Understanding Practices of Patient and Family Centred Care in Hospitals

by

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Abstract

In Canada, the adoption of Patient and Family Centred Care (PFCC) initiatives for adult patient populations across hospital care settings are thought to improve quality of care, safety, and cost effectiveness. However, PFCC strategies have been reported to be difficult to implement and sustain at the direct level of acute patient care due to a variety of issues including competing organizational priorities, paradoxical ethical implications, and insufficient conceptual knowledge about PFCC in practice. These persistent difficulties suggest that care in general may actually be more complex than often assumed. As such, this study investigates everyday care practices to explore how patient and family centredness is enacted in acute care. The main research objective of this study is to think about the possibilities of improving care for patients and families in hospital settings by paying attention to the complex and entangled relations, actors, technologies, and politics involved in organizing care. A practice view of work and organization is used to explore how care of families and patients is enacted in hospitals. Ethnographic methods, including participant observation, document analysis, and interviews with patients, families and members of patient care teams were conducted over one year. The study took place in a teaching hospital located within Alberta and included two surgical wards that specialized in the delivery of orthopaedic care to adult patient populations. Five patients and their family members were recruited as case study participants. Nurses and unit managers were also shadowed, interviewed, and observed while organizing everyday care. Findings in this study are organized around three observations. First, hospitals are not neutral settings of care in which PFCC can simply be implemented. Second, there were multiple values entangled in nursing practices and these were not always aligned with the values, desires, or preferences of patients. Third, despite, or perhaps because of, significant material and bodily precarity, patients and families in this study worked actively to ‘centre’ themselves in day-to-day orthopaedic care practices. These findings are relevant for nurses and researchers interested in reinventing ideas about good care practices for patients and families experiencing hospitalization.

Preface

This thesis is an original work by Harkeert Kaur Judge. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Health Research Ethics Board, “Understanding Practices of Patient and Family-Centred Care in Hospital,” Ethics ID# Pro00098424, renewed June 09, 2021.

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I would like to acknowledge that I have had many kind and supportive individuals in my life who helped me complete this work.

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Table of Contents

List of Figures

Chapter 1

Centredness in Hospitals and Nursing Practices

This research investigates the ways in which Western health systems promote the idea that patients and families should be centred in hospitals and nursing practices. Gorli and Barello (2021) describe patient centredness as an umbrella approach that includes a variety of conceptualizations and as well as concrete care practices, which aim to further involve patients in their care management by attending to their desires, preferences, values, and priorities. In Canada, there are a range of health care organizations which accept patient and family centredness (PFCC) as a fundamental approach to frame health provider and patient relationships (Accreditation Canada, 2015; Canadian Agency for Drugs and Technologies in Health [CADTH], 2015; Doktorchik et al., 2018). A conceptualization of PFCC developed by the Institute for Patient and Family-Centered Care (IPFCC) (2017) is often utilized by hospitals within the Canadian health care context. And although the IPFCC is an American organization, their conceptualization of PFCC and strategies to involve patients and families in care underpin global trends to strengthen collaborative care models.

The IPFCC (2017) identifies dignity and respect as foundational values for PFCC, and information sharing, participation, and collaboration as central strategies for their enactment. PFCC initiatives range from broader level organizational policies to changing specific individual health care provider values and behaviors. For example, a PFCC curriculum developed by patient safety and quality assurance groups across Canada advises hospitals to incorporate specific PFCC initiatives such as open visitation policies, bedside shift reporting, and the creation of patient and family advisory groups (Emanuel et al., 2016). However, these PFCC initiatives, such as open visitation policies and bedside shift reporting, have been difficult to implement in hospital care settings and nursing practices (Brownjohn, 2019; Milner et al., 2021).

Difficulties implementing PFCC initiatives within hospital care settings are described as involving ineffective organizational strategies and/or individual health professional failures, such as unsupportive attitudes and culture or lack of knowledge (Kiwanuka et al., 2019). Even with the development of significant organizational resources for PFCC implementation in hospitals (CADTH, 2015; Emanuel et al., 2016), the difficulties of enacting PFCC suggest the context of patient and family involvement in care is perhaps not well understood. A strong ideological and moralized acceptance of centring patients and families in acute care settings has persuaded researchers to seek stronger evidence and practical support for implementing PFCC as a practice in hospital care (Mackie et al., 2018). Therefore, this research aims to further explore PFCC in an acute care setting that has implemented PFCC initiatives. However, this research, through the use of ethnographic methods, develops a different account of PFCC by specifically exploring how nursing practices involve patients and families and how these are in many ways historical, produced and reproduced through our collective material and social engagement with the world.

Background

Over the past four years I have followed PFCC implementation closely. I began the study with two exploratory questions: 1) How is PFCC as outlined in policy accomplished, not accomplished, or partially accomplished? 2) In an adult acute care setting, how is patient and family centredness in care enacted and with what effects for patient and family hospital experiences? These exploratory questions arose from my experiences and training as a registered nurse.

As a registered nurse working on a trauma ward, I came to know PFCC as an organizational goal for hospital care through changing local policies and practices. I first noticed discourses of PFCC in 2017, when adult acute care wards across a Western province in Canada began adopting family presence policies as a formal strategy. As a practicing nurse I wondered how an unrestricted visitation policy would improve patient and family involvement. I also wondered if increased family presence would interfere with nursing work and how it would impact or improve the care of patients and families? My nurse colleagues were skeptical, many anticipating "a tsunami of visitors" in the hospital when open visitation hours were enforced. In the same year, individualized bedside whiteboards were introduced by managers across adult surgical care wards as a PFCC strategy. These whiteboards had demarcated areas for the staff to write their names and information such as the patient's diet, activity level, and when their next analgesic was due. The nurses on the wards were asked to fill out the bedside whiteboards daily, "another task" many lamented.

Around the same time, in 2017, hospitals across the province also began to restructure care practices, shifting from primary nursing care towards a team-based collaborative model of care titled CoACT (Hastings et al., 2016). Interestingly, the CoACT implementation resembled PFCC discourses and strategies. For example, the CoACT organizers utilized what, throughout this thesis I refer to as 'centring discourses' such as "putting patients and families first" and "working together" with patients and families when describing the CoACT program. The CoACT implementation also consisted of strategies such as bedside shift report and bedside whiteboards, which were identical to PFCC strategies. Clearly there appeared to be relationships and similarities between CoACT and PFCC implementation, which made me question how and if patients and families were becoming more involved in their day-to-day care practices.

In 2019, the patient engagement services of the provincial health authority aimed to celebrate PFCC in action through a province wide event titled “Patient and Family Centered Care Grand Rounds: Family Presence a Crucial Conversation.” This event was held virtually and in-person in a provincial hospital auditorium on February 28, 2019. Although the children’s hospital care services celebrated their 10th annual PFCC week in October 2021, the PFCC event organizer stated the “Grand Rounds on family presence was the first of its kind” and “with more to come.” Since these PFCC strategies and values were put in action, the patient engagement services of the local health authority have created and publicly shared 90 patient and family digital stories. These stories illustrate how patients and families participate and are engaged in their health care journey; they offer successful accounts of centring care. More recently, federal and provincial health research funding has also been transformed to support the exploration of patient-oriented research, which overlaps with and also builds upon PFCC sentiments of “putting the patient first.” Within a few years I have noticed that the ideals of centring, involving, and collaborating with patients and families have become increasingly embedded across various places and activities within the organization and study of hospital care in Western health systems.

Proposing PFCC as a Research Topic

The research proposal for this study was created in 2019, during a time when PFCC strategies were widely taken for granted. For example, the Canadian Foundation for Healthcare Improvement (CFHI) (n.d.) published a summary report describing their partnership with the IPFCC in 2015 and campaigns for improved family presence policies. Since then the CFHI (n.d.) indicated that 73% of Canadian hospitals had adopted accommodating family presence policies by 2020 (up from 32% in 2015). While developing this study proposal, the hospital atriums and conference rooms were available for the public to book for events and large in-person gatherings. Security staff loosely patrolled hospital areas and people were able to freely enter the hospital to use the public bathrooms, visit the wards or even the cafeteria. Aside from patient rooms, hospital spaces were very public and easily accessible. However, as I prepared to begin my data collection in March 2020, the COVID-19 pandemic quickly shifted hospital accessibility and at first glance disrupted a key PFCC strategy- family presence. The CHFI (n.d.) found that by April 2020, all hospitals that had adopted flexible family policies across Canada had changed their policies to severely restrict visitors due to COVID-19.

With the initial COVID-19 outbreak in March 2020, families were severely restricted from visiting patients due to the risk of spreading infection. Relations between hospitals, health care providers, patients and families shifted in response to a need to manage the threat of global communicable disease. Certain kinds of patients were restricted access too, by way of non-urgent surgeries being cancelled. New personal protective equipment standards, such as face masks and COVID-19 screening tools, have since been required for all people entering the facility. Among many other kinds of health care professionals, my key informants from the Patient Engagement services offices were redeployed to other care areas. My data collection in the hospital began during the Fall of 2020 and was paused twice due to the second and third waves of COVID-19 cases. I recommenced data collection in the summer of 2021, after the loosening of public health restrictions and in the fall, I exited the field, while the fourth wave of COVID-19 began to spike.

As I write this thesis throughout 2022, the hospital entrances remain guarded by security and screening staff due to evolving COVID-19 case counts. Yet while the COVID-19 pandemic was particularly challenging for patient and family presence in hospitals, and infectious disease protocols were heightened, much of the day-to-day hospital ward routines also remained the same. My background as a registered nurse working in hospitals prior to and throughout the COVID-19 pandemic has significantly informed this research and served as a pre-field work phase- by way of shaping the research problem, questions posed, analytical gaze, and ethnographic processes.

PFCC Problems Foreshadowed First for Hospital Based Nursing

Most activities and performances related to organizing and involving patients and families in day-to-day hospital care require some extent of participation from nurses. However, researchers claim that nurses can resist organizational change adopting PFCC initiatives (Carlstrom & Ekam, 2012). This is interesting, because PFCC core concepts, such as respect, dignity, and collaboration, are also reflected in ethical statements (e.g. American Nurses Association, 2015), codes of conduct, and guidelines for nurses across the world (International Council of Nurses, 2020). Over the last fifty years, nursing has made jurisdictional claims to provide patient-centred care as a key characteristic of their professional identity (Allen, 2014). Yet, further nursing work and engagement is frequently considered imperative for implementing and sustaining PFCC in acute care (Small, 2018; Small & Small, 2011). Hammersley and Atkinson (2019) would describe these concerns as foreshadowed problems or sets of issues that offer a starting point for exploratory research.

Unlike research projects that begin with a set of hypotheses or a well-developed theory, this study is spurred by surprising observations made of organizational policy changes and ordinary nursing practices with patients and families in hospitals. A key observation that propels this study is that there appear to be complex practical, political, and historical issues related to involving patients and families in hospital settings where PFCC strategies have been implemented. There are researchers who interpret nursing hesitancy towards embracing PFCC initiatives as being uncaring or a problem situated intrinsically within nursing attitudes (Gottlieb, 2003). However, these claims appear overly simplistic because practices of caring are complex and often contain multiple meanings which change in relation to how people are situated.

Concerns about Nursing 'Care' with Patients and Families

In organizational settings like a hospital, nurses, patients, and families enact different and multiple kinds of care. Therefore, when diverse actors are attempting to care in their own sense, conflict may arise. According to the Merriam Webster (n.d.) dictionary, there are multiple definitions of care. Care can describe a kind of service or performance, so that a person or object is kept healthy or in good condition. Caring can also refer to a feeling, to have a liking, a fondness, or a concern. Furthermore, the concept of care can be used to portray a state of possession or responsibility for taking charge of someone. As such, it is not surprising when researchers, such as Mikesell and Bromley (2012), suggest aspects of patient centredness may conflict with nurses' professional identities as caregivers. Patient and family involvement in the hospital is usually negotiated with nurses and this can be challenging when nursing expertise, responsibilities, and organized care work becomes disrupted or undermined by the family or patient's expertise (Allen, 2000a & 2000b).

Research studies commonly report a range of nursing concerns when open visitation or bedside shift reporting are introduced as PFCC initiatives: risks to patient privacy (Rippin et al., 2015), interference with nursing work (Coats et al., 2018), and increased risk of physiological stress and infection for patients and their families (Fumagalli et al., 2006). These hesitations towards adopting PFCC strategies appear multifaceted because they are related to additional nursing practices, such as creating safe working environments, maintaining professionalism, and cost containment. Other nursing concerns noted across the research include insufficient time to address visitor concerns during bedside shift report (Roslan & Lim, 2017), overcrowding and noise pollution in shared patient rooms (Reiling et al., 2008; West et al., 2005), constrained environmental and physical space for family members (Baker et al., 2016; Chang & Chien, 2017; Choi & Bocsh, 2013) and restructuring of care towards a customer service model (Mikesell & Bromley, 2012; Rankin, 2015).

The concerns described above are shared among my nurse colleagues today, however some researchers claim that many of these concerns, such as infection and physiological stress, are unfounded or lack supportive evidence (Davidson et al., 2014; Gregory et al., 2014; Khaleghparast, et al., 2015). And although the research remains limited, nursing concerns that patients and families might spread infection in hospitals have re-surged during the COVID-19 pandemic. As well, the physical separation of family members from inpatients renewed serious debates on the ethical and psychological implications of physical isolation (Voo et al., 2020). These concerns do not appear to stem from a lack of caring attitudes, rather there are historical, philosophical, material, and structural issues that are organized by and organizing nursing practices for patients and families in hospitals.

The complexities of nursing care with patients and families in hospitals appears to have received little empirical and theoretical analysis from researchers. One explanation offered by researchers for the lack of attention to the sociomaterial conditions of nursing practices is that many aspects of nursing work within hospitals are invisible (Allen, 2015; McWilliam & Wong, 1994; Mikesell & Bromley, 2012; Wolf, 1989). Thus, a different research lens, one that endeavors to understand these complexities, by attending to the ordinary political, material, and fluid arrangements of nursing practices with patients and families in hospitals settings is necessary.

Attending to how Nursing Practices Involve Patients and Families

In this study, I emphasize and question the meaning of patient and family ‘involvement’ in nursing practices. I utilize quotation marks to show my skepticism with the formal use of this centring discourse in PFCC initiatives. On one hand, patients are always ‘involved’ in organizing nursing practices in hospitals and I will describe how this has historically been the case as Western medicine developed. On the other, to understand the practical and political challenges of ‘involving’ patients and families in nursing care, it seems necessary to understand care has many meanings, involves many actors, and emerges in different ways in hospitals. Researchers such as Jeannette Pols, Mary Ellen Purkis, and Annemarie Mol to name a few, attempt to do this both philosophically and empirically. Their work approaches nursing care as an open event, emerging from bodies, materialities, institutional norms, and aesthetic values. They draw on several fields including medical sociology, organizational studies, and science and technology studies to examine the ways in which care practices are emergent and distributed among collectives of people and things. Their work inspires a different way to conceive nursing care with patients and families in hospital settings adopting PFCC strategies, which is to privilege studying nursing care as empirical practices that occur in organizational contexts (Ceci et al., 2017). That is, as Ceci et al. (2017) state, to consider “nursing practice to be an unfolding activity situated in collective and material worlds” (p.53). Following this line of thinking, it becomes necessary to understand how hospital-based nursing care of patients and families emerges. Therefore, this study begins with a brief historical review of why and how PFCC has become significant in Western hospital-based nursing care.

History of Hospital Care: Turning Towards Centredness

The implementation of PFCC initiatives in hospital care in Western health systems has a history spanning over 50 years. Historical accounts tracing the uptake of PFCC initiatives in hospital care point to heterogeneous elements, such as ideological and risk-related discourses, as well as advancements in germ theory and evidence-based research (IPFCC, n.d.), which have influenced hospital organization and public desire for patient and family centredness in care. Historical accounts, such as writing by IPFCC (n.d), Jolley and Shields (2009), and Rosenbaum et al. (2009)[1], appear to assume that hospitals are neutral, container-like entities, shifting and adopting PFCC policies according to new evidence or advocacy work. However, hospitals are not natural structures within the health care system and thus it is equally important to understand how hospitals, as social institutions, have evolved and shifted relationships and roles among patients, families, health care providers, and the lay public. Charles Rosenberg (1979), a historian of medicine and science, states:

> It is natural for us to see the hospital as central to the provision of medical care, to medical education and to clinical investigation. For historians concerned with such matters, it is equally natural to see the hospital as reflecting in its evolution and present shape all those factors which have made the modern world modern - increases in scale, the dominance of professional elites and bureaucratization of human relationships, tendency toward technological approaches to social problems, the legitimation of social roles and policies in terms of that technology. (p.346)

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[1] Rosenbaum et al. (2009) suggests family centred initiatives spurred due to advocacy work of parents with special needs children in the 1940s. In America, parents were encouraged to institutionalize their children with disabilities up until the 1940s. Growing psychological research (Carl Rogers client- centred theory) and concerns of paternalistic care models encouraged advocacy of family ‘centred’ care.

In this quote, Rosenberg suggests hospitals are not merely container-like structures offering key medical care for patients and families. Instead, he suggests that hospitals have become essential to Western health services due to political, economic, and cultural conditions. Societal conditions such as urbanization, advancing technologies, and professionalization of health care provider roles continue to make-up hospital and organize acute care today. Rosenberg's writing describes the rise of American hospital systems, and he suggests that many of the present-day concerns related to the organization of hospital care for patients and families, such as financial costs, technological nature of medicine, and professional bureaucracy, can be found in discourses more than a century ago. Patients and their families were not always considered to be at the 'centre' of care or care decision-making in hospital settings, and there appear to be multiple factors as to why this was and, in some ways, remains the case today.

Patient and Family Involvement in Hospitals During the 19th Century

There were no discourses related to centredness in care before the 20th century because formal care by health professionals and organizations was quite limited, and care was generally provided by family members themselves**.** Rosenberg (1987) describes how almshouses in the 1800s were the very first kinds of hospitals, housing and caring for poor people who were often without family. Since such institutions for care had high rates of mortality and were often volunteer run by religious organizations, upper and middle-class families mostly refrained from accessing them, typically hiring private care providers for care at home. Though Rosenberg's work focuses on American hospitals, his descriptions of 19th century hospital care appear to be echoed in other Western parts of the world.[2] Higgins (2008) also describes how infirmaries

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[2] Although Rosenberg provides insights of the rise of hospital care in North American context, other researchers have developed strong historical analysis related to the colonial roots and power of Western medical care to influence hospital organization and care in other parts of the world. For example, see Greenwood (2016) who describes colonial medical services in Africa and Pati and Harrison (2018) who describe colonial medicine in India.

established by settler colonies in Canada were the first kinds of hospital structures, and primarily provided care for military personnel (i.e., men far from their families). Fissell (1989) conducted a social history of the poor in the United Kingdom and found that a lack of local family resources resulted in individuals seeking care from infirmaries. Rosenberg (1979) claims that hospitals up until the 1880s were a marginal aspect of medical care for most patients and families in America. There were limited medical interventions which could improve a patient's illness and admissions were often lengthy, because it simply was not possible to provide care for people who were imminently dying. With greater technological medical innovation, hospitals increasingly became sites for teaching medicine, offering clinical experience, and places for physicians to perform and publish therapeutic treatments.

Although pioneer hospitals in North America were organized by people from similar social backgrounds (e.g. nurses, doctors, and lay trustee members), Rosenberg (1979) suggests that there has always been tension around who was the central authority and decision-maker for organizing care of patients and families. For example, as hospitals became a key site for medical instruction, many trustees in both public and private hospitals were cautious of allowing medical students to perform medical activities and were concerned with "the right of patients to refuse to serve as clinical material" (Rosenberg, 1979, p.354). There were, as described by Rosenberg, recurrent issues and tensions between physicians and lay trustee board members regarding authority and hospital decision-making. Up until the late 19th century, lay trustees in hospital committees would discipline hospital staff, sample the hospital diet, and even evaluate which patients should be admitted. However, with greater immigration and an increasing population of possible patients in America, Rosenberg described how the nature of trustee work shifted towards balancing economic responsibilities and the rapidly rising cost of hospital care.

Although hospital care has changed a great deal since the late 19th century some concerns are not remarkably different from the modern form of seeking centredness of patients and families known today.

Interestingly, contemporary literature on centredness in health care assumes that family involvement and collaboration with hospital care is a novel approach to organizing good care, with centredness approaches often framed as a change in paradigm (Accreditation Canada, 2015; Clark & Guzzetta, 2017; Regan et al., 2017). A paradigm shift implies that the usual or accepted way of doing or perceiving something changes drastically. To understand PFCC as a paradigm shift reveals a fundamental assumption that formal health care services (e.g., physicians, nurses, and hospitals) entirely organized hospital care practices. However social histories of the evolution of hospital care demonstrate that while PFCC discourses were absent in 19th century, Western hospitals, patients and families were not passive or disinterested in organizing hospital care (Renshaw, 2009). That is, even as hospitals became key sites of medical care, research, and training, patients and families were actively involved in organizing and making up hospital care.

Patients and Families Making up Hospital Care

Across North America, and outside of current, formalized PFCC discourses and policies, there is a long history of patients and families actively ‘involved’ in care, including actions challenging socioeconomic and racial barriers to receive more equitable care. For example, prior to and alongside the growth of hospitals as formal sites of care, some patients and families were often denied hospital access by Western health systems due to their social backgrounds. Renshaw (2009) describes how, in early 19th century American hospitals, visitation by formalized female groups and charitable organizations, primarily of higher economic status, was typically permitted while poorer visitors and families were often rejected. In addition to socioeconomic status, racial discrimination and segregation played a significant role in determining hospital admission.

Such racial disparities within health care institutions continue to exist (Mahabir et al., 2021), despite efforts to present the health professions and hospitals themselves as scientific, democratic, and neutral institutions when implementing PFCC strategies (Ahlberg et al. 2022). Gamble (1995) explains that, historically, hospitals were often segregated along racial or religious lines, as in the case of Black Americans who were put into a position of needing to establish their own hospitals in America. Erickson's (2016) masters thesis also describes the development of African American hospitals in early 20th century Indianapolis, demonstrating the ways in which racial inequities in health care treatment spurred further advocacy work.[3] Historically, white nurses and doctors in North America occupied roles of organizing and delivering hospital care, while also restricting black people from becoming health care providers and receiving care as patients.[4] Therefore, patients and families who experienced racial disparities were particularly active in arranging and organizing hospital care for themselves.

In Canada, practices of racial segregation and discrimination have also organized hospital care of Indigenous patients and families since the 1800s. Early Christian missionary work organized the so-called Indian hospitals in Canada (Lux, 2017). Lux (2017) describes how Indian hospitals were expanded by the government after the Second World War to inhibit the spread of tuberculosis and as a response to treaty negotiations, which promised Indigenous peoples of Canada better health care. However, Indigenous patients were admitted to these hospitals according to their Indian status as opposed to the acuity of their illness and perhaps more

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[3] Erickson (2016) found that in 1901 The City Hospital in Indianapolis admitted 362 African American patients and 1, 245 white patients

[4] Gamble (1995) chronicles key events from 1920-1925 which spurred The Black Hospital Movement in the Unites States.

importantly they did not have the same rights as other Canadians in hospital care (Lux, 2017). Even today, Indigenous peoples in Canada continue to fight and advocate for a re-organization of hospital care that addresses systemic racism and lack of access to quality health care.

Hospital care has also been organized around religious values since the early 1900s[5,6]. These values have real effects on marginalized groups through discriminatory care practices. As recently as the 1980s, people living with HIV/AIDs in North America did not have the same visitation rights in hospitals as heterosexual couples (Levine, 1990). In 2010, President Obama signed a presidential memorandum to declare that hospitals that participate in Medicare or Medicaid, which are publicly funded health programs, must not deny visitation for people based on their race, color, national origin, sex, sexual orientation, gender identity or disability (Human Rights Campaign Foundation, n.d.)[7]. Legal definitions of family have since evolved in the hospital context to be more inclusive than traditional Western ideals of nuclear families. More importantly to note however, is that patients and families have had to be 'involved', advocate and make hospital care arrangements for themselves. Thus, it seems fair to observe that while centring discourses have not existed since the inception of the hospital, patients and family members have not been passive care recipients and instead have been actively attempting to gain access and be involved in care[8].

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[5] Halperin (2012) describes the rise and fall of American Jewish hospitals and in Canada the Jewish General Hospital (n.d.) was formed in 1930 due to religious persecution of Jews, but its patients and staff are from all religious, ethnic, cultural and linguistic backgrounds

[6] Wall (2011) traces changes and challenges to Catholic hospitals during 20th Century

[7] CNN Writers wrote an article about the presidential referendum and shared the influential advocacy story of Janice Langbehn. Janice was denied visitation when her partner of 17 years, Lisa Pond, was hospitalized. Despite providing legal documentation that they were a family with children, Lisa died before being able to be seen by her family.

[8] The racial discrimination that I described in the history of hospitals emerged as an ongoing problem (albiet in a different guise) while I conducted this study. This section aims to foreshadow a discovery from my observations where racism manifests as an ongoing problem for hospital-based nursing practice.

20th Century: Rise of PFCC

Although influential non-profit organizations within America, such as the Picker Institute, are thought to have coined the term “patient centred care” (Everhart et al., 2019), researchers suggest centring discourses were first established in the late 20th century in the context of Western pediatric care and were further supported by developments in psychological research (Renshaw, 2009). Other American organizations, such as the IPFCC and Plantree Inc., were also actively using PFCC discourses in the 1970s and their definitions and ideas of PFCC continue to circulate globally (Everhart et al., 2019). These institutions facilitated PFCC implementation in hospital care by building on the early advocacy work of parents who had hospitalized children in Western pediatric care settings during the 1940s (Bamm & Rosenbaum, 2008; Everhart et al., 2019). Parents of hospitalized children reported grievances and challenges arranging visits during their work hours, which resulted in families experiencing emotional distress and dissatisfaction with care (Giganti,1998). Research describing ‘maternal deprivation’ and psychological harm began to emerge after World War II when children and their parents were separated for long periods of time (Jolley & Shields, 2009; Renshaw, 2009).

Interestingly, these issues related to hospital visitation, arguably a foundational strategy for PFCC implementation in hospitals, persist a century later. Visitation policies in hospitals were questioned during the mid-1950s (Giganti, 1998), yet restrictions continue to be enforced in hospitals for a variety of reasons including fear of spreading infection, interference with health care providers’ work, and confidentiality (Voo et al., 2020). As researchers continue to discuss what policies make good care for patient and family care experiences, a key logic underpinning the exponential growth of psychological research and advocacy work further supporting PFCC discourses are health care provider endeavors to further humanize care.

PFCC is to Humanize Care

Health care provider ideals of centring care on adult patients and their families have drawn on the visitation debates within the pediatric care literature and psychologizing discourses of treating adult patients as individualized or 'whole' persons. During the latter half of the twentieth century, May (1992) describes how critical sociologists problematized medical institutions for treating patients as objects or things, rather than 'whole' persons with feelings situated in social settings. Concerns regarding the objectification of patients not only contained moral values, but clinical research began to suggest that social factors of patients', such as social and familial supports, influenced their care outcomes. Therefore, various kinds of centring models of care, which aimed to foster more individualized health care practices, began to flourish alongside attempts to improve the quality and conduct of care (Hughes et al., 2008). Health care professionals began to use 'centring' language to describe humanistic approaches, which were concerned with the "inner or emotional significance" of a patient rather than just treating them as a biological object (Hughes et al., 2008, p.461).

Many disciplines, advocacy groups and contexts of care were instrumental in the widespread adoption of centring care models. Carl Rogers' (1959) 'client-centred' theory within the discipline of psychology informed some of the earliest scientific literature on the role of family life and interpersonal relationships in therapy. Within medicine, Michael Balint and Enid Balint (1969) led early discussions around the possibilities of patient-centred medicine as a way to shift away from 'illness-oriented medicine'. Their research stemmed from their clinical backgrounds in child psychology and social work. Interestingly, their work raised questions around the nature of medical work itself, and whether general medical practitioners should view illness in the context of the whole patient and offer some form of psychotherapy to patients

(Balint, 1969). Researchers also suggest PFCC initiatives emerged in opposition to practices of care that seemed overly disease or physician/health system centred (Taylor, 2008; van der Eijk et al., 2013).

Ideals of humanizing care through centring discourses have become global in the 21st century. The World Health Organization (2007), a leader in advancing global health care standards, has developed a policy framework for people-centred health care. Campbell and Thiessen (2021), who consider themselves patient leader experts within the Health Standards Organization of Canada,[9] expand on the WHO framework:

> In the first decade of the 21st century patient- and family-centred care became the new "it" thing. Unfortunately, switching to this new model of care wasn't without difficulties. Problems started to appear when health providers became fearful of saying anything that could be perceived as negative, oppositional to, or against patients and family members. We were still in a unidirectional system of health. We'd simply switched from a clinical-led to a patient-led system, or from one extreme to the other. We needed something in-between. An approach that includes ALL voices. A people-centred approach. (para, 5-6)

There appears to be very little consensus going into the 21st century regarding who should be centred in hospital care and yet discourses of centredness continue to seem critical to different stakeholders organizing health care services. In the following section I focus on describing various stakeholders endorsing PFCC today in hospital care and the proposed benefits in the context of the Canadian health care systems.

21st Century Hospital Care and Centring

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[9] The Health Standards Organization of Canada is a non-profit organization formed in 2017 that works closely with Accreditation Canada to develop evidence-informed standards and quality improvement initiatives across Canadian health care settings.

The Institute of Medicine's (2001) *Crossing the Quality Chasm* report identified centredness as a key element to improve health care quality in the 21st century. Within the context of hospital care, PFCC discourses merged with larger health care planning strategies that attempted to maximize engagement and involvement of patients and their families in health care practices. PFCC policies in Canadian hospitals often reference the Institute of Patient and Family Centred Care (2017) and are defined as "an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among patients, families, and health care professionals" (p.2). Across Canada, PFCC policy initiatives have been theorized as being practiced within strategies such as the implementation of family presence policies (e.g. open visitation hours), bedside shift reporting, creation of citizen advisory teams or patient and family advisory committees, utilization of bedside communication whiteboards, and team-based health care models for service delivery (Emanuel et al., 2016; Hastings et al., 2016).

These policy initiatives are framed and implemented in diverse ways across Canadian hospitals. For example, the British Columbia Ministry of Health (2015) state "there are examples of excellent work being done within the B.C. acute care health system to promote patient-centered care and its benefits to the health system" (p.1). The Ontario Hospital Association (OHA) (2018), another large Canadian health service provider, utilizes PFCC components to focus on improving policies around transitions of care (e.g. discharge) and to develop outcome measure tools that incorporate the patient voice (e.g. Patient Reported Experience Measures or Patient Experience Surveys). The Government of Saskatchewan (2015) released a provincial framework for adopting PFCC in June 2011. These PFCC policy initiatives are broadly described as beneficial because patients were given opportunities to provide feedback, and the implementation of these policies also coincided with reported improved operational efficiencies.

However, the relationship between improved hospital efficiencies and the implementation of PFCC initiatives remains questionable.

PFCC Improving Hospital Efficiency

While PFCC strategies may have been promoted as ways to humanize patient and family care experiences, researchers suggest PFCC initiatives also reduce cost and waste within hospital. For example, PFCC strategies are thought to be compatible with hospitals which have restructured to adopt Lean principles (Digioia et al., 2015). Lean was an initiative developed in the 1990s by The Toyota Production System and has since been incorporated in health care as a quality improvement strategy, with the aim to include customer (i.e. patient) values and remove organizational waste and inefficiencies (Womack & Jones, 2005). In Canada, hospital care costs approximately 66 billion dollars a year, making it the largest health spending sector, with employed staff accounting for over 70% of the costs associated with hospital stays (Canadian Institute for Health Information [CIHI], 2017a). Costs of health care are expected to rise, therefore PFCC strategies involving patients and families in their own care practices are increasingly adopted alongside Lean principles to reduce this anticipated economic burden (D’Andreamatteo et al., 2015; DiGioia & Shapiro, 2017; DiGioia et al., 2007). For example, Rankin (2015) analyzed how hospitals have a managerial focus on PFCC as a way to recruit patients’ family members to work on behalf of hospital bed utilization efficiencies (e.g. discharge planning).

Organizational Support for PFCC

Several leading Canadian health care organizations mandate PFCC initiatives within hospital settings. For instance, the components of PFCC have been included for evaluation of hospital care settings by Accreditation Canada (2015) since 2016. The IPFCC and CFHI (2015) spearheaded the “Better Together: Partnering with Families Campaign” in 2014. This campaign remains active across social media and provides national level recommendations for Canadian hospitals to implement PFCC policy initiatives. The Canadian Patient Safety Institute partnered with the Patient Safety Education Program, a leading organization on Aging and Health in America, to develop a Canadian curriculum for PFCC (Emanuel et al., 2016). In addition to the development of formal organizational strategies and processes for PFCC policy implementation, other strategies include health professions adopting and promoting PFCC values and philosophies (o, 2015).

Health Care Provider Support for PFCC

The following are only a few examples of different health care provider groups across Canada promoting PFCC approaches to improve the quality of patient care. Nursing regulatory bodies across Canada offer position statements that outline the role of nurses in centring care on patient and families (College and Association of Registered Nurses of Alberta, 2019; Nova Scotia College of Nursing, 2017; Registered Nurses Association of Ontario, 2015). Physician associations in Canada have been partnering with PFCC advisory committees to develop conversations around the Choose Wisely Campaign, which aims to reduce unnecessary care in hospital settings (e.g. tests, treatments, and procedures) (CIHI, 2017b).

In addition to Canadian acute care hospitals (CFHI, 2015), PFCC is accepted and endorsed across many academic health disciplines, such as nursing (International Family Nursing

Association, 2018), medicine (Igel & Lerner, 2016), disability and rehabilitation (Leplege et al., 2007), physical therapy (Bamm & Rosenbaum, 2008), and psychiatry (Petr & Allen, 1997). Clearly PFCC discourses and materials have been broadly marketed and readily accepted in many Canadian health care contexts. Patient and family 'involvement' is increasingly advocated for across many locations near and far from a hospital bed. Today, Canadian hospitals appear to be in the ongoing phase of monitoring the impact, sustainability, and spread of PFCC policy initiatives, yet little empirical work documents what patient and family involvement looks like in day to day hospital care.

A Bridge Towards Understanding PFCC in Care

In sum, this is an introductory chapter to the topic of PFCC and my background as a nurse and researcher. I described how I have followed PFCC discourses over two years at the study site, prior to conducting fieldwork. As a point of departure for this research, I describe foreshadowed problems of centring patients and families within everyday nursing practices. In doing this I suggest that concerns of centring patients and families in care (i.e. infection control, physiological stress and physical space) are related to everyday nursing practices- which are sociomaterial, political, and historical. Through the brief introduction and historical review of centredness in hospital care I have aimed to draw attention to two main ideas. Firstly, hospitals are social institutions in which patients and families have had to actively advocate and make good hospital care practices for themselves. Patients and families have occupied and continue to occupy various identities in hospitals, arguably centred or de-centred by factors such as socioeconomic status, race, and religion. And from the 20th century onwards Western medical discourses of centring utilized seemingly neutral identities of patients as whole persons, clients, and consumers to further encourage their involvement in hospitals. Secondly, values of humanizing care and mitigating costs of hospital care underly health care provider and organizational support for implementing PFCC initiatives. As such, there is a vast and growing body of literature and research on the benefits, challenges and impacts of centring patients and families in hospital care.

Chapter 2

How has PFCC been studied?

This chapter is a literature review of PFCC research in hospital care. Over the past 50 years, the research literature concerned with the implementation of PFCC initiatives in hospital care settings has proliferated. Assessing and synthesizing this literature is not straightforward in part because multiple framings of PFCC are used interchangeably, alongside, or even in contrast to, the conceptualization developed by the IPFCC (2017). Different kinds of centredness, including Person-Centered Care, People-Centredness, Client-Centered Care and Carer-Centredness, have all been studied in the healthcare context (Coyne et al., 2018). PFCC has also been described by researchers as a kind of paradigm (Orgas, 2019), a theoretical framework (Van mol et al., 2017), a model of care (Ewart et al., 2014), and a culture (Williams, 2014), which leads to further theoretical ambiguity both for researchers studying PFCC initiatives, and those interested in analysing the outcomes of this research. Therefore, in this chapter I summarize the reported benefits and barriers of implementing PFCC initiatives by researchers. I also describe how PFCC initiatives have been studied in hospital-based settings and the methodological limitations of extant research approaches.

The Benefits of Implementing PFCC Initiatives

PFCC initiatives are frequently adopted in hospitals due to the wide range of benefits they are said to confer for all kinds of people involved in organizing and receiving care. In this section, I review the expected benefits for various stakeholders, such as patients, family members, public health consumers, taxpayers, health care professionals, and managerial staff organizing hospital care.

Improves Care of Patient and Families in Hospitals

Patients and families are said to occupy a range of different roles in PFCC literature, including that of taxpayer, consumer, and/or whole persons, with the benefits accrued from the implementation of PFCC initiatives closely related to the ascribed positioning. When patient and family roles as taxpayers are highlighted, economic impacts of PFCC interventions are described by researchers (e.g., DiGioia et al., 2015). When patients are positioned as clients or customers receiving hospital care services, researchers suggest PFCC initiatives improve the patient and family care experience and satisfaction (e.g., Leone et al., 2012). When patients are identified as 'whole' persons or as autonomous individuals situated in unique and social contexts with their families, PFCC initiatives are described as supporting dignity and respect in hospital care (e.g. Johnson et al., 2009). These various roles of patients and families in hospitals are not mutually exclusive, and many of the proposed benefits of PFCC initiatives, such as improved communication, information sharing, and engagement share commonalities and interrelate.

Reducing Economic Burden of Hospital Care

Researchers suggest the economic burden of health care could be reduced by PFCC initiatives because activities involving patients and families in their own care provide opportunities for patients and families to communicate, share information and be more engaged in their care decision-making (Smith, 2013). Improved communication between patients and health care providers is often correlated by researchers with reduced adverse events in hospitals (Weingart et al., 2005), and improved patient safety and fewer malpractice claims (Charmel & Frampton, 2008). Researchers also suggest that when values of PFCC are incorporated in health care policies there is improved trust and information sharing between members of the care team, which can further reduce resource utilization such as unnecessary diagnostic tests and referrals

(Epstein et al., 2005; Epstein et al., 2010; Stewart et al., 2003, 2011). Patient and family engagement during care coordination (Hearld & Alexander, 2012) and discharge planning (Lackman, 2015) is thought to improve the operational efficiencies of hospitals. Researchers also suggest that patient engagement improves patient accountability and self-management of care, which can result in more sustainable behavioral health changes and improved long-term health outcomes (Dambha-Miller et al., 2016; Poochikian-Sarkissian et al., 2010). However, other researchers suggest that more evidence and research specifically analyzing the economic benefits and costs of implementing PFCC initiatives is still needed (Bechel et al., 2000; Smith, 2013).

