group, allowing all participants to engage with the knowledge and its construction. However, its central focus remains personal experience, often of illness, which may prioritise the importance of knowledge that relates to those with ‘lived experience’ of cancer. It is a knowledge that is inseparable from the individual who shares it, creating and reinforcing social bonds.

This has important implications concerning how knowledge relates to power in the informal domain. As there is no set form of knowledge, there is no control or domination over its use. Despite this, there is a trend in these communities to prioritise knowledge based on personal experience, such as the ‘lived experience’ of cancer when discussing topics related to illness. In contrast to knowledge in formal health care, it inverts the power dynamics, facilitating patients to have greater authority in these discussions. Their status as cancer patients qualifies them as having greater insight into this knowledge.

This suggests a potential subversive quality of the informal domain. It may reflect the inability of formal medical discourse to properly interpret and communicate the full experience of illness, the profundity of which is lost in its reductionist focus on human biology. The knowledge of the informal domain thus focuses on what the medical discourse cannot fully comprehend, likely as a manner in which the individuals can share the exigency of these experiences, make sense of their meanings, and can do so in a forum that recognises their significance. Through placing emphasis on knowledge formed through lived experience, it enables individuals to take control of this experiential discourse.

11.4 Structures

Relational Structures

The relationships of the informal domain are fluid and evolving, yet also substantially influenced by the formal roles of the hospital space. Throughout the empirical studies, the roles of patient, visitor or health care professional influenced the interactions, and how the participants categorised and perceived the other participants. Whilst these roles are an important scaffold, unlike in the formal domain the participants are not limited by these behavioural expectations. The results are relationships in which formal roles are present, but participants are able to negotiate their own dynamics and boundaries of interactions beyond them. This facilitates personal control of participation in these encounters, as individuals moderate their involvement and the course of interaction, through engaging in behaviours and sharing of information when they feel appropriate. These formal roles may serve as a manner by which they can limit interaction, just as the manner described in the ethnography study that individuals employed objects, such as the curtains around their beds or televisions as barriers to social intercourse.

Informal communities are characterised by a mutuality of relationships, in which the participants share aspects of their selves. The individuals engage in mutual disclosure of information and through this can negotiate the dynamics of the interaction and fields of contents which they wish to explore. This sharing is not always equal, but it is in contrast to the unilateral disclosure of the formal domain, in which the patient discloses a wide range of personal information and the health professional none. As a result, in these interactions where health professionals do wish to disclose elements of a personal nature, they do so through the informal domain, and thus employ its narrative discourse and act outside of their formal roles.

Relationships of the informal domain are internally oriented, predominantly focusing on personal and inter-personal goals. In the formal system, relationships are task oriented, aimed to realise an external objective that the relationship may help to facilitate, such as the diagnosis of a medical condition, correctly deciding upon a chemotherapy regime, or administering medication. The care that results from informal communities is not the primary outcome of these relationships but is embedded within these processes of relating. The focus of these communities are the processes of relating, with outcomes and care often a by-product of these relationships.

Organisational Structures

The formal health care system has a clear organisational structure, with specific roles, tasks, and occupational foci. This organisation is strengthened by a regulatory framework governing health professional credentialling (through formal health care institutions), and thus professional roles and the tasks which particular staff members can conduct. Tasks are rationalised according to role within a clear organisational hierarchy. It has an organisational identity, as individuals are able to clearly describe their role and the tasks they are undertaking as part of this system.

Informal communities do not demonstrate such clear organisational structures. There are no defined roles, tasks or behaviours that individuals adhere to, and they act malleably to the situation and dynamics of interaction. These behaviours are the result of a range of influences, most notably the formal roles that are still relevant in this domain, as identified in the descriptions of the participants in the interview study. Yet participants are not constrained to these role behaviours in the informal domain; instead they are able to engage in a wider range of activities and tasks. Outside these roles, there is not an explicit hierarchy or ordering of relationships, and thus individuals negotiate the terms of their interaction. Tasks are not rationalised in the informal domain, with individuals engaging in multiple care acts through these interactions, ranging from practical assistance, information, and social and emotional support as described in Chapter ten.

There is no specific regulation of informal communities. However, the regulation of the formal care tasks enforces which acts are part of this domain, thus defining the boundaries of what might be considered formal and informal tasks. The regulation of the formal health care system influences the tasks and outcomes possible in the informal domain. This is an important consideration, as there are some provisions of care that are not possible within the formal domain, and thus health professionals may resort to informal communities to engage in these tasks. One example from the interview study was that of a patient’s wife who continued to visit the hospice regularly after the death of her husband and formed friendly longstanding relationships with a number of the nurses. The staff member interviewed described implicitly how through this relationship they were able to engage in long term bereavement support, while developing an enjoyable and deeper relationship than would have been possible formally. This care could not be provided through formal channels and thus the staff turned to the informal domain in order to provide care.

Discourse

The formal clinical consultation occurs within the medical discourse, informed by the knowledge of medical understandings of illness. The concepts which it discusses – cancer, chemotherapy and investigations etc. – are fixed concepts, with meanings that are supported by the medical evidence and practice. The focus of the interactions is explicitly understood to be the illness, and a familiar approach is followed in which the experiences of the patient are interrogated by the professional, who then conclude with their professional advice. The discourse uses language that is abstract, taking the specific personal experience of phenomena and relating to them as global concepts such as ‘pain’ and ‘nausea’.

Informal communities converse through discourses that are primarily focused on personal experience. The discourse often takes a narrative form, where personal experience is shared with reference to the chronology of events and the relationship of these events to the storyteller. It is not a singular discourse, taking on many forms and domains of content, that are negotiated between the participants. The language relates to concrete experiences of phenomena, rather than abstract or universal terms. The experiential concepts that are discussed do not have a fixed meaning, and thus the participants converse with different understandings. At times, participants may converse in differing discourses, where key concepts have differing significances, and thus they may fail to find common ground. Through other interactions the individuals may engage together in negotiating meanings or reconsidering existing understandings. As with knowledge, it is an emergent and evolving discourse.

Content

The contents of both formal and informal domains are broad, covering similar fields of speech content that were described in the interview study: greetings, social, personal, emotional and illness. Whilst these fields of content overlap, there are distinctions relating to how the informal domain manages content. This is especially evident when illness is discussed, most frequently by conveying personal experiences in the informal domain. The formal interaction accesses illness content through differing paradigms, patients and carers focusing on personal experience, and health professionals utilising the abstract language of the medical discourse to relate to concepts of illness and its effects.

The sharing of content is distinct between the two domains. Formal interactions occur largely through unilateral disclosure, where the health professional will divulge little personal content of their own, apart from greetings and superficial social details. The progression of the interaction is not dependent on this disclosure, and in fact the objective role of the health professional and the resulting care are facilitated by this unilateral dynamic. In contrast, the informal interactions focus on sharing of content. The progression of these interactions is dependent on mutual disclosure of information, particularly when discussing personal history, emotions or experiences of illness. Through mutual disclosure, participants share increasingly personal and intimate content, thus building and strengthening relatedness (Altman and Taylor, 1973). Through declining to share their own content, participants may purposefully limit their involvement in interactions, or bring them to a conclusion.

11.5 Functions

Care provision

The formal domain focuses on care provision that is identifiable, tangible and measurable: administering medications, pathology testing, recording observations, and deciding upon medical management through the clinical consultation. Whilst there are care processes that occur outside these tangible tasks, many may not be recognised, such as the psychological support provided by a nurse every fortnight at chemotherapy that occurs within the clinical consultation. In this domain, care provision is limited to the health professional, with patients being the recipients of the care. These relationships are focused on achieving these care outcomes, and thus discourse and tasks are ordered to realise these objectives. Once the desired care outcomes have been reached, the relationship usually concludes.

In the informal domain, care is broad, covering many aspects that contribute to health and well-being. These processes may not be readily identifiable and may differ according to the individual in terms of significance and relation to their needs. The formal domain is focused on medical care, in contrast to the informal one that has a broader context, often addressing social and personal care needs. All individuals are able to provide and receive care within these relationships. This results in opportunities for care that are not available in the formal domain.

Informal communities are not defined by care provision, which is not a primary outcome from these relationships. They are defined by their relational nature, by the manner in which the individuals relate to and interact with each other. Through providing care for another these relationships are strengthened by caring and being cared for. Care provision is a key function of this domain as it reinforces the social system around it.

Power

As discussed in Chapter two, the formal clinical consultation uses the (potential or actual) power of its knowledge and social position to influence behaviour on a societal and individual level. This facilitates acceptance of medical treatment and advice, and the medical discourse as being the authority of illness. It establishes the social conditions for the clinical consultation to take place and then enact its resultant care outcomes.

In contrast, the informal community does not appear to utilise power, at least not is such a conspicuous manner. There is no set discourse, meaning perspective or social order, and therefore no unified knowledge to promote. The knowledge incorporated within the informal domain is multiple, emergent and dependent on the individual.

Making Sense

Informal communities function with open knowledge frameworks, so that the individuals can formulate their own understandings. These understandings may be consistent with medical knowledge, but for other phenomena, such as the experiences of cancer and illness, this knowledge may be lacking. Thus, the participants are able to engage in making sense of these experiences, often through collective discussion. In the formal domain meaning is fixed, and therefore sense is already made.

Developing these understandings enables the individuals to better engage with their illness, treatment and the social processes that are conducted in the hospital. This could include a deeper understanding of the effects of chemotherapy enriched through the narrative of another patient or a better appreciation of how to act within the hospital in order to reach a desired outcome, such as gaining the attention of the nurse or asking for the results of a scan. As described in the ethnographic study, this learning occurring in the informal domain could then be applied to the formal clinical consultation. Making sense of these illness, medical and social phenomenon enable the individuals to engage with formal and informal care processes. In this manner the processes of making sense act as a function, to enable individuals to relate to others, and provide care and information through the informal domain.

Connecting

In the formal domain there are boundaries to role behaviours, content and mutual disclosure occurring within relationships. This preserves the objective nature of the clinical consultation, yet is relationally limiting, reducing the potential to connect on a deeper level. The connection between the participants is not a key function of the formal domain, as these interactions are perceived according to their outcomes, such as treatment and diagnosis.

Connecting to others is a key function of the informal community, in particular due to its ability to strengthen ties to others, reinforcing the community. This enables these communities to grow, strengthen bonds, and endure over time. It encourages the provision and receipt of care, facilitating reciprocity between the constituents. Connecting in this manner collectivises care: not a product of single interactions but as that which is embedded throughout these multiple and complex networks of relationships.

Table 3 – Contrasting the structure and function of formal health systems and informal communities

	Formal	**Informal**
Institutions	- Universities, Hospitals, Professional bodies, regulatory bodies	- No identifiable institutions
Knowledge	- A logically coherent body of knowledge - There is agreement regarding the terms / frameworks of knowledge - Knowledge has specific focus on medicine - Knowledge is controlled by the health professional - Health professionals as experts - Knowledge is explicit, formalised in guidelines / textbooks	- Knowledge relates to many fields – social / medical / emotional - Knowledge and meaning open to questioning and interpretation - Knowledge applied to many fields, hence use of multiple sources of knowledge - Knowledge is not controlled by a singular person / profession - In some forms of knowledge, those with lived experience have expertise - Knowledge is tacit - transferred through socialisation, locally and situation dependant, transient

Structures		
Relational	- Relationships occur within formal roles set within the clinical encounter - Relationships are fixed, with clear boundaries associated with provision of medical care - Relationships formed through unilateral disclosure on behalf of the patient - Participation in formal clinical encounter is necessary for clinical care - Relationships are focused on the realisation of external objectives (provision of treatment, diagnosis)	- Relationships are influenced by formal roles but also function outside of this - Relationships are fluid and evolving, with unclear boundaries and dynamics - Relationships are based upon mutual engagement and sharing - Personal control of participation (able to negotiate participation through object, role behaviours, but is not always free participation) - Relationships are predominantly focused on internal goals (personal and inter-personal goals)
Organisational	- Clear formal roles, each with specific tasks, behaviours, foci, and approaches to illness - Rationalisation of tasks - Care is formalised through institutional regulation and credentialing - Clear organisational identity based on care outcomes - Clear and set hierarchy	- Formal roles influence but do not define tasks and behaviours of the individuals within informal communities. - Individuals engage in many differing tasks - Regulation of formal system enforces what outcomes / care cannot be provided in the informal (thus defines its boundaries) - The 'group identity' is unclear or socially defined - No explicit hierarchy
Discourse	- Uses abstract and universal language - Discourse controlled by health care professional - Meaning and understandings are set in accordance with medical discourse	- Use of local and concrete language - Discourse is negotiated between participants - Uses knowledge related to many fields and understandings
Content	- Fields of content are broad, involving social, personal, emotional, illness and greetings. - Illness content is addressed differently by the participants; patients through experience, health professionals through medical discourse - Unilateral content – health professional's content confined to greetings, social and illness - Progression of interaction is not limited by unilateral disclosure	- Fields of contents are broad, covering social, personal, emotional, illness and greetings. - Illness content focused on personal experience - Shared content – participants mutually engage in fields of content - Progression of interaction is dependent on mutual disclosure
Functions		
Care provision	- Focused on identifiable and tangible provision of care (i.e. medication, surgery, diagnosis) - Care provision is limited to health professionals - Care tasks are specific and limited - Care is the outcome of these relationships - Relationships are limited to care provision, as once care has been completed, the relationship has reached its conclusion	- Care is broad, covering many aspects that contributed to health and well-being - All participants are able to provide care - Care tasks are non-specific, limited by care tasks of the formal domain - Able to provide care outside of formal structures - Care is not the specific outcome of these relationships - Through care, relationships are strengthened through caring or being cared for.
Power	- Encourage 'healthy' behaviours through implicit expectations of patient conduct (i.e. to follow treatment) - Acceptance of the medical discourse as the authority on illness and treatment - Enables the clinical consultation to take place	- Not evident that knowledge and power are functions of informal communities, in that they do not use them to support social system or its outcomes.