Improving Patient and Family Experience and Satisfaction

By centring patients' values and preferences, the IPFCC (2017), among other researchers, suggest PFCC initiatives improve patient and family members' experiences as individuals in hospitals (Clay & Parsh, 2016; Frakking et al., 2020). Patients and families, it is argued, are not only the consumers or users of hospital care, but the hospital is supposed to be designed as a system that meets their individualized care needs and priorities (Marshall et al., 2012). Therefore, the patient 'voice' is increasingly advocated for in the organization and delivery of hospital care (Kilpatrick et al., 2019). PFCC initiatives, such as patient and family advisory groups, are considered beneficial because they incorporate feedback from patients and family members to further improve hospital services (McTavish & Phillips, 2014; Okun et al., 2014; Wong et al., 2020). More recently, researchers are developing patient-reported outcome measures (PROMS) to promote PFCC and individualized care services in hospitals (Naik & Catic, 2021). PFCC initiatives are thought to be better than 'traditional' hospital care because they encourage more flexibility and personalization than standardized hospital care (The Health Foundation Inspiring Improvement, 2014; Hsu et al., 2019).

PFCC is the 'Right' Thing to do

Centring care approaches can also be understood as embedding a specific normativity in discourses concerned with approaches to patient care. Often they are framed as simply the 'right' thing to do and as a moral obligation for health service providers (Millenson et al., 2016). In ethical terms, PFCC initiatives are argued for on the premise that by partnering and engaging with families, health care providers will further respect patient autonomy and choice (Igel & Lerner, 2016; Sedig, 2016). For example, strategies to centre care, such as participation, information sharing, and collaboration are presented as encouraging providers to view patients as experts on their lives and as having the right to choose their preferred health intervention (Emanuel et al., 2016). Alongside the rights-based rationale, PFCC initiatives are thought to be good because they encourage providers to share decision making power and responsibility with patients and families (Health Innovation Network, n.d.). Centring initiatives are presented as more democratic than usual practice by researchers, and as the solution to shifting away from paternalistic health professional practices (Delaney, 2018). For example, statements of "doing with" as opposed to "doing to" in hospital care provider relationships are widely adopted across Canadian hospitals utilizing centring care initiatives (Emanuel et al., 2016, p.5).

Improves Care Experiences for Health Care Providers

The IPFCC (2017) suggests health care providers also benefit from the implementation of PFCC initiatives. There is some overlap in the kinds of benefits described for both health care provider groups and patients because PFCC is traditionally understood as an endeavor that foregrounds mutual interests (IPFCC, 2017). For example, in addition to improved patient satisfaction, researchers report that staff satisfaction levels are also improved alongside the implementation of PFCC interventions (CADTH, 2015; Emanuel et al., 2016). PFCC implementation is thought to create collaborative relations with patients and families, which are seen as characteristic of supportive work environments that can then also result in improved staff retention (Avgar et al., 2011; Balbale et al., 2014). However, as De Rosa et al. (2019) show in their scoping review, "connections between PFCC initiatives and health outcomes or staff satisfaction should be evaluated cautiously, because evaluative data were often limited to surveys of small convenience samples or anecdotal evidence" (De Rosa et al., 2019, p.320). Methodological limitations of the PFCC research literature are discussed more fully below.

Empirical research directly exploring the outcomes of the implementation PFCC initiatives for health care providers in hospital is limited. Instead, much of the research more loosely assumes positive implications for health care workers when PFCC implementation is successful. For example, improved communication between health care providers and patients and families may reduce hospital errors and improve patient safety, which is beneficial to health care providers (Avgar et al., 2011). However, an umbrella review of systematic reviews undertaken by Rossiter et al. (2020) also found that while an abundance of literature suggests there are positive implications of PFCC initiatives on patient and healthcare provider well-being, there is limited research specifically looking at the impact of PFCC on patient safety. Therefore, it becomes unclear whether beneficial outcomes linked to PFCC initiatives, such as improved patient safety or satisfaction, are actually related to these initiatives or to other technological changes in hospital care (e.g., electronic health care records).

Barriers to Implementing Centring Care Approaches

As the values and strategies of centring care initiatives become increasingly taken for granted in hospitals, problems of implementation appear diverse and are located across organizational and individual health care provider levels (Thirsk et al., 2021). Hospital staff who do not work at the bedside, such as administrative staff, suggest barriers to implementing centring care strategies occur at the individual health care provider level. These barriers are described as health care providers having unsupportive attitudes, limited experience, high workloads, time pressures and resource constraints (Lloyd et al., 2018; Luxford et al., 2011; West et al., 2005). Researchers also suggest individual health care provider barriers include paternalism (Moore et al., 2017), limited evidence to support centredness (Goodridge et al., 2018) and practices of tokenism where patients and families are physically present but not meaningfully consulted and involved in the day-to-day care practices (Kiwanuka et al., 2019). The barriers at the individual health care provider level are quite broad, and while some of these could be overcome by more education, many of these appear to be outside the control of individual health care providers who provide care at the bedside (Bokhour et al., 2018). Instead, health care providers describe barriers that are outside of their control, such as workload challenges, environmental constraints and time pressures as competing organizational priorities (Emanuel et al., 2016; Kiwanuka et al., 2019). For example, many health care providers state additional resources or infrastructure is required to sustain PFCC implementation (Emanuel et al., 2016). In this case, infrastructure refers to a variety of structural and organizational level processes, such as formal policies, space, time, and technologies to support communication and information sharing between patients, families, and health care providers.

Within the research, centredness appears to be meaningful for a range of stakeholders, including patients, families, hospital administrators, and bedside health care providers, and thus it carries diverse values. Kreindler (2015) suggests that when all people involved in organizing care claim to be 'centered' on patient and families, there can be intergroup conflict during PFCC implementation. For example, if hospital administrators, doctors and nurses all claim a version of centredness is implicit to their work, and each version is different, then failures to meaningfully involve or centre patients are typically blamed upon the practices of other health care providers. In this way there is little collective or interdisciplinary ownership of failures to meaningfully involve patients and families. Furthermore, Kreindler (2015) describes how conflict also arises in part due to the multiple definitions and politics underpinning centring discourses. For example, at the direct point of care, PFCC approaches by nurses may foreground humanistic or shared decision-making values, whereas health administrators at the organizational level may describe PFCC approaches as policies and interventions that are designed with consumer input. Nurses and doctors may be hesitant to adopt a view of patients as consumers, in part because the consumer identity of the patient transforms their work from a professional and ethical service to a type of commercial commodity (Kreindler, 2015). PFCC policies and interventions that are directed to elicit consumer input appear in tension with health care providers' values and ideals of humanizing care through PFCC initiatives. Other barriers that have been posited as being implicated in the implementation of PFCC initiatives include factors specific to patients and families, such as concurrent illnesses, health literacy, and lack of assertiveness with health care decision making (Emanuel et al., 2016).

Theoretical Challenges for Researchers Studying PFCC

As mentioned earlier, there are many different kinds of centring discourses, which results in theoretical ambiguity for researchers who are interested in improving PFCC implementation within hospitals. Concept analyses conducted by Coyne et al. (2018), Morgan and Yoder (2012), and Smith (2018) have attempted to differentiate and clarify these centring approaches, but uncertainty remains as to how to move forward in this field of research. For example, Kokorelias et al. (2019) conducted a scoping review on centredness and suggested researchers should consider developing a more universal centring model which incorporates components from patient and person-centred care. Other researchers such as Lines et al. (2005) and Starfield (2011) argue that there are significant discrepancies between what is understood as *patient* centred and what has been conceptualized as *person* centred care. For example, upon reviewing extant reviews on person centred and patient centred care, Eklund et al. (2019) concluded that these approaches should not be blended, because the goal of *person*-centred care is a meaningful life and the goal of patient centred care is a functional life. A critical review conducted by Hughes et al. (2008) also demonstrated that there are different and competing centring care approaches (e.g., Family centred, Patient centred, Client Centred). In this way, it seems fair to assume that theoretical ambiguity persists for researchers interested in studying the aspirational goals and practicalities of PFCC implementation in hospitals.

Hospital-based PFCC Research

Research on the benefits, challenges, and implementation processes of PFCC initiatives for adult hospital-based patient populations has been conducted internationally. Geographically, the United States produces a leading amount of research on patient and family involvement or centredness for adult patients in acute care settings, followed by some European countries, Canada, and Australia (Olding et al, 2015). In the context of adult care, there have been a variety of hospital care areas adopting PFCC strategies (Kokorelias et al., 2019), including emergency (Almaze & Beer, 2017), critical care units (Mol et al., 2017), palliative care (Arora et al., 2017), and inpatient rehabilitation (Bamm et al., 2015). A large majority of studies on patient and family involvement in acute care appear to be published in journals targeting critical care audiences and the nursing profession (Olding et al., 2015). This is in part because large organizations, such as the Institute of Medicine (2001), World Health Organization (2007), and critical care organizations (e.g. Canadian Association of Critical Care, 2018) have developed practice guidelines and position statements to support patient and family involvement in acute and critical care areas.

Review of Studies in Acute Care Settings

Adult acute care settings have been identified as an area significantly requiring more high-quality empirical research on patient and family involvement and centring care strategies (CADTH, 2015; Manafo et al., 2018; Olding et al., 2015). Empirical PFCC studies vary widely in terms of evaluating different kinds of interventions, such as open visitation hours (Ciufo et al., 2011; Lolaty et al., 2014), development of patient advisory committees (Kendell et al., 2014; McTavish & Phillips, 2014; Perreault et al., 2010; Sharma et al., 2017) and bedside shift reporting (Gregory et al., 2014; Jeffs et al., 2013; Mackintosh et al., 2017; Tidwell et al., 2011). Despite the diversity in centring care interventions, most studies on centredness and patient and family involvement in adult acute care settings largely recruit nurses and/or family members of critically ill patients as participants (Mackie et al., 2018; Olding et al., 2015). In addition, outcome measures are typically self-reported and surveys related to satisfaction (DiGioia et al., 2007), experience (Ewart et al., 2014), and patient and family preference (Olding et al., 2015).

Other outcome measures related to effects of centring interventions include length of hospital stay (Boltz et al., 2014), emotional support/empowerment (McMillan et al., 2013), and cost of care (CADTH, 2015; DiGioia et al., 2015). In addition, the standard of care is not well described prior to the implementation of centring care approaches (CADTH, 2015).

Qualitative study designs usually collect data through interview methods and utilize grounded theory and phenomenological approaches (Fix et al., 2018; Marshall et al., 2012; Power et al., 2020; Wong et al., 2019). Although there are many qualitative studies on patient and family involvement, few observational study designs have been conducted in acute care (Olding et al., 2015). However, observational studies have provided instrumental information on how and where patient involvement occurs in acute care settings. For example, through observation Happ et al. (2007) described patterns of negotiating patient involvement in an ICU as a way for clinicians to navigate ambiguity and receive validation for treatment plans. Rippin et al. (2015) used structured observation and behavior mapping to identify the frequency and location of patient and family communications with clinicians on a PFCC unit. Their exploratory study suggested that environmental design can facilitate important opportunities for communication and collaboration between families and clinicians. More commonly, observational studies focus their gaze upon specific centring care interventions, such as clinician-family meetings (Kvæl et al., 2019). However, many studies continue to report that the scope and nature of patient and family involvement in hospital care remains largely unknown (Burns et al., 2018; Olding et al., 2015).

Ethnographic studies in hospital care settings have begun to offer some insights on the nature of patient and family involvement (Dellenborg et al., 2019; Subramony et al., 2014). For example, Allen (2000a, 2000b, 2002) has conducted ethnographic studies exploring the practices of creating participatory care environments and the negotiation of care work between health professionals and lay persons in acute care settings. Alongside the collection of primary empirical data through multiple methods (e.g. interviews, participant observation, document analysis), Allen's (2000a, 2000b, 2002) research utilizes sociological theories to understand how tasks and roles are divided between health care staff and lay people (e.g. families and patients). Findings from Allen's (2000a, 2000b, 2002) studies include examples of how participation from families can take various forms, and descriptions of how resource constraints can significantly influence nurses' abilities to create participatory caring contexts. With a specific focus on the enactment of patient-centred care, Byrne et al. (2019) conducted an ethnographic study to understand how multiple tensions arise when patient-centred policies are implemented. They demonstrated how conflicts and concerns may arise around environmental space constraints, demands of care productivity and poor coordination. Furthermore, these tensions are reinforced due to the complexities of standardizing all services for patients, while also raising discussions about individualizing care (Byrne et al., 2019). Ethnographic research appears to offer grounds for further theorizing and understanding the nature of centring care on patients and families in acute care.

Empirical Challenges to Understanding Centredness

Evidence for the benefits of PFCC initiatives, and further understanding of the barriers, is actively sought by health care providers (CADTH, 2015; Ciufo et al., 2011). For example, Emanuel et al. (2016) state "within a clinical and scientific community, it is understandable to want and seek evidence, or scientific proof, that [PFCC], and the practice of partnering with patients is effective and should be adopted as a leading practice" (p. 18). Many literature reviews claim that more high-quality empirical research is needed to improve centring care initiatives

(Eklund et al., 2019; Kiwanuka et al., 2019; McMillan et al., 2013; Park et al., 2018). A common concern expressed about current research and knowledge practices investigating centring initiatives is that they are “qualitative in nature” or have “methodological limitations due to lack of blinding or external validity in issues of control studies, thus making empirically-based conclusions difficult” (CADTH, 2015, p. 2). This means that researchers have found it difficult to synthesize and empirically summarize the extant data due to the high degree of heterogeneity in the types of PFCC interventions, study settings investigated, and the lack of randomized control trials (CADTH, 2015; Emanuel et al., 2016). Common research practices assume that we can learn most about PFCC in care strategies through greater control of study variables, the use of standardized measurement tools (e.g. patient satisfaction surveys), and narrower sampling of populations or specific settings of care. In this view, controlled intervention studies with outcome measures that can be synthesized are thought to improve the generalizability of findings – these are considered to be better, or rather ‘good ways’ to study care practices due to their seemingly neutral approach to knowledge. However, given the following limitations of current approaches, it is perhaps the politics and complexities of organizational practices that requires further empirical and theoretical attention.

Limitations of Current Approaches to Studying Centredness

Despite decades of research, centring care initiatives remain ambiguous and appear to compete as care philosophies, paradigms, models, policies, and frameworks (Hughes et al., 2008; Morgan and Yoder, 2012; Park et al., 2018). Kreindler (2015) suggests that lack of researcher attention to intergroup politics (i.e. tensions between physicians, nurses, and managers) makes centring care approaches challenging to discern, implement, and sustain in hospitals. Therefore, further ‘neutral’ research (e.g. randomized control trial) is unlikely to explore the heterogeneous values and actors concerned with centring patients and families in care. Review-type studies suggest that although centring care research has been conducted internationally over the last two decades, American-based studies account for a large majority (CADTH, 2015; Olding et al., 2015). In Canada, policy documents in acute care appear to largely reference centring care principles from American Organizations, such as the IPFCC (e.g. See AHS, 2014; OHA, 2018). A concern with this kind of research informing Canadian health policy is that this body of research may not adequately address the organizational capacity, infrastructure, and social processes of Canadian health care facilities **(**Doktorochik et al., 2018**;** Kowalewski et al., 2014).

Survey-based Research Concerns

Many of the studies on the effects of centring initiatives utilize patient satisfaction questionnaires (Ciufo et al., 2011; Fumagalli et al., 2006; Lamb et al., 2019; Quinlan et al., 2003; Shulkin et al., 2014), and though offering some important insights about patient experiences, satisfaction levels may not necessarily equate with better health outcomes for patients. Edmund (2019) describes three concerns with patient satisfaction surveys. First, survey responses can be unreliable quality metrics because of sample size and recall bias depending on when the patient completes the survey in relation to when they received their treatment. Second, physicians may feel pressured to provide unnecessary, low-value tests or unneeded treatments to fulfill patient preferences and thereby potentially improve patient satisfaction. Thirdly, financial incentives are often offered to hospitals with the highest patient satisfaction scores and these may increase disparities for safety-net hospitals who provide care to underserved populations and often score lower on patient satisfaction. Patient satisfaction outcome measures are tied to a business model of health care delivery, which is more commonplace in America than in Canada (Rankin, 2003). Rankin (2003) further suggests the use of these survey-type methods can constrain the type of knowledge that can be accessed because focused questions force specific answers from participants. Patients and families responding to these surveys must generalize from their experiences with the many different actors organizing their care trajectory in the hospital to respond to simple statements such as, 'the nurses listened to my concerns.' As Rankin (2003) argues, the patients' complex hospital experiences cannot be condensed into such responses.

Another concern is the ability for patients with English as their second language or lower health literacy levels to express their experiences or concerns through survey-based self-reported data (Hunt & Bhopal, 2003). Canada is an ethnically diverse country and although surveys are commonly used to collect public health data, there are significant concerns of cultural appropriateness and translation of survey questions (Pasick et al., 2001). For example, researchers have argued for survey approaches that include Indigenous specific measures related to health and family well-being (Smylie & Firestone, 2015). Although surveys provide an avenue for anonymous patient and family feedback, rich and detailed data on the implicit social factors and politics related to practices of centring care in Canadian hospital care remain mostly unexplored through this approach.

Anecdotal Evidence Concerns

Evidence to support centredness in hospital care is also largely based on anecdotal experiences (CADTH, 2015; Emanuel et al., 2016; OHA, 2018). Many Canadian health care providers and organizational leaders offer grey literature to support PFCC initiatives through sharing and accumulating patient and family engagement success stories (OHA, 2018). Anecdotal information can be a powerful teaching tool in health care and allow for narratives or situated stories of care that cannot be captured by surveys or other intervention studies (Campo, 2006; Dohan et al., 2016). As a method primarily intended to collect data on successful centring care events, this approach raises concerns of the silenced narratives and background actors interfering with patient and family engagements strategies. For example, after attending PFCC discussion rounds with local health service providers and watching online patient and family engagement videos, it seemed to me that many of the advocates of PFCC appear to be Caucasian and from a higher socioeconomic background. Based on my review of multiple social media presentations (e.g. Patient and Family Engagement YouTube Channels), patient and family centring care stories of success are largely shared by persons with locally available support systems and higher English literacy levels. Anecdotes allow for narratives of care often missed by survey data or controlled intervention studies (Dohan et al., 2016). However, it is important to consider the stories and contexts of care that are made visible or left unobserved and perhaps taken for granted.

Attending to the Social in Hospital-based Care

Researchers typically characterized the organization of hospitals through the language of shared sense of systems, supportive management structure, and cultural improvement (Smith, 2013). Across management and organizational studies, these approaches to understanding organizational work have been theorized and critiqued extensively (Alvesson & Spicer, 2012; Law, 1994; Suddaby et al., 2011). While systems, cultural, and structural approaches offer a range of insights, they also have specific effects on the focus of subsequent theoretical and methodological explorations of patient and family involvement in care. Most studies make sense of centring care activities by separating them into macro and micro levels of care, presupposing a hierarchical relationship and a natural divide between the diverse organizational actors. Foregrounding systems or health care provider cultures can make invisible key non-human actors (e.g. politics and technologies) influencing patient and family involvement in hospital care (Fox

& Alldred, 2016; Snyder et al., 2011). While this approach can be informative, the networked relations of bedside and organizational practices may need different methods and theoretical orientations to be more fully explored. This is in part because the boundaries of the caring division of labor are increasingly difficult to draw and are shifting in relation to rising discourses of centring care and patient and family engagement strategies (Allen, 2000a; Allen, 2000b). As centring care strategies are not value-free, the politics and sociomaterial contingencies of their enactment also require further research. While some researchers argue it is necessary to have separate conceptual frameworks to compare hospital policy actors and healthcare systems, others as I will describe in the next section demonstrate the value of symmetrically attending to the social relations and networks of materially heterogeneous actors involved in organizations.

Problematising Centredness in Hospital Care

Upon reviewing the literature concerned with PFCC policy and initiatives in hospitals, I encountered exponential growth in publications utilizing discourses of centredness from the 1990s till the present, across both academic and grey literature. As I described in my historical account and review of the literature, the theoretical ambiguity and the heterogenous difficulties implementing PFCC initiatives in hospitals are persistent issues, which indicates that perhaps the assumptions guiding PFCC research need to be re-examined. Therefore, a problematization approach was used to explore how researchers come to know and shape PFCC as an object of scientific investigation (see Judge & Ceci, 2021). In the study by Judge and Ceci (2021), Alvesson and Sandberg's (2013) structured problematization approach was used to analyze the underlying assumptions informing PFCC intervention research. Judge and Ceci (2021) highlight three predominant areas within PFCC intervention research that may benefit from rethinking, including Vitruvian spatiality, democratising care, and centring positioned as primarily a problem and accomplishment for nursing.[10] As a way to re-think these assumptions, Judge and Ceci (2021) argue for the adoption of theoretical lenses that de-centre individual actors to better account for the relations, politics, and multiple actors, both human and nonhuman, which work to involve patients and families in hospital care practices.

There is a group of researchers who studied the implementation of PFCC strategies in Italian hospitals by exploring the social, material, and relational networks that enact care for patients and families (e.g., see Gorli et al. 2016; Gorli & Barrello, 2021; Liberati et al. 2015; Liberati et al., 2013). Their work brought attention not only to the complexities of involving patients and families in day to day care, but also raised questions about whether PFCC strategies make everyday care good for patients and families. For example, Gorli et al. (2016) investigated how a hospital was reorganized to actualise patient centred care. However, as they observed, new arrangements of hospital space that were intended to make care more efficient, did not necessarily improve the patient's experiences. Instead, Gorli et al. (2016) described for example, the ways these changes made it more challenging for patients and families to find their physicians and vice - versa in the hospital. Gardner and Cribb (2016) also explored the sociomaterial dimension of patient centred medicine and illustrated how non-human elements, such as the Canadian occupational performance measure, structured power relations in clinical settings. Their work builds on insights from Liberati et al. (2013) who suggested that although there are many artifacts and institutional devices which seemingly aim to put the patient at the centre of hospital care, there are contradictions between these explicit organizational policies and day to day care practices. Other researchers also allude to the idea of non-coherence between

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[10] Judge and Ceci (2021) describe how the root metaphor of centring and dominant nursing perspective encourage Vitruvian thinking, which is a narrow theoretical gaze of researchers to overwhelmingly focus on a fixed position of a patient's body and their 'innate' concerns within hospital care. Thereby neglecting the collective organizational work and sociomaterial practices that constitute day-to-day care.

policies encouraging patient involvement and day-to-day care practices, such as Phillips and Scheffmann- Petersen (2020) and Gardner and Cribb (2016) who suggested that there is a ‘gap’ between policies and practices of centredness. Therefore, it seems imperative to empirically explore the daily practices and ordinary ways health professionals involve patients and families in hospital care settings that embrace PFCC initiatives.

Chapter 3

Studying Nursing Practices with Patients and Families in Hospitals

This chapter is an overview of the theoretical and methodological considerations that informed this study. First, I begin by providing an overview of practice theory as a package of theory, vocabulary, and methods (Nicolini, 2017). Then I will describe the steps and approaches I took in conducting this ethnographic study. This includes information about how I obtained access, recruited research participants, and navigated operational approvals. I provide details about my research activities, such as timeframe in the field, fieldnote taking, interviewing, approach to analysis, and data management.

This research project began with foreshadowed problems of involving patients and families in nursing care through PFCC strategies in hospitals. Following a critical review of PFCC intervention research, Judge and Ceci (2021) made a case for studying everyday nursing care of patients and families through a practice-based approach. To summarize, the difficulties of 'centring' patients and families in care, despite significant efforts, suggests care practices are more complex than often assumed. Instead, care practices with patients and families may involve an array of diverse and interconnected actors, discourses, and technologies that, to date, have received little attention. While it is broadly accepted that patients and their family members should be involved in their care, very little is known about what patients and families are doing in hospital care settings and their interactions with nursing networks and others. There are heterogeneous actors and networks of materialized practices organized by and organizing nursing care that warrant further research exploration.

Research Objective

In this research, I aimed to improve understanding of PFCC initiatives and knowledge of how patients and families are involved in their care. I did this by exploring the complex and entangled relations and actors organizing everyday hospital care. I began this study by questioning the overwhelmingly taken for granted aspirations of centredness in hospital care discourses, more specifically the idea that care may be exclusively ‘centred’ on patients, families, nurses or even health systems. This is not to say that PFCC strategies are merely rhetoric or that patient and family involvement does not exist. Instead, I adopted a practice-based approach to explore how care in an institutional setting that has adopted PFCC strategies is an ongoing accomplishment of materialized practices among heterogeneous networks of people, discourses, and artefacts. Ultimately, the purpose of this research was to explore how patient and family involvement is enacted or being done, in order to innovatively think about what makes patient and family involvement in care difficult or good in everyday care practices.

Research Questions

This study began with two exploratory research questions: 1) In an adult acute care setting, how is patient and family centredness in care enacted? Specifically, how do practices intended to centre families interact with the sociomaterial contexts of care including evolving technologies, and with what effects for patient and family hospital experiences? 2) In what ways is PFCC as outlined in policy accomplished, not accomplished or partially accomplished? These questions offered a starting point for investigating the foreshadowed problems of enacting PFCC and involving patients and families in everyday nursing care. However, these questions changed as I began conducting fieldwork.

As Hammersley and Atkinson (2019) explain, research problems can change in ethnographic exploration. For this study, the questions changed or rather evolved for two main reasons. First, as a novice researcher I had a somewhat naïve assumption that something like ‘centring’ could be clearly observed in hospitals; that because PFCC strategies were very visible in hospital policy, resources and discourses, they could also be concretely seen and identified in everyday hospital care. As my supervisory committee offered feedback, the second question of PFCC being accomplished, not accomplished and partially accomplished seemed to suggest that a judgement or some measurement of PFCC could be determined. However, the question of accomplishing PFCC was one that my fieldwork data could not answer. After spending time in the field, analyzing data, discussing some of these tensions with my supervisory committee and comparing extant literature, it became clearer that the data I gathered was descriptive and specific to how everyday nursing care is being done in an organizational context that contains PFCC strategies.

Ethnography, like most qualitative research, is reflexive and it is not unusual that research questions may be refocused when there are factors outside the control of the researcher (Hammersley & Atkinson, 2019). In this study, research circumstances also shifted the kinds of questions that were asked. For example, access to the field and key informants was challenging due to the COVID-19 pandemic. The orthopaedic surgical wards were not admitting patients with COVID-19, unlike the medicine and neurology wards that I had originally proposed as study sites for this research project. Internal factors shifted the research questions as well. My insider knowledge as a nurse allowed me to more easily and safely follow the staff who were physically working on the wards. These were predominately nurses, health care aides, and unit clerks. Other allied health members such as occupational therapists, transition coordinators[11], and doctors were only periodically present on the wards during periods of participant observation. Their routines were not as well known to me and thus I was more careful and hesitant about interfering with their work. Therefore, through reflexive writing and analytic processes, I decided to refocus my research questions as follows:

- In what ways are PFCC resources and policy statements discoverable inside patients' and families' experiences of care?
- In descriptions foregrounding sociomaterial contexts of care, how are patients and families involved in everyday care?

Theoretical Orientation

I utilized a practice view of work and organization to explore how care of families and patients is 'made' or enacted in hospitals. Traditional approaches to studying PFCC strategies or patient and family involvement foreground either individual behaviors or organizational structures. However, a practice lens explores multivalent relations and heterogenous actors enacting nursing care in organizational settings. This approach de-centers the human subject to consider sociomateriality seriously and symmetrically in day-to-day nursing practices. Attending to care practices through this theoretical orientation was important for my study because most studies concerned with PFCC or patient and family involvement in care have not attempted to account for the material and discursive practices organizing patient and family care. Instead, as Gorli et al. (2016) state, “it is frequently – and implicitly – assumed that putting patients at the centre of care will more or less spontaneously lead to fully engaged patients” (p.152). Practice-

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[11] Transition Coordinators at the study site were registered nurses with specialized roles to arrange complicated patient discharges or transfers of patients to other care facilities. For example, they arranged transfers for patients that could no longer return home or required specialized home care arrangements.

based approaches are thus gaining considerable interest in studies of PFCC strategies because they illuminate the everyday practicalities and sociomaterial conditions of hospital care for patients and families. Gorli et al. (2016), Liberati et al. (2015) and Liberati et al. (2013) propose further research on PFCC strategies utilize practice theory approaches to investigate the relationships between artifacts, institutional norms, and the daily practices that enact care for patients and families in hospitals.

Practice Theory Approaches

Practice theories have developed from long-standing debates within the philosophy of science regarding the nature of knowledge and the relationship between humans and the world. Since the 1970s, a range of contemporary practice theories in the study of social organization have emerged from Western and European philosophy under diverse labels such as praxis, praxeology, practice as activity, and practice as community or tradition (Nicolini, 2012). Practice theory approaches have informed researchers from various disciplines, such as Ceci et al. (2017) studying nursing care practices as described in chapter one. Nicolini (2012) encourages researchers to view these as families of practice-based approaches. While specific practice views, such as discourse analysis or cultural historical activity theory may differ in their methodological implications, where the focus on the former may be on individual discursive activity and the latter on collective actions, recognizing the plurality of the practice theory lens reflects the idea that practices are not fixed activities, ideas, or rules. Rather practices in this study are conceptualized more openly and in terms of everyday care activity, which is unfolding and situated in collective and material worlds.[12] As suggested by Nicolini (2017), I used practice theory as a package of theory, method, and vocabulary to guide this study.

Origins and Background of Practice-Theory Approaches

Practice theory approaches and interest in exploring the knowledge within everyday activities of our world can be traced back to highly influential Aristotelian philosophy. Aristotle assumed a difference between rational or intellectual knowing and knowledge attributed to everyday material and practical activity (Stewart, 1979). While many scholars and researchers continued Aristotle's traditions of metaphysics, such as Cartesianism (i.e., subjectivism/ objectivism) and transcendental knowing, as modern explanations for scientific developments in the world, Nicolini (2012) suggests that other scholars, such as Heidegger and Wittgenstein, rethought Aristotle's work related to multiple ways of knowing (i.e. *episteme, phronesis,* and *techne)*. Nicolini (2012) suggests that Wittgenstein and Heidegger argued against privileging and reducing 'knowledge' to an intellectual or rational activity of the human mind. Instead, they considered conscious knowledge and the practical or un-theorized wisdom related to everyday material and bodily activity as equally knowledgeable activities. Sandberg and Tsoukas (2015) also interpret the scholarship of Wittgenstein and Heidegger and suggest their work drew attention to how humans make meaning of the world through their relations with other things in the world, as well as their background experiences.

Sandberg and Tsoukas (2015) interpretation of Wittgenstein's work highlights that while much of social order and human action may appear to be guided by people following rules, the logic of obeying rules is not solely determined through human interpretation or rational activity.

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[12] Gherardi (2019) also writes about how to do practice-based research in a nonconventional way, rather than describing how to do practice theory in a routinized or prescriptive methodological sense, she suggests researchers develop a methodological sensibility. In this way, it becomes important to understand what sorts of research questions are asked, how sense is made of the data, and then what questions remain for future academic inquiry.

Wittgenstein offered the example of how people learn to play games (e.g., chess). For instance, even if individuals read the rules of a game themselves, it does not mean that they will necessarily follow or interpret them correctly. Briefly summarised, Wittgenstein and Anscombe (2001) described how people can learn to obey the rules of playing a game appropriately through multiple practices, including instruction, applied training, and also from simply observing how others play. Sandberg and Tsoukas (2015) suggest that a key idea for practice-theorists from Wittgenstein's work is that human action and social order, either in a game or in everyday life, is not necessarily based on the ability of a person to rationalize or intellectualize a rule, rather people draw on an array of background social practices to make meaning of activities and take further action.

Sandberg and Tsoukas (2015) and Nicolini (2012) also interpret Heidegger's work to suggest that individuals primarily make sense of the world through practical activity and by 'being-in-the-world'. Nicolini (2012) describes Heidegger's analysis of utilizing a hammer as a practical activity which involves different kinds of knowledge. At times, the knowledge that is activated when using a hammer may become visible when a person physically holds a hammer, or by observing another person using a hammer and by paying attention to what is needed when contingent materials, such as the work bench or nail, fail to activate the intended results (Nicolini, 2012). Nicolini (2012) describes how Heidegger's analogy of utilizing a hammer demonstrated how knowledge in the everyday world is structured by social and material practices, which remain background or invisible until their normalcy or functionality is disrupted. As an alternative to the Cartesian subject-object ontology of the world, Sandberg and Tsoukas (2015) suggest that Heidegger posited the idea of entwinement as the ontological condition of 'being-in-the world' and knowing the world. The idea of entwinement suggests "we are never separated but always already entwined (internally related) with others and things in specific socio material practice worlds" (Sandberg & Tsoukas, 2015, p.186). In other words, the starting point of understanding social phenomena in the world is not a pre-determined or isolated knowing subject, but rather subjects' relations with other things in the world and their practical activity (Nicolini, 2011).

Practice-based theories not only draw on ideas from Heidegger's and Wittgenstein's work as discussed above, but they are also informed by Schatzki's writing on *social practice* and Garfinkel's ethnomethodology (Nicolini, 2012). Theoretically, Wittgenstein and Heidegger argued the premise that all knowledge is situated or housed within practical or everyday human activities and is inescapably a product of our relations with the world (i.e., relational ontology). A relational ontology presumes that there are no isolated subjects making sense of objects in the world (i.e., subject-object dichotomies), instead we make sense of our everyday activities because we are inescapably related to them. Ethnomethodologists share these ideas and consider practices "both as the inescapable texture of everyday life and the contingent, ongoing accomplishments of the same practices" (Nicolini, 2012, p.134). In other words, for the purposes of this study, practices are not only theoretical ideas of how hospital care consists of multiple activities, performances, and accomplishments of everyday life, but practices are also the methods and instruments of how we (e.g., social scientists, nurses, students etc.) make sense of, account for, and identify daily activities (Nicolini, 2012). In summary, practice-theory largely developed from a critique of scientific rationality, which assumes social identities (e.g., subject/object, mind/body and nature/culture) are isolated and pre-given entities of the world (Sandberg & Tsoukas, 2015). Additionally, practice-based theorists challenge the assumption within traditional scientific rationality that individual cognitive activity is the place from which humans begin to make meaning and take action in the world (Sandberg & Tsoukas, 2015). Instead, practice-based theorists believe that people make meaning through being in the world and through their practical activity.[13]

What are Practices?

For this study and in line with Nicolini's (2017) definition, practices are understood as reproduced performances of social organisation. Activities such as eating, dressing, and mobilising in the community as parts of daily living can be thought of as practices. Practices are actual performances and activities that are mediated through or enacted by available material or discursive resources and arrangements. For this study, this means conceiving care of patients and families and PFCC strategies as being more than cognitive activities, but as 'real' and situated enactments. Practice-based approaches have been utilized to rethink traditional social explanations of care as an affective or cognitive activity. For example, by drawing on practice-based approaches, such as Actor Network Theory, Allen (2015) described how care is collectively organized through tools, humans, technologies, rules, and other non-human actors. Allen (2015) described care practices of patient handover, which often rely on material actors, such as paper records. The handover records are agential and can help accomplish other tasks, such as preoperative checklists and patient referrals to other services. However, if the handover sheet is lost it can also interfere with care, as it can create concerns of patient confidentiality and loss of knowledge for future care planning.

Schatzki (2012) further elaborates on the nature of practices, as "open-ended, spatially-temporally dispersed nexus of doings and sayings" (p.14). This means that care is constantly

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[13] Gherardi (2019) provides a timeline of the various streams of practice-based studies that have emerged, by building on the work of other critical social theorists since the 1960s. She provides a figure which outlines how her own Knowing in Practice lens has been influenced by Lucy Suchman's (1987) writing on Situated Action, which was in turn informed by Alfred Schutz.

unfolding and when practice-based researchers approach caring as an activity, there are implications for the vocabulary used to make sense of and describe patients' experiences. Allen (2015) provides an example of this in the following quote: "apparently durable social structures such as gender and organisation are understood as verbs rather than nouns, that is, as an ongoing practical accomplishment" (p.10). Through a practice view lens, nursing care of patients and families is also described and understood as verbs. More specifically, as ongoing practical accomplishments that involve a range of different elements including human bodies, artifacts, and texts. Nicolini (2017) and Schatzki (2012) provide the following list of theoretical commitments, which provide both a vocabulary and methodological considerations to make sense of practices in organizational settings.

- Social and material practices are the point of departure or unit of analysis for theorizing and making sense of socially organized human activity.
- Practices cannot be reduced to words or cognitive activity; the role of human bodies and artefacts and performativity is foregrounded.
- Practices are not enacted by individual persons or systems, but they are "organized constellations of material activities performed by multiple people" (Schatzki 2012, p. 14).
- Practices are not pre-existing or stable entities; they constantly unfold and therefore require some form of productive work that allows them to reproduce.

These theoretical commitments have also guided the methodological considerations made throughout the study design, a key principle being that observing ordinary or mundane nursing care activities is the starting place to gather data and knowledge about how patients and families are involved in care. PFCC strategies and patient involvement is something that is not just talked about, rather it is enacted and performed. Therefore, practice-based approaches necessitate diverse methods to gather empirical accounts of the heterogeneous sociomaterial activities related to organizing care around patients and families in hospital settings.

Methodological Considerations

Ethnography is the recommended methodological approach to study multiple practices of care (e.g., material and discursive) as networks of situated accomplishments (Nicolini, 2016). In this practice-based ethnographic study I developed accounts of nursing practices through formal interviews, participant observation, informal conversation, and artefact collection. The intent of utilizing ethnographic methods in this study was not to create a grand theory or produce generalizations of what patient and family centredness entails. Rather the use of ethnographic methods alongside practice-based theorizing was more exploratory. Descriptions which foreground sociomaterial contexts of care were necessary to understand and describe how patients and families involved/consulted in everyday care. Hammersley and Atkinson (2019) suggest that there are no hard or strict boundaries of what is entailed in ethnographic data collection, instead research activities should be reflexive. For my study, this required careful consideration around public health restrictions, workload and time constraints of research participants. Day-to-day reflexivity was necessary to ensure ethnographic research activities such as observations and interviewing did not interrupt or interfere with the day-to-day activities of research participants. As well, reflexivity was facilitated when I was given opportunities to respond to questions and comments from my committee members while analyzing my data and writing the chapters of this thesis.