Making sense	- Meanings are fixed	- Developing understandings enable better engagement and control of health processes - Engagement in accessing / providing care in informal domain - Promotes relating to and sharing with others
Connecting	- Relationships are bounded, in terms of mutuality and dynamics. - Ability to connect on a deep level is mitigated through professional distance - Relationships perceived according to the outcomes of the relationship (i.e. treatment or diagnosis) - Relationships are of lesser importance	- Facilitates strengthening of ties to others - Promotes continuation of relationships - Through connecting, strengthens the impetus to participate in care for others - Communities are perceived according to the nature / meaning of the relationship - Outcomes of relationships are of secondary importance

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Chapter 12

A Framework for Engagement

The initial hypothesis, of an existing social system adjacent to formal care processes constructed through informal interactions, is a substantial claim. To verify this proposal, I engaged a mixed-methods approach through review of the clinical and sociology literature, development of a theoretical model, and conducted two empirical studies that explored this phenomenon from differing perspectives. Finally, a structural model representative of these informal communities was developed to demonstrate their structures and functions, and contrasted these with the formal domain. Such a hypothesis is challenging to prove conclusively, and this is made more difficult by the evolving and fluid nature of informal communities. Despite this, the data from each of the studies are consistent and reflect the available literature, identifying patterned social behaviours within these interactions, representative of a distinct social system.

This chapter discusses the wider implications of the research findings, in particular the impact on health practices, policies and research. Additionally, I will reflect upon the methodological and theoretical frameworks of this thesis, engaging in a discussion regarding the complexities, strengths and limitations of the approach taken.

12.1 Major Findings

This work has demonstrated that informal communities in cancer treatment settings are important, fluid and complex social entities. They are a phenomenon that is irreducible and exhibits patterned structures and functions, indicating that they exist as specific social systems. Our model describes the intricacy of these systems, complete with specific structures and functions that act to facilitate and sustain them. As opposed to the formal clinical interactions that operate alongside them, informal communities exhibit different characteristics, reflective of post- or late modernity, with fluidity of participation, knowledge and focus.

Previous research examining informal interactions in the cancer treatment setting focused on their content, yet did not progress this research from a structural viewpoint. An understanding of what they represented as a social entity, particularly in reference to existing social relationships in the hospital space, was not developed. This existing literature was extremely valuable, as it enabled the formation of the research hypothesis and methodology, without which I would not have been able to initiate this work. The results of these existing studies provided evidence of informal communities as not only a local entity, but one that exists as a broader phenomenon in other hospital settings.

The fluidity of informal communities offers opportunities that are not available within the confines of the formal consultation. As described in Chapter ten, the range of potential outcomes realised through these communities are broad. Care is able to be accessed which is not available through formal pathways, and individuals receiving care are themselves are able to provide care. The participants relate to and connect with others on a deeper level, and focus on other aspects of self that are not based on illness. These communities offer the individual other possibilities extending beyond their formal roles: to use and develop knowledge gained through experience, to make sense of their ordeals, and to engage in positive actions for themselves and others. Specifically, individuals are able to access and provide information, emotional support, anticipatory care and practical assistance. For health care professionals the informal domain provides an alternative interactive field of possibilities that can enrich their ability to understand the individuals' needs and provide care not possible within formal structures.

The focus on interpersonal relationships is a key attribute that facilitates these communities and their broad range of outcomes. The significance of these interactions is perceived according to the nature and meaning of the relationships: in their ability to make sense of illness and experience, connect with and help others. The outcomes related to these communities are of secondary importance. The functions of these social systems aim to strengthen these relational bonds, and in doing so reinforces the impetus to provide care for others, share experiences and personal narratives, and accept the support of the other participants. The absence of a set framework of meaning promotes this connection, as the participants can focus on what is personally relevant and engage together in exploring new meanings. Outside of the confines of the clinical discourse and roles, the individuals can display other qualities, expertise and aspects of their self, that they may employ to contribute to the community around them.

Alongside these opportunities presented by informal communities there are challenges. They function adjacent to formal care systems, which are highly structured in their approach to social organisation and task management. They engage in care provision alongside formal care tasks, yet lack regulation or recognition of these processes. The relational focus of the informal domain emphasises personal connectivity, and with this has the potential to expose vulnerability, in patients, visitors and staff members. I will elaborate further on these implications in the following section. It is important to consider that those aspects of informal communities that offer difference to the formal domain also have the potential to challenge such formal structures. Such a challenge is not necessarily negative, but is likely to be disruptive to existing social orders.

12.2 Implications

Recognising informal communities as social entities has substantial implications for health care practice, policy and research. Our model proposes that these communities function through patterned social relations, through which we can determine their likely impacts on health care practice, and also the manner in which we might adapt formal care provision to best engage with them. This work represents an initial step in understanding informal communities in cancer treatment, and to fully comprehend and harness their potential will require considerable further attention.

The most substantial of these implications is the recognition of existing social systems functioning within the hospital space. This is a significant and disruptive premise, and one which this research has only begun to understand and document. As informal communities are recognised as active systems in the hospital, we must consider how they interface with formal care systems, governance and processes of care and communication. This research represents this initial step, and as a result, many of the implications which follow from this are areas for further research. Caution is required in such consideration in view of the ephemeral nature of these communities, since attempting to control or engage with these communities in a manner that is not responsive to their local influences has the potential to significantly disrupt or extinguish their existence.

Health Care Practice

Awareness

The most important consideration for health care practice and professionals is an awareness of the existence of informal communities. Staff members should be conscious of the informal interactions that occur in the hospital, recognising them as important processes which they contribute to and participate in. They have the ability to facilitate or negate these interactions, often unintentionally. Enabling informal interactions to be seen as important social and care processes is a vital first step, so that they are not dismissed as valueless relationships as described in the literature reviewed in Chapter four (Larsen et al., 2014). Through recognising these communities it is to be hoped that staff can become aware of the significant opportunities they create for the individuals involved and their care. Equally, better awareness may enable these communities to be witnessed, to understand them and their influences, and identify their positive and negative outcomes.

Informal communities function adjacent to formal care systems, which are highly structured in their approach to social organisation and task management. They cover similar areas of practice and both engage in the provision of health care. At present, the care processes of informal communities are mostly overlooked, and therefore continue unrecognised alongside formal care tasks. Promoting awareness of informal communities may provide an important way to monitor informal care processes, to recognise these as contributing to care and also having the potential to lead to challenging or negative outcomes. An example from the interview study was bereavement care that was provided informally by staff to the wife of a deceased patient over an extended time period. The staff did not immediately recognise this relationship as providing care and described the relationship with great affection. Yet these relationships may have had potential for negative consequences, as this person did not access formal bereavement supports as a result of these relationships, and a formal assessment of her bereavement needs was not conducted. Such care could have also been accessed through formal channels, though doing so may have ceased the impetus for the relationship. Greater recognition may facilitate understanding of these social and care processes, and an appreciation of when these practices may conflict with formal structures or have unintended outcomes.

Another aspect of these communities that may benefit from greater awareness is their emotional nature and content. The relational structures of this domain encourage connectivity, which may present challenges in the hospital setting. These communities are formed predominantly of cancer patients, many of whom may have limited life expectancies. They enable emotional connection and consequently vulnerability, a fact remarked upon by many of the participants in these studies. These communities may enable connection and subsequent bereavement, as the other members become increasingly unwell or die. The content may cover many fields, including emotionally provoking subjects such as death, dying, loss of function and control. It may cover contents which are distressing, as the experiences shared may be frightening and have personal implications for the participant. Additionally, it enables connection between health professionals, patients and family members, and has the potential to challenge the limitations of the professional role and the perceived objectivity of the clinical gaze (Komesaroff, 2008). Facilitating awareness may enable us to better identify and reflect upon the relational significance and challenges present in informal communities.

Education

Education is central to promoting awareness of informal communities, and there are specific competencies that such education may address to facilitate negotiating these interactions. This education would be ideally directed towards staff members, given that in their work they regularly engage in communication in both domains.

Firstly, education should address facilitating communication in the informal domain. This would allow staff members to feel comfortable communicating outside of the formal discourse and sharing social content with other participants. As the informal domain often occurs adjacent to formal discussions, staff may benefit from understanding how to negotiate and direct these conversations in a manner that is respectful to the other participants and clinical responsibilities. Whilst this research does not specifically address this interface between the formal and informal domains, I am hopeful that future research will focus on this aspect so that staff education programs can address this through specific communication strategies. However, broad education programs that cover informal communication skills and practice sharing content could facilitate staff to feel comfortable and encourage other participants to do likewise.

In providing education it is hoped that this will enable informal communication to be better monitored and scrutinised. Education may address potential challenges of the informal domain, such as detecting when conversations become uncomfortable or distressing for participants, and engaging in strategies to provide comfort and re-direct conversation. This education would also promote self-reflection on behalf of health professionals, to better appreciate the dynamics of their relationships with other participants and its personal significance. Expectations and clinical scenarios focusing on professional conduct might guide future interactions and enable staff to define their engagement in this domain.

In the interview study, experienced staff discussed how they used the informal domain to achieve care objectives, such as better understanding the patient and their social situation, translating to better care. This has enormous potential, especially in difficult social situations, where there is family conflict, or individuals who disagree with medical approaches to illness and treatment. The full breadth of possibilities for use in this manner is not fully understood, and further research would ideally focus on those experienced staff members to explore its use in this area. Such learnings could be employed in communication skills training for such challenging situations.

Environment

The ethnography study documented the important influence of the hospital environment on social interaction. This includes the physical layout of the hospital space, the design and occupancy of the rooms (private versus shared rooms), the objects which fill these spaces, and the ability for patients and visitors to access the environment. The hospice was designed with a central kitchen and meals area, a place that allowed patients and visitors to congregate and feel relaxed, thus facilitating interactions in existing and new communities, and with staff members who also used this space. In contrast, the acute hospital wards had little space for visitors and patients outside the patient room, limiting the time that individuals spent in these areas and the informal interactions occurring there. Many acute hospitals have limited provision for visitors, who contribute significantly to the support and care for their family, friends and informal communities. Providing spaces, couches, tables, drink facilities and other amenities for visitors recognises and facilitates their important contributions to the social system. Hospital environments should take into consideration the social nature of the hospital environment in their design, allowing for social interaction, space to relax, and privacy when needed.

Aside from the physical design of the hospital space, there is a need to fashion the environment to facilitate the social and personal aspects of the individuals who inhabit it. The ethnography study described the undifferentiated uniformity of the hospital and its limiting influences on the manner in which the individuals related to the space and presented their selves. Patients wore identical drab hospital clothes, their rooms filled with the same characterless objects, whilst the staff wore uniforms specific to their professional role. These objects and uniforms reinforce the power dynamics of formal health systems, reducing the capacity for individual expression and interaction outside of the formal domain. In the hospice, it is usual practice for patients to wear their own clothes and decorate the rooms with their own photographs, books, and other objects reminiscent of their homes, translating to numerous interactions that featured these objects and the personal narratives they evoked, particularly with staff members. Encouraging the presence of personal objects and clothing in the hospital may facilitate individuals to feel more comfortable and interact beyond the borders of their formal role, expressing their social and personal selves.

Health Care Policy

From a health policy perspective, the existence of a parallel social and care system within the hospital is a radical proposition. Most notable is the finding that these communities are engaging in care tasks that are unregulated, undocumented and have the potential for negative outcomes.

To address these challenges from a policy perspective, a considered and thorough approach is required. Such an approach would consider how the formal and informal systems interface, the processes that relate to care provision, the outcomes that may overlap, and focus on supporting and monitoring these communities through iterative policy development. I would consider it a misguided approach to ‘formalise’ these communities, in which the formal health system attempts to subsume these systems, controlling their organisation and processes. Such a response would interrupt the functioning of these systems as described in our model, eradicating their relational focus, fluidity and responsiveness to the individual’s needs, and inevitably ending in failure. Attempts to impose controls on these communities would likely result in alternative forms of communication arising in different ways. Instead, a response that preserves the independence and determination of the communities is imperative.

The current challenge is how health services can begin to engage with these informal communities in a considered manner. Health services and policy documents need to acknowledge informal communication as contributing substantially of the care processes of the hospital. Hospital medicine, due to the acuity of patient care and competing demands, can be very task focused, and staff members may neglect the informal domain of communication due to the belief that it does not contribute to care. Health services can highlight the impact informal communication can have on patients, family and staff members, and their contributions to care, communication and personal well-being. Importantly, it can be utilised in challenging situations by skilled practitioners to realise outcomes that may not be possible using formal clinical communication. From a patient and carer perspective, the promotion of communication in the informal domain may enable care that is increasingly ‘patient-centred’, enabling discussion which is focused and controlled by the individual (Richards et al., 2015).

To develop future guidance, health services would ideally focus on mapping care processes occurring in informal communities and identify those that interface or conflict with formal tasks. It might be fruitful to begin in settings which are more conducive to informal interaction, such as the chemotherapy centre. This could establish how these processes are contributing to care, and the potential risks and benefits associated with these processes. Through such an exercise, health services can identify processes that may be problematic, and formulate approaches to engage with these processes whilst preserving the independence of these communities. Additionally, it may identify formal care processes that are enhanced, are performed in alternative manners, or potentially better accomplished in the informal domain. This may serve as a guide for formal care or as a space where informal communities can be promoted and supported in their activities.

The development of specific guidance for health services regarding informal communities in hospital settings will be a long-term process, requiring further research to consider how these systems operate and interface with local care systems. This research has only considered cancer care, but it is expected that these communities are not limited by disease, which is reflected by literature in medical and psychiatric wards(Album, 1989, Sandford and Elzinga, 1990). These communities may be subject to differing influences and outcomes of care, and will require further appraisal to consider how their structure and functions may vary.

Research

Whilst this thesis has proposed a structure of informal communities, there are many questions that remain unanswered. To develop an understanding of informal communities through which we can engage and realise their significant potential, there are key aspects that need to be addressed. Whilst I am hopeful of their potential, this hope includes embracing the challenges that they may pose to formal health systems and their potential negative outcomes.

A major challenge to activating this potential is health professional and system engagement, as at this time we lack a thorough understanding of how these systems interface with each other, and the potential ways to facilitate this interaction. In this research I have described the structure, functions and knowledge of the informal domain and the formal clinical consultation. However, we do not understand how individuals move between these systems and domains of communication. In the ethnography study many people moved fluidly between the formal and informal, and were able to access outcomes available in both domains. Identifying a theoretical framework to understand how individuals negotiate these differing structures and knowledge would prove invaluable towards developing future communication education and guidance for health professionals. Such research might focus on those staff members skilled in interacting informally, and the contents and dynamics of discourse.

The empirical research from this thesis is limited to cancer treatment within a local hospital network, forming the basis for our model of informal communities. Further research might focus on informal communities in other settings and illness types, and apply the model to these findings. Due to the fluidity of informal communities I expect there to be variability in the underlying structures and outcomes of these groups. Indeed it is interesting to consider how community outcomes may differ in other environments and sets of influences, and alter systemic structures. Such research would enable a broad mapping of the care processes in which informal communities engage in, and thus a greater appreciation of their impact and potential beyond this project.

This work has demonstrated the impact of informal communities on personal meanings and care-related outcomes. It does not, however, describe the relationship with care needs of the individual. Research could assess the care needs of individuals and identify how these people access informal communities, the processes they engage in and outcomes realised. Additionally, it could map the relationship between these needs, how the formal system addresses these needs, and the outcomes and functioning of informal communities. It is possible that informal communities may function in a manner to support care needs that are not provided for in the formal care system, however, our research questions did not directly address this.

Since the beginning of 2020 dramatic shifts in social functioning related to the coronavirus pandemic occurred. In the health sector these were profound, with normal care practices altered to minimise contact, or the mediums of communication shifted entirely to telephone or digital spaces. The empirical research for this thesis all occurred in 2017 and 2018, prior to these interruptions. With these dramatic changes that have altered the manner of communication, the space of the hospital, and the ability to connect with another (whether it be through a face-shield or the reluctance to provide physical assistance), informal communities are likely to be significantly disrupted. Yet, due to their fluid and evolving nature, it is likely that will adapt, or emerged with increasing significance and new outcomes related to the lack of connectedness present in formal care. Informal communities may hold important lessons for the formal health care as to how we can facilitate connectivity whilst being physically separate. This is a vital domain of research that has broad implications across health care.

This research has demonstrated that informal communication and relationships are often entered into as part of formal care provision. With the aforementioned alterations to care provision prompted by the coronavirus pandemic, the shifts away from physical consultations are likely to diminish these opportunities for contact outside the formal discourse. Evaluation of tele- and video-consultations has primarily focused on delivery of formal care outcomes, and has not taken into account the dynamics of care, interactions between these processes or unanticipated outcomes (Larsen, 2007, Chuo et al., 2020). The model and methods employed in this thesis may assist in this interpretation, in addition to consideration of a broader range of outcomes related to health care interactions.

12.3 Methodological Considerations

The methods employed in this studied have examined the phenomena of informal communities through differing methods of access. Firstly, a theoretical model was developed based on review of the literature of informal interactions in cancer treatment, informed by sociology and philosophy theory. We then applied two differing empirical methods - ethnography and phenomenological interviews – to further explore this phenomenon, and to test and develop our theoretical model. I have concluded by describing a structural model of these informal communities developed from all these data, drawing upon many and varied methodological approaches. This approach is influenced by a postmodern epistemology, making use of multiple theoretical positions and research methodologies in order to explore from differing perspectives, employing methods best suited to accessing and describing the phenomena.

Such an approach comes with complexity yet offers significant rewards. The complexity of these interwoven methods needs to be expanded upon, to consider the relationships between these differing theoretical and empirical works, and the final model. Each methodological approach is accompanied by its own strengths and limitations, which will be discussed in greater detail in the following section.

Relationships between Theoretical, Empirical and the Model of Informal Communities

The theoretical model of informal communities described in Chapter six was developed upon the literature discussed in the first section of this thesis. Firstly, I considered the structures and functions of formal health care in Chapter two, in order to appreciate how this formal system operates, relates to knowledge, and promotes and provisions health care. The following two chapters (Chapters three and four) addressed the informal health domain, at the level of the health collective and patient interaction. In the fourth chapter, I discussed possible structure and functions of informal interactions in cancer treatment. However, the existing literature describing informal interactions did not propose a model to understand these phenomena or what they represented as a social entity. In response to this challenge, a model of informal communities was developed to define and describe them from a theoretical perspective.

The results of this theoretical research proposed a model to define ‘informal communities’ and a scaffold through they could be understood. It was a model that was incomplete, as it lacked data to describe many of the variables. Through developing such a model, it enabled the empirical studies to proceed. Most importantly, it defined the research focus of these studies, and research questions were formulated in order to address these deficiencies in our model. Methods of data collection and analysis were chosen that were best suited toward accessing these phenomena, and complemented the theoretical approach. The model defined informal communities, provided a terminology to describe the interactions that I witnessed, and delineated the formal and informal domains of communication.

The empirical methods applied in this research examined informal communities through differing methods of access and analysis. In the ethnography study, I observed the informal communities in cancer treatment settings, describing their existence, functioning, content and influences. In the following interview study, the participants described their perceptions of the communities in which they had been engaged, through the results described their phenomenological structure. Both these studies provided complementary descriptions of these communities and their functioning, and confirmed their importance to the participants and to health care provision. Through these studies I established the applicability of the theoretical model. Using these expansive data describing informal communities through differing perspectives, the specific variables describing their structures and functions could be identified, populating the theoretical model.

The model of informal communities was the final result of this process, formed through careful and iterative analysis of existing literature, theoretical analysis and empirical studies. The resultant model uses a structural functionalist framework to describe the functioning of these communities. However, it is a model that is derived from and reflects both structural and lifeworld perspectives. This model is the core result of this thesis, describing the specifics of informal communities as irreducible and complex social systems.

Strengths and Limitations

Each research methodology has its own strengths and limitations. The research approach to this project was iterative, using those methods that were most appropriate to the theoretical framework of informal communities developed through this project. In the empirical studies, I sought and applied methods befitting the data and its interpretation, and in the case of the ethnography study, multiple layers of analysis.

The major strength of this approach was the use of complementary empirical and analytical methods that enabled access to differing aspects of informal communities. The ethnography study provided a deep and textured exploration of the functioning and content of informal communities, although it could not gain insight into personal significance and a structural understanding of these systems. The final model was thus constructed from many parts and paradigms, which demonstrated consistency with many aspects of these communities. This model represents a triangulation of data, promoting a deeper understanding of informal communities, and the scope, depth, consistency and trustworthiness of these interpretations (Seale, 1999). Through applying multiple methods and perspectives provided methodological rigour and an expansive empirical dataset to develop the model of informal communities.

This approach was guided by attempts to maintain theoretical consistency throughout the project. As detailed in Section II, the project framework was influenced by postmodern thought, as it was perceived that informal communities reflected key aspects of late modernity. The theoretical study applied postmodern, phenomenological and functional structuralist framework to construct the theoretical model. In the empirical work, I then utilised broad qualitative resources through ethnography, hermeneutic phenomenology and symbolic interactionism to explore and analyse these data, embracing the different perspectives and understandings these methods enabled. Having this theoretical consistency from the outset of the project enabled the use of differing research methods and application of the results into a coherent model of a social system.

The vignette analysis approach for the ethnography study typifies an iterative approach to data analysis. The raw observational data conferred a rich and nuanced appreciation of informal communities and their relationship to the hospital setting and formal care provision. Informed by postmodernity, I wished to preserve this continuance with the raw data, to enable the reader the see the complexity and imperfect nature of these communities, and to challenge them to pursue their own conclusions. The result is a novel methodological approach that applies aspects of hermeneutic phenomenology, thick description, feminist theory and postmodernism.

The major limitation of this research is its setting, which is confined to a single hospital network. Whilst it does access differing hospital environments at two separate hospital sites, the structures of formal health care remained consistent and the population was specific to this location. The literature reviewed in Chapter four pertaining to informal interactions in cancer treatment described hospital sites in Europe, but these included studies were small and representative only of resource rich countries. Thus the major challenge to our model of informal communities is its generalisability, given it is primarily developed from one setting. To address this, I am hopeful that this model can be applied to other hospitals, sites of care, and illness types, that will enable the development of the model through accruing additional data and will facilitate an appreciation of its strengths and constraints.

I conducted the data collection for the empirical studies as a solitary researcher. I brought my own experiences and perceptions of the space, interactions and language as a doctor and a researcher. In addition, I had pre-existing relationships with some of the staff members. These influences were taken into account from the beginning of this project, through tailoring of the research processes and methods. Through both empirical studies, I paid particular attention to my own pre-existing perceptions and interpretations, which were continually recorded as part of data collection. My supervisors were closely involved in the data analysis processes, and we openly discussed how my personal history and perceptions may have influenced interpretation of the data. In the ethnography study we analysed the data using two differing frameworks that placed emphasis on personal relatedness. Through data analysis I aimed to maximise transparency of the source data and research processes, employing methods such as vignette analysis. Whilst I acknowledge these influences and obstacles to conducting data collection and analysis, I believe the research processes took these considerations into account and into the processes of data analysis.

12.4 Reflections

This thesis represents a first step in recognising the impact of interactions outside the formal consultation. It is a premise that is disruptive and has widespread implications for formal health care systems. Whilst it is easy to focus on these large-scale conclusions, it remains yet a first step. The methodological approach has enabled the development of a robust model of informal communities; however, to make meaningful impact it requires more data, to apply it to other settings and contexts, and understand the significant untapped potential embedded within.

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Chapter 13

Conclusions

It is a busy day in the chemotherapy centre, with staff working frantically and most of the cubicles filled with patients and visitors. A lady in her fifties – Mrs Q – is sitting in the chemotherapy chair. She is smartly dressed, like someone you would see at a shopping mall, looking youthful, happy and physically well.

She is talking pleasantly with a male nurse who is setting up the chemotherapy. They discuss Tasmania, where it appears Mrs Q is from, as they tell stories of visiting that state, and the nurse makes a few jokingly disparaging remarks. They both laugh together.

A female volunteer approaches and joins in the conversation about Tasmania. The male nurse slowly drifts out of the communal discussion as he focuses on practical tasks. The volunteer sits down next to Mrs Q, as they share stories about growing up. They are both around the same age and share similar cultural backgrounds judging by their stories.

The discussion turns to stories about the illnesses of families and friends, becoming increasingly emotional and intense. The volunteer moves her seat closer to Mrs Q and the conversation becomes quieter. These stories are difficult to hear, but contain elements of very personal information, and their own emotional responses to these situations. The volunteer details the story of her brother, who first became socially isolated, then medically unwell. She discusses her reflections of dealing with his loss and her own grief.

They sit in silence as the volunteer finishes her story, both appearing quite emotional.

The silence is interrupted by another patient – Mrs R – who comes over to say hello to Mrs Q.

- Vignette from ethnography study

The formal clinical discourse is a powerful tool applied to the diagnosis and treatment of medical illness, yet with this focus on bodily processes and professional distance, it carries limitations (Komesaroff, 2008). Within the care processes of the hospital, there are spaces where the formal domain is inadequate or constricting, and individuals have the possibility to act outside of it. This is the informal domain, where individual roles, forms of knowledge and structures of discourse are not concrete. Interacting within this domain shifts the underlying structures that order formal discourse, instead promoting personal connectivity, reciprocity, and sharing of experiences and knowledge. This connectivity is central and it facilitates the development and strengthening of relationships, and is representative of a community. These informal communities exist as complex and evolving social systems, with their own structures, knowledge and functions. In contrast to the formal domain, these structures allow for fluidity on behalf of the participants, who may enact differing roles, engage with various forms of knowledge, and participate in many acts of care. Through this malleable dynamic, informal communities offer considerable opportunities for participants and outcomes of care not possible within the formal discourse. Yet, together with these opportunities there are challenges - in particular for the hospital system, where they function alongside formal care structures and processes.

At the basis of informal communities is the process of communing, relating to the other, sharing, and being present. The word ‘community’ was one I chose at the beginning of this project as an interim term. It proved to be a well-considered choice, one that was used by many of the participants in the interview study. This community was articulated in the manner in which individuals related to each other, the commonalities they discussed, and the stories they shared. These stories and their characters were intertwined, linking the participants as a large network, the people inseparable from the knowledge. As I became immersed in these communities, I met new individuals whose stories I had already heard. There were certain people – both patients and staff members – who featured repeatedly in these stories: the chemotherapy nurse who liked to play practical jokes, the pastoral carer who was always keen for a chat about the football, the patient in the chemotherapy centre who frequently overshared, and the hospital socialite ‘Jackie’ whose experiences of informal communities introduced this thesis. The data described networks of interconnected people, these bonds strengthened by the stories of other participants which continued to be shared.

This process of communing is central to understanding informal communities. Outside the structures of the formal clinical consultation and its discourse, participants negotiate their own terms of engagement (Altman and Taylor, 1973). This is articulated in the accompanying vignette, in which the volunteer discloses particularly intimate details of her life and feelings. The disclosure of such information establishes social bonds in multiple ways: individuals are able to create shared meanings, develop empathy for the other participants, and contribute information that is embedded within personal experiences. The resultant knowledge is inseparable from the persons who shared it and is then shared with others, broadening the knowledge and the community. The outcomes and functions of informal communities are closely aligned with the act of communing; focusing on developing and maintaining connectivity, support and understanding.

> *Mrs R is a lady in her forties, dressed casually, and is identifiable as a patient due to the intravenous drip and attached chemotherapy which she wheels around on a mobile pole. She enters the conversation of Mrs Q and the volunteer as they sit in silence, reflecting on the story of the volunteer's brother.*
>
> *The volunteer appears to know Mrs R, and greets her enthusiastically when she appears beside them. Mrs Q is equally enthusiastic, declaring to the volunteer that "we are already old friends." The volunteer departs and offers her chair to Mrs R. The two women talk loudly and happily, as they share recent gossip and stories involving other mutual acquaintances who are also having cancer treatment.*
>
> *They continue talking for about half an hour, and over time the timbre of their conversation becomes more subdued and intimate. Mrs R has moved her chair closer to Mrs Q. It is again difficult to hear the full contents of the discussion. They share the current difficulties they face, in particular the social challenges of being a parent, contributing to the family, and the physical issues of cancer. They compare and contrast their experiences. Mrs R states "I don't want too much information".*
>
> *Mrs R leaves the conversation to return to her cubicle. "I will be back soon…"*

Informal communities offer considerable opportunities for participants and outcomes of care not possible within the formal discourse. Yet, together with these opportunities there are challenges, in particular for the hospital system, where they function alongside formal care structures and processes. This thesis represents an initial step in understanding these communities, in order to facilitate future engagement.

At the end of this thesis I pose two challenges for the hospital system. The first, is to promote awareness of the informal domain, and the competencies and methods to engage with it. This has largely been addressed in Chapter twelve, where a framework to undertake it is proposed. The second, is to expand the current perceptions of the notion of care.

In order to maximise the potential of informal communities, it is imperative that we are able to develop systematic methods of working to enable the practices and processes of informal communities to continue, and for their potential to develop in the future. The manner in which informal communities are embedded within the hospital environment alongside formal care systems poses challenges from an organisational perspective. This is heightened by the understanding that these communities are also engaged in care provision. To ensure that the response to these communities is constructive rather than defensive, a multifocal approach is needed that addresses these communities from a staff, patient, visitor, and organisational perspective, and considers the broad array of formal processes that interface with informal communities.