Reflexivity

The notion of researcher reflexivity has developed as a way to better understand and articulate how the researcher's situatedness and interpretive practices impact their ethnographic processes and findings (Hammersley & Atkinson, 1983). Many ethnographers choose to describe their situatedness as either an 'insider' or an 'outsider' based on their familiarity with the phenomena under observation. Some scholars may argue that I had an insider positioning that may have allowed me to produce a more accurate account of health care practices, and others may suggest that I am biased. However, a reflexive and relational understanding of knowledge creation assumes that researchers always generate their data based on their background experiences, through intentional and non-intentional activities in the field. My dual role as a nurse and researcher allowed me to understand and navigate some of the social norms for nurses working in the hospital. For example, after morning shift change, I would try to not ask too many questions while shadowing nurse participants because I knew they were juggling many time-sensitive tasks.

As a researcher, I positioned myself as a participant observer with an ontological commitment to practice-based knowing. Therefore, my ability to recognize, identify and 'know' social phenomenon at hand depended on my situatedness, reflexivity, and active participation within a network of hospital-based sociomaterial practices (Nicolini, 2012). Practice- based studies assume that nothing, including the researcher, is outside the nexus of sociomaterial practices. This assumption has specific implications for my role as a researcher who is generating data. Through this understanding, as a researcher I am not entirely inside or outside the fieldwork. The 'insider' position supports the idea that the researcher is familiar or an 'expert' of the practices under investigation (Allen, 2004). The 'outsider' or observer role is often advocated on the grounds that the researcher is a stranger to the practices, therefore less likely to fall victim to ‘bias’ (Allen, 2004). However, insider or outsider researcher roles are “predicated on assumptions about the existence of an objective reality that can be scientifically observed” (Allen, 2004, p.15). Instead, Nicolini (2009) suggests researchers should develop reflexive understandings of the contingencies related to their fieldwork processes. For this study, I had to not only consider and cautiously respond to challenges of conducting fieldwork in a dynamic setting, but also reflect upon how my own clinical experiences prior to and during the pandemic shaped my understandings of what was going on with patients and families in hospitals.

Reflexivity throughout the research process produces a sense of uncertainty to remain with the findings, not in the sense that the findings are weaker, but in the sense that the interpretations and data in view is contingent upon the methods, researcher’s identity, and the social conditions of the research setting. As Allen (2004) suggests, reflexivity requires both psychological introspection and consideration of the social and material circumstances of the researcher’s fieldwork. In this study reflexive work included conversations about field experiences with my supervisor and day-to-day management of my social appearance. For example, I intentionally wore business casual clothes to look more like a researcher than a nurse. I wrote my fieldnotes around the nursing station, so that I could continue to observe while I wrote. I structured my conversations with hospital staff, patients and families, based on their busyness and reflections from my interim analysis. I also attempted to split my time equally while collecting data on two wards during my fieldwork, in an attempt to not overburden the same nurse participants during shadowing. Reflexive work also guided my decisions around ethical concerns, while gaining access and exiting the field due to changes in COVID -19 case counts and public health restrictions.

Ethical Concerns

Due to the emergent design of ethnography and the uncontrollable character of the study site, ethical considerations were attended to on an ongoing basis throughout the research processes (Hammersley & Atkinson, 2019). I was not able to control the hospital setting, so there were constant changes, such as new people walking through the study site, staffing shortages, and evolving risk of exposure to disease. Therefore, there were wide ranging strategies employed to navigate ethical concerns, such as not contributing to the spread of communicable disease (COVID 19), maintaining people's privacy, and concerns of interrupting patient care. Ethical concerns were discussed, and mitigating strategies were outlined in the University of Alberta Ethics board approval processes (Pro00098424). For example, data was anonymized, and no personal or identifiable data was recorded. Other ethical considerations included the vulnerability of hospitalized patient and family participants due to their illness. Therefore, interview and observation periods did not extend more than 45-minute intervals as to not physically exhaust patient and family participants. The study processes were clearly outlined to all research participants verbally and though written records.

Informed Consent

Informed consent was obtained from all study participants in accordance with institutional policies and procedures. There were different consent forms created for research participant types, such as hospital staff (See Appendix A), patient (See Appendix B), and family member (See Appendix C). As well, there were different consent forms for different research activities, such as observation and interview. Written consent was obtained from research participants who were formally interviewed and shadowed. A verbal consent script was used for other people encountered during the field work (Appendix D). Informed consent from case study patient and family participants was obtained 24 hours after an initial introductory meeting, so that they had time to carefully consider the risks of participating in this study. An information sheet about the study was given with the consent form to all research participants. Ongoing verbal consent was obtained from participants as I continued to meet or engage with them during my fieldwork. As a way to obtain passive consent, there was a poster on the unit next to the sign in sheet at the nursing station informing people passing by on the unit about the researcher's presence and the name of the study (see Appendix E). Patients and families were also informed that study participation did not influence the care they received should they participate or opt out.

Whenever I was on the wards, I introduced myself to the hospital ward staff, so that they had ongoing opportunities to ask questions and go over the study information sheet. Only descriptive accounts of practices involving patients and families were recorded and no identifying information was documented. I worked closely with the unit managers and staff to ensure that I did not disrupt their tasks and would ask for written and ongoing verbal consent while observing or shadowing their care practices. In addition, I wore a name tag and dressed in business casual clothing so that I was not mistaken for a nurse. Many hospital staff, such as the clinical nurse educators, health care aides and nurses initially thought I was an auditor when they first saw me walk onto the wards. However, by immersing myself through persistent fieldwork the hospital staff were able to get to know my research aims, methods, and researcher role. I shared my research timeline and exit strategy early on with my research participants and they were aware that I was making research decisions day-to-day depending on whether research participants were safe to shadow or interview and if I was fit or free of flu like symptoms.

Data Management

Multiple sources and types of information (e.g., oral, observational, and documents) were gathered, so various strategies were used to anonymize, record, and organize the collected data. Documents or other artefacts (e.g., signage) that were unavailable for download from the internet were photographed. This allowed the data to not only be recorded, but also collated electronically and backed up on a password protected hard drive for safekeeping. Interview data was collected through audio recording from a hand-held device. This was because the audio devices allow for better quality data as they record data in 'real-time' and help overcome concerns of memory recall (Hammersley & Atkinson, 2019). Observational data was handwritten in a field journal, through a combination of techniques (e.g., writing during observation, jottings notes, and later-day fieldnote entry). This data was transferred into an electronic format at the end of the project, so that all the data can be managed on a password protected device as per institutional protocol.

Study Design

This ethnographic study took place in a large teaching hospital in a Western Province in Canada that has embraced PFCC strategies and discourses. Due to the vulnerability of patients in ICU and limited resources during the COVID-19 pandemic, primary observation and recruitment of patient and family research participants occurred within two lower acuity orthopaedic care wards. These sites were also chosen pragmatically, because the patient care manager of the orthopedic surgery program was the only one of five people who responded to the recruitment email (see Appendix F). Many of the other medical and surgical care wards in the hospital were converted into COVID-19 wards during my time in the field. Although neurology wards were proposed as study sites, orthopaedic care is also an interesting area for exploring patient and family involvement (Digoia et al. 2007; Rickert, 2014; Stalenhag & Sterner, 2019).

Study Setting

Ward A and Ward B specialized in orthopaedic care. Patients were assigned to these wards if they required orthopaedic intervention to improve injuries to their musculoskeletal system. However, if there were empty beds on the orthopaedic wards and shortages of adult patient beds in other speciality areas (e.g., medicine, urology, or trauma), then patients requiring different treatments would at times be admitted to the study sites. The kinds of treatments provided on the wards ranged from diagnostic testing, surgery, palliative medicine, elective and emergent procedures. Therefore, the average length of stay for patients varied greatly and in relation to diagnosis, treatment complications, and patient care needs. To examine how patients and their families were involved with care, other auxiliary care areas within the hospital were accessed while following research participants (e.g., Rapid Room Meetings, Outdoor Picnic Table Station). These sites within the hospital were only accessed if the research participants invited me to accompany them during these events and experiences related to their care. Other people encountered during these settings were notified about my role as a researcher and the nature of my study. I would explain that I was not collecting information about them as individuals, but rather descriptions of practices involving patients and their families in care.

Gaining Access

The approvals to gain access took over four months. Uncertainty around the COVID-19 pandemic also significantly delayed my access and field work in the hospital. The pandemic began in March 2020 and the University of Alberta had given instruction to pause research activities till June 2020. During this time, I developed and adjusted my ethics approval according to shifting public health restrictions (Pro00098424). Once I received the ethics approval, I had to obtain operational approval from the study site. Chambliss (1996) recommended utilizing a slide-in access approach to familiarize oneself with potential gatekeepers in hospital settings and establish trust before the study begins. Therefore, before I submitted a formal request for access to a study site, I sent out recruitment emails and shared my study information with potential study sites. The orthopaedic patient care manager responded to the recruitment email and met with me to discuss the study with the unit managers under his supervision. Once I received the necessary approvals, the unit managers circulated information about my study via email to their hospital staff.

While both wards provide orthopaedic care, share resources, and follow similar care routines, there were differences in their histories and the individual people either working there or receiving care. The transition coordinators of both wards stated that they have different cultures when asked if they observed differences between the two places. Without giving concrete examples, one transition coordinator said she would describe the wards as having "different management styles" (Fieldnotes, Summer, 2021). These differences were not particularly observable through my own research activities. However, while seeking access and recruiting research participants I noticed the staff of Ward A were more active research participants. Whenever I visited Ward A there was usually a nurse who would offer to let me shadow him or her on the same day, would work to identify possible patient participants, and ask me general questions about my day or research project. My engagement with the staff of Ward B seemed to proceed much more slowly. Ward B staff allowed me to generally observe activities on the ward but were more hesitant in volunteering for shadowing activities or engaging in casual conversation, particularly when I first began my fieldwork. I came to know Ward A first and was introduced to Ward B, one week after beginning data collection on Ward A.

Timeframe for Fieldwork: Two Phases

I initially planned to conduct at least six months of continuous data collection. However, due to the COVID-19 pandemic my time in the field was split into two phases. Phase one was from September 2020 till November 2020 (70 hours of observational field work). Phase two was from June 2021 till September 2021 (60 hours of observational field work). There is no standardized or defined timeframe for prolonged fieldwork (Hammersley & Atkinson, 2019). Rather the timeframe for fieldwork was dependent upon the quality and richness of the collected data. Early traditions of ethnographic research typically lasted around 12 months or were developed throughout the researcher's whole career life with intermittent data collection (Jeffrey & Troman, 2004).

I believe the two phases and total of six months of intense data collection provided enough opportunity to recruit participants, collect data and ensure rich descriptions of the complexity and specificities of care for patients and families in hospitals. During the initial phase of research my main objective was to introduce myself to the hospital staff as a researcher and observe orthopaedic ward routines. I observed shift changes (at 0700, 1500, and 1900) and I wandered the halls to get a sense of the unit space, how the care work was divided, how staff began their shifts. Once staff had become familiar with myself and study aims, they were asked to approach their patients who met the study criteria with my research flyer. I also observed non-human actors, so I would observe the contents on walls, computer movement, and how ward censuses travelled. I documented the artefacts- specifically, the signs addressed to staff, family, and patients with photographs. During the second phase I primarily recruited patient and family case study participants. While meeting patient and family participants, I would audio record the interviews and write jottings by hand in my journal describing what the patient or family member was doing during the interview. For example, notes about the patient interacted with their family member at the bedside, body language, and if the physical arrangements in their room had changed. This allowed me to be more attentive in our conversations and less concerned with how accurately I was capturing their words.

Recruitment and Sampling

Recruitment of study participants occurred through the unit managers, nurse participants, and recruitment posters. A six-month study design was chosen to increase variation of sampling. Palinkas et al. (2015) suggest that maximum variation of sampling strategies allows for the diversity of organizations and their health practitioners to be captured. Therefore, purposeful, convenience, and criterion sampling strategies were utilized. Data collection occurred during weekends and weekdays with purposive sampling of day and evening shifts as deemed necessary by research participants. I attempted to shadow nurses and meet with patients and families at different times of the day and week. Purposive sampling of various shift routines allowed me to observe multiple contexts of care and see if there were any differences or similarities. Nurses were the first participants recruited in this study. Once they had been shadowed, they were asked to consider informing patients and family members about this study with a recruitment poster and study information sheet. A recruitment poster was placed on the wards (see Appendix G) to allow for convenience sampling, so that patients and families could directly contact me if they wished to participate. Potential patients and family participants were not approached directly by me. Rather a professional member of the care team, usually a nurse research participant, informed patients and family members about my research to determine if they wished to learn more about this study and potentially participate.

Research Participants

The following types of participants were recruited in this study:

Orthopaedic Unit Staff

The orthopaedic wards contained diverse staff members, from nurses, physicians, students, and health care aides as well as other milieu participants (e.g., porters, unit clerk, cleaning staff). I shadowed 14 nurses from Ward A and 10 nurses from Ward B, including a mix of registered nurses and licensed practical nurses. Shadowing involved actively following and having conversations with nurses while they worked (e.g., assessed patients, received or gave report, documented, administered medications). The timeframe for shadowing these nurses ranged from two to four hours. I had the opportunity to shadow and have conversations with transition coordinators for two hours. The transition coordinators are also registered nurses, but they are responsible for arranging transfers from the unit to other facilities. As well, the clinical nurse educators would have casual conversations with me whenever they visited the wards. Doctors, surgeons, and other allied health staff were observed on the ward but did not engage in any formal participatory research activities, such as shadowing or interviewing. This was in part due to the fact that many of them would walk around the ward once to check on their patients, but then continue to do their work physically off the ward in their offices. Therefore, the research participants from the ward were predominantly staff nurses.

Key Informants

I attempted to recruit patient and family advisory members and other key informants or experts implementing PFCC strategies through the local Patient Engagement services. I sent an email to recruit participants for interview (See Appendix H.). Two staff from the patient engagement services met with me online to discuss the study and while eager to connect me with other members organizing patient and family involvement in the hospital, they were not interested in participating themselves. In addition, throughout the COVID-19 pandemic these key informants were redeployed to other care areas.

Patients and Families

Patient and family members were recruited primarily through nurse participants and one family was recruited through the poster on the unit. Patients and family members that did not require isolation precautions and had an anticipated discharge date of at least one week from admission were included. A minimum one-week length of hospital stay was a criterion because I needed at least one week to arrange meetings and get to know the patient and family participants. Three patient and family case studies were recruited from Ward A and one from Ward B. One participant was recruited from both Wards because they were admitted to Ward B and then re-admitted to Ward A. The following patient and family participants were recruited consecutively throughout Phase 2 of my fieldwork:

- Tom: 4 hours of observation on Ward B and 1 hour of observation on Ward A
- Betty and Sue: 6 hours of observation on Ward A and 3 hours of phone interviews
- James and Kim C: 3 hours of observation on Ward A
- Darlene: 2 hours of observation on Ward A
- Abby and Lynn: 1 hour phone interview and was recruited from Ward B

Other People Encountered During Fieldwork

As I observed research participants within the hospital wards, I came across other people during my fieldwork (e.g., physiotherapy aide and x-ray technician). In these instances, I introduced myself as a researcher, explained my research area and obtained verbal consent. I also explained that I was not collecting data about them as individuals but was gathering descriptions of practices and activities involving patients and families in their hospital care. The data collected from other people present during observations in the public areas of the hospital wards were descriptions of the events observed and no identifiable or personal information of the individuals was recorded.

Data Collection Methods

Ethnographic studies of hospital care have been conducted by social scientists since the late 20th century and have utilized a variety of methods to capture the richness and complexity of hospital life (Long et al., 2008; van der Geest & Finkler, 2004). Ethnographic methods support practice-based theorizing because they allow researchers to employ a range of diverse methods or tools to investigate research problems (Hammersley & Atkinson, 2019; Rashid et al., 2015). This multiplicity encourages researchers to be thoughtful and purposeful as they seek to understand the diverse actors and networks of relations involved with social practices, and in the case of this study, practices of care. For example, Emerson et al. (2011) emphasises that an ethnographer's fieldnotes are constrained or influenced by where they look. Therefore, multiple data collection methods were utilized to create my fieldnotes, including participant observation with diverse actors, formal interviews, casual conversations, photographic images, and artefact analysis.

Multiple sources of data supported a broad strategy of comparison. For example, I compared how nurse participants described the patient participants' care trajectory and how patients themselves described their care trajectory. Furthermore, I was able to compare these accounts to my own observations and understandings of patient care trajectories from my clinical experiences as a registered nurse. I also collected accounts of how nurses described their role in doing patient and family centred care and compared these descriptions to PFCC policies and artefacts, such as the educational PFCC vignettes. These diverse sources of data at times offered complementary information, where I noticed people utilize similar ‘centring’ discourses. However, there were also times that I noticed differences or tensions between what participants said they did and what I observed them doing.

Documents and Artefacts

Documents and physical objects can be significant sources of information because many social and organizational practices are self-documenting (Hammersley & Atkinson, 2019). For example, hospital members produce and utilize different kinds of paper or electronic records (e.g., policies, organizational charts, and financial records). Atkinson and Coffey (2011) describe how documentary sources construct reality, such as facts, records, rules for social practices. In addition, images and material objects construct reality and offer information of social practices. Carter (2019) explored how hospital signage is a political activity and portal for institutional messaging, such as instructing visitors to wash their hands, smoke less, and immunize themselves. A great deal of practical knowledge related to ordinary activities of hospital care require the manipulation of artefacts. For example, Xiao (2005) describes how whiteboards have developed in trauma centers to help communicate and divide the labor among the health care team. Therefore, hospital documents including ward censuses, policies, and pamphlets for patients and families were collected.

Observations

While building rapport with the staff on the wards in the first month of data collection, observations were initially guided to learn about the routines, how the spaces were arranged, what sorts of people and things entered and made up the care arrangements. Once the staff became familiar with my research activities, some volunteered to participate in shadowing activities. My observations of the wards and patient and family experiences were guided by the following questions:

- Who or what is drawn upon to involve patients and families?
- What are the involved actors (peoples, things, and technologies) attempting to accomplish during these practices?
- How do the actors involved relate to one another and other care practices?
- What kinds of questions are asked ordinarily by the actors and what kind of answers are ordinarily given?
- How are these practices accounted for?

Observation in studies of health care organization can bring to focus the materiality, performativity, and the contingencies of care practices. This approach allowed me to access different types of knowledge that cannot be acquired through utilizing interview questions. This approach allows for casual conversations or access to ‘backstage’ talk. ‘Backstage talk’ refers to Goffman’s (1959) idea that some types of knowledge are foregrounded in public conversation and others are left hidden or made background. Observation thus allows access to information that researchers may be unaware of, or participants may withhold.

Formal Interviews

When used in conjunction with observation methods, oral accounts obtained through interview can improve and complement the observational data that is collected (Nicolini, 2009). Only formal interviews with patients and families were audio recorded in this study because conversations with hospital staff were often more easily interrupted by other people in the field.

Patient and family interview data was audio taped to improve accuracy and so that I did not have to rely on partial jottings. Additional observations were recorded immediately after the interview in the fieldnote journal. Interviews allowed for research participants to articulate specific insights and descriptions making up everyday care activities, which may not be available for observational study (Nicolini, 2009). Through interviews, researchers can document the accounts field experts, and in this case patients and families, generate in relation to their performances and day-to-day activities. Open- ended questions allowed participants to use more of their own language and concepts in response to the questions. See Appendix I for the interview guide and questions for the patient and family participants. See Appendix J for the interview guide and questions for hospital unit staff participants. The interview guide questions also guided and facilitated casual conversations on the hospital wards. However, these casual conversations were recorded through hand writing in the fieldnote journal.

Interviews are inherently social practices. For example, interviews allow the researcher to play a more assertive role in eliciting information from study informants. Hammersley and Atkinson (2019) state that interviews "can be used both as a source of information about events and conditions, and as revealing the perspectives and discursive practices of those who produced them" (p.124). Communicating and articulating practices requires discursive work and material activity, therefore Nicolini (2009) suggests interview methods can act as heuristic devices by encouraging research participants to observe and become more aware of their own work. For example, while interviewing I used additional questioning probes for research participants to further reflect and expand upon their responses. Discussions with nurses about 'centring' practices included probes such as "how would you teach someone to do that?" And in talking with patients, I would probe their care experiences by asking questions such as "what factors made this situation better or worse than others?” These kinds of questions encouraged the participants to extend their descriptions of activities, people, or techniques involved in specific care situations. For example, through the use of probing questions, nurse participants described how specific procedures, bodily capacities, and scarcity of resources limited their ability to ‘involve’ patients or provide individualized care. Thus interviews allowed me to learn something about the sociomaterial conditions of patients’ contexts of care from the perspectives of those involved.

Fieldnotes

Fieldnotes were created throughout the study with a combination of data collection activities on the orthopedic wards. These included photographs, notes from informal conversations, and primary observations while shadowing research participants. As a novice researcher, I positioned myself as an interested observer, so that I could directly record fieldnotes while I observed and had informal conversations on the hospital ward. This approach allowed me to capture as many details as possible without relying on my memory at a later time. However, at times I would make jottings while shadowing when nurses moved faster than I could record or when counter space to write was not available around the nursing station.

As Hammersley and Atkinson (2019) recommended, my field journal allowed me to record detailed descriptions for further theoretical analysis, reflexivity, and to maintain a paper trail of the data collection for later reference. The fieldnotes are primarily written accounts, however some objects were better documented through a photographic image. Therefore, some fieldnotes included pictures of the materials and non-human actors involved in patients’ care, such as signage on the walls, whiteboards, and computers. Personal information either of the participant or institution was blurred out or covered before the picture is taken. This was to ensure research participant confidentiality. No photographs of participants or other people in the field were included.

Rigour

Study rigour was ensured through multiple strategies including the collection of multiple sources of data, prolonged engagement, and reflexivity (Hammersley & Atkinson, 2019). Fieldnotes contain concrete sensory details, such as time, description of setting, character of objects, and specific actions of people (Emerson et al., 2011). These were recorded as soon as possible in order to depict rich and vivid details about the observations and to avoid utilizing generalizations and visual clichés (i.e., stereotypes) (Emerson et al., 2011). I conducted approximately 2-3 hours of fieldwork at a time so that I had time in the day to finish writing reliable and detailed fieldnotes and also time to reflect (Emerson et al., 2011). The concepts or ideas are primarily identified by my own analysis and reflection. Confidence in these ideas is supported through data source triangulation, which is the process of relating events across the research phases and comparing accounts from different participants and other data sources (Hammersley & Atkinson, 2019).

Approach to Data Analysis

Processes of analysis and sense-making began prior to entering the field, when I first proposed the study, conducted a literature review, and created my research questions. Ethnographers approach their field with some kind of prior knowledge and logic-making; thus, it is important to note that my analyses of the ethnographic data collected built upon my foreshadowed problems, research questions, and my earlier assumptions about PFCC and everyday hospital care with patients and families. Moreover, my clinical experiences as a registered nurse working in the hospital have also significantly shaped my interpretations of the data. For example, while observing nursing practices, I had some prior understandings of the social and material arrangements necessary to mobilize a patient, manage pain, or to provide personal hygiene – and it required some work to articulate these understandings, and hold them open for analysis, rather than allow them to remain taken for granted.

As discussed earlier, the data collected in this study is made sense of through the theoretical underpinnings of practice-based approaches. Therefore, I attended to both human and non-human actors during my observations and while building descriptions of nursing practices. Formal processes of analysis began as I developed descriptions of the field and research participants with the collected data. For example, while collecting data I followed recommendations by Emerson et al. (2011) who suggests writing in-process memos or commentaries in a separate section from the fieldnotes. These were considered discrete moments of analysis that highlighted linkages within my empirical data and provided me leads for further observation and analysis. These commentaries were closely read and further reflected upon when I had to step away from the field due to increasing Covid-19 case counts.

The initial fieldnote narrations and descriptions are selective processes of ordering ideas and are thereby inherently analytical. These provisional analyses were made explicit or reflected upon through a number of ways. I attempted to describe events and provide “analyses that are comprehensible to readers who are not directly acquainted with the social world at issue” (Emerson et al., 2011, p.595). In a similar line of thinking, Hammersley and Atkinson (2007) state that the process of analyzing relations across all the data sources is “to compare and relate what happens at various places and times in order to identify stable features (of people, groups, organization, etc.) that transcend immediate contexts” (p.163). To do this, it was necessary to write up descriptions of the field and stories of research participants, so that a wide range of people may begin to understand what is going on with PFCC and patient and family involvement in hospital care.

Theoretical insights from practice-based research informed the descriptive writing as well. While writing fieldnotes, I attempted to make jottings of how both human and non-human actors were involved in organizing care. In the empirical accounts that follow, I included data that highlighted the sociomaterial conditions of care, such as spatial arrangements of the room, medical equipment, and policies. Early drafts of analytical writing were also shared with members of my research committees, which allowed me to obtain feedback and suggestions to strengthen my analyses from more experienced ethnographers. These opportunities to receive feedback helped identify areas of analysis that needed to be made more explicit. Particularly, practice-theory was something that I needed to make more explicit in the written analytic commentary that I developed from my data.

Processes of Data Analysis

The analysis process was iterative and reflexive, shifting in relation to the kinds of research questions posed to study participants, the data collected during fieldwork, and the ideas that emerged from broadly reading extant literature on PFCC (Judge & Ceci, 2021) and nursing practices with patients and families in hospitals. Upon completing fieldwork, I followed recommendation by Emerson et al. (2011), who suggested that novice researchers begin with a concentrated or fine-grained analysis of their fieldnotes after openly reading all the data as it was collected over time. In this way, I did a line by line reading of my fieldnotes, policy documents/artefacts, and interview data. While doing this I developed more analytic commentaries over a year long period, which were guided by the following questions as recommended by Emerson et al. (2011):

- What are people doing and what are they trying to accomplish?
- How, exactly, do they do this? What specific means and/or strategies do they use? How do members talk about, characterize, and understand what is going on? What assumptions are they making?
- What do I see going on here? What did I learn from these notes? Why did I include them?
- How is what is going on here similar to, or different from, other incidents or events recorded elsewhere in the fieldnotes?
- What is the broader import or significance of this incident or event? What is it a case of?

These questions helped break down complex events and observations of everyday hospital care, so that I could develop descriptions of what is going on with patients and families. As a nurse, I quickly learned how much knowledge of nursing practices I took for granted, and I found these questions helped me to develop more descriptive accounts. As suggested by Hammersley and Atkinson (2007), analysis requires a process of moving back and forth between ideas and data. This process is often likened to the concept of grounded theorizing, where ideas, questions, or themes are inductively derived from the data collected and not entirely from preconceived concepts (Charmaz, 2016). The process of moving between the data and guiding questions required a lot of written work. As I identified the data to include in this study and began developing analytical points, I had to also return to the theoretical insights from practice-based research which informed how this study was designed and the research questions.

Writing Ethnography

Writing ethnography is the process of transposing fieldnote data into ethnographic writing, so that there is an analytic point, orienting information (i.e. data) and commentary that tells a story (Emerson, et al., 2011). However, it is not possible to collate all sources of data and stories into ethnographic form and there is no singular mode for organizing the findings through a practice-lens. Ethnographic writing is a medium through which the ethnographer/writer can invite readers/audience to participate in or connect to a discourse. As Marilyn Strathern (1991), an anthropologist, would suggest, there is no analysis or description that is neutral or complete, only ‘partial connections.’ Strathern’s (1991) work builds on ideas from feminist theorists and scholars from science and technology studies, such as Haraway (1988). Strathern and Haraway write against ‘objective’ and ‘complete’ accounts of knowledge by researchers. I use inverted commas, because both researchers highlight how subject/object dichotomies and neutral standpoints utilized by researchers are problematic when taken for granted. Strathern and Haraway encourage researchers to illustrate how situated knowledges are embodied and embedded within material conditions, social relations, and specific contexts.

In the chapters that follow I have reflexively selected ‘pieces’ of data to show those who may lack an insider view an accessible version of everyday hospital care for patients and families. As Emerson et al. (2011) state, “having been trained in a particular discipline (such as sociology, anthropology, or folklore), the field researcher draws upon and develops ideas that make sense within the conceptual language of that discipline” (p. 201). My nursing background provided a foundation for understanding, from a nursing perspective, how care of patients and families was organized and who was involved. In some respects, this offered me an insider advantage as everyday discourses on the wards can be exclusionary for those without a clinical background. For example, I was able to shadow nurses safely and understand what was happening when they used shorthand to describe patients during shift report. As well, there were areas and routines on the ward that I could physically access unlike my patient and family research participants, such as meetings with interdisciplinary staff and shift handover reports. My insider status, and the assumptions of understanding that may inhere in this, meant however, that it was important to question my own common-sense descriptions and analyses of hospital care for patients and families. There are a range of factors that influenced the selection of excerpts from my fieldnotes to be interpreted, interrogated, and selected for inclusion in ethnographic writing. Factors such as relevancy of data to research questions and richness of data influenced whether the excerpts would be included. As well, observations or descriptions that were strange, warranting further exploration and sense-making were included. One way to describe this process of ethnographic writing is 'making the familiar strange,' which is a common expression in sociological research.

Making the Familiar Strange

Gunderson et al. (2020) argue that sociological exploration demands researchers to 'make the familiar strange.' I have been trained primarily as a nurse and although I have studied a range of sociological theories, I could also see that my early attempts at analysis and ethnographic writing were composed in what could be described as a nursing way. The knowledge that I was familiar with and took for granted became evident while sharing drafts of my early writing with my research committee, who pointed out descriptions of care routines and hospital actors that required a lot more detail and explanation. For example, various health professional roles, routines, and organizational practices on the wards required further elaboration and descriptions, so that readers from different backgrounds may have a deeper understanding of what is going on.

Gunderson (2020) describes different ways in which researchers may seek strangeness and unfamiliarity by largely referencing the work of Alfred Schutz (1964), a philosopher and social scientist who has significantly informed practice-based research.

One way is recognizing that not all experiences or stories can be fully known no matter how familiar we are with the phenomenon or experience. Gunderson (2020) cites Schutz and Luckmann (1973) who state, “there is always something unfamiliar sketched behind the familiar” (169). This quote alludes to the idea that despite having nursing expertise, there are nursing phenomena which are unfamiliar and remain unexplored. In this way, ethnographic writing by nurse researchers has richly and expertly described somewhat hidden, surprising, and taken-for-granted aspects of nursing work. For example, Allen (2015), describes the ‘invisible’ organizing work nurses do in everyday hospital-based care. Campbell and Rankin (2017) uncover how relations between nurses and electronic health records become oriented towards making care more efficient. This empirical work describes familiar or ordinary nursing phenomena, such as electronic documentation and handover report, in new ways and as being sociologically relevant for further research and debate.

Another approach stated by Schutz (1964), as cited in Gunderson (2020), is to look at the fieldnotes or aspects of data that were surprising, problematic, and perhaps even absurd.

> Strangeness and familiarity are not limited to the social field but are general categories of our interpretation of the world. If we encounter in our experience something previously unknown and which therefore stands out of the ordinary order of our knowledge, we begin a process of inquiry. We first define the new fact; we try to catch its meaning; we then transform step by step our general scheme of interpretation of the world in such a

> way that the strange fact and its meaning become compatible and consistent with all the other facts of our experience and their meanings. (Schutz, 1964, p. 105)

Schutz describes how strangeness and familiarity are sense making and analytical processes. Experiences that are both strange and familiar demand interpretation. However, Schutz explains that when there is an event that is incoherent or an incident that stands out from previous experiences, it often raises additional questions and a process of inquiry. This approach was important in selecting important and meaningful excerpts of data to be included in the analysis. In other words, surprising events or observations that were not coherent with my previous nursing knowledge and experience were opportunities for learning and required analytical writing. These observations and descriptions are my findings and are organized into the following chapters. Chapter four describes the field and research participants. Chapter five describes the ways in which PFCC is discoverable in everyday nursing care. Chapter six describes how patients and families are active and involved in everyday care. Finally, chapter seven discusses the implications of this work.

Chapter 4

Introducing the Field and Research Participants

In this chapter, I describe the study site and the PFCC initiatives implemented here, and then introduce the field and research participants using excerpts of data collected through observations, interviews, photographs, and sketches. Overall, these descriptions aim to provide context for the analysis developed in the subsequent chapters.

The Study Site

The hospital in which this study took place was one of many publicly funded health services under the management of a Regional Health Authority (RHA). This means that neither the hospital, nor the orthopaedic wards, were self-governing. Instead, as organized sites of care they were a product of diverse types of hierarchical working groups, which extended in and out of the ward and hospital. For example, the RHA worked with a Governance Board, which is made up of various committees and is then accountable to an elected public servant, the Minister of Health. A provincial and health advisory council also advises the RHA's executive leadership team, which is made up of many different people with various roles and management titles. In addition to a long list of people in executive positions, there were documents clearly outlining general bylaws, mandates, roles, and governance procedures to enact and sustain hospital organization. Within the hospital there were multiple operational and medical leaders further managing a wide range of services within the hospital. These leaders it seemed were responsible for creating and organizing PFCC initiatives.

PFCC Initiatives

PFCC initiatives were neatly labeled and made publicly available by the RHA on their institutional website. The RHA's PFCC mandate is perhaps most clearly symbolized in the image below with patients and families depicted at the centre of all their organizational strategies.

Figure 1

Four Foundational Strategies

This content is unavailable. Please consult the figure list for further details and direct link to to the redacted content.

Figure 1: Unpermitted third-party content.

This version of PFCC is similar to other health care organizations adopting PFCC strategies across Canada (i.e. Western Health Strategic Plan, Manitoba Health). The circular shape with a focal point of patients and families in the centre, has also been modeled by researchers encouraging implementation of PFCC in hospital care practices (Frakking et al., 2020). It could be argued that this version of PFCC is ordinary and if simply taken for granted, it suggests that all health facilities under the RHA incorporate PFCC into all organisational practices, including those related to research, direct patient care, finances, and best practices. The graphic implies that by simply placing patients and families at the centre of various corporate strategies, they are then ‘centred’ in all aspects of hospital-based decision-making. The image is purposefully placed in a few areas on the RHA’s website. For example, it can be found embedded within their Vision, Mission, Values and Strategies on their web page. It is also located near various web-based resources, which outline a collection of projects that aim to implement PFCC into organizational practices, such as the *Patient First Strategy*.

Patient First Strategy

The main objective of the Patient First Strategy is to “strengthen [RHAs] culture and practices to ensure patients and families are at the centre of all health care activities, decisions and teams.” This strategy was developed in 2015 and can be electronically downloaded as a 32-page document. The electronic version of the document is embedded on the RHA website, alongside other ongoing organizational projects, such as updated visitation policies, patient and family advisory groups, as well as a link to videos of patient engagement stories. These are depicted as collective strategies intended to fulfill the RHA’s commitments to strengthen the voices of patients and families, create partnerships with patients and families, and further invest in research to improve PFCC. *What matters to you matters to me* is the RHA’s slogan for the Patient First Strategy, intended to capture their mission while also creating PFCC as a kind of commercial brand for their business of caring. There are images of people from various age groups and ethnicities, displayed across the web page highlighting the Patient First Strategy, and within the document, seeming to suggest that these PFCC initiatives are sensitive to the diversity among patient populations.

The Patient First Strategy document is a PFCC artefact and has some characteristics which appear quite authoritative. For example, multiple people from the RHA’s executive leadership team are listed as consultants and members of the PFCC working groups at the beginning of the document. The document also provides definitions and explanations for adopting PFCC, by referencing the IPFCC, an American organization, which is considered an advocate, expert, and leader in the development of PFCC initiatives. The document also describes how these initiatives were validated and measured through patient satisfaction surveys in acute care. As well, stories shared by patients and families of their great experiences in the RHA's health care facilities are used as performance measures. The Patient First Strategy outlines many plans to enact PFCC, such as providing training, developing a campaign (i.e. Code Pink resources), and hiring individuals who demonstrate PFCC behaviors (e.g. active listening).

The 101 on PFCC in Practice

Another PFCC artefact at the study site is the *Patient and Family Centred Care 101* online study module. All staff at the study site are expected to complete this module every three years. The module is divided into two channels, a clinical and non-clinical pathway. This suggests the PFCC initiatives may look different for staff, depending on where they are working. The non-clinical module, for non-clinical staff, has short video dialogues from actors involved with quality improvement, information technology, and management roles. The clinical staff module takes twice the amount of time to complete and includes longer videos of family members sharing experiences, as well as vignettes exemplifying how PFCC can be incorporated into clinical practices.

The PFCC educational module is organized around four key components- information sharing, participation, collaboration, and respect and dignity – reflecting the ways that most PFCC policies and artefacts appear to slice PFCC into these four themes. For example, these themes were also listed in the Patient First Strategy, as well as used to order information in the

RHA’s PFCC resource kit. The PFCC resource kit is a 102-page document that includes the specific technologies of PFCC that can be implemented on hospital wards, such as liberal family presence policies and patient bedside whiteboards.

Fieldwork Site: The Orthopaedic Wards

The orthopaedic wards were only a small portion of the care services organized at the hospital site. There were many other specialized medical programs, such as cardiology, neurology, transplants, and pediatrics. The hospital was also considered a research and teaching facility, which means that it provided learning opportunities for health professionals and clinical researchers. It was a large multilevel structure, containing cafeterias, an art gallery, a pharmacy, a library, and a gift shop for staff, students, patients, and families to access. As one can imagine, there was a lot of coordinating activity among people, technologies, and procedures to maintain acute care service availability for 24 hours a day and 365 days a year.

The orthopaedic wards located within the hospital were also busy places offering employment to health care providers and practical training to students in health-related fields. As well, the wards were places for patients to receive various kinds of care, such as ongoing nursing assessments, surgeries, nutrition, wound treatments, physiotherapy, and medications. At times patients who did not specifically require orthopaedic services would be admitted to Ward A and Ward B. The unit managers explained that this was often the case if the emergency room and other specialty wards did not have empty beds to accept patients. Diverse actors and networks of activities worked together in a seemingly organized or orderly manner. Key actors on the orthopaedic wards such as the unit managers and nurses were followed at the beginning of fieldwork in order for me to observe, learn about and describe how care for patients and families was organized.

Management of the Wards

The orthopaedic wards each had their own *unit* manager who worked under the supervision of a *patient care* manager. The patient care manager introduced me to Ward A and Ward B as “sister units,” a description suggesting that there were relations between the two, but they were not quite the same. The patient care manager also supervised another surgical ward, which specialized in spinal and orthopaedic surgeries. Ward A and B specialized in providing surgical intervention for people with injuries impacting muscles and bones. The patient care manager usually worked from their office, which was located directly outside all three wards. Observing their work was made difficult due to the closed office door and the nature of computer work which, when observed uninterrupted, is simply typing. During our initial meeting, the patient care manager explained that they report to other ‘site leads’ and manage the ward budgets. An interesting example they gave of their day-to-day management work is that they try to keep the workloads of each ward similar: “If one ward has a lot of hip fractures, then I may send one of them to the other ward” (Fieldnotes, Summer 2020). In this way it seemed that the patient care manager attempted to regulate resources and patient admissions in a way that maintained balance or fairness between the ‘sister’ wards.

The patient care manager and unit managers worked at the hospital Monday through Friday from 0700 till 1500. The unit managers’ role was much more visible for an observer because they regularly worked on the ward, in close physical proximity with the ward staff, such as nurses, health care aides, and unit clerks. They would very rarely have scheduled office days, in which case they worked from a shared office located off the wards. The unit managers would usually be found at the nursing station and often seated in front of a computer and next to a unit clerk. For example, one morning I observed the Ward A unit manager accept a delivery of new patient footwear:

> The unit manager opens the box, pulling out a pair of blue socks with black plastic soles. A nurse walking by excitedly says, “I didn’t know we had ordered these! These are way better than those old booties.” The unit manager responds, “yeah, we got them for Accreditation, but these are expensive! I had to ask [the patient care manager] for money for these, because you know the patients need footwear, those old booties are so slippery. So, we also got them for falls prevention… and can you make sure you give a medium and large size box to [Ward B]. I don’t want to hear them complaining that we don’t give them stuff…” As more nurses excitedly gather to look at the new delivery, the unit manager say, “ok everyone, before you give these out make sure you ask the family to bring footwear to the hospital. These are not cheap, so if they can get footwear from home that is better…don’t give these out like candy. One per patient.”
>
> - Fieldnotes, Ward A, Fall 2020

Here we can see that the unit manager performs a range of organizational duties, ordering new footwear for patients and setting limitations around how they are supplied to patients by the nurses on the wards. It can also be seen that the unit manager does not have complete authority to manage and organize resources for care on the wards, because they require authorization from the patient care manager for new expenses. There is an expectation that Ward A shares their resources, in this case shoes, with their sister unit. The unit manager is seen accomplishing diverse organizational tasks, such as accounting for expenses, preparing for hospital accreditation processes, implementing new workplaces practices to ensure patient safety. These are only a few aspects of their day-to-day work to manage orthopaedic care on the wards. The unit managers also interviewed and hired new personnel and managed the staff requests to change their shift schedules. Managerial activities thus included acquiring resources, ensuring that sufficient staff were scheduled to work each shift, and that all ward staff consistently adhered to hospital policies and procedures such as infection control.

A nurse who is assigned to overall responsibility for the ongoing activities (admissions, discharges, emergencies, sick calls and so forth) on a patient care unit is referred to as a “charge nurse”. During most of my observational field research activities, the unit managers simultaneously occupied the role of charge nurse during the day shift from 0700 till 1500. When the unit managers were away or when they ended their workday, a specially trained registered nurse occupied the role of the charge nurse on the wards. Both Ward A and B always had a registered nurse in the charge nurse role 24 hours a day and 7 days a week. The charge nurse was generally not assigned to the care of specific patients and did not usually perform bedside patient care tasks. Typically they remained at the nursing station, coordinating patient transfers, admissions, and discharges. For instance, people from diagnostic imaging services or the operating room telephoned the nursing station regularly. The charge nurse would often answer the phone if there was no unit clerk and then relay new information to the bedside nurses who would do the necessary work for upcoming patient procedures. The charge nurse would speak with family members who were requesting access to visit or were asking for an update regarding patient conditions and plans. They communicated with allied health professionals through messenger apps on the computer and in-person conversations around the nursing station. Other activities included balancing nurses’ patient assignments, following up on doctors’ orders, and clarifying treatments or procedures.

Also notable were the seemingly symmetrical physical layouts of Ward A and Ward B. Figure 2 is a photograph of a nursing station, the physical space in which many of the managerial tasks are undertaken.

Figure 2

Nursing Station

The nursing station appeared to be the command hub of the wards, where actors with authoritative qualities were positioned. These included people in leadership roles as well as paper documents outlining ward procedures and protocols. This space contained binders full of information for operational and medical protocols, lists of phone numbers for different hospital services, and schedules outlining responsibilities for the ward staff. Although the photograph above is of Ward A's nursing station, Ward B nursing station looked identical. Both wards had the same spaces and layout.

Symmetry of the Wards

Similarly trained staff, objects, spaces, and schedules organized everyday care on the wards. Upon entry to both wards, hospital staff and visitors would be confronted with the same kind of fire safe doors, profuse signage, blue walls, artificial white lights, and a stagnant air often smelling of chemical disinfectants. Figure 2 was captured at 0645, right before day shift was about to begin on Ward B.

Figure 3

Entrance to Ward

This image shows what both wards looked like upon entry each morning I arrived. Although the long hallway pictured above is absent of nurses, patients, and other human actors, it is crowded with various objects. The hallways were always full of equipment - computers on wheels, supply carts, and stretchers. These ordinary objects were agential and essential to enacting day-to-day nursing practices on the wards. For example, without stretchers or wheelchairs, patients would not be able to go off the wards for diagnostic tests. Every person and piece of technology could be said to have some purpose in relation to organizing specific nursing care on the wards. This is an important assumption underlying my practice-based lens - non-human actors, such as the computers, posters, and the railing along the wall, enacted ordinary care practices. The rails supported patients while ambulating in the hallways after surgery. The posters reminded people to sign in and wash their hands. The computers would be plugged into the electrical outlets on the walls, so that their batteries were charged for mobile use. These objects were not simply resources to be drawn upon. For example, computers organized a range of nursing care process, such as documentation, communication between staff members, and medication administration. The computers often traveled with the nurses to different spaces on the wards and along the hallways.

The wards were divided into designated spaces for different kinds of nursing care activities. When travelling down the hallway in Figure 3 pictured above, there were patient rooms along the right side and different nursing workspaces on the left. The dirty utility room was located in the first corridor space, see Figure 4 below.

Figure 4

Dirty Utility Room

As shown in the image above, the dirty utility room contained many kinds of cleaning supplies, from chemical disinfectants, garbage bags, and bins. This space was often utilized by ward staff to discard biohazardous materials and also to clean equipment in between patient use. The medication room was on the other side of the dirty utility room, similarly, situated between two walls, see Figure 5 and 6 below.

Figure 5

Medication Room Left Wall

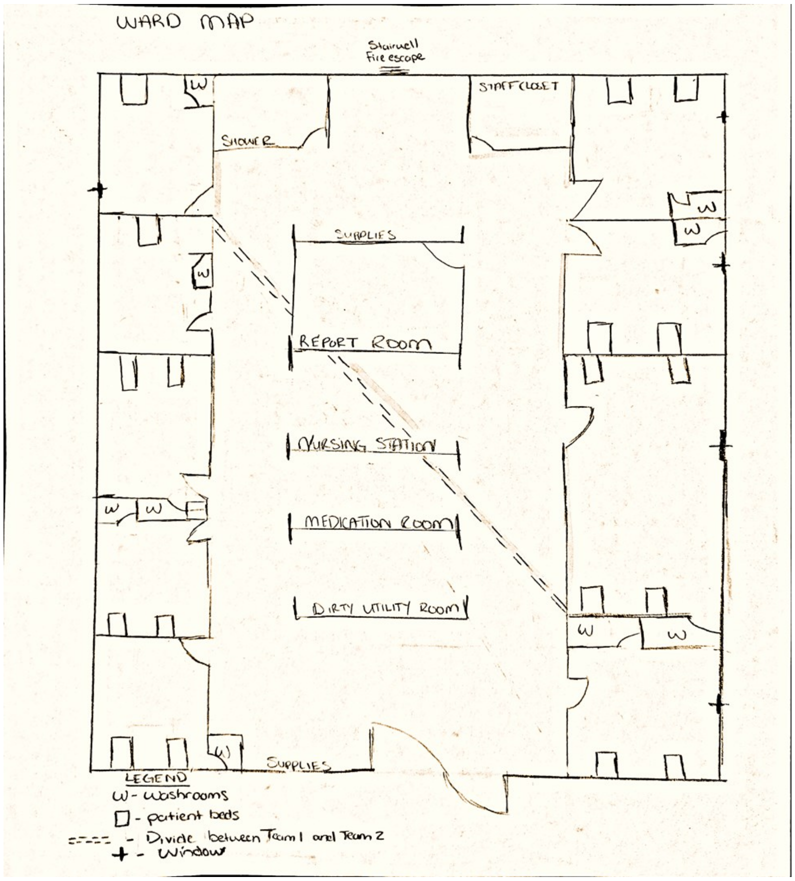
Figure 6

Medication Room Right Wall

The medication room had limited counter space for nurses to mix and measure drugs, as well as a machine to dispense medications, a refrigerator for cold storage, and drawers with patient specific medications. Figure 7 is a sketch of the ward floor plan, offering another perspective of how ward activities and spaces were arranged:

Figure 7

Sketch of Ward Floor Plan



As depicted in the image above, long hallways ran along either side of the nursing station and passageways existed across the nursing station, medication room, and dirty utility room. These ordinary spatial and material arrangements enacted different kinds of nursing practices. Patient rooms were more closed off with single door entry ways and the rooms were physically located in a roundabout way, circling the designated nursing workspaces. There were 18 patient beds on each ward, including two private rooms, one 4-person room, and six semi-privates. Each patient room contained beige-colored curtains, electronic beds, and bedside tables. The perforated line across the sketch of the ward floor plan shows the division of patient rooms between Team 1 and Team 2. The wards were split diagonally, so that the floor nurses could work in pairs and each

Team could have a workload of up to nine patients. In addition to having similarly organized workspaces, the ways in which the workloads and care of patients and families were distributed, divided, and routinized was identical across both wards.

Organisational Routines of Nursing Care

Nursing care on the orthopaedic wards maintained routine orderliness through a few time-based procedures. Nurses, health care aides, and the unit clerks would work in similar shift rotations on both wards. However, nurses were the only staff scheduled to be on the wards 24 hours/day (i.e. there were no unit clerks, managers or health care aides scheduled at night). Nursing shift changes always began with a shift report, which occurred at 0700, 1500, 1900, and 2300, regardless of the day. The shift report marked the transfer of patient responsibilities from one nurse to another and the exchange of critical patient information.

A Nurses' Day Shift

The day shift started at 0700 with a range of orthopaedic staff arriving. During day shifts, from 0700-1500, each ward would typically have a charge nurse, a unit clerk, three registered nurses, two licensed practical nurses, a housekeeper, and a health care aide. A registered nurse and a licensed practical nurse would be paired and given an assignment of either Team 1 or Team 2. These nurses would work together till 1500 or 1900, depending on whether they were scheduled for an 8- or 12-hour shift. From 0700-1500 the third registered nurse would be assigned the role of "resource nurse". The resource nurse did not have a patient assignment but rather acted as additional support for Team 1 and 2 nurses, the charge nurse, and health care aides, assisting them as needed with diverse patient care practices. The resource nurse would also take over the charge nurse role from 1500-1900 once the unit manager left (if they were scheduled for a 12-hour shift)[14]. The health care aide would be responsible for offering patients assistance with their washes and personal hygiene. The unit clerk could be seen doing payroll, answering the telephone, and coordinating diagnostic tests. Day shift routines from Monday through Friday varied from the weekend. For example, the unit managers did not work the weekends, so a registered nurse would occupy the charge nurse role. The observational fieldnotes below, show how the day shift report began on a typical Monday morning:

> The unit manager, nurses, health care aide, and unit clerk are all seated around the nursing station on short stools chatting with one another. They become silent when the clock strikes 0700 and the charge nurse from the night shift begins reporting on each patient as numbered on the census sheet. Their voice is monotone, and the information is delivered with a quick pace while the day shift nurses make notes on their census sheet with a pen "…. 10 was cancelled and also got mad that he was cancelled. He said that if he loses his leg, it is our fault, so hopefully he goes today too. 18 bed 1 is non-weight bearing to the left leg, so we asked to get that foley out. [The resident] read the message, but I think they forgot because there is no order yet for the foley to come out. She had 1 unit of packed red blood cells, so she is much better now. 18 bed 2, so ortho wants a joint aspiration, but [another service] says no. So, we have to figure out what we're going to do next. 20 bed 1 is very impulsive. She was up to the bathroom every 1 to 2 hours...She makes many sudden movements and screams when she is moving. She requested to see a social worker. We told her it is a Monday thing.
>
> - Fieldnotes, Ward A, Summer 2021.

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[14] The nurses worked a mix of 8 and 12 hour shifts depending on whether they were employed on a part-time, full-time, or casual basis. Full time staff typyically worked 12 hour shifts and part time would work 8 hour shifts. The casual staff would work more unpredictable hours, as they usually filled in on an as needed basis (e.g. sick call or vacation relief).

The excerpt above makes clear that there are many time-based routines organizing orthopaedic care. The shift report always started at the same time and usually lasted 15 minutes. The night shift charge nurse also shared that there are some care activities that occur only on Mondays. The nurses' focus on patients' mobility, bones, and joints made the ward appear 'orthopaedic' here, but it seemed the purpose of the report was to illuminate the care practices that remained outstanding. For example, surgeries, mobilizing, and personal care practices still required to be completed were rolled over onto the next shift. Although the ward patients and their needs changed across various shift reports, most shift change reports followed a similar pattern. The charge nurse always verbalized report with a printed census with the names and location of each patient on the ward in hand, while the oncoming staff listened and wrote memos for themselves on their own copy of the census.

Following the brief shift report, Team 1 and 2 nurses would decide how to divide their patient assignment amongst themselves. Typically, the registered nurse on Team 1 and Team 2 would take the more complex patients and the less acute patients would be assigned to the Licensed Practical Nurses. The nurses would then go find a computer and gather supplies, such as thermometers, stethoscopes, and alcohol swabs to then begin assessing their assigned patients. The most acutely ill patients would be assessed first and then the nurses would begin administering their medications. Medication times for all the patients were usually scheduled around four-hour intervals (0830, 1230, 1630, 2030 etc.) and alongside mealtimes. During the day shift the unit manager who doubled as the charge nurse would begin the day by reviewing the patients' care plans and updating the patients' anticipated discharge dates on the computer for the bed coordinator. The unit manager explained that if they did not do this, sometimes they would be assigned more patient admissions than they could physically accept on the ward.

Meanwhile the resource nurse would begin by checking which patients required blood sugar monitoring and dressing changes. They would then attempt to get as many of the blood sugar checks done before the breakfast trays arrived and before they had to leave for the Rapid Rounds meeting with the Unit Manager.

Rapid Rounds

From Monday to Friday, both wards participated in their own interdisciplinary meetings titled "Rapid Rounds" following the day shift report. The meeting for Ward A would begin at 0810 and 0830 for Ward B. These meetings were implemented as part of the CoACT Collaborative Care Model which claimed to create a greater focus on patient-family centredness (Birmingham et al., 2018). The charge nurse usually facilitated these meetings as described below:

> It is 0810 and the unit manager leaves the ward with the resource nurse. The meeting room for Rapid Rounds is about a two-minute walk from Ward A. Upon entering the room, the unit manager says hello to some allied health care professionals, including the physiotherapist, occupational therapist, and the transition coordinator[15], who are already seated around a rectangular table. The unit manager begins to give report once the doctor, called a hospitalist, arrives. The unit manager starts with the patient in room 2 bed 1 and quickly reads off their notes on a long sheet of paper that is called the ward census. While the unit manager begins to describe the patients' care plans, all attendees look down at their own census sheets and appear to follow along, making notes as needed.

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[15] Transition coordinators at the study site were registered nurses with specialized roles to arrange complicated patient discharges or transfers of patients to other care facilities. For example, they arranged transfers for patients that could no longer return home or required specialized home care arrangements. Whereas a bed cooridinator is also a registered nurse by training, however their role is to plan and track bed utilization in the hospital (e.g where emergency patients will be admitted).

- Fieldnotes, Ward A, Summer 2021.

The name of the Rapid Rounds meetings is appropriate because they were conducted quickly, conveying a large amount of information in a short amount of time. The purpose of these meetings were to provide nursing updates to the other health care professionals organizing patient care. Similar to the shift change report, the charge nurse would begin by saying the patients' room number, name, and then describe their needs. Through this format, the care plans and needs of 20 patients on Ward A, such as "needs a psych consult, "main concern is pain", "needs to mobilize", "and is experiencing urinary retention" were shared by the charge nurse in about 10 minutes. At times, the resource nurse would provide input, such as describing how a dressing change looked or if there was a critical blood sugar of a patient. The transition coordinator would sometimes comment if they had concerns or plans with arranging patient transfers to other care facilities. The physiotherapists would describe mobility progress or limitations of patients in more detail as needed. There was no informal conversation before, after, or during these meetings. Ward A's charge nurse and resource nurse would leave as soon as they discussed the last patient to allow Ward B to begin their own meeting with the attendees.

Both wards shared the same distributed care arrangements and interdisciplinary staff. For example, they had the same occupational therapists responsible for helping patients arrange activities of daily living. They also had the same hospitalists, medical doctors, who discharge and monitor patients before and after their orthopaedic surgeries. After Rapid Rounds, the interdisciplinary staff would leave the meeting room and continue providing different aspects of care for the patients, either from their offices or from the wards. For example, the charge nurse would return to the nursing station on their ward, while the resource nurse would go for their first break. The hospitalist and the pharmacist would pick either Ward A or Ward B to begin 'rounding,' meaning they would go physically check in and answer questions of all the orthopaedic patients.

In addition to these human actors organizing and coordinating care, a non-human actor, the ward census was active in facilitating these time-based wards care routines. Each ward had census, which was a list of all the patients admitted on to the ward.

Sample Patient Census

WARD A	**Date: Jun 07, 2021**	**Plan**	**Info**	**Lines/Drains/Airway**
18.1	**Last name, first name 123456 Dr.X 43 M** **Date: ORIF left Distal femur** **Hx: Etoh, alcoholic cirrhosis, malnutrition**	From: no fixed address Plan: Subacute ALC Listed ADOD: 14 June	NWB on Zimmer	
18.2	**Last name, first name 123457 Dr.X 27 M** **Date: Right knee septic arthritis (non-op)** **Hx: healthy**	From: home Plan: home ALC: Listed: ADOD: 10 Jun	AAT	
22.1 **R1**	**Last name, first name 123458 Dr.X 62 M** **Date: Widening of Pubic Symphysis** **Hx: HTN**	From: home Plan: RAAPID ALC: Listed ADOD: 10 June	Bedrest- Pelvic Binder	
22.2 **M1**	**Last name, first name 123458 Dr.X 87 M** **Date: Amputation Lt. Lower Extremity Through knee** **Hx: Rt through knee amp, Afib, HTN, Parkinson's, BPH, COPD, Anemia CHF, Anemia, TIA, Pacemaker**	From: home Plan: Rehab hospital ALC: Listed: ADOD: 14 Jun	Daily Weight NWB left amp WBAT Rt amp	

The census printout was a key document orienting all the nursing and interdisciplinary orthopaedic staff to the admitted patients. The census had key information about patients, such as their names, age, date of admission, medical history, and their plan of care. It would indicate if a patient had plans for surgery, transfer to home or another care facility (e.g., different ward, rehabilitation, subacute facility). It would also suggest an anticipated date of discharge and identify the physical location of the patient (i.e., bed and room number). As well, the patients' Goals of Care Status were included in the census (e.g., R1 and M1), which indicated the degree to which advanced life saving measures could be performed. The census organized key information so that staff did not have to rely on their memory to know these details of the patients. This was evident, because orthopaedic ward staff often carried their census with them throughout their shift and would also use it during their Team Huddles.

Team Huddle

Team Huddles occurred around 0930 to 0945 everyday on both wards during day shift. The practice of Rapid Round meetings and Team Huddle was introduced as part of the CoACT collaborative care model (Birmingham et al., 2018). The purpose of the Team Huddle was to inform nurses of any new care plans that may have been decided during the Rapid Rounds meeting, such as possible discharges or the commencement of different medications for patients on the ward. The Team Huddle occurred after the Rapid Rounds meeting and once the resource nurse returned from their morning break. During the Team Huddle, ward staff including the Team nurses, unit manager, resource nurse, and at times the health care aide, would attend. Nursing staff would gather around the nursing station with their ward census in hand and ready to share patient updates.

> It is 0945. There are two nurses from Team 2 at the nursing station waiting for the Team Huddle to begin. A nurse from Team 1 comes out of a patient room and says, “it’s fine we can start, [referring to her partner] is on her way. So, 2-1 their dressing has been done, 2-2 is good, 4-1 is in a lot of pain.” The charge nurse responds, “I think he has some psych issues, but I will page the docs again to see him… like he will be fine, but then the moment he’s due [for pain meds] he acts up.” The other nurse from Team 1 arrives to the nursing station and chimes in saying, “4-2 is good, eating well and was up to the commode.” The charge nurse comments, “yeah, I think he is going home today.” The same nurse continues giving an update on her other patients, “... so I found IV fluid on his bed…not sure how.” The charge nurse interrupts and says, “yeah I think he’s off.”

> The resource nurse then interjects and says, “no, I think he might have tipped it when he moved his bed. Sometimes when you raise the head it can catch on the pole… but I don’t think he is a good candidate for [rehabilitation hospital], I think he is better for subacute.” The charge nurse responds, “ok, so I won’t push for [rehabilitation hospital].” ….
>
> - Fieldnotes, Ward A, Fall 2020.

Team Huddle followed a similar pattern to the shift report and Rapid Rounds report, in the sense that the patients on the ward were discussed as listed sequentially on the ward census and the report occurred over 10 to 15 minutes. However, the nurse that assessed the patient would give a quick update and the charge nurse would provide any new information they may have learned from the interdisciplinary staff at the Rapid Rounds meetings. For example, the charge nurse confirmed they had followed up on the patient’s pain concerns and anticipated a discharge. The Team Huddle also allowed for nursing staff to clarify their assessments. The resource nurse, for example, clarified that the patient in room 6-1 may not have been responsible for spilling their IV fluid, but rather it was an accident. Once all the patients on the ward are discussed during the Team Huddle, one nurse from each Team and the unit manager would go on “first break”. In this way, the Team Huddle allowed all the staff on the ward to share information with one another, so that they could also cover for one another while they began breaks.

Day shifts from Monday through Friday would appear to be the busiest. My ethnographic observations revealed that there were many more staff and students present during the day shift on Monday to Friday than on the weekends. For example, social workers, managers, and the clinical nurse educators were only available during weekday day shifts. Students completing their practicums and clinical nurse educators would also be present during weekdays. Medications, linen carts, and other ward supplies would also usually be delivered at scheduled times during the day shift. The hospitalists usually physically assessed and monitored orthopaedic patient needs during the day shift. However, there were times that there would be no unit clerk, health care aide, or no resource nurse for the day shift. In these cases, the workload of these staff would then be distributed across the nursing staff who arrived as scheduled for their shift.

Care During Evenings and Nights

The evening and night shift had different routines from the day shift, with fewer hospital staff and different care arrangements. There was reduced baseline staffing during the evening and night shifts suggesting that there were fewer patient care needs during this time. Evening shifts would at times have a scheduled health care aide and unit clerk. During the evening there were no managers present, so one of the RNs who had been involved in direct patient care during the day was reassigned to the nursing desk to be charge nurse. Thus, from 1500 till 2300 there would be one less floor nurse. Dressing changes, diagnostic tests, and procedures that could not be completed during the day would be attempted during the evening shift. However, diagnostic tests and surgeries not be completed during the evening shift would be usually rescheduled for the following day shift. Admissions, transfers, and discharges of patients could occur over any shift, however, there would be fewer nursing staff to assist with these practices.

During the night shift, from 2300 till 0700, there would be no unit clerks or health care aides. There were no hospitalists rounding on patients during night shifts, instead surgical residents would be “on call.” Two registered nurses and a licensed practical nurse would be scheduled to work on the ward over the night shift. A registered nurse who completed charge nurse training would occupy the charge nurse role overnight. They would continue to review patients’ medical orders, admit, and transfer patients as needed by the bed coordinator. However, they would also have to provide direct care to the patients on the ward. There was no Team 1 or 2, instead the three nurses worked together to share workloads and provide care for all the orthopaedic patients on the ward. Each nurse would work within their scope of practice and alongside various technologies, policies, and materials.

Contingencies of Care on the Wards

Although I have described ward routines, activities and actors that were regularly observed, it is important to note these routines were contingent upon time and the availability of various health care professionals and medical equipment. For example, Rapid Rounds did not occur on federal holidays or weekends, because certain health care professionals worked Monday through Friday schedules. Overnight medication administration routines would change when the mobile workstations (i.e., computers) were scheduled for application updates. During the updates, which were often referred to as “down times,” the night nurses would not be able to electronically scan patient medications and document their administration. This meant that during these times, medication administration would involve different actors, such as printers, papers, and ink for paper-based documentation. During the day shift, the pharmacy could be called to deliver necessary medications and nutrition services could be called to deliver meal trays. However, these services were closed overnight, therefore night shift nurses would have to make different arrangements to obtain missing medications and food for patients. Through these examples, a key point to note here is that day-to-day care practices on the ward were complex, dependent upon circumstances of staffing and availability of material resources. Furthermore, the orderliness of the nurses’ day-to-day routine served as a backdrop while I was getting to know what was going on with the patient and family participants’ care trajectories. The concept of ‘care trajectories’ is used in this research as described in Allen’s (2014) ethnographic study of hospital-based nursing work[16]. While orderly activities, such as shift reports, team huddles, rapid rounds, surrounded the patient participants, their care experiences seemed to emerge in non-routine and more unpredictable ways – as unique and varied individual “trajectories”.

Patient Care Trajectories

Despite the apparent orderliness of the ward spaces and organisational routines, the care trajectories of the patient and family research participants in this study appeared to emerge with more uncertainty within the sociomaterial contexts of their care. My inclusion criterion for the case study participants was that they were admitted into hospital care for at least one week. An unanticipated consequence that may have been related to this inclusion criteria was that the patient participants each had prolonged hospital stays, mainly due to complications post-surgery. These complications or unexpected events, for example poor wound healing or difficulties with mobilizing, contributed to longer admission periods than these participants had anticipated. Although each of the patient participants required some form of orthopaedic care, their stories are illustrative of the complex and entangled relations, actors, technologies, and politics organizing hospital care. In this section, I introduce five patient participants. I provide background information describing the events that led to their admission and their experiences while admitted.

Tom Wilson

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[16] Allen (2015) developed the concept of ‘care trajectory’ while empirically studying the organizing work of nurses. This concept assumes that there is continuous, collective, and emergent activity organizing patient care. As Allen (2015) suggests, this concept is useful because it foregrounds the complexities of arranging patient care. Care of patients often unfolds in unpredictable ways and does not simply follow illness pathways or planned organizational routines. Rather Allen (2015) states that we can think of ‘care trajectories “as referring to the unfolding of a patient’s health and social care needs, the total organization of work carried out over its course and the impact on those involved with that work and its organization” (p.20). This concept can be useful for practice-based analysis because it also assumes that networks of interrelated practices, consisting of different actors and social conventions, emerge to organize patient care.

Tom Wilson was a 58-year-old retired truck driver who lived alone in an assisted living facility near the hospital. The Ward B transition coordinator identified Tom as “possibly an interesting case” (Fieldnotes, Summer, 2021). The transition coordinator told me that they had not met him yet, but “on paper” he appeared to be a patient that may be here for a while. Tom was admitted August 6 after having surgery on his left foot. The surgery involved an incision and drainage (I&D) and open reduction and internal fixation (ORIF) of his left foot. Although Tom’s anticipated date of discharge was listed as August 08 on his ward census, the transition coordinator predicted that Tom would be admitted for a much longer period of time. From the information they had gathered from the Rapid Rounds meeting, the transition coordinator believed that Tom was likely to have difficulty mobilizing and might not be able to return home to his assisted care facility.

From the ward census and through conversations with Tom, I learned that he had a complex medical history. Tom was morbidly obese, asthmatic, lived with many kinds of heart diseases, managed chronic pain with 1000mg morphine per day, and had a long list of medical diagnoses. When I asked Tom why he was in the hospital during our first interview outside by the hospital picnic tables he said:

> Well, what happened was it was about supper time on Thursday. And I made a lazy man supper like a TV dinner in the microwave and the only place I got to eat is on my bed, eh? And I usually eat from there. And what happened is that I dropped my tray. And I tried to pick it up and then I ended up on the floor. And I was trying to get to the phone, but it was too far away. So, I was screaming for some help eh. And no one was hearing me. So, I tried to lift myself up because I've done this a few times before but being at 335

> pounds is pretty hard too. And when I did get myself up, all of a sudden, I heard this big crack like, like, really super, super loud.
>
> - First Interview, Participant A, Summer 2021.

In the conversation above, Tom describes a traumatic incident of falling from his bed, and then trying to stand which led to him breaking his leg. Tom shared that he has always lived independently with mobility issues and that he did not plan on being hospitalized or needing surgery. Tom was very dissatisfied with the care he received on Ward B and told me that he was eager to leave during our initial conversations. During his first hospitalization, Tom and I had two interviews. One interview outside by the hospital picnic tables and another in his room. These interviews were recorded and lasted around 45 minutes. However, after arranging to meet with Tom for a third conversation, on my arrival I was surprised to find that Tom left Ward B without official leave. Despite having poor pain control, challenges mobilizing, and a freshly operated wound, Tom left the ward and refused to return when the nursing staff called him.

Tom was re-admitted back to Ward B one month after his first hospital stay, because the hardware that was inserted in his foot during his surgery had become infected. During his second admission on Ward B, we had one 25-minute interview outside the hospital where Tom liked to smoke. However, when I had arranged to visit Tom again I was told by a nurse that he had once again become absent without leave (AWOL). His second admission was as long as his first, lasting one week. The Ward B nurses told me that Tom left because they stopped giving him more pain meds. Unfortunately, Tom ended up requiring further hospital care and was re-admitted two weeks later, but this time he was admitted onto Ward A.

During Tom’s third admission, I was unable to meet with him for an interview on Ward A. When I would go to the ward, Tom would often be sleeping or gone for a smoke. Tom also did not pick up my phone calls. However, I was able to talk to two nurse participants from Ward A and together they shared some information about Tom's third stay. During the third admission Tom underwent an amputation of his left foot. According to the Ward A nurses, Tom went AWOL again after his amputation, but this time after a two-week long stay. The nurses both described Tom's hospital care experience as a sad and unusual circumstance. It was sad because they believe Tom left because he "felt rejected" by the physician who did not admit him into the rehabilitative hospital, which is designed to improve patient's mobilities after amputations (Fieldnotes, Ward A, Fall 2021). Tom's final departure was also atypical because the Ward A nurses arranged homecare wellness checks for him. Typically, the hospital routine for patients who are AWOL is that they do not generate any follow-ups, as was the case when he left Ward B.

Betty Moore

Betty was an 84-year-old who lived alone in an apartment prior to her hospital admission. A nurse from Team 1 identified Betty as a possible patient participant. The nurse explained that Betty was pretty confused at the beginning of her admission, but said "I think she's doing better now, so I can ask her if she wants to participate. Her daughter also comes to visit sometimes, so you can talk to her too" (Fieldnotes, Ward A, Summer 2021). The information on the ward census revealed that Betty was admitted in early July. I was initially hesitant to recruit Betty as a participant, because according to the census her surgical operations were completed. However, the Team 1 nurse stated that Betty would still be on the ward for a while, because there were many discharge barriers.

Prior to being admitted onto Ward A, Betty appeared to have a medical history consisting of insulin dependent diabetes mellitus, hypertension, and atrial fibrillation. However, after getting to know Betty through interviews and observations, her immediate medical history and experiences with hospital care seemed to be much more complex. The ward census revealed that Betty had a thoracic and pelvic instrumentation, L2 biopsy of the vertebral body and decompression, and duraplasty when she was admitted early July. These were complex surgical interventions, which aimed to better understand and resolve her back pain. However, these procedures were also the beginning of a very complicated and long hospital stay. Betty endured many unforeseen obstacles and medical complications throughout her 7- week hospital admission on Ward A. Midway during the first month of Betty's hospital stay, she had an adynamic or paralytic ileus, which is a disorder of the intestine, a surgical complication that can sometimes be prevented by astute nursing assessment. In the same week she had more surgery for an intramedullary rod and nail of her right femur, as a prophylactic or preventative surgical procedure to avoid future fractures. Towards the end of her first month in hospital Betty also experienced a Type II Myocardial Infarction and suffered severe allergic reactions to her antibiotics. Along with experiencing several unforeseen health related interventions and complications, Betty was also newly diagnosed with cancer.

During my first interview with Betty, I asked if she could explain what happened, and how she ended up on the ward.

> Betty: I feel fine at home. No problems that I know of. But on the Friday that I go to bed. About midnight I wake up. Something not right. So, I get out of bed and I go sit in the corner of couch. And I not be able to move again. I just lay there. And I did a call afterwards to a friend I have there. I wanted her to kind of know what happening. I do not mean to disappear in middle of the night. So, I wait till morning and then I phone her and tell her I'm in big trouble. I need to get an ambulance to come get me. And she phoned

> the ambulance and she made sure my apartment safe and locked. And she came right out to ambulance. And I sit in ambulance. They find where they can take me. Only bed then out at [rural hospital].
>
> - First Interview, Participant B, Summer 2021

Betty's description of events leading to her admission on Ward A and the course of her stay seemed chaotic. She had a soft-spoken voice and conversed in short sentences during our conversations, often pausing it seemed to carefully select her words. Betty described how the rural hospital was not equipped to handle her complex medical needs, so they arranged for a transfer to a more critical care facility. Betty described how her hospitalizations were dependent upon the availability of specific materials, such as beds, accepting physicians, as well as the findings from her diagnostic tests. In addition to these sudden and unexpected changes related to her health, Betty had also experienced changes in her family dynamics and support systems while hospitalized.

Betty was estranged from her biological family prior to her hospitalization and described having complicated and distrusting familial relationships. Sue, Betty's daughter, only became involved in Betty's care two weeks after Betty was admitted onto Ward A. I had conversations with Sue and Betty in-person on Ward A and through follow up phone calls when I left the field. While Betty was hospitalized, Sue described emptying Betty's apartment and storing her belongings until there was more clarity on Betty's future care plans. Midway through September Betty was transferred to a rehabilitative centre for mobility with a medical wing for six weeks. Betty described feeling hopeful that she could continue her physical rehabilitation and cancer care treatment outside of Ward A.

James Smith

James Smith was a 48-year-old male, who had a motorcycle accident while on vacation with his brother and his wife, Kim, in a neighboring Canadian province[17]. When James was admitted to Ward A, the unit manager had left me a sticky note on a research binder with his room number. I asked one of my nurse participants if they could share the study information sheet with him. The nurse said:

> “Oh, he would be a good one to talk to. He has been through a lot. You know [the other hospital] discharged him without anything, no pain killers or even antibiotics! We were going to call you yesterday, but he had his amputation, and he was pretty upset so we decided to wait.”
>
> - Fieldnote, Ward A, Summer 2021

The nurses and unit manager figured James was a good candidate for this research study. From the conversation above, it seemed that their recommendation of James as a research participant was related to a series of unexpected and apparently neglectful care practices in another hospital rather than my weeklong hospital admission criteria. James shared the study information with his wife, Kim, who also agreed to participate in the study. During their hospital stay in a four-bed patient room on Ward A, I got to know James and Kim through two formal interviews. They would do these interviews together, while James lay in bed and Kim sat in a chair next to the bed. James and Kim shared their experience from the initial accident to his hospital admission on Ward A.

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[17] Despite claims for universality and accessibility across the nation, the Canadian health care system is administered provincially. Each province has its own Ministry of Health. Issues generated by the provincial jurisdictional arrangments were relevant to James who sustained his injury in a province where he was not a resident.

> James: So, it was just kind of a nice and beautiful ride. And I come around the corner and all of a sudden there was a truck there and I'm like, oh, I don't have enough room here. And I chose to either lay [the motorcycle] down and go underneath the truck or keep it upright, which is what I did. I kept it up right and just rode down the side of the truck. So more or less like a sideswipe.
>
> - First Interview, Participant C, Summer 2021

From James' description, he was having a great day, which then unfolded in an unimaginable way. He explained that he did not have many options as to how to navigate a high-impact collision between his body on a motorcycle and a much larger moving vehicle. James' accident occurred on secondary highways, so he was surprised and grateful that an ambulance was able to come out to the accident site and then connect him with a medical flight crew. The medical flight crew took James to a hospital near the collision site. James described being medicated for pain while on the flight and drifting in and out of sleep. Shortly after arriving at the hospital James had his toes amputated. James was unsure of the state of his injury and his family was even less informed about what was going on.

According to James and Kim, his first hospital admission in the other province was extremely difficult. Kim explained that she was not allowed onto the ward due to pandemic related visitation restrictions, but she did not necessarily follow the rules. Kim would try to sneak up to the ward anyway to get information about how James was doing. However, she would get caught by nursing staff and be asked to leave. Despite experiencing a traumatic accident and surgery, James was discharged abruptly after two nights in the other hospital.

> James: They also said that I would be released tomorrow morning, because billing is very hard to do with the [RHA] and [the other regional hospital's health authority]. So, it was

> going to be a fight from here on out trying to get money for [the hospital admission] anyway through [RHA], so we're really releasing you tomorrow morning. I asked them do you think I am fit to be released? And [the doctor] was like, oh, yeah, no. My suggestion is you just go to a hospital first when you get [to your home province] and they'll take you from there.
>
> - First Interview Participant C, Summer 2021

James' care and particularly his discharge from the other hospital appeared forced and distressing. The doctor suggested that James seek further hospital care through his own RHA. James and Kim described being quite powerless and vulnerable during this initial admission. James' release appeared to be based on the hospital's billing processes more than his actual care needs. James and Kim lived in a rural town that did not have a large tertiary hospital equipped to care for his injuries. Therefore, James decided to fly with his wife to the city with a tertiary hospital nearest home after leaving the first hospital. When they landed, James took a taxi with his wife to the nearest hospital-based emergency center. James describes waiting in the emergency room for a few hours before he was admitted onto Ward A.