Care is so much more that the clinical consultation, provision of medications, taking of blood or surgical intervention; it is found within and around these processes, in the spaces where individuals can relate to, and connect with each other. This is a more challenging concept, as it fundamentally shifts the manner in which health care is perceived and its outcomes are measured. It demands that we review and look beyond the current processes of formal health care to focus on care as a broad term that cannot always be measured objectively, and to direct attention to the individual needs of patients and their care networks: medical, social, emotional and spiritual.

This has never been more apparent than now, when clinical interactions are frequently negotiated through telephone or video-conferencing, or obstructed by protective shields. The processes that have been embedded in our usual care practices – the chat about the grandchildren, the handshake, or the caring touch during an emotional moment – have been disrupted. The interactions and care tasks of the hospital have been rationalised to minimise infectious exposure. It is not clear what has been lost with these changes in circumstances, but I would dare to suggest that it has been considerable. Much has already been discussed about the social processes of death and bereavement being altered by the pandemic, with family members being unable to visit dying relatives or give them a final kiss goodbye, and to restrict access by informal caregivers to those for whom they care (Rhee et al., 2020). If cancer treatment is considered to contain many important and distinct social processes that significantly contribute to care for the patient and family, the impact is considerable. Additionally, it is likely to have had a great impact on staff members, who are key constituents of these communities.

In this disruption there is, however, also an opportunity to reset, and for formal health systems to adapt to these perturbations. This experience has provided the opportunity to consider what aspects of care were lost during this period, and the impacts of that loss. I am hopeful that this may prompt a re-assessment from many health practitioners of their roles, of the importance of communication, and the development of a broader view of care and its contributors. As hospitals approach a return to normality, a renewed vigour for personal contact and communion may emerge. It is imperative that we prioritise these aspects of care that are often neglected from an organisation viewpoint, and that we do not continue to be perceive them only as by-products of hospital care. Future care systems should incorporate these broader care processes and informal communication into health practitioner roles and accomplishments.

Whilst this thesis portrays informal communities as existing within the interstices of care, this is a temporary space of existence. As our understandings of these communities and their contributions to care develops, I am hopeful to see shifts in their nature and perception by formal care systems, so that they are considered simply an essential part of care.

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Bibliography

ABNER, C. 1985. *The Symbolic Construction of Community,* New York, Tavistock Publications.

ADLER, P. & ADLER, P. 1994. Observational techniques. *In:* DENZIN, N. K. & LINCOLN, Y. S. (eds.) *Handbook of qualitative research.* London: Sage Publications Inc.

ALBUM, D. 1989. Patients' knowledge and patients' work. Patient-patient interaction in general hospitals. *Acta Sociologica,* 32**,** 295-306.

ALLAN, K. 2005. *Explorations in classical sociological theory: Seeing the social world*, Pine Forge Press.

ALTMAN, I. & TAYLOR, D. A. 1973. *Social penetration: The development of interpersonal relationships*, Holt, Rinehart & Winston.

ANDERSEN, L. S., LARSEN, B. H. & BIRKELUND, R. 2015. A companionship between strangers–learning from fellow people with cancer in oncology wards. *Journal of advanced nursing,* 71**,** 271-280.

ANDREWS, T. & NATHANIEL, A. 2015. Awareness of Dying Remains Relevant after Fifty Years. *Grounded Theory Review,* 14.

ANSPACH, R. R. & MIZRACHI, N. 2006. The field worker's fields: ethics, ethnography and medical sociology. *Sociology of Health,* 28**,** 713-731.

AUSTRALIA, C. & ECONOMICS, D. A. 2015. The economic value of informal care in Australia in 2015. Canberra: Deliotte Access Economics.

BAGWELL, C. E. 2005. “Respectful image”: revenge of the barber surgeon. *Annals of Surgery,* 241**,** 872.

BAKER, L. 2006. Observation: A complex research method. *Library Trends,* 55**,** 171-189.

BANDURA, A. 1977. Self-efficacy: toward a unifying theory of behavioral change. *Psychological review,* 84**,** 191.

BARTHES, R. & DUISIT, L. 1975. An introduction to the structural analysis of narrative. *New literary history,* 6**,** 237-272.

BAUMAN, Z. 1996. From pilgrim to tourist–or a short history of identity. *In:* STUART HALL, P. D. G. (ed.) *Questions of cultural identity.* SAGE publications.

BAUMAN, Z. 2001. Identity in the globalising world. *Social anthropology,* 9**,** 121-129.

BAUMAN, Z. 2013a. *Community: Seeking safety in an insecure world*, John Wiley & Sons.

BAUMAN, Z. 2013b. *Liquid love: On the frailty of human bonds*, John Wiley & Sons.

BAXTER, H. 1987. System and life-world in Habermas's theory of communicative action. *Theory Society,* 16**,** 39-86.

BECKER, H. S. 2002. *Boys in white: Student culture in medical school,* Chicago, Transaction publishers.

BELL, K. 2014. Resisting commensurability: Against informed consent as an anthropological virtue. *American Anthropologist,* 116**,** 511-522.

BERGER, P. L., LUCKMANN, T. & ZIFONUN, D. 1967. *The social construction of reality,* London, Penguin.

BIDDLE, B. J. 1986. Recent developments in role theory. *Annual review of sociology,* 12**,** 67-92.

BLUMER, H. 1986. *Symbolic interactionism: Perspective and method*, Univ of California Press.

BLUMER, H. J. 1994. Society as symbolic interaction. *In:* LARRY T. REYNOLDS, N. J. H. (ed.) *Symbolic interaction: An introduction to social psychology.* Altamira: Walnut Creek.

BORKMAN, T. 1999. *Understanding self-help/mutual aid: Experiential learning in the commons*, Rutgers University Press.

BORREANI, C., MICCINESI, G., BRUNELLI, C. & LINA, M. 2004. An increasing number of qualitative research papers in oncology and palliative care: does it mean a thorough development of the methodology of research? *Health and Quality of Life Outcomes,* 2**,** 7.

BOWTELL, W. 2005. Australia's response to HIV/AIDS 1982-2005. *Lowy Institute for International Policy.*

BROWN, L. M. & GILLIGAN, C. 1993. Meeting at the crossroads: Women's psychology and girls' development. *Feminism & Psychology,* 3**,** 11-35.

BROWN, N. 1995. *Governing Prosperity: Social change and social analysis in Australia in the 1950s*, Cambridge University Press Cambridge.

BROWN, P. & ZAVESTOSKI, S. 2004. Social movements in health: an introduction. *Sociology of Health & Illness,* 26**,** 679-694.

BROWN, P., ZAVESTOSKI, S., MCCORMICK, S., MAYER, B., MORELLO-FROSCH, R. & GASIOR ALTMAN, R. 2004. Embodied health movements: new approaches to social movements in health. *Sociology of health & illness,* 26**,** 50-80.

CALNAN, M. 2015. Eliot Freidson: Sociological narratives of professionalism and modern medicine. *The Palgrave Handbook of Social Theory in Health, Illness and Medicine.* Springer.

CANTOR, D. 2014. Before Survivorship: The Moment of Recovery in Twentieth-century American Cancer Campaigns. *Social History of Medicine,* 27**,** 440-465.

CARTER, N., BRYANT-LUKOSIUS, D., DICENSO, A., BLYTHE, J. & NEVILLE, A. J. The use of triangulation in qualitative research. *Oncology nursing forum*, 2014.

CASSELL, E. J. 1991. Recognizing suffering. *Hastings Center Report,* 21**,** 24-24.

CHAPMAN, M., PHILIP, J., GARDNER, S. & KOMESAROFF, P. 2019. Fragile objects: A visual essay. *J Bioeth Inq,* 16**,** 185-189.

CHARMAZ, Kathy 1987, Struggling for a self: Identity levels of the chronically ill. *Research in the sociology of health care,* 6.

CHUO, J., MACY, M. L. & LORCH, S. A. 2020. Strategies for Evaluating Telehealth. *Pediatrics,* 146.

COFFEY, A. & ATKINSON, P. 1996. *Making sense of qualitative data: complementary research strategies*, Sage Publications, Inc.

COLLIER, A. 2016. Practice development using video-reflexive ethnography: promoting safe space (s) towards the end of life in hospital. *International Practice Development Journal,* 6.

COLLIER, A., PHILLIPS, J. L. & IEDEMA, R. 2015. The meaning of home at the end of life: A video-reflexive ethnography study. *Palliat Med,* 29**,** 695-702.

COUNCIL, V. A. 2017. *On Australian Shores* [Online]. Available: http://undertheredribbon.com.au/our-story/1983-1987/on-australian-shores/ [Accessed 1 December 2017].

COX, A. 2005. What are communities of practice? A comparative review of four seminal works. *Journal of information science,* 31**,** 527-540.

CROWE, S., CLARKE, N. & BRUGHA, R. 2017. ‘You do not cross them’: Hierarchy and emotion in doctors' narratives of power relations in specialist training. *Social Science and Medicine,* 186**,** 70-77.

DEBESAY, J., NÅDEN, D. & SLETTEBØ, Å. 2008. How do we close the hermeneutic circle? A Gadamerian approach to justification in interpretation in qualitative studies. *Nursing Inquiry,* 15**,** 57-66.

DENZIN, N. K. 2008. *Symbolic interactionism and cultural studies: The politics of interpretation*, John Wiley & Sons.

DERRIDA, J. 1973. *Speech and phenomena, and other essays on Husserl's theory of signs*, Northwestern University Press.

DERRIDA, J. 1982a. *Margins of philosophy*, University of Chicago Press.

DERRIDA, J. 1982b. *Positions*, University of Chicago Press.

DIEPPE, P., RAFFERTY, A.-M. & KITSON, A. 2002. The clinical encounter--the focal point of patient-centred care. *Health expectations : an international journal of public participation in health care and health policy,* 5**,** 279-281.

DIXON-WOODS, M. & BOSK, C. 2010. Learning through observation: the role of ethnography in improving critical care. *Current Opinion Critical Care,* 16**,** 639-42.

DOWNS, S. D. 2012. A Phenomenologically Informed Theory ofSelf-Observation: Intra-Spection as Hermeneutic Reduction on the Self. *Self-Observation in the Social Sciences***,** 173-194.

DRASS, K. A. 1982. Negotiation and the structure of discourse in medical consultation. *Sociology of Health and Illness,* 4**,** 320-341.

EDWARDS, R. & WELLER, S. 2012. Shifting analytic ontology: Using I-poems in qualitative longitudinal research. *Qualitative research,* 12**,** 202-217.

EGESTAD, H. 2013. *The significance of fellow patients for head and neck cancer patients in the radiation treatment period*, European Journal of Oncology Nursing. .

FEATHERSTONE, K., NORTHCOTT, A. & BRIDGES, J. 2019. Routines of resistance: an ethnography of the care of people living with dementia in acute hospital wards and its consequences. *International journal of nursing studies,* 96**,** 53-60.

FISHMAN, J. 1971. *Sociolinguistics. A brief introduction,* Massachusetts, Rowley.

FOUCAULT, M. 1972. *The archeology of knowledge,* New York, Tavistock.

FOUCAULT, M. 1979. *Discipline and Punishment*. New York:: Random House.

FOUCAULT, M. 1980. *Power/knowledge: Selected interviews and other writings, 1972-1977*, Vintage.

FOUCAULT, M. 2007. *Security, territory, population: lectures at the Collège de France, 1977-78*, Springer.

FOUCAULT, M. 2012. *The Birth of the Clinic,* London, Routledge.

FOUCAULT, M. 2013. *History of madness*, Routledge.

FOUCAULT, M. 2019. *The History of Sexuality: 1: The Will to Knowledge*, Penguin UK.

FRANK, A. W. 2013. *The Wounded Storyteller: Body, illness, and ethics,* Chicago, University of Chicago Press.

FRANK, A. W. 2015. *Introduction to symbolic interactionism* [Online]. Available: http://www.arthurwfrank.org/introduction-to-symbolic-interaction/ [Accessed 3 March 2019].

FROGGATT, K. A., FIELD, D., BAILEY, C. & KRISHNASAMY, M. 2003. Qualitative research in palliative care 1990–1999: a descriptive review. *International Journal of Palliative Nursing,* 9**,** 98-104.

FRY, R. & KOLB, D. 1979. Experiential learning theory and learning experiences in liberal arts education. *New directions for experiential learning,* 6**,** 79.

GADAMER, H.-G. 1989. *Truth and Method,* New York, Continuum.

GAINES, J., JONES, D. L., HONNETH, A. & JOAS, H. 1991. *Communicative action: essays on Jürgen Habermas's The theory of communicative action,* Massachusetts, MIT Press.

GARCIA, J., COLSON, P. W., PARKER, C. & HIRSCH, J. S. 2015. Passing the baton: community-based ethnography to design a randomized clinical trial on the effectiveness of oral pre-exposure prophylaxis for HIV prevention among black men who have sex with men. *Contemporary clinical trials,* 45**,** 244-251.

GEERTZ, C. 1973. *The interpretation of cultures,* New York, Basic books.

GELVEN, M. 1989. *A commentary on Heidegger's being and time*, Northern Illinois University Press.

GENETTE, G. 1983. *Narrative discourse: An essay in method,* New York, Cornell University Press.

GIJSBERTS, M.-J. H., ECHTELD, M. A., VAN DER STEEN, J. T., MULLER, M. T., OTTEN, R. H., RIBBE, M. W. & DELIENS, L. 2011. Spirituality at the end of life: conceptualization of measurable aspects—a systematic review. *Journal of palliative medicine,* 14**,** 852-863.

GIJSBERTS, M.-J. H., VAN DER STEEN, J. T., MULLER, M. T., HERTOGH, C. M. & DELIENS, L. 2013. Spiritual end-of-life care in Dutch nursing homes: an ethnographic study. *Journal of the American Medical Directors Association,* 14**,** 679-684.

GILBERT, R. 1971. The Thinking of Thoughts, What is Le penseur doing? *Collected Papers Volume 2.* London: Hutchinson.

GINEV, D. 1999. On the hermeneutic fore-structure of scientific research. *Continental Philosophy Review,* 32**,** 143-168.

GIRVAN, C., CONNEELY, C. & TANGNEY, B. 2016. Extending experiential learning in teacher professional development. *Teaching Teacher Education,* 58**,** 129-139.

GLASER, B. G. & STRAUSS, A. L. 2017. *Awareness of dying,* New York, Routledge.