Hospital nurses, James, and his wife Kim provided accounts of how neglectful care in another province led him to being admitted onto Ward A. From the emergency ward, James went to the operating room to have a partial degloving of his left foot. During this surgery he also had a debridement and revision of his left trans metatarsal amputation of his toes (D1-D5). After the surgery he was admitted onto Ward A for further monitoring. He described how the Ward A staff managed his pain and monitored his injury, routinely assessing the color, sensation, temperature, and movement of the left foot. Unfortunately, he said the muscle tissue was assessed as no longer viable and that he had to have an amputation of his left foot. James was put on call for the operating room three days after being admitted onto Ward A and the same day he had a below knee amputation of his foot.

James described his care as unfolding in surprising ways. He never imagined that he would have to have an amputation. Furthermore, he was unsure of whether he would be eligible for admission to a rehabilitative facility or if he would be discharged directly home. James was assessed by the [rehabilitation] doctor one week after his amputation around lunch time and by 1900 he was discharged from Ward A and transferred to the rehabilitative hospital. Due to how quickly the transfer was arranged, I was unable to be present for their discharge. However, from my nursing experience I believe this was an unusually rapid transfer and discharge. Beds at the rehabilitative hospital are typically limited and there are very specific criteria to qualify for the program.

Darlene Adams

Darlene was a 60-year-old female, who lived with her husband in their daughter's home while their own home renovations were being completed. Darlene was admitted to Ward A in early Fall 2021. The Ward A staff anticipated that she would be discharged in a few days upon admission, so she was not identified as a possible case study until one week into her hospitalization. When I met Darlene to describe the study, five days into her admission, she was sitting in her semiprivate room wearing her own clothes and she had her cell phone in hand. She was cheerful and agreed to participate in the study but said that she may be discharged the following day. However, I when I checked in with the charge nurse on the same day, they said:

> "Yeah, I think she is going to be here for a while, because we're not sure what the next step is. She needs antibiotics still and maybe even more surgery."
>
> - Nurse- Fieldnotes, Ward A, Fall 2021

There appeared to be a confusion and uncertainty related to Darlene’s care during her admission. Although the charge nurse was unsure of Darlene’s care plan, the anticipated date of discharge listed on the ward census suggested Darlene would be in hospital for at least five more days. Darlene also had different ideas about how her care was going to unfold than her nurses. Darlene would often be off the ward with her visitors, so we only had a one-hour long interview in her semi-private room. During our conversation, I learned that the course of her hospital stay had emerged in unexpected ways.

Darlene decided to come to the hospital emergency, because a wound from a previous surgery on her foot had opened. She said the emergency staff admitted her and decided to send her to the operating room to do an exploratory surgery on her dehisced wound. After this initial surgical procedure, she said she was transferred to Ward A. The Ward A census listed all of Darlene’s surgical operations. It stated that she had an incision and drainage (I&D), and another surgical procedure on her left achilles two days after her admission. Darlene explained that after the second surgery, she was sent back to Ward A with an open wound and specific instructions for the nursing staff to follow for wound care. However, it was later discovered that during her first surgery, the surgeon was supposed to have taken a tissue sample for diagnostic purposes. The sample was supposed to determine precisely what the infectious pathogen was, so that the appropriate antibiotics could be ordered. However, it took a few days of waiting for the orthopaedic staff to discover that the sample of tissue was never taken during the initial washout procedure.

> Darlene: Yeah, so then that night they didn't know that right? Because they were just looking for the results to be uploaded. So that night they started me on IV antibiotics and then they found out that surgeon didn't remember to take the samples. So now not only

> have I had an infection since June that I've been on mega antibiotics for, a wound vac, and an open wound and all this crap… now they're just blindly trying to treat me because they don't know exactly what bug they're up against. So now I'm waiting. I was supposed to have an MRI on Friday because they wanted to get the MRI to see if there's any infection in bone tissue tendon and to see if you know there was a deeper source of infection. Because the plastic surgeon wanted me to get on the wound vac, with the one that does the flushing as well. I forgot the name of it something flow. And so they asked me today. The plastics said why aren't you on that vac and I said because they still haven't done the MRI. And apparently the reason the radiologist wouldn't put me through for an MRI, because it's all prioritized with the cutbacks and COVID and all that is because in his estimation, he assumed it was a follow up MRI. Which the follow up would be from when I had it prior to my repair.
>
> - First Interview, Participant D, Fall 2021

Darlene's time in the hospital continued to be extended and her care plan became increasingly more uncertain, since the tissue sample was not obtained. Darlene frustratingly described how she has been treating this wound since June with various therapies, including antibiotics and a wound vac, which is a device that promotes blood flow to a wound. Therefore, a Magnetic Resonance Imaging (MRI), which is a procedure that can create detailed images of the organs and tissues in the body was supposed to have been arranged for Darlene. However, Darlene explained that the MRI remained outstanding during our interview, because the radiologist misunderstood why it had been ordered. The radiologist assumed the MRI was simply a follow-up procedure. However, Darlene needed the MRI to determine if she needed more surgery or more intensive wound care. I never had the opportunity to talk with Darlene again, because I also had to exit the field due to another rise in COVID-19 cases. Darlene and I were unable to connect over phone despite me leaving her two voicemails. However, I phoned Ward A and learned from the unit clerk that Darlene was discharged after a two-week hospital admission and without undergoing further surgery

Abby Lee

Abby and Lynn explained that they spent two weeks on Ward B after Abby, a 33-year-old female, was admitted into care due to a broken leg. Lynn, who was Abby's mother, had seen my posters on Ward B and left a voicemail asking questions about the anonymity of participating in this study. Unlike my other research participants, Abby and Lynn decided to do this interview together from the comfort of their home. For both Abby and Lynn, it was important to maintain anonymity about their participation in this study from Ward B staff. This interview occurred after Abby was discharged from Ward B. I began the interview by asking Abby to introduce herself and describe how and why she was hospitalized on Ward B:

> Abby: I came into the hospital on October 29, with a broken leg. It didn't look right to me at all, but they sent me home. They told me it's normal.
>
> Lynn: With swelling.
>
> Abby: Yeah, so that swelling, I had massive swelling in my leg which was not normal for a broken bone. I told my [sports medicine physician] and they sent me home too. They contacted the surgeon who had seen me and set up an appointment for that Wednesday, because the sports medicine physician is just out of his league with the severity of the break. I went to the surgeon and his resident, and I told them about the swelling, that the brace that they were putting on was very heavy for me and that my leg did not look normal. It looked extremely swollen as compared to three days ago. They sent me home

> that night too. Then I had an anal prolapse and I was taken to the hospital via ambulance at about 12 in the morning. Then when they fixed the anal prolapse, I spoke to them about the brace that the swelling in my leg was, again, getting worse and worse. They still sent me home. I then was home on Thursday. And I was noticing signs of what appeared to be a blood clot in my leg. And it was still massively swollen. By this time, my whole entire body was swollen. Then I called the surgeon's office, they advised me to go to emergency. I went to the emergency and I was fully admitted that Friday.
>
> - First Interview Participant E, Fall 2021

Abby's voice sounded tearful while sharing these unsettling events of her trying to get critical medical attention for her swollen leg. Abby described experiencing anxiety, increasing swelling in her leg, and discomfort with her brace to numerous health care providers. Even during her sudden anal prolapse, she appeared to be quite worried about her leg, and yet the various medical care personnel she actively sought out and unexpectedly came across seemed to disregard her concerns. Abby knew that something was wrong with her leg early on and that it was not 'normal,' however, her concerns were not taken seriously. Based on her account, it seems that her concerns were neglected one week prior to her first hospital admission for her anal prolapse. Abby's concerns for her leg seemed to only be taken seriously once she started to experience severe symptoms. For Abby's surgeon, dangerous symptoms, such as swelling across the body and blood clot symptoms, which include throbbing, cramping, redness to her leg, were indicators that she should seek emergency hospital care services again. Abby's sepsis could have been prevented with earlier intervention, such as antibiotic treatments. However, due to the lack of thorough assessments and timely interventions from numerous health professionals, Abby required significant antibiotics and surgical intervention to clean out her wounds. Abby arrived on Ward B after going though many procedures, such as blood tests, surgery, and antibiotic treatments. Abby described herself as someone who is not a very healthy person due to severe osteoporosis and has had a long history of being in and out of hospital. In addition to the anal prolapse, broken leg, and sepsis treatment, Abby claimed to have been admitted to the medicine ward in this hospital as well.

Lynn said that she has also been present for all of Abby's hospital experiences as an essential care giver. In a way, Abby appeared to be quite familiar with hospital care routines and was able to identify the health care professionals on Ward B. During our interview Abby described some hospital staff as being better at providing care than others. For example, the surgeon who cleaned out her wound was phenomenal whereas the physiotherapists and some nurses were described as being detrimental to her care trajectory. Even once being discharged from the hospital, Abby gave the impression that she was still unsure about her bone health. She and her mom seemed worried that a new problem had emerged, because she was experiencing new pain localized on her arm after her discharge.

Summary: Contextualizing the Complexities

This chapter aimed to contextualize the environment and patient and family experiences in which I attempted to discover PFCC. At the outset of the chapter introduced and described the PFCC initiatives that had been introduced on Ward A and B. On the surface, each shift I observed seemed to be organized around established schedules and routines. However, within the description of each of the five patient cases, a great deal of complexity and the need for specific nursing care became apparent. As well, I introduced the five patients and their family members who participated in the study. To summarize, Tom experienced a fall at home and broke his leg, which led to a series of hospital admissions and eventual amputation of his foot. Darlene brought herself to the hospital emergency room because an almost healed surgical wound on her ankle had re-opened and was infected by an unknown bacterium. Betty was transferred from a rural hospital to the orthopaedic ward due to severe back pain, which required multiple surgical interventions and additional specialized oncology care. James came to the emergency room after receiving inadequate care in another hospital following a motorcycle accident, which resulted in him having his lower leg amputated. And Abby, who was admitted into orthopaedic care due to sepsis occurring in a broken leg. Nurses played a significant role organizing these patients' care trajectories, most notably arranging day-to-day care activities on the orthopaedic wards such as cleaning surgical wounds, pain management, and coordinating care with other health care providers.

The overview of the PFCC documents expected to guide patient and family centered practices, the physical layout and staffing practices on the orthopaedic wards, and the overview of each of the five patients' hospitalizations described in this chapter begin to show the sociomaterial complexities organizing care in hospital settings. Notably, despite there being many PFCC artefacts produced and interrelated with other policy priorities, these seemed somewhat detached from the day-to-day practices I observed organizing the orthopaedic ward routines. Finding something I could label "PFCC" proved difficult. The day-to-day organizational routines, while appearing stable and orderly, were also complex, relying on a mix of health care providers with different skillsets, different practices of report giving, and time-based procedures. The patients' care trajectories were even less predictable, with the unique and individual circumstances of patients and family members standing in contrast to the general orderliness of how care activities were arranged on the wards. The arrangements of bedside nursing care for these patients were complex. The nurses were key actors in the network of care, integrating organizational routines into their work in response to unpredictable patient needs. And while on one hand, nurses seemed to mediate the sociomaterial conditions organizing care, they were also organized by these same conditions. In order to more fully explore the tensions among these intricately interrelated actors, and the practices of which they were a part, I have organized my analysis by focusing Chapter 5 on ethnographic data from the nursing participants, while Chapter 6 foregrounds my observations and interviews with patient and family participants. Ultimately, my task was to "discover" PFCC in everyday nursing care. As I go onto elaborate, the apparent reasonableness of my two research questions: 1) In an adult acute care setting, how is patient and family centredness in care enacted? Specifically, how do practices intended to centre families interact with the sociomaterial contexts of care including evolving technologies, and with what effects for patient and family hospital experiences? and 2) In what ways is PFCC as outlined in policy accomplished, not accomplished or partially accomplished? turned out not to be straightforward or easy to "find".

Chapter 5

Discovering PFCC in Everyday Nursing Care

During my time on the wards I observed ongoing complexities while nurses arranged patients' care trajectories. Patients' care needs often unfolded unexpectedly and required nurses to obtain the right materials, coordinate with other health professionals in a timely manner, and follow organizational procedures. Moreover it was often the case that nurses did not have readily available resources to arrange patient care, rather they accomplished patient care in the context of staffing shortages, time constraints, and unanticipated patient events. In making these care arrangements, I noticed many values being enacted by nurses, including those I judged to be values about efficiency, resource protection, and supporting communication with other hospital staff. I describe how the all-encompassing instructions about how to incorporate PFCC values as described in educational resources and policies, including for example, respect for patients' choices and unimpeded family visitation, overlook the sociomaterial complexities in everyday nursing care. There were multiple, and not always congruent, values enacted in the day-to-day organization of care. Neither the organizational routines, nor the actors involved in care – patients, policies, and nurses – were value-free. Rather, values and practices were intertwined and so discovering what PFCC *is*, how it was being 'done', and/or how the 'values' expressed in the organizational PFCC initiatives were being implemented, required understanding of the multiple practices that were producing patients' experiences.

As Mol (2008) argues, "the logic of care has no separate moral sphere" (p.79), and this observation has important implications for this practice-based study. Mol (2008) is arguing that "'values' inter-twine with 'facts' and caring itself is a moral activity" (p.79). Therefore, moral activities, including the values and ideas described in PFCC policies and educational resources, cannot be isolated from the practicalities, routines, and ordinary activities that shape everyday nursing care. Values do not precede the multiple decisions that are made in everyday care practices, rather diverse values are entangled in how care emerged through people, discourses, and materials on the wards. To develop this analysis, in this chapter I draw on conversations with nurse participants and observations of nursing practices from Ward A and Ward B. I also employ a technique practice-based researchers Gherardi and Rodeschini (2016) refer to as a "critical incident analysis" (p.3).

As Gherardi and Rodeschini (2016) state, a critical incident is "an opportunity to look at a breakdown in the course of what is taken as '*normality*,' in order to gain deeper understanding of the values, rules, and behaviours that are taken for granted and are therefore almost invisible for most of the time" (p.272). In other words, I looked for moments and events I recorded while conducting fieldwork which were 'out of the ordinary'. This was important for me for the ways this technique aligns with a broader analytic strategy of 'making the familiar strange' as described in Chapter 3. 'Making the familiar strange' encouraged me to reflect more deeply about what I, as an experienced nurse, might be taking-for granted in a situation, including knowledge and assumptions related to what I considered to be 'normal' in nursing practice. For example, in my eight years of hospital-based nursing practice, I have encountered many instances of poor wound care coordination, patient falls, new cancer diagnoses unrelated to the reason for admission, and patients leaving hospital without official discharges – these sorts of events are not 'surprising'. Yet even though somewhat 'normal', they may also be understood as uncommon, and, in some sense disruptive. In this chapter, I consider those events that seemed to not only disrupt ward routines, but also show the challenges of overlying PFCC, as articulated in the formal policy and educational discourses, onto or into everyday nursing care.

Disrupting ‘Routine’ Nursing Care

Although many of the patient care trajectories on Ward A and Ward B might be considered abnormal or even horrific to an ‘outsider’, or someone without any familiarity with hospital-based care, they are part of ordinary or routine life on orthopaedic wards. While admitted to the wards, all the patient participants underwent surgical interventions. For example, both Tom and James lost limbs, a common outcome for some of the injuries and conditions for which patients require orthopaedic admission to hospital. The surgical amputations that Tom and James experienced are simply routine for nurses who have expertise in providing amputee care. The expectedness of such procedures was evidenced, in part, by posters and pamphlets that shared information about amputation support groups on the walls of Ward A and Ward B, recognition that this was a place of life altering events for patients. Alongside receiving major orthopaedic surgical interventions, patients were also routinely injected with medications, such as antibiotics, analgesics, or extra fluids in preparation for surgery. Patients experienced insertion of various medical tubes, such as intravenous lines or foley catheters (flexible tube inserted in a urethra to drain a bladder), and had their blood drawn regularly for different diagnostic tests. Patients’ bodies were routinely examined by many strangers, sometimes by experienced health professionals and other times by students completing their practicums. While looking down the ward halls it would not be unusual to see patients’ gowns loosely tied and exposing some of their naked skin while completing their physiotherapy. As a nurse with experiences in surgical care settings, I did not initially view these aspects of hospitalization as strange – to me, at first glance, they appeared simply “routine”.

Many researchers have observed and written about the routine elements of the everyday nursing care of patients in hospitals. For example, Chambliss (1996) ethnographically studied ethics in hospital-based nursing care almost thirty years ago. Although many of Chambliss' observations took place in more critical care wards, such as Intensive Care Units and Operating Rooms, his descriptions resonated with my observations of ordinary nursing care for patients having hospital experiences. Chambliss (like me) observed an array of specialized medical services, nonstop record keeping, and the existential suffering of patients in hospitals. He described these organizational aspects of nursing care as the *routinization of disaster*, a still apt description when even the disruption of routine is handled routinely:

> It is 0845 and the ward is busy as usual for a day shift. All the patient beds are occupied, and the staff are spread across different spaces on the ward. There is a nurse in the medication room and nurses inside patient rooms assessing and documenting their patients' conditions. A porter arrives on the ward and takes a patient on a stretcher off the ward for an X-ray. Among this routine activity, there is a sudden and loud bang from a patient room. Followed by a cry out for "HELP" as a woman dressed in jeans and a grey jacket runs out of the patient room at the end of the hallway. The charge nurse and four other ward staff immediately run towards the room. Upon entering, one nurse quickly steps out of the room and leaves the ward, returning almost immediately with a mechanical lift. A different nurse speaks with the visitor in the hallway. Two nurses remain in the patient room. After about two minutes, the charge nurse returns to the nursing station and then the licensed practice nurse from Team 2 comes to the nursing station with their computer on wheels. They ask the charge nurse if this fall counts as unwitnessed, because a staff member was not in the room. The charge nurse suggests it was witnessed because a visitor was in the room. "So much paperwork", the Team 2 nurse says, and then asks, "do I need to do an RLS and the Fall Risk form?" The charge

> nurse responds, “yes…. looks like she’s also going to need an X-ray and CT [Computed Tomography]”. The charge nurse then picks up the phone to call another ward: “Hey are the docs there...no, ok thanks.” After hanging up they call locating and ask, “could you page the Trauma PA [Physician Assistant]?” Almost immediately the phone rings back. The charge nurse answers: “Hey…Remember [Patient F]? The one that always removes her collar. Yeah, she just had a fall. Vitals are ok. She tripped while going to the bathroom with the gutter walker. There was a visitor in the room who says she may have also hit her head. They are using a lift to get her into the bed….”
>
> - Fieldnotes, Ward A, Winter 2020.

This fall, a fairly dramatic incident, seemed to very quickly ‘centre’ Patient F in the attention of many nurses, interrupting the usual Monday morning routines on Ward A. Many nursing staff stopped their medication administration and assessments of other patients to respond to this one patient’s cry for help, physically running towards the patient room. While this was a somewhat jarring event for the patient and for the visitor who rushed out of the Patient F’s room, for the nursing staff involved it seemed to be more of a rehearsed situation. Without knowing what was wrong with the patient in the room and without appearing to have to provide each other with much verbal direction, the staff worked together seamlessly. While some staff gathered equipment, like the mechanical lift, others assessed Patient F’s body and then helped transfer them back to bed.

The nursing care for Patient F while a seemingly routinized and ‘normal’ response, was actually quite complexly coordinated. For example, a nurse from Team 2 immediately began completing the standard forms for reporting and documenting a fall[18]. The charge nurse's reporting of the situation to the physician assistant was abrupt and focused, seeming to follow the standard Situation-Background- Assessment-Recommendation (SBAR) communication framework used between health care providers in hospital. With a calm tone of voice, the charge nurse described the patient situation as a "fall" and provided a brief background of how the fall happened. They shared their assessment of Patient F's vital signs as being normal and then described how they responded by moving Patient F's body with the mechanical lift. While notifying the necessary care providers, the charge nurse anticipated additional diagnostic tests for the patient, knowing that they may have compounded injuries from their previous fall. This disastrous event for Patient F was quickly and competently addressed by the nurses on the ward and by 0930, the physician assistant had ordered the additional diagnostic tests. As well, all the nursing staff had resumed the activities they had been involved in prior to the fall, as though the fall never happened.

While the notion of routinized disaster may seem a fitting description of everyday nursing care, it is not entirely satisfactory. Patient F's care as described above was a collective endeavour with work distributed across networks of nursing practices, including the initial response in the room, the assessment, lifting back to bed, documentation, and report giving. As a registered nurse, I often assume that responses to incidents such as this fall are 'normal' or just routine. However, my 'insider' view does not do justice to the knowledge these nurses displayed while arranging care for Patient F, enacting procedural and experiential knowledge to quickly coordinate activities with one another to address Patient F's situation and enable their (the

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[18] The RLS is an acronym for Reporting & Learning System, which is a technology used to track adverse advents, generate reports of safety trends, and communicate information of hazardous events with the hospital system leaders (i.e., managers). It is mandatory to complete and report after a critical incident, such as a fall with a patient

nurses) return to their other patients. Pentland and Feldman's (2005), writing about organizational routines describe both the generative capacities of routines and their internal dynamics, suggesting these allow for or institute important organizational phenomena such as flexibility, stability, and continuity. Flexibility, stability, and continuity are more than just organizational outcomes, the description of the response to Patient F's fall is an exemplar of how these sorts of values are enacted by nurses, as well as demonstrating the value of nurses' flexible/stable response that ensured the continuity of each patient's care.

The nursing care for Patient F after their fall was not *simply routine* (although it could be read as such). Rather it unfolded in relation to nurses' knowledge of this patient's previous fall history, assessments (i.e., vital signs measurement of blood pressure, temperature, pulse, and respiration; careful assessment of a possible head injury and so forth), and their ability to work collaboratively with the patient, with the visitor and with one another. Additionally, Patient F's nursing care adhered to organizational rules, such as fall checklists and reporting protocols. Continuity and return to 'stability' are achieved by sociomaterial conditions, coordinating work, and collective nursing knowledges. So rather than seeing these observations of nurses' organizing patient care as simply routine, we can see continuity and collaboration as examples of values being enacted through nursing practices. Certainly the nurses' production of these values (to generate order and calm during an emergent situation such as a serious fall) have a significantly different character than the democratic ideals and principle-based values (such as "involvement", consultation and communication) described in PFCC policies and educational resources, where the skills inherent in nurses' 'routine' responses seem to be isolated from the overall context of what is happening. This raises a question of how these 'sets' of values relate, and whether and how they have effects in producing patients' experiences of care. I will describe these differences in the next section and show how the abstracted “overlay” of the aspirational PFCC literature and training may be incongruent with what is needed from nurses in the day-to-day complexities of practice.

‘Instructions’ for Putting PFCC into Practice

As introduced in Chapter 4, PFCC values are described in the hospital’s policies and educational resources and emphasize the idea that care for patients and families should always reflect four key components: 1) respect and dignity; 2) information sharing; 3) participation; and 4) collaboration. Scenario-based videos of these PFCC components are presented in a required organizational learning module titled, *Annual Continuing Education (ACE): Patient & Family Centred Care (PFCC) 101*. Here filmed vignettes show clinical and non-clinical staff how to put these values into practice. The vignettes are presented as a “reflexive learning strategy” intended to show health professionals how to better ‘centre’ patients and individualize their care experiences. Quite noticeably the narration that accompanies the films describes PFCC values using bioethical principles, such as dignity and respect. The aim of this training is to teach staff how to respond in individualized ways for patients. A key message from these vignettes is that PFCC can be accomplished by attending to patients’ values, preferences, and priorities. However, the films and other PFCC artefacts I examined during this study do not account for the complexities I observed when nurses provide care for people in highly routinized settings with finite and shared resources. In the films, the staff did not appear pressured to find material resources, the patients and family members seemed uncomplicated with predictable care needs, and there were no apparent time constraints for the health professionals. These films also stressed an individual clinical health professional responding to a single patient concern, rather than demonstrating how care of patients is actually distributed across multiple actors and networks of activities.

PFCC values are also outlined in a document titled *Patient and Family Centred Care Resource Kit: How to Improve the Patient Experience at the Point of Care*. This 'kit' is a 102-page document that includes specific suggestions and concrete practices for hospital wards to implement to improve patients' and families' experiences of care. Some of the PFCC resources described in this document, such as bedside communication whiteboards, were located in the patient rooms on the wards where I conducted observations. However, when I asked nurses about the use of bedside whiteboards, rather than commenting on their usefulness for communication purposes, nurses described how auditors would come to the wards unannounced and secretly count and then report the number of bedside whiteboards that were updated. The nurses described being extra vigilant about updating whiteboards if they were made aware that these surveyors may come visit the wards. This idea of auditing the use of PFCC artefacts, in this case the whiteboards that had been installed at the foot of each patient's bed, shows a different value than simply centring an individual's needs or preferences. It points to a bureaucratic interest in surveillance and monitoring. That is not to say that whiteboards did not (sometimes) work to support patients' and families' knowledge about the hospitalization by communicating specific information (e.g. the assigned nurses' names, the current date, dietary restrictions and so forth). Rather, it seemed that in practice, this PFCC strategy had greater resonance for nurses as part of an accreditation process. Nurses seemed to consider the boards an intrusion on their professional judgment. Although they did not dispute the usefulness of the boards for some patients and their families for whom the information on the boards acted as a memory aid, nor did they have a quarrel with the effectiveness of clearly posting limitations in physical activity (such as non-weight bearing) or dietary restrictions (such as fasting for a procedure). But nurses' focus on the boards was how they were disciplined as a "standard" for *every patient*, and how *the boards* were surveilled as an indicator of nurses' patient centring practices. As a bureaucratic *program* of patient centredness, the whiteboards were viewed as an extra task that needed to be completed when the accreditors were coming.

There are many PFCC artefacts created and celebrated by the RHA, but, like the use of whiteboards, these tools arose as an overlay on nursing practice as a site of knowledge. They are written in a highly aspirational tone. The underlying values being communicated (compassion, cultural competency, asking people what matters to them etc.) cannot be disputed. But as my data analysis in this chapter elaborates, the instructional resources do not seem to be aligned with the demands being made on the overly busy nurses I observed, shift over shift. They cannot accommodate nurses' responsive "in situ" actions, such as those I observed during patient F's fall. The following figure is a screenshot from a six-page online publication from the RHA titled the *PFCC Week Toolkit 2022:*

Figure 8

PFCC Week Toolkit 2022

This content is unavailable. Please consult the figure list for further details.

Figure 8: Unpermitted third-party content

This figure is a small snapshot from a multi-page document that contains many more ideas and suggestions for clinical and non-clinical staff to put PFCC in their practice. There are hyperlinks displayed on the right-hand column which connect people who are viewing this document to additional PFCC educational materials and PFCC policies. For example, the bullet point in the document "Encourage Patients to Get Dressed and Moving" suggests that patients' dignity in clinical settings can be maintained if they are encouraged to wear their own clothes. This suggestion is usually highly impractical in the orthopedic wards where the traditional hospital gowns with the button snaps had particular affordances for both patients and nursing staff, allowing easy access to the various tubes, intravenous lines, and bandages on patient bodies after surgery. Moreover, after orthopaedic surgery it is often physically difficult for patients to put their own clothes over limbs encumbered with casts, splints, or braces.

Despite that the suggestions listed in Figure 8 are of the "pick and choose" variety, the suggested activities such as writing gratitude messages on patient bedside whiteboards, learning about the power of compassion, or about cultural competence, introduce a patronizing tone for nurses whose professional education incorporates courses and theory focused on effective communication and caring. [19] At the same time, my observations of nursing practices and conversations with nursing staff suggested that the conditions of practice often worked against these professional aims.

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[19] See for example the work of nurse scholars, such as Sister Calista Roy (1988), Jean Watson (2009), and McCormack & McCance (2017) whose scholarship embodies humanistic qualities such as compassion, empathy and mutuality in nursing education.

Nursing Care: “Just doing it all”

As described in Chapter 1, nurses are concerned in different ways with centring care on patients and families in hospital care. When I talked with nurse participants about what their role in ‘centring’ patients and families looked like, a typical response is captured in the fieldnote below:

> Sally finishes charting on the computer and takes a seat on a stool next to her computer in the hallway. I ask her “so, could you describe your role on the ward?” Sally has been working for about six months since graduating. She responds, “well as a nurse you are in charge of doing nursing assessments, interventions, monitoring, and advocating to doctors, working with other nurses and pharmacists. You know advocating with a large team of people, so there is a lot of coordinating. Between all of that you are doing basic care, meds, hygiene, and just doing it all you know.” I respond, “yeah, I observed you do all of that today.” I then ask her “so what would you say centring care for patients and families looks like in practice?” She takes a moment to respond and says, “well it depends, you have your tasks for the day, but you try to ask for patient preferences.” I then ask her “are there any challenges for doing that?” Sally says, “well I have two patients right now who don’t speak English, so it’s hard when they don’t have any visitors. And sometimes they have translation sheets and sometimes you know we do charades, so they laugh and then I laugh because neither of us knows what is happening. This guy [points to a patient room] says OK [with emphasis], so it seems like he is fine, and we leave it at that.”
>
> - Fieldnotes, Ward B, Summer 2021

Sally’s response is like many of the nursing staff I interviewed. In her description of her role as a nurse, routine nursing care activities on the ward are listed - assessing, monitoring, and performing basic care for patients. However, there are also complexities in the continuous accomplishment of these activities during her shift, including documentation, patient advocacy and the coordination of care. Sally states that she is advocating for patients by coordinating care work with other nurses and a range of other health professionals. She says that she is “doing it all” and then when asked to describe what centring patients in care looks like, she links the idea of centring with her tasks for the day. “It depends”, she says, “you have your tasks for the day, but you try to ask for patient preferences”. For Sally, activities of centring do not appear easily separated from accomplishing day-to-day nursing practices.

From Sally’s perspective, PFCC is described in the language of including patient preferences. This resembles the suggestion in previously described *PFCC Week Toolkit 2022* to ask patients “what matters to you”. However, Sally’s response shows that there are sociomaterial complexities involved in determining patient preferences. To start with, nursing tasks for the day need to be accomplished, but then patients also need the ability to communicate their preferences. When asked about what makes ‘centring’ challenging, like many other nurses, Sally provides the example of caring for patients who do not speak fluent English. Interestingly, patients who do not fit into the norms of Western care, such as being fluent in the English language, continue receiving nursing care even when they cannot communicate their preferences easily. This was also the case for patients on the orthopaedic wards who had varying cognitive challenges, difficulty hearing or speaking, and for those who could not physically reach and press the buttons on their call-bells. The activity of communicating through charades shows another kind of complexity for Sally's practice, one that involves guesswork, bodily gestures, and even laughter when it comes to understanding the preferences of patients.

In general, the nursing staff always seemed to be busy doing something related to organizing patient care even when they were not directly in patient rooms. This critical work that revolves around patients and their care is *not* included in most of the PFCC literature. As though the coordination of responding to patients' medical, nursing and social needs is not integral patients' and families' hospital experiences. Nurses would often be giving report to other staff or helping one another with patient transfers, admissions, and sterilizing medical equipment. And even Sally, while talking with me, was busy documenting and being available to help other ward staff. During the fieldwork, when posing questions about what centring care looks like, I needed to wait until after the early evening shift report. This was one of the only times when there was a lull in the activities. However, even during these "quieter" times, our conversations were still regularly interrupted by other hospital staff needing assistance, phone calls, visitors coming up to the nursing station, and the ringing of patient call bells.

One evening I talked with Jane, an LPN who had just started working on the ward, about her role and how she centred care on patients and families. Like Sally, she lists her activities but eventually gives up, stating "I don't know, I do everything":

> "Well, I am an LPN (pauses)... Um here on the surgical ward, you know this is a hard question! Its just routine I guess, I assess, give meds, and then go do comfort rounds. Once in a while I offer emotional support for those who don't have support from family. And then extra things sometimes like washing the floors. I help with all the bed baths… I don't know I do everything." The call bell rang, and Jane left to go answer it at the bedside. She came back after five minutes and when she returned, I asked her what

> patient and family centred care looks like. She responded, “the main focus of care is on patient and family concerns, I guess. You know its just natural because they are the reason that we have a job.” I asked her “is it different then what you do everyday?” She takes another pause and then says, “no (pause), I don’t think so, it is just natural.”
>
> - Fieldnotes, Ward B, Summer 2021

Like Sally, Jane begins by describing the routines of nursing care for patients - some nursing activities like medication rounds and providing comfort care are similar to those described by Sally. However, she expresses hesitation when separating the unique concerns of patients and families from the tasks that encompass most of her job – so much so, that she understands that even on those occasions when she is washing something that has contaminated the floor, she is acting on behalf of patients. Belying her professional education, where Jane would have learned the underpinnings of her nursing acumen, she suggests that ‘centring’ care is ‘natural’. It seems that Jane has completely absorbed those professional nursing skills that focus her work around patient and family concerns. She says she would not be employed as a nurse if the nursing responsibilities she undertakes on behalf of patients and their families were not integral to her day-to-day practice. Jane highlights her nursing knowledge about how the nursing routines she accomplishes are always conditional on, or at least closely related to, the interests and concerns of patients and families. As our conversation continued, I asked her, how would you teach me to do it if you had too?

> She responded, “that is hard to describe.” I follow up with another question and said, “well maybe then, what makes it hard to centre people in care?” She again hesitantly responded and said, “if they are difficult. Because then you are not getting their concerns right. But nobody is really difficult right? It’s just how we address their concerns. So, the

> active listening is required, like if the issue is not easy to resolve - then it really matters how you explain the issue to them. You need a better understanding of the patient, but I mean then that means you need time which we don't always have. But it is doable (pause) so that is why staffing is so important. But then again not everybody wants to do it. So, you could teach it to someone or give more education, but I don't think that always works either. There are challenges you know, sometimes there are staff who are closed minded, every personality is different. Resources also matter- I said time, right?"
>
> - Fieldnotes, Ward B, Summer 2021.

When pushed to describe 'centring', Jane seemed to struggle to reconcile the ways that nursing care of patients and families may be routinized as well as constrained by organizational factors such as time and resources, pointing to the sociomaterial characteristics of the care setting that can complicate how nurses can attend to specific patient preferences and concerns. For example, Jane describes concerns such as staffing, time and resources as influencing how care is enacted. She also identifies psychological characteristics, suggesting not "everybody wants to do it" which belies her earlier point that "it's just natural." There are additional problems of close-mindedness, she suggests, or gaps in nurses' knowledge about how to understand patients and address their needs. So, there is an idea in Jane's response that centring can also be a choice, because even if staff are informed about PFCC, they might not be willing or find it valuable to include patients' preferences. And then there is the problem that patient and family concerns cannot always be addressed such as when a patient's needs are "difficult".

In conversations with nurses, exploring and explaining what centring care looked like was not easy. This difficulty could be interpreted in a few different ways. It could be that nurses have difficulties separating out from their everyday care activities those that might be said to address the unique concerns of patients and families (as those have been constructed within the PFCC discourse that nurses have absorbed). Nurses describing the *challenges* of centring care elicited more detailed accounts. Nurses could reference those specific situations with actual patients and families who had *not* received PFCC. The accounts of the challenges nurses faced in their efforts to centre care were entangled with complex nursing values and practicalities, such as needing to accomplish specific tasks during their shifts, coordinating multiple types of care activities, and still being available to respond to unpredictable patient needs.

At the same time, nurses like Sally and Jane, in response to my questions, did draw on discourses similar to those found in PFCC educational resources to describe PFCC ideals. For example, they described practices such as advocacy, addressing patient concerns or including patient preferences, and mostly did this by utilizing the rights-driven and moralistic vocabulary found in these documents and resources. Yet these ethical ideals are sometimes difficult to discern against the ongoing, complex, and often unpredictable patient care trajectories nurses organize during their hospital shifts. This points to a problem Chambliss (1996) identifies when dealing with the abstractions of bioethical terminology (e.g., justice, respect for autonomy, non-maleficence, and beneficence), that is, that these principles may fail to describe what can be done with patients and families among the often routinized and bureaucratic settings of nursing care. Like Jane and Sally, Chambliss (1996) interviewed nurses who stated “I do everything” when asked about their roles (p.67). Chambliss also observed nurses take on more tasks when other hospital staff were unavailable, such as housekeeping, transporting, and administrative duties. Patients and families need these activities arranged and thus nurses fill in the gaps. Sally’s floor washing example supports Chambliss’ (now decades old) research. It suggests that nursing work is always, in some way, ‘centred’ on patients and families – even if such centring is not included in the PFCC discourses. A key ethnographic description arising out of my observations and conversations is of the essentially open-ended nature of nursing activities. Indeed, nurses seem to "do it all". Thus, although nurses have absorbed the many PFCC artifacts that now infuse their work setting, the practicalities of consistently including patient preferences does not always make sense in the contexts of care. The act of asking patients about their preferences and actually including those preferences in everyday nursing care in the ways laid out in the PFCC resources may be "difficult."

Troubling Patient and Family Preferences in Nursing Care

A coherent story of centredness as indicative of 'good care' is evident in the institutional policies, and often in conversations with nurses – to the extent that within PFCC discourses 'good care' is often judged by whether or not it contains elements of 'patient preferences'. Most descriptions of PFCC, in which healthcare providers include patients' and families' preferences, are described as positive and relatively straightforward encounters. These positive descriptions are prevalent in the PFCC vignettes and digital patient engagement videos I reviewed. However, a conversation with one nurse, May, challenged the idea that nursing care should always include patient and family preferences.

My conversation with May took place on Ward B as the early evening shift report was taking place. During this report, May, who was working a 12hr shift asked me, "what are you going to write about and ask patients and families? I mean are you watching if we wash our hands and answer bells?" – her comment suggests that surveillance of nursing practices was an ordinary or routine activity on the orthopaedic wards. I explained that I was interested in understanding what 'centring' patients actually looks like in practice. May began to describe a situation in which she had had difficulty 'including' a family member's preference:

> Like we had this transfer today from another ward. He was an old man and his son was there. Mid transfer the son asks about his dad's glasses. This is as we are trying to get this patient into bed, but the son needs to know right away where the glasses are. I told him I just need to get the patient in bed first. The son then says "do you even care?" …. That is a death trap question (pause). If I said yes, then they obviously would not have asked that question. I mean what does he think I am doing? I'm trying to get his father comfortable in our bed. Mid transfer he is asking something not that important. I am doing the important thing. You know I found his glasses right away after in a bag. The family didn't look close enough. So, you know l don't care.
>
> - Fieldnotes, Ward B, Fall 2020.