GOFFMAN, E. 1961. *Encounters: Two studies in the sociology of interaction,* Oxford, England, Bobbs-Merrill.

GOFFMAN, E. 1968. *Asylums: Essays on the social situation of mental patients and other inmates,* New Brunswick, AldineTransaction.

GOFFMAN, E. 1974. *Frame analysis: An essay on the organization of experience,* Massachusetts, Harvard University Press.

GOFFMAN, E. 1978. *The presentation of self in everyday life,* London, Harmondsworth.

GOLD, R. L. 1958. Roles in sociological field observations. *Social forces,* 36**,** 217-223.

GOLDSTEIN, J. L. 2012. Paradigm shifts in science: insights from the arts. *Nature medicine,* 18**,** 1473.

GOODSON, L. & VASSAR, M. 2011. An overview of ethnography in healthcare and medical education research. *J Educ Eval Health Prof,* 8**,** 4.

GRANT, M. P., PHILIP, J. A., DELIENS, L. & KOMESAROFF, P. A. 2019. Communal responsibility: a history of health collectives in Australia. *Internal medicine journal,* 49**,** 1177-1180.

GRASSI, L. & RIBA, M. 2012. *Clinical psycho-oncology: an international perspective,* West Sussex, John Wiley & Sons.

GREENE, K., DERLEGA, V. J. & MATHEWS, A. 2006. Self-disclosure in personal relationships. *The Cambridge handbook of personal relationships.* Cambridge: Cambridge University Press.

GRIFFITHS, J., EWING, G. & ROGERS, M. 2010. " Moving Swiftly On." Psychological Support Provided by District Nurses to Patients With Palliative Care Needs. *Cancer nursing,* 33**,** 390-397.

GRIFFITHS, J., EWING, G., ROGERS, M., BARCLAY, S., MARTIN, A., MCCABE, J. & TODD, C. 2007. Supporting cancer patients with palliative care needs: district nurses' role perceptions. *Cancer nursing,* 30**,** 156-162.

HABERMAS, J., MCCARTHY, T. & MCCARTHY, T. 1984. *The theory of communicative action,* Boston, Beacon press.

HAMMERSLEY, M. 1990. What's wrong with ethnography? The myth of theoretical description. *Sociology,* 24**,** 597-615.

HARGITTAI, E. & HSIEH, Y.-L. P. 2010. Predictors and consequences of differentiated practices on social network sites. *Information, Communication & Society,* 13**,** 515-536.

HEATON, J. 1999. The gaze and visibility of the carer: a Foucauldian analysis of the discourse of informal care. *Sociology of Health & Illness,* 21**,** 759-777.

HEIDEGGER, M. 1996. *Being and Time: A Translation of Sein und Zeit,* New York, State University of New York Press.

HIGGINSON, I. J. 2016. Research challenges in palliative and end of life care. *BMJ Support Palliat Care,* 6**,** 2-4.

HODNETT, E. D., GATES, S., HOFMEYR, G. J. & SAKALA, C. 2007. Continuous support for women during childbirth. *Cochrane Database of Systematic Reviews*.

HUBERMAN, A. M. & MILES, M. B. 1994. Data management and analysis methods. *Handbook of qualitative research.* Sage.

HUMPHREYS, M. & WATSON, T. J. 2009. Ethnographic practices: from ‘writing-up ethnographic research’to ‘writing ethnography’. *In:* SIERK YBEMA, D. Y., HARRY WELS (ed.) *Organizational Ethnography: studying the complexities of everyday life.* London: Sage.

HUSSERL, E. 1999. *The essential Husserl: Basic writings in transcendental phenomenology,* Bloomington, Indiana University Press.

ISAKSEN, A. S. & GJENGEDAL, E. 2000. The significance of fellow patients for the patient with cancer: what can nurses do? *Cancer nursing,* 23**,** 382-391.

ISAKSEN, A. S. & GJENGEDAL, E. 2006. Significance of fellow patients for patients with myocardial infarction. *Scandinavian journal of caring sciences,* 20**,** 403-411.

ISAKSEN, A. S., THUEN, F. & HANESTAD, B. 2003. Patients with cancer and their close relatives: experiences with treatment, care, and support. *Cancer Nursing,* 26**,** 68-74.

JACOBSEN, M. H. & KRISTIANSEN, S. 2014. *The social thought of Erving Goffman,* Los Angeles, Sage Publications.

JONES, W. T. 1975. *The twentieth century to Wittgenstein and Sartre,* New York, Harcourt Brace Jovanovich.

KABA, R. & SOORIAKUMARAN, P. 2007. The evolution of the doctor-patient relationship. *International Journal of Surgery,* 5**,** 57-65.

KAREN TWIGG, J. B. 2012. "Mother to Mother": Mary Paton's Leadership in the Nursing Mother's Association of Australia, 1964-1975. *In:* FRANCIS, R. G., PATRICIA; AND STANDISH, ANN (ed.) *Seizing the Initiative: Australian Women Leaders in Politics, Workplaces and Communities.* Melbourne: The University of Melbourne; eScholarship Research Centre.

KELLEHEAR, A. 2012. *Compassionate cities,* London, Routledge.

KLEIN, P. & WESTCOTT, M. R. 1994. The changing character of phenomenological psychology. *Canadian Psychology/Psychologie Canadienne,* 35**,** 133.

KNOX, H., O'DOHERTY, D., VURDUBAKIS, T. & WESTRUP, C. 2008. Enacting airports: Space, movement and modes of ordering. *Organization,* 15**,** 869-888.

KOCH, T. 1995. Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of advanced nursing,* 21**,** 827-836.

KOHLI, E., PTAK, J., SMITH, R., TAYLOR, E., TALBOT, E. A. & KIRLDAND, K. B. 2009. Variability in the Hawthorne Effect With Regard to Hand Hygiene Performance in High- and Low-Performing Inpatient Care Units. *Infection Control,* 30**,** 222-225.

KOLB, D. A. 1984. *Experiential Learning: Experience as the source of learning devolopment,* Englewood Cliffs, Prentice Hall.

KOMESAROFF, P. 1995. *Troubled bodies: Critical Perspectives on Postmodern Medical Ethics, the Body*, Duke University Press.

KOMESAROFF, P. 2008. *Experiments in love and death: medicine, postmodernism, microethics and the body,* Melbourne, Melbourne Univ. Publishing.

KOMESAROFF, P. A. 2020. John Wiltshire, Frances Burney and the doctors: Patient narratives, then and now. *Journal of Bioethical Inquiry,* 17.3**,** 449-453.

LABOV, W. 1997. Some further steps in narrative analysis. *Journal of Narrative & Life History,* 7(1-4)**,** 395–415.

LABOV, W. & WALETZKY, J. 2003. *Narrative analysis: Oral versions of personal experience,* Seattle, University of Washington Press.

LARSEN, J. A. 2007. Understanding a complex intervention: Person-centred ethnography in early psychosis. *Journal of Mental Health,* 16**,** 333-345.

LARSEN, L. S. 2013. *A companionship between strangers: patient-patient interaction in oncology wards.* PhD dissertation, Aarhus University.

LARSEN, L. S., LARSEN, B. H. & BIRKELUND, R. 2013. An ambiguous relationship–a qualitative meta-synthesis of hospitalized somatic patients' experience of interaction with fellow patients. *Scandinavian journal of caring sciences,* 27**,** 495-505.

LARSEN, L. S., LARSEN, B. H. & BIRKELUND, R. 2014. A companionship between strangers–the hospital environment as a challenge in patient–patient interaction in oncology wards. *Journal of advanced nursing,* 70**,** 395-404.

LAVERTY, S. M. 2003. Hermeneutic Phenomenology and Phenomenology: A Comparison of Historical and Methodological Considerations. *International journal of qualitative methods,* 2**,** 21-35.

LAW, J. 1994. *Organizing modernity,* Oxford, Blackwell.

LAW, J. 2009. Actor network theory and material semiotics. *Companion to Social Theory.* Blackwell.

LAWLOR, L. 2002. *Derrida and Husserl: The basic problem of phenomenology,* Bloomington, Indiana University Press.

LECOMPTE, M. D. & SCHENSUL, J. J. 2010. *Designing and conducting ethnographic research: An introduction,* Maryland, Rowman Altamira.

LINGARD, L., ALBERT, M. & LEVINSON, W. 2008. Grounded theory, mixed methods, and action research. *British Medical Journal,* 337**,** a567.

LIPSON, J. G. 1994. Ethical issues in ethnography. *Critical issues in qualitative research methods.* Sage.

LOCK, M. & GORDON, D. 1986. Biomedicine Examined. Netherlands: Springer.

LOFLAND, J. & LOFLAND, L. H. 2006. *Analyzing social settings,* Belmont, Wadsworth Publishing Company.

LONG, D., HUNTER, C. & VAN DER GEEST, S. 2008. When the field is a ward or a clinic: Hospital ethnography. *Anthropology & Medicine,* 15**,** 71-78.

LUDVIGSEN, M. S. 2009. *Patient life in hospital: A qualitative study of informal relationships between hospitalised patients.* PhD, Aarhus University.

LYOTARD, J.-F. 1984. *The postmodern condition: A report on knowledge,* Minnesota, University of Minnesota Press.

MÄKELÄ, K. 1996. *Alcoholics Anonymous as a mutual-help movement: A study in eight societies*, Univ of Wisconsin Press.

MCCAUGHAN, E., PARAHOO, K. & PRUE, G. 2011. Comparing cancer experiences among people with colorectal cancer: a qualitative study. *Journal of Advanced Nursing,* 67**,** 2686-2695.

MCDONNELL, O., LOHAN, M., HYDE, A. & PORTER, S. 2009. *Social theory, health and healthcare,* Hampshire, Macmillan International Higher Education.

MCKNIGHT, J. & MCKNIGHT, J. 1995. The careless society: Community and its counterfeits.

MEAD, N. & BOWER, P. 2002. Patient-centred consultations and outcomes in primary care: a review of the literature. *Patient education and counseling,* 48**,** 51-61.

MERLEAU-PONTY, M. 1964. *The primacy of perception: And other essays on phenomenological psychology, the philosophy of art, history, and politics,* Illinois, Northwestern University Press.

MERLEAU-PONTY, M. 2006. Eye and mind. *In:* SUNIL MANGHANI, A. P., JON SIMONS (ed.) *Images: A reader.* London: Sage.

MICHAEL, M. & ROSENGARTEN, M. 2012. Medicine: Experimentation, politics, emergent bodies. *Body and Society,* 18**,** 1-17.

MIETTINEN, R. 2000. The concept of experiential learning and John Dewey's theory of reflective thought and action. *International Journal of Lifelong Education,* 19**,** 54-72.

MILES, M. B., HUBERMAN, A. M., HUBERMAN, M. A. & HUBERMAN, M. 1994. *Qualitative data analysis: An expanded sourcebook*, Sage.

MILTON, M. 1971. *On Caring,* New Yord, Harper.

MISHLER, E. G. 1984. *The discourse of medicine: Dialectics of medical interviews,* New Jersey, Ablex Publishing.

MOL, A. 2002. *The body multiple: Ontology in medical practice,* Durham, Duke University Press.

MOORE, G. F., AUDREY, S., BARKER, M., BOND, L., BONELL, C., HARDEMAN, W., MOORE, L., O'CATHAIN, A., TINATI, T. & WIGHT, D. 2015. Process evaluation of complex interventions: Medical Research Council guidance. *British Medical Journal,* 350.

MORAN, D. & COHEN, J. 2012. *The Husserl Dictionary,* London, Bloomsbury Publishing.

MORGAN, S. J., PULLON, S. R., MACDONALD, L. M., MCKINLAY, E. M. & GRAY, B. V. 2017. Case study observational research: A framework for conducting case study research where observation data are the focus. *Qualitative health research,* 27**,** 1060-1068.

MORGAN-TRIMMER, S. & WOOD, F. 2016. Ethnographic methods for process evaluations of complex health behaviour interventions. *Trials,* 17**,** 232.

MUNSON, T. N. 1962. Wittgenstein's phenomenology. *Philosophy and Phenomenological Research,* 23**,** 37-50.

MURPHY, E. & DINGWALL, R. 2007. Informed consent, anticipatory regulation and ethnographic practice. *Social science and Medicine,* 65**,** 2223-2234.

NEUWIRTH, G. 1969. A Weberian outline of a theory of community: its application to the 'Dark Ghetto'. *The British Journal of Sociology,* 20**,** 148-163.

NG, K.-Y., VAN DYNE, L. & ANG, S. 2009. From experience to experiential learning: Cultural intelligence as a learning capability for global leader development. *Academy of Management Learning and Education,* 8**,** 511-526.

O'CONNOR, K. 1989. *Our Babies: The State's Best Asset: a History of 75 Years of Baby Health Services in New South Wales,* Sydney, NSW Department of Health.

ORD, J. 2012. John Dewey and Experiential Learning: Developing the theory of youth work. *Youth and Policy,* 108**,** 55-72.

OSUCH, J. R., SILK, K., PRICE, C., BARLOW, J., MILLER, K., HERNICK, A. & FONFA, A. 2012. A Historical Perspective on Breast Cancer Activism in the United States: From Education and Support to Partnership in Scientific Research. *Journal of Women's Health,* 21**,** 355-362.

PACKER, M. J. & ADDISON, R. B. 1989. *Entering the circle: Hermeneutic investigation in psychology,* New York, State University of New York Press.

PALMER, G. R. & SHORT, S. D. 2000. *Health care and public policy: an Australian analysis,* Melbourne, Macmillan Education AU.

PALMER, R. E. 1969. *Hermeneutics,* Illinois, Northwestern University Press.

PARSONS, T. 1991. *The Social System,* Hove, Psychology Press.

PENNER, J. L. & MCCLEMENT, S. E. 2008. Using phenomenology to examine the experiences of family caregivers of patients with advanced head and neck cancer: Reflections of a novice researcher. *International Journal of Qualitative Methods,* 7**,** 92-101.

PERCIVAL, T. 1803. *Medical Ethics: or, a code of institutes and precepts adapted to the professional conduct of physicians and surgeons,* Manchester, S. Russell.

PETRI, S. & BERTHELSEN, C. B. 2015. Lived experiences of everyday life during curative radiotherapy in patients with non-small-cell lung cancer: A phenomenological study. *International journal of qualitative studies on health and well-being,* 10**,** 29397.

PLUMMER, D. & IRWIN, L. 2006. Grassroots activities, national initiatives and HIV prevention: clues to explain Australia's dramatic early success in controlling the HIV epidemic. *International journal of STD & AIDS,* 17**,** 787-793.