The conversation with May is analytically useful for several reasons. Unlike the other nursing staff who mostly talked in general ways about valuing patients' preferences and respecting their choices, May told a story in which the way she provided nursing care was questioned by a patient's family member. As well, May questioned the timing and reasonableness of the son's need to find his father's glasses. The questions about why transferring the patient was the most important thing to do for May, and why locating his father's glasses was most important for the son, cannot be answered here. What is analytically interesting is the frictions generated in this occasion of May's nursing practice and whether or how her decision to get the patient settled into bed constitutes PFCC.

Transferring patients to their beds is an ordinary occurrence, and doing this carefully and safely is always an important part of orthopaedic nursing practice. This ward is a place that specializes in repairing bones and protecting injured bones during possibly precarious instances when a patient is moving or being moved. Likely while arranging this patient transfer May was attempting to prevent a fall or even a physical injury to herself. May says that completing the transfer was the more important thing to do, describing how her care during the transfer allowed the patient to be in a more comfortable bed. However, the patient's son preferred his father to have his glasses. The son's focus on the glasses is likely linked to his knowledge about how is father relies on the glasses to see, and also that glasses are expensive and hard to replace. Whatever the reasons, in this instance, values, priorities (and frictions) unfolded in relation to specific material and bodily circumstances. The values and priorities between May and the son did not match, so much so that the son asked, "do you even care?" May describes this as a "death trap question", resigning herself to being characterized as uncaring – so even in this apparently minor conflict of priorities, quite a lot seems to be at stake. After this interaction, May and I talked some more:

> I am checked out, busy day you know (pause). This other time I was working with [Charge nurse] and a family member called. She [the family member] had gotten into a fight with me before. So, she called the unit to complain about me, but I don't think she knew I was on the phone. She said, you know that little Asian nurse doesn't know what she's doing. I had explained everything that morning to her.
>
> - Fieldnotes, Ward B, Fall 2020.

Though describing herself as "checked out" from her busy day, May spoke quite passionately during this conversation and quickly, so it was challenging to write down everything she said. Especially details about the second incident she described with the family member on the phone. Unlike some of my other conversations with nurses, May disrupts her 'caring' identity as a nurse, going so far as to say she has "checked out" and sometimes "fights" with patients' family members. In doing this, May troubles the smooth surface of including family member preferences in care. In the interaction with the family member on the phone, May has some authority to handle this family member's complaint herself. However, this conversation also pointed to the racism that occurs everyday in the hospital setting, a reminder of the ways 'externalities' seep through the hospital walls and have effects on the people both organizing and receiving patient care.

Hearing racialized descriptions of patients and nurses was a disconcerting and not infrequent occurrence during my conversations with nursing staff about the challenges of including patient and family preferences. Perhaps because I was paying close attention to the words people were using, it was startling to me how often and how casually stereotypes were used and then quickly dismissed:

> Harkeert: What does it mean or what does patient and family centered care look like?
>
> Charge nurse: Well lately I have not had too much interaction with family because of COVID. We started with 1 visitor and then now we allow 2. But I would say it looks different for people from different cultures. Like for Canadian families they sometimes do not have too many visitors, but then Aboriginals have lots of family members. Same with oriental peoples.
>
> Harkeert: What are some challenges then with involving or centring patients and families?
>
> Charge nurse: I think some people just want to be visitors. They don't want to bring their family member water, help feed or even organize the room. Sometimes I have five patients and then its hard for me to do all the work and then family members can sometimes interfere. Like they sometimes don't clean up after themselves. You know and I like to make sure that the patient's room is clean and organized.
>
> - Fieldnotes, Ward B, Fall 2020.

This conversation with the charge nurse shows how racialized stereotypes and other preconceived ideas about people based on their perceived ethnic backgrounds occur within hospital settings. Even though the charge nurse suggests she has limited interactions with patients and families given her positioning at the nursing station, she also claims that ‘centring’ looks different based on ethnic or cultural characteristics of people – whether they be “Canadian”, “Aboriginal” or “oriental”. The charge nurse has some practical concerns when there are too many visitors in patient rooms, extra bodies that interfere or create more work. There are some people who just want to be visitors and other groups of people that are perhaps more helpful. The charge nurse suggests that not all patients have the same values – which is likely the case, but notable here is that these differences are articulated in the context of preconceptions about racialized groups. As well, these differences are drawn in opposition to the charge nurse’s beliefs concerning how families should be helpful and maintain cleanliness in the hospital.

My conversation with the charge nurse and May, raised questions for me about how racism in everyday nursing care may interfere with the possibilities of including a patient’s unique needs, preferences, and priorities in care. How do PFCC artefacts that highlight respect and dignity ‘fit’ into the realities of racism in nursing care? What are the challenges of including patient and family concerns or priorities, in a context of longstanding discriminatory care practices for racialized persons? Accounting for racism, whether for nurses like May or racialized patients and families, seems to be a reality that is commonly overlooked in, and detached from, PFCC discourses.

It is important to highlight how values of all sorts may clash in everyday care, and the ways in which this may happen is very much intertwined with the diverse social identities of people receiving and providing care. By observing nurses' routines and having conversations about including patient and family preferences, it became clear that within institutional care settings people relate to one another in many ways through their intersecting social identities. For example, another nurse, Nate, described his experience of being the subject of racist comments during the height of visitation restrictions in the hospital during the pandemic. Because orthopaedic surgeries had been cancelled, Nate was redeployed to work at the hospital entrance screening stations. He described his experience when he refused to allow a visitor through the main entrance of the hospital:

> You know how racist some people were… Like I had this guy come in and say that "he wasn't Chinese" so he didn't have the flu…he even accused me of having it! I was SO mad, like what do you even say to that!?
>
> - Fieldnotes, Ward B, Fall 2020.

As Nate finished this story, a family member interrupted our conversation and asked for Nate's help. Further conversation about racism, and how a racist family member, their preferences, and values, could be 'centred' in care was quickly interrupted by the care needs of patients on the ward. It is hard to reconcile the discriminatory realities of hospital settings with PFCC discourses, which often assume democratic ideologies, uninflected identities of the persons involved, and hospital neutrality. For nurses like May and Nate, racist remarks from patients are exemplary of socially oppressive practices in hospital settings. Yet despite experiencing discrimination, these nurses continued arranging care for patients and families. PFCC artefacts, educational resources and policies, instruct nurse to always accommodate patient preferences in nursing care, failing to recognize that nurses' interactions with patients always unfold within a context, a relationship, and that in some contexts, it may not be appropriate for a nurse to 'centre' a patient's or a family's preferences. And, as in Nate's case, at the same time as he is subject to racist remarks, he is also mediating the hospital rules and policies about visitor restrictions – rules that simply may not accommodate patient or family preferences.

I am personally familiar with racism in everyday nursing care. While working as a registered nurse, I have been asked what kind of Indian I am, “dot” or “feather”, by patients. I have also worked alongside nurses who have refused to call me by my name and would instead call me anything but my name. I have been called “George” and “The Gavel” as wordplay with my surname, and possibly with humorous intent, showing how ridiculous these nicknames were in light of my presentation as a generally soft-spoken female nurse. These are anecdotal accounts, but they are safer to share than revealing further specificities of the study participants’ social identities. Upon reflection I realized I had difficulty responding to these racialized comments – both in my own experiences but also in the study setting. As a nurse, I would often laugh with the nurses at the absurd names they gave me, because to a degree I was avoiding conflict so that I could just continue working. I work collaboratively, therefore I need to maintain open communication, collegiality, and membership with all kinds of people involved in hospital care. As a researcher, responding to racialized comments by nurses and patients remained a challenge. Addressing racist comments is disruptive and requires deeply sensitive conversations in a busy setting, where people are juggling many responsibilities alongside their multi-faceted social identities.

As described in the history of hospital care in Chapter 1, the administrative interest in initiating programs to direct professional practices that can be fit into the category of patient and family ‘centredness’ unfold in settings that reflect the same social, economic, and racial stratifications found outside the hospital walls. Thus, the ‘one size fits all’ instructions of the

PFCC discourse cannot accommodate the multiple sites of power and oppression that nurses and patients encounter in the day-to-day happenings in hospitals. As a nurse and as a researcher, the racism I experienced or observed was never intervened upon in the moment, largely because I valued maintaining the orderliness of nursing care and organizational routines with patients and families. For nurses, confronting racism where and when it happens raises both ethical and practical problems. Doing antiracist work interrupts and disrupts the necessary work. It would interfere in the therapeutic regimes of patients. It is simply not practical or ethical to do antiracist work in each moment of racialized prejudice. Allen (2015) describes nurses as key "coordinators". Nurses' are critical actors in keeping the work of wards functioning aligned with many departments, hospital employees and visiting medical staff. In his hospital ethnography, Chambliss (1996) also noted the crucial institutional work nurses do that protects routinized care from falling into chaos. He wrote:

> We note only that she (sic) has become for good or for ill, part of the hospital itself, and she has done this in a certain style: that of the nurse. Routinization affects physicians, aides, and other hospital workers as well as nurses. But nurses have a special place in this organization, and the particulars of their role are vital for understating what goes on there. (p.60)

Chambliss (1996) suggests that nurses, for good or for bad, are deeply entangled with the smoothly running hospital that is dependent on routine: both organized by daily routines of the ward *and* the routines built around each patient's assessment and plan of care. Nurse May described politics around the valuing of family preferences, such as the son's concern for his father's glasses and the racialized phone complaint. But among all these divergent frictions and politics, nurses consistently try to smooth over those instances that threaten to disrupt the production of care, such as earlier described in the team response to the patient who fell.

From my experiences as a nurse, as well as in my conversations with nurses like May and Nate, what is notable is that it is very difficult to launch a challenge, even against racist incidents; such a challenge would likely disrupt how care must unfold in an efficiently running ward. Initiatives that promote idealized, rehearsed responses (such as PFCC) cannot accommodate the dynamic social context of hospital practices. Racism is entrenched and complex. This study took place during growing Black Lives Matter protests across North America after the death of George Floyd [20]. Xenophobia against Asians had also increased during this study[21]. Racism is a serious concern that PFCC seems to gloss over. Moreover, what the PFCC instructions also seem to obscure are nurses' responsibility to keep things flowing along (the routine). It largely falls to nurses to establish the terrain upon which to accomplish what is necessary in the setting. Patient and family values and priorities are situated in these challenging settings where nursing care must continue even when there is unfair or prejudicial treatment of the various persons involved in caring. My conversations with nurses illustrated the sociomaterial complexities and different types of conflicts that must be continuously negotiated in everyday nursing care. Nurses keep patients' care trajectories flowing, maintaining the constant flow of patient admissions and discharges even when there are troubling patient and family preferences, practical constraints, and limited resources in the hospital setting.

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[20] BBC News (2021) reported a timeline from highlighting key incidents involving police officers which resulted in deaths of black Americans from 2014 through 2021.

[21] Balintec (2022), a CBC news reporter, reported anti-Asian hate increased since the pandemic and continues to rise in Canada.

‘Centring’ Families: Challenges of Inclusion

Similar to the ideals of always including patient and family preferences, PFCC consultants at the study site advocated for the practice of unrestricted visitation in hospital settings. In 2017 the study site adopted open family presence policies, however, the COVID-19 pandemic impacted the sociomaterial conditions in which patients and families were able to be ‘centred’ through severely restricting visitation practices in hospital. My field work was conducted during the global pandemic during which time there were public health concerns of spreading COVID 19, and intensified demands on nurses. Policies enacted on both wards placed strict limits on outside visitors. The Regional Health Authority developed a policy and screening procedure to manage visitation across all clinical sites in the province. Each patient was allowed two “designated visitors”, but only one visitor could be there at a time. This rule was developed to support social distancing in shared patient rooms. Visitors were asked to sign in and out of the ward, so that contact tracing could be done in the event there was a COVID-19 outbreak on the wards. The sign-in table on both Ward A and Ward B held a hand sanitizer dispenser, pencils, and sign-in sheets to log the people coming and going. Patients who tested positive for COVID-19 were not permitted visitors until their quarantine time passed and their flu-like symptoms were resolved. Symptom screening of visitors occurred at the hospital entrances. Wards with more than two patients who tested positive for COVID-19, were declared as an “outbreak unit” initiating further restrictive visitation practices for all the patients on the ward.

During the pandemic, politics regarding poor hospital staffing levels also influenced the visitation practices. For example, on October 26, 2021, more than 1000 nursing care and support workers participated in a wildcat strike in approximately 30 facilities across the province. These workers were striking against proposed layoffs and wage cuts during their union negotiations with the RHA. While shadowing a nurse the day after the strike, I learned that the strike resulted in a disruption in the visitation practices. The hospital site further restricted visitors in the hospitals, only "essential" visitors, specifically those needed to sign consent forms for patient procedures were allowed. The nurse was unsure as to why this decision was made and if the visitation restrictions were still in effect. Therefore, during that morning's Team Huddle the floor nurse asked the unit manager if they were allowing visitors on the ward.

> Unit Manager: So, there is no new visitor policy yet, but I have a meeting at 1130 and will call to let you know if the visitors at the bedside can stay.
>
> Floor Nurse: Is this because of the strike or because of rising COVID numbers?
>
> Unit Manager: Well, I am not sure, because the numbers are going up and we don't know about the strike and how that's going to go. Just make sure that when visitors are here, they wear a mask and gown up properly. You are all [Personal Protective Equipment] coaches and if you have a visitor who refuses just ask them to respectfully leave. There is no need to further engage and if there is a problem, just call security and they can no longer visit.
>
> Resource nurse: So technically right now we don't know if visitors are allowed?
>
> Unit Manager: Yeah, so try to make an executive decision. You know if there are translation issues or someone is an essential caregiver, then that makes sense to let them stay. But I will call you if I learn more. You know with the outbreak on [Ward X], it's linked to a relative and even our case was linked to the visitor in room 24, so just be careful. Let them stay for now, but also let them know that they may be asked to leave if there is a new policy….
>
> - Fieldnotes, Ward A, Fall 2020

The questions that were asked by the nurses during the Team Huddle reveal a lot about how visitation practices were enacted by nurses and how various politics influenced the presence of family members at the bedside. In the excerpt above, one floor nurse appears to rely on updates to the family presence policy to inform and dictate their decisions regarding whether patients can have people visit in hospital. However, the policy was not accessible during this conversation. In the moment, the unit manager seemed to be unsure and instead emphasized that visitation practices are related to the risks and threats posed by the people visiting. Patients and families were considered risk factors for spreading disease during COVID-19 outbreaks, as evidenced when the unit manager stresses the importance of personal protective equipment and reminds the staff that the outbreak on another ward was caused by a visitor. In the conversation above, family members are also positioned as potentially 'essential' caregivers, for example, in the context of needing language translation for a patient. It seems that family members can be positioned and 'centred' in many ways, however, this exceptional instance of visitors being labeled either essential, or a threat, amplifies some of the tensions that family visitors bring into nurses' work.

Nurses often described how family members as visitors were both 'essential' and 'challenging' with stories that were both situated within pandemic protocols of visitation and others that reflected more general tensions of nurses' experiences of responding to family visitors. My conversation with a nurse, Mary, who has worked on Ward A for over 10 years, elicits a list of both 'good' and 'bad' scenarios of including patient and family preferences and priorities in care – here through a lens of an experienced nurse. These types of stories were echoed by many of the other nurse participants I shadowed. This is a long excerpt because it was a rare conversation that was not interrupted by other work demands, and allowed Mary to expand on her ideas. I started by asking Mary if she was around for all the different policy changes related to family presence, a key endeavor of PFCC initiatives, in the hospital:

> Mary: Yup, and I hated the 24/7 visiting.
>
> Harkeert: Oh, what was that like?
>
> May: Well, there are like two sides to it. You know you need patients to sleep and most of our patients as you have seen are older. It is frustrating when you get families calling and I tell them the patient is sleeping… and the family is like but they were sleeping earlier can you wake them up? Sometimes you know that is fine, but when it is this 80-year-old and you wake him up, what is he supposed to do while awake? Then there is the other side. Just yesterday we had this patient come up from emergency. When we did our vitals he was very hypertensive and like bat shit crazy. So, I called the number on the chart and his family told me that he is supposed to be on blood pressure meds, but somehow those fell off - maybe they were not prescribed again. They also told me not to worry because apparently that was his baseline home too. They were able to give me the grand scheme of things. So that was good you know.
>
> - Fieldnotes, Ward A, Fall 2020

In this initial overview Mary offered an example of how (in her view) families interfere with what she understands of her patients' needs. In the example about how a family member wanted her to wake a patient, she is enacting her knowledge about how hospitals are difficult places for sleep and her ideas about the importance of rest. In the second instance, she describes how families can be a key resource; how they can provide insight into a patient's "baseline" condition, which supports her clinical judgement. Our conversation continued:

> Harkeert: So, what do you think about this two-person visitor policy?

> Mary: I prefer this… but again there is the good and the bad. Now you have people coming in wearing masks and it is all fine, but then they leave the patient rooms without masks. It is hard to sometimes to explain why the patient does not need one, but family members do.
>
> - Fieldnotes, Ward A, Fall 2020

Here Mary suggests that she prefers visitation limits, however, she notes that even when fewer people visit there are demands on nurses, who must educate patients about the correct use of personal protective equipment and monitor unmasked visitors who have their own preferences about where the masks are needed. She goes on to elaborate about how she needs to mediate family visits with patients' needs for nursing care (her time):

> With the 24/7 policy we had patients with their family members in bed, so they are cuddling or whatever and you are trying to do an assessment. Or you have a fresh post op [a patient who has been recently operated on] and the family wants an update, but the patient is still coming out of surgery and it is like give us a minute we still need to assess. …Or you know you can have a very timid patient. I once had this woman and I had to in and out them [medical technique to drain the bladder with a tube], but the husband would not leave and she would not say anything either. I think the husband was an extrovert and the wife more introverted. So, I asked the husband, hey can you give us some privacy and he just kind of laughed and said it is fine, she is my wife.
>
> Harkeert: So, did you just do it in front of him?
>
> Mary: Yeah, and it was pretty awkward I think for the wife to have to have her husband see that.
>
> - Fieldnotes, Ward A, Fall 2020

For Mary, it was uncomfortable to perform an intimate clinical procedure without privacy. She was balancing her impression that the patient in her care was uncomfortable but timid, with the patient's husband who seemed simply to brush off issues of privacy because "she's my wife". This data surfaces the subtle tensions embedded in a patient's, a husband's and a nurse's "preferences" and whose preferences are given priority. In the next instance, Mary's professional response to "force feeding", to being yelled at, and her skilled work with the family.

> We also had this patient where the family did not really get along with us. This was not actually that long ago. When we would feed the patient, he did not really want to eat all his food and when the wife would come in to visit she thought we were not feeding him… Like we are not going to keep forcing food down his throat you know. Anyway, she was just yelling at us so I called the other number on the chart hoping that this person could be like a mediator between us. It was the son and he told us that his mom does this all the time, that she always forces him to eat more than he wants and then he asked to speak with her. He calmed her down over the phone.
>
> - Fieldnotes, Ward A, Fall 2020

In her final example, Mary describes how families make demands on the nursing resources (and on her back). In this example, the complex work of mobilizing orthopaedic patients comes into view. She understands the family "mean well", but that orchestrating a patient out of bed takes three to four people. In orthopaedics, nurses routinely plan and coordinate with their team to support patients to sit up in the chair for meals and then to go back to bed to rest after meals. The following excerpt suggests that family may not grasp this complexity:

> You also get family members who actually mean well, because they want their family up all the time, but it is challenging because it takes us at least three to four people to get

> someone up. You first of all do not have time to get them up all the time… plus my back can only take so much…
>
> - Fieldnotes, Ward A, Fall 2020

In this conversation, Mary lists different situations that she has encountered with patients and families. Each scenario describes how family preferences and 'involvement' were navigated by Mary. These accounts show that there were occasions of contradictory values between Mary and the specific interests of the patients' family members. For example, Mary did not particularly respect a family's wishes to keep an elderly patient awake. However, she did value those family members who were able to provide background information and explanations about the patient who was confused. These two different situations show how Mary reflects on the complexities of family involvement, and ways in which for her, family involvement can be (in her view) hazardous or helpful.

Mary suggests that family members can be disruptive. In Mary's detailed accounts the sociomaterial complexities of nursing care, including the policies, organizational routines, and bodily capacities that shape nursing care practices are made clear. For Mary, her work of assessing a patient is made difficult when a family member is cuddling in the bed. As well, she describes how difficult it is to respond to questions at a critical juncture of care. Transferring a patient from the recovery room to the ward is infused with the complex practicalities of the portable oxygen equipment, tubes, lines, dressings, pain and level of consciousness etc. She also described additional work of policing family members to follow the rules of wearing masks in the hospital. These appear to be moments of "preference tension" that are embedded into the work of caring for patients and their family members. The clashing of values related to feeding that Mary describes are not well served in the educational vignettes that nurses are expected to model whilst enacting PFCC. Moreover, Mary notes that even in instances when nurses and family are in agreement about what constitutes best care practices (such as a family request to get their relative up) there are material limits related to the strength and stamina of nurses' backs, the availability of other staff to assist, the physical weight or limitations of patient bodies, and the ever-present strain of time.

Summary: Trying to Discover PFCC in Everyday Nursing Care

A recurring analytical point from the nurses' accounts of organizing patient care described in this chapter is that there are sociomaterial complexities that continuously impact the ways in which PFCC, as described in educational resources and policies, could be enacted in hospital settings. The descriptions of nursing practices discussed in this chapter demonstrate that many of the elements of formal PFCC discourses align with nurses' professional education and intentions, specifically the ways nurses worked to include patient and family preferences in their practices and the efforts they took to facilitate visitation. However, nurses' professional acumen, that is so critical to patient care, seems to be paradoxically positioned within the *program* of PFCC as *strategy.* The logical rationality of putting patients and families at the center of a conceptual model (the artifact from Figure 1 represented below), with an executive "patient and family first strategy" that is administered and audited seems somehow to subordinate nurses' disciplinary education and contextual knowledge of each unique moment of practice.

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Figure 1: Unpermitted third-party content.

When I ethnographically went looking for PFCC it was not a simple task of discovering “patient and family involvement” and/or their “preferences”. I consistently observed that there was much more going on – there were multiple and at times, divergent values between nurses, patients and family members during necessary nursing activities of assessing, feeding, and transferring patients to bed. The examples provided demonstrate that values in nursing care are not entirely related to individual nurses’ feelings, ethical codes, or emotional dispositions of caring for patients and families. Instead, multiple practicalities materialize within everyday nursing care practices. Values and practices of maintaining continuity, stability, and documenting care, for example, are situated within and unfold according to nurses’ relationships with organizational routines, unpredictable patient care trajectories, and open-ended caring responsibilities.

As noted at the outset of this chapter, my research interest was to explore the ways in which PFCC resources and policy statements might be discoverable in everyday nursing care practices. I explored values as being materialized in relation to nurses' knowledge that could be observed in the ways nurses practiced; that is, what nurses said, what they did, and how they coordinated care activities. Activities of visitation and the inclusion of patient and family preferences as expressed in the PFCC artefacts were challenging for nurses to articulate and integrate in their nursing practices. The nurses revealed that they knew something about PFCC as described in the policy and promoted in the 'toolkits', specifically the idea that 'centring' is important as a way to individualize care based on the unique and specific needs of patients. However, it was difficult to reconcile these formal discourses with the data. My conversations with nurse participants revealed that nurses were challenged to separate out 'centring' actions from everyday nursing care. Nurse participants such as Jane inhabited open-ended roles of 'just doing it all' when giving care to patients and families. In her view, *everything she did* had patient care at its centre. In this respect, 'centring' as a distinct form of practice makes little sense.

At the same time, in the course of this analysis, what became more apparent was the diversity of values both organized by, and organizing, hospital care. The social identities of nurses and patients, particularly racialized preconceptions, raised questions regarding the 'inclusion' of people's diverse values or preferences in care. The COVID-19 pandemic also raised questions about the family presence policy, a key PFCC strategy. The risk of spreading communicable disease created complex visitation practices in which people visiting were 'centred' as both threats and as essential to patients' wellbeing. Of note is my analytical observation that although the patients and families I recruited into the study did not 'know' PFCC discourses and values in the same way as nurses did (i.e. through the organizational resources and on-line education), the participants were actively involved in their care. However, like nurses, what patients and families needed in the settings, and what they did to meet those needs did not always “match” the formal PFCC discourse. As with the nurses’ data, when I foregrounded the sociomaterial contexts of care in which the patients’ accounts were embedded, the question, ‘how ***are*** patients and families involved in everyday care practices?’, became imbued with the materiality and particularities of each situation. The data analysis in the next chapter reveals nuanced insights into what can be known about the intentions and activities of agents (nurses and patients) who are entangled with the structures and conditions of the hospital acute care; and whether and how these practices fit into the institutionalized visions of PFCC.

Chapter 6

‘Involving’ Patients and Families in Care Practices

In the previous chapter I explored how values expressed in PFCC educational resources and policy might be discoverable in day-to-day nursing care practices. There were many nursing practices organizing care of patients and families, and it became evident that values nurses enacted through materialized practices (e.g. transfers, feeding, and assessments) would at times clash with the preferences and desires or values of patients and their family members. I continue to build on this analysis and foreground the sociomaterial contexts of care - that is, descriptions of care that attend to how humans, technologies, and discourses alike organize patients’ care experiences. However, in this chapter I more closely examine what came to matter for the patient and family participants during their hospital stay in everyday care practices. To do this, I describe wound care practices, pain management practices, mobilizing practices, and personal care practices. Each of these practices were part of day-to-day orthopaedic care for all the patients admitted into Ward A and Ward B. However, for some patient participants it seemed as though specific nursing practices came to matter more than others and these instances lend themselves to a more practical understanding of the principles or values of the centredness discourse, such as advocacy, dignity and respect, and the involvement of patients.

Wound Care Practices

All the patient and family participants experienced wound care practices after their surgical procedures. Betty required daily wound care to her incisions on her spine after undergoing multiple back surgeries during her hospital stay. Abby, James, and Tom required wound care to their legs after undergoing multiple surgical procedures. Wound care practices required an array of materials and time intensive and time-based procedures, such as antibiotic treatments, gauze, tape, sterile solutions, and vigilant monitoring to ensure that the wound was healing and not developing an infection. Darlene was especially concerned about wound care practices as she had been on a wound care regime at home where nurses had regularly attended to manage seven weeks of wound vac[22] treatment and 10 weeks of antibiotics prior to her hospital admission. When I met with Darlene, she described how despite receiving various wound care interventions at home, her achilles tendon wound had a brewing infection. Darlene showed me pictures on her phone that she had taken of her wound at various stages, as a kind of documenting practice of her own. She said she often used her own pictures to show the doctors what the wound looked like, especially if they came in to see her after the nurses had already cleaned out her wound for the day and covered it with new gauze and tape.

When Darlene described the various complications with her wound and care trajectory, she shared some of her observations, stating “I find there is a big lack of communication in a lot of areas.” Her critique seemed understandable, given the chronicity of the wound. Her situation was also complicated by the fact that an orthopaedic surgeon had forgotten to collect a critical wound sample during her first surgery upon admission. Darlene described having to fill in information for various health care providers who were organizing her wound care plans. For example, Darlene described how, just prior to our conversation, a plastic surgeon had come to check on her wound and had asked why Darlene had not recommenced her wound vac treatment. Darlene had to explain to the surgeon that the radiologist delayed approving her MRI, the diagnostic images that were necessary prior to beginning another round of wound vac treatment.

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[22] A wound vac is a device that allows for vacuum-assisted closure of a wound. It can help reduce the swelling of a wound, by pulling fluid drainage from the wound into a closed container. The constant suction also helps pull the edges of a wound together to promote healing.

Darlene expressed being frustrated with what she saw as a lack of communication regarding her wound care in the hospital:

> Darlene: And now I'm sitting waiting for this MRI so that we can get this thing closed up. So, I'm getting a little frustrated to say the least…So anyway, when they sent me for an X-ray in June, they took me in and they gave me an X-ray of the chest and abdomen. And I said you do realize I'm here for my foot, right? And they were like, what was the doctor's order? So, when I went back out, they ended up doing another one. And I said to the doctor, why did I need a chest and abdomen? And he said, oh, that was a mistake. You should not have had that done.
>
> - First Interview Participant D, Fall 2021.

This is one example of many instances in which Darlene concluded there was a lack of communication between health care providers organizing her wound care practices. In the account above she described how the X-ray technicians did not seem to know that she had a wound on her foot that required further imaging. Although Darlene described herself as just "sitting waiting" while in the hospital, she was active and involved in her care for example, following up with her doctor about why an X-ray of her chest and abdomen had been done. Darlene's questioning was important. It prompted the staff to look at the doctors' orders again and attend to the wound on her foot, which had somehow been overlooked during this diagnostic procedure. Darlene actively communicated with the nursing staff as well. She described *her* practice of asking questions about *their* wound care practices:

> Darlene: So needless to say, I am paranoid about infection just because of what has been going on with me. I had a nurse, not during this hospital stay, where she was doing the wound vac dressing. And she had rubber gloves on, and she walked across the room

> picked up the garbage can and brought it over to put the stuff in. And I freaked and said please change your gloves. And she could not understand why. And I said you just touched the garbage can. And now you're touching my open wound. So, I am not being very nice about it. But this time, I'm being very high alert. Like I'm looking over my shoulder and I'm saying you know, I hope you have sterile gloves to change when you are doing my dressing. Like I realize you are opening packages, but I don't know how many nurses I have had to tell. Also, when Dr. [X] had ordered the wound care, I started using [special wound care solution]. And he said it has to be activated with sterile water, because saline does not work. I don't know how many times I have said this to the nurses. A lovely nurse was here with Dr [X] and he said just put [special wound care solution] and activate with sterile water. She came in and I looked at the red label and I asked do you have sterile water? She said oh I just brought saline and then I say the doctor even told you it has to be sterile water. The silver won't activate with saline… Three nurses I have explained this to already…
>
> Harkeert: And is that communication?
>
> Darlene: Lack of detail, like you're not paying attention to your orders.
>
> - First Interview Participant D, Fall 2021.

Darlene expressed a lack of confidence with how her wound care was being organized and she had to be vigilant to ensure her wound was cared for properly – both during her previous hospitalization and now during the current stay when this interview was conducted. She identifies communication as a part of the problem, but it is not her only concern regarding the organization of her wound care. There are details that seem to be missing or completely neglected, such as nurses following the current physician orders for prescribed wound care solutions. She questions the nurses' adherence to sterile procedures and the materials they are using during her dressing changes. Later on in our conversation she raises a more general question about how nurses are educated nowadays, and that perhaps nurses do not have enough clinical training regarding maintaining cleanliness of wound care and even the cleanliness of her room. However, in the same conversation Darlene stresses her experiences of the staffing shortages affecting nursing care. Recognition of these complexities is part of Darlene's vigilance – she knows that appropriate materials, education, and staffing are needed to organize wound care practices that will ensure healing, and that limitations in such resources require her to fill in critical information, coordinate people's actions, and even redirect nursing staff who are treating her wound in the wrong way. For Darlene, the consequences of a non-healing chronic wound are seriously debilitating. I asked her more about how this constituted her "active involvement" and she indicated that it was necessary to "advocate" for herself. Our conversation continued:

> Harkeert: So, I think that you've been kind of actively involved in your care? Because one thing I'm looking at is so what families do when they come in here? And what are patients doing for themselves?
>
> Darlene: Oh, I know, there's a lot of people that just like, I mean, when my mother was alive, she would have been completely opposite. I mean, she put all of her faith and trust in the doctors and the nurses, because in her mind, they were educated, they were smart, they knew their job. She never questioned anything. And I was always saying, you have to be an advocate for your own health…
>
> - First Interview Participant D, Fall 2021.

This notion of "advocacy" is complex. In PFCC materials, advocacy is most often described as a formal activity organized by health professionals (on behalf of patients) with input from members of the public. There are people, in both paid and volunteer positions, whose titles indicate that they are ‘advocates’ for patients and families in the RHA’s clinical settings. For example, there is an organized Patient and Family Advisory Council whose mission statement is to “advocate for a patient and family centred, quality health system that is accessible and sustainable.” The role of the members on the council is to act in consultation with RHA “senior leaders, healthcare providers, staff, and physicians on policies, practices, planning, and delivery of Patient & Family Centered Care,” and as part of this advocacy for PFCC, to manage conflict between organizational actors and patients and families. However, in Darlene’s case, she has recognized that she must be the advocate for her own health, and that achieving this meant that sometimes she would be in conflict with hospital staff. Being an advocate for herself, she says, involves being ‘not nice’, not necessarily trusting the staff who are organizing and performing her wound care. Her work to advocate for herself includes confronting staff with questions about how clean their gloves are and asking if the proper dressing change solutions are being used. Darlene stated that her vigilance had been necessary while receiving wound care at home from nurses, and during her various hospital admissions.

Moments of vigilant wound care monitoring, such as the need to correct nurses’ breech of sterile technique, suggest that good wound care practices are what mattered the most to Darlene, and were likely most consequential for her hospitalization experience. To achieve good wound care, Darlene was clearly active in her treatments, ensuring the wound technique was done correctly – she was fully involved in preventing the infection in her wound from becoming worse. The context of care required her to do this – and raises questions not so much about ‘centring’ Darlene in her care but, as she herself observes, about nurses’ time, education, and the various other complexities of the practice setting that instituted Darlene’s necessary vigilance about inadequate wound care practices. It also raises the question, is *this* what is meant by patients ‘being involved’? What sorts of professional expertise should patients be able to rely on; what sorts of things should nurses “involve” them in? Is Darlene’s an experience of PFCC?

Mobilizing Practices

Patients on Ward A and Ward B were all expected to mobilize, meaning to get out of bed and move their limbs as soon as possible after their surgical procedures. Nurses’ work supporting patients to be physically active is critical for various reasons including preventing blood clots and bed sores, and supporting physical therapy and rehabilitation. Mobilizing can be difficult and complex, especially for patients who experienced falls or required multiple staff to help. Helping a patient to mobilize after surgery requires judgement, skill and experience on the part of nurses and health care aides, as well as different kinds of equipment, including the challenge of fitting this equipment into the small spaces of patients’ rooms. The patient participants in this study used hospital-provided wheelchairs that were supposed to be shared among all the patients in the hospital, some of the wheelchairs had missing foot rests and others had taped paper signs stating the chair “Belongs to PT [Physiotherapy]”. There was a variety of equipment designed to assist patients to mobilize. There were wheelchairs for different purposes and bodily capacities. James had an extra-large wheelchair with a specialized leg extension and cushion to support his amputated appendage. As well, walkers came in different designs. Depending on the strength and abilities of the person using the walker, it might be designed without wheels or have glides on the back legs. Betty and Darlene had the standard two-wheeled walker at their bedside. Having the correct equipment was necessary for both nurses and patients during mobilizing practices.

While conducting fieldwork, there were many indicators that mobilizing care practices were valued. In each patient room a poster intended to “involve” patients and visitors titled

"Attention Patients and Families" which listed the risks of bed rest, including muscle weakness, bone loss, joint stiffness, infections, bed sores, reduced appetite, dehydration, poor mood, reduced lung volume, and increased resting heart rate. These "education" posters encouraged patients and families to be active in their recovery; to consciously and routinely move. Specific direction to change positions in bed every two hours, walk three times a day, to get up to the toilet and to sit in a chair to eat. Getting patients moving was an important and frequent part of nursing practice on Ward A and Ward B. In Tom's case, throughout his care trajectory, 'getting moving' was what mattered most to both him and the nursing staff. But moving and being moved was also a frequent source of difficulty and conflict.

Prior to my first interview with Tom, I met the unit manager in the hallway and checked in to see if the research interview was still appropriate. This form of check-in was important to get a sense of what the nursing staff were doing 'for' or 'with' the patient and family participants. As well, it was a way to ensure that it was safe to visit the patients I had recruited as my participants, especially during the COVID pandemic where concerns of communicable disease were forefront. The unit manager stated:

> "[Tom] had chest pain overnight and the pain control has been poor, but this one complains a lot and is also not motivated to move. The trops [a type of protein found in blood that indicate heart damage] are fine and I think we're going to do another ECG now."
>
> - Fieldnotes, Ward A, Summer 2021

Tom was presenting with the serious medical concern of chest pain. The unit manager's judgment was that Tom's overnight pain was not cardiac in origin. The serum diagnostic tests have ruled out cardiac ischemia. Another ECG will be done to confirm that finding. It is the manager’s impression that Tom’s pain control is poor. They also characterize “this one” as a complainer and is unmotivated. In the manager’s view, in order to recover, Tom needs to be motivated to be more active – this is how he needs to be involved. However, the manager’s view of the situation conflicts with Tom’s experience of his night, his pain, and his ability to get out of bed. This misalignment was reflected in Tom’s angry exclamation, “I want to get out of here!” when I walked into his room after my conversation with the unit manager.

Being mobile was one of Tom’s priorities - getting out of his bed, going outside for a smoke, or going to the bathroom:

> While laying in bed Tom suddenly yells out, “hey I need to have a poop” to the nurse standing outside of his room behind the curtain helping another patient brush his teeth at the sink. The nurse pulls the curtain back and says “what”? Tom tells him “I need to have a poop and if I hold it for too long then I get constipated.” The nurse says, “okay can I get you a bedpan?” He responds “no, I need to go to the bathroom right now.” The nurse sighs out loud and says okay and begins to move the patient he was helping at the sink back to their bed in this four-bed room. The nurse comes back into Tom’s room and begins rearranging equipment. He moves Tom's wheelchair away, so there is space for the commode, and he moves the bedside table behind the curtain. Another nurse arrives with the mechanical lift machine, that they had used moments ago to return Tom back to his bed after he had been for the ECG. After the two nurses finish clearing some room and making a pathway for Tom to be rolled via the commode to the bathroom, they put a green colored extra-large sling under Tom. Once Tom is being lifted up in the sling he yells “you can’t lift like that” and “get my leg.” The nurse operating the lift stands back and moves Tom up and down with a remote in one hand and attempts to steer the lift with

> the other. Tom is heavy, so she has to set down the remote and use both hands to push and steer the lift until Tom hangs over the commode. The other nurse, who is standing behind the commode tries to lift Tom up with the handles on the sling, so that his bum can slide better into the back of the chair. While awkwardly trying to lift Tom up, the second nurse also tries to use his legs to tilt the commode back at an angle, so that Tom's backside is placed as close as possible to the back of the commode seat.
>
> - Fieldnotes, Ward A, Summer 2021

In this excerpt Tom appears very motivated to move and is involved in his transfer, insisting on going to the bathroom instead of using a bed pan. For Tom, being moved to the bathroom required a lot of activity. The objects in his room had to be rearranged to make space for the nursing staff, the mechanical lift and the commode. The gathering of supplies, and coordinating another nurse to help required time, space, and bodily capacities. Perhaps more importantly for Tom, he requires his body to be carefully attended to, especially his leg that had recently been operated on. There is urgency for Tom and the two nurses to move Tom's body into the commode as quickly as possible. Although I could not see their faces, the nurses' exasperated sighs appeared as heavy as Tom's body. Tom is an active and involved patient during this practice of being 'mobilized', yelling at the nurses to pay attention to the leg that was operated on as it hung loosely in the sling.