POLLNER, M. & STEIN, J. 1996. Narrative mapping of social worlds: The voice of experience in Alcoholics Anonymous. *Symbolic Interaction,* 19**,** 203-223.

POPAY, J., ROBERTS, H., SOWDEN, A., PETTICREW, M., ARAI, L., RODGERS, M., BRITTEN, N., ROEN, K. & DUFFY, S. 2006. Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC methods programme* Lancaster.

POPE, C. & MAYS, N. 1995. Qualitative research: reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *British Medical Journal,* 311**,** 42-45.

PYPE, P., MERTENS, F., HELEWAUT, F. & KRYSTALLIDOU, D. 2018. Healthcare teams as complex adaptive systems: understanding team behaviour through team members' perception of interpersonal interaction. *BMC health services research,* 18**,** 570.

RAPPAPORT, J. 1993. Narrative studies, personal stories, and identity transformation in the mutual help context. *The journal of applied behavioral science,* 29**,** 239-256.

REEVES, S., KUPER, A. & HODGES, B. D. 2008. Qualitative research methodologies: ethnography. *British Medical Journal,* 337**,** a1020.

REICH, W. 1995. History of the notion of care. *Encyclopedia of bioethics.* New York: Simon and Schuster.

RHEE, J., GRANT, M., DETERING, K., CLAYTON, J. & ARTHURS, K. J. A. J. O. G. P. 2020. Dying still matters in the age of COVID-19. 49.

RICHARDS, T., COULTER, A. & WICKS, P. 2015. Time to deliver patient centred care. *BMJ : British Medical Journal,* 350**,** h530.

RIESSMAN, F. 1990. Restructuring help: A human services paradigm for the 1990s. *American Journal of Community Psychology,* 18**,** 221-230.

RISSE, G. B. 1999. *Mending bodies, saving souls: a history of hospitals,* Oxford, Oxford University Press.

ROBINSON, D. & STUART, H. 1977. Self-help and Health, Mutual Aid for Modern Problems. London: Martin Robertson.

ROSE, A. M. 1962. A systematic summary of symbolic interaction theory. *Human behavior and social processes: An interactionist approach*, 3-19.

SANDFORD, D. & ELZINGA, R. 1990. Patient interactions in four psychiatric wards. *Acta Psychiatrica Scandinavica,* 82**,** 125-129.

SANJEK, R. 1990. A vocabulary for fieldnotes. *Fieldnotes: The makings of anthropology*, 92-121.

SAVAGE, J. 2000. Ethnography and health care. *British Medical Journal,* 321**,** 1400-1402.

SCHACHTER, E. P. 2005. Erikson meets the postmodern: Can classic identity theory rise to the challenge? *Identity,* 5**,** 137-160.

SEALE, C. 1999. Quality in qualitative research. *Qualitative Inquiry,* 5**,** 465-478.

SILVERMAN, D. 1993. *Theory and method in qualitative research,* London, Sage.

SMITH, R. 2019. The public health of death, dying, and grief has been neglected, but now is the time. Available from: https://blogs.bmj.com/bmj/2019/02/07/richard-smith-the-public-health-of-death-dying-and-grief-has-been-neglected-but-now-is-the-time/ [Accessed 13/07/2020 2020].

SMITH, V.-M. 2010. A study of clinical behaviour in Intensive Care Unit. *International Journal of Research in Nursing,* 1(1)**,** 21-24.

SMITH-MORRIS, C., LOPEZ, G., OTTOMANELLI, L., GOETZ, L. & DIXON-LAWSON, K. 2014. Ethnography, fidelity, and the evidence that anthropology adds: supplementing the fidelity process in a clinical trial of supported employment. *Medical anthropology quarterly,* 28**,** 141-161.

SNOWDEN, D. 2000. The Social Ecology of Knowledge Management. *In:* DESPRES, C. & CHAUVEL, D. (eds.) *The Present and the Promise of Knowledge Management.* Woburn: Reed Elsevier.

SORENSON, O. & STUART, T. E. 2008. Bringing the context back in: Settings and the search for syndicate partners in venture capital investment networks. *Administrative Science Quarterly,* 53**,** 266-294.

SPENCER, H. 1898. *The Principles of Sociology,* New York, D. Appleton & Company.

SPRADLEY, J. P. 2016. *Participant observation,* Illinois, Waveland Press.

SYMONDS, T., DADICH, A. M., COLLIER, A., HOSIE, A., DE BELLIS, A., BEVAN, A. & MORGAN, E. Video reflexive ethnography in hospital with people with dementia and delirium: can it be done? Conference Proceedings: ACSPRI Social Science Methodology Conference, University of Sydney, 12-14 December, 2018, 2018. 130-140.

THE, A.-M. & LINSSEN, C. 2008. Euthanasie. *In gesprek met de palliatieve patiënt.* Houten: Bohn Stafleu van Loghum.

THE, A.-M., PASMAN, R., ONWUTEAKA-PHILIPSEN, B., RIBBE, M. & VAN DER WAL, G. 2002. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. *British Medical Journal,* 325**,** 1326.

TIMMERMANS, S. & OH, H. 2010. The continued social transformation of the medical profession. *Journal of health and social behavior,* 51**,** S94-S106.

TOMKINS, L. & EATOUGH, V. 2013. Meanings and manifestations of care: A celebration of hermeneutic multiplicity in Heidegger. *The Humanistic Psychologist,* 41**,** 4-24.

TREPTE, S. & REINECKE, L. 2013. The reciprocal effects of social network site use and the disposition for self-disclosure: A longitudinal study. *Computers in Human Behavior,* 29**,** 1102-1112.

UNAH, J. I. 2000. Postmodernism is Existential Phenomenology. *The Origins of Life.* Dordrecht: Springer.

URQUHART, L. M., KER, J. S. & REES, C. 2018. Exploring the influence of context on feedback at medical school: a video-ethnography study. *Advances in Health Sciences Education,* 23**,** 159-186.

VAN DER GEEST, S. & FINKLER, K. 2004. Hospital ethnography: introduction. *Social science & medicine,* 59**,** 1995-2001.

VAN MAANEN, J. 2011. *Tales of the field: On writing ethnography,* Chicago, University of Chicago Press.

VAN MANEN, M. 2017. But Is It Phenomenology? *Qual Health Res,* 27**,** 775-779.

WADE, D. T. & HALLIGAN, P. W. 2004. Do biomedical models of illness make for good healthcare systems? *British Medical Journal,* 329**,** 1398-1401.

WAITZKIN, H. 1991. *The politics of medical encounters: How patients and doctors deal with social problems,* New Haven, Yale University Press.

WALSHE, C., EWING, G. & GRIFFITHS, J. 2012. Using observation as a data collection method to help understand patient and professional roles and actions in palliative care settings. *Palliative Medicine,* 26**,** 1048-54.

WARDLE, J. L., SIBBRITT, D., BROOM, A., STEEL, A. & ADAMS, J. 2016. Is health practitioner regulation keeping pace with the changing practitioner and health-care landscape? An Australian perspective. *Frontiers in public health,* 4**,** 91.

WEEDON, C. 1997. *Feminist practice & poststructuralist theory,* Oxford, Blackwell.

WENGER, E. 1998. Communities of practice: Learning as a social system. *Systems Thinker,* 9**,** 2-3.

WILCE, J. M. 2009. Medical discourse. *Annual Review of Anthropology,* 38**,** 199-215.

WILLIS, E., REYNOLDS, L. & KELEHER, H. 2016. *Understanding the Australian health care system,* Sydney, Elsevier Health Sciences.

WILSON, K. & LUKER, K. A. 2006. At home in hospital? Interaction and stigma in people affected by cancer. *Social Science & Medicine,* 62**,** 1616-1627.

WILTSHIRE, J. 1993. Early nineteenth-century pathography: the case of Frances Burney. *Literature and History,* 2**,** 9-23.

WIND, G. 2008. Negotiated interactive observation: Doing fieldwork in hospital settings. *Anthropology & Medicine,* 15**,** 79-89.

WISEMAN, H. 2015. *10 minutes with Mike Kennedy* [Online]. Palliative Care Australia. Available: http://palliativecare.org.au/palliative-matters/10-minutes-with-mike-kennedy/ [Accessed 1 December 2017].

WITTGENSTEIN, L. 2009. *Philosophical Investigations,* West Sussex, John Wiley & Sons.

WOLF, M. 1992. *A thrice-told tale: Feminism, postmodernism, and ethnographic responsibility,* California, Stanford University Press.

YLI-UOTILA, T., RANTANEN, A. & SUOMINEN, T. 2014. Online social support received by patients with cancer. *Computers, Informatics, Nursing,* 32 (3)**,** 118-126.

YOSHIDA, K. K. 1993. Reshaping of self: a pendular reconstruction of self and identity among adults with traumatic spinal cord injury. *Sociology of Health and Illness,* 15**,** 217-245.

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Appendices

Appendix 1:

Participants Semi-structured interview questions

For Patients

Preamble:

Thank you for agreeing to attend today's interview. We want to make sure that you are comfortable throughout the interview, and, of course, you are free to stop at any time. We would like to record the interview to help us record the information and your answers will be kept strictly confidential.

Notes: The researcher will collect demographic information prior to the interview. Interviews will be semi-structured in nature providing the interviewer the latitude to adapt on a case by case basis the emotional needs of the interviewee.

Hospitals are busy places, and a short appointment can lead to meeting many people – doctors, nurses, reception staff, other patients and their families. These interactions can be many and varied, and for some people play an important role in their cancer treatment. We are interested to hear your experiences about the people you meet when you come to the hospital, the things you talk about, and how this impacts you.

1. Can you tell me about the most recent conversation you had with someone here?
   a. What did you talk about?
   b. What did you take from the interaction?
   c. Why did the conversation take place?
2. Can you tell me of another interaction you had with someone in the hospital last time you were here?
   a. What did you talk about?
   b. What did you take from the interaction?
   c. Why did the conversation take place?
3. Tell me about the people you talk to when you come to hospital / day oncology?

4. What things might you talk about with these people?
5. How are those conversations started?
6. Are these people you meet once, or see on multiple occasions?
7. How do you find it talking with other people having treatment?
8. Where do you get information about your cancer?
9. Have you accessed any support or internet groups for cancer?
   a. What are your thoughts on these groups?
10. Have you seen internet forum's or articles written by people with cancer?
11. Have you been connected with other people through family or friends who are undergoing treatment for cancer?
12. How would you describe your social life since your diagnosis?
13. How is it talking with family and friends about your treatment?
14. Do you talk to other people with cancer about your treatment?
15. Would talking with other people who are undergoing or gone through the same treatments as you be something worthwhile?
16. How do you feel about the hospital environment as a place for talking to people? Could anything be altered?

Thank you for being so generous with your time, is there anything you would like to add?

Appendix 2:

Participants Semi-structured interview questions

For Support Group Members

Preamble:

Thank you for your time today. Having cancer treatment involves meeting many people – doctors, nurses, reception staff, other patients and their families. These interactions can be many and varied, and for some people play an important role in their cancer treatment. We are interested to hear your experiences about the people you met throughout the course of treatment and the support group, the things you talk about, and how this impacts you.

Firstly, can I ask you few questions about yourself?

- Can I ask your cancer diagnosis?

1. Can you tell me about the people you met during treatment?
2. Can you tell me about a specific interaction that wasn't planned?
    a. What did you talk about?
    b. What did you take from the interaction?
    c. Why did the conversation take place?
3. How did you become involved with the support group?
    a. Was there any event that drove this?
    b. What do you take from this group?
    c. What sort of things do you discuss?
    d. What things does the group do?
4. Why do people come to these groups?
5. How was your group started?
    a. Is there a convener?
6. Where do you get information about cancer?
7. Are you a member of other groups?
    a. Advocacy groups?
    b. Internet forums?
8. Have you been connected with other people through family or friends who are undergoing treatment for cancer?
9. How would you describe yourself since your diagnosis?
    a. How is it talking with family and friends about your treatment?
    b. How is it talking to other people with cancer about your treatment?
10. How might hospital be able to better support people going through cancer treatment?

Thank you for being so generous with your time, is there anything you would like to add?

Appendix 3:

Participants Semi-structured interview questions

For Staff Members

Preamble:

Thank you for agreeing to attend today's interview. We want to understand about the interactions you have with patients, and the interactions you witness between patients, and the impacts on medical care and psychosocial well-being.

We want to make sure that you are comfortable throughout the interview, and, of course, you are free to stop at any time. We would like to record the interview to help us record the information and your answers will be kept strictly confidential. All information will be de-identified.

Notes: Interviews will be semi- structured in nature providing the interviewer the latitude to adapt on a case by case basis the emotional needs of the interviewee.

Hospitals are busy places, and a short appointment can lead to patient's meeting many people – doctors, nurses, reception staff, other patients and their families. These interactions can be many and varied, and for some people play an important role in their cancer treatment. We are interested to hear your experiences about the interactions and social networks you see developing around the patients here at the hospital.