Moving and being moved was a frequent issue for Tom throughout his care trajectory. When I went to visit Tom the next day, upon my arrival, he needed to go to the bathroom again. Once again, two nurses in the room attempted to use the mechanical lift and transfer Tom into the commode. Like déjà vu I saw the same sling, the same mechanical lift, and the same commode arranged around his hospital bed. Again I heard Tom yelling during the transfer while a nurse attempted to pull on the sling straps and tilt the commode as Tom was lowered. This time I heard Tom yell out, “good luck, I'm 300 lbs so watch your back…Oww! I don't think I'm in the sling right…Don't do that!” These daily practices of being mobilized elicited a lot of pain, conflict, and anger for Tom. The experience was undignified, with Tom dangling in the air and his buttocks exposed during the transfer. Dignity is a core value in the PFCC resources where it is described as a principle for honouring patients’ and families’ perspectives and choices. In Tom’s case his, his dignity seemed at stake each time I witnessed him being mechanically lifted out of his bed – on every occasion there was pain, commotion, and a general sense of disrespect between Tom and the nursing staff helping him to get up. After this particular transfer, Tom described the event as being painful and himself as not being very nice:

> Tom: Yeah, well you know what I said to that guy. He said ‘hey do you need your, your leg. You want to lift it a bit higher’. Right and I said, here come a little closer you know? So I could kneel my knee in your sack. That's what I told him eh. (laughs)
>
> Harkeert: Oh, that's not nice
>
> Tom: I know its not nice. But he was pissing me off like really bad, cause he was hurting me. They had me slide this way and my legs were going up and they're taking on all my weight and the pain was like oomph.
>
> Harkeert: So, does every transfer feel like that or are some better than others?
>
> Tom: No, some people do it better than others and the last one that did it, did not know shit when it comes to transfers with that machine. You know, some are really goodfully trained and some are poorly trained. You know, and they shouldn't be using that. Because they don't know how to use it properly or centre the person probably because what

> happened was my ass was going up this way and my head was going down you know? And my legs are like way up here.
>
> - Second Interview Participant A, Summer 2021

Tom describes threatening the nurse who was causing him pain during the transfer, by physically kneeing him in “the sack”. Tom’s threat to ‘sack the nurse’ shows that there is little mutual respect in this patient transfer situation. There is communication between Tom and the nurses during his transfer, but it is not this sort of democratic dialogue depicted in the PFCC vignettes where the staff and patient carefully stop to listen to one another. In practice, the nurses and Tom are in the midst of navigating the complexities of utilizing a mechanical lift, Tom’s size, the design of the commode and so forth, that make predicting the issues that might arise during the procedure difficult to pause in order to consult. There is tension rather than ‘teamwork’, and also a sense of vulnerability and precarity for Tom as he hangs in the air yelling out in frustration and in pain. From Tom’s experiences being mobilized, he observes that some instances of being transferred were better than others. He contemplates that there is perhaps better training needed for nurses to learn how to centre his body in the sling. As well, he suggests that he has better transfers when nurses attend to the specificities of his body, such as how the sling straps cause pain around his groin and dig into his legs.

Tom used the same words to characterize his involvement that Darlene used. They both said they were “not nice”. In Tom’s case, the nurses’ sighing and eye rolling was also not “nice”. Arguably, with Darlene, the nurses who were breeching sterile were also not giving “nice” care. It seems that being involved and being “nice” are complicated features of patients’ experiences of themselves and their nurses. However, for patients, their “not nice” practices accomplish what they need. Despite the seeming chaos and pain of transferring Tom, he managed to get to the bathroom and did not have to use a bedpan. This can be seen as self-advocacy, because as Nurse Mary described in the previous chapter, it is not always possible to mobilize patients and get them up out of bed. Tom was insistent though, stating, “I'm not the world’s most patient person. I admit that. I'm very impatient. You know, when I want something done, I want it done now, not an hour later or two hours later. It's just going to get my blood pressure you know like volcanic.” It seems likely that Tom’s “volcanic” disposition organized more urgent responses to his demands. His angry outbursts disrupted the necessary orderliness of the ward. As outlined in the previous chapter, orderliness is necessary for nurses to manage their work setting so that they can accommodate and attend to the needs of multiple patients. In lots of ways Tom worked against this orderliness to have his particular needs met - in my fieldnotes I described him as ‘volcanic’- angry, rude: a man who resists working with the time and routines of the nurses or doctors. Yet Tom’s actions and disposition did work to ‘centre’ him in the nurses’ practices – he did seem to get what he thought he needed done, and in line with his particular preferences – although this did not play out in accordance with the PFCC notions of dignified or respectful or even collaborative care. These aspirational notions intended to shape nursing work cannot accommodate the complex, sometimes tense, negotiations that arose for Tom, his body and his behaviours as those predispositions encountered his nurses and their experience, capacities and skills, the ward resources and equipment, other patient needs and so on – Tom and his complexities are the reality of everyday life on the unit.

Through a practice theory lens, the complex and entangled relations needed to accomplish Tom’s everyday care come into view – and they belie the tidy, controlled, social niceties portrayed in the institutional PFCC initiatives. The manager’s characterization of Tom as “unmotivated” and “complains a lot” hinted towards Tom’s rough and caustic responses to his nurses. The nurses' sighs and eye rolling in the face of Tom's "volcanic" outbursts evidenced the conflicts I observed. However, the puzzle of whether and how Tom's ability to get nurses to attend promptly to his needs is representative of PFCC remains. Is PFCC simply being nice? Is it about patients and families effectively getting nurses to do what they need? Where does the PFCC initiative feature within these entangled relations of equipment, bodies, angry outbursts, impatient responses and so forth?

Pain Management Practices

Pain management practices were a part of every patient participants' day to day nursing care activities. Pain management practices included activities of pain assessment, which were documented by nurses in each patient's record as a number. Patients were asked to rate their pain on a scale of 0 through 10 and then nurses would document the patient's response in an electronic flowsheet on the nurses' computers. Patients' pain management practices also required doctor's orders that instructed nurses on the type of analgesics to be administered and how frequently (e.g. continuously, on a regular 3-4-hour schedule, or PRN [as necessary]). Analgesics were administered as pills or injections by nurses at a patient's bedside. For Betty and Darlene, pain management never seemed to arise in conversation as an issue in their day-to-day care. That is not to say they did not receive analgesics or did not experience pain. They described isolated moments of pain. Betty described pain in her back if she sat in the chair or lay in bed for too long. Darlene experienced pain while waiting for the plastic surgeons to come look at her open wound one morning, which required her to lay on her stomach for a long period of time until they eventually came to check in on her. Tom and Abby struggled with chronic pain prior to hospitalization. Therefore, pain management was a daily concern for them, intertwining with all of their other routine care practices such as mobilizing or having to go to the bathroom. For

James and Kim pain management practices were what mattered most to them during their care trajectory:

> James: Yeah so, I pretty much wake up. More or less, you know. I go to the bathroom. The staff come in and they are doing their assessments or whatever. Then you get your pills and stuff. And my first thing is to make sure that the pills are coming in on time… You know like I said the pain that I am in, so I want my pills every three hours. And sometimes they get it stretched to three and half hours or so?
>
> Harkeert: I see they got rid of your pain pumps? The nerve blocks?
>
> Kim: Yeah, the rest of them just now.
>
> James: Yeah so now I need them to be more prompt with me. Like it has been three hours right now and I don't want to fall off the train.
>
> Harkeert: I guess you almost need like a timer.
>
> Kim: We have a timer.
>
> - Second Interview Participant C, Summer 2021

James' wife Kim remained at his bedside throughout his hospital stay and was actively involved changing linens, assisting with baths, and also watching the time for when James was due for more analgesic. For James, pain management was his first priority among other morning personal care practices. It was important for him that the nurses were punctual when his pills were due. Like Tom, James seems impatient and the consequences for him not having his medication on time were serious - described as like "falling off the train". James is describing how his pain can become too severe if he does not keep on top of it by taking his analgesics precisely as scheduled or on track. If there is too much time between doses, the pain becomes more acute and difficult to control. Clearly James values pain relief from his surgical amputation, both as a way to control his experience and avert suffering. However, enacting adequate pain management requires coordinated nursing work and involvement from James and Kim. During the day, the pain control pump, oral pills, and cell phone timer, alongside Kim and James' vigilance, were necessary to arrange pain management practices. Overnight, James and Kim also had to be active with coordinating, and ensuring, pain management:

> Kim: It's just hard like, pain management is fairly easy throughout the day, but at the night shift it is not. It is just hard to get the APS [Acute Pain Services] team. So, if it gets out of control at night, then usually all night you are in serious pain.
>
> James: And then they don't make calls to the APS or any of them, to wake them up in the middle of the night. But it took Kim the other night to make them call to help get me under control.
>
> Harkeert: Oh, okay so when you asked nothing happened?
>
> James: No.
>
> Harkeert: But then a phone call from Kim did? So, you have to advocate?
>
> Kim: Oh, for sure, I would never send anyone to the hospital alone that was in serious like pain or health conditions. I think everyone needs an advocate and it makes me so sad and scared for like with COVID when nobody was allowed in. Because I don't think that should ever happen.
>
> - Second Interview Participant C, Summer 2021

James' pain management at night is a problem, and Kim's example shows how she needed to actively intervene to ensure James received adequate analgesia. Nights are a problem for several reasons: the expert pain team are not in the hospital 'after hours', although they are "on call" for pain emergencies. Nurses are reluctant to wake "on call" staff during the night when James asks for more analgesic, but interestingly, they do respond to Kim's call suggesting ways in which family members may be seen as powerful intervenors. Kim's advocacy and action supports the nurses' in responding to James' pain situation as serious enough to phone a sleeping consultant.

Kim also experienced being unable to advocate for James during his first admission in the other hospital, where she was unable to visit and thus had limited communication with James and the hospital staff. This impeded advocacy was described "like hell", for both James and Kim. James stated that he was "loopy", a common physiological side effect of analgesics used in pain management practices. Therefore, he described feeling drugged up and going along with whatever the staff from the hospital suggested. James also said that he could not really explain what was going on to Kim during this time, and did not necessarily feel that his life was in his own hands. Throughout his hospitalization James was vulnerable while attempting to organize pain control and heavily relied on Kim's advocacy and involvement. For James, Kim was an advocate in relation to the particularities of his pain management practices, being his timekeeper and, in a way, being his guardian while he was experiencing side effects from his analgesics. Are these pain management practices on the part of Kim and James what are meant in PFCC initiatives as patient and family 'involvement'?

Personal Care Practices

While admitted into hospital care, my patient participants expected to receive attention to personal elements of daily living on the wards. The needed to bathe, to eat and to have their toileting needs met. Such needs are referred to by nurses as the "activities of daily living" (ADL) and are considered basic (not complex) aspects of nursing care. A record that accounts for the ADL is kept on a separate electronic flowsheet. This was a "catch all" list of personal activities for daily living, from hygiene/skin care, nutrition, elimination, mobility, and comfort care. Health care aides were responsible to arrange daily personal care interventions for patients, such as setting patients up for breakfast, bathroom use, and repositioning. Typically there would only be one health care aide available, so nurses also participated in arranging or carrying out these personal care practices. Patients and their family members were also active in arranging personal care. Kim, for example, described actively finding and changing James' linens and helping him with personal hygiene in the bathroom. Tom would often have to ring the call bell when he was in the bathroom to request a urinal, so he could avoid accidentally spilling urine on the floor. Betty disliked the hospital food, therefore her daughter, Sue, would bring fresh vegetables from their summer garden and homemade sandwiches to assist with nutrition. For Abby, voiding demanded a lot of work and coordination with her mother Lynn:

> Abby: There were a lot of incidences with nursing staff. So, I can't go to the bathroom on my own. With the bedpan. I would ask them to watch to make sure I wasn't going onto the bed. Or they would dump the bed pan onto the bed when they pulled it out from under me. And I would have urine on myself.
>
> Harkeert: Yeah.
>
> Abby: That happened about five times. And so that wasn't a pleasant experience.
>
> Harkeert: It sounds like having your mom there was really important.
>
> Abby: It was essential. My mom did the majority of the work. Without my mom there, I would have sat waiting for hours having to go to the bathroom or in my own urine or something like that.
>
> - First Interview, Participant E, Fall 2021

Abby describes uncomfortable and messy experiences using the bedpan provided by nursing staff, which resulted in urine spilled in her bed and her feeling dirty. Therefore, she began to hold her urine, a painful and physically distressing situation, until her mother was available to assist. So Lynn began extending her hospital visits to be as long as possible, to avoid having to make Abby wait. Lynn described being at the hospital between 19 and 21 hours a day. Abby suggests that using the bed pan was cleaner and timelier when her mom was involved. Whereas Lynn described these elimination practices as a way to protect her daughter's dignity:

> Lynn: Okay. And there's no way, like if I could not have been there, I think that neither one of us would have made it through this ordeal. Um, it would not have been pleasant would be an understatement. At first, I would be away I think five hours, but I had to bump it to only being away for four hours due to the bedpan incidents continuing to occur. And so, I mean, she would even hold it till I got there. So it was that severe.
>
> Harkeert: Yeah, it mattered.
>
> Lynn: Oh dignity, right? Being in your own urine and feces. If I hadn't been there, that would have been her entire experience. Because there they were like half hour late hour late just for meds let alone bedpans.
>
> - First Interview, Participant E, Fall 2021

Lynn described being at Abby's bedside as though it was shift work. Dignity, a key tenet of PFCC, is described by Lynn in relation to specific material and bodily practices. Here dignity is situated in specific daily care practices, it is about preventing urine spilling on Abby and minimizing the wait time for Abby to use the bedpan. Dignity, as it unfolds in the day-to-day reality is closely tied to personal hygiene, timeliness, and, in this case, within the apparent shortage of nurses and aides to respond to Abby's needs, it is enacted by Lynn. Ensuring Abby's dignity took a significant amount of time and work from Lynn:

> Lynn**:** We were only allowed a maximum of two family members. And this one time we were on our way to meet our other family member at the elevators. The screening people called up one day and they said, oh no, they've left their room and said that my family member was no longer on the list. So, I got a frantic call from my family member in the basement at screening main floor. And so, we, my daughter and I rushed back wondering what the heck's going on? As politely as possible we were like what? Why is she off the list? What's going on? And then they gave us two answers. One was you guys were not in your room. Well, my personal opinion without stating this opinion to them was, who are you to just decide that they can't come up. Our other family member has been here several times before. And then the second thing was that she's off the list. And so this was very concerning. And it caused us a lot of stress, it cost us 40 minutes of a two-hour break that I had. We only had two hours a week with this family member to visit, so I could go and obtain groceries. Exactly two hours, and we lost 40 minutes of the two hours.
>
> - First Interview, Participant E, Fall 2021

As described above, being involved and arranging time to be physically present to ensure dignified care for Abby was what mattered to Lynn. In this situation, Lynn's involvement was a critical adjunct to the work of the nurses, who as Lynn noted, were "like half hour late hour late just for meds let alone bedpans." Lynn understood that nurses' time was scarce. There were consequences to both Lynn and Abby when they began to understand that nurses who were rushing to meet the multiple demands being placed on them were more likely to spill the bedpan and then not have time to change the linen. As well, they understood that medications took priority over full bladders. For this patient and her mother, the need to augment nurses' work with their own had consequences. Abby experienced an uncomfortably overfull bladder and/was left to lie in bed linens soiled with urine. For her mother, it impacted when she could shop, cook, and manage her own needs outside the hospital.

Moreover, even though Lynn's ability to spend many hours with Abby supported the nursing care, the family got caught in the COVID restrictions related to infection control and managing the number of people entering and leaving the hospital. To be physically present on the wards, Lynn and the other family members' name had to be on the visitor list. Although the visitor list was updated every day, it seemed that somehow this other family member's name fell off. Lynn states it was important when having these concerns and frustrations with the nursing staff to be as "polite as possible." Lynn was aware that she was in a particularly vulnerable position and that the gatekeeping practices, which involved the use of the visitor list and nurses' screening processes, were powerful. Lynn did not take her ability to be physically present for granted. Here you begin to see the "flaws" in care that strategies such as PFCC are expected to address. But you also see how such flaws are systemic (issues of staffing) rather than individual (issues of kind communication and time for interactions about "what matters").

In much the same way, another patient participant, Betty, often began her day feeling uncertain that her daily personal care interventions, such as going to the bathroom and getting set up for breakfast, would occur in a timely manner. Betty described having "accidents" in bed and even on the floor on the way to the bathroom when she was not helped by a nurse or health care aide in a timely manner. Given the number of medical complications she had suffered, Betty had moments in which she described feeling hopeless and helpless. She stated that the hard part of being in the hospital in a semiprivate room was that “other people here, they just come here to recover from surgery and then they go either to rehab or go home. I have to recover from a whole big mess that is taking longer.” Due to her extended hospital stay, Betty had grown accustomed to particular daily activities. Some she characterized as more personalized than others:

> Betty: I don't like being here. I like being able to walk, but I do not like going to stupid physiotherapy class. There is nothing wrong with my mind but I understand I've been here longer than most of the people that go there in the morning. And maybe in some way I help show them that they are able to get better. But some people at the class are forgetting... But I don't know, I would rather have a lady who walks with me, exercises me, and sees me twice a day. To me, group physio is not what I need, but other people do.
>
> - Second Interview, Participant B, Summer 2021

Betty states that she would much rather have someone that walks her one-on-one than attend a group exercise class. On some days, Betty would negotiate with a physiotherapist to walk with her instead of going to group therapy. These would be ‘good’ days Betty said, and perhaps they are instances of ‘patient centredness’ insofar as Betty’s preferences are incorporated in her daily care. When the physiotherapist would take Betty on individual walks, they would also walk her to the bathroom in the morning. This allowed Betty to freshen up and use the bathroom, so that she would not have to use the toilet during her dressing change, which often took place in the early afternoon. In many ways, Betty was highly aware of the ward routines and described the material and bodily specificities of having her daily care practices personalized or arranged according to her preferences:

Betty: Eight o'clock everything hits the fan. The man with food comes to put the tray of food down in front of you.

Harkeert: Yeah

Betty: But you are not in any position to eat. I'm laying like this. Like I have been laying all night. So, I do not even want to see the stupid tray. I know that I can access the tray. And if I start on the tray, 2 to 1, I bet that somebody is going to walk in here and say oh, I have morning pills for you in the middle of me eating my meal. So I'm not touching food until they get pills now. I learned that one thing that will bring them is if they got a handful of pills to make you take. I do not understand why I take all these pills. But that is how they are, so I put them in my mouth. But sometimes there is a lot of staff on and they are able to get to you up. Wash your body. Wash your face and get cleaned up. I have false teeth, I need to get cleaned up. I do not want to eat breakfast with my teeth not clean. Sometimes there are not enough people to help to get cleaned up. It is a whole procedure. Like say you're coming to help me in the morning and you go get what you need. Then I get out to clean my teeth. I already put my teeth in containers to soak for little bit to clean. And once teeth get clean and get back in mouth. You feel okay.

Harkeert: Yeah. You feel like yourself?

Betty: Yeah. You can talk better. Be understood better.

- Second Interview, Participant B, Summer 2021

Here, Betty appears to be quite informed about the ward routines and describes how her personal care, such as sitting up for breakfast and denture cleaning fit into the nurses' medication administration and assessments practices. Betty highlights how these daily care practices require having enough nursing staff working during the day shift. As well, Betty works with the staff to arrange more personalized care by soaking her dentures and waiting to eat her food once her mystery morning pills arrive. “It is a whole procedure”, she states, to feel like herself and to feel like a person who can talk and be understood. Being able to have clean teeth before eight o’clock is part of what makes Betty feel like a person. There is perhaps a kind of dignity being described here by Betty, that is again material, timely, and bodily. Betty shared her understanding of the ward routines and intense demands of nursing work:

> Betty: So, from seven to 730 they are updating what is going on. And then they sort of get signed in and they scatter. But each team of two nurses has maybe four or five people to get cleaned up. They get set for breakfast and then they bring the tray at eight o'clock or just after eight o'clock. And it might take up half of the table till 930. The tray does not stay on the table too long, but if you're not ready to eat it then it has to stay. So, it's like a catch. If the staffing has a lot of staff some days it is. Today they ran short. I suddenly realized one person did not show today.
>
> Harkeert: How did you realize?
>
> Betty: Because I have good hearing (laughs).
>
> Harkeert: Excellent.
>
> Betty: So, because of that I try not to put stress on staff that is here.
>
> - Second Interview, Participant B, Summer 2021

As a patient, Betty appeared to be quite attentive and well-informed about what was happening on the ward. Betty paid attention to the ward schedules and resources, such as the staffing levels, so that she would not overly burden the staff when there were “no-shows”. In this way, it appeared Betty was maintaining respect for the demands of nursing work, by attempting to avoid adding stress on the staff. Betty described how some of the patients she shared the semiprivate room with were not as conscientious of sharing the nurses' time and efforts with other patients. Betty seemed aware of the need for ward efficiencies, describing the urgency of nurses as "zoom zoom". My conversations with Betty contrasted the conversations I had with Tom, who likened the nurses' movement to that of slow turtles. Unlike Tom, Betty was particularly careful not to disrupt the nurses' work while they cared for other patients. However, the respect Betty expressed was also closely tied to feelings of fear. Betty stopped journaling during her hospital stay, because she did not want the nursing staff to read her entries about what care had been accomplished, and what was missed or forgotten that day. When asked what she was worried about, she was unable to articulate her concern and just stated that she got rid of them.

Betty, over the course of her long hospitalization, was particularly active in arranging her room, the contents on her bedside table, the positioning of her bedside table, and the arms-length distance to reach her call bell exactly as she preferred. Betty worked hard to keep her room exactly as she liked it, in a way that allowed her to move easily in and out of bed or do a puzzle or write notes in her diary. Figure 9 is an image of Betty's room, a place where we had many conversations:

Figure 9

Betty's Room

Betty's room is ordinary, in the sense that all the patient participants had the same bed, bedside table, linen, curtains and space in their room. However, Betty always attempted to keep her room precisely as shown in Figure 9. She preferred to have her wheelchair by the wall facing out towards the hallway with a blanket and pillow on it. She kept her bedside table by the curtains. And her things, like her notebook and puzzle book on her bedside table, were always organized and kept in the same spot. However, there were moments when Betty's individualized room arrangements would be quickly dismantled. For example, towards the end of one interview a nurse rushed into Betty’s room bumping their computer on wheels into Betty’s bed and also her bedside table:

> The nurse exclaimed “oh my god” as they continued on their way to first go see Betty’s neighbor patient. Betty asks them, “what are you doing?” The nurse laughs and says, “I don't know” as they go into visit the other patient in Betty’s room. Betty says to me, “okay, I think that is [Nurse] Bill.” She talks to Bill through the thin curtain and says “[Bill], slow down and count to ten. Everything will be better. Oh, go talk to her first. I think it may be time for my meds too”. I ask Betty if she is feeling tired. Betty responds, “no, but they are going to start messing with me. Messing with me for all kinds of crap”, she laughs with the nurse who now comes into Betty’s room. And then she says, “see he is already in process”. As he moves her table further away to make space for his computer on wheels. The nurse says, “yeah, I don't stay long that much. Unless you want me to stay long. Betty responds “I know that you could do whatever you want. You go right ahead. As the nurse scans Betty’s medication, we say goodbye. And then I walk out with the nurse, who leaves her bedside table out of reach at the foot of her bed.
>
> - Fieldnotes, Ward A, Summer 2021

With Betty’s table left out of reach, her room did not appear to be hers anymore and she again seemed quite vulnerable laying in bed. The personalization or individualization of Betty’s care was contingent upon things like time, availability of resources, and specific material and bodily arrangements. There is a certain instability and precarity to these individualized and personalized moments of Betty’s care, that are overlooked by PFCC discourses.

Summary: ‘Involved’ Patients and Families

The descriptions of the ways in which the patient and family participants came to be ‘involved’ in their hospital care and how their care trajectories unfolded in unexpected ways illuminated their precarity. Patients find ways to mediate the limitations of rationed care. They produce performances that they know make it more likely that they will get what they need – such as Tom knowing how to get fast attention from nurses by being belligerent and Darlene who assertively directed the nurses to use sterile water and to change their contaminated gloves, and even Betty who generated a performance of polite acquiescence to ensure that her breakfast was not interrupted and to negotiate 1:1 physiotherapy—these strategies seems to be more than simple ‘involvement’. These patients and families actively organized their care by bringing their knowledge about their bodily needs into the fore. Moreover, they are activating their knowledge about how hospitals work, what they need to do to get the attention they need in a setting that, in the case of these patients, is not consistently meeting their needs. These patients have had to learn how the system works. Their knowledge includes expertise about how the nurses must ration their time and in the absence of nurses who have the time to attend to them, they have learned how to manage their wounds, limbs, washes and meals. The patients interviewed for this study activated critical strategies during instances when their care was going awry.

The sociomaterial features of care going awry seem to make a mockery of the PFCC discourse, focused as it is on abstract ideas of ‘dignity’ and ‘respect’ or ‘involvement’. The patients interviewed for this research experienced complex and troubling hospitalizations. The excerpts analysed above reveal the work they did to make a hospitalization not only habitable but therapeutic. Even Tom who twice left the hospital against medical advice was working to meet his needs for care. Kim demanded that the nursing staff wake-up the physicians specializing in pain control at night, so that James may get better analgesics. These patients produce these performances in a way that goes well beyond ideas about ‘being involved’. Moreover, the nurses interviewed also troubled the paucity of ideas of ‘dignity’ and ‘respect’ in instances of patients’ and families’ racist views. In specific care practices, such as mobilizing, pain management, wound care, and personal care, the abstract PFCC values and the material arrangements of care become contestable. For patients like Tom, Betty, Abby, James, and Darlene, being ‘involved’ in their care required a lot of work.

Chapter 7

Attending to the Complexities of Care

Despite global trends in hospital care to adopt PFCC interventions, researchers continue to report that patients and families experience dehumanization during situations of critical illness (Nielsen et al., 2023). As well, even with the adoption of PFCC frameworks there continue to be issues with patients and families not feeling listened to or feeling constrained in their abilities to improve their own experiences in hospitals (Ocloo et al., 2020). In undertaking this study, I wanted to better understand why PFCC initiatives did not seem to be accomplishing their stated goals - despite significant resources being deployed to these ends. The PFCC initiatives described in this study took resources to develop and implement – but other 'significant' resources that are critical to day to day care, such as staff time, were not a part of the solution. Rather the rhetoric of dignity and respect were expected to "fix" people's attitudes and communications skills – but this research shows that such programs overlook the core problems in contemporary hospitals – those of professional time and capacity to respond to complex patient situations. The system seems to work well for uncomplicated patients, but for those with complex needs, such as those involved in this study, it falls short.

The persistent difficulties described in the research literature, including competing organizational priorities, paradoxical ethical implications, and insufficient conceptual knowledge about PFCC on the part of practitioners, gesture to the complexity of care. However, such complexities are subordinated to the aspirational conceptual discourses of 'communication' and 'involvement' that are being touted as a solution. To explore this possibility, in this study I examined the ways in which the formal implementation of PFCC (using value statements embedded in policies and the educational resources), the administrative approach to PFCC in hospitals, is discernable or discoverable in everyday care practices. I was specifically interested in exploring the sociomaterial contexts of care to trace the effects of these contexts in shaping the ways in which patients and families became ‘involved’, experienced individualized care, and had their preferences or choices included – or not.

PFCC was proposed as a research topic in part because of my background as a nurse and my interest in how ideas of patient and family involvement in care have evolved over time in hospital care. While conducting fieldwork, my research questions changed from exploring how PFCC was accomplished in day to day practice to instead exploring how or if ‘centring’ values, as expressed in formal policy discourses, were discoverable in everyday nursing care. As described in Chapter 3, this exploratory shift occurred due to research circumstances in which I largely observed nursing practices. As well, I had come up against a conundrum, that although PFCC initiatives were very visible in policy and educational resources, the idealized framework of what constitutes PFCC did not appear to be a very visible accomplishment in everyday care – at least not in the terms set out in formal policy documents. Therefore, I explored how PFCC values were discoverable in care and, given the sociomaterial contexts of care, how patients and families were involved in the care practices that produced their experiences.

This research endeavor was more difficult than I anticipated. Although there were many PFCC artefacts at the study site encouraging patient and family involvement in everyday care, PFCC was not a specialized activity in the nursing practices and patient care trajectories I observed. During my fieldwork I observed nursing care practices and procedures, the schedules and routines, and the material and spatial contexts of two orthopaedic wards. While doing this I also talked with the nurses I was observing about PFCC and how it figured into their daily practices. As well, I observed and talked to patients and families about what mattered most in their care, and about their preferences, and their vulnerabilities, while being ‘involved’. In the data I collected from both types of research participants, and analysed in chapters five and six, PFCC initiatives, as expressed in formal policy initiatives, appeared peripheral to the fundamental complexity and dynamic context of hospital care. For example, nurse participants described a wide range of barriers to their capacity to include the idiosyncratic preferences of patients and families in care, but they also described their work as being ‘centred’ on patients and families – it seemed that everything that nurses did was responding to what they knew was needed to accommodate the various trajectories of the numerous patients and their families who were present, coming or going on the wards. On the other hand, patient and family participants described how their ‘involvement’ in day-to-day care practices was necessary, not only to prevent their care trajectories from going awry, but to ensure their needs, as they defined them, were met. My observations and analysis have practical significance for understanding the complexities of improving care for patients and families in hospitals - complexities that I argue, are overlooked in PFCC discourses.

Based on my observations of nursing practices and conversations with nurses about their practices, and the discussions I had with patients and families about their experiences, there are three findings that are relevant to consider in efforts to improve hospital-based care. Firstly, hospitals are not ‘neutral’ settings of care in which PFCC initiatives can simply be implemented as an overlay to professional knowledge and judgment. Secondly, there are multiple values, knowledge, and experience entangled in nursing practices. Moreover, there are competing needs and therapeutic regimes among the numerous patients a nurse is assigned to provide care to. These are not always aligned with the desires or preferences of individual patients. Finally, while experiencing precarity and vulnerability, patients who participated in this study were actively involved in day-to-day orthopaedic care practices. These findings, to be clear, are not ‘problems’ to be addressed through an even greater effort to implement more directive PFCC models and imperatives, but rather the three observations suggest the extent to which PFCC discourses overlook the material and social conditions of care.

Hospitals Are Not ‘Neutral’ Care Settings

PFCC implementation practices in hospital care overlook the non-neutrality of the setting, assuming that social stratifications that occur in the world do not permeate the hospital walls. Social stratifications, such as race, income, and support networks, impact the ways in which patients and their family members can be ‘involved’. For my patient participants, it was not simply the case that patients and families should be given a choice to participate and be ‘involved’. Tom had no family members to draw upon and relied upon his case manager, a formal social support worker organizing financial aid in the community, to help maintain his apartment and car while he was hospitalized. Kim relied on friends to help watch her children at home, so that she could be at James’ bedside and advocate for better pain management. Lynn too, drew upon other family members, so that she could arrange as close to 24/7 involvement as possible so that Abby could comfortably void. The social networks and resources patients and family members had available outside the hospital setting directly impacted the ways in which they could be involved.

The social inequities people experience, particularly those related to racial biases, also impact the ways that people experience personalized care and the ways in which values such as dignity and respect were enacted. Nurses Nate and May described experiencing racism from patients, eroding possibilities for mutual respect and democratic or collaborative partnerships in care as described in PFCC discourses. Patients too were subject to racial stereotyping, which researchers suggest can further damage their sense of trust and participation in health care (Mahabir et al., 2021). At the risk of sounding redundant, respect, dignity, and personalized care are ethical goods that PFCC approaches aim to improve (Hughes et al., 2008). Yet, PFCC approaches, while foregrounding these as ethical goods, seem to neglect critical attention to the experiences of everyday racism for people – both patients and practitioners - in hospital settings. As Ahlberg et al. (2022) argued through their investigation of the ways in which ethnic minority healthcare staff manage encounters with racism, "the rational practice of solidarity with the patient at the center acts as a hindrance to discussing the occurrence of racism" (p.2). By assuming the hospital is a neutral setting, unmarked by the social problems that exist outside its walls, or that hospital care is organized solely based on rational evidence, PFCC discourses have worked to silence and dismiss the social inequities that occur within the hospital. While PFCC initiatives proliferate and become increasingly taken for granted, it becomes more difficult to discuss the everyday violence that people marginalized by various social inequities experience.

The following quote from a participant in Ahlberg et al.'s (2022) study resonated strongly with my own experiences of racism as a nurse: "just, throw it behind you and just keep going" (p.6). Despite experiencing blatant racism throughout my nursing career, I ignored these threats to my dignity and personhood, and focused instead on my need and responsibility to protect workplace cohesion and routines. However, there is more to it, as Ahlberg et al. (2022) observe, including a lack of space or time for discussing and reporting racism in health care contexts.

Also, in doing this work I became concerned about the ways in which organizational routines, more so than the people involved, were morally problematic to the extent that they work to make oppressive experiences invisible. Hamed et al. (2020) explored the experience of racism by health care users through a theoretical lens of structural violence. Their research suggested that the impacts of everyday racism upon people's agency is not so much because this form of violence is hidden, "but precisely the opposite—it is hardest to perceive because it is right before our eyes. Arguably, it is through repetition and reiteration that violence becomes invisible and assumed to be a normal status quo" (p.1664). Given the extant literature exploring the impacts of racism in hospital settings and my own observations of racism in this study, the non-neutrality of hospital settings and the social inequities embedded in hospital care are in need of further empirical investigation as a potentially effective strategy to actually improve patient care.

Multiple Values in Nursing Practices

During fieldwork, significant time was spent conversing, shadowing, and observing nurses getting patients ready for surgeries or procedures, giving treatments, documenting, and reporting their assessments to other health care providers. In some respects, it seemed obvious that these sorts of nursing practices must be centred on patients and families, because without patients and families there would be no care of any kind occurring on the wards. As Rankin and Campbell (2006) states, without nursing care practices "knots would appear in the smooth rolling out of the collective endeavor that is hospital care" (p.162). Nurses, like Sally and Jane, described "just doing it all", valuing their professional roles, continuity of care, and also patients' preferences. The nurses were critical actors performing, managing, and arranging the care of patients and families that was at once many things: efficient, safe, accountable, professional, informative, and continuous. Nurses' roles at first glance were limitless, and inextricably tied to patient and family involvement in hospital care. However, there were multiple, and not always congruent, values entangled and materialized in day-to-day nursing care practices.

More than one thing happening simultaneously was characteristic of all the observations of nursing care being enacted for patients and families on the wards. It was not just that I witnessed simultaneous activities occurring, such as a nurse taking a phone call while typing into their computer at a nursing station. But also, that all the nursing care practices were complex, contingent upon diverse technologies, distributed workloads, and the pragmatic management of patient outcomes after orthopaedic surgery, including management of pain, mobilization, and wound care. To carry out these care practices and also include patient and family preferences, required consideration of material, bodily, and practical complexities. Of all the comings and goings of other health professionals, it was clear that nurses spent the most time with patients and families, and had the most frequent in-person interactions. Thus, it is not surprising that nurses are the actors most often held accountable for enacting PFCC policies, primarily the inclusion of patient preferences. But there was a tension insofar as nurses were 'just doing it all', but at the same time, also constrained by the material and practical affordances of organizational routines. To me it seemed that nurses valued the ward routines and that they did so for multiple reasons - to allow for ongoing care, team nurse cohesion, and as a way to control the unpredictable care needs of patient in the context of finite resources. This was evident for example, when nurses described family members interrupting their nursing assessments by asking questions too soon or even disrupting the physical environment, some even laying in the bed with a patient.

Nurses did not always attend to arrangements that might foster further patient and family 'involvement' in care - there were often material and social complexities to be navigated, as well as differences concerning what was considered 'good' involvement. For example, allowing the presence of family member translators for patients who did not speak English was considered helpful, despite tightened visitation protocols and threats of communicable disease transmission during the pandemic restrictions. But involvement of families was not considered so helpful when patient rooms were left untidy or dirty. In attempting to describe these complexities, or the mix of goods and bads, I take direction from Law and Mol's (2002) suggestion that researchers "treat complexity as if it were more than one but less than many- as a set of possibilities that are partially connected" (p.17). Involving patients, including their preferences and priorities, could be complex for nurses and it seemed as though there were many possibilities in the ways in which this could be done (or not done). Nurses described making compromises to visitation restrictions, being creative while playing charades to communicate, and even hiding or fighting for resources that were shared between the wards, so that they could provide more personalized care.

Everyday nursing care practices are impacted by organizational routines and unpredictable patient needs, and given the implications for 'centring' patients, this play of complexity and routinization warrants further attention. When comparing normative understandings of PFCC values as expressed in policies and procedures, with descriptions of how the care of patients and families is enacted in everyday orthopaedic care practices, it seems as though "things relate but don't add up" (Law & Mol, 2002, p. 20). By this I mean, there were relations between specific materials, bodies, and technologies on the ward that both created opportunities and challenges to involve patients and families and include their preferences in nursing care. There was both a presence and absence of PFCC ideals. Nurse Mary's list of both good and bad experiences with patient and family involvement is a good example of this complexity. Patient and family involvement was supported when there was sharing of information, help with communication, and when mediation was needed during disagreements.