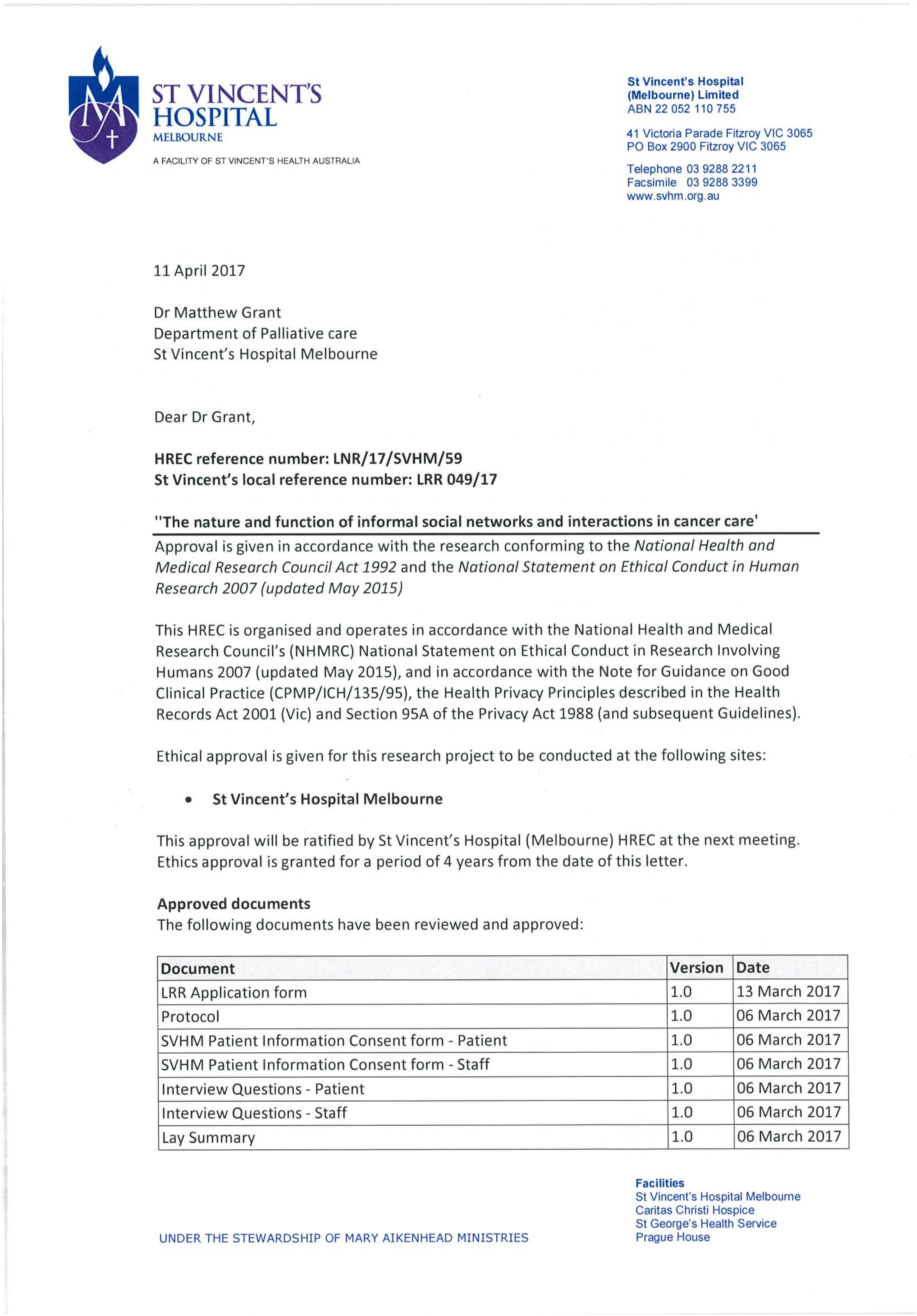
Firstly, can I ask you your role here at St Vincent's?

1. Can you tell me about the most recent conversation you had with someone here?
    a. What did you talk about?
    b. What did you take from the interaction?
    c. Why did the conversation take place?
2. Can you tell me of another interaction you had with someone in the hospital last time you were here?
    a. What did you talk about?
    b. What did you take from the interaction?
    c. Why did the conversation take place?
3. Tell me about the interactions you have with patients and carers
4. What are the things you talk about with patients?
5. What do you feel patients and carers take from these interactions?
6. Are these once off or ongoing relationships?
7. Tell me about some of the other interactions you see occurring
8. Tell me about patients talking with other patients
9. What were you perceptions of these interactions?
10. Where do these interactions occur?
11. What role might patients fulfil for other patients?
12. Do you feel this unit has a social role?
13. Can you tell me any experiences of the social role of the unit?
14. How is the set-up/environment of the unit? Does it influence interactions?

15. What are your thoughts on how a diagnosis of cancer might influence an individual’s social functioning?
16. What are your perceptions of cancer support groups? Internet forums?
17. What are your thoughts on the roles of these groups?
18. Do you recommend them to patients and carers?

Thank you for being so generous with your time, is there anything you would like to add?

Appendix 4: Human Ethics Committee Approval Letter



ST VINCENT'S HOSPITAL
MELBOURNE
A FACILITY OF ST VINCENT'S HEALTH AUSTRALIA

St Vincent's Hospital
(Melbourne) Limited
ABN 22 052 110 755

41 Victoria Parade Fitzroy VIC 3065
PO Box 2900 Fitzroy VIC 3065

Telephone 03 9288 2211
Facsimile 03 9288 3399
www.svhm.org.au

11 April 2017

Dr Matthew Grant
Department of Palliative care
St Vincent's Hospital Melbourne

Dear Dr Grant,

HREC reference number: LNR/17/SVHM/59
St Vincent's local reference number: LRR 049/17

''The nature and function of informal social networks and interactions in cancer care'

Approval is given in accordance with the research conforming to the *National Health and Medical Research Council Act 1992* and the *National Statement on Ethical Conduct in Human Research 2007 (updated May 2015)*

This HREC is organised and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Research Involving Humans 2007 (updated May 2015), and in accordance with the Note for Guidance on Good Clinical Practice (CPMP/ICH/135/95), the Health Privacy Principles described in the Health Records Act 2001 (Vic) and Section 95A of the Privacy Act 1988 (and subsequent Guidelines).

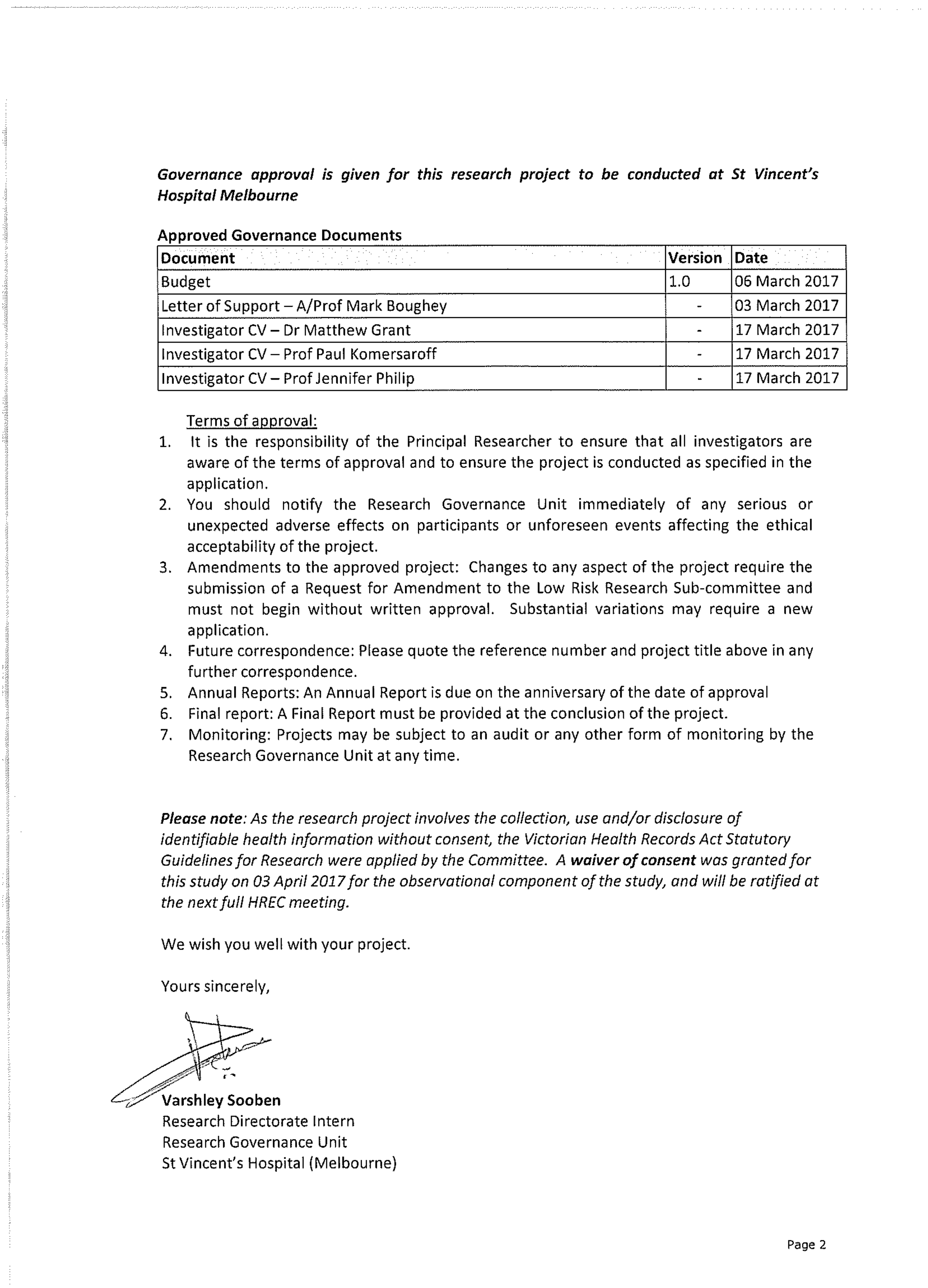
Ethical approval is given for this research project to be conducted at the following sites:

- **St Vincent's Hospital Melbourne**

This approval will be ratified by St Vincent's Hospital (Melbourne) HREC at the next meeting. Ethics approval is granted for a period of 4 years from the date of this letter.

Approved documents
The following documents have been reviewed and approved:

Document	**Version**	**Date**
LRR Application form	1.0	13 March 2017
Protocol	1.0	06 March 2017
SVHM Patient Information Consent form - Patient	1.0	06 March 2017
SVHM Patient Information Consent form - Staff	1.0	06 March 2017
Interview Questions - Patient	1.0	06 March 2017
Interview Questions - Staff	1.0	06 March 2017
Lay Summary	1.0	06 March 2017



Governance approval is given for this research project to be conducted at St Vincent's Hospital Melbourne

Approved Governance Documents

Document	**Version**	**Date**
Budget	1.0	06 March 2017
Letter of Support – A/Prof Mark Boughey	-	03 March 2017
Investigator CV – Dr Matthew Grant	-	17 March 2017
Investigator CV – Prof Paul Komersaroff	-	17 March 2017
Investigator CV – Prof Jennifer Philip	-	17 March 2017

Terms of approval:

1. It is the responsibility of the Principal Researcher to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as specified in the application.
2. You should notify the Research Governance Unit immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
3. Amendments to the approved project: Changes to any aspect of the project require the submission of a Request for Amendment to the Low Risk Research Sub-committee and must not begin without written approval. Substantial variations may require a new application.
4. Future correspondence: Please quote the reference number and project title above in any further correspondence.
5. Annual Reports: An Annual Report is due on the anniversary of the date of approval
6. Final report: A Final Report must be provided at the conclusion of the project.
7. Monitoring: Projects may be subject to an audit or any other form of monitoring by the Research Governance Unit at any time.

***Please note**: As the research project involves the collection, use and/or disclosure of identifiable health information without consent, the Victorian Health Records Act Statutory Guidelines for Research were applied by the Committee. A **waiver of consent** was granted for this study on 03 April 2017 for the observational component of the study, and will be ratified at the next full HREC meeting.*

We wish you well with your project.

Yours sincerely,

Varshley Sooben
Research Directorate Intern
Research Governance Unit
St Vincent's Hospital (Melbourne)

Appendix 5: Description of Participants for Interview Study

Participant	Role	Location of interview	Age	Sex	Diagnosis	Treatment Intention	Duration (min)
1	Patient	Palliative Care Ward	57	F	Breast Cancer	Palliative	25
2	Patient	Chemotherapy day unit	67	M	Colorectal Cancer	Palliative	93
3	Patient	Chemotherapy day unit	63	M	Multiple myeloma	Chronic	44
4	Carer for 3	Chemotherapy day unit	-	F			44
5	Patient	Chemotherapy day unit	83	F	Multiple myeloma	Chronic	18
6	Patient	Chemotherapy day unit	78	F	Breast Cancer	Curative	45
7	Carer for 6	Chemotherapy day unit	-	M			45
8	Patient	Chemotherapy day unit	49	F	Colorectal Cancer	Palliative	19
9	Patient	Chemotherapy day unit	73	M	Colorectal Cancer	Palliative	28
10	Patient	Palliative Care Ward	38	F	Renal Cancer	Palliative	51
11	Carer for 10	Palliative Care Ward	-	M			51
12	Patient	Chemotherapy day unit	84	M	Myelodysplastic syndrome	Chronic	43
13	Patient	Chemotherapy day unit	74	M	Lymphoma	Chronic	45
14	Patient	Palliative Care Ward	79	F	Ovarian Cancer	Palliative	43
15	Carer for 14	Palliative Care Ward	-	F			43

16	Staff - Administration	Hospice	-	F			43
17	Staff - Administration	Chemotherapy day unit	-	F			22
18	Support group member	Support Group	-	M	Prostate Cancer	-	91
19	Support group member	Support Group	-	M	Prostate Cancer	-	91
20	Support group member	Support Group	-	M	Prostate Cancer	-	91
21	Support group member	Support Group	-	F	Breast Cancer	-	91
22	Support group member	Telephone Interview	-	M	Prostate Cancer	-	43
23	Staff - Nurse	Palliative Care Ward	-	F			23
24	Staff – Pastoral Care	Hospice	-	F			26
25	Staff - Haematologist	Office	-	M			24
26	Staff - Nurse	Hospice	-	F			18
27	Patient	Hospice	48	F	Breast Cancer	Palliative	22
28	Staff – Oncology Registrar	Office	-	M			23
29	Staff – Palliative Care Physician	Office	-	F			30
30	Patient	Oncology Ward	34	F	Breast Cancer	Curative	50
31	Staff - Psychologist	Office	-	F			30

Appendix 6:

Understanding complexity in care: opportunities for ethnographic research in palliative care[2]

Matthew Grant, Jennifer Philip, Luc Delians, Paul Komesaroff

Abstract

Background: Ethnography has been used to address a broad range of research questions in health care. With ethnographic research methods, it is possible to gain access to the complex realities of health care practice as it occurs, through interpreting the nuances of individual and team behaviours, the roles and dynamics of care provision, and the social impacts and influences of illness. The provision of clinical palliative care is complex, involving multidisciplinary collaboration across different health systems, and is subject to a multitude of personal, cultural and environmental influences. This complexity demands creative methodological approaches to research in palliative care, of which ethnography plays an important, if infrequently utilised, role.

Aim: This article aims to explore potential opportunities of ethnographic methods for palliative care research.

Findings: Ethnographic methods focuses on behaviour in the 'natural' setting of participants, to create theoretical descriptions of events, cultures, interactions and experiences. In palliative care these methods may provide nuanced understandings of illness, relationships and teams, communication, medical education, complex care provision, and novel or changing health practices. Of particular importance is the potential of these methods to understand complex practices and processes, and engage with under-represented population groups who may be excluded from interview research.

Conclusion: Ethnography offers important opportunities for future research in palliative care and should be considered as part of the 'research toolbox' to improve understanding of the complex nature of care provision and the experiences of illness and loss.