However, ‘involvement’ seemed problematic at times for nurses when they were asked by family members to frequently mobilize physically heavy patients or when family members disrupted patient privacy. In this way, it would seem that PFCC principles, or those that express a practice of relentlessly attending to patient and family preferences, would clash and not ‘add up’. So, my analytic questions I wrestle with are: what to do with these complexities and non-coherences in nursing care practices?

Ideas of non-coherence and complexity have been noted by other researchers examining the proliferating PFCC discourses. See for example, Tanenbaum (2015) who discursively analyzed PFCC models in health policies and stated that their meaning is “at once obvious and obscure” (p.273), and that the various competing PFCC models are “neither entirely compatible nor entirely incompatible” (p.272), further concluding that these contradictions disrupt a coherent picture of PFCC. Also conducting a discourse analysis of PFCC research, Pluut (2016) suggested that although the concepts of PFCC are popular, they are simultaneously fuzzy and often lead to unproductive debate. These findings of both complexity and muddiness were similar to my observations of nursing care practices, which were neither inclusive nor entirely exclusive of the ideas contained in PFCC policies.

Some researchers advocating for better implementation of PFCC initiatives have attempted to reduce the complexity of hospital care by opposing PFCC initiatives against standardized or routine nursing care. However, as Zuiderent-Jerak et al. (2015) suggest, the juxtaposition of PFCC against routine care activities as antonyms is predicated on researchers’ assumptions that there are only two values at stake (e.g. patient and family values vs. organizational values). Agreeing with Zuiderent-Jerak et al. (2015), I suggest that it is not particularly helpful to analyze the routines of care as in opposition to PFCC endeavors – at least to the extent that these endeavors seek to improve patient care experiences. However, complexity, multiplicity and the materialities of practice, and the ways these produce possibilities for care, must be better accounted for. Perhaps as Gibson et al. (2019) suggest, rather than investing further effort in pinning down a PFCC definition that can then be operationalized, it may be more productive to leave conceptual and theoretical understandings of 'centring' patients in care open to empirical investigation.

Patients and Families are Always Already 'Involved'

While experiencing significant uncertainty, and often physical precarity and vulnerability, patient and family participants demonstrated diverse ways in which they worked actively to 'centre' themselves in day-to-day orthopaedic care practices. And in each case, there were specific sociomaterial circumstances associated with the ways in which particular patients and families were active in practices of wound care, mobilization, and personal hygiene. The term precarious is defined as "dependent on chance circumstances, unknown conditions, or uncertain developments" and can be used to describe a situation that is "characterized by a lack of security or stability that threatens with danger" (Merriam-Webster, n.d). This notion of precarity reflects some aspects of my observations of the care conditions in the hospital, particularly when research participants related the ways that the material and bodily resources to meet their care needs were not readily available. I also use the term precarious as a way to account for the observation that patients were vulnerable to experiencing further bodily injury if their care needs were not met, and to underline that the consequences of 'non-involvement' on their part were often quite serious. For example, Darlene knew the possible consequences of further infection and prolonged healing time if she was not 'involved' in wound care practices. As well Kim, knew that James would experience pain all night she did not call the nursing staff.

There were some similarities in the descriptions patients and families provided of organizing care that overlapped with my observations of the nurses' efforts to arrange care. That is, patients also highlighted how their activity to 'centre' care was contingent upon specific materials, such as adequate staffing, appropriate wound care supplies, and timeliness of medication administration.

To a degree my observations and conversations with Betty, James, and Abby support findings in extant PFCC research, that is, that involving their family members improved their comfort and psychological well-being (Kokorelias, et al., 2019). However, this involvement required a lot of work on the part of these family members, as I noted in the descriptions of Sue, Kim, and Lynn's hospital experiences. Each of these family members were women, and each described doing their best to spend as much time as possible at the patient bedside. Sue, who could not tolerate sitting for long periods of times, often coordinated her visits around my research activities, so that Betty did not feel as lonely. Kim and Lynn very rarely left the ward and described the challenges of being physically present while balancing their other responsibilities at home. Each highlighted different types of hurdles they overcame to be physically present, including visitation policies, parking expenses, and scrutiny at the hospital entrance screening stations. These are ordinary and yet noteworthy lengths they took to be active and involved in everyday care. Hirsch (2021), a social worker, published a reflection of her own experience of having her father hospitalized for surgery. In much the same way as the patients and families who participated in this study, Hirsch experienced similar material and practical limitations to being involved in hospital care during the COVID-19 pandemic. Hirsch described herself as being "powerless" when she encountered nurses that were not willing to make more flexible visitation arrangements. However, I think precarity may be a better term as it helps to shift focus away from a personal attribute, such as powerlessness, to the conditions shaping these participants' experiences. Further, highlighting the ways patient and family involvement in this study was dependent on the unknown conditions of the pandemic, uncertain developments in patients' illness trajectory, and chance circumstances on the ward (e.g. family member names remaining on the visitor list or staff not showing up during a strike).

The idea of patients and families experiencing powerlessness is well documented in PFCC research (Marmo & Hirsch, 2022), and is, in fact, one of the major impetuses behind the PFCC movement. Frequently the 'cause' of these experience of powerlessness is explained with reference to the undermining of ethical principles, such as patient autonomy or patient rights, by health care professionals (e.g. Olson, 2019). And while on the one hand, it did seem to be the case that patients involved in this study were vulnerable to missed or rushed care or having their preferences ignored, and that families were susceptible to being denied hospital access, they were not entirely powerless. Indeed, I would argue that a vague referencing of 'violations' of abstract ethical principles does not do much to explain the experiences of patients and families in hospitals. In fact, it seems to me that the narrative of patients and families as being 'powerless', as often found in PFCC discourses, actually undermines the constant efforts of patients and families to arrange care that is 'centred' on their needs. That is, the issues that arose for patients in this study were different than those that tend to be identified as problems in the PFCC literature.

In day to day care, patient preferences and family involvement were interconnected with the seemingly mundane aspects of living on the wards, such as getting to the bathroom, eating, or getting their teeth cleaned, as well as the more intensive management of postoperative surgical complications (e.g. wounds, pain, and mobility). For example, while Darlene described the confusion associated with her wound care management and her need to direct health care providers, Betty described how she arranged to get her teeth cleaned before breakfast. While Kim demonstrated vigilance in ensuring James' pain was well managed, Tom ensured he was moved to the bathroom on time. Each example highlights how personalized or individualized care was operationalized by patients or families and nurses, but always connected to and contingent upon specific materials being available, adequate staffing, and attention to physical spaces and routines of the ward.

At the same time, it was clear that care did not always proceed smoothly, most noticeably for me during conflict between staff and patients and families. Open conflict was visible when I observed Tom's transfers, he would yell out loudly that he was in pain and threaten to reciprocate physical pain upon the nursing staff as he transferred to the commode. Betty's exchanges with the hospital staff were more muted, as when she confronted staff to have more personalized care, and simply quietly refused to go to group exercise classes, negotiating with the physical therapist for one-on-one walks. Lynn did not trust the nurses not to spill urine on Abby while using a bedpan, and so took the role of helping Abby void. James and Kim did not trust the nurses to manage his pain, so they used a timer to stay on top of his analgesics. These patients organized and 'centred' their care as needed, because they had to be involved. At times the patient and family participants echoed language used in PFCC discourses, such as a need for advocacy, but their accounts of being involved also highlighted the challenges of advocacy in the context of limited resources and the busyness of the hospital staff. Darlene and Tom suggested that it would be futile to file complaints with patient relations about their concerns, so they voiced their needs and their critique of staff during specific practices of wound care and mobilization. Darlene and Tom, while having bodily precarities, were powerful actors in arranging their care trajectories.

The patient and family participants in this study show that perhaps patients are more ‘involved’ than we think in day-to-day hospital care, advocating for themselves in sometimes unconventional ways, including through conflicts with hospital staff, filling in the gaps in care and raising questions. Patients find ways to mediate the limitations of rationed care, and they produce performances that they know will make it more likely that they will get what they need from nurses. In these terms, powerlessness seems to be an insufficient way to frame patient experiences of care, implying patients and their families are passive recipients of standardized, depersonalized or inadequate care. Patients and families both relied upon and arranged personal resources, as well as institutional resources, to improve their hospital care experiences. And it seems unlikely that further education concerning PFCC values or the creation of more PFCC artefacts would improve these patients’ care trajectories. Rather, these patients and their family members would perhaps have benefited from better arrangements of material and social resources - more timely personal hygiene, more timely medication, more staff to manage careful patient transfers. Activities such as these, among others, require attention to a sufficiency of material and bodily resources.

Implications for Nursing Practice

Nurses play a critical role organizing hospital care for patients and families, yet the notion of ‘centredness’ as discussed in most PFCC discourses does not fit smoothly into the realities of nursing practices. Nursing practices are organized around patient and family needs, yet they are also entangled with diverse workplace conditions including the management of threats of communicable disease, staffing and equipment shortages, shared workloads and even “difficult” patients. Nurses do not work in isolation to ‘involve’ patients and families in care or to include their preferences; they rely on technologies, institutional policies, organizational routines, relations with other staff and practices of report giving to coordinate care of patients and families. Nurses’ workplaces are also social settings, they are not neutral or empty containers in which PFCC ideologies may be simply inserted. Rather than psychologically seeking PFCC values ‘in’ individuals, it would be more useful, and beneficial to nursing care practices, to examine the ways in which racism, pressures to maintain organizational efficiencies, and the lack of specific material and bodily resources, impact patient care experiences.

Nursing Education Implications

In this section, I consider three implications for nursing education. It is important for nurses to learn about the history of PFCC endeavors and hospital practices - that is, how the social conditions of nursing care for patients and families have evolved (or not). A key learning being that PFCC innovations have not addressed concerns of care for racialized populations. Nor have PFCC initiatives improved care of persons with limited social and familial support systems. It is also important for nursing students to learn that nursing practices in the hospital do not attend to patients in a one-on-one manner. Instead, nurses care collectively alongside a team of other actors and network of activities. Nurses’ performances and caring activities are distributed across various hospital spaces and not just at the patient bedside. Finally, the patient stories shared in this study may serve as case studies for nursing students to reflect upon when learning about patient and family ‘involvement’. For example, nursing students may learn and discuss how patients and families are not necessarily powerless, rather their agential abilities are precariously situated in a hospital setting.

Policy Implications

Current implementation processes and auditing practices of PFCC policy in practice have ignored the concerns and consequences of social inequities for people receiving hospital care. Moreover, it does not seem that PFCC policy can solve concerns voiced by the nurse participants' concerning experiences with racism or resource constraints, both of which may influence the ways patients and family members work to organize care that actually meets their needs. As such, I recommend people involved in the organization and management of hospital care take action on the everyday occurrence of racism in caring institutions and ensure that it is not tolerated in hospital spaces. As well, it is important for governing officials in hospital care to organize a care setting that ensures hospital spaces are well resourced, so that patients do not have to rely on family advocates or need to vigilantly monitor and correct poor organizational care practices related to their care.

Implications for Future Research

The main objective of this research study was to think about the possibilities of improving care for patients and families in hospital settings by paying attention to the complex and entangled relations, actors, technologies, and politics involved in organizing care. A practice view of work and organization was used to explore how care of families and patients is ordinarily done in a hospital setting that has adopted PFCC initiatives for many years. Enactments of PFCC, as described in organizational policies and resources, in day-to-day care were not particularly visible, instead I observed the flow of care practices, learning about the tangible, material ways care was enacted in this setting. From these observations and my conversations with nurses, patients and families, I came to understand that something that could be described as 'centring' patient and families in care cannot be understood outside of the sociomaterial contexts in which such care occurs. Indeed, I would argue that the values that are so strongly espoused by PFCC initiatives, values such as respect, dignity and collaboration, can only gain material presence when the sociomaterial conditions of care practices are foregrounded and attended to. The specific findings of this study thus have implications for further research. First, understanding and changing the impacts of people's experiences with racism, along with other social inequities, in hospital settings is essential. Second, 'values' such as those described in PFCC initiatives need to be reattached to the sociomaterial complexities that produce them. Finally, rather than positioning patients and families as being powerless, as described in PFCC narratives, knowledge should be developed that examines the materials and resources patients need when they are hospitalized to foster healing and prevent further injury. These insights invite researchers to examine the complex social, material, and political conditions that are necessary for patients and families to experience good care.

New Questions

Similar to other ethnographic and practice-based studies, this research has political and ethical significance by prompting research questions that attend to the particularities and complexities of nursing care in the hospital context. My observations show how each patient's and nurse's experience carries the history of what practices came before, what activities are happening alongside, and what needs to be done in the next moment. PFCC has been developed as though nursing care is performed through one on one interactions with patients and families that are isolated from the other activities taking place on the ward. For example, PFCC discourses presume that communication is vested in reciprocal aims for dignity and respect, rather than precarious patient care conditions and frequent practices of report giving by nurses. Although PFCC initiatives may be well-intentioned, they misconstrue how nurses organize patient care and the efforts of patients and families to be ‘involved’ in hospital settings. In order for care to be dignified and respectful of patients and nurses, attention to material and bodily resources is necessary.

The stories that I shared of my patients’ care experiences, and the accounts of my conversations with nurses and observations of nursing care, disrupted some ideals that are secured in PFCC discourses- for example, that nurses should always include patient and family preferences in care planning or that patients and families need to, somehow, be more ‘involved’ in their hospital care. PFCC success stories make invisible the vulnerabilities and precarities that people involved in caring, including nurses, patients, and families, experience in an institutional setting. There are realities of care, such as inadequate resources, communicable diseases, and racialized stereotyping, which not only undermine PFCC ideals but also cannot be improved with more PFCC initiatives. Practice-based and ethnographic research helps to make these concerns more visible. As Chambliss (1996), Pols et al. (2018), and Mol (2008) argue, morals or ethical principles cannot be separated from practical or actual activities of care. This argument has important research implications for continuing to explore and improve the social, practical, and political elements shaping patient care experiences. Notably, Pols (2019) established empirical ethics as a research approach to investigate how values materialize in everyday care practices, by drawing from feminist research traditions and science and technology studies. Empirical ethics is an approach that does not predefine ethical values, rather looks at how norms, goods, or values like ‘dignity’ emerge as a result of networks of activity, including human and nonhuman actors. It is this approach that seems to me a useful strategy to explore how care of patients and families can be improved.

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Appendices

Appendix A: Hospital Staff Information Sheet and Consent Forms

PARTICIPANT CONSENT FORM

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals
(U of A Ethics ID #: Pro00098424)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co Investigator: Harkeert Judge, PhD student Ph: 780-802-2060
Email: harkeert@ualberta.ca

Why am I being asked to take part in this research study?

You are being asked to be in this study because you have hands on experiential knowledge related to practicing patient and family centred care in an acute care ward with adult patients.

This study is focused on learning about the ways in which patients and families are involved in hospital care. This research would like to learn about your experiences at work, so we can study ways to improve hospital care and policy in Alberta.

Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

This study is interested in finding out more about the ways in which patients and families are involved in their hospital care. This study is also part of one of the researcher's (Harkeert Judge) doctoral studies at the University of Alberta.

What will I be asked to do?

You will be asked to participate in an interview and workplace observation with the researcher.

Observations will focus on how patients and families are routinely involved in care. For example, what kinds of things are involved and are there any barriers or things that make it easier to involve patients and families. Observations will not focus on specific individual behaviors and will instead include casual conversations related patient and family centred care as they arise. The researcher will introduce herself to other people encountered during the observations and will not record information of non-participants. Should non-participants want the researcher to leave, she will respect their wishes.

The observations will take up to one-two hours and will be done on the hospital ward during your workday. The researcher will primarily record observations into a field note journal. As well, you may see that the researcher has a camera. The researcher will not take any pictures of you or personal information of people in the hospital. The researcher is only taking pictures of things and objects involved in facilitating patient and family care. Personal and institutional information will be covered before the picture is taken. At any point in time, you can ask the researcher to stop taking pictures or taking field notes.

What are the risks and discomforts?

There is minimal risk involved with your participation in this study. Possible discomfort may include feeling anxious talking about or sharing your experiences at work. If you experience discomfort, you can ask the researcher to stop at any time.

Meetings with the researcher may increase your risk to Covid-19. To minimize risk of infection transmission, the researcher will maintain physical distancing and go over the Covid-19 self-assessment questionnaire. As well, the researcher will use and provide face masks and hand sanitizer throughout the observation period as needed.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant

What are the benefits to me?

You are not expected to get any benefit from being in this research study.

This study may help hospital staff plan better care for patients and families who have to be hospitalized in the future

Do I have to take part in the study?

Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect your employment.

During the observations you do not have to answer any questions that you are not comfortable with. You can also request that notes about your care routines be removed at any time during the shadowing or observation period.

After the data collection, if there are parts of the observations that you later decide you do not want to be included in the study, you can notify the researcher and they will exclude this information.

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected. You can decide that all the information collected from you be destroyed and not used in the study.

This data can only be destroyed or excluded up to 30 days after the data was collected. This is because after 30 days it will not be possible to identify your data.

Once the study is completed the researcher will be unable to remove your information.

Will my information be kept private?

All information from the observations will be kept confidential. The observations will be recorded into a field note journal. We will do everything we can to ensure this document is kept private, including storing it in a locked filing cabinet.

Unless you direct the researcher otherwise, your name will not be attached to any data collected and a pseudonym will be used instead. Identifying information related to your specific place of work will not be attached, but your role may be included (e.g. manager, nurse, health care aide, coordinator etc.).

Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

After the study is done, we will still need to securely store data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

By signing this consent form, you are saying it is okay for the study team to collect, use and disclose information about you as described above.

What if I have questions?

If you have any questions about the research now or later, please contact Harkeert Judge at harkeert@ualberta.ca or her supervisor: Dr. Christine Ceci at 780-492-8911

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals (Pro00098424)

Principal Investigator(s): Dr. Christine Ceci **Phone Number(s):** 780-492-8911
Co Investigator: Harkeert Judge, PhD student **Phone Number**: 780-802-2060
Email: harkeert@ualberta.ca

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your employment?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant____

(Printed Name)
____

Date:_______________________

Signature of Witness
____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ___________________________ Date ________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix B: Patient Observation Information Sheet and Consent Form

PARTICIPANT CONSENT FORM

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals
(U of A Ethics ID #: Pro00098424)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co- Investigator: Harkeert Judge, PhD student Ph: 780-802-2060
Email: harkeert@ualberta.ca

Why am I being asked to take part in this research study?

You are being asked to be in this study because you are a patient receiving care on this hospital ward.

This study is focused on learning about the ways in which patients and families are involved in hospital care. This research would like to learn about your experiences during your hospital stay, so we can study ways to improve hospital care and policy in Alberta.

Before you make a decision, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

This study is interested in finding out more about the ways in which patients and families are involved in their hospital care. This study is also part of one of the researcher's (Harkeert Judge) doctoral studies at the University of Alberta.

What will I be asked to do?

You will be asked to allow the researcher to meet and observe you and your family within the hospital throughout your stay.

The study will begin with the researcher meeting you and your family in your assigned hospital room to discuss the study, go over any questions and for you to share your experiences so far in the hospital. This meeting will last around 30 minutes and a follow-up meeting within the same week will be scheduled. During the follow-up meetings, you may be asked interview questions that will focus on how patients and families are involved or centred in their hospital care. All information in the meeting will be kept confidential and names will not be attached to the data.
The researcher will primarily record observations into a field note journal. Formal interviews will be audio recorded and transcribed for better data analysis. As well, you may see that the researcher has a camera. The researcher will not take any pictures of

you or your personal information. The researcher is only taking pictures of things and objects involved in your care. Personal and institutional information will be covered before the picture is taken. At any point in time, you can ask the researcher to stop recording, or taking pictures and field notes.
The study will then involve the researcher spending time with you and your family as you go about your routine care activities in the hospital. You are not required to do anything outside of your normal hospital care activities. The researcher will basically meet with you to have conversations and watch activities related to your care. These visits will take place throughout the duration of your stay and will last no longer than 45mins. The times and the places within the hospital will vary depending on your preferences.

The following events would be the type of activities the researcher would like to observe:

- Nursing and physician shift reports
- Time during visitation
- Different time periods during the day - mornings and evening shifts
- Discharge

While these are examples of activities the researcher is interested in, the decision of what activities are observed, where and when the observations take place is up to you and your family. These meetings can be changed by you at any time during the study.

You will also be asked to allow the researcher to access your health records related to your current hospital admission. Your chart will be reviewed to see when, where, why and how you and your family members' involvement is documented or accounted for. The chart will be reviewed to see which kinds of care providers attend to your involvement. As well, the charts will be analysed to see how your care is organized and how your involvement changes or does not during the hospital stay. For example, the researcher may look over the nursing notes, progress notes and the admission and discharge papers. Therefore, the researcher will need to collect your personal health information to obtain access to your hospital records.

What are the risks and discomforts?

There is minimal risk involved with your participation in this study. Possible discomfort may include feeling anxious in discussing your involvement with your care. If you experience discomfort, you can ask the researcher to stop at any time and to go find the most responsible health care provider if you need more help.

Participating in this research may increase your exposure to Covid-19, as you will be interacting with one more person in addition to your day-to-day encounters at the hospital. However, the researcher will minimize the risks by going over the Covid-19 screening tool before every meeting. The researcher will maintain physical distancing and wear a mask. As well, the researcher will use and offer you and your family hand sanitizer throughout the meetings. It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks.

What are the benefits to me?

You are not expected to get any benefit from being in this research study.

This study may help hospital staff plan better care for future patients and families who have to be in hospital.

Do I have to take part in the study?

Being in this study is your choice and your participation will not affect the care you receive. You may also leave the study at any point, without affecting the care that you receive. You can also decide what parts of your hospital care you would like to have observed. During observations and interviews you do not have to answer any questions from the researcher that you are not comfortable. You can also ask the researcher to leave at any point

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected. You can decide that all the information collected from you be destroyed and not used in the study. This data can only be destroyed up to 30 days after the data was collected. This is because after 30 days it will not be possible to identify which data belongs to you.

Will my information be kept private?

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

The investigator or their study staff may need to look at your hospital chart during your stay. Any information that we get from these records will be only what is needed for the study.

By signing this consent form, you are saying it is okay for the study team to collect, use and disclose information about you from your personal health records as described above.

After the study is done, we will still need to securely store your data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

What if I have questions?

If you have any questions about the research now or later, please contact Harkeert Judge at harkeert@ualberta.ca or her supervisor: Dr. Christine Ceci at 780-492-8911

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals (Pro00098424)

Principal Investigator(s): Dr. Christine Ceci **Phone Number(s):** 780-492-8911
Co Investigator: Harkeert Judge, PhD student **Phone Number**: 780-802-2060
Email: harkeert@ualberta.ca

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your study records, including personally identifiable health information?	☐	☐

Who explained this study to you?

____

I agree to take part in this study:

Signature of Research Participant

____

(Printed Name)

____

Date:______________________________

Signature of Witness

____

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e. not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e. not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix C: Family Observation Information Sheet and Consent Form

PARTICIPANT CONSENT FORM

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals
U of A Ethics ID #: Pro00098424)

Principal Investigator: Dr. Christine Ceci 780-492-8911

Co Investigator: Harkeert Judge, PhD student Ph: 780-802-2060
Email: harkeert@ualberta.ca

Why am I being asked to take part in this research study?

You are being asked to be in this study because you have a family member receiving care on this hospital ward.

This study is focused on learning about the ways in which patients and families are involved in hospital care. This research would like to learn about your experiences during your family member's hospital stay, so we can study ways to improve hospital care and policy in Alberta.

Before you decide, one of the researchers will go over this form with you. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be given a copy of this form for your records.

What is the reason for doing the study?

This study is interested in finding out more about the ways in which patients and families are involved in their hospital care. This study is also part of one of the researcher's (Harkeert Judge) doctoral studies at the University of Alberta.

What will I be asked to do?

You will be asked to allow the researcher to meet and observe you and your family member during their hospital stay.

1. The study will begin with the researcher meeting you and your family in your assigned hospital room to discuss the study, go over any questions, and share your experience so far in the hospital. This meeting will last around 30 minutes and a follow-up meeting within the same week will be scheduled. During the follow-up meetings, you may be asked interview questions that will focus on how patients and families are involved or centred in their hospital care. All information collected from the meetings will be kept confidential and names will not be attached to the data.
2. The researcher will primarily record observations into a field note journal. Formal interviews will be audio recorded and transcribed for better data analysis. As well, you may see that the researcher has a camera. The researcher will not take any pictures of you, your family member, or your personal information. The researcher is only taking pictures of things and objects involved in your family member's care.

Personal and institutional information will be covered before the picture is taken. At any point in time, you can ask the researcher to stop recording, or taking pictures and field notes.

3. The study will then involve the researcher spending time with you and your family as you go about your routine care activities in the hospital. You are not required to do anything outside of your normal hospital care activities. The researcher will basically meet with you to have conversations and watch activities related to your family member's care. These visits will take place throughout the duration of your family member's hospital stay and will last no longer than 45mins. The times and the places within the hospital will vary depending on your preferences.

The following events would be the type of activities the researcher would like to observe:

- Nursing and physician shift reports
- Time during visitation
- Different time periods during the day - mornings and evening shifts
- Discharge

While these are examples of activities the researcher is interested in, the decision of what activities are observed, where and when the observations take place is up to you and your family. These meetings may be changed by you at any time during the study.

What are the risks and discomforts?

There is minimal risk involved with your participation in this study. Possible discomfort may include feeling anxious in discussing your involvement with your family member's care. If you experience discomfort, you can ask the researcher to stop at any time and to go find the most responsible health care provider if you need more help.

In-person meetings may increase your risk to Covid-19. To minimize risk of infection transmission, the researcher will maintain physical distancing and go over the Covid-19 self-assessment questionnaire. As well, the researcher will use and provide face masks and hand sanitizer for in-person interviews.

It is not possible to know all the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me?

You are not expected to get any benefit from being in this research study. This study will not affect the care that your family member receives in hospital. This study may help hospital staff plan better care for future patients and families who have to be in hospital.

Do I have to take part in the study?

Being in this study is your choice. You can also decide what parts of your hospital visit you would like to have observed. During observations and interviews you do not have to answer any questions from the researcher that you are not comfortable with. You can also ask the researcher to leave at any point or to stop recording data.

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected. You can decide that all the information collected from you be destroyed and not used in the study. This data can only be destroyed up to 30 days after the data was collected. This is because after 30 days it will not be possible to identify which data belongs to you.

Once the study is completed the researcher will be unable to remove your information.

Will my information be kept private?

During the study we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

By signing this consent form, you are saying it is okay for the study team to collect, use and disclose information about you as described above.

After the study is done, we will still need to securely store your data that was collected as part of the study. At the University of Alberta, we keep data stored for a minimum of 5 years after the end of the study.

What if I have questions?

If you have any questions about the research now or later, please contact Harkeert Judge at harkeert@ualberta.ca or her supervisor: Dr. Christine Ceci at 780-492-8911

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Understanding Practices of Patient and Family-Centred Care in Hospitals (Pro00098424)

Principal Investigator(s): Dr. Christine Ceci **Phone Number(s):** 780-492-8911
Co Investigator: Harkeert Judge, PhD student **Phone Number**: 780-802-2060
Email: harkeert@ualberta.ca

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your family member's care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐

Who explained this study to you?
____

I agree to take part in this study:

Signature of Research Participant
____

(Printed Name)
____

Date:______________________________

Signature of Witness
____

A Witness line is only required if you anticipate that your participants will be unable to read the consent for themselves. If so, an impartial witness (i.e. not associated with the study team) must be present during the entire informed consent discussion and is witnessing that the participant understood what was discussed (i.e. not just witnessing the signature process).

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee ______________________________

Date ___________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix D: Verbal Consent Script

Hello,
I am a PhD Candidate in the Faculty of Nursing at the University of Alberta. I am conducting a research study titled Understanding Practices of Patient and Family-Centred Care in Hospitals.

This study has been approved by the Health Research Ethics Board (U of A Ethics ID# Pro00098424).

Why am I being asked to take part in this research study?
You are being asked to participate in this study because your work or your care intersects with this research participant's care practices.

What is the reason for doing the study?
This study is focused on learning about the ways in which patients and families are involved in hospital care. I am interested in collecting descriptive data on how patients and families are involved in their care, so that we can improve hospital policies and gain more knowledge.

What will I be asked to do?
Your involvement in this study would not involve anything outside of what you are currently planning on doing with (________Participant's name).

What are the risks and discomforts?
There is minimal risk involved with your participation in this study. Possible discomfort may include feeling anxious with having someone sit and observe your care routines.

If you experience discomfort, you can ask the researcher to stop at any time and to go find the closest responsible health care provider if you need more help.
Participating in this research may increase your exposure to Covid-19 as you will interacting with one more person in addition to your day-to-day meetings at the hospital. However, the researcher will minimize the risks by going over the Covid-19 screening tool before every meeting. The researcher will maintain physical distancing and wear a mask. As well, the researcher will use and offer you hand sanitizer during the meeting.
What are the benefits to me?
You are not expected to receive any benefit from this study and this study will in no way affect your (employment/care that you receive).

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.
Do I have to take part in the study?
You can also decide what parts of your hospital care you would like to have observed. During observations and interviews you do not have to answer any questions from the researcher that you are not comfortable. You can also ask the researcher to leave at any point

If you decide that you do not want to participate any further, you will be given the choice to withdraw and have no further information collected.

Once the data collection is completed, the researcher will be unable to remove your information. This is because it will be impossible to identify your data. I will not be recording any personally identifiable information. I am only recording descriptions of what sorts of people and things are required to have patient and family involvement.

If you do not want to be even peripherally involved in this study, you are entitled to ask the researcher to leave.

Will my information be kept private?

We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers.

Sometimes, by law, we may have to release your information with your name so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private.

Do you have any questions or concerns related to my presence right now?

Do you agree to take part in this study?

Yes or No.

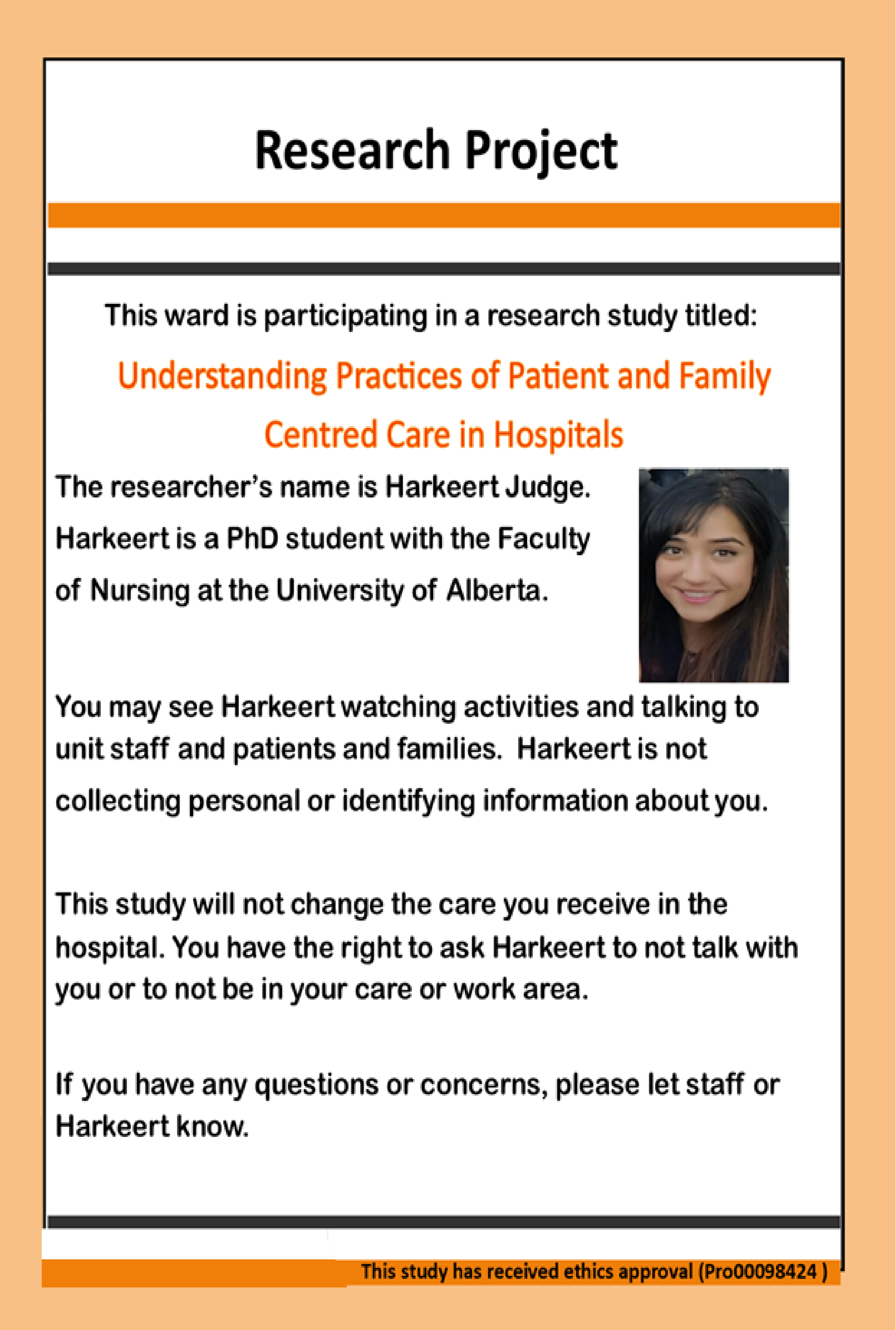
By saying 'yes' to allow, you are saying it is okay for the study team to collect, use and disclose information about you as described above.

What if I have questions later?

If you have any questions about the research now or later, please contact Harkeert Judge at harkeert@ualberta.ca or her supervisor: Dr. Christine Ceci at 780-492-8911

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

Appendix E: Passive Consent Poster



Research Project

This ward is participating in a research study titled:

Understanding Practices of Patient and Family Centred Care in Hospitals

The researcher's name is Harkeert Judge. Harkeert is a PhD student with the Faculty of Nursing at the University of Alberta.

You may see Harkeert watching activities and talking to unit staff and patients and families. Harkeert is not collecting personal or identifying information about you.

This study will not change the care you receive in the hospital. You have the right to ask Harkeert to not talk with you or to not be in your care or work area.

If you have any questions or concerns, please let staff or Harkeert know.

This study has received ethics approval (Pro00098424)

Appendix F: Hospital Unit Manager Recruitment Email

Subject Line: Understanding Practices of Patient and Family-Centred Care in Hospitals Research

Study

Hello,
I am a PhD Candidate in the Faculty of Nursing at the University of Alberta. I am conducting a research study titled Understanding Practices of Patient and Family-Centred Care in Hospitals. This study has been approved by the Health Research Ethics Board (U of A Ethics ID# Pro00098424). I would like to invite you and your hospital staff to participate in this study. I am interested in collecting observational data on how patients and families are involved in their care. Your involvement in this study would be further discussed in an online or in person meeting, so that I can further explain the study and answer any questions. It would last approximately 45 minutes and would be scheduled at a time and location of your choice. If you would like to know more about this study please see the attached information sheet and feel free to contact me or my supervisor, Dr. Christine Ceci, by phone or email. Our contact information is available below.
Contact information
Phone: 7804928911
Email: ceci@ualberta.ca and harkeert@ualberta.ca

Thank-you,
Harkeert Judge
University of Alberta, Faculty of Nursing
Email: ceci@ualberta.ca and harkeert@ualberta.ca

Appendix G: Patient Recruitment Poster

Understanding Practices of Patient and Family-Centred Care in Hospitals

Are you interested in being part of a study about how patients and families are involved in their hospital care?

We are looking for:

- Patients currently admitted into care on this hospital ward and family members who are involved in care.

What is required of you in the study:

- This study involves a family interview and ongoing observations of your hospital experiences on this ward for short periods of time during your hospital stay
- These meetings will last around 30 mins and will occur 1-2 times a week up until you are discharged
- Participation is voluntary and people can opt-out of the study whenever they feel

For more information please contact:
Harkeert Judge at 780-492-8911 or
harkeert@ualberta.ca

This study has been approved by
Health Research Ethics Board
U of A Ethics ID # Pro00098424

Appendix H: Key Informant Recruitment Email

Subject Line: Understanding Practices of Patient and Family-Centred Care in Hospitals Research

Study

Hello,

I am a PhD Student in the Faculty of Nursing at the University of Alberta. I am conducting a research study titled Understanding Practices of Patient and Family-Centred Care in Hospitals. This study has been approved by the Health Research Ethics Board (U of A Ethics ID# Pro00098424). I am interested in talking with people who have professional experience related to coordinating patient and family centred care strategies in hospital care settings. I have received your name as a possible participant. Your involvement in the study would include an interview that would last approximately 60 minutes and would be scheduled at a time and location of your choice. If you would like to know more about this study please see the attached information sheet and feel free to contact me or my supervisor, Dr. Christine Ceci, by phone or email. Our contact information is available below.

Contact information
Phone: 7804928911
Email: ceci@ualberta.ca and harkeert@ualberta.ca

Thank-you,
Harkeert Judge
University of Alberta, Faculty of Nursing

Appendix I: Patient and Family Interview Guide

Patient and Family Interview Guide

1. Explain research project and review information sheet and consent form.
2. Explain that they may opt-out of interview at any time.
3. Ask patient and family to begin to share their story regarding their hospital experience

Questions

Initial Interview

- To begin, can you tell me who is part of your care team?
- How did you come to be hospitalized?

Ongoing informal interviews will include questions such as:

- What does/did your day at the hospital typically look like?
- Can you tell me about when you and your family are/were involved with hospital care? And what does/did that involvement look like in the hospital?
- How does your own or your family's involvement make hospital care good?
- Are there are any challenges for yourself or your family of becoming involved in or participating in your care?
- Are there things that I have haven't asked you, that you think would be important for me to understand around how patient's and families are involved in their care?

Appendix J: Interview Guide Hospital Staff

1. Explain research project and review information sheet and consent form
2. Explain how long the interview may last and that they may opt-out of it at any time.

Questions

- To begin, can you tell me about your role on the unit?
- What kinds of things do you ordinarily do for or accomplish with patients and families?
- Can you describe ordinary practices of 'centring' patients and families in care? And what kinds of tools, materials, and technologies are involved?
- What kinds of challenges or benefits are there to 'centre' patients and families or involve them in their care?
- Are there things that I have haven't asked you, that you think would be important for me to understand around how patient's and families are 'centred' in their care?