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[2] This article is currently under review for publication. This article was developed from the contents of this thesis and thus, some contents is shared.

1. Introduction

In 1965, Glaser and Strauss published “Awareness of Dying”, exploring the experiences of death in hospitals (Glaser and Strauss, 2017). This work involved six years of ethnographic observation, witnessing how dying occurred in hospital, and the behaviours, provision of care, and communications related to death. At a time when terminal diagnoses were frequently concealed it illustrated the challenges of communication and aligning awareness between staff, patients and families, and through this described systemic issues of dominant knowledge frameworks and institutionalised roles (Dixon-Woods and Bosk, 2010). This was revolutionary research, illuminating the tensions related to dying in the hospital, the differing patterns of ‘awareness contexts’, and provided a framework to improve provision of end of life care (Andrews and Nathaniel, 2015, Froggatt et al., 2003). In addition, this research lead to the development of ‘grounded theory’; a methodology which informs a significant share of current qualitative research.

Despite the major attention upon the work of Glaser and Strauss in the field of social sciences, ethnography has remains an underutilised method in palliative care research (Borreani et al., 2004, Froggatt et al., 2003). Ethnographic methods have significant potential to progress understanding and inform future palliative care provision. These methods can shed light on the complex realities of the clinical and social practice of palliative care, through interpreting the nuances of individuals’ and teams’ behaviours, the roles and dynamics of care provision, and the influences of culture, society and relationships on illness. Ethnographic methods can enable insights not accessible from other data collection methods, including structures, processes, and behaviours the interviewed participants may be unaware of themselves (Morgan et al., 2017). Ethnography can access how life and care occurs in reality, rather than ‘how it was perceived’ (Walshe et al., 2012). Of particular importance in palliative care is the potential of these methods to bring about understanding of complex practices and processes, and engage with population groups who may be unable to participate in interview research.

Ethnography methods are very suitable to apply in palliative care. The provision of palliative care is complex, involving multidisciplinary collaboration across different health systems and teams at the site of care provision; and is subject to a multitude of personal, cultural and environmental influences (Pype et al., 2018). Palliative care provision is the result of many process and relationships between formal and informal caregivers. To understand the impact of care requires an appreciation of the dynamics, influences and relationships, in addition to the outcomes (Larsen, 2007). This demands creative methodological approaches to research, of which ethnographic methods play an important, if infrequently utilised, role.

This article aims to explore potential opportunities of ethnographic methods to be applied in palliative care research, to inform palliative care clinicians and researchers of how it might be applied for future work. To do so, it has focused on aspects of palliative care research where ethnography may provide important or new insights, with existing literature used to illustrate application of these methods. In addition, it provides an overview of ethnography methods and considerations.

2. Ethnographic methods: an introduction

Ethnography is a domain of research arising from sociology, directed towards undertaking first-hand observation and participation in the natural setting of the participants (Hammersley, 1990, Geertz, 1973). Its epistemological basis is constructionist; that knowledge is socially constructed and embedded (Goodson and Vassar, 2011). It is underpinned by the fundamental premises that (i) behaviours have meanings, (ii) actions make sense in context, and (iii) actors are knowledgeable in their own culture and actions (Goodson and Vassar, 2011, LeCompte and

Schensul, 2010). This places particular emphasis on the research context, in particular accessing the ‘natural setting’ of the participants, and thus observing behaviours in the social environment that they occur.

The research methods applied in ethnography are heterogenous, focusing on the collection of data from the natural setting of the participations through observation and/or participation in their environment (Goodson and Vassar, 2011). Historically ethnography has been characterised by complete immersion in the research environment over long time periods; yet modern applications have placed greater emphasis on accessing the natural setting through a variety of means, often for shorter duration with defined research foci (Reeves et al., 2008). Fieldnotes, based on the observations, interactions and reflections of the researcher are the major form of data collection. These data are frequently supplemented with interviews, document review, and potential media such as video or the creation of artwork. Whilst primarily a qualitative methodology, quantitative data may be collected (such as numbers of participants engaging in a specific behaviour) to support results. Data analysis may be informed by differing analytical frameworks, with commonly used methods including thick description, grounded theory and forms of thematic analysis.

Ethnography methods may sit alongside other qualitative and quantitative methods to explore research questions. In contrast to interview research the researcher is able to witness health care being enacted, rather than participant’s reflections and perceptions. This may result in differing and complementary viewpoints, each focusing on different aspects of a phenomenon to construct a deeper understanding. For example, a study of district nurses providing palliative care demonstrated they engaged in many differing care tasks, roles and behaviours when observed (Griffiths et al., 2007, Griffiths et al., 2010). Through interviews the participants were unable to describe many of these tasks or did not associate them with formal care, but detailed important perceptions on how they fulfilled their roles and the significance of this.

Ethnographic methods can be applied to a range of research questions. Notable examples of its use in health care settings include Erving Goffman’s study of institutionalising behaviours of patients in psychiatric facilities, *Asylums*; Becker’s *Boys in White*, exploring medical student culture as they transition to becoming doctors; and the work of Glasser and Strauss (Becker, 2002, Goffman, 1968). LeCompte and Schensul suggest these methods may be of significant utility for research focused on (Savage, 2000, LeCompte and Schensul, 2010):

- defining complex problems and their boundaries, effects, and stakeholders;
- accessing systemic, cultural and environmental influences on behaviours;
- exploring complex processes that involve many participants and systems, with the potential to understand measures of outcome, and unanticipated effects; and
- answering questions and accessing populations that cannot be addressed with other methods.

3. Opportunities for ethnographic research in palliative care

Ethnography has been utilised in a range of health care settings, focusing on numerous aspects of care provision and participant experience. Reflecting upon recent empirical studies and LeCompte and Schensul's framework for potential applications of ethnography, we will explore aspects of palliative care research that may benefit from the use of ethnographic methods.

A central premise of medical sociology is that the practice of medicine reflects and reinforces dominant cultural and social processes (Van der Geest and Finkler, 2004). The context and nature of palliative medicine continues to evolve in relation to the societies and personal influenced. For instance, the general practitioner who is not talking to his patient with advanced cancer about potential support by palliative care is determined by the structural elements of the palliative care provision in the country, by his training at medical school, by his own attitudes towards palliative care, but also the attitudes of the patients towards palliative care and the overall death literacy and societal culture regarding death and dying. Technological advances (e.g. telemedicine, social media), changes in legislation and medical practice (cannabinoids, palliative sedation) and social processes (death cafes, perceptions of palliative care) represent alterations to the structures of care provision. Ethnography enables exploration of these influences and their impact upon individuals, relationships, teams and care provision; to make sense of this 'messy world' in which palliative care is provided. Anne-Mei The's ethnographic studies on the withholding artificial hydration and euthanasia depicted the narratives of the patients, health professionals and families as they were confronted by these challenging situations, describing the nuances of decisions to withdraw care and the dying process (The et al., 2002, The and Linssen, 2008). Through interviews and observation, The's work described how these challenging practices were perceived by participants, and how they were approached and enacted in practice.

A common challenge to palliative care research is understanding the issues relevant to end of life care, particularly those that are difficult to enunciate or emotional (Higginson, 2016). How an issue is discussed as a concept may differ considerably from how the same interviewees or respondents relate to, and enact behaviour relating to that same issue. This was a key premise of Awareness of Dying; that health professionals engaged in behaviours to anticipate dying, yet failed to recognise or communicate the dying process (Andrews and Nathaniel, 2015). Ethnography offers the opportunity to witness how these issues are enacted and discussed in real life. For example, spirituality is a concept that has historically been difficult to define, that many individuals may relate to and interpret in diverse ways (Gijsberts et al., 2011). In a study of spiritual end of life care in nursing homes, Gijsberts et al demonstrated that staff were involved in many activities and interactions that engaged spiritual dimension of care, despite being unable to identify many of these acts formally (Gijsberts et al., 2013).

Ethnography in medicine has frequently focused on care practices occurring within the clinical encounter. These methods allow for the full context of the clinical interactions to be explored, including non-verbal behaviours, the impact of the physical space, recording of clinical data, care provision activities, and team collaboration (Dixon-Woods and Bosk, 2010). Collier et al recent video-reflexive ethnography study used the novel medium of video to detail the relationship of palliative care patients to the home environment (Collier et al., 2015). It highlighted important safety and quality issues, the expertise of patients in care provision, and the reshaping of care practices in the home setting (Collier, 2016, Collier et al., 2015). This method observed participants and then engaged them in self-reflection, providing complementary accounts of the (Dixon-Woods and Bosk, 2010). One recent study using video-reflective ethnography explored the use of feedback in clinical teaching, identifying factors that influenced and supported in use, in order to develop strategies to facilitate its future use (Urquhart et al., 2018). These methods may be highly relevant in health professional communication and education.

Palliative care provision involves technical and procedural skills, while engaging forms of emotional and moral work that place significant responsibility on individuals, which in turn influences collaborative efforts (Dixon-Woods and Bosk, 2010). An Australian study examining end of life care in an Intensive Care Unit (ICU) described the processes and tensions involved in care provision when staff believed care to be futile (Smith, 2010). The authors highlighted the lack of control many staff perceived in the ICU context and identified communication and coping strategies employed to influence clinical decision making 'upstream', engage in self-management practices, and improve patient care. Ethnographic methods are ideally suited towards understanding these influences and relational dynamics that form the bases of care provision, especially given the multidisciplinary nature of palliative care.

A challenge of qualitative interview research is the need for participants to communicate verbally, leading to the exclusion of populations who may be unable to vocalise, or whose voices may be difficult to interpret. This is particularly relevant in palliative medicine, where conditions such as stroke, dementia, head and neck tumours, and neurodegenerative diseases are common. Observation allows access to these important populations who are under-represented in research. While it is acknowledged that there must be important ethical safeguards in place when including those with cognitive impairment in research, there is also an obligation to include such frequently neglected and vulnerable individuals (Symonds et al., 2018). Ethnographic observation provides a considered approach to elucidate their behaviours and experiences which has been used in dementia research (Featherstone et al., 2019, Gijsberts et al., 2013). A recent article by Chapman et al. poignantly portrays the profound meanings communicated through behaviours and objects by a man with dementia who was no longer able to verbalise, and whose deliberate actions observed by the researcher conveyed both intention and meaning

(Chapman et al., 2019). There are many populations that are poorly represented in research and ethnography may enable a greater understanding of their experiences.

A novel application for ethnography has developed in interventional research (Morgan-Trimmer and Wood, 2016, Smith-Morris et al., 2014). This is recognition of the complexity of many interventions: involving multi-component care provisions and numerous providers, health systems, and care processes. Outcome measures frequently only assess results of these processes and do not take into account the dynamics of care, interactions between these processes or unanticipated outcomes (Larsen, 2007). The Medical Research Council's recent guidance on complex intervention evaluation focused on three components; the evaluation of what is delivered through the intervention, how the impact delivers change, and the context of the intervention and how it affects implementation and outcomes (Moore et al., 2015). A study by Finch et al used ethnography to construct a complex behavioural and educational intervention in HIV pre-exposure prophylaxis (Garcia et al., 2015). It identified particular social and structural factors that affected medication adherence and acceptability, to inform the design of an intervention that addressed the behaviours related to medication use at multiple points. A Danish study embedded a researcher within the clinical environment through a complex intervention for first episode psychosis to explore the impacts and processes of a clinical trial (Larsen, 2007). This study examined the intervention processes, impacts, and outcomes. An interesting focus of this research explored the outcomes of the intervention for the patients, who derived value from the systematic approach to support and education through a period of significant personal instability (Larsen, 2007). Ethnographic methods are uniquely placed to examine many aspects of inventions, to explore first-hand how staff, patients and their families engage with these care processes, and identify unintended outcomes as they occur (Morgan-Trimmer and Wood, 2016).

4. Methodological considerations

Ethnographic methods are heterogenous, and their empirical application may differ significantly in accordance with research focus, methods of data collection and practical considerations. Historically, ethnography is time consuming through data collection and analysis. Yet for many research questions extensive periods of observation may not be required, and could be addressed through shorter and well-defined periods of observation focused on matters pertinent to the research aims (Morgan-Trimmer and Wood, 2016).

In Palliative Care, there are important considerations relating to study design, with requirements varying widely between environments and populations. Ethics committees may have minimal experience in appraising these methods, in particular in palliative settings, thus engaging proactively with well-articulated research plans may prove fruitful (Walshe et al., 2012). The consent process may alter behaviours and relationships with participants, as it is widely described that participants behave differently when aware they are being observed, known as the Hawthorne effect (Morgan-Trimmer and Wood, 2016). When consent is appropriate, developing strong relationships with participants over time may diminish these effects.

The palliative care research environment and data may pose further considerations. Hospital spaces are traditionally occupied by individuals in formal roles (staff, patient, visitor), each with differing activities and levels of access (Van der Geest and Finkler, 2004). Embedding oneself in a staff role may allow observation of many health care practices, but also limit the availability to collect data due to competing tasks and influence how other participants act around the researcher. The role taken within the research environment and any pre-existing professional roles or experiences can influence data collection and analysis, thus self-reflection on how these may influence the collection and interpretation of data is important (Morgan-Trimmer and Wood, 2016). Data analysis is frequently complex and informed by sociology and philosophy literature, and the authors would encourage engaging interdisciplinary research teams with relevant expertise to advise and supervise analyses.

There are limitations to ethnographic methods regarding generalisability of results (Morgan-Trimmer and Wood, 2016). Most ethnographic research is confined to a single or a small number of research sites, and are reflective of these communities. However, the results aim to construct theories, understand processes and outcomes that may have broader applicability. Other study methodologies may be used to evaluate the extent or applicability of these changes in larger or different populations. In interventional research, these methods may be of considerable utility for pilot design and to identify how and which processes of the intervention to evaluate (Morgan-Trimmer and Wood, 2016).

5. Implications for future research

Ethnographic methods offer important opportunities for palliative care studies and should be considered as part of the ‘research toolbox’ to improve understanding of the complex processes of care provision and the experiences of illness and loss. This ethnographic approach may address blind spots in palliative care research, enable access to under-represented populations, allow exploration of clinical interactions and communication, and changing health practices and care provision as they unfold. Palliative care is embedded within local, national and international health, cultural and social systems, and ethnography may facilitate an understanding of the complex relationships that contribute to the provision of palliative care and identify factors and behaviours that may be amenable to future service development. In the fifty years since ‘Awareness of Dying’ was published, societal and clinical factors have shifted immeasurably, and it is anticipated that the results of ethnographic research will continue to have a significant role informing the future of palliative care